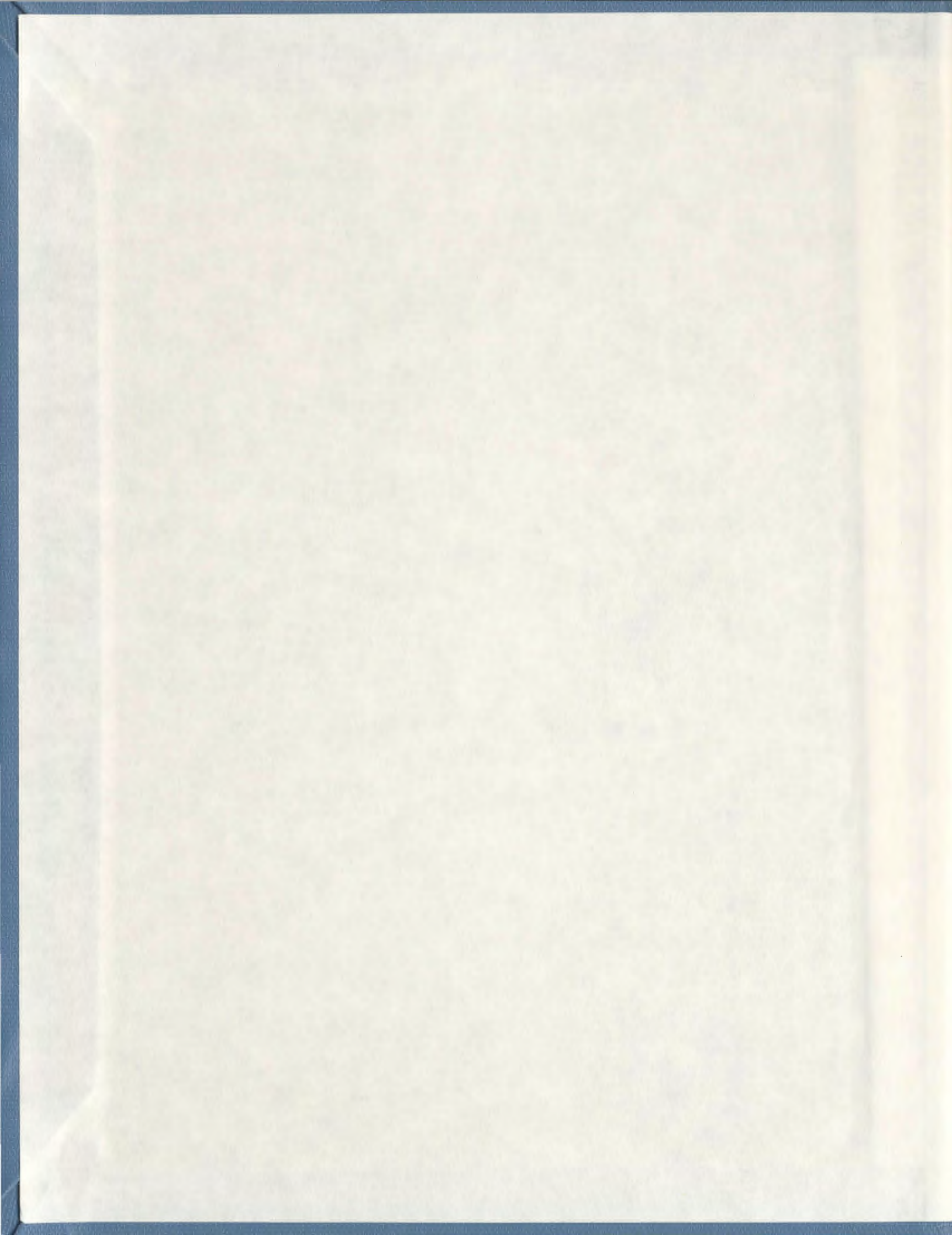


WOMEN LIVING WITH PSORIASIS:  
A PHENOMENOLOGICAL STUDY

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Women Living With Psoriasis: A Phenomenological Study

by

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## Abstract

Psoriasis is a chronic condition of the skin for which there is no cure. There are over 1 million people in Canada with psoriasis and it is estimated that 2-3% of the population of Newfoundland and Labrador are sufferers. The lived experience is important for people suffering with psoriasis and encompasses more than treatment modalities. The clinical manifestations, diagnosis and treatment, physical and psychosocial effects of psoriasis, and quality of life issues have been covered in the current literature. Little research has been conducted on the lived experience of individuals with psoriasis. By using phenomenology as a research method, the lived experience of four women living with psoriasis in Newfoundland is explored. The analysis reveals the themes from the lived experience of these women. These themes are: 1) More than just a rash – physical symptoms; 2) Understanding from others – support; 3) Creative clothing – covering up; 4) The good, the bad, and the scary – treatment options; 5) Looking for answers; 6) Managing the public gaze – avoidance; 7) Knowing triggers – observing patterns; and 8) Moving on – developing comfort. It is hoped that nurses and other health care professionals will gain a better understanding of the lived experience of these women and be better able to provide holistic care to those suffering from psoriasis.

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## CHAPTER 1

### Introduction

Psoriasis is a chronic condition that carries a significant personal and health care burden (<http://www.psoriasis.org/about/stats>). The quality of life for those with psoriasis is greatly affected (Mauri-Sole, 2006; Weiss, Bergstrom, Weiss, & Kimball, 2003). As psoriasis is primarily a disease of the skin, it is one that is often quite visible to others. This visibility represents some unique challenges for the person who has psoriasis (Uttjek, Nygren, Stenberg, & Dufaker, 2007). Living with a disease that has such an outward presentation has the potential to have a negative impact on self-concept and self-esteem. Physical symptoms such as itching, soreness and pain, and flaking of the skin affect quality of life as well (De Arruda & De Moraes, 2001; Feldman, Behnam, Behnam, & Koo, 2005). Currently, there is no cure for psoriasis and treatment options require a great deal of time and commitment on the part of the affected person. Genetic implications of the disease may have an impact on childbearing decisions (van Steensel & Steijlen, 1997).

Although both men and women are affected in equal numbers by this condition, women may be affected differently than men due to the physical manifestations of psoriasis which may be more visible due to the difference in men's and women's clothing style. There has not been an extensive amount of research involving the experience of women living with psoriasis and how it affects their daily lives. No research was located that included women in Newfoundland and Labrador, where psoriasis is a more common

problem than in the rest of Canada. In this thesis, the impact of this disease on women's lives will be investigated using a qualitative approach, specifically phenomenology.

### Background

Psoriasis is a chronic inflammatory disease of the skin that is currently incurable (Fox Quillen, 2004). There are several types of psoriasis and these take many forms. While it is not curable in many instances, for many, the condition can be successfully managed (Joseph, 2005). Management, however, is very time consuming and getting the optimal management regime can be difficult (Nijsten, Margolis, Feldman, Rolstad, & Stern, 2005).

There are 10 million individuals across North America who have psoriasis; about 1 million of these are in Canada (Mediresource, 2005). This is quite a significant number of people and about half of these are women, as this disease can occur in equal numbers in men and women (Joseph, 2005). In Newfoundland and Labrador, it is estimated that the incidence is higher, with 2-3% of the population having some form of psoriasis (Nall, Gulliver, Charmley, & Farber, 1999). This high incidence may be due to the fact that Newfoundland and Labrador is genetically isolated and a higher incidence of certain genetic traits has been identified, including one causing psoriasis and psoriatic arthritis (Rahman et al., 2003).

Psoriasis is a very complex condition that involves a relationship between genetics, environment, and an inflammatory process. Women in our society live complex lives having many roles, such as partner, mother, nurturer, and bread winner among others. Psoriasis is a multidimensional condition that encompasses physical suffering as well as psychosocial suffering, in the areas of body image and self-esteem (Weiss et al.,

2003). Self-esteem and body image can have a great impact on how women are able to deal with their expectations and roles (Choi & Koo, 2003). In turn, having a chronic inflammatory skin condition, which can reoccur without warning and alter the physical appearance, has to have an impact on the lives of these women. Psoriasis can also come with other physical symptoms such as itching, flaking of the skin, soreness and tightness of the affected skin (Jones, 2005). These physical symptoms will also affect the lives of the sufferers.

### Significance to Nursing

With the large number of people affected by psoriasis, it is inevitable that nurses will come in contact with a patient with psoriasis at some point in their practice, whether or not it is the individuals' primary reason for seeking health care. The impact of psoriasis on many aspects of a woman's life makes it important that nurses are aware of the physical and psychosocial issues affecting women with psoriasis. With this awareness, nurses may be thus better able to understand these women and provide them with more holistic care and the support necessary to live as a person with psoriasis. Holistic care must take into account the patient's medical, social, psychological, and spiritual care as well as encompassing quality of life issues and patient and caregiver education (Yosipovitch & Tang, 2002).

The diagnosis of psoriasis brings with it unique issues and challenges (Finlay, 2005). As with many skin conditions, the visibility of the condition makes it different from other chronic conditions that are less visible, and this brings with it many psychological factors such as embarrassment, and self-concept and self-esteem issues (Weiss et al., 2003). The treatments for psoriasis are very complex and involved, and the

control of a common symptom such as itch can be difficult (Aerlyn & Yosipovitch, 2006). Often, in my experience, when patients with psoriasis are admitted to hospital, nurses are unfamiliar with the treatments and routines that the patients are undergoing. It is especially difficult if the patient is unable to perform these complex treatment regimes themselves due to being incapacitated by another medical or surgical condition. The topical treatments and frequent moisturizing can be very time consuming and nurses on busy units may not have the time required to perform these complex routines or simply not understand how important they are to the patient. For example, if there is scalp involvement, there may be multiple lotions and shampoos that need to be applied during the day, which the nurse may see as secondary to the treatment for the illness for which the patient has been hospitalized. If nurses have an understanding of the lived experience of psoriasis, they may be able to view the disease and its treatment as an integral part of their patient's life.

There has been much research on the physical treatment of psoriasis in the form of quantitative methods such as clinical trials, which test new medications to treat psoriasis. There are several clinical trials underway in Newfoundland and Labrador currently involving new medications to treat psoriasis and psoriatic arthritis (personal communication, W. Gulliver, 2006). Little research has been done qualitatively to determine the individual's lived experience of psoriasis.

The psychosocial factors associated with psoriasis have also been explored, many concentrating on quality of life (Skevington, Bradshaw, Hepplewhite, Dawkes, & Lovell, 2005) or severity of the condition (Finlay, 2005). These two factors, physical treatment and psychosocial effects, have been the focus of much of the research into psoriasis.

Most of the research conducted on psoriasis has been of two types, clinical trials of treatments or quantitative measures of psychosocial aspects of psoriasis. A few qualitative studies were found whose author's looked at living with psoriasis; a phenomenological study (Chrissopoulos & Cleaver, 1996) and another study used a sociological approach to explore the visibility of psoriasis (Uttjek et al., 2007).

There is limited literature for nurses to access when wanting to provide evidence based care for people with psoriasis in the psychological and psychosocial realms to complement their physical care. Evidence based practice (EBP) has been defined as

“a problem solving approach to practice that involves the conscientious use of current best evidence in making decisions about patient care; EBP incorporates a systematic search for and critical appraisal of the most relevant evidence to answer a clinical question along with one's own clinical expertise and patient values and preferences” (Coopey & Nix, 2006, p.195).

The description of EBP above makes health care professionals aware of the value of having current research available to nurses so that they can provide the best care to their patients. Norberg (2006) stresses that not only research findings must be taken into account in evidence based nursing, but also the nurses clinical experience, the patients' preferences, and the local context. This makes phenomenological research all the more important because it allows health care professionals to understand the participants' lived experience. This type of research will complement the available literature to enhance the holistic, evidence based care that nurses are able to provide to patients suffering from psoriasis.



Phenomenological research begins with what deeply interests the researcher and is a phenomenon or an experience that human beings live through (van Manen, 2007). The limited amount of qualitative research on living with psoriasis, the need for evidence based care, and the large number of patients with psoriasis that I have cared for in my nursing career have contributed to my interest in exploring the phenomenon of living with psoriasis further. The findings of this study have the potential to improve nursing practice through holistic care for women with psoriasis because they allow nurses to have a better understanding of the lived experience of these women.

#### Research Purpose

The purpose of the research is to describe the experience of women living with psoriasis and also to gain understanding of that experience.

#### Research Question

The specific research question that will be explored is: What is the experience of women living with psoriasis?

#### Outline of Thesis

The outline of this thesis is as follows. Chapter 1 provides an introduction to the thesis. In chapter 2 a review of the literature on psoriasis is presented. In chapter 3, I will give a brief overview of the methodology that was used, namely phenomenology, and also describe the methods used. In chapter 4, I will describe the lived experience of the women through identified themes. A discussion of the findings will be presented in chapter 5 and finally, in chapter 6, I will present the limitations of the study and implications for nursing practice, research, and education.

## CHAPTER 2

### Literature Review

There has been a significant amount of research conducted on psoriasis. In these studies there has been a separation between the physical and the psychosocial factors of psoriasis, which has resulted in two different streams of psoriasis related research (Perrott, Murray, Lowe, & Mathieson, 2000). A majority of the research seems to concentrate on treatment options and new medications. There has been some research conducted on the psychosocial aspects of psoriasis and how it affects the daily lives of those affected (Adams, Glenn, & Byatt, 2001; O'Leary, Creamer, Higgins, & Weinman, 2004). Much of this work is quantitative in nature, often using standardized questionnaires to determine the impact of psoriasis on peoples' lives. There is also information in the literature about the psychosocial aspects of this disease and many of these articles are not research studies, but are often based on the findings from research of several different studies and contain practice implications. Patient descriptions of living with psoriasis presented from a laypersons' perspective are also seen in the literature (Horigan, 2005; Paranzino, 2004). These accounts give a unique perspective of what it is like to have psoriasis from someone actually in the situation and having to deal with psoriasis throughout their lifetime.

#### *Literature Search Strategy*

A literature review was conducted using the CINAHL and PubMed (MEDLINE) data bases via the Health Science Library at Memorial University. As an adjunct, the

internet search tool Google was also used. Key words included psoriasis and skin disorders, which were used alone and combined with qualitative and quantitative research, quality of life, psychosocial, treatment, clinical manifestations, clinical trials, phenomenology, lived experience, incidence, and coping. Limits that were used included journals that were printed in English and were published from the year 2000 to the present day, although some of the references in the located journals led me to articles published prior to 2000. The Electronic Journals list was also searched using the subset of Medicine, then the subset of Dermatology.

The literature review is divided into the following: 1) Clinical manifestations of psoriasis; 2) Diagnosis and treatment; 3) Effects of psoriasis; 4) Quality of life; and 5) Living with psoriasis.

### *Clinical Manifestations of Psoriasis*

The clinical manifestations of psoriasis are important to be aware of, as they mediate the experience of living with psoriasis as well as the patient's perception of the severity of the disease (Finlay, 2005). Psoriasis was first recognized as a clinical entity about 200 years ago in a detailed description by Robert Willian (Jankowiak et al., 2004). Psoriasis is now recognized as one of the most common dermatologic diseases in the world. It is estimated that up to 5% of all people in the world suffer from psoriasis (Jankowiak et al.). It is chronic but not life threatening and therefore it is more likely for health care professionals and others to minimize the psychological impact of the disease on the sufferers (Choi & Koo, 2003).

To understand the clinical manifestations of psoriasis, a brief description of the condition is necessary. Psoriasis is a chronic inflammatory disease of the skin which is

currently incurable (Young, 2005). There are several types of psoriasis and these take different forms. The most common form, chronic plaque psoriasis is characterized by red scaly lesions which may occur anywhere on the body but are most common over joints such as elbows and knees and on the lower legs, back, and scalp. Guttate psoriasis is characterized by small red lesions that may eventually join together to form a plaque and may lead to plaque psoriasis. Inverse or flexural psoriasis forms smooth, dry, red lesions that do not scale and occur in the folds of skin in areas such as the groin or under the breasts. Pustular psoriasis has red pustular lesions scattered over a wide erythematous base on the skin. Erythroderma psoriaticum is characterized by the entire body surface becoming reddened with severe skin peeling. Pustular psoriasis and erythroderma psoriaticum are considered to be severe and may require treatment as an inpatient in a hospital setting. Psoriatic arthritis is one sequelae that may occur in a person with psoriasis. It affects approximately 23% of those with any other form of psoriasis and causes joint pain, mobility problems, morning stiffness, fingernail deformities, eye pain and redness, degenerative changes, and bone loss and can lead to permanent disability (Fox Quillen, 2004).

Psoriasis is mediated by the immune system, specifically a dysfunction of the T-lymphocytes which trigger an immune response and the resultant inflammation in the skin (Schon & Boehncke, 2005). The second factor in the etiology of psoriasis is hyperproliferation of skin cells and both the dermis and epidermis is affected. Normally, the basal layer of the epidermis produces new keratinocytes which, over the course of approximately 30 days, slowly become mature and move through the epidermal layers and are then shed. Due to the inflammatory process, the rate of keratinocyte production is

about 10 times more rapid than normal, taking only 3 to 4 days. This hyperproliferation leads to skin cells not being shed and produces a build up of immature skin cells which produce the silvery white scales evident in psoriasis. The capillaries in the dermis become dilated resulting in the red inflamed skin that accompanies the plaques (Joseph, 2005).

Although the exact cause of psoriasis is unclear, in about 30% of patients there may be a genetic predisposition to the condition (Joseph, 2005). There have been studies on families where psoriasis is evident in its members, which have provided evidence of a genetic predisposition, although the pattern of inheritance remains unclear (Schon & Boehncke, 2005). Several genes located on various chromosomes have been identified as increasing the susceptibility to developing psoriasis (Khachemoune & Guillen, 2006). There is ongoing research in this area to try to develop more effective treatments or perhaps a cure for psoriasis in many areas of the world.

Genetics is only one part of the psoriasis puzzle. Environment also plays a role in this disease. In people who are genetically predisposed to psoriasis, certain environmental factors can initiate exacerbations of the disease (Khachemoune & Guillen, 2006). These environmental triggers include trauma to an area of skin; infection such as streptococcus or HIV; sunlight which improves psoriasis in some, but 10% of patients react with deterioration; drugs such as beta blockers, antimalarials, lithium, and withdrawal of steroids; stress; excessive alcohol intake and smoking; and hormonal changes such as those occurring in pregnancy (Joseph, 2005; Khachemoune & Guillen).

Diagnosis of psoriasis, and differentiation of the type of psoriasis, is based on several criteria and these determine treatment modalities. As mentioned before, there are



several categories of psoriasis, the most common being chronic plaque psoriasis. A person may suffer from more than one type of psoriasis at a given time, and the disease can have remissions and exacerbations in an unpredictable pattern, but can be triggered by life events such as stress, injury to the skin, medications, and infection (Fox Quillen, 2004).

Severity of psoriasis is also a contested area (Finlay, 2005). Physicians and patients may use different criteria. In the past there has been some disagreement about which assessment tools should be used, for example, if they should be patient specific, condition specific, or if generic measures should be used (Fortune, Main, O'Sullivan, & Griffiths, 1997). Many patients with this condition use a number of factors to assess severity. The degree to which symptoms are a problem, how it affects everyday life and relationships, and psychosocial consequences are some of the factors that patients use to determine the severity of the condition. It is the complexity, unpredictability, and uncertainty associated with this condition that causes so many challenges for the person affected.

### *Diagnosis and Treatment*

Both the diagnosis and treatment of psoriasis can be difficult for the person affected. It involves being told you have a chronic and perhaps debilitating disease. There is no cure and it frequently has a relentless course of relapse and remission that fluctuates and is unpredictable (Pearce, Boles, Greist, & Feldman, 2005). The fact that the person has already experienced the cosmetic disfigurement characteristic of psoriasis prior to diagnosis also may have a negative impact on the person's contact with others, as well as their own self-concept (Chrissopoulos & Cleaver, 1996). The visibility of this

disease of the skin brings with it unique physical and psychological issues for the sufferer. Along with the diagnosis of a chronic disease, the treatment for psoriasis brings with it its own unique challenges. There is no cure and the treatments are complicated and can be unpleasant and can carry worrisome side effects.

### *Diagnosis of Psoriasis*

Diagnosis of psoriasis is mainly a clinical diagnosis based on observation of the skin but if it is not clear from observation, it can be differentiated from other skin conditions by biopsy and microscopic examination of the specimen (Khachemoune & Guillen, 2006). There has been evidence of a strong genetic link for psoriasis, however the basis of this genetic link is far from simple (van Steensel & Steijlen, 1997). There have been several large studies suggesting a genetic link; however, the environment is also implicated in its development (Galadari, Sharif, & Galadari, 2005). This strong familial link makes a good family health history an important tool in the diagnosis of psoriasis.

### *Treatment Options*

There are three generally accepted methods of treatment for psoriasis. These include topical agents, phototherapy, and systemic agents (Khachemoune & Guillen, 2006). There are a variety of topical creams, ointments, shampoos, lotions, gels, and bath oils that are used alone or in combinations in conjunction with moisturizers to keep the skin moisturized. Topical corticosteroids, coal tar preparations, keratolytics, vitamin D preparations, vitamin A creams, and anthralin are some of the products that are used in the first line of treatment of psoriasis, each having their own side effects and unpleasant effects such as odor and staining clothing (Fox Quillen, 2004).

Phototherapy is the next step in psoriasis treatment for those who do not have good results with topical treatments. This involves clinic visits several times a week for ultra-violet B light therapy (UVB), which is conducted in a medical tanning booth. Another option for light therapy is combining ultra-violet A light therapy with a systemic medication such as Psoralen®, also referred to as PUVA. This also requires several visits a week to a dermatology treatment center equipped for these treatments and both of these treatments carry significant risk such as burns, skin cancer, and particular side effects from the PUVA such as headache, fatigue, nausea, and itching (Fox Quillen, 2004; Khachemoune & Guillen, 2006).

The third set of treatment options include systemic treatments including medications such as methotrexate or cyclosporine. These drugs have a number of potential side effects and require close monitoring. There is also a new class of drugs called the biologics which are having some positive effects in the treatment of psoriasis. These treatments are given by injection on different schedules, depending on the specific medication. These biologics seem to have relatively few side effects cited in the literature so far, but are still new medications (Khachemoune & Guillen, 2006). Many of these newer medications have recently been, or are currently being, tested in clinical trials. Most of these studies involve patients with moderate to severe psoriasis, have a certain percentage of body surface area involved, and a high score on the Psoriasis Area Severity Index (PASI). Often, these patients must have undergone other types of treatments without success in order to qualify for clinical trials (Reich et al., 2005). In these clinical trials, the participants are followed closely and indicators of disease severity are measured at variable intervals, depending on the study. Different measures may be used, including

the PASI and other indexes measuring other factors such as quality of life (Feldman, Boer Kimball, et al., 2005).

The treatments for psoriasis are varied and are often used in combination with each other. No matter what the treatment, they are usually time consuming and may have potential for undesirable side effects. Time is a common factor in psoriasis treatment, no matter which treatment option is used; whether it is the time to put on the topical preparations, time for close medical monitoring for side effects, or time in the clinic for light therapy. The potential for negative side effects can be worrisome for the patients and the medications can be very costly, especially for someone without medical insurance. These factors will emerge in every person suffering from psoriasis at some point in their lives and therefore, provide an important context for understanding the lived experience.

### *Effects of Psoriasis*

Chronic skin diseases are often different from other chronic medical disorders in that they are highly visible to both the sufferer and frequently to others. This visibility carries with it a special kind of distress (Weiss et al., 2002). The general public often reacts negatively and with aversion to diseases of the skin and this may cause problems in adjustment for the person with psoriasis (Chrissopoulos & Cleaver, 1996). There are several issues that emerge repeatedly in the literature about psoriasis.

### *Physical Effects*

The physical effects of psoriasis present important problems and are often the most difficult for the person to manage. Physical suffering is a part of psoriasis. It has been reported that the more problematic physical aspects of psoriasis are itching, scaling,

and the appearance of the skin (Feldman, Behnam, et al., 2005). Skin soreness, pain, burning, and dry skin were also reported as physical symptoms (De Arruda & De Moraes, 2001). Itching has been identified as one of the worst factors and the severity of this symptom is often not recognized (Aerlyn & Yosipovitch, 2006). Almost two-thirds of hospitalized patients identified itching as the principal symptom of psoriasis (Sampogna et al., 2004) and among those with psoriasis in a community based study, almost 80% of the participants rated it as the second most distressing symptom (Krueger et al., 2001). Continuous itching may distract the person from daily activities and become more than a minor irritant. Compounding the problem of itching, if the person scratches the areas frequently, is the potential of breaking skin integrity, opening a portal for infection to occur.

### *Psychosocial Effects*

The psychosocial health of the patient with psoriasis may also be affected in various ways. Psoriasis has been explored using quantitative measures such as the Psychosocial Adjustment to Illness Scales – Self Report (PAIS-SR) (Adams et al., 2001) and the Dermatology Life Quality Index (Jones, 2005), as well as many other types of quantitative measures such as questionnaires. The most commonly used index in practice today is the PASI or the Psoriasis Area Severity Index but this has been criticized for not being sensitive enough to psychosocial aspects of the disease (Perrott et al., 2000).

Psychosocial distress was found to elicit the highest score on the Psychosocial Adjustment to Illness Scale – Self Report in a survey of 50 people with chronic plaque psoriasis (Adams et al., 2001). These people were often shunned or discriminated against and some of the resulting problems include low self-esteem and a distorted self-



perception. Both of these adverse outcomes can cause individuals difficulties in relationship formation and social interactions (Rolfe, 2004). Social vulnerability has been identified as a main consequence, with sufferers having a keen desire to keep the disease secret (Wahl, Gjengedal, & Hanestad, 2002). Many others with psoriasis have suffered social rejection and stigmatization which can lead to lack of confidence and feelings of anger, frustration, and embarrassment (Feldman, Behnam, et al., 2005). Stankler (1981) and Weiss et al. (2002) both stated that participants in their studies reported embarrassment from their psoriasis and avoided activities such as swimming, sunbathing, sports, going to hairdressers, and buying clothes. Participants also reported avoidance of short sleeve shirts and shorts which may expose the rash and dark clothes, which emphasize the skin flakes. Sexual and intimate relationships can also be affected (De Arruda & De Moraes, 2001; Feldman, Behnam, et al., 2005). Psoriasis can inhibit intimacy and lead to a decline in sexual activity. Since sexual and other forms of intimacy are important and necessary parts of life, if affected they can further contribute to lack of self-esteem and damaged self concept.

Depression has also been found to be prevalent among people with psoriasis. Thirty two percent of the participants in one study screened positive for depression and this finding was positively correlated with their lower self report of health related quality of life (Schmitt & Ford, 2007a). Being dissatisfied with their treatment protocols and psoriasis related stress were both found to be highly associated with depression (Schmitt & Ford,a). It has been suggested that it is crucial that health related quality of life should be evaluated regularly in patients with psoriasis, regardless of the severity of disease. If

the degree of impairment is high in this area, the patients should be screened for depression (Schmitt & Ford, 2007b).

A person's work life and financial situation can be affected by psoriasis (Pearce, Thomas, Fleischer, & Feldman, 2004). In one study up to 37% of the participants stated that psoriasis had affected work or school (Young, 2005). In severe cases, especially those involving the hands or face, certain occupations would be ruled out. In an occupation where frequent hand washing or exposing hands or skin to harsh chemicals, a person with psoriasis may not be able to accept a position. An employer may not be as anxious to offer a position to someone with severe psoriasis on visible areas, especially if the job required client interaction or if the worker had to be in the public domain (Young).

The financial aspects of psoriasis are substantial, including cost of treatment, care, the time needed for treatment, and interference with work (Feldman, Behnam, et al., 2005). Psoriasis treatment involves various modalities ranging from topical preparations to subcutaneous injections, all of which can be quite costly. In addition to this cost, there is also the time it takes to perform the treatments, which can be up to several times per day and sometimes having to be done during the work day. Time lost from work during relapses and for doctor appointments and treatments must also be taken into account when assessing the financial and other impact on the work life of people with psoriasis. A study of 201 people with psoriasis found that health related quality of life had a greater impact on work productivity and limitations than actual clinical disease severity (Schmitt & Ford, 2006). Intervention to improve patients' quality of life may have an effect on time lost and productivity at work.

### *Quality of Life*

A number of authors are now stressing the need to look at quality of life assessments in addition to traditional clinical assessments in the treatment of patients with psoriasis (Choi & Koo, 2003; De Arruda & De Moraes, 2001). In current nursing journals, clinical articles are informing nurses of the need to consider quality of life when caring for patients with psoriasis (Weiss et al., 2003). In a review of literature from 1970 to 2003, published in 2003, recommendations have been made to involve the patient in the care of psoriasis; quality of life is stressed in this call for patient centered care in which two-way communication is important (Feldman, Behnam, et al., 2005).

Some researchers have examined quality of life in this patient population. Quality of life can encompass multiple factors including physical health, psychological health, levels of independence, social relationships, environment, spirituality, religion, and personal beliefs (Skevington, et al., 2005). The effect on quality of life was examined using several questionnaires, including the Satisfaction with Life Scale, the self assessed PASI, and the Medical Outcomes Study Short Form 36. The results showed that people with psoriasis were significantly affected in their perception of general health and social functioning compared to people not suffering from chronic disease (Weiss et al., 2002). One study found that quality of life was markedly reduced in people with psoriasis and these findings were based on a non-specific disease questionnaire that measured health related quality of life in 317 patients with psoriasis (Rapp, Feldman, Exum, Fleisher, & Reboussin, 1999). In this study, the participants judged themselves to have a decrease in physical and mental functioning that was comparable to the responses by patients with cancer, arthritis, hypertension, heart disease, diabetes, and depression (Rapp et al., 1999).

Along with quality of life, coping strategies have also been explored using quantitative measures with psoriasis sufferers. Rapp, Cottrell, and Leary, (2001) surveyed 318 people and found that quality of life was decreased in all domains studied and that coping strategies that the patients used had an impact on their quality of life in various ways. It was also found that maladaptive coping strategies, such as denial and alcohol abuse, were associated with psychological distress and subjective disability in a study of 89 psoriasis sufferers which used 4 different questionnaires (Hill & Kennedy, 2002).

The quality of life of the family members and partners of people with psoriasis may also be affected in various ways. At least one study showed that several aspects of everyday life are affected, including having to do extra housework, anxiety and worry about the patients' future, social disruption, and limitations to holiday plans, sports and leisure activities and evenings out, limitations to shopping, work, and time spent with other family members (Eghileb, Davies, & Finlay, 2007). Thirty seven percent of these family members felt that their close relationships had deteriorated. The quality of life scores for the family members and partners was more closely related to the quality of life scores of the patient than to their objective disease severity score (Eghileb et al.). Quality of life must be assessed in both the person with psoriasis and their family members, especially spouses or partners, in order to get a complete picture of the impact of psoriasis on the quality of life.

### *Living With Psoriasis*

Quantitative studies are valuable for informing us about psoriasis but the literature is not complete without also looking at qualitative research studies; there have been fewer

qualitative studies conducted to explore the influence of psoriasis on the individual. In one study, a sociological approach based on grounded theory was used to explore the visibility of psoriasis and found that the participants felt marked and discredited by their psoriasis and could find nothing positive about psoriasis (Uttjek et al., 2007). Another study focused on a phenomenological approach in which the researchers delved into the lifeworld of one subject and described the effects of psoriasis on the life of the sufferer (Chrissopoulos & Cleaver, 1996). These authors found that interpersonal relationships, self concept, and mood were all negatively affected by having psoriasis.

### Summary of Literature

Psoriasis has serious effects on many areas of a person's life and the lives of their family members. The effect of skin conditions such as psoriasis on overall well being is often underestimated due to the fact that they are most often non life threatening or fatal. The impact on quality of life is not correlated with the objective severity of the disease. The impact on quality of life issues is comparable to those associated with other chronic diseases such as heart disease, diabetes, cancer, and clinical depression.

The review of current literature has highlighted some of the factors that impact on living with psoriasis. There are many parts of the illness experience to be explored to further examine what it means to be a woman living with psoriasis, such as the impact of the physical symptoms, the role of support, and feelings about treatment options. In order for nursing to provide holistic care to those living with psoriasis, it is important to increase the knowledge and understanding of this phenomenon. This will allow nurses



and other health care professionals to better care for and support these people in many aspects of their care.

## CHAPTER 3

### Methodology

A phenomenological methodology was used to investigate the experience of living with psoriasis for women in Newfoundland and Labrador. Nursing embodies care of people as human beings. Nursing practice is grounded in a holistic belief system in which nurses are involved in caring for body, mind, and spirit (Streubert-Speziale & Carpenter, 2003). Phenomenology is well suited to studying the lived experience of psoriasis in women as a phenomenon which requires a holistic perspective. In this chapter, I will first provide a brief description of phenomenology as a guide for the study. The second section contains the methods used to complete this study, including a description of the recruitment of participants, data collection and setting, data analysis, credibility of findings, and ethical considerations.

#### Phenomenology

van Manen (2007) defines phenomenology as the study of one's lifeworld with the aim of gaining a deeper understanding of the meaning of experiences. Phenomenology as a methodology enables the researcher to understand and explain phenomena in the human consciousness and describe the essence of a phenomenon, or what makes the experience what it is (van Manen). Phenomenology has been described as a human science; a scientific study of human activity in order to have greater understanding of how humans act and react as they do. Phenomenology attempts to explain the meanings of experiences as we live them in our everyday existence, known as our lifeworld (van Manen).

Thoughtfulness is a key concept of van Manen's method and is critical in the search for what it means to be human. Thoughtfulness is a quest to interpret a phenomenon by looking into all facets of that phenomenon and trying to determine the meaning or the essence of the experience. Thoughtfulness encompasses using four existentials, lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relations (relationality) as guidelines for reflection (van Manen, p. 101). Through this reflection and thoughtfulness, the researcher searches for themes in the data that allows for a greater understanding of the lived experience.

This study was guided by the six research activities as outlined by van Manen (1990, p. 30-31).

1. turning to a phenomenon which seriously interests us and commits us to the world;
2. investigation of experience as we live it rather than as we conceptualize it;
3. reflecting on the essential themes which characterize the phenomenon;
4. describing the phenomenon through the art of writing and rewriting;
5. maintaining a strong and oriented pedagogical relation to the phenomenon;
- and
6. balancing the research context by considering parts and whole.

Living with psoriasis is a phenomenon that has interested me throughout my nursing career. A large number of patients have this disease and it is often a secondary condition to the cause of their seeking care. Psoriasis is often not seen as an important issue in clinical settings where another acute, perhaps life threatening illness is the focus of the treatment and care. The psoriasis may be seen as a secondary condition, yet, as the

review of the literature demonstrated, psoriasis has an enormous impact on the lives of those who have this condition.

The phenomenon of living with psoriasis was studied through the lived experience of four women who deal with psoriasis on a daily basis. Lived experiences were obtained through one interview with each woman. Once all the interviews were conducted, the transcripts of the interviews were read and reflected on and the themes were identified and reworked several times until I was confident I had identified the essence of this particular lived experience. The results allow for an understanding of the lived experience of the participants by looking at the whole as more than the sum of its parts; psoriasis is a multidimensional condition which must be looked at in the context of the person living with psoriasis.

By following the six research activities listed above, the lived experience of the individual was explored. Phenomenology does not seek to be predictive or offer explanations into the phenomenon (Morse, 1994). What it does is offers the possibility of understanding the experiences of the people living the phenomenon, encourages reflection on the meanings, offers the possibility of 'plausible insight' into the phenomenon, and brings us into the world being investigated (van Manen, 2007). By conducting this study, a greater understanding of the lifeworld of women living with psoriasis was gained and through this understanding, nurses will potentially be enabled to offer more holistic care for these women when the opportunity arises.

## Methods

### *Participants and Recruitment*

Participants for this study were four women between the ages of nineteen and sixty. These participants were from a city in eastern Canada and surrounding areas, as I wanted to conduct face-to-face interviews and needed to keep travel to a minimum due to time and cost. The women were all able to speak and read English as language is an important aspect of the data and that was my language as the researcher of the study. All of the women had been diagnosed with psoriasis for a minimum of one year that had required treatment prescribed by a physician. I selected these inclusion criteria as I wanted the participants to have had time living with this condition and the treatment. Although the number of men and women are equally affected by this condition, women were the focus of this study. Women have a unique perspective of psoriasis due to the outward visibility of its presentation and the stereotypical view of a woman that emphasizes outward appearance.

Participants were recruited with the assistance of a local dermatologist, both in his office and through the dermatology treatment center in the city. The dermatologist and the treatment center are under the administration of the Eastern Health Board of Newfoundland and Labrador. This physician was contacted through his office regarding the study and agreed to meet with me to discuss my recruitment needs. He enlisted the assistance of his research recruiter who recruits participants mainly for clinical trials of new treatments and had access to over a thousand women living with psoriasis. The research recruiter supplied me with the names and contact information of three women

fitting the inclusion criteria for the study. All of these women were first contacted by the research recruiter and had agreed to speak to me as potential participants.

To increase the number of potential participants I also requested permission to ask for the aid of the nurses working in the treatment unit. The nurses indicated they were willing to assist me, however during the time of recruitment, the number of patients involved in treatment at the unit who met the criteria was low and they could only provide one additional potential participant's name. At least one other potential participant was approached in this unit, but declined due to the time commitment. Both the physician and the dermatology treatment unit were given a copy of a letter requesting their assistance (Appendix A).

The potential participants meeting the study criteria and interested in further information about the study were given a one page information sheet explaining the study (Appendix B). Those who were interested in gaining more information about the study filled out a form with their name and contact information which I later collected from the office and treatment unit. I contacted the potential participants to provide further information about the study and answered any questions they had. Interviews were scheduled with the four women who indicated they were interested and they signed a consent form before data collection began.

### *Setting*

The setting for all the interviews was a small, comfortable, private room at Memorial University School of Nursing. To maintain the participants' confidentiality, the meetings were held outside of the normal school hours and at the participants' convenience. The participants were given a choice of location; either at the School of

Nursing or in their homes and all chose the School of Nursing. Since the interviews were all held in the evening, there was little noise or distraction. These conditions provided both privacy and comfort for the participants.

### *Data Collection*

The data were collected in one initial unstructured interview per participant, each interview lasting approximately one hour. If needed I facilitated the participants in discussing their lived experience by using open-ended, clarifying questions. The interview generally followed the participant's lead; however Appendix C contains a list of possible questions that were used to guide the interview and to facilitate the participant's discussion.

All the interviews were audio taped with the participants' written permission. None of the audio tapes contained any information which could lead to identification of the participants. Upon completion of the interview, it was sent to a transcription service to be transcribed verbatim. Prior to data analysis, I checked each of the transcribed interviews with the audio taped version to ensure the text was accurate.

### *Data Analysis*

Data analysis began by reading through each of the interview texts carefully to get a sense of the experience as a whole. Next, I read through each of the interview texts and identified significant statements made by the participants about what it was like to live with psoriasis. I took each of these statements and then looked for the meaning of each of them. This approach has been identified by van Manen (2007) as the "highlighting approach". Once I had highlighted significant statements in the four interviews, I completed a thematic analysis on this data. Thematic analysis involves identification of



common threads that extend through the series of interviews (Morse & Field, 1996). This was facilitated by reading and rereading the interviews, reflecting on the themes and then writing and rewriting as complete of a description as possible of each of the identified themes. The themes are supported by direct quotations from the participants. I noted my thoughts and any emerging themes during data analysis and I identified any assumptions I had about the phenomenon being studied as to not inject any bias into the analysis.

### *Issues of Rigor*

Accurate representations of the participants' experiences are ensured through rigor. Lincoln and Guba's (1985) model for qualitative research uses four aspects of rigor or trustworthiness that need to be applied to research- credibility, dependability, confirmability and transferability. Credibility is the believability of the results of the study. In qualitative research, the participants must judge the believability as they are the only ones who can judge the result, as it is their lived experience. Credibility can be achieved by having a lengthy engagement with the participants (Streubert-Speziale & Carpenter, 2003). This was done through an in-depth interview with each participant in which I tried to make sure I understood what they were telling me. The use of clarification throughout the interviews enhanced the quality of the data. All the women were clearly able and freely willing to talk about what it was like to have psoriasis and were actively engaged in the interview process.

Dependability is the researcher's need to account for the constantly changing context in which the research occurs, as the participants' lives change every day. Confirmability is the ability of the results to be corroborated by others, which is difficult to establish in qualitative research. Dependability and confirmability are enhanced by the

researcher when he or she leaves an audit trail. The audit trail can be easily reviewed by peers who would reach similar conclusions (Streubert-Speziale & Carpenter, 2003).

Throughout my data analysis I worked closely with my thesis supervisory committee who also had access to my transcripts. We met and discussed the early themes, how I came to the identification of the themes I did, and eventually came to an agreement on the final form of the themes. Since my committee members had a copy of the interview transcripts, they were able to confirm the identification of a particular theme.

Transferability allows the findings to be applied in other contexts or similar situations. This is helped through thick descriptions that define the context of the sample population (Streubert-Spezial & Carpenter, 2003), however it is the user of the research that determines whether the findings are transferable to his or her situation or not (Lincoln & Guba, 1985). The goal of phenomenological research is to provide in-depth understanding and knowledge of phenomena, rather than generalizability and therefore transferability in these instances must focus on similarities under similar conditions or contexts (Leininger, 1994).

### *Ethical Considerations*

Phenomenology is a human science and as such includes human participants in the research. The inclusion of human participants in research means that there are several ethical considerations that must be addressed.

*Adherence to the Tri Council Policy Statement.* The research followed the principles and policies contained in the statement of the Tri Council Policy Statement regarding ethical conduct for research involving humans (CIHR, NSERCC, & NSHRCC, 2005). The research study was approved by the Memorial University Human

Investigation Committee prior to the study's commencement. See Appendix D for approval from the Human Investigation Committee. The particular ethical aspects that needed to be considered were informed consent and risk, and confidentiality.

*Informed consent and risk.* During the initial meeting with the participant, the purpose and procedure of the study, maintenance of confidentiality, and the rights of the participant to refuse to answer any question, or to withdraw from the study at any time without their treatment being affected in any way were discussed. I reviewed the consent form with each participant and clarified whether or not she had any questions or concerns about the study prior to asking the woman to sign the form. Permission to be interviewed was granted to the researcher through the signing of a consent form.

Although the participants were informed they would not directly benefit from the research process, they had the opportunity of sharing their thoughts and feelings in regard to the experience of living with psoriasis. For some women, this was a helpful experience. One woman commented on how she was glad that this study was being done to get the message of what it is like to live with psoriasis out to the public. I felt that the potential for psychological harm in this study was low, but was aware that talking about this experience had the potential to create some emotional discomfort or distress in some of the participants. There was no emotional distress evident during the interview while sharing this personal experience, therefore, I did not deem it necessary to contact any participant regarding follow-up and no participant needed referral to an appropriate support person.

*Confidentiality.* Participants were informed how confidentiality would be addressed. Personal information was not shared with others and the interview tapes are

being kept under lock and key in my office and are accessible only to me. Real names of the participants did not appear on any form of data that were collected during the study. Only members of my supervisory committee had access to the transcribed tapes and they did not have the names of any participants. The original transcribed interviews are also locked in my office. The participants were informed of this and that the transcriber was asked to take an oath of confidentiality on the chance that the participants' voice may be recognized. I remain the only person who knows the identity of the participants. Participants will not be identified in any way when presenting the findings of this study.

## CHAPTER 4

### Findings

In this chapter I will present the findings from the research. The chapter is divided into two sections. The first section is a brief description of the participants who took part in the research. The second section contains the themes that were identified from the interview data.

#### Participants

Four women volunteered to take part in this study. There were several similarities among them. There were, however, several distinct differences and the data captures some of the diversity of the women's life experience while still enabling a description of the lived experience of having psoriasis.

The four women ranged in age from late thirties to early fifties and all have been living with psoriasis for several years, the minimum being eight years. Two of the women were diagnosed with psoriasis at age 17, one at approximately age 13 and the other not until age 31. They were all engaged in active treatment regimes and had received a number of treatment options over the years.

Three of the participants were married or in a long term relationship and had one or more children and one was single and did not have any children. All the women were from Newfoundland and Labrador and were Caucasian. The educational level of the participants ranges from completion of high school to having a post-secondary degree. All four women worked in full time jobs outside the home in various capacities.

## Themes

Analysis of the data resulted in eight themes being identified that seemed to provide a more complete picture of the experience of these women than has been previously identified in the literature. These themes are: 1) More than just a rash – the physical symptoms; 2) Understanding from others – support; 3) Creative clothing – covering up; 4) The good, the bad, and the scary – treatment options; 5) Looking for answers; 6) Managing the public gaze – avoidance; 7) Knowing triggers – observing patterns; and 8) Moving on – developing comfort.

Taken together these themes allow for a greater understanding of these women's lived experience of having psoriasis. These themes are not presented in order of importance, neither one being more important than the next.

### *More than just a rash – the physical symptoms.*

While the outward or visible physical manifestation of psoriasis is in the form of a rash, the experiences of these women with the physical aspects of this condition demonstrated that it is much more than having a rash. One factor common to all the women were the number of physical symptoms that each experienced because of the psoriasis.

*I had these little spots that were coming out red... and the spots started getting bigger and bigger and they were getting itchy.*

Others described the other physical manifestations of the condition, how invasive it was as it spread over their entire body, how they experienced the 'rash', and what some of their fears were as the condition spread.

*I had this horrible flaky, itchy rash almost everywhere, on my arms, legs, back, bottom, and a few spots on my stomach. The only place I didn't have it was on my face and that was what terrified me as it spread, would it get to my face?*

Along with the outward rash, there was also a physical discomfort associated with the rash. Psoriasis was experienced as something that caused pain and made the women aware of their bodies in other ways; as a discomfort. The physical discomfort frequently impeded their activities of everyday living because of the pain and discomfort they felt.

*Sometimes your knees are sore, trying to lean down and put stuff on the shelf and that and you're trying to get up because it hurts, it cracks sometimes if it's not really moist, if it dries up and stuff so it cracks a bit, its sore and if you strike yourself it hurts, you know.*

Two of the women had developed psoriatic arthritis, a common sequelae of psoriasis which carries with it its own pain and stiffness primarily in the joints (Young, 2006). The arthritis and symptoms associated with it demonstrates how pervasive the physical symptoms could be and how daily life could be affected.

*Now I have arthritis too... There are mornings that I get up that you know you kind of have to sit on the edge of the bed and make sure that everything gets moving before you take a step.*

*Now my bones are sore and stiff which is arthritis, and psoriasis does bring on the arthritis for most patients.*

The women felt that people who had not experienced psoriasis could not fully appreciate the seriousness of the physical symptoms. Since the main manifestation of psoriasis is a rash on the skin and pain is not something normally associated with a rash, psoriasis would not be seen or understood to have the repercussions it has for the person affected.



*I think for me the worst part is the pain. I don't have as much itching as pain, I still have the itching, but for me the pain is worse. When you are moving around, you just feel like your skin is pulling and tearing and it hurts. Yeah, it is painful and I don't know if people realize that.*

Other than the rash, the women described such symptoms as itching, flaking of the skin, and pain. The symptoms were quite distressing and made the women more conscious of their bodies. For example, they were constantly aware of leaving skin cells around from the flaking. Flaking of the skin was a source of embarrassment. They talked about always being aware of “flakes” on their shoulders from the itching and flaking of the scalp.

*I was scratching and constantly checking my shoulders and flaking into peoples lunch or something.*

Many people can relate to itching, as most people have had this symptom at one time in their lives, whether from an allergic reaction or an insect bite. Usually those conditions are self-limiting but, as the participants indicated, this is usually not the case for individuals with psoriasis. While occasional itching can be unpleasant, it is another thing to live with this sensation on a daily basis. The itch can be relentless and scratching may cause the already damaged skin to crack and bleed.

*I could say to someone who doesn't have psoriasis “Oh I feel lousy today, its itchy, I can feel it cracking”; They have no idea what you are talking about. They don't know how bad it is, they don't know that underneath your clothes you probably got a spot of psoriasis and there's a crack in it and you can feel the blood running down from that.*

### *Understanding from others – support*

Having psoriasis has a huge impact on the women's lived relationships – relationships with family, friends, and others they came into contact with during their daily lives. Needing and having support was a big part of all the women's experiences in their day-to-day struggles with psoriasis. In fact, the issue of support emerged in all the interviews. There were several different sources from which the women received support such as family and friends, co-workers and employers, and health professionals. Not surprising many turned to and received support from their immediate family. One of the women found her parents and siblings to be very supportive of her.

*My family is my support...my mother knew what I was going through and she is around to this day and sees me cripple up, moaning and groaning about the arthritis and my father too, two of them are real good supports. They are my support, I have to be honest with you, anytime that I've been in a bad mood when I'm in the throws of an outbreak and they'll do whatever they can. They put up with the smell of the tar shampoos, tar body lotions and stuff like that.*

Other participants acknowledged that while their family and friends were supportive, that support went only so far, as they were either unsure of the other person's true feelings, or unsure if that person truly understood what they were going through. Having psoriasis affected the quality of their personal relationships and thus the level of support the woman had in that relationship.

*Now I'm involved with another person and he understands, he's understanding to a certain degree. He's not going to come out and say... "well I don't want you near me or you know" ... it's hard to describe.*

Others questioned the level of understanding that friends and families could be expected to have under the circumstances. Can other people who do not have psoriasis

really understand what it is like to have this condition? While other people can see that it is difficult for the person affected, do they understand fully? And how do you deal with seeming detachment from your spouse that one of the participants described? The need for understanding and someone to talk to came through in many of the interviews.

*I can talk to my friend about it and she can see the toll it takes but I don't think she truly understands... My husband doesn't really want to hear about it, I don't think. He doesn't seem to mind me having it, or has never said anything but you always wonder what he is thinking about it, especially when it was really bad. I was always a little self conscious about it and there were times I had to ask him to help me put on lotions on patches that I couldn't reach, or on my scalp. He did it but I think he didn't really want to.*

The previous woman's experience of support can be contrasted with another participant who felt that she had a very supportive husband. The second woman's experience demonstrated how important it is to have this type of support. It also reinforces the need for support that these women had and how having the support enabled them to persevere with their treatment and perhaps cope in a more positive manner with the condition.

*My husband is really great too. If I am down about a treatment not working well, he pats me on the back and says that the next one will be better and to keep going with it. He gives me that little push.*

Support from sources other than family and friends helped as well. As all of the participants worked full time outside the home, a large part of their lives were spent at work. Due to the nature of psoriasis, some people had to take time from their work day for treatment applications and/or going to clinics for treatments or physician appointments. If the employer is not supportive of the time required from work to do these things, the women may feel that they would lose wages or their jobs, which would

have a huge impact on their lives, however this was not the case for the participants in this study. Three of the women indicated that their co-workers and employers were very supportive, some with emotional support and also with providing accommodations in the work place and accommodation of time off for appointments.

*My employer has been great about it. For instance, my job usually just involves me being in my office and only my co-workers are in and out, but part of my job is also to relieve on the switchboard and it is more than that, I am out in the reception area of the building and have to greet clients coming in for appointments. Well one time, I was having an outbreak and I had patches coming down low on my forehead and around my nose. I really didn't want to go out and everyone see me like that, and I told my employer how I felt and they were really supportive and told me to just take my time and I didn't need to go out there until I was ready and felt I could do it. They were really great. I don't have any trouble getting time off to go to my appointments either.*

People with psoriasis spend much time trying to hide or cover up their psoriasis and it is difficult to have to go to your superiors at your work place and your co-workers and reveal to them that you have this condition. The participants talked about not liking to go to their employer and ask for special accommodation. Co-workers are different from your family who generally are more accepting. There is no guarantee of acceptance from these relative strangers even though a large part of a person's time is spent with them in the workplace. To get understanding and support from employers and co-workers was very reassuring and important because it meant that they viewed the woman as a valuable asset to the workplace and were willing to make accommodations in order to keep them on the job.

*My co-workers are supportive; I have to say this organization here is wonderful for that... There was never a question here, I went in and said, "I have a problem, I have psoriasis and I have to go and have tar treatment" and I explained it to him and said, "for a period of time I'm going to have to wear jeans sweat sweaters and stuff like that or I could go in hospital. (They said) "You just wear your jeans and sweat sweaters, we would rather have you here than in hospital". They have been fabulous ever since. I do Remicade treatment now and have to leave and go have blood work and I have to take time off to have the infusion done, no problem, never a question.*

Another woman, a shift worker, had no difficulties with her employer arranging her shifts to accommodate her appointments and treatments. She appreciated the concern her co-workers had for her condition. She says:

*The people I work with know I have it and they know I do these treatments and stuff. There's one in particular, I'll say I'm going to my doctors appointment or whatever and he's sensitive because he'll say "How are you doing with it or "is it worth it, are you coming around?"...He'll make a comment that you feel that at least you know he is a little bit concerned.*

Another source of support that was discussed by the participants was from health care professionals involved in their care. Most of these experiences were positive, which assisted the participants in accepting or coping with the disease and treatments. For the most part, the physicians and nursing staff involved in these women's care were positive influences.

*My doctor has done so much, I keep going back to him but he has done so much for people with psoriasis in this province, the man deserves a medal...He has always given that hope...I was his first patient actually...and his comment was well, "were going to try this and if that doesn't work, we'll try this and if that doesn't work, we'll try this".*

The participants encountered nurses at the dermatology treatment unit who are specially trained to provide treatments to those suffering from psoriasis. These nurses

dealt almost exclusively with diseases of the skin and the people who have them. The nurses interact with their clients and listen to their issues, both physical and psychosocial and through this have gained an understanding of what it is like to live with a skin disorder. Thus, they were able to offer support based on this clinical experience and that support had a big impact on how the women felt about their clinical appointments.

*They were so great, I guess they understood and had probably had people like me before, they were so great, they didn't get mad back, they were just always nice to me. I remember the first time that I had to go into the UVB booth and the nurse said to take off my Johnny coat so she could see my skin. Well, I was naked and I was not taking off that gown in front of her, a stranger. I almost walked out but she was very good at talking me down, and she did get me to take off my gown so she could see. I think she made me understand that she understood how I felt and that this was actually necessary.*

The most significant source of support for the participants came from others who are also living with psoriasis, whether they were family, friends, co-workers, or relative strangers. One of the women had others in her immediate family with psoriasis. She found that this was helpful at the time of diagnosis as she already knew something about the condition. It also meant that her family was familiar with the disease and its manifestations. One commonality with regards to support was that all the women felt that there was a great deal of support and understanding among other psoriasis sufferers. They felt that they could truly relate to these individuals because they have had similar experiences. One woman had siblings with psoriasis and found them supportive. Another participant found her co-workers who had psoriasis and the workplace became a good venue for discussing issues:

*Well I have a few co-workers and ex co-workers who have it and we have talked about different things, they know what it is like.*

Two of the women spoke of meeting people at the dermatology unit and finding others there who could understand what they were going through. One of the women even went to the unit on request from the nursing staff to act as an informal support person to other women with severe psoriasis.

*It is better to talk about it with someone who has it. I met a few people who had psoriasis when I was going to the derm unit and we would chat about it while sitting waiting.*

One woman described an informal support system that she has noticed in her social interactions. She found that wherever she went there were others with psoriasis. She found that the commonalities of the effects of psoriasis brought people who had the condition together and resulted in informal support. If someone else has the same problems as you have, the understanding is there already, and there is no need to try to explain what it is like. Experiences can be shared, understood, and support given without difficult and embarrassing explanation.

*There's a support group among psoriasis people, it may not be out there in the open, but its there. You go where there's a bunch of psoriasis sufferers and they are going to be the group over in the corner having a chat about the aches and pains... You had a comradery because we all had the same aches and pains.*

#### *Creative clothing – covering up*

Having psoriasis, especially if the woman did not want the physical manifestations visible, meant some lifestyle limitations. Nowhere was this more evident than in their choice of clothing. A theme that ran throughout all the interviews was the fact that the women had to adapt their wardrobe at one time or another to hide the rash or flaking. Wardrobe adaptation often included hiding the rash because of embarrassment, other



times it was to help in avoiding questions or stares, or for some it was simply for comfort. The amount of time and thought that went into the planning of the wardrobe around psoriasis was considerable.

*You'd go out and you would wear long sleeves and long pants all the time, no matter what you were doing, and then you wouldn't have to explain that this rash is not a disease, it is just a skin condition, you can't catch it.*

One woman talked about how embarrassed she was by the flaking of her scalp and likened it to having dandruff. When she had a flare-up she had to limit wearing her favourite color, black, as it showed up the flaking from her scalp. However, when her psoriasis was not bad she was able to wear black clothing.

*I love wearing black, I can now more so because mine [psoriasis] is not (bad) ...it's just like having dandruff if you got it in your scalp...it's embarrassing, it's uncomfortable but you got to live with it.*

Another woman who also experienced visible flaking of her scalp stated that she primarily wore white tops to hide the flakes. She did not like this limited choice of wardrobe. She found that when she wore a color other than the white she usually wore, it made her psoriasis more 'visible' and she discovered that it would come up in conversation with others.

*The other thing is your clothes. I have so many white shirts it is not funny. One day I wore red or pink or something because I was so sick of white and my psoriasis wasn't too bad at the time, and you would not believe the number of people who commented that looked great in color and why didn't I wear it more. Well, after explaining it to a couple of people, I gave up and said yes, sure, like whatever, I just didn't want to talk about it anymore.*

The clothing choices for some people with psoriasis are much more complicated than having to wear white tops. One woman described how much thought about the

condition went into a shopping trip. There is more than ‘do I like this item’ and ‘will it fit me’ for the person with psoriasis. There are such aspects as how to conceal the rash that must come into play; making clothes shopping a more complicated endeavour rather than an enjoyable process.

*Everyone goes out and sees a dress and says, “oh I’m going to buy that if it fits me great”. Psoriasis patients says, “okay, if I’m having an outbreak is it long sleeve, is it long enough, does it cover up the psoriasis”, if you buy pantyhose if you are in the throws of an outbreak, are they dark enough so that no one is going to see the spots of psoriasis through them?”*

#### *The good, the bad, and the scary – treatment options*

Managing psoriasis meant having a treatment that the condition responded to and while that may sound simple, it was not. Treatment was a huge issue for all of the women as was the diagnosis. Some of the participants described how they had a problem getting the correct diagnosis from general practitioners. Even some who received the correct diagnosis early did not necessarily feel that they got the best support or treatment at that time.

*I went to see my family doctor, but she was away and the person replacing her told me that my hair was too thick and heavy and that I should cut it and the rash would go away. That wasn’t an option for me and was really ridiculous, so I went to a different doctor who gave me some stronger shampoos and referred me to dermatology. I had a pretty long wait at the time to get in to see dermatology, I think like 10 to 20 months.*

One participant felt she was not given any “real” medical treatment and was told only to keep her skin moisturized which, although an important part of psoriasis treatment, is just that, a part of the treatment. Medication or other proven therapies are necessary to keep psoriasis under control.

*The doctor just told me to keep it well moisturized, to keep Vaseline on it all the time and that was pretty much it.*

One woman recalled how relieved she was that she finally had a diagnosis and the way the doctor presented it led her to believe that psoriasis was easy to cure. Because psoriasis is a skin condition and usually not life threatening, sometimes it is not treated with the same consideration that other chronic conditions are even though it can be clearly as devastating to the person who is affected by it as other chronic conditions.

*I went to my doctor and I remember I was so happy because his words to me were "Oh that's nothing, it's only psoriasis", so he gave me some cream and I walked out of his office thinking this is going to be one in ten days. Its thirty four years later and it's still not gone, so it's not only psoriasis and anyone who thought (that) should get a kick.*

Currently there is no cure for psoriasis, nor does everyone with this diagnosis respond to the same treatment regime (Nijsten et al., 2005). There are many and varied treatments for psoriasis ranging from creams and ointments, to UV light therapy, to systemic medications. Patients who have had moderate to severe psoriasis for any longer than a few years have usually had several of these treatments in a series. This was certainly the situation for the participants. In addition, with each of these treatments there is a time commitment that is far beyond the treatments for many conditions which often involves taking oral medication and following up with physicians at various frequencies.

People with psoriasis generally start out their treatment journey with creams, ointments, shampoos, and moisturizers that must be put on in various combinations, at various times in the day, often several times a day. Some of the participants went through these treatment regimes but did not have promising results from these types of treatments:

*You always had to be putting creams on or trying to find a cream that worked for you and a lot of them didn't work. A lot of the creams didn't work because if just wasn't strong enough or it just didn't work.*

Local applications of creams or ointments were found to be messy, uncomfortable, and bulky. One participant recalled one treatment that stained her skin, so that even when the psoriasis had cleared, she still had a reminder of where it was.

*We used to do a treatment called anthralin, a purified form of tar on your spot, then you put powder over that and then they bandaged you with this cast material and they tied it all together and off you went. Anthralin stains your skin so when your psoriasis went away, if it did go away, there was still a dark spot, it looked like a bruise.*

The time commitment of these routines and the other unpleasant factors that went along with them caused two of the participants to give up on the creams or not follow the prescribed regime:

*I am now intimately acquainted with the whole psoriasis treatment gamut, and let me tell you there are a lot of treatments out there, of course, none of them seemed to really work for me. Perhaps I am partly at fault though; I really couldn't seem to make the time to do all those routines. I have a super busy life, with my job, and my kids, and then to try to have time to do this complicated routine of moisturizing and putting on creams in a certain order and different ones at different times of the day. Then coating your head in this really oily lotion at night and then having to get up and try to wash it out, and I mean try to wash it out, it was really hard to get out and then you have to go around looking like you didn't wash for a few days.*

Sometimes it was the smell associated with the treatments that made it difficult to remain with the treatment. For some participants, it was a balance of not having a strong odor associated with the treatment versus finding something that would control the psoriasis. It was a difficult choice.

*And the shampoos that you had to use... they stink, plain and simple, they stink. You have to go around smelling like tar all the time and who wants that. My kids used to say, "Mommy why does your hair smell like when Daddy fixed the roof?". It was disgusting and if small kids notice it, you know that everyone else can smell it too and just don't want to say anything. It was all too much for me. I just stuck to the simpler creams and the non smelling shampoos and they didn't work that well anyways.*

At times the treatment seemed to be more experimental in that the women would receive a new topical treatment when they went back to see the specialist. Some felt disappointed that the treatments were not more effective in controlling their psoriasis.

*The dermatologist always gave me something new to try but again with the complicated routines, and as soon as you missed a day or two I found that my psoriasis would come back with a vengeance, it would be even worse than before. None of the creams worked for me and they just stained my clothes, the tar based ones.*

One participant found the time commitment to be quite overwhelming at times and she decided to discontinue treatment. She also sustained damage to her clothing and bedding as a result of the treatment. The stains left behind by the treatments were a reminder of the psoriasis. It is also costly for these women to have to replace clothing and bedding.

*The treatments are time consuming, especially when I was on the creams and ointments, but I won't do them now, I said no way. You have to put cream on in the night and wash it off in the morning and use tar shampoo and then put on a different cream after the shower and then moisturize during the day. The creams would ruin your bedclothes and your clothes would get stained.*

The routine of creams and ointments is only part of the time factor involved in psoriasis treatment. Even when the women were not undergoing these treatment routines, the alternative treatments also took time, whether it was visiting the dermatology



treatment unit for light treatments or bath treatments or visiting the physician's office for follow-up or to receive IV or other injectable treatments:

*Well there are the treatments, and they take a lot of time. I have been on every treatment available so far I think, the lights, baths, I have been on oral treatments, like cyclosporine and methotrexate and they worked for a while and I was on the intravenous treatment, remicade, and on a few others where I had to go get needles every month and it takes about an hour...you really have to plan your life around them.*

The time spent involved with psoriasis treatment took time from other activities that the women felt they could have been doing. All the women had busy lives, all were employed, and three had children which meant that the time spent in treatment was time taken away from their families, jobs, and social lives. It required extra planning for them to live their lives with psoriasis, it was another time commitment to be fitted into already busy schedules.

*Everything to do with psoriasis treatment takes a lot of time from other things. Whether it is putting on creams or washing off creams and putting new ones on, or going to the derm unit and getting treatments there or now going to get the injections, it all takes a lot of time...you really need to plan your life around it.*

There is currently much ongoing research to find new and improved treatments for psoriasis and all of the women in the study had at one time or another been involved in clinical trials for new medications for psoriasis. Prior to involvement in a clinical trial the women had been on other systemic medications to treat their symptoms. While these treatments had some effectiveness, the women were concerned about the possibility of serious side effects from these medications.

*Cyclosporine® was one I really worried about...that's a transplant drug, that's really heavy duty. You know its funny, you kind of block things out, I did the trials on cyclosporine and that's heavy duty but I refused to do anything to do with*

*methotrexate, now cyclosporine is just as bad as methotrexate but it was just the word methotrexate and the word cancer, this is a cancer drug and I was just twenty five years old.*

One woman talked about her worry over the medications that she had been taking but now prefers to look at the benefits and the risks together. However, she does have some concerns in the back of her mind about the future and if these drugs will result in any serious side effects down the road.

*I was a bit worried about (the medications) but I don't think about it much. I have to look at the benefits of them too. I worry about cancer though...I have pretty well accepted that I am going to get cancer at some point so I just hope that these drugs don't speed it up.*

Although the women do continue to worry about the side effects, they were willing to take the risks. They weigh the risks against the benefits of the treatments and decide that the benefit of having clear skin is worth the risks.

*I am on a good drug right now and don't have very much active psoriasis right now. I have to go every month for injections of this drug and there are some risks but I try not to think about them. Sort of like when I was spending a lot of time in the sun, you look at the risks and the benefits and just do what you can to keep your skin clear.*

Another reason that the women said they did not mind trying out these medications was altruistic; they wanted to help others in the same situation that they were in find some relief from this condition.

*I have been in a lot of studies over the last 8 or 9 years. Some of them have been great and some didn't work for me at all, but I figure that someone has to be the guinea pig and why not me, it might help someone down the road.*



There was a feeling that even though there may be some unpleasant and potentially serious side effects, it was important to take part in the clinical trials. One woman felt that even if the medications she is testing harm her, she is doing her part to help someone else who is suffering from psoriasis. She felt her efforts were not in vain.

*There might be some side effects but there's someone down the road that might need this and without me testing it they'll never get it so that's what I look at and I don't worry about side effects anymore. If it happens, if happens. If I pop off tomorrow, I pop off tomorrow but at least I've done some good, right?*

#### *Looking for answers*

A common experience for all the women was a search for a 'cause' of the psoriasis that went beyond knowing about the etiology of the disease. It was a search for why they were the person to be afflicted. All of the women reported strong emotions upon diagnosis and realizing the effect of this diagnosis. The predominant feeling was that of being devastated. They wondered why they had gotten this disease and looked for answers within themselves and their families:

*I felt self conscious and then I had the 'why me's'. Like, why did I get this. I am not a bad person, why didn't so and so down the road get it, she's not that nice.*

Anger was also a common reaction to the diagnosis and manifestations of this disease. One woman felt that she had enough going on in her life and she did not need any more problems.

*Pissed off, probably. Yes why did it happen to me, I had enough you know?*

Some of the women had an idea of what psoriasis was and what it entailed because other family members had the disease. For one woman, psoriasis was completely

new. She had never been in contact with the disease before and wondered what it was about her that made her end up with this condition.

*I never saw anyone with psoriasis before. I was the first person that I had ever heard of having psoriasis and that's exactly what came in my mind was, what did I do? You know, what did I do to deserve this? Did I eat something wrong, what caused it, what was it and at that time no one knew it was genetic.*

After the initial feelings of anger and wondering “why me”, some of the women felt that if they could find a cause and then get a treatment that worked, they could deal more effectively with the disease.

*After I got over the anger and the bad case of why me's that I had, I tried to look for what had caused it in me. I had gone off birth control and thought that maybe that had caused it, or a change in my diet, or something in my house, or anything.*

Psoriasis has a genetic component and researchers are at the early stages of finding out more about the genetic aspects of this condition. Two of the participants were familiar with this possibility as their siblings had been diagnosed with psoriasis before they were but another was not as aware of this component of psoriasis upon diagnosis. One of the participants had no one in her family history that she was aware of that had psoriasis. While looking for a cause, one of the participants discovered an extensive family history:

*I started asking around my family and although no one had ever talked about it, I found out that I had several aunts and uncles on both my mother's and father's side that had it. I was like, why didn't anyone tell me this before? This now makes more sense.*

Two of the other participants also found a family history of the condition after their diagnosis. Psoriasis can be a hidden condition among family members and as these

women's experiences illustrated was not talked about openly in these families. One participant found out about a strong family history by accident when talking about it to a cousin she met at a family gathering.

*I told her I was 'lucky' enough to have psoriasis and she had this look of relief on her face and told me that she is being treated for it up in Ontario and the doctors were baffled because she didn't know anyone else in the family had it, so she was really relieved that she had found a link. When we started thinking about it and talking to the other family that was there, we realized that a lot of our older relatives like grandparents and aunts and uncles had it too, but it wasn't something that you talked about much really.*

A consideration with any genetic disease in women is the impact it might have on their decision to have children. Only one of the women had been diagnosed with psoriasis before she had children however she said that that having psoriasis did not factor into her decision to have children. She was relieved that her child does not have psoriasis. Two of the women were diagnosed shortly after they had children and were unsure whether or not they would have reconsidered having children had they been diagnosed earlier. One participant who was diagnosed in her teens made a conscious decision not to have children:

*The reason I wouldn't have children is because just the thought of passing on the gene and possibly having a child go through what I've gone through and you know I said, "I can't do it". I've never had children.*

One of the participants had two children who have psoriasis and she feels guilty about passing on this genetic disease to her children:

*One winter a few years ago, two of my kids got this rash, well, I freaked. Now I knew a lot about the disease by this time and knew it was passed on through families but that didn't make me feel any less guilty. I couldn't help it but I knew what I was going through and they were only little kids and had a long, long time to suffer with this.*

*Managing the public gaze – avoidance*

Having a skin condition that manifests itself as a rash that can be visible to others carries with it a special kind of stress. Many chronic diseases have no outward signs and a person can choose whether or not to reveal their condition to others. Psoriasis is visible unless the person goes to great lengths to cover it up. If uncovered, it can draw the gaze of the passer-by. It is human nature to look at anything that is different. The physical manifestations of psoriasis may elicit many emotions from curiosity, to pity, to fear of contagion. The participants realized this, however, as the ones being stared at it was an unpleasant sensation and they tried to avoid the gaze.

Some of the women talked about periods in their lives where they avoided going out in public or doing activities where their psoriasis may be exposed. In order to avoid unwanted attention due to psoriasis, one woman used her children and the time and care they required as an excuse for not going out in public.

*I also used having kids as an excuse to not go out a lot for a while, saying that I was busy with the kids was easier than explaining that I felt like I didn't want to go out in public and be scratching and constantly checking my shoulders and flaking into peoples lunch or something. I am OK with going out now that my rash is under control now though.*

Another woman changed her lifestyle when she was diagnosed with psoriasis. She avoided activities that resulted in her psoriasis being visible. She found that this was not a satisfying way to live and adapted again and made another change. She found other activities that she could engage in and enjoy but keep her psoriasis hidden from sight. She carried on with a more normal life, although it may not be the life she would have lived, if she did not have psoriasis.

*I remember my whole lifestyle changed because I just stopped everything, I just didn't do anything...It got to the point where I couldn't switch everything around, I just couldn't go swimming and I couldn't do this, the worse I got I couldn't do it and then I got to the point, well the hell with it, I'm going to do nothing so my life was, go to work and come home, go to work and come home. I never went to dances, I never went to parties, I kind of ostracized myself. That went on for a while until I realized I'm not the only one, am I going to be like this for the rest of my life and if I am, am I just going to put myself in a hole for the rest of my life? So then I went the opposite, I became involved in things that I didn't need people to know that I had psoriasis.*

The participants felt somewhat uncomfortable when looked at and some even had comments made about their psoriasis by strangers that either embarrassed or angered the women. One woman's psoriasis was mistaken for bruises and she was thought to be a battered woman.

*I finished up my grocery shopping, went out and sat in the car and cried and cried because I said to myself, "Christ, I've gone from a skin condition to all this trouble and now they think I'm a battered woman. How much worse is this going to get?"*

Another woman's rash on her arms was mistaken for paint by an acquaintance that was not aware of her psoriasis. She went along with the other person's mistaken assumption to save both of them the embarrassment of explaining what the spots really were.

*I was at a soccer game with my son and just got to chatting with another mom there, and she said to me 'you must have been painting too, look I have paint on my arms to, like yours. Of course, the white spots on my arms that she was referring to was psoriasis spots, but I just went along and made up a story about painting the hall to save her the embarrassment of bringing it up.*

#### *Knowing triggers – observing patterns*

Living with psoriasis for some time and engaging in some of the introspection the women had done into treatments and finding out more about the condition allowed the

women to discover some of the triggers for their psoriasis. Two of the women remarked that sun made their symptoms better and one woman found that sun had the opposite effect on her, making her psoriasis worse. One thing that all of the women had in common was that they found stress had a detrimental effect in their attempts at controlling their disease. Over time, they had noticed the pattern of when they were having a great deal of stress, it was more likely that they would have a flare-up.

*Stress makes my psoriasis worse. If I am under any kind of stress I can almost feel the psoriasis popping out on me. If it's a lot of stress, like if it's really really stressful I have to be really , really careful... When I find myself getting stressed out, I say stop, don't do this to yourself.*

They noticed other triggers as well. One factor that seemed to have a negative impact on these women is an illness such as a sore throat or a cold. Along with the misery that a cold or flu can bring with it, these women also had an added worry of the illness exacerbating their psoriasis.

*If I get stressed at work I can almost watch the spots appear. I really have to watch out when I am feeling stressed and try to control it. If I get a cold or a sore throat or anything, I'll see the spots coming out.*

All four women have found that stress had an impact on their psoriasis and they have all come to the realization that they must attempt to control their stress levels in order to properly care for themselves. One participant related that she needed to take time to eat properly, get enough rest, and make time to relax in order to limit the number of breakouts she got.

*If I am stressed out or run down from being sick or too busy, I will get a worse break out. I really need to be conscious now of eating right and getting enough sleep cause if I let myself get sick or tired, I get worse. Stress is the worst though. I can see a definite pattern in my amount of stress at work and home and my breakouts...I try to unwind and take care of myself now, I didn't do that at first.*

*Moving on – developing comfort*

The women have come to grips with scrutiny from others and have learned to deal with the visibility of psoriasis to the public. They use their wardrobes to cover it and the treatments to keep the symptoms under control. They realize that this is something they have to live with and they live their lives with adaptations:

*I just pick myself up and tell myself I got to go on with it.*

Discovering triggers meant that the women were able to be proactive in trying to prevent flare-ups of their psoriasis. This proactive approach gave them at least a greater feeling of control than they previously experienced.

*You just have to change; you can't let it control your life. I did, I went there, I let it control my life and then I said, 'no it ain't going to control my life anymore'.*

One woman talked about the consequences of living your life around psoriasis, letting it limit your activities and confining you to your house. She felt that if you do not take back your life, getting up every morning and going about your day, you will break psychologically and as a consequence can become depressed. She felt that there are worse things in life that she could be dealing with.

*You have to deal with it or you go insane, you probably wouldn't go insane but like you'd probably get depressed. Like you wouldn't want to go out through the door or wouldn't want to do nothing with yourself, don't want to make yourself even half look respectable or you just kind of go into a hole and stay there. Until somebody gives you a shake and say now there are worse things that can happen.*

The key to a greater acceptance of the disease and being able to carry on with their lives with psoriasis was time. The participants have been diagnosed anywhere from eight to thirty-four years and all of them have found that the passage of time and their

experience has helped them accept that they have psoriasis and will have it forever and that they have to live their lives with psoriasis.

*Over the last 8 years or so, I have come to realize that it is just one of those things that I have to cope with and live with and do my best to control. I take it day by day and I am just thankful for each day that I wake up and don't have any spots coming out.*

One participant felt that the maturity that comes with age and living with psoriasis for a number of years has helped her with acceptance.

*I can accept it now and cope with it much better now than when I was younger, I don't let things bother me so much and I think that some day they will find a cure.*

One woman felt that she needed to give herself time to get used to the diagnosis. The diagnosis is a shock at first but over the course of time you learn what it is that you have to do to cope.

*You kind of have to give yourself a chance to get use to it, like when I first got it, I didn't want to have it. I was kind of upset and everything about it but 'time', that's what a lot of people need, just time to get use to the idea of what you got and what you have to do in order to put up with it.*



## CHAPTER 5

### Discussion

Research using phenomenology endeavours to describe and understand how people experience different phenomena. This study explored the lives of four women living with psoriasis to understand what it is like to live with this condition. Psoriasis had a profound effect on all aspects of the women's lives including the physical and psychosocial realms. Research into these areas is becoming more prominent in the current literature, indicating that the effects of psoriasis on all aspects of a person's life and the lives of his or her family and friends is being recognized as an important part of the holistic care of a patient with psoriasis. Previously, most research on psoriasis was centered on treatment modalities, however researchers are now focusing on wider topics such as psychosocial effects and quality of life issues of living with psoriasis.

Several themes were identified in the accounts of these women's lived experiences with psoriasis. These themes are: 1) More than just a rash – physical symptoms; 2) Understanding from others – support; 3) Creative clothing – covering up; 4) The good, the bad, and the scary – treatment options; 5) Looking for answers; 6) Managing the public gaze – avoidance; 7) Knowing triggers – observing patterns; and 8) Moving on – developing comfort. Some of the experiences captured in these themes have also been examined in the more recent literature, although qualitative literature on the topic is limited. In this chapter a discussion of the findings from the study is presented and the findings are related to the current literature.

*Living With the Physical Manifestations*

Although psoriasis may be perceived to be trivial to some individuals, research has supported the view that psoriasis can be highly distressing (Finlay, 2005; Fried, 1995). People with psoriasis experience a large amount of physical distress. The predominant clinical manifestation of psoriasis is a reddened flaky rash on the skin that can occur in various places on the body and can spread over the entire body. All four women in the study reported physical symptoms that were consistent with the literature such as itching, scaling and flakiness (Feldman, Behnam, et al., 2005) as well as pain (De Arruda & De Moraes, 2001). These symptoms are due to the etiology of the disease in which skin cells replicate approximately eight times faster than in unaffected skin but do not slough off, causing a build up of the dead skin cells (Bren, 2004; Fox Quillen, 2004). This results in a reddened inflammation of the underlying skin and a plaque of silvery scales covering this which results in itching, scaling and flaking of the dead skin cells, and pain due to the inflammatory process (Bren). The description of the disease process does not adequately portray the discomfort and challenges physically that this disease causes the sufferers. This is seen in the women's descriptions of their living with the physical symptoms and the degree of distress they experienced because of their symptoms. Their experience of itching supports the claim by Aerlyn and Yosipovitch (2006) that this is a generally underestimated symptom for those with psoriasis.

Although psoriasis is primarily thought of as being manifested as a skin rash, it is so much more in the physical lives of people with this disease. The physical effects of psoriasis are pervasive and it affects every part of a person's life including activities of daily living, socializing, and working (Finlay, 2005). Although psoriasis has been

described in health related literature since the mid 1800's (De Jong, 1997), the effects of the physical symptoms on the patients' lives has not been heavily researched and therefore are poorly understood. The majority of research on psoriasis in the past has been focused on they physical symptoms or treatments, however this type of physiologic data often is poorly correlated with the well-being of the person with psoriasis (Weiss et al., 2003).

*Physical treatments.* A factor in the physical experience of psoriasis is treatment for the disease. Treatment for psoriasis is focused on abating the physical symptoms of the disease as there is currently no cure available. Treatment options are generally progressive, starting with topical agents, progressing to phototherapy, and then to systemic agents if warranted by the severity of the disease (Khachemoune & Guillen, 2006). The treatments are varied and all the women had gone through topical treatments, phototherapy, and systemic treatments, following the standard progression of treatment modalities. All of the treatments for psoriasis are time consuming no matter which one is used. The topical preparations are often used in combinations that involve a complex routine which must be done several times a day. These methods are often not enough to control the symptoms of psoriasis and have negative side effects such as ruining clothing and bedding and being malodorous. Time required to apply the topical treatments are very time consuming, taking away from other important daily tasks which along with the other side effects can cause non-compliance and non-adherence to the treatment regime. These types of treatments are often not effective, making moving on to the next steps in psoriasis treatment necessary. One common reason people with psoriasis do not have optimal results with topical agents is due to lack of compliance caused by stickiness,

length of time to rub in the agent, lack of efficacy, and irritation caused by the agent (Gottschalk & Johnson, 2007). Since topical agents are the first line of treatment, if they do not produce the desired result, phototherapy or systemic agents are the next step and these also carry their own risk of serious and even life threatening adverse effects (Khachemoune & Guillen).

The experience of the women who took part in this study illustrates the difficulty of adhering to prescribed treatment regimes and how these treatments affect not only their lives but that of family members. Their experiences also speak to the somewhat experimental approach to treatment and the anxiety that this can cause patients especially if the treatment regimes have the potential for serious side effects or long-term outcomes are unknown. Concerns about treatment and side effects also helps understand why patients quality of life could be negatively impacted by treatment (Krueger et al., 2001).

#### *Living With the Psychological Consequences*

The physical effects of psoriasis can lead to psychological consequences for people living with psoriasis. These consequences can include feelings of depression and anxiety, guilt, and problems with self-esteem and body shame (Adams et al., 2001). The women in this study reported frustration regarding diagnosis and treatment, worry over side effects, embarrassment, and body image concerns.

*Diagnosis.* Diagnosis of the disease is not always easy; often it may be mistaken for another skin condition, as many have similar presentations (Khachemoune & Guillen, 2006). Referral to a specialist may incur a lengthy wait which can increase anxiety about the condition. Due to the fact that there are several types of treatments, there may be several attempts to control the symptoms with different medications before an effective

treatment is found. This can add to the stress and frustration experienced by patients with psoriasis. Misdiagnosis and the search for an effective treatment can prolong the time people with psoriasis suffer with having the rash.

The women who took part in this study were relieved to have their skin condition diagnosed and have appropriate treatment. It was only after they had this condition for sometime and learned more about it, what effect it had on their lives, and how to identify triggers that seemed to make the condition worse, that they came to realize what living with psoriasis meant for them.

*Comfort level.* The road to developing a level of comfort with psoriasis is long and convoluted. When first diagnosed, patients may search for reasons why they were afflicted with this condition. They may search for a cause for their psoriasis in their lives such as diet or environmental factors. Anger may be the predominant feeling once the chronic nature of the disease is fully realized. Feelings of anger are common among people with psoriasis (Rolfe, 2004). Some may reach a comfort level with their psoriasis in order that they may live their lives without psoriasis having too much of a negative impact on their daily lives, but the length of this process will differ for everyone.

All of the participants were quite familiar with their condition and had been dealing with it for some time. While they had developed a degree of comfort and a great deal of understanding of their condition, they still were concerned about the future and how they might be affected. Women with children because of the familial aspects of psoriasis were concerned about their children's future.

*Triggers.* As time went on and the women learned to adapt their lives to psoriasis, they developed insight not only into how this disease affects them, but how things in their

lives affect their psoriasis. Stress is considered to be influential in the course of psoriasis (De Jong, 1997). The amount of stress a person is experiencing should be determined when assessing psoriasis and stress relief and reduction strategies could be utilized to help psoriasis patients control the amount of stress in their lives. Several authors report that life changing events and emotional distress can be contributing factors to the course of psoriasis (De Jong). Other factors that the women felt were helpful in decreasing exacerbations were keeping healthy with a good diet and proper rest also helps keep exacerbations of psoriasis limited, as well as avoiding illness such as colds and sore throats. Knowing what triggers psoriasis in each individual is important to recognize and avoid.

*Treatment stress.* Another factor that can cause stress and anxiety for people with psoriasis is dealing with the treatments. The treatments themselves can be stressful and time consuming but the potential side effects of treatments can be worrisome. Time is also a factor in the other types of treatments and includes time taken to go to appointments, undergo light treatments, or to go to a clinic to receive injections. All of this time must be taken into account as the women plan their daily lives. It could take priority over other activities and the lives of the women were planned around psoriasis rather than the treatments planned around their lives. This is quite significant for people who work full time outside the home; they may have to take time from work, which may necessitate revealing their condition to their employer, causing added stress.

As topical treatments are sometimes ineffective or the physical side effects and time taken to apply them is undesirable to the patients, often they must move on to the next step in treatments. Phototherapy carries with it the chance of sunburn and the long



term risk of skin cancer. The systemic medications to treat psoriasis have become more widely used in psoriasis treatment. There is concern among patients who must advance to these newer treatments to control their psoriasis about the side effects of the medications. As some of these medications are relatively new there are more questions than answers about their long term safety and efficacy (Pearce et al., 2005). There may worry among those taking newer treatments that there may be some negative consequences later in their lives, but they may feel that living psoriasis free is worth the risk. There were no studies found that explored the concerns about side effects of the patients on systemic therapy. This could be an area for further exploration.

*Adjustment.* Many people with psoriasis go through an adjustment period after which they are able to interact freely again and go on with their lives. This is consistent with the findings in a study in which all the participants, after living with the disease for many years, had all adjusted in their own way to psoriasis. There were periods of acceptance which are longer and shorter periods of frustration when the disease is active (Uttjek et al., 2007). The women found that they still want to hide the physical symptoms as much as possible but living with the disease over time has brought them to a realization that they have to accept that this disease is a part of their lives; they have adapted their lifestyles and continue to live life to the fullest despite psoriasis. Time appears to have been the key to this accomplishment for these women. The experiences that they have been through over the course of their disease have allowed them to adjust and grow and come to terms with psoriasis.

*Body image concerns.* Embarrassment, lack of self esteem and self confidence are also psychological factors in psoriasis (Young, 2005). Visibility of the rash can cause

embarrassment in certain situations. There is a degree of discomfort associated with having abnormal skin, as the visibility of the skin to the public can make psoriasis difficult to conceal. The degree of discomfort is higher if the rash is in an area that is hard to cover such as the scalp, hands or face (Wahl et al., 2002). Self esteem entails how people feel about themselves and their concern about how others view them. People with psoriasis have to deal with both of these factors. They feel embarrassed about how they look and go through great lengths to cover their psoriasis so others will not see it. Body image is the mental picture we have of ourselves and people with psoriasis often have a poor body image. There may be a gap between what they look like and what they would like to look like (Penzer, 2003). People with psoriasis can go to great lengths to cover up their psoriasis and this can have a great impact on their social adjustment.

#### *Living With the Social Consequences*

*Stigma.* The social realm was a real concern for these women. There is a stigma in society associated with the visible signs of psoriasis. The skin in ordinary experience disappears from consciousness, but if there is a defect the skin can come to the forefront (Neil, 2001). Clear skin is the norm and abnormal skin brings with it a degree of public scrutiny, people are curious about what is not considered normal, and there may also be fear about contagiousness among the public (Uttjek et al., 2007). Social vulnerability is an issue and psoriasis sufferers try to keep their disease secret from the public. They use caution and pay attention to reactions from their surroundings and other people, making them vulnerable to public scrutiny (Wahl et al., 2002). This was confirmed to an extent by this study in that all the women went through a period of time in their lives in which they avoided public exposure and contact with others. Excuses were made for not joining



others for social occasions and sports and activities were stopped or changed so that the rash could be kept hidden. Psoriasis has been misinterpreted by the public in some cases. Damaged skin can have a connotation of contagion or uncleanness and can result in social fear or shame for the person with psoriasis (Neil).

*Covering up.* Clothing was used by all the women to hide their psoriasis. In fact, the women used inventive ways of covering any lesions they could when they had a flare-up. This strategy has been found to be the most common way to cope with psoriasis (Rapp et al., 2001). The choice of type and color of clothes people with psoriasis wear requires thought and planning so that their psoriasis will not be visible to the public. Long sleeves and long pants are worn to cover the rash no matter what the weather. The person's choice of clothing can be severely limited as was the case with the women in this study.

*Social support.* The findings of this study reinforce the importance of social support in helping individuals with a chronic disease. Social support can buffer the potentially negative effects of stressful situations by providing reassurance that can make situations appear less threatening and provide experience, advice and solutions to problems that can aid in coping (Cohen & Wills, 1985). Support from others was one thing that helped these women in their struggle to live with psoriasis. Support can come from a variety of different sources including family and friends, employers and co-workers, health care professionals, and other people with psoriasis. Family and friends, although supportive, sometimes fail to understand the whole experience. High quality support and close relationships are associated with psychological well-being and self esteem among disfigured people (Furness, 2005).

Employers were very accommodating to the women if their psoriasis or treatments interfered with their job. Co-workers provided support to the women as well in showing concern and asking how their treatments were progressing. Health care professionals were seen as a good source of support. Health professionals are also seen as an important facet of social support especially if support from family and friends is inadequate (Gale et al., 2001). All the women were under the care of the same dermatologist and feel he is a source of hope and will try different treatments until they find one that works. The nurses at the Dermatology Treatment Unit were also found to be a good support due to their clinical experience dealing almost exclusively with people who have diseases of the skin. Their experience gives them a unique perspective about living with psoriasis that nurses in other areas may not attain. The greatest source of understanding and support came from others who are living with psoriasis. The women felt that with having this disease comes an understanding that cannot be replicated by anyone who does not suffer from psoriasis. There is a sense of comradery as they have experienced similar things. One study revealed that approximately 80% of respondents felt that friends and family understood psoriasis, only 47% believed that co-workers or schoolmates did, and only 8% felt that the general public understood psoriasis (Young, 2005). Support from these many different areas helps the women cope with their disease in different ways.

*Financial concerns..* One issue that was brought forth in the literature but did not arise in any of the interviews was the financial burden associated with psoriasis. Feldman, Behnam, et al. (2005) reported that financial stress is a factor in psoriasis; however this did not seem to be a factor in the lives of the women in this study. This may be explained by the nature of the health care system in Canada as well as the fact that all

the women were employed in long term positions which provided private health care benefits. All the women had also been involved in clinical trials for different medications that provided medication without a charge. Financial factors may be more of an issue for those without private health care benefit plans or those who are unable to qualify for clinical trials.

### *Quality of Life*

All of the issues that deal with the physical, psychological, and social consequences of living with psoriasis have an impact on the quality of life of the person with psoriasis. People with psoriasis feel they have a lower quality of life than the population in general (Choi & Koo, 2003). This must be taken into consideration by health care professionals when caring for patients with psoriasis and quality of life must be assessed. Assessment of psoriasis must go beyond the traditional physical measures and be able to determine the ability of the patient to overcome depression and anxiety and the limits of social functioning brought about by psoriasis (Weiss et al., 2002).

There is no doubt that living with psoriasis has an indelible impact on the lives of those that must live with the disease, but that is what they must do, live with this disease. There is a complex relationship between the physical, psychological and social impacts that living with psoriasis has on the quality of life of these people. These women have gone through many experiences with psoriasis over the time since they have been diagnosed, but the key to being able to live with this disease seems to be being able to adapt your lifestyle and realizing it will take a period of time to come to acceptance. Support from others plays a role also, but internal acceptance needs to occur before life can be lived to the fullest.

*Summary*

The findings of this study suggest that psoriasis is indeed a complex disease that has an impact on all areas of the life of a person with psoriasis. From the themes that were identified, it has been shown that the four women who participated have had many facets of their lives affected by psoriasis. The physical symptoms are much more serious than a rash and discomfort is pervasive in the lives of these women. There were also several lifestyle limitations imposed by trying to conceal their psoriasis with clothing. Anger was a common emotion upon diagnosis. Emotional support was an important factor to the participants and there were several sources of support, the most helpful being others with psoriasis. Family and friends, employers and co-workers, and health care professionals were also identified as good sources of support.

The women in this study had been living with psoriasis long enough to recognize the triggers of their psoriasis, such as illness, sunlight, and stress, and are able now to better control their psoriasis outbreaks through self-care. Treatment options were complex and time consuming, and often messy and uncomfortable. Newer and improved treatments are currently available, but can carry risks of unpleasant and dangerous side effects that are worrisome; the participants all determined that for them, the benefits outweighed the risks. There was also an element of altruism evident in wanting to help others with psoriasis by participating in clinical trials for new medications. Avoidance of the public and changing their lifestyles to hide their psoriasis from others was used by some of the women as a coping strategy at first, however over time all the participants have come to accept their psoriasis and have learned to go on with their lives.

They refuse to let it control their lives. This was a long process for the participants over the course of the disease.

## CHAPTER 6

### Limitations, Implications for Nursing, and Conclusion.

The final chapter consists of three sections. The first section contains some of the limitations of the study. The second outlines some of the implications for nursing practice, education, and research. The third section is the conclusion.

#### Limitations

One of the limitations of this study was the small number of women recruited. I had proposed to interview six to eight women; however, despite every effort to recruit this number, there were only four women who volunteered to participate in this study. The number of women willing to participate may have been limited because psoriasis is such a personal issue that it may have been difficult for women to talk about. All of the women in the study had been living with psoriasis for a number of years and had learned how to deal with their disease. Women who were not yet at this stage of their disease may not have been as comfortable discussing their lives with the researcher.

Although there is not a specified number of participants needed for a phenomenological study, often the researcher attempts to recruit a number of participants “diverse enough from one another to enhance possibilities of rich and unique stories of the particular experience” (Laverty, 2003, p.18).

Within the small number of participants there was not a great deal of diversity. The participants in this study were all within a 15 year age spread, were all diagnosed with psoriasis for a significant period of time, all worked outside the home, and lived in an urban setting. The participant group was somewhat homogenous in these respects.

Having psoriasis for a significant amount of time, as opposed to a very recent diagnosis, may have had an impact on their outlook and their ability to have adapted and coped with living with psoriasis, and different results may have come from a group of women diagnosed for a year or less. Also, these women had access to dermatologists within the community that they live and had major medical centers in their immediate areas. There may be different experiences among women who live in more isolated rural areas of Newfoundland and Labrador, who perhaps do not have the same access to medical supports as urban women.

The time commitment for the interview may also have been a deterrent for some, because so much time is already taken up with treatments for psoriasis. That factor coupled with the fact that all the women had at some time or another taken part in a clinical trial, may have contributed to the feeling that they simply did not have any more time that they could or were willing to spend on this condition. The potential participants were informed that the interviews would be about one hour in length. At least one person declined to participate due to this time commitment.

A second limitation may be uneven interviewing techniques. The interviews for this study were completed as much as possible using an unstructured, open-ended question format. Some of the women spoke very freely about their experiences and required very little prompting. Others required some facilitation on my part to relate their experiences and as a consequence the interviews were more structured. While this is the nature of this type of research, my questions and prompts may have led some participants in a different direction than they may have gone in relating their experiences, than they would have if left alone.

### Nursing Implications

As there is such a large population of people in the world living with psoriasis, and Newfoundland and Labrador is an area that has been identified as having a proportionately larger number of individuals with psoriasis, nurses can have an important impact on the lives of these people. To do this, nurses must be aware of how these individuals' lives are affected. The findings of this study have a number of implications for nurses in practice, in education and for further nursing research.

#### *Implications for Nursing Practice*

Only a small percentage of nurses will actually be involved with patients for the primary treatment of psoriasis, however since it is such a pervasive disease, many nurses will have to care for people with psoriasis as a secondary condition in hospitals and the community. Although it may not be the primary reason for requiring nursing care, nurses must not overlook psoriasis, as it has such a great impact it has on many facets of the person's life.

It is important for the nurse to acknowledge a diagnosis of psoriasis as either the primary or a secondary diagnosis. The nurse will then be able to work with the patient to incorporate the care and coping with psoriasis into the overall nursing care plan. One major way nurses can care for patients with psoriasis is by assisting them in managing the physical symptoms of psoriasis. Management of symptoms such as itching, flaking, and pain are some of the problems that can be addressed by nurses. The nurse can assist the patient with symptom control through both medical and non-medical measures.

It is important to incorporate the time needed for treatment of psoriasis into the care, either by accommodating the time that the patient needs to perform this care or if the



patient is unable to complete the care, the nurse will need to take over this role. The nurse needs to be cognizant of, and sensitive to, the potential need for the patient with psoriasis to cover and conceal the lesions and allow for this as much as possible.

Psychological and emotional support is another role that nurses can incorporate into their practice with patients with psoriasis by acknowledging the psoriasis and working with the person to assist them to cope with the disease. The findings from my research indicate that support is vital to the coping of patients with psoriasis and that health care professionals can play a significant role.

Patient education is crucial in the treatment of psoriasis. Knowledge is power and the more the patient and their family know about psoriasis and treatments, the more they can become empowered and involved with their own care and health related decisions. Patients with psoriasis and their families need to be knowledgeable about the disease, such as the physical manifestations, the course of the disease, treatment options and side effects, recognizing triggers of psoriasis, and how to prevent remissions. There is a certain amount of knowledge essential for the patients with psoriasis to have and understand to enable them to be able to undertake self-care and have long-lasting remissions of this disease (Jankowiak et al., 2004).

Nurses can also provide education for the general public about psoriasis. It is important that others understand that this condition is not contagious or dangerous and that the condition can have major physical and psychological effects.

Recent research has found a genetic link for psoriasis, however the etiology of psoriasis is complex, involving more than genetic predisposition alone. Nurses can play a role in both education and genetic counselling when working with women of childbearing

age and their partners. They can teach these individuals about the complex interaction between genetics and psoriasis. The choice of having children should be an informed decision for these women and their partners, when this chronic condition is present. However, they require the information to enable them to make this choice.

Nurses need to be aware of the physical and psychosocial concerns that arise for women with psoriasis so that when nurses are faced with caring for people with psoriasis, they can help patients with these issues. This will allow for a greater understanding of the extent of the disease, and the ability to treat their patients holistically, and to provide the support, education and physical care necessary for the patient with psoriasis.

#### *Implications for Nursing Education*

Education for nurses about this disease and how it affects those with the disease is crucial to enable nurses to care for patients with psoriasis when they encounter them in their practice. Nurses who are knowledgeable will be better able to assess the coping skills of patients with psoriasis, understand their feelings about the disease, and thus be able to provide more holistic care.

Education about psoriasis is required for all levels of nursing, because of the widespread occurrence. Even if it is not the primary reason for seeking care, general practice nurses should have enough information about the disease to be able to competently care for the patient's physical symptoms and know about common treatments for psoriasis. Nurses also need to be aware of the psychosocial effects of the disease in order to provide emotional support to the patients with psoriasis.

Nurses working in dermatology require a greater familiarity with the effects and treatments of psoriasis as they would be expected to provide more in-depth care. These

nurses often play an instrumental role in administering treatments and teaching the patients to self-administer these treatments. They must be knowledgeable about potential side effects and be able to answer any questions the patient may have. There are new medications available for use as a result of current research and the nurse working in dermatology must keep abreast of these new developments. These nurses must be familiar enough with psoriasis to be able to teach patients about all aspects of the disease, and also have an understanding of the psychosocial effects to provide support.

#### *Implications for Nursing Research*

The findings from the study also have implications for nursing research. There has been very little qualitative research conducted on psoriasis sufferers. This type of research is very important and has implications for the care of those with psoriasis in various health care settings. Research could be conducted on the amount of education and understanding that nurses have about psoriasis and other skin conditions and how they feel about caring for these people. Does the skin disease have any impact on the care the nurse provides to the patient? Do nurses have sufficient preparation to allow them to properly care for psoriasis and other skin diseases?

The women in this study felt that family members were also affected by them having this condition. Quality of life of partners and relatives of people with psoriasis has been found to be affected (Eghlileb et al., 2007). Further exploration into how this disease affects the families could be useful. Is there any work time or wages lost by family members caring for the psoriasis sufferer? How does knowing that psoriasis has a genetic component affect other family members? Do the many changes to the person's lifestyle to cope with psoriasis have an impact on the sufferers' family? Qualitative

research into these questions could further increase the body of knowledge of what it is like to live with psoriasis and give further insight into the disease from the families' perspective.

The findings from this study suggested that women experienced an 'acceptance' of their psoriasis. Another area for further research is on the process of the acceptance of the disease. Using grounded theory, the process could be identified together with factors that facilitate or act as a barrier to acceptance. If this process could be better understood, there would be nursing implications into how nursing and other health care professionals could assist and facilitate this process.

Women and men are affected in equal numbers by psoriasis. This study focused on women but it is important to explore men's experience of living with psoriasis. This could offer some insight into whether men and women share the same feelings and experiences. Do men perceive some aspects of psoriasis differently than women? This could have implications for nurses caring for both men and women with psoriasis in knowing how to approach them and give gender sensitive care.

### Conclusion

This phenomenological study on the lived experience of women living with psoriasis in Newfoundland helps to better understand that experience. There were four women who participated in unstructured, face to face interviews in which they described their experience of being a woman living with psoriasis. Each participant had a unique experience of living with psoriasis yet there were some commonalities. There were some common themes that were identified in the interviews and these include: 1) More than just a rash – physical symptoms; 2) Understanding from others – support; 3) Creative

clothing – covering up; 4) The good, the bad, and the scary – treatment options; 5) Looking for answers; 6) Managing the public gaze – avoidance; 7) Knowing triggers – observing patterns; and 8) Moving on – developing comfort.

The findings of this study can contribute to the understanding of women living with psoriasis and what they go through in their every day experiences. This knowledge can help nurses and other health care professionals who may care for women with psoriasis to better understand what it is like for these women and lead to more holistic care of patients who have psoriasis.

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## Appendix A: Letter to Dermatologist and Dermatology Treatment Unit

95 Middle Cove Rd.  
Middle Cove, NL  
A1K 2A6  
709-437-1266  
[eglynn@nf.sympatico.ca](mailto:eglynn@nf.sympatico.ca)

March 15, 2006

Dear

My name is Erin Glynn and I am a graduate nursing student at Memorial University of Newfoundland. I am conducting research into the experiences of women living with psoriasis. I hope that this research will give some insight to nurses and other health care professionals into what it is like to be a woman with psoriasis.

I am looking for potential participants for this study. Participants for this research should be women between the ages of 19-60; be able to speak, read and write English; are followed by a local Dermatologist either in their office or the Dermatology Treatment Center run by Eastern Health Board in St. John's; and have been diagnosed with psoriasis for at least one year.

I am requesting your help in accruing participants for this study. If you have patients who fit this criteria, could you please provide them with the potential participant letter and if they are interested in participating, have them consent to providing me with their name and contact information. I will pick up any completed forms periodically from your office or the treatment unit.

If you would like any further information about this research or have any further questions, please contact me at 437-1266. This research will be confidential and has been approved by Memorial University's Human Investigation Committee.

Thank you in advance for your cooperation.

Sincerely,

Erin Glynn, RN, BN.

## Appendix B: Form for Physician/Treatment Unit to Recruit Participants

95 Middle Cove Rd.

Middle Cove, NL  
A1K 2A6  
709-437-1266  
[eglynn@nf.sympatico.ca](mailto:eglynn@nf.sympatico.ca)

March 15, 2006

Dear Woman Living with Psoriasis,

My name is Erin Glynn and I am a graduate nursing student at Memorial University of Newfoundland. I am conducting research on the experiences of women living with psoriasis. It is my hope that the results of this study will allow nurses to have a greater understanding of what it is like to be a woman living with psoriasis.

I am looking for participants for this study. Participants for this research should be women between the ages of 19 and 60; be able to read, speak and write English; be followed by a Dermatologist or be a patient of the Dermatology Treatment Unit of the Eastern Health Board in St. John's; and have been diagnosed with psoriasis for more than one year. Participation in this study will involve two audio taped interviews, each lasting 45 to 60 minutes each.

If you are interested in getting more information about this research and your participation, I would like to contact you. If you are willing Please provide your name and contact information on the next page and give it back to your doctor or nurse. I will pick up this form and call you. This research will be confidential. It will not affect your current health care. Although your doctor will know you provided me with contact information, he or she will not know whether you decide to participate in the study or not. This research has been approved by the Human Investigation Committee at Memorial University of Newfoundland.

Thank you for your consideration and I hope that you will allow me to contact you and give you more information about the research.

Sincerely,

Erin Glynn RN, BN



**Women Living with Psoriasis**

I \_\_\_\_\_ would like more information about the research study on the experience of women living with psoriasis.

I give permission for the researcher to contact me at the phone number below.

I understand that I am under no obligation to participate in the research after learning more information about the study.

Name: \_\_\_\_\_

City/Town: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix C: Interview Guide

### Interview Guide

Thank you for agreeing to take part in my research study about women living with psoriasis in Newfoundland. Please tell me about your experience of being a woman living with psoriasis.

The following questions may be used as a guide by the researcher in exploring women's lived experiences with psoriasis.

When did you first experience psoriasis?

When were you diagnosed with psoriasis?

How did you feel about this diagnosis at the time?

How has your life changed since the diagnosis?

Tell me about the things that make the psoriasis better or worse.

Who has provided you with help or support?

What are some of the things that help you to cope with psoriasis?

Tell me about some specific instances that psoriasis has affected your life?

Describe your feelings about psoriasis being an inherited condition.

Did/ Will having psoriasis have any impact on your decision to have a family?

## Appendix D: HIC Approval



# Memorial

University of Newfoundland

Human Investigation Committee  
Research and Graduate Studies  
Faculty of Medicine  
The Health Sciences Centre

June 9, 2006

**Reference #06.64**

Ms. E. Glynn  
C/o Dr. S. Solberg  
School of Nursing  
Memorial University of Newfoundland

Dear Ms. Glynn:

This will acknowledge your correspondence dated June 6, 2006, wherein you clarify issues and provide a revised consent form, revised letter to women and revised letter to the dermatologists, for your research study entitled **"Women living with psoriasis: A phenomenological study"**.

At the meeting held on **April 13, 2006**, the initial review date of this study, the Human Investigation Committee (HIC) agreed that the response and revised consent form could be reviewed by the Co-Chairs and, if found acceptable, full approval of the study be granted.

The Co-Chairs of the HIC reviewed your correspondence, approved the revised consent for, revised letter to women and revised letter to dermatologists and, under the direction of the Committee, granted **full approval** of your research study. This will be reported to the full Human Investigation Committee, for their information at the meeting scheduled for **June 22, 2006**.

Full approval has been granted for one year. You will be contacted to complete the annual form update approximately 8 weeks before the approval will lapse on **April 13, 2007**. It is your responsibility to ensure that the renewal form is forwarded to the HIC office not less than 30 days prior to the renewal date for review and approval to continue the study. The annual renewal form can be downloaded from the HIC website <http://www.med.mun.ca/hic/downloads/Annual%20Update%20Form.doc>.

**Modifications of the protocol/consent are not permitted without prior approval from the Human Investigation Committee. Implementing changes in the protocol/consent without HIC approval may result in the approval of your research study being revoked, necessitating cessation of all related research activity.**

**Request for modification to the protocol/consent must be outlined on an amendment form (available on the HIC website) and submitted to the HIC for review.**

For a hospital-based study, it is **your responsibility to seek the necessary approval from the Health Care Corporation of St. John's and/or other hospital boards as appropriate.**

This Research Ethics Board (the HIC) has reviewed and approved the application and consent form for the study which is to be conducted by you as the qualified investigator named above at the specified study site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Human Investigation Committee currently operates according to the Tri-Council Policy Statement and applicable laws and regulations. The membership of this research ethics board complies with the membership requirements for research ethics boards defined in Division 5 of the Food and Drug Regulations.

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

We wish you every success with your study.

Sincerely,

John D. Harnett, MD, FRCPC  
Co-Chair  
Human Investigation Committee

Richard S. Neuman, PhD  
Co-Chair  
Human Investigation Committee

JDH;RSN\jd

C     Dr. C. Loomis, Vice-President (Research), MUN  
       Mr. W. Miller, Director of Planning & Research, HCCSJ



