

THE LIVED EXPERIENCE OF PATIENTS WITH PSORIASIS

by

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TABLE OF CONTENTS

1. INTRODUCTION	1
Problem	1
Purpose.....	2
Framework	2
Impact of the Study for Nurse Practitioners and Nurses.....	3
Definitions.....	4
2. LITERATURE REVIEW	6
3. METHODOLOGY	11
Design	11
Procedures for Data Collection.....	12
Data Analysis.....	13
Human Rights and Consent Process	14
4. RESULTS	15
Sample.....	15
Lived Experience Statements.....	16
Childhood Treatment Experiences.....	16
Adult Treatment Experiences	17
Stopping Treatment.....	17
Family Support and Awareness	18
Lack of Public Awareness About Psoriasis	18
Communicating With Others About Psoriasis.....	19
Self Consciousness	19
Statements Regarding Intimacy	20
Defense Mechanisms	21
Telling Self “It could be worse.”	21
Isolation.....	21
Hopelessness.....	22
Fantasy of Disease Free Skin.....	22
Guilt	23
Perceived Positives	23
Acceptance.....	24
Employment Issues	24
Financial Burden.....	25
Concerns About Future	25
Provider Relationships.....	25
Why Did You Agree to Participate.....	26
5. DISCUSSION	27
Summary	31
Limitations	32

TABLE OF CONTENTS- CONTINUED

Recommendations for Further Study	32
Conclusion	33
REFERENCES	35
APPENDICES	38
APPENDIX A: SUBJECT CONSENT FORM	39
APPENDIX B: INTERVIEW GUIDE	42
APPENDIX C: SECOND INTERVIEW GUIDE	44
APPENDIX D: POSTER.....	46
APPENDIX E: FULL INTERVIEW QUOTATIONS	48

LIST OF FIGURES

Figure	Page
1. Psoriasis and Adaptation.....	2

ABSTRACT

Psoriasis is a chronic skin disease affecting an estimated 4.5 million adults. Symptoms can be mild to severe, and consist of silvery exfoliative plaques of skin. Although there are various forms of treatment, there is no cure. Existing data regarding psoriasis confirms a link between decreased quality of life and psoriasis. Subjective data regarding the disease has been documented since 1976, however, there exists a lack of qualitative nursing research regarding psoriasis. Additionally, only one study was found in which the lived experience of psoriasis patients was documented. This phenomenologic study explores three patient's lived experience with psoriasis in Montana. One on one interviews were conducted with the participants to document the experiences of living with psoriasis. Using the Roy Adaptation Model as a framework, particular emphasis is given to adaptative versus maladaptive responses. Entitled "lived experience statements", quotes were taken from the interview transcripts and organized by common themes as well as individual statements. This was done, in part, due to Roy's belief that living systems are complex, and that adaptation can be an individual and dynamic response to the environment. An individual's experience, while not common among all participants, is still reflective of their adaptation to disease. Participant responses illustrate concerns of patients with psoriasis and day to day events that may occur in their lives. By becoming familiar with lived experience statements, nurses, nurse practitioners and other health care providers can develop a deeper appreciation for the impact a diagnosis of psoriasis carries. This understanding may foster holistic care for the psoriasis patient, as well as encourage the nurse to be more aware of adaptation and the nurse's role in the adaptive process.

CHAPTER ONE

INTRODUCTION

Psoriasis is a chronic skin disease characterized by silvery, exfoliative plaques of the skin. It is a genetic disorder in which the epithelium reproduces more rapidly, resulting in erythema, pruritis and scaling (Hill, 1998, p. 81). Psoriasis symptoms can be mild to severe, and can be manifested on any part of the body. “Common areas (for psoriasis) are the elbows, knees, scalp, gluteal cleft, fingernails, and toenails” (Hill, 1998, p. 81). Psoriasis has periods of exacerbation and remission, yet there is no known cure.

In addition to physical symptoms, psoriasis places the individual at risk for altered body image, self-esteem disturbance, anxiety and social isolation (Hill, 1998, p. 81). The National Psoriasis foundation found 75% of respondents surveyed considered their psoriasis a “moderate to large problem” in their lives. Further, Krueger and Koo found greater than 10 percent of patients surveyed had contemplated suicide because of their disease (2001, p. 281).

Problem

Psoriasis is a common skin disorder, affecting an estimated 4.5 million adults (National Psoriasis Foundation benchmark survey on psoriasis and psoriatic arthritis, 2002, p.2). The physical effects of this chronic disease have been described and studied with frequency. However, little nursing research in the United States explores the lived experience of individuals with psoriasis or offers practical tools to assess the patient’s adaptation to the disease.

Purpose

The purpose of this phenomenological study is to qualitatively explore three individual's lived experience with psoriasis in Montana.

Framework

The framework used in this study was based on Sister Callista Roy's Adaptation Model. According to Roy, the goal of nursing is to facilitate the individual's adaptation in four arenas: physiologic needs, self-concept, role function, and interdependence relations (Roy, 1999). If positive adaptation does not occur in these arenas, quality of life will be impacted. As emotional reactions and stress are thought to contribute to psoriatic exacerbation (Hill, 1998, p. 81), maladaptation can contribute to a vicious cycle.

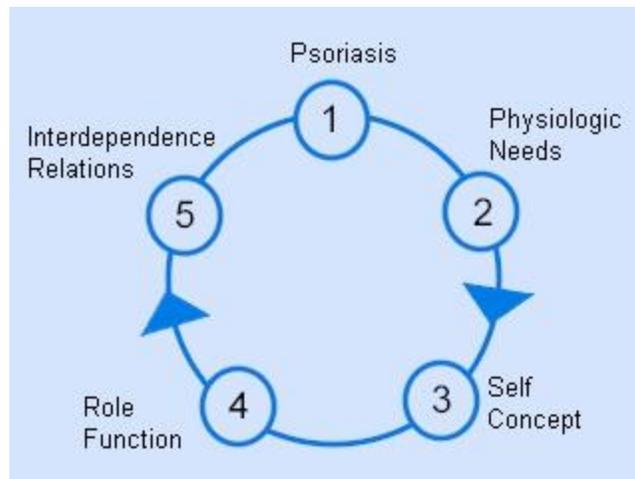


Figure 1. Psoriasis and Adaptation

Figure 1 shows how exacerbating effects of psoriasis impact adaptation. Psoriasis symptoms create increased physiologic needs. Self-concept, which is based on interactions with others, is at risk because of visible psoriatic lesions. Role function can

be impacted in the home or workplace by physical symptoms, or altered body image. Finally, changes in daily interactions with others can be produced by all of these areas, and affects interdependence systems and relationships with others. Each phase in the cycle can impact all the other phases, and adaptation as a whole.

Impact of the Study for Nurse Practitioners and Nurses

Ersser, Surridge, & Wiles performed an extensive literature review on the topic of psoriasis (2002). They reported multitudes of clinical criteria that dermatologists use to assess and monitor the physical manifestations of psoriasis. These include the “clearance,” or the percentage of the skin that has healed from the psoriasis, or has had a reduction in redness, spread or scaling. These criteria also include “increased patient comfort” from the physical symptoms, such as improvement in itching or in the patient’s perception of severity (p. 371). Although some studies list quality of life indexes, they appear to be employed in the early part of psoriasis evaluation. Ersser and colleagues state “Whilst reference is made to the psychological and social criteria during the history-taking process, the precise part they play in formulating an evaluation of the effectiveness receives little discussion” (2002, p. 370).

This thesis provides direction for nurse practitioners, health care providers and nurses topics of key importance for individuals with psoriasis. Nurse practitioners in the dermatologic setting can use the data to reinforce the importance of assessing adaptation as a routine part of initial diagnosis and follow up. Nurse practitioners in a non-dermatologic setting, particularly in rural areas, provide primary or ancillary care to individuals with psoriasis. Therefore, it is important for lived experience issues to be

addressed initially, and throughout treatment.

Finally, the data could be used to develop a practical adaptation assessment tool for clinic use. Nurses could serve an important role in providing these assessments as part of the patient's ongoing care. For example, patients receiving phototherapy have weekly communication with the nurse, rather than nurse practitioner or physician, and the nurse is ideally positioned to administer an adaptation assessment.

To provide holistic care, nurses need to understand how the disease specifically impacts areas of the individual's life so they are better able to facilitate adaptation (Roy, 1999) to the disease.

Definitions

Individual – For this study, individual will be defined as a person with a medical diagnosis of psoriasis for a minimum of 5 years, classified with mild to severe psoriasis. If mild, psoriasis must be visible to others (scalp, face or hands).

Psoriasis – Hill (1998) defines psoriasis as “An inflammatory skin disease characterized by rapid cell growth at the epidermal layer. Lesions present as scaling silver or white patches and plaques” (p. 81). This definition will be used for the purposes of this study.

Quality of Life - For this study, quality of life will be defined as the “summation of functional health, well-being, and participation” (Bergstrom, Kimball, Weiss, & Weiss, 2003, p. 120).

Adaptation - Roy's (1999) definition of adaptation will be used in this study, and states “The process and outcome whereby thinking and feeling persons, as

individuals and in groups, use conscious awareness and choice to create human and environmental integration” (p. 3).

CHAPTER TWO

LITERATURE REVIEW

While it is imperative to approach participants without preconceived ideas and perceptions about their experience, it is also important to have a grasp of existing qualitative studies to justify the need for further research and exploration.

Extensive review of the literature was performed to determine the following:

- a. What is the existing level of qualitative data about psoriasis?
- b. Do any studies observe the patient's lived experience with the disease?
- c. How much subjective data about psoriasis is contributed by nursing research?

Perrott, Murray, Lowe, and Mathieson (2000) believed research regarding psoriasis had one of two focuses: pathogenesis, etiology and physical symptoms or psychosocial impact of the disease. This divergence becomes apparent when reviewing the literature. Significantly more information is available regarding clinical symptomatology and treatment of psoriasis than qualitative data on the disease.

Research regarding psoriasis and quality of life began to emerge from the literature during the late 1970's. Jobling (1976) published a preliminary questionnaire regarding the psoriasis sufferer's subjective experience in 1976. This was the first study to look solely at the relationship between having psoriasis and the psychosocial consequences of the disease.

This study showed a specific link with a reduction in quality of life and psoriasis. When asked to describe the worst aspect of having psoriasis, 84 percent described

difficulties with establishing social contacts and relationships. Jobling stated “the experience of many respondents indicate the personal aspects of psoriasis are probably underestimated by many doctors” (p. 236).

Jobling continued to contribute to this area of study, publishing an article review that stressed the importance society and patients place on the outward appearance of skin. He further described the role of different treatment modalities and how they, too, can contribute to the patient’s perception of stigmatization (Jobling, 1992).

Other early reports confirmed that psoriasis had emotional and social impact on the individual experiencing the disease. Based on interviews by Ramsay and O’Reagan, over fifty percent of patients with psoriasis had “negative feelings about their condition and also about the way other people viewed them” (1988, p. 200). Having psoriasis was found to alter clothing choices, and perpetuated avoidance of social and functional activities, such as going to the hairdresser and playing sports. Eleven percent of the respondents felt so strongly about the negative effects of psoriasis on their physical and mental health that they would not have children to prevent passing the disease on to them (Ramsay & O'Reagan).

Only one study emerged that reflected research on lived experiences. Chrissopoulos and Cleaver found a need for lived experience research stating “A literature study of psoriasis reveals a lack of research on the psychological impact of psoriasis, although research indicates that psychological factors are involved in the aetiology as well as the experiences of psoriasis” (1996, p. 39).

Chrissopoulos and Cleaver (1996) used qualitative study in a South African state to explore lived experience and psoriasis. One subject was selected from an initial group

of six participants to be interviewed in depth about her experience. “The aim of the interviews was to describe the sufferer’s experience of her disease, and therefore an unstructured format was used” (Chrissopoulos & Cleaver, p. 40).

Themes found included loss of control, negative self-concept, social isolation, impairment of sexual relationships, and stigmatization. Chrissopoulos and Cleaver intended to “create an in-depth description of one psoriasis sufferer’s lifeworld, and to facilitate understanding and empathy for the experience of psoriasis it is hoped that this description will facilitate adjustment to the skin disease and eliminate secondary problems” (Chrissopoulos & Cleaver, 1996, p. 42).

The authors did not explicitly state the implication of this research to healthcare providers, nor did they suggest research needs for the future. It remains to be seen whether the lived experience of a psoriasis patient in South Africa is congruent with that of a patient in the United States.

Perrott, Murray, Lowe, and Mathieson discussed the need for additional lived experience research, stating “it is clear that much is yet to be learned about how people living with psoriasis experience the disease” (2000, p. 571).

Few nursing articles specifically addressed the psychosocial impact of psoriasis on the life of the patient. In a published review article, Wahl looked at existing psychosocial studies that contributed to psoriasis research. A nurse, Wahl criticized existing data as not being holistic in its assessment of the impact on quality of life. Based on the definition of quality of life and known domains regarding psoriasis, Wahl (1997) developed a model that encompassed these areas. Wahl’s literature review found only one study that addressed all pertinent domains. While data may shed light on quality of

life research and psoriasis, Wahl stated “because the original aim of most of the studies reviewed has not been to measure quality of life, and because the studies only cover certain aspects of the patients’ total situation, it is difficult to incorporate them into quality of life research” (1997, p. 248).

Wahl also noted a lack of nursing research available regarding psychosocial demands on patients with psoriasis and noted only one research study in the field of nursing care and psoriasis that had been conducted. Taylor and Buckwalter (1988) performed a qualitative and quantitative study exploring coping mechanisms of psoriatic patients. They believed psoriasis as a disfiguring skin disease imparted unique psychosocial stressors to the patient. The most frequently used coping device was trying to maintain control in a stressful situation. This finding was echoed in both the survey, and open ended question responses. Taylor and Buckwalter believed support groups, education of patients and the public, and research to be the most effective means in which nurses could help psoriatic patients. Future research was suggested to determine the most effective coping mechanisms employed by psoriatic patients, so that they might be fostered and encouraged in the patient population (1988).

Adams, Glenn, and Byatt (2001) responded to a lack of nursing research, noting “... because of their close and continuing relationships with patients, nurses are in a better position than most health care professionals to provide psychosocial support” (p 129).

Adams et al. (2001) performed a quantitative study with this goal in mind. They found among 50 in-patient participants, of 7 domains of The Psychosocial Adjustment to Illness Scale, psychological distress was the most significantly elevated. This elevation

was also correlated with the following behaviors: crying, increased smoking, and alcohol intake. The authors responded “significant numbers in the group studied appear to be affected to the extent that specialized intervention is warranted, yet the methods of assessment and management continue to focus on the physical and as such psychological needs may remain largely unmet” (p. 131).

While quantitative data does contribute to quality of life research, they called for additional nursing research from a subjective viewpoint and stated that “a necessary first step is to understand how psoriasis affects individuals (Adams et al., p. 129)”.

In addition to recommending additional nursing research, they supported frequent assessment of the psoriasis patient’s coping, reporting “Failure to formally assess the psychosocial domain and devise appropriate interventions may increase the burden of illness experienced” (Adams, Glenn, & Byatt, 2001, p. 131).

Chronic skin diseases create complex life situations. When unable to mask their symptoms from others, they are forced to deal with the emotional consequences of being different. Burr (1996) notes

As the skin changes, or is seen to be different from normal, it becomes increasingly the focus of attention. This is especially important as psychologically our skin reflects and registers our emotions and plays a large part in non-verbal communication (p. 1177).

Although nearly thirty years have passed since the beginning of subjective research and investigation on the topic of psoriasis, researchers continue to cite a lack of qualitative data about the disease.

CHAPTER THREE

METHODOLOGY

The purpose of this study was to qualitatively explore individuals' lived experience with psoriasis.

Design

Holloway and Wheeler found that “researchers use qualitative approaches to explore the behavior, perspectives, feelings, and experiences of people and what lies at the core of their lives” (2002, p. 3). Phenomenological exploration of the lived experience of individuals with psoriasis provides a description of the disease experience. This understanding is vital to fostering empathy as well as guiding future research.

A phenomenological approach with semi-structured interviews was used to acquire qualitative data from the participants. Responses from the participants were intended to be a narrative or an autobiographical report of their experience. According to Mischler, qualitative data is best achieved by narrative analysis. A narrative or story, Mischler wrote, “brings out problems and possibilities of interviewing that are not visible when attention is restricted to question-answer exchanges” (1986, p. 67). He also stated “a general assumption of narrative analysis is that telling stories is one of the significant ways individuals construct and express meaning” (Mischler, 1986, p. 67). This method was chosen as means of allowing the participant to portray and tell his or her “story” of living with psoriasis.

Procedures for Data Collection

Convenience sampling was used to invite participants for the study. As the lead investigator was employed as a registered nurse within the clinic from which the subjects were selected, care was taken to avoid coercion of participation. Interested parties were invited, by a printed poster in the clinic, to participate in the study (see Appendix D). If interested, the potential participant was instructed to call or email the lead investigator to further discuss participation.

The poster outlined eligibility requirements and stated that participants must be English-speaking, and a minimum of 18 years old. Additionally, participants must have been diagnosed with psoriasis a minimum of 5 years, and be currently under a physician's care. These eligibility requirements were also reviewed with the participants prior to signing the informed consent.

Verbal and written information was given to all eligible parties stating that their participation was not mandatory to receive health care within the clinic. Participants were also informed that declining participation would not have any deleterious effect on their receipt of their care.

One-on-one interviews were scheduled in a location of the participant's choosing. All three participants elected to be interviewed privately at the outpatient dermatology clinic after business hours. Interviews were audio recorded to prevent loss of data.

Interviews were transcribed verbatim, and each participant was assigned a code letter to ensure confidentiality. Once the researcher listened to the recorded interviews again to verify transcription accuracy, the recordings were destroyed.

An interview guide was developed to ensure all participants were asked similar questions. The semi-structured format encouraged participants to tell a narrative of their experience with psoriasis (see Appendix B). After the first set of interviews and initial data analysis, a second interview guide was developed (see Appendix C). The second interview guide was used to clarify findings, and encourage extrapolation on the part of the participants.

Data Analysis

Data were analyzed using procedures based on one of Colaizzi's (1978) methods of phenomenological data analysis. According to Colaizzi, the dialogue is read for understanding and content. Phrases or sentences are then extracted from the dialogue (p. 59). Meaning of thesis phrases are formulated, and the researcher designated the phrases to one of Sister Calista Roy's four areas of adaptation. After clusters of themes were determined, they were referred back to the original dialogue to ensure they were placed in the appropriate area of adaptation. According to Colaizzi, this serves as a way of validating that the themes were correctly interpreted (Colaizzi, 1978, p. 59).

A second group of questions was formulated to clarify and seek elaboration. A second interview was done with each participant. This process ensures complete understanding, or "exhaustive description" of the participant's experience. This technique is supported by Holloway and Wheeler as a method of ensuring rigor (2002).

The interviews were then grouped by common themes, as well as by individual statements. In the interest of inclusion and acceptance of the individual's experience with psoriasis, quotes were entitled "lived experience statements" rather than themes. This was

done, in part, due to Sister Callista Roy's belief that living systems are complex, and that adaptation can be an individual and dynamic response to the environment (Phillips et al., 1998). An individual's experience, while not common among all participants, is still reflective of their adaptation to the disease.

Human Rights and Consent Process

Approval was obtained from the Institutional Review Board of Montana State University-Bozeman, on July 26, 2004. Participants in the study signed an informed written consent, and were given copies of this consent (see Appendix A). The lead investigator ensured understanding by verbally explaining the research, in addition to asking the participant if he or she had any questions prior to proceeding with the interview.

Participant's names were known only to the principle investigator. Interviews were transcribed without identifying data such as name, birth date or physical descriptions. Audio tapes were erased after transcription was completed, and all interview data, including computer disk and paper copy of interviews, were secured in a locked cabinet in the lead investigator's home.

Participants were advised that they could withdraw from the study at any time, and were free to decline answering any question or questions with which they did not feel comfortable. Any participant experiencing untoward emotional effects would have been removed from the study, and referred to their primary care provider for a mental health evaluation.

CHAPTER FOUR

RESULTS

The purpose of this research was to explore the lived experience of people with psoriasis. Of six people that expressed interest in participation, one was excluded for not meeting eligibility criteria. Two potential participants, elected to not participate when they learned they would be asked questions about their emotional response to psoriasis.

The resulting data from interviews comprises the findings in this chapter. As the participants were encouraged to share their stories, many of the responses were lengthy. For reader ease, quotes were edited for length, but not content, and are presented briefly in this chapter. The full transcripts may be found in Appendix E.

Sample

Three participants comprised the sample group. All participants, two females and one male, were single at the time of interview and none of them had been previously married. The participants' ages were 47, 37 and 23 years old, respectively. All participants had been diagnosed with psoriasis for a minimum of seventeen years. Age at diagnosis varied from infancy to age 30.

All participants elected to be interviewed at the physician's office in which they learned of the study. Two of the participants were active patients of the practice. One participant was currently under the care of another dermatologist.

Lived Experience Statements

Childhood Treatment Experiences.

Two of the participants had the diagnosis of psoriasis as children. They recalled being treated by their parents. These treatments were elaborate, often painful experiences that patients were expected and even coerced into tolerating. One participant elaborated about her refusal of treatment.

“Every night before bed I’d sit on the floor and mom would pick my head till it bled. Hurt like hell. It was horrible, and uh, I think it probably hurt her more than it hurt me, and uh, it was so hard for her to make herself do that but... Well, after she picked it to bleed, she put some kind of burning stuff on it. It hurt. It’s been a series of topical things, that’s pretty much all I’ve ever done. Oh God, she (Mom) hated it, to this day, she hates having done that.”

“Doctor N. got me into a clinic in California. I lived with my grandparents. I would go 4 times a week for 4 or 5 hours a day. I would go there and they would wash my hair with these super jet-powered things that would rotate back and forth across my head, and I think I would bleed. I think the shampoo was medicated, too, and then a light booth.... I had to put on white clothes, because it would draw all the blood to the surface. So for one thing it would stain my clothes. And if I got it any where on my body, except the psoriasis, it looked like I had been flogged. I was just covered in bruises. Um, and I was in that for a couple of hours. So that was the majority of the treatment was sitting, marinating in this stuff, watching a soap opera or whatever was on TV. Then I would take a tar bath, then shower and go home. So that went on for 8 weeks I think. It was really intensive. Every day, for several hours a day. Um that cleared it up for a couple years afterward. Then, I started doing PUVA (phototherapy combined with oral sensitizing agents) when I was a junior in high school. ...It worked really well but the medication made me really upset to my stomach. So I would have to sit through my last period of class just sort of nauseous. Um, and I had to be really careful with my eyes. Sort of risk of cataracts – I can’t remember all the rationale behind it. I had these awful sunglasses my dad bought me, which were – they covered my eyes, but were ...just plain ugly.”

Adult Treatment Experiences.

All of the adults in the study discussed current and past treatment regimes. Many similarities were stated, consisting of numerous topical therapies as well as phototherapy treatment in a clinic setting.

“And basically it would work for a little bit and then it would just quit working. Then in 2001 I tried that methotrexate. And then that didn’t really work. It cleared up my scalp... and then we started the PUVA treatments... And then, things just weren’t working again. And I was getting shots, about every 3 months. Sometimes I’d clear up really well, and it would be great, and then it seems like, through the summer, I would just have minimal coverage, because you know I’d be out in shorts and no shirt, sun seemed to help a lot, and then um, but then starting about September, I would start having more problems. And um light treatments weren't working, and the topicals I was getting weren't working, it was just getting worse and worse. Or I would be pretty good, and then I would get some viral infection, and it would flare. I was really clear at one time, then I caught a cold, and within days, it was just like on 80 percent of my body... Then I started doing, May to June, doing different type of light treatment. And all I did was burn. (laughs) But um, then, I no longer had insurance, so...I really couldn't keep doing anything. And um, so I've just been, up until three weeks ago, just been doing some different topicals.”

Stopping Treatment.

The three participants had all stopped treatments at various points in their lives. Many cited frustration, and being overwhelmed by the amount of time treatment took, in addition to poor results as reasons for stopping treatment. Eventually, all the participants returned to treatment fearing skin would get out of control.

“I was too frustrated with it. It was also like a subconscious protection, I felt like, if my skin was not treated I have to be that much more cautious and it can prevent me from doing other things. But like a lot of medication will get on your clothes, and it is like most of it would stain your clothing. That used to just drive me nuts! Because I could only wear it at bedtime, there is an extra 20 minutes, putting on all of that crap on your skin, you know, and then you have to shower, because if you don’t it is still on your clothes... So I think sometimes it was just the general frustration

with the treatment. I'm like Gosh this is too much work. It is not working fast enough. The most common reason for me to go back to treatment is some sort of interpersonal relationship. Like I started realizing that I am going to want people to see certain parts of my body or I am in a relationship where that is going to come up, or I am hoping to be in a relationship where that will come up, and I am aware of it, and so...It is going to be summer, I am not going to want to have this problem."

Family Support and Awareness.

The participants had differing levels of family involvement and support. One participant reported that she felt she had developed closeness with her family as a result of her psoriasis. In contrast, another participant did not tell his family until after he had been diagnosed with psoriasis fifteen years.

"I think (knowing grandmother had psoriasis) what it did was make me more comfortable, that it's not going to be that bad. Grandma's fine, she's fully functioning, she's married, she has kids. It's not the end of you world, you know? So I'm not going to be maimed in some way... you think of all the horrible things that could happen to you..."

Lack of Public Awareness about Psoriasis.

Childhood teasing, as well as comments from strangers reflected a lack of information in the public regarding psoriasis. Comments from strangers included suggestions for dry skin, ring worm, and vitamin supplementation. Both participants felt obligated to reassure the individual that it was not contagious.

"Kids would tease me about having dandruff and not showering. (In 6th grade) this girl named----was just horribly mean to me. And she used an eraser, making flakes on her paper and dumped it on herself and was mocking me- which was just mortifying, and obviously, very vivid."

"I don't feel like I have a lot of choice (in who I disclose my diagnosis to) because it is visible and if somebody asks me, I don't object to telling them. But even if I did object, the question is always, "is it contagious?" And I feel an obligation to tell people. You can kind of tell, somebody noticing and thinking about it, and not comfortable saying

anything, but a lot of people ask. Sometimes I feel like that is a responsibility, to reassure people that they are not going to catch the creeping crud.”

(Mom’s response to learning about participant’s diagnosis) “Oh my gosh, that’s just something old people get!” My sister was in town, and we were having lunch and I ordered an ice tea, and she said “Aren’t you having a beer?”, and I said “No, ice tea.” Then I started talking to her and told her that I had it, and the first thing out of her mouth was, “No wonder you’re not drinking!” And I’m like “do you know anything about this? Anything about it at all? She says “no.”, and I said, then why would you say that? She said, “Well because, just people who drink get that.”

Communicating With Others About Psoriasis.

The respondents agreed that when talking to someone about psoriasis, it was very helpful if that person had baseline knowledge of psoriasis.

“It kind of takes the pressure off, because people are like “oh.” I figure if they know someone who has it, or have heard of it, they know it’s not contagious- it’s not going to rub off on them. I’m not dying.”

”So you don’t have to try to explain. I think if somebody knows people and knows about it, it is kind of a relief that way. Because you don’t have to go and explain, and go through digging up all that terrible stuff...”

Self Consciousness.

All the subjects reported being self conscious at times with their psoriasis. This included being concerned about clothing choices; both the need to cover lesions, as well as disguise flaking skin by avoiding dark colors such as black. Concerns were voiced about changing clothes in front of peers, as well as avoiding certain activities, such as swimming or going to the beach.

“I’m not comfortable. I’m going to go to the gym after this, and I’m not comfortable right now dressing in the locker room... Even the little bit I have right now, you get people staring and stuff, so it’s just...I would um make sure that my shirt lengths were down, or I would start buying just the half-sleeve shirts...”

“I mean your relationship with day-to-day people, and what is the

first thing that someone notices about you when they meet you, and they see these scabs on your arm or on your face, or whatever, you know? How hard do you have to work to compensate for that?... I mean, like, nobody's ever going to find you attractive.”

“If it gets bad, I usually just wear a camisole that tucks in, so that if my skin starts to flake, it won't flake out from under my shirt. I haven't owned a two piece bathing suit in a long time, just because my torso is the worst part. And even if it's (the psoriasis) not there, I still have to answer questions about it, and that, I don't want to do.” “I must have had some (psoriasis) on my body, because we had a pool in the school that I went to, and we had to take swimming, and I remember not wanting to be in a bathing suit because I looked different...(and was) self-conscious.”

Statements Regarding Intimacy.

Intimacy was mentioned as an ongoing problem with the participants. All participants voiced concerns about others viewing their psoriasis in an intimate situation.

One participant felt so strongly about this concern that he stopped dating.

“But I mean, nobody ever said I don't want to go out with you because...but it definitely affects (whether or not) you want to take your clothes off in front of this guy? Hell, no. So... Which I probably shouldn't have been doing. But would I have done some things if I hadn't had it, you bet.”

“He (my first sexual partner) was just very compassionate about it...Initially, I just told him (about the psoriasis), if I remember right. He just set the bar at what was appropriate.... He was just very compassionate about it. Like this obviously makes you uncomfortable. I'm not going to stop touching you, putting my hands on you. You're my girlfriend, that's how this works (laughs). But... my sexuality was definitely behind the curve – because I'm so not available, not interested in it, don't touch me, like it's not part of the equation for almost all of high school. And so, it took me awhile- especially in college...to catch up to that, just being kind of haphazard or you know, experimenting or things like that because I never went through that whole initial sexuality discovering yourself, and that kind of thing. I never allowed myself to do it. I was just really uncomfortable. That was kind of hard for me at first. Especially when I first started college...It was really important for me to trust somebody, because I expected that from them. You know? And without that, I was really kind of icy. Like, I'm not sure you really care enough about me that you're going to be compassionate about it and I would rather not (be intimate) than get hurt by it. But I think that it has definitely created some intimacy issues.”

Defense Mechanisms.

All the respondents, without being asked specifically about defense mechanisms, mentioned them. Statements were made about being overweight, being “standoffish” and unapproachable.

“I just formulated a natural defense like “no”. If I’m unavailable, then they won’t ask me and I won’t have to go through this whole fiasco about explaining it or talking about it or anything like that. ...I was very standoffish. Sort of like an anticipatory strike kind of thing.”

“I definitely feel like it’s my responsibility to tell other people, because I don’t want their reactions to be negative or to impact their initial impressions of me, but it also gives me a some sense of control that I have already answered the question and it opens the door from them to ask questions if they have any and I am not surprised by it.”

Telling self “it could be worse”.

Two participants downplayed their concerns and problems with psoriasis by focusing on more significant illnesses or problems that they could be dealing with.

“I sometimes start to feel sorry for myself, but there’s so many worse things that you could be born with, I work with veterans, and I read their medical records all day long, and when you see what’s happened to some of these guys, it’s like ‘Oh my god, don’t feel sorry for yourself.’ You could have lost an eye or a leg, or an arm, or everything. There are so many things you could be born with that would kill you. (inaudible) So I try to keep it in perspective, but it’s hideous. When you start feeling sorry for yourself, you could have a terminal illness. You could live in India in poverty.”

Isolation.

One participant did not discuss psoriasis with anyone other than a health care provider and a few family members. The participant expressed feeling isolated because he did not talk to others. This participant voiced concerns of the benefit of

counseling if the counselor had no personal experience with psoriasis.

“...if I ever get back in with insurance, I might talk to somebody and find out if they had it, if they knew somebody who has dealt with patients before who have psoriasis...because I don't have anybody to talk to...That's one of the worst things too, you just don't have anybody to talk to about it. And I don't really care about looking for advice. I'm just looking for somebody that'll listen to me and understand what I'm feeling like. There are some times this is tough to talk about, and then it's kind of a bad thing...You know, you look in the mirror and it's like, oh man! ...It does bother you and it works on you a lot.”

Hopelessness.

One participant spoke at length about his frustration and lack of hope of his psoriasis symptoms resolving.

“Every single day, you have this bottle of cream...and every single day, you're doing this, day after day after day after day. And sometimes you see something happen and sometimes you don't. Sometimes (no matter) what you're doing, it just gets worse. Right now, it is getting a lot harder for me to really accept it, you know. I don't want it, I want it to be gone, or I would just like it to be manageable. You know, I told one doctor, sometimes, I think I wish I had cancer. Because you could do something with that. But what are you going to do with this? And it's just really frustrating, because...regardless of what you do, eventually, the psoriasis seems to be stronger than whatever you're doing. Eventually it finds a way. It just makes you really angry. Or you're looking good, you're really looking pretty good, you might have a little spot here, a little spot there, and it may just look like a little pimple, no big deal. And uh, all of a sudden you get one of these viral infections and everything you did for the last three or four months is just gone.”

Fantasy of Disease Free Skin.

One participant did not have specific fantasies about having disease free skin. The other two participants verbalized improvements in self-esteem. One simply looked forward to wearing more attractive clothing.

“Well, I think I'd be a lot happier...I know um my self-esteem

would be a lot higher. I carry it around, and I let it knock me down a lot...I do think about the day, maybe where I don't even have to think about it...I know that I'll have it. But I won't even have to give it a second thought. Because I know that there is the medications, and I'm doing other treatments, that are just going to keep me in remission and that I won't ever have to worry about it again. I do think about that day. And I really wish that day was here. I wish it was here a while ago."

Guilt.

Two participants, while discussing their desire for a cure, reported feeling guilty about resources being directed to a non life threatening illness such as psoriasis.

"When I think about I wish that they would find a cure, then I always think, you know really they should devote resources toward curing cancer or blah blah blah. I feel like I am always talking about how you should accept yourself, and really just be comfortable with who you are, and I work really hard at it...and so when my skin flares up and I am just really irritated with it, I feel like I am letting myself down in some way. I am not taking my own advice about accepting who you are and being comfortable with yourself because there are some things you can't change."

Perceived Positives.

Two of the three participants initially responded that there were no positive results of having psoriasis. With additional discussion, the following statements were made.

"I think in the long run, the older I've gotten and longer I've had to live with it, I think the more assertive its made me...it's also made me more compassionate to other people, too. Because, I would want people to ask...ultimately I prefer that people just come to me and that's so there is kind of a reciprocity there. So I find myself just asking people themselves, instead of my friends...but I have zero tolerance for gossip...I'm like, you know, this is somebody's life and why don't you just ask them how it went rather than asking someone else who heard it from someone else? And I think, in some respect because I wish people would just ask me. I wish people would just come to me and say "I heard this, or I saw this"

"I've met some pretty nice people...I'm talking about nurses, they're pretty good about it, so that's basically about it... Obviously it's not making me a stronger person... I'm not looking in the eye of storm, and being confident I will beat this."

“No, there's nothing positive I can think of about it. It costs a fortune to treat, it's hideous to live with, and sometimes it hurts or itches, and I've been miserable my whole life.”

“It makes me more conscious- and very aware if other people have something visible that you think would make them feel self-conscious. It makes me feel very empathetic.”

Acceptance.

Only one participant made a comment about coming to terms with the psoriasis, and being more comfortable as time went by.

“I think as I got more comfortable with myself, it stopped bothering me in terms of accepting who I was, and it stopped being something I wished was different...”

Employment Issues.

None of the participants indicated problems with current employers and their psoriasis. Needing a job with health insurance was mentioned as being valued by all participants. One participant shared her experience of entering employment as a teenager.

“When I was in high school, I asked my mother if I could work at the mall. She would say, “Well, you won't be able to work at the mall if you don't take care of your skin. You'll flake all over yourself, and that's not how to sell clothes, honey.” I think she was trying to instigate me participating in my treatment....I remember my first job. We had a little practice session, my dad and I, about what it would be like, and I should tell my boss straight away what's going on. ...So, I just told my boss that I have psoriasis, this is what it is. I'm telling you because you're my supervisor, but if other people want to know, would you send them to me, please? It's not going to affect my ability to do my job, but... and she was fine with it, but she was sort of “why did she just tell me that?”. She just sort of looked at me like, well if it's not going to be a medical emergency, and you're not going to pass out at work- and it's not going to interfere with your ability to do your job, but thanks for the information.”

Financial Burden.

All participants discussed psoriasis having a negative financial impact on their lives. One participant felt frustrated that the medications are expensive, and not wholly successful in resolving his lesions. Another participant stressed that spending time on application of medications, in addition to cost was frustrating.

“Even if you have insurance, it costs a lot of money to do. When you’re doing three or four light treatments a week, plus the prescriptions on top of that, whether you’ve got insurance or not, it doesn’t take long to rack up a bunch of cash...But right now, when I’m bad, I’ll be sitting down for anywhere from half hour to forty-five minutes putting this stuff on...Well, you know, I probably wouldn’t care a lot about that, if you got results. But after while...you’re doing this and using your sick time or whatever, your vacation time or whatever, to do it and nothing’s happening. Then again, that all falls back into you don’t have any money to sit down and let it all out with. Sometimes I think I need to do that.”

“Boy, well, I don’t know how much the light treatments are going to cost. But that’s however much three times a week. That dovonex ointment is \$300 bucks a tube. Thank God I have prescription coverage. Still, I’m paying, every time I get my meds refilled, it’s 5 prescriptions. I pay 30 bucks a co-pay. That’s \$150 bucks every time I refill every three months. Then there’s the doctor visits.”

Concern about future.

Participants expressed concern about passing psoriasis on to their children, or on to their grandchildren. Additional concerns expressed were lack of hope for a cure of psoriasis, and concern of worsening symptoms, including psoriatic arthritis.

“I wonder about having kids. Will they have this disease? Do I want to take a chance of passing that on, and what’s the likelihood that it might be cured? ...That’s pretty devastating. You could pass something along to your children that would give them as much unhappiness as you’ve had with it.”

Provider relationships.

All of the participants discussed interactions with health care providers and

counselors as being positive if the provider was compassionate. Additionally, participants also voiced concern that providers and counselors do not know how it feels to have psoriasis and may not be able to understand the impact psoriasis has on their life.

“I did see one dermatologist in (nearby city). I don’t know if I just didn’t like her, or she just wasn’t nice to me, or I just didn’t get what I was looking for, but she bothered me... I guess she was a little too clinical for me. Like I was without my head, like “this is the body and this is the problem- your skin. O.K. and here is your chart, here’s your prescription, thank you for coming. Not like “tell me about it, where is it bothering you?” ...And I needed, apparently, for her to take an interest.”

“It’s just, psychologically it’s been very difficult. And I sometimes, I’ve thought about going and seeing somebody, but then, you know, what are they going to do?... If you don’t have this... how do you really know how I feel? For her to tell me that “it’s OK, don’t worry about this”, it’s like yeah, right. Just pull off your shirt in a room full of people when you’re all broke out and see what happens.”

Why did you agree to participate?

Agreement to participate in the study was based on a desire to help others in the medical community learn more about psoriasis. One participant felt that participation would help him open up about his feelings. Another wanted a “guided discussion” so she could reflect on her feelings about the disease.

“I thought for myself, it would help- that things like this would help with the research. And getting more people involved in the research. To try to come up with answers with this...I still really strongly believe that there’s this social stigma with this stuff, and that if more people could be aware of it – and more scientists and doctors and stuff could involve themselves with it. And also to really let the medical field out there know just how many people are afflicted with it. That it may aid in advancements of it. That’s a big reason for me... Well, and a lot of that is because we never talk to anyone about it, but nobody ever asks “how do you feel about it”. The doctors never ask. I think that it could be really good for all of us.”

CHAPTER FIVE

DISCUSSION

Exploring lived experience is a unique, in-depth approach to learning about a disease process. The lived experience statements reflect each participant's individual response to questions about their disease, and their independent train of thought on how psoriasis affects their daily lives. In many instances, the responses had common themes and meanings. In contrast, some experiences were individual and yet still significant as they reflect that person's "story".

In addition to being read solely for content, the lived experience statements can also be viewed within the conceptual framework of the Roy Adaptation Model. Each statement can be assigned one, and sometimes several, adaptive modes.

Physiologic adaptive mode is related to the individual's response to stimuli. While this can be applied to the cellular level, in this case, the stimulus is the individuals' psoriasis. The following examples are taken from the lived experience statements as both effective and ineffective responses to the stimulus.

Effective

- In reaction to worsening of the subject's condition, the child agreed to participate in her treatment.
- Commitment to care - Although all subjects reported abandoning treatment of the physical symptoms at some point in time, all patients resumed treatment as a positive adaptive response.

Ineffective

- ❑ Childhood Refusal of Treatment - The subject as a child refused to participate in lengthy treatment sessions with her parent.
- ❑ No perception of positive benefit - One subject complained that there was no benefit to having psoriasis. She reports that it is disfiguring, painful and itchy.

Self-concept adaptive mode is defined as “the composite beliefs and feelings that a person holds about herself at a given time. Formed from internal perceptions and perceptions of others, self-concept directs one’s behavior” (Phillips et al., 1998, p. 246). The majority of the lived experience statements reflect effective and ineffective adaptation in this mode. The following are examples taken from the statements.

Effective

- ❑ Acceptance - Psoriasis became something the subject came to terms with, adapting positively to her symptoms.
- ❑ Disclosure - Rather than feeling the need to react to others’ questions, one subject took responsibility for talking to others openly about her disease. This allowed her a positive sense of control over the situation.

Ineffective

- ❑ Self Consciousness - All subjects talked at length at how and why the psoriasis symptoms cause them to have negative self awareness.
- ❑ Defense Mechanisms - Being overweight and unavailable to criticism were cited as defensive actions.

- ❑ Guilt - Although all three respondents felt guilty about different things, such as not thinking psoriasis research was worthy of receiving funds in comparison to other life-threatening disease, respondents all expressed guilt as an ineffective adaptation response.
- ❑ Anger and frustration were emotional reasons given for stopping treatment.

Role Function Adaptive mode is reflective of the participant's role in society.

“The basic need underlying the role function mode has been identified as social integrity- the need to know who one is in relation to others so that one can act” (Phillips et al., 1998, p. 246). There is significant data regarding the impact the psoriasis has on an individual's societal role.

Effective

- ❑ Helpful when people know about psoriasis already - this serves to “level the playing field” and allow for normal discourse and role function.

Ineffective

- ❑ Teasing by peers - Psoriasis causes subject to be isolated at times by peers. This results in impaired role function.
- ❑ Comments by strangers - Also causes impaired role function by altering the normal discourse and interaction. Subjects are in a position to reassure strangers that the condition is not contagious.
- ❑ Sexual exploration - Psoriasis impairs role function by interfering with sexual discovery and self awareness. Subjects report difficulty in relationships with the opposite sex because of this.

- ❑ Financial Burden - Spending money to treat psoriasis limits some subjects financially. This imposes lifestyle restrictions, which may limit the subject's typical role function.
- ❑ Concern about having children - Two subjects stated concern about having children for fear of passing on genetic predisposition toward psoriasis. This impacts the subject's potential role of parent and may disrupt life plans.

Interdependence Adaptation Mode focuses on the interactions related to the “giving and receiving of love, respect, and value. The basic need of this mode is termed affectional adequacy- the feeling of security in nurturing relationships” (Phillips et al., 1998, p. 246). Lived experience statements here include family, and friends. As there is marked dissatisfaction with provider relationships, provider relationships that foster secure nurturing relationships may benefit the psoriatic patient if they were developed within this adaptation mode. By asking the patient about their coping and adaptation to disease within a nurturing atmosphere, effective interdependence might be fostered. All subjects suggested that they participated in this research with the desire that providers could learn about the daily experiences with the diseases, and the hope that it would enlighten their interactions with psoriasis patients.

Effective

- ❑ Intimacy - A subject's positive experience with a considerate partner led to effective interdependence within the relationship.
- ❑ Positive Family Support - These statements from one subject reflected how a positive, nurturing environment with family can lead to effective

adaptation.

- Compassion - All subjects cited being compassionate as a positive consequence of having psoriasis.

Ineffective

- Fear of Intimacy - All subjects reported psoriasis symptoms interfering with their ability to date and be intimate.
- Negative Family Support - The participant who did not have many supportive members of his family experienced negative adaptation in this arena. He had minimal support systems in place, and could only talk with his sister in law.
- Poor provider relationship - by not acknowledging the impact psoriasis has on the psychosocial aspects of the patients lives, the providers inadvertently encourage maladaptation.

Summary of Results

By looking at the participant's responses in conjunction with the Roy Adaptation Model, we come to a deeper appreciation for the role of the lived experience in adaptation. Clearly, although some positive adaptation responses exist, many are ineffective. Nurses in practice and research have noted that there is much overlap within the adaptive modes and patient care (Phillips et al., 1998). This is also congruent with the findings of this study. For example, almost all of the adaptation stems from physiologic adaptation. The physical symptoms of psoriasis lead to ineffective self-concept adaptation which can then result in impaired role function and or interdependence. None

of these stages occur within a vacuum.

Limitations

The participants were composed of patients from the same city in Montana. All participants had the same treating physician at one point in time. The possibility exists that based on the care received in that geographic vicinity, the participants had similar experiences with providers, staff or community members. This similarity in treatment could potentially have resulted in similar answers to questions regarding psoriasis.

The lead investigator, a nurse employed by the dermatology clinic, had contact with the participants prior to, and after, the interviews. This contact may have influenced the way participants answered questions. This familiarity with the lead investigator could have made the participants more comfortable in the interview setting, or conversely, may have inhibited responses based on embarrassment or fear.

Recommendations for Further Study

Although subjective data regarding psoriasis has been available for over twenty five years, there are no standards regarding how to best utilize this knowledge to improve patient care. Existing assessment models (McKenna et al. 2003) are not available for clinical practice at the time of this writing. Psoriasis patients, like many other patients with chronic disease, may benefit from initial and ongoing assessment of lived experience and adaptation.

Some subjects report better adaptation than others. It would be worthwhile to determine what differences these subjects have from those with negative adaptation

responses. Consideration might be given to age at diagnosis, level of family and peer support, and perception of symptom severity.

Ideally, development of an assessment tool that is psoriasis specific should be done and introduced to all health care providers that are working with this population. Initial and frequent use of such a tool could provide baseline and periodic follow up regarding the individuals' experience and adaptation to their psoriasis.

Finally, further exploration should be considered to compare the value of using lived experience as qualitative means of exploring consequences of disease. Lived experience reports may provide a more graphic and tangible picture for health care providers than other forms of research, both qualitative and quantitative. Nurses, nurse practitioners and other health care providers may view psoriasis differently after reading lived experience statements, and this understanding may lead to alterations in their approach to patients.

Conclusion

Psoriasis is a disease that impacts multiple facets of a person's life. Daily experiences occurring in a psoriasis patient's life can cause positive or negative adaptation.

Psoriasis patients have the perception that nurses and health care providers do not know what it is like to live with their disease. Yet qualitative data regarding psoriasis and quality of life has been available to nurses and health care providers since the late 1970's. By becoming familiar with the lived experience statements of these patients, nurses can develop a deeper appreciation for the impact and fear a diagnosis of psoriasis carries. The

nurse is responsible to begin a dialogue with the patient that allows the patient to share the unique experience of their disease.

When viewing psoriasis within the framework of The Roy Adaptation Model, nurses need to facilitate and foster adaptation. Physiologic adaptation can be directly encouraged by reviewing treatment regimes, teaching basic tenets of skin care, and patient education about psoriasis as a disease. The result of these actions can be considered measurable or concrete in that physical symptoms may be improved.

However, self-concept, role function and interdependence adaptation are more challenging in that the nurse may not directly impact the adaptive response. The nurse supports and fosters positive adaptation indirectly, through her interaction with the patient. It is hoped, through this therapeutic relationship, that the nurse may identify ineffective adaptation more readily, and encourage the patient to modify their response to their psoriasis. If ineffective adaptation occurs, intervention may be required.

Frequent assessment of the patient's coping ability, depression risks and psychosocial needs are necessary at the onset of diagnosis. As the patient's lived experience is constantly changing, coping and adaptation should be revisited periodically throughout treatment. Time should be allowed at every patient encounter to foster interdependence and to discuss the patient's adaptation.

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APPENDICES

APPENDIX A

CONSENT FORM

SUBJECT CONSENT FORM
FOR
PARTICIPATION IN HUMAN RESEARCH AT
MONTANA STATE UNIVERSITY

PROJECT TITLE: The Lived Experience of Patients with Psoriasis.

PARTICIPATION: You are being asked to participate in a study regarding your experiences of living with psoriasis. To participate in the study you must be able to speak and understand English, be under a doctor's care for psoriasis, and have had the diagnosis of psoriasis for a minimum of 5 years.

PURPOSE: Your experiences with this disease may help nurses and health care providers better understand the experience of living with psoriasis.

HOW YOU WERE SELECTED: You, or someone you know, identified yourself as a possible participant after reading a poster about this study in the lobby of a doctor's office.

PROCEDURES: If you agree to participate, you will be interviewed in your home, Dr. Vellanki's office, or via telephone. These interviews will be scheduled according to your availability and will take approximately 40 minutes. As a participant, 2 interview sessions will be expected and will be completed before October 1st 2004. After completing your final interview, no further contact will be initiated by the investigator.

RISKS: This study will require detailed discussions about personal experiences, which may include your feelings. While you may experience negative emotional effects from participating in these discussions, there is no physical risk to participation.

BENEFITS: The study is of no benefit to you. You will not receive compensation for your time, however, information you give us will help us in caring for and treating others with psoriasis.

DECLINING PARTICIPATION: Declining to participate in the study will not have any adverse effect on you or your receipt of future health care.

SOURCE OF FUNDING: There is no source of funding for this project.

COST: There is no cost to participation.

CONFIDENTIALITY: Your identity will be known only to the principle investigator and her faculty advisor. The information obtained in this study will be published for a Master's thesis, and may be published in a health related journal, but your identity will not be revealed. After your interview is transcribed, the written material will be given a

code number, and the audio tape will be erased. All interview data will be stored on a disk in a locked case. Only the principle investigator will have access to this disk.

DISCOMFORT: In the event your participation in this research directly raises discomfort in you, a mental health referral will be available, but there is no compensation for this referral available. Further information about this referral may be obtained by calling Megan Gittings at (406) 431-1611.

LIABILITY: Montana State University is not responsible for injuries or costs incurred as related to the subjects' involvement in this study.

ADDITIONAL QUESTIONS: Additional questions about the rights of human subjects can be directed to Mark Quinn, Chairman of the Institutional Review Board at Montana State University, at (406)994-5721.

AUTHORIZATION: I have read the above and understand the discomforts, inconvenience and risk of this study. I, _____, agree to participate in this research. I understand that I may later refuse to participate, and that I may withdraw from the study at any time. I have received a copy of this consent form for my own records prior to beginning my interview.

Signed: _____

Witness: _____

Investigator: _____
(Graduate Student)

Date: _____

APPENDIX B

INTERVIEW GUIDE

Interview Guide

I. Overview of the interview process

II. Please tell something me about yourself your marital status, age, age at diagnosis, location and extent (mild, moderate, severe) of psoriasis, current treatment.

III. Please tell me what is it like for you to live day by day with psoriasis? I am interest in your experience when you were first diagnosed and your experience now.

(Explore thoughts, feelings, reactions, imaginations or fantasies, relationships with self and others - spouse, family, nurses, strangers).

IV. What are aspects of this experience that you have struggled with?

(Sexuality, exposure of affected area, daily tasks.....)

V. What has been positive for you about this experience?

APPENDIX C

SECOND INTERVIEW GUIDE

Second Interview Guide

I. When meeting someone who already knows about psoriasis...Statement “somebody else already did the work”. Does that make sense to you?

II: Responsibility: Do you feel responsible for protecting others from being shocked? For telling others that psoriasis is not contagious?

III. Do you ever console yourself thinking “at least I don’t have...Cancer, AIDS, etc”

IV. Do you ever wish you had another disease that was potentially worse, but more likely to be cured?

V. Do you ever feel guilty for wanting your skin to be better?

VI. Have you ever stopped treating your psoriasis out of frustration? What happened? How did you feel?

APPENDIX D

POSTER

Do you have Psoriasis?

You are invited to participate in a research study about your experiences living with psoriasis.

To be eligible you must:

- ✓ Speak English
- ✓ Have been diagnosed with psoriasis for at least 5 years
- ✓ Currently be under a doctor's care for psoriasis
- ✓ Be over 18 years of age
- ✓ Be available to participate in 2 interviews, each approximately 40 minutes in length, prior to October 1st

Interviews will be conducted in a location of your choosing.

Participation is completely confidential, and will not affect your ability to receive medical care in this, or any, medical office.

If you have questions about the study, or would like to participate, please contact

Megan Gittings RN,

Graduate Nursing Student

Montana State University – Bozeman

(406) 431-1611 in Helena

APPENDIX E

FULL INTERVIEW QUOTATIONS

Full Interview quotations

Positive Family Support

(knowing grandmother had psoriasis) “I think what it did was make me more comfortable, that it’s not going to be that bad. Grandma’s fine, she’s fully functioning, she’s married, she has kids. It’s not the end of your world, you know? So I’m not going to be maimed in some way... you think of all the horrible things that could happen to you...”

“And my brother, he’s married to a...um...I don’t know if she still is or not, she just got her Ph.D. a couple years ago, and she was in charge of student nursing at the U of Iowa. So I can talk with her sometimes because she doesn’t get all caught up in...but I was talking to her at some point in time to see if she had any ideas relating to this.”

Negative Family Support

“My mom, well, I talked to them about it because I was wanting to know, I was wanting to find out, you know, who, where this came from. I was just interested in knowing. And my mom is like “Oh my gosh, that’s just something old people get!””, and my sister says, (And um I just started working out, and hadn’t been drinking for a while, just because I wanted to get my workout going,) and um, my sister was in town, and we were having lunch and I ordered an ice tea, and she said aren’t you having a beer, and I said no, ice tea. Then I started talking to her and told her that I had it, and the first thing out of her mouth was, no wonder you’re not drinking. And I’m like do you know anything about this? Anything about it at all? She says no, and I said, then why would you say that? She said, well because, just people who drink get that.”

Childhood Comments

“Kids are cruel. Especially in middle school, that was probably the worst. You couldn’t hide it because my hair was falling out, so I had to cut my hair, which was very upsetting to me.”

“Kids would tease me about having dandruff and not showering. Especially, the medication. If I put it on my scalp it made my hair really oily. That led to the “not showering” thing. (6th grade) This girl named----- was just horribly mean to me. And she used an eraser, making flakes on her paper and dumped it on herself and was mocking me- which was just mortifying, and obviously, very vivid.”

(Relating to light treatment) “It was really intense and I looked

Cuban, but I had stark white lines where my goggles were. So that caused a lot of questions a lot of “fake and bake” and that kind of thing. And I’m like “you have no idea” It’s not as cheap, either!”

Stranger Comments

“I’ve had people come and tell me “that looks like ringworm”. Somebody will say something, you know, like I told this one person, I told him, “Oh, my skin’s just all dried out”. That was just last year. “My skin’s just dried out, it’s just this weather”. They come to me, a little too forward sometimes. And I try to hold myself back a little bit. Not go right into an immediate defense. Really it’s none of your business, I don’t know who you are, so... Once in a while I get worked up. I pretty much keep it hid. You know, where a lot of the problem is the nails. At one time, it would start back here and go down into a deep crevice and come up to a big hump, and they were all like that. That was hard.

“But I’ve had, “well you need vitamins, you need zinc, you need this,” it’s like “No”.

“People ask, people assume...a lot of what people see is on my elbows and arms, and they assume I’ve got like an abrasion. Like I was sliding home base or something. I get a lot of “omigod, what happened to your arm?” I’ll say, “nothing, it’s psoriasis”, “oh what’s that?” you have to go through the it’s hereditary, and no it's not contagious, and..”.

Interviewer: “You tell all people that, that it's not contagious?”

Subject B: “Yeah, because not everyone has the balls to ask, and you know that everyone’s thinking it.”

“I don’t feel like I have a lot of choice (in who I disclose my diagnosis to) because it is visible and if somebody asks me, I don’t object to telling them. But even if I did object, the question is always, “is it contagious?” And I feel an obligation to tell people. You can kind of tell, somebody noticing and thinking about it, and not comfortable saying anything, but a lot of people ask. Sometimes I feel like that is a responsibility to reassure people that they are not going to catch the creeping crud.”

Childhood Refusal of Treatment

“Because at that time it took a lot to get it under control, and I was not interested in participating in treatment of any kind. I was like “go away” or whatever; I don’t want to sit down every night and bakers P&S my head. So I would just refuse to do it, or pitch a fit, you know, and try to outlast my parents which meant that I didn’t want to do it , but I would have to go to school every day and be flaking...it just got harder and harder to hide it

which meant I had to participate in the treatment. I had to give in and do it.”

“They would do things like buy me white clothes instead of black clothes. They would bribe me. ...Because I started doing light treatments really early on, and so I couldn’t always go after work everyday, so they got me a (bus pass) and I would take (the bus) go get my treatment, and then go to my dad’s office. He would bribe me at the end of the week, if I went every day that I was supposed to, I would get a pop or something.”

Self Consciousness

“I remember being very self conscious about my clothing.”

“I just, overall, made me very self conscious of myself at a young age, which was, kind of counter to my natural personality. “

“It was pretty much constantly on my mind. You know, I’d have to change in gym class and someone might see it”

“I’m not comfortable, I’m going to go to the gym after this, and I’m not comfortable right now dressing in the locker room right now. Even the little bit I have right now, you get people staring and stuff, so it’s just...

“I would um make sure that my shirt lengths were down, or I would start buying just the half-sleeve shirts and um I really didn’t change anything.”

“But I never was in any place where I was very comfortable with it. That’s when I started hiding a lot and being very aware of how much skin I showed. I never was a long-sleeved shirt person, but I have a whole closet full of them now.

“I was freaked out at the time. (of diagnosis) I was kind of depressed because I always liked being out, being around water, being out in summertime with just a pair of shorts on, and I’ve always been pretty fit, you know, and I never really considered myself an ugly person, you know, I just like to be out. And now all of a sudden you have to cover everything up and you can’t do that stuff anymore, and it just, when you look at yourself, it really is, it’s terrible. And I just get sometimes, I get really angry and really frustrated, and I get more frustrated than anything, because it just doesn’t go away, it’s not going to go away, and it looks bad, it’s this horrible...”

Interviewer: “was there a relationship in which someone said something to you, or you just wouldn’t let that happen?”

Subject C: “No, just self conscious about it. I’ve always been kind of self conscious about things, which probably doesn’t help much. But I’ve always been self conscious about things, and there’s no way.”

“It is protective, and it’s still very secretive. You know, if I tell this person, will she go off and tell other people about me, and stuff. I’m very protective, very secretive about it. This is, and I don’t know if that’s really good though. That’s why I thought about talking to somebody. I don’t think

it's really good to be that sheltered about stuff, but then I don't, I haven't figured out a way to be not so sheltered. But still maintain that, have an image about it, which to me is very important. And I imagine it would be important to other people, but for me that's very important. It's my secret. A friend of mine, he's asked me, and I just said, it's just something I don't talk about. He says OK, fine. He doesn't push it, he just knows it's nothing physical, he's seen me work out, and we've gotten together, and stuff so he knows. I've had people ask, and I just tell them I don't talk about it. So, I can be forceful enough with my voice, you know, and of course shut down, and I don't think I should be pressed. But I am very self-conscious, very protective, whatever, and that seems to be getting worse."

"I mean your relationship with day to day people, and what is the first thing that someone notices about you when they meet you, and they see these scabs on your arm or on your face, or whatever, you know, how hard do you have to work to compensate for that, or..."

Interviewer: "Do you feel like you find yourself trying to compensate?"

Subject B: "I mean, like, nobody's ever going to find you attractive, so...and I'm sure a lot of people feel that way for a lot of different reasons. It is for me, anyway."

Treatment Experiences

"In 4th grade we lived in Switzerland, and we went to another doctor and he told my mom that the right way to treat it, and I think at that point it was mostly on my scalp, the right way to treat it was to pick it until it bled every night, and so every night before bed I'd sit on the floor and mom and pick my head till it bled. Hurt like hell. It was horrible, and uh, I think it probably hurt her more than it hurt me, and uh, it was so hard for her to make herself do that but... Well, after she picked it to bleed, she put some kind of burning stuff on it. It hurt. It's been a series of topical things, that's pretty much all I've ever done. Oh God, she (mom) hated it, to this day, she hates having done that. She said she knew that wasn't the right thing to do, but the doctor was telling her, so she did it. In retrospect, she feels horrible about it."

"Currently I'm taking light treatments. I was doing this three times a week, and now down to two times a week. I use Elocon on my face where my goggles cover and around my eyes and eyebrows, I still get psoriasis there sometimes. And then I use Ultravate ointment underneath my breasts where the light doesn't reach."

"I can't remember what it's called exactly, but I distinctly remember my mom and I would put paraffin on every one of my spots, one by one, and then we would cut up saran wrap, cover each one and then tape it. every night. That one was very memorable. I used to use Bakers P&S on my

scalp. and then my mom would scrape the scales off which would take hours. At that time all of the treatments were alcohol based, but this one was aerosol which was excruciatingly painful., because it's like a fresh wound, and that was being sprayed on – plus it's alcohol based It was very painful. And I used to do a lot of Balnetar baths which would stain the bath tub, stain me, stain my clothes....Everything. I've done almost every ointment there ever was.”

“I would go 4 times a week for 4 or 5 hours a day. I would go there and they would wash my hair with these super jet powered things that would rotate back and forth across my head, and I think I would bleed I think the shampoo was medicated, too, .and then a light booth – or whatever the designated treatment was. And then they would put something on. I don't remember what it was called. I had to put on white clothes, because it would draw all the blood to the surface. So for one thing it would stain my clothes. And if I got it any where on my, except the psoriasis, it looked like I had been flogged. I was just covered in bruises. Um, and I was in that for a couple of hours. So that was the majority of the treatment was sitting, marinating in this stuff, watching a soap opera or whatever was on TV. Then I would take a tar bath, then shower and go home. So that went on for 8 weeks I think. It was really intensive. Every day, for several hours a day. Um that cleared it up for a considerable length of time, a couple years afterward. Then, I started doing PUVA treatments when I was a junior in high school. And that was...it worked really well but the medication made me really upset to my stomach. I would have to take it a couple of hours before I went, so I would take it while I was still in school. So I would have to sit through my last period of class just sort of nauseous. Um, and I had to be really careful with my eyes. Sort of risk of cataracts – I can't remember all the rationale behind it. I had these awful sunglasses my dad bought me, which were – they covered my eyes, but were anything but fashionable, they were just plain ugly.”

“From 1990, until about 1987, I was using topical stuff. And I used just about everything that was out there. Um, ultravate, dovonex, lidex, something by westcort, some stuff worked some didn't. And here again, I didn't know the whole ramifications of psoriasis, except for it was real curse to have, I never really knew a lot about that until I started seeing a dermatologist regularly. My other dermatologist would, he didn't have a light box, so I didn't know about a lot of these options. I was down in Colorado Springs. I really didn't know about it, and I wasn't one of those...I always figured if one doctor had an idea about how to do things, then most doctors would be that way. I really didn't realize there were differences. And I really didn't realize what the different treatments could have done for me. So, um, up until then, just a lot of topicals. And basically it would work for a little bit and then it would just quit working. Then in 2001 I tried that methotrexate, that was the first thing we tried. And then that didn't really work. It cleared up my scalp, but it didn't do anything, and then we started

the puva treatments. And I was doing puva treatments sometime late fall of 2001 up until about um uh May I believe of 2004. And then, things just weren't working again. And I was getting shots, I can't remember the name of the stuff. I was getting an injection about every 3 months. I can't remember the name of that stuff I was getting every three months. sometimes I'd clear up really well, and it would be great, and then it seems like, through the summer, I would just have minimal coverage, because you know I'd be out in shorts and no shirt, sun seemed to help a lot, and then um, but then starting about September, I would start having more and more problems. And um light treatments weren't working, and the topicals I was getting weren't working, it was just getting worse and worse and worse. Or I would be pretty good, and then I would get some viral infection, and it would flare. I was really clear at one time, then I caught a cold, and whatever, and just within days, it was just like on 80 percent of my body. So, and it changes. I started off just with the scabs, because that's what they look like, just the scabs, and I just had maybe 15 or 20 of them on my body, and back, and lower legs, lower back, and then it changed into that rash-looking stuff, that's what it's changed to, so then I started doing, May-June, doing different type of light treatment. And all I did was burn (laughs) I seem to have problems burning. But um, then, I no longer had insurance, so...I really couldn't keep doing anything. Because I'm into this for quite a bit of money. And um, so I've just been, up until three weeks ago, just been doing some different topicals."

"I used a lot of, and I just know it by Wescort in the blue and white tube, that's basically all I used. And that seemed to work very well. But the problem was it just kept coming back and coming back. And then there were times when it would just really get bad. And it seems to get worse about every year, just kind of a progression. And then I think Dovonex just came out, I think back in the late, oh early 90s I started using a combination of Dovonex and Ultravate, and it was on for a week, then off for a week."

Defense Mechanisms

"I just formulated a natural defense like "no". If I'm unavailable, then they won't ask me and I won't have to go through this whole fiasco about explaining it or talking about it or anything like that. ...I was very standoffish. Sort of like an anticipatory strike kind of thing."

"I suspect that part of the reason that I'm fat is that I'm self-conscious about the way I look and so it's kind of a defense mechanism."

"I have my comfort level barriers. I know who I can say something to, and who I can't say something to. Its like my married friend, they seem to think whatever you tell them, it's O.K. for them to tell their wives. And, so I don't say anything to them. I'm not saying their wives would, but then that's somebody else. And just in passing conversation, that's something

that could come up. Nothing against wives. “ (laughs)

“I think it is also kind of like a self-preservation. It (controlling who and how people find out about your psoriasis) helps you get some control over like if you made the initial step or, if you feel like you are in control of how people find out or what they know, then you are in some way preventing them from making assumptions, and you are prevented from being yourself caught off guard later...I definitely feel like it's my responsibility to tell other people, because I don't want their reactions to be negative or to impact their initial impressions of me, but it also gives me a some sense of control that I have already answered the question and it opens the door from them to ask questions if they have any and I am not surprised by it.”

Increased Tolerance With Age

“It was a lot easier to cope with personally. It wasn't the end of the world. Like, ‘oh god, not this again, you know?’ Well, it's going to keep happening, so it's a fact of life. I'm not going to get away from it. It was easier for me to say “I need to do this. I'm like, this is the way it is.”

Fearing Intimacy

“Still, the thought of dating anyone, or being intimate in any way (during high school)...that was something I could never handle. Like I could not... there was just not way. It was out of the question.”

“It was still in the back of my head sometimes, just like ‘oh god, I wonder if I look O.K.? Did I put medicine on last night? I wonder what it looks like.”

“But I mean, nobody ever said I don't want to go out with you because...but it definitely affects do you want to take your clothes off in front of this guy? Hell no. So... Which I probably shouldn't have been doing. But would I have done some things if I hadn't had it, you bet. Be that for bad or for good.”

“High school it was mostly boys, just driven by boys because I wasn't allowed to date till I was 16. And I thought well, that's coming, and god help me if anyone were to touch me and I would have to explain it, and that would just be mortifying, not to mention ruin the mood!” (laughs)

(to women) “I don't say anything. I don't bring it up. Because I'm afraid of the negative reaction. I'm afraid of their reaction being bad, and I just, I guess in ways I'm withdrawn so much that I just don't want to get, you know – you're in a good relationship, and I don't want this to be the cause of the end of the relationship because they don't want to be with somebody like that, or have somebody like that in their lives. I just don't

want that. So I just kind of make other excuses, so I guess it's more protecting me."

"I stopped dating. I mean, how do you explain this to somebody? And what are you going to do when they go mmm? because there's always this stigma with psoriasis, only alcoholics get psoriasis, or whatever, these other things. So it was always pretty difficult doing that. And I'm still not really, oh there are times, this is going to sound terrible, but it's true, when it does clear up pretty good, that I do go out and try to date. And then when it flares up again, then I back off. And there are a lot of times I don't give explanations as to why or whatever, it's just kind of, I get like a shut in, not real social, or be careful how social you are."

Disliking Feel of Own Skin

"Because even though my skin was much better, but I could still feel it like every time I put my hand against my skin myself, I was like (shudders)."

"I think it was more me saying "I'm not really sure and, don't know enough about you, or I just don't.... It's something that's going to come up relatively soon, you know what I mean? If my skin is not completely in remission, it is what it is so that's going to come up relatively early in a relationship and I just was like "if you're not going to understand - I just assume you won't, or that you'll be weirded out by it then I don't want to go there, then we'll just flat line at friends, you know? But I have definitely cut myself off – on more than one occasion but, on the flip side I think its kept me from being irresponsible. Making stupid decisions ...getting drunk, going home with somebody...I think it's definitely prevented me from doing something like that. The thought of having to tell somebody right then and there, its one of those things, I think it's not OK for me and it's also not appropriate to just spring that on somebody, you know what I mean? It kind of ruins it. It's something that I should have said before hand because it's my responsibility. So, you know, I just knew that – I don't know. I definitely think it prevented me from doing some stupid things, but I might have enjoyed – that might have been rewarding for me personally."

"Well, see, what am I ever going to do if I ever meet that girl? What am I going to do, I'm going to tell her. If I look OK when I tell her, and it's not a bunch of, the shock factor isn't there, but if something happens and it's there, what's she going to do? Because you have to admit it's not something you'd want to touch. (inaudible) I don't think I would."

Dealing With Questions Now

“The older I get, people are just more compassionate. I don’t know if I just anticipate that people might be mean, or they were to some extent, it’s the manner in which people say “I notice that, or what is that?” like they’re asking me because they want to know, not like they’re asking me because “oh I’m going to go tell my friends that we talked about it”

Helpful When People Know About Psoriasis Already

“It kind of takes the pressure off, because people are like “oh.” I figure if they know someone who has it, or have heard of it, they know it’s not contagious- it’s not going to rub off on them. I’m not dying. If they already have some sort of background knowledge about it, you know somebody else already did the work.”

Provider Relationships

“She (the doctor) told me what I’ve heard a hundred times before,” there’s no miracle There’s no cream that we’re going to put you on you skin that’s going to make it all better, so let’s go back to something that works ...”

“I saw doctor----- for so long...basically until I went to college. And he was always very compassionate with me, and I felt comfortable too. Since I had been going to him since the time I found out that I had it. He already knew, he knows what’s up, he’s not going to be wierded out by it – it’s his job. I did see one dermatologist in ----- . I don’t know if I just didn’t like her, or she just wasn’t nice to me, or I just didn’t get what I was looking for, but she bothered me.”

(Discussing failed provider relationship): “ I guess she was a little too clinical for me. Like I was without my head, like “this is the body and this is the problem- your skin. O.K. and here is your chart, here’s your prescription, thank you for come. Not like “tell me about it, where is it bothering you?” She just gave me the once over and said “ok, I see what’s going on here, here you go. And I needed, apparently, for her to take an interest. Like why are you here?”

“He (my primary care provider) always makes sure to ask about it, even if I’m there for a cold.”

“It’s just, psychologically it’s been very difficult. And I sometimes, I’ve thought about going and seeing somebody, but then, you know what are they going to do? I don’t mean to sound like, there are professionals, but if you don’t have this, or if you’ve never had say breast cancer, if you’ve never had these things, how do you really know how I feel? You

really don't know. For her to tell me that it's OK, don't worry about this, it's like yeah, right. Just pull off your shirt in a room full of people when you're all broke out and see what happens.”

“You know, I've never had...all the doctors I've had I feel have been really good, worked hard at trying to find different things, and if I wasn't doing treatment, I don't know how bad I'd be.”

“I've been in therapy a billion times, like 7 times, and no ones, they've never talked to me about it. They've never talked to me about anything. But I have severe depression, and I've always wondered if that was a component of it, or I don't know, you'd think if you've got somebody with really terrible self-esteem issues...”

Interviewer: “But I'd be curious to know what your therapist said if you said I want to talk about my skin. I mean wouldn't you?”

Subject B as therapist: “Why do you want to talk about your skin? “
“ Yeah.”

“I was saying before there's nothing you can do about it, but just the acknowledgment that this has an impact on your life other than just being a red patch on your skin. And it does, it really does. And nobody has ever acknowledged that, really.”

“I've found that uh, as a good example, and as it would turn out you're sitting here. I've found that at the one doctor's office, I could really trust you. Because you actually did listen, you know, and you did....Maybe you didn't have all the great clinical answers, but we're not looking for those. At least, I was looking for someone who would at least, kind of listen a little bit. And really did understand. And um, that's been kind of lost. And when you're talking to the doctor about it, and really letting your feelings out about it, to get a bunch of clinical responses back is not what a person's looking for.”

Interviewer: “Have you ever switched health care providers because of that?”

Subject C: “Yeah. Yes I have.”

Friends and Support System

“I have a lot of deeper, more meaningful friendships and so they ask, ‘how are you doing’ and ‘how is that going’ or they're a lot more compassionate about it and want to know. Obviously it's part of who I am and they make sure to check up on it. It's become more of a support system, instead of something I don't want to talk about with them. (On relying on friends) I think I do because the thought of having a boyfriend for so long was out of the question for a number of reasons, but mostly because of my skin- because I couldn't fathom going there- and that required me to have that companionship in other areas of my life. Especially early on, I became really dependent on my girlfriends to help me figure out who I was. Not that

there's anything wrong with figuring that out with the opposite sex, I think that early on I wanted to have a deeper relationship with my girlfriends."

"I got over my self consciousness with my family pretty early on...O.K. you're my family, whether you like it or not, you have to take me how I am."

Clothing Choices and Restrictions

"If it gets bad, I usually just wear a camisole that tucks in, so that if my skin starts to flake, it won't flake out from under my shirt. I haven't owned a two piece bathing suit in a long time, just because my torso is the worst part. And even if it's (the psoriasis) not there, I still have to answer questions about it, and that, I don't want to do."

"As an adult, I never wore short sleeves or shirts till I moved out to MT, and I was doctoring out here, and I thought, I don't know anybody there and I'm starting over and I'm wearing short sleeves."

"Then I remember, I must have had some on my body, because we had a pool in the school that I went to, and we had to take swimming, and I remember not wanting to be in a bathing suit because I looked different.

(inaudible) self conscious."

"Do I wear something black or something white? Do I wear short sleeves or do I wear long sleeves?"

Interviewer: "So if you have flare ups, that alters your decision about what color? Subject B: "Yeah, not as much as the weather does, but..."

"But day to day, it doesn't really stop me from doing things that I want to do much of the time, it does stop me from wearing what I want to wear sometimes. That sounds so vain, and it is vain, but dammit, it's important."

Mood Changes With Flare

"I don't notice it when(the flare) it's happening, but like I notice it now, my behavior now, if I go out, or what I wear or how I carry myself. I noticed a difference to when I had a flare up, but when I 'm in the middle of it, I don't notice it. It's not till it's over and I go "oh god. But definitely, looking back on it once it's over and my skin clears up again, I'm like "god!" you know? What was that? I have cut myself short because I wasn't all the way there and didn't really feel like I could do it."

Employment Issues

“When I was in high school, I asked my mother if I could work at the mall. She would say, “Well, you won’t be able to work at the mall if you don’t take care of your skin. You’ll flake all over yourself, and that’s not how to sell clothes, honey. That’s just a fact of life” I think she was trying to instigate me participating in my treatment...I remember my first job. We had a little practice session, my dad and I, about what it would be like, and I should tell my boss straight away what’s going on. ...So, I just gold my boss that I have psoriasis, this is what it is. I’m telling you because you’re my supervisor, but if other people want to know, would you send them to me, please? It’s not going to affect my ability to do my job, but... and she was fine with it, but she was sort of “shy did she just tell me that?”. She just sort of looked at me like, well if it’s not going to be a medical emergency, and you’re not going to pass out a t work- and it’s not going to interfere with your ability to do your job, but thanks for the information.”

Sexuality

“He (my first sexual partner) was just very compassionate about it . Like “this obviously makes you uncomfortable. I’m not going to stop touching you That was, I think, (he) was really good with me about that. For as big of a jerk as he was it still flabbergasts me. But he was, I mean just initially, I just told him, if I remember right. He just set the bar at what was appropriate, because he was. He was just very compassionate about it. Like this obviously makes you uncomfortable. I’m not going to stop touching you, putting my hands on you. You’re my girlfriend, that’s how this works (laughs). But it definitely, my sexuality was definitely behind the curve – because I’m so not available, not interested in it, don’t touch me, like its not part of the equation for almost all of high school. And so, it took me awhile- especially in college. Your hormones are raging and people are just completely without inhibitions for a while there. So, it took me a while to catch up to that, just being kind of haphazard or you know, experimenting or things like that because I never went through that whole initial sexuality discovering yourself, and that kind of thing. I never allowed myself to do it. I was just really uncomfortable. That was kind of hard for me at first. Especially when I first started college. But I think after him I was kind of well...that’s how it should be. I kind of wasn’t interested in having like random hookups, or just screwing around. It was really important for me to trust somebody, because I expected that from them. You know? And without that, I was really kind of icy. Like, I’m not sure you really care enough about me that you’re going to be compassionate about it and I would rather not than get hurt by it. Which is such a set back for me. I only had one ...where he was a total jerk, so I just told him off and left. But I

think that it has definitely created some intimacy issues. Like with my boyfriend kind of toward the end of college because. I mean it would get bad and I couldn't allow myself to think that he wasn't going to ...that it wasn't going to translate into another problem in our relationship. The worse it got, the more stressed out I got, the worse my skin got, and the more stressed out I became and more tense. And he knew that was going on and so it was like, it became pretty hard for me to let it go, and trust myself and trust him to like not be total jerk. I think probably the biggest part was that I never did any of that when I was 16 or in high school, whenever everybody did that, so I felt behind the curve. And I kind of felt like a prude even though it wasn't because I wasn't interested in that, it was like "you people already know all that stuff!" I might want to get on the ball here."

"There's some people out there I wouldn't mind pursuing. But they're not short-term people. They would be more, they are looking more into the long term type relationship. I'm just afraid of getting into that, and having something happen that I would have to try to explain this. And I just don't want to do that. I don't want to do that. Maybe I should, I don't know, but I don't want to take that chance. I really don't. I know the way I feel, as it is now, without explaining myself, which is pretty crappy, and then to have to do that, you know, and then, I don't want the rejection or the negative reaction. I don't want them to go off the deep end and "go postal" or anything. That would hurt pretty bad, that would be a pretty tough thing to get over with."

Perceived Positives

"I think in the long run, the older I've gotten and longer I've had to live with it, I think the more assertive it's made me. It's made me feel like, it's also made me more compassionate to other people, too. Because, I would want people to ask me. I would want people to just say "what is that?" "I notice... or you know "I saw" or whatever it was they....I would rather they just ask me than to go to one of my best friends and say "what's with K's skin?" you know? Or "I saw her hair was up the other day and " or whatever it is. And that's O.K., but ultimately I prefer that people just come to me and that's so there is kind of a reciprocity there. So I find myself just asking people themselves, instead of my friends (whispers "did you see that guy?") I just ask, I noticed so and so the other day and they had... (whatever it is) and I find myself being more assertive about my own psoriasis and also asking other people directly. And also, I don't know if this comes with age, or if it's life experience that you go through at some point, but I have zero tolerance for gossip. I can't stand it. I don't know if it's because it's affected me personally in my own life, or if you just kind of grow out of it and are disgusted by it, but. I hate it, can't stand it. I'm like, you know, this is somebody's life and why don't you just ask them how it

went rather than asking someone else who heard it from someone else? And I think, in some respect because I wish people would just ask me. I wish people would just come to me and say "I heard this, or I saw this"

"I think it really opened up the channels of communication with me and my parents, they're both therapists, so I don't think. I think it probably would have been that way anyway... I just always felt like there was a medical part of me and a personal part of me in some respects. And so the medical part of me was just "clinical" in some ways. You know? I mean it is what it is. All girls get their periods, such is life. So, when I got my period, or when it got to be really bad (I have endometriosis) and so when that first started happening it was always sit down with both of my parents, I mean, even my dad. So my poor friend m was like, Oh, I would rather die. If that was my dad, I mean he would rather die! (laughs) Even if it wasn't a problem for me. But I think it is what it is... But I think that's what really opened up the communication for me and my parents. I figure if I can talk about these kinds of things, if I was having this kind of open relationship with my parents – and not inappropriate, but then there probably wasn't anything else I wasn't going to be able to talk to them about. So, that's been really helpful for me."

"I can't think of anything right now. Well, um some of the people I've met. I've met some pretty nice people. You know, within this. Um, and how they are to me, I'm talking about nurses, they're pretty good about it, so that's basically about it, but I can't think of anything. Obviously it's not making me a stronger person, and it's not making me a real better person. I'm not looking in the eye of storm, and being confident I will beat this. I just don't feel that. So, no, I really can't, just some of the nurses. There are some pretty nice people out there. And that's about it, yep."

"No, not one. Am I missing something? Did anybody else come up with something? No, there's nothing positive I can think of about it. It costs a fortune to treat, it's hideous to live with, and sometimes it hurts or itches, and I've been miserable my whole life."

Financial Burden

"Because it's (enbrel) \$595 a pop, so I just started my third shot with that. So I've only been doing that for 3 weeks. I could tell, 3 weeks ago. I've been getting my prescriptions like through my family doctor. So I haven't really been seeing anybody. I owe a lot of people a lot of money for this."

"From 1990, until about 1987, I was using topical stuff. And I used just about everything that was out there. Um, ultravate, dovinex, lidex, something by westcort, some stuff worked some didn't. And here again, I didn't know the whole ramifications of psoriasis, except for it was real curse to have, I never really knew a lot about that until I started seeing a

dermatologist regularly. My other dermatologist would, he didn't have a light box, so I didn't know about a lot of these options. I was down in Colorado Springs. I really didn't know about it, and I wasn't one of those...I always figured if one doctor had an idea about how to do things, then most doctors would be that way. I really didn't realize there were differences. And I really didn't realize what the different treatments could have done for me."

"Even if you have insurance. It costs a lot of money to do. When you're doing three or four light treatments a week, plus the prescriptions on top of that, whether you've got insurance or not, it doesn't take long to rack up a bunch of cash. So you're looking at that. You're looking at the results, which are, sometimes good, and most times, not good. It all just kind of piles into that. But right now, when I'm bad, I'll be sitting down for anywhere from half hour to forty five minutes putting this stuff on"

"Then a lot of times, it depends on how much I have to spend on this, whether or not I can go out. Because I don't go out that often anyway, and then sometimes I do get depressed. And I just go home, my dog doesn't care about this. So I go hang out with my dog and just watch movies."

"Boy, well, I don't know how much the light treatments are going to cost. But that's however much three times a week. That dovonex ointment is \$300 bucks a tube. Thank God I have prescription coverage. Still, I'm paying, every time I get my meds refilled, it's 5 prescriptions. I pay 30 bucks a co-pay. that's \$150 bucks every time I refill every three months. Then there's the doctor visits."

"Well, I now understand my mother's frustration. It's not going to kill the insurance company, but this is the first time I have ever been on my own insurance, so doctor-----told me how much it would be for my light treatments and what not, so I started looking at my insurance coverage. She said you want to think about that...and I went home and looked at it (my deductible), and I was like "oh my god, by the time I meet my deductible, I would be long done with the treatment, and I will still be paying on it forever". So I called the insurance company just to make sure I understood because it is pretty confusing and they started explaining to me that I have like a \$1200 deductible and I am just thinking... I started crying on the phone with this poor insurance woman and I said "I will have to call you back I called my parents and I'm crying and I'm like, "I can't do this, like there is absolutely no way I could pay for it. I absolutely cannot!" An so my dad said maybe you don't have all the information, call the insurance company back and they explained to me that like she (my doctor) was a participating provider so that changed the whole cost thing, so it has been a lot easier for me to handle. It is completely reasonable now. I remember one time my parents had insurance that you had to mail your prescriptions away, and they would send the medications back to you. But I couldn't wait one time, so I had this one filled and it cost me like 400 and some odd dollars. I thought" My God, if I ever didn't have insurance, I don't know what I

would do”. Like I honestly don’t know if I would treat it. “

“Well, you know, I probably wouldn't care a lot about that, if you got results. But after while, see that’s another thing, too is after while, you’re doing this and using your sick time or whatever, your vacation time or whatever, to do it and nothing’s happening. Then again, that all falls back into you don't have any money to sit down and let it all out with. Sometimes I think I need to do that.”

Fantasy of Disease Free Skin

“Well, I think I’d be a lot happier. I think my self-esteem would be...I know um my self-esteem would be a lot higher. I carry it around, and I let it knock me down a lot. You know, but I don’t...I don’t really fantasize about that. I do think about it, I do think about it. So...I do think about the day, maybe where I don't even have to think about it, I don't even have to think about it anymore. I know that I’ll have it. But I won’t even have to give it a second thought. Because I know that there is the medications, and I’m doing other treatments, that are just going to keep me in remission and that I won’t ever have to worry about it again. I do think about that day. And I really wish that day was here. I wish it was here a while ago, but...I do think about that, yeah.”

“I’d have so many cuter clothes, I think. When you’re 13 it’s important.”

Interviewer: “Well, it’s important as an adult too. I mean, we tend not to fixate on it as much.”

Subject B: “Yeah. It would take me half an hour to figure out what to wear to work every morning. Thank God, I don’t have to call a friend and say what should I wear to work today? (laughs) Yeah, it would definitely have been different. “

Treatment Failures

“So, um, up until then, just a lot of topicals. And basically it would work for a little bit and then it would just quit working. Then in 2001 I tried that methotrexate. That was the first thing we tried. And then that didn’t really work. It cleared up my scalp, but it didn't do anything, and then we started the puva treatments. And I was doing puva treatments sometime late fall of 2001 up until about um uh May I believe of 2004. And then, things just weren’t working again. And I was getting shots, I can't remember the name of the stuff. I was getting an injection about every 3 months. I can’t remember the name of that stuff I was getting every three months. sometimes I’d clear up really well, and it would be great, and then it seems like, through the summer, I would just have minimal coverage,

because you know I'd be out in shorts and no shirt, sun seemed to help a lot, and then um, but then starting about September, I would start having more and more problems. And um light treatments weren't working, and the topicals I was getting weren't working, it was just getting worse and worse and worse. Or I would be pretty good, and then I would get some viral infection, and it would flare. I was really clear at one time, then I caught a cold, and whatever, and just within days, it was just like on 80 percent of my body. So, and it changes. I started off just with the scabs, because that's what they look like, just the scabs, and I just had maybe 15 or 20 of them on my body, and back, and lower legs, lower back, and then it changed into that rash-looking stuff, that's what it's changed to, so then I started doing, May-June, doing different type of light treatment. And all I did was burn (laughs) I seem to have problems burning. But um, then, I no longer had insurance, so...I really couldn't keep doing anything. Because I'm into this for quite a bit of money. And um, so I've just been, up until three weeks ago, just been doing some different topicals."

Hopelessness

"So it was just, there was really nothing you could do, it was just a matter of how bad it's gonna get. Where some people just get a little bit of it, and that's it, some people get um, I did like to party a lot, and I don't know how much I really don't know how much drinking has affected it. Because I quit drinking for a year and a half, and it never did anything, so I don't know. I know that, well I don't know it, but I've been told that it can cause a flare-up, stress can cause a flare-up, a viral infection can cause a flare-up, you know, but as far as changes in my diet or anything like that, I never really, it just seemed to me I started making more conscious changes about physically."

"Every single day, you have this bottle of cream or bottle of whatever, and every single day, you're doing this, day after day after day after day. And sometimes you see something happen and sometimes you don't. Sometimes what you're doing, it just gets worse. Right now, it is getting a lot harder for me to really accept it, you know. I don't want it, I want it to be gone, or I would just like it to be manageable. You know, I told one doctor, sometimes, I think I wish I had cancer. Because you could do something with that. But what are you going to do with this? And it's just really frustrating, because you start doing things, regardless of what you do, eventually, the psoriasis seems to be stronger than whatever you're doing. Eventually it finds a way. It just makes you really angry. Or you're looking good, you're really looking pretty good, you might have a little spot here, a little spot there, and it may just look like a little pimple, no big deal. And uh, all of a sudden you get one of these viral infections and everything you did for the last three or four months is just gone."

“And you still hope that there's a cure someday soon. Like now, would be good. But chances are slim, and...(voice trails off) “

“There's no other, there's nothing that you can do to make it any better. I just hope that somewhere a long the line they have something different for you. And instead of being angry all the time, just plain being angry. Still being angry, but understanding that, well, this is how this goes. And you know, I've been doing that Amevive thing. And it was great for five weeks, and now all of a sudden I'm starting to break out on my sides again. And that's not supposed to happen. And so, there I am. And this is one of the hottest things that's supposed to be out there.”

Isolation

“Sometimes, you know, I've thought about that the other day, that if I ever get back in with insurance, I might talk to somebody and find out if they had it, if they knew somebody who has dealt with patients before who have psoriasis. Has worked with them before, and they know. because I don't have anybody to talk to. You know, I don't, that's one of the worst things too, you just don't have anybody to talk to about it. And I don't really care about looking for advice. I'm just looking for somebody that'll listen to me and understand what I'm feeling like. There are some times this is tough to talk about, and then it's kind of a bad thing. But that is bad. Just, you know, you look in the mirror and it's like, oh man, it does. It does bother you and it works on you a lot.”

Stress

“I gotta believe that people have this, especially moderate to severe, it adds a lot of stress to them. And it's kind of a double edged sword there. You know. I think a lot about that. Because I get stressed out about it. And I think...if I try to be calm and relaxed about this, but it just doesn't seem to work. But I like doing it, this is the first time I've ever said any of this stuff. I've never talked like this to anybody else. So, I think it's pretty good for me to do this too. And if anything can come out to help, or just anything, I'm all for that too. I'm definitely all for that.”

Telling Self “It Could Be Worse”

“Well, I'll tell ya, I sometimes start to feel sorry for myself, but there's so many worse things that you could be born with, I work with veterans, and I read their medical records all day long, and when you see what's happened to some of these guys, it's like omigod, don't feel sorry for yourself. You could have lost an eye or a leg, or an arm, or everything.

There are so many things you could be born with that would kill you. (inaudible) So I try to keep it in perspective, but it's hideous."

"I try to keep it into perspective. When you start feeling sorry for yourself, you could have a terminal illness. You could live in India in poverty."

"I definitely think something could be worse than that, like just sort of I give myself a little silver lining talk. Okay, so you have had it this long, there are ways around it. There are a lot of things in your life that could not be going well, and you should count your blessings, but this is the thing that is not going well."

Concern About Future

"I have a horrible fear of the arthritis, psoriatic arthritis. Just a couple years ago I was having some foot pain, and I went to see the doctor, and he asked me about my medical history, and I said I had psoriasis. He said Oh, I'll take an X-ray right now, and I'm like OK, this is obviously significant, what is this? He's the one that told me about it. I mean this is bad enough, but chronic pain? I'm not the type."

"One of the aspects that's a biggie, I didn't think of it (until now), but I wonder about having kids. Will they have this disease? Do I want to take a chance of passing that on, and what's the likelihood that it might be cured, and that's pretty devastating you could pass something along to your children that would give them as much unhappiness as you've had with it."

"You know, the way it was explained to me in the very beginning was, there's no point in changing because it was explained to me that it was hereditary, that somebody in my family had this, that was just unfortunate to get this, that I was...they told me that I could have kids, and they wouldn't have any problems. But they could have kids and their kids could have problems."

Guilt

"As bad as it is, on the other hand, it's something that keeps it in perspective, it could always be worse. There is a fear that this could progress to something like that, and that is getting way beyond vanity, that is something pretty serious, I would think. I've never known anybody that had it, but it strikes me as being a really really difficult thing to live with. I'm going for the cure. It would make somebody rich. I'd be happy to participate in that. On the other hand, you know, I wonder shouldn't they be putting their money toward cancer research, or AIDS research? This is horrible to live with, but it's not gonna kill me. So there's a little guilt there."

"I've made a comment a couple of times, that I wish I *had* some

other things. At least they could cure those. ... (I've thought) it either could be worse, or why can't I have something that isn't so visible. Something like that. I more think about why can't I have something that might have been terrible to have, but at least they can cure it."

Interviewer: "Do you ever feel guilty for wanting your skin to be better?"

Subject C: pause... "Sometimes I do. I feel guilty about it on the side of what I would have to do... Would I have to do something that's really painful. If I would have to go through a really long, extensive process of getting it done. Like a complete body skin graft, or something like that, but I don't really feel guilty about that. I lay around a lot wishing that I could. And I have no guilt about that."

"When I think about I wish that they would find a cure, then I always think, you know really they would devote resources toward curing cancer or blah blah blah. I feel like I am always talking about how you should accept yourself, and really just be comfortable with who you are, and I work really hard at it, a lot of times I do, and so when my skin flares up and I am just really irritated with it, I feel like I am letting myself down in some way. I feel like I am not taking my own advice about accepting who you are and being comfortable with yourself because there are some things you can't change.

Compassion

"I actually think after having this... Before I never really gave things a second thought, but now that I've had this. If somebody does have a problem or something, you know I can understand – especially something if they're going to have it for a long time, I can understand how they would feel. I wouldn't say anything, but, I would think a little more about it than just "oh, bummer" or whatever. I would definitely think more about it"

"It makes me more conscious- and very aware if other people have something visible that you think would make them feel self-conscious. It makes me feel very empathetic."

Talking To Others

"um that by them knowing somebody else who has it, they might possibly know the problems with it. The gal that's drawing my blood right now. They know they're drawing it for a certain test, but they really don't know what it is. And I told her I had psoriasis. She said that a good friend of her moms has it, and she made that comment to me that "you don't look like you have it" because this person had it all over, and so she knew. So I knew that she knew. So you don't have to try to explain. I think if

somebody knows people and knows about it, it is kind of a relief that way. Because you don't have to go and explain, and go through digging up all that terrible stuff..."

"It has definitely made me more aware of other people's feelings from little things, not just warts, but little things that other people don't notice they do. You know not necessarily intentionally either, but it had definitely made me more compassionate."

Stopping Treatment

"At the time I stopped treating it, I was just very angry and very frustrated about it and then just went and got, just kept getting worse and worse and worse. I just got madder and more frustrated about it and more withdrawn. I, you know, some of that – or even quite a bit of that- was my real lack of knowledge about it. When I first got it, they gave me this pamphlet on it, but I never really understood. I thought that if I got this stuff and put it on that it would work. That's just what you did. I didn't really understand that it was going to stop working at some point in time and then you'd have to change to something else. I never understood a lot of things. For a lot of years, I never understood a lot of things. And so I just... And I still get frustrated. You know, it's just like you go along and things will be O.K. and then whatever you did wasn't working again. And then that trial and error thing. They give you something, and I ever understood why they always started you off with the real weak stuff and then worked you up to something that did work. Because by the time you got there it was really bad. And when you had used everything that was basically out there and it didn't work, then I – yeah. I did, I stopped. I know I stopped a couple of times. I was really angry about it. "

"When it gets worse, even if it is just a little bit worse (I return to treatment) out of the fear of letting it go and getting out of control again."

"I was too frustrated with it. It was also like a subconscious protection, I felt like, if my skin was not treated I have to be that much more cautious and it can prevent me from doing other things. But like a lot of medication will get on your clothes, and it is like most of it would stain your clothing. That used to just drive me nuts! Because I could only wear it at bedtime, there is an extra 20 minutes, putting on all of that crap on your skin, you know, and then you have to shower, because if you don't it is till on your clothes... So I think sometimes it was just the general frustration with the treatment. I'm like Gosh this is too much work. It is not working fast enough. The most common reason for me to go back to treatment is some sort of interpersonal relationship. Like I started realizing that I am going to want people to see certain parts of my body or I am in a relationship where that is going to come up, or I am hoping to be in a relationship where that will come up, and I am aware of it, and so... It is

going to be summer, I am not going to want to have this problem.”

Why Did You Agree to Participate?

“I thought for myself, it would help- that things like this would help with the research. And getting more people involved in the research. To try to come up with answers with this. And then that possibly things coming out of this um, not only to get something to help this, but to get it where everybody could use it. You know. Because I’m not really sure. It seems to me that I still really strongly believe that there’s this social stigma with this stuff, and that if more people could be aware of it – and more scientists and doctors and stuff could involve themselves with it. And also to really let the medical field out there know just how many people are afflicted with it. That it may aid in advancements of it. That’s a big reason for me. And plus, nobody ever asks us. No body ever asks these things. Well, and a lot of that is because we never talk to anyone about it, but nobody ever asks “how do you feel about it” The doctors never ask. I think that it could be really good for all of us. I’m glad I did this. Like I told you before, I’ve never spoke about this. And I’ve thought a lot about it too. I’ve thought a lot about things. And I’ve thought a lot about when I get back in and get some insurance, I’ve thought about talking to somebody.”

“To be helpful. I don’t think people know a lot about psoriasis, it is not a perspective you can have if you don’t live with it every day.”

“I think to have some sort of guided discussion about where have you been, what have you gone through. It is good for me to think about it, plus, I just think if other people understood what it was like, yes in health care, but in other places as well, if people understood what it was like, they would phrase their questions differently, because I don’t think it is not okay for people to ask, but I think some people don’t realize that it is rough around the edges and that it hurts other people in some manners. If you are already self-conscious about something else, then that just piles it on.”

Acceptance

“I think as I got more comfortable with myself, it stopped bothering me in terms of accepting who I was. And it stopped being something I wished was different, and it is what it is.”