

The Lived Experience of Psoriasis Patients from Social Stigma and Rejection: A Qualitative Study

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Abstract

Background: Psoriasis is a common, chronic skin disease that causes challenges such as stigma and labeling from both the community and individuals due to its effects on appearance.

Objectives: The objective of this study was to describe and explain the social stigma and rejection experienced by patients with psoriasis.

Patients and Methods: The present research is a qualitative study with a hermeneutic phenomenological approach conducted among psoriasis patients referring to the dermatology clinic and ward of Imam Khomeini hospital in Ahvaz, Iran between June and December 2014. In this study, 15 patients with psoriasis were selected by purposeful sampling, and they were asked to express their experience of stigma and rejection. The data were collected through in-depth semi-structured interviews, and Diekmann and colleagues' method was used for data analysis.

Results: After analysis of interviews, four themes were extracted: lack of social support, unrealistic and inappropriate labeling, rejection and isolation, and feeling of absurdity and futility. These can be indicative of the patients' experience from social stigma and rejection phenomena.

Conclusions: Patients' experiences of stigma and rejection phenomena indicated that all aspects of their lives are affected. Moreover, these findings highlight the significance of stigma and rejection concepts in providing better care to these patients.

Keywords: Psoriasis, Qualitative Research, Stigma, Rejection

1. Background

In the present era, chronic diseases have become more of a scourge of human life than other diseases and have created several challenges for human beings' lives (1). One of these chronic diseases is psoriasis, a common chronic skin disease that has many effects and complications in these patients' lives (2). This disease, in which skin cells divide rapidly, may affect up to 90 percent of the skin (3). Since its main cause is unknown, there is no definitive treatment for this disease (4, 5). In a study, psoriasis was observed in 9.1 percent of subjects in Iran (6). On average, the prevalence of the disease is 1% to 3% worldwide (7, 8).

Psoriasis complications are varied. Although often seen on the surface of the skin, it can have devastating physical, mental, and psychosocial consequences (9, 10). Because of the obvious cosmetic side effects, this disease in many cases influences how others deal with patients and patients' feelings about themselves (11). Among the worst complications of the disease are the phenomena of stigma and labeling from individuals and community. Individuals

avoid having contact with the patients, which is very agonizing for the patients and leads them to develop an improper image of themselves. These attitudes, if repeated, may cause anger, shame, or despair for the patients. Ultimately, this makes the patients concerned about encountering others, and they refrain from social activities (12, 13).

Stigma is defined as a mark of disgrace or discredit that prevents the formation of normal relationships in a patient's life and will lead to discrimination (14). Stigma is known as a social process with personal experiences related to rejection, acceptance, blame, or devaluing the life of the patient, combined with unreasonable social judgments about the patient (15-17). Skin diseases often lead to rejection of the patients due to their aesthetic aspects and have negative impacts on their lives. Social rejection is an outcome variable and result of the accumulation of objective and subjective deprivations of those who have a relatively high level of deprivation, have experienced significant losses in their life, and feel that belonging to a particular group, different from normal people, places them in

the space of discrimination in the margins of public life in the community (18). The skin plays an important role in interpersonal relationships; therefore, skin diseases have obvious effects on patients' appearance and change people's attitude toward them (19). Such skin changes may cause hatred, fear, and even intolerance, and others may avoid contact with the patient due to fear of the possibly contagious nature of the disease. Various studies report stigma and rejection as a consequence of psoriasis (20-23). For instance, in one study the rate of stigma and rejection among psoriasis patients was reported as 90.2% (24). There is also research to suggest that 20 percent of patients with psoriasis have been rejected from the hairdressers, swimming pool, gym, or workplace due to this disease (25). Moreover, stigma is likely to disturb the patients' social activities, general health status, and life quality (26, 27). The above results are indicative of the serious harm to the quality of life of these patients in today's society.

The effect of the disease on self-confidence, family relationships, friends, society, and social activities is undeniable. Furthermore, preventing social isolation in these patients and encouraging their participation in support groups require plans to provide a high quality of living (28). Considering that studies conducted on the perceptions and attitudes of nurses living with dermatologic patients mainly have been performed with a positivist approach and using quantitative methods, and also given the importance of providing care and treatment for patients and nurses, the researchers chose the philosophy and method of phenomenology for this study. This approach is similar to Heidegger's hermeneutic phenomenology philosophical approach, which can inspire the researchers in study design, data collection, and the kind of interaction with colleagues. For this reason, identification and exploration of individual experiences are essential, and the present qualitative study can substantially clarify the existing gaps in care and treatment processes. Better understanding and interpretation of opinions, beliefs, interests, and values about social stigma and rejection can be gained using patients' first-hand experiences. In addition, studies conducted in Iran suggest that no qualitative research has been undertaken, to date, regarding the experiences of stigma and rejection in patients with psoriasis. In sum, social rejection and stigma are yet to be properly conceptualized in Iran.

2. Objectives

The purpose of this study was to describe and explain the social stigma and rejection experienced by patients with psoriasis.

3. Patients and Methods

This study was a qualitative research with a phenomenological approach. The inclusion criteria for the participants are as follows: being male or female diagnosed with psoriasis by a dermatologist; having an active hospital file in Imam Khomeini hospital (General, governmental and referral) in Ahvaz, Iran; suffering a minimum of 6 months from the disease; being aged 14 years and above; being willing to communicate their experience of the disease; and having no previous history of mental disorders and acute physical illness. The exclusion criteria were individuals who did not want to participate in the study.

In this study, 15 psoriasis patients were selected through a purposeful sampling strategy between June and December 2014 in the dermatology ward and clinic of the Imam Khomeini hospital. This hospital takes referrals mainly from across the Khuzestan province in southwest Iran. They were chosen by using maximum-variation sampling to capture a range of perspectives. In this sampling method, the individuals are selected to participate in a qualitative research on their first-hand experience with a phenomenon of interest. The saturation method has been used for sampling, and since after 20 interviews the 21st, 22nd and 23rd did not have any extra information, the study sample was limited to 15 psoriasis patients. In-depth semi-structured interviews were used to collect the data necessary for the research. The interviewer accomplished this study after extensively and thoroughly studying qualitative research methods and attending the necessary workshops, as well as enjoying the views of expert teachers in this regard. Prior to the interviews, permission was obtained from the ethics committee of Ahvaz University.

After obtaining the necessary permissions, sufficient information was provided to patients regarding the nature and purpose of the study. Each participant separately signed a consent form and declared their willingness to participate in the study. The main question of the interview was "What were others' reactions and behaviors once they learned about your psoriasis?" Then, exploratory questions were asked to encourage participants to provide more profound information. The interviews lasted 40 - 70 minutes and the number of sessions per patient ranged from two to four (23 interviews in total). Participants were asked to determine the time and place of the interviews. Interviews were taped with the permission of the participants, and immediately after the interview, the interview texts were transcribed and thematic analysis was performed with Diekmann and colleagues' seven stages method (29) using MAXQDA ver. 10. Data collection and analysis were performed simultaneously and interviews

were conducted.

The seven stages of thematic analysis was conducted as follows: 1) All interviews were reviewed to obtain a general understanding; 2) Interpretive summaries were written for each interview; 3) Group analysis of selected versions of interviews was conducted and themes were identified; 4) Referring to interviews or participants continued regularly to explore, clarify, and classify the disagreements and controversies in interpretations and wrote an overall and combined analysis of the text (Interview); 5) The texts (interviews) were compared to identify, specify, and describe the same meanings and functions; 6) Identification and extraction of fundamental patterns was continued to connect related themes in an appropriate manner; 7) A draft of the themes, with selected excerpts of the interviews, was provided to the interpreter team members and experts who were familiar with the methods and content, so they could extract and apply the answers and suggestions to write the final version.

The data were evaluated to confirm the trustworthiness, credibility, dependability, and confirmability of the research (30). To ensure the credibility, the findings of this study were presented to the participants, who expressed their views on the consistency of the findings with their own experiences. Collaborative thematic reflection was conducted by the research team at different stages of the study. The researchers secured the confirmability of the research by maintaining the documentation at all stages of the research. Researchers' interest in the phenomena under consideration, long-term exposure to the data, and elicitation of other views in the field were other factors ensuring the confirmability.

Furthermore, the present study was performed through teamwork and under the guidance and supervision of experts, which enhanced the dependability and the confirmability of the data.

3.1. Ethical Considerations

The present study (code of ethical conduct: 1393.264) was approved by the ethics committee of Ahvaz University of Medical Sciences. For moral considerations, participants were informed of the purpose and significance of the research before starting the interview following their submission of informed consent forms. Permissions were obtained from the participants who volunteered to take part in the study and accepted the use of a tape recorder to record the interviews. They were assured that the obtained data would be used solely for research purposes and would not be available to persons other than the research team. Moreover, participants were assured that they could leave the study at any stage of the research and that their profiles would be kept confidential during and after the study.

4. Results

Interviews were performed with 15 patients (6 men and 9 female) with psoriasis, aged between 18 and 58 years, with an average history of 6.3 years. The demographic characteristics of participants are shown in Table 1.

In the thematic analysis of data, more than 700 initial codes were extracted from the interviews. In later stages, these themes gradually decreased through the elimination of similar and overlapping themes, and they finally came down to four main themes. The most important themes that were extracted included lack of social support, unrealistic and inappropriate labeling, rejection and isolation, and absurdity and futility, all of which were named as the main theme of social stigma and rejection (Table 2) and will be separately presented in this section.

4.1. Lack of Social Support

Social health can be defined as individuals' assessment of the quality of their relations with family, others, and social groups, indicating the individuals' satisfaction or dissatisfaction with their life and social environment. This includes inner responses, feelings, thoughts, and behaviors. Evidence suggests that patients were not satisfied with their lives and social environment, which led them to hide their disease. In the present study, lack of social support was one of the themes of the experience of stigma and rejection. In their descriptions, patients had specific references to their feelings of loneliness due to deprivation from natural rights, dependencies, and lack of formal and informal supports.

In this regard, one participant stated, "Our quality of life is not good. They do not pay attention to me; even my friends. I do not want anyone to find out about my disease because his or her behavior will change" (A 38-year-old woman).

A participant said, "When they found out that I have a problem at work, I stopped going to work. My problems increased since then, I mean economic problems. My family do not help me, they say go to work, why are you at home? I became a recluse" (A 42-year-old man).

One participant said, "I have a sister-in-law who lived with us previously. We lived together in a house. She kept ridiculing me and telling me what are those on your skin? Why do not they disappear? You should go to a physician. Maybe you got a bad disease. My brother and my mother did not care and never supported me." (A 36-year-old woman)

4.2. Unrealistic and Inappropriate Labeling

Most participants in this study expressed that they received labels such as bad person, corrupted, infected, and

Table 1. Demographic Characteristics of the Participants, n = 15^a

Participant	Age	Sex	Marital Status	Occupation	Educational Level	Duration of Disease, y
1	42	M	Single	Employed	Secondary	6
2	38	F	Married	Housekeeper	Diploma	3
3	46	M	Married	Retired	Primary	2
4	40	M	Married	Employed	Diploma	8
5	36	F	Separated	Employed	Secondary	4
6	31	F	Married	Employed	University	9
7	54	F	Married	Housekeeper	Primary	6
8	28	M	Single	Employed	Secondary	1
9	28	F	Married	Housekeeper	Diploma	12
10	39	M	Single	Unemployed	Secondary	4
11	33	F	Widow	Housekeeper	University	6
12	18	M	Single	Employed	Secondary	8
13	44	F	Married	Unemployed	Primary	3
14	48	F	Widow	Unemployed	Secondary	9
15	58	F	Married	Retired	Primary	14

^aValues are expressed as No. (%).

words such as these when others got informed of their disease. This was very painful for them and sometimes caused psychiatric diseases, disruption of family and marital relations, divorce, and separation.

A participant said, "One of my friends told me: people say you're infected, for this reason people do not talk to you" (A 31-year-old woman).

Another participant also said, "My relatives do not come to our house since they found out about my problem. They say your disease is contagious and we might get infected" (A 46-year-old man).

4.3. Rejection and Isolation

Stigmatization leads to social rejection of the individual from society, and the patients frequently develop psychological problems.

One participant stated, "Once my friends and family found out about my disease, they gradually took distance from me" (A 40-year-old man).

Another participant said, "I am still afraid to tell my family what my disease is. I am afraid to tell them what my problem is because then they would not care about me." (A 28-year-old man)

A participant said, "My brother does not visit me anymore since he found out about my disease. He used to visit me but not anymore" (A 54-year-old woman).

4.4. Feeling of Absurdity and Futility

A number of participants expressed that the attitude of the people around them has changed and they do not treat them with respect like before. Others do not even pay attention to their speech, which leads to their feelings of absurdity and humiliation.

In this regard, a participant stated, "Previously, when I went to a store for shopping, the shopkeeper was so warm to me and told me to take whatever I wanted myself. Previously, we used to kiss each other but now, he does not even shake hands with me. Sometimes I have suicidal tendencies. I am disappointed of my life, why me?" (A 39-year-old man).

Another participant reported that, "When I want to go out, I have to cover all parts of my body because I am worried that others may see my spots and develop bad thoughts about me. I used to go out with my friends, for football and sometimes we went swimming, but now, I feel like they will ridicule me and do not care about me. I feel weak and I tell myself I am not useful for anything." (A 28-year-old woman).

In general, according to quotations and themes, patients had experienced stigma, rejection, lack of support, deprivation of social rights, isolation, and withdrawal in the course of the disease.

Table 2. The Development of 'Stigma and Rejection' Theme^a

Meaning Units	Code	Sub-Categories	Categories
One day I went to the bakery to get bread. I said hi to a few of our neighbors but they were not kind to me and answered me cold-heartedly.	Disrespect	Lack of social support (12 (80))	Stigma and rejection
My family and my friends did not pay attention to me.	Neglect of family and friends		
When they recognized I have problem at work told me I was fired	Expulsion and unemployment		
The government is responsible for this disease and it does not educate people on television and in newspapers	Lack of information		
There are no facilities for us. For example, they do not create an environment for work	Deprivation of civil Rights		
Since I have been unemployed I had to ask my family even for taxi fare.	Dependency		
People deal with us differently. As if we have killed their fathers They look at us like Creditors.	Society's negative attitudes	Unrealistic and inappropriate labeling (13 (86.66))	
One of my friends told me people say you're infected, for this reason Infected and contaminated person people do not talk to you.	Infected and contaminated person		
My brother said that your disease is contagious and we will not come Being contagious to your house.	Being contagious		
Sometimes I think this disease is not curable and even my family said this to me.	Thinking of the disease as incurable		
Because of my symptoms in my face, anyone who knows me says what are these spots? They said they destroy your face and they are disgusting	Disgusting disease		
No one comes to us like we were not human beings in this community. I'm alone and I'm sitting in my house too far from the others.	Feeling of being forgotten by the society	Rejection and isolation (14 (93.33))	
Once my friends and family found out about my disease, they gradually distanced themselves from me; even my brother did not come to my home.	Infected and contaminated person		
I got all kinds of disease. Because of my psychological problems I had to consult a psychologist. But I still have problems, for example, I quickly and easily get angry.	Psychological weakness		
Formerly I went into my local football team but now I do not go. I do not have any contact with my friends. I do not go to any wedding ceremonies and I do not want people to see me in this condition.	Inappropriate social interactions		
Before, I went to work; I think I was more useful than now. I'm at home and I cannot do anything	Feeling of incompetence	Feeling of absurdity and futility (11 (73.33))	
I do not know why neighbors treat me this way and I am tired of it. I am disappointed in my life, why me?	Disappointment		
Our quality of life is not good. If you have no money you are not satisfied. We do not sleep and eat as we used to.	Decline in quality of life		
When I go out, I have to cover all parts of my body because I am worried that others may see my spots and develop bad and feelings and thoughts about me. I tell myself I must have done something wrong in life, for which God wants revenge.	Shame and guilt		

^a Values are expressed as No. (%).

5. Discussion

This study, which aimed to explore the experiences of patients with psoriasis regarding social stigma and rejection, has been performed with respect to the main research question: "What are psoriasis patients' experiences about stigma and rejection?" Psoriasis creates various problems for patients in the society as it affects individuals' beauty. One of these problems is the patients' communication with their friends and families where they are challenged, labeled, and rejected.

In the present study, receiving unrealistic and inappropriate labels was the experience of most participants, which led to psychological disorders or disruption of their interpersonal relationships. In this regard, the results of the Shenefelt and Shenefelt (31) study showed that most participants were accused and misjudged by others, receiving inappropriate labels. Feelings of stigma lead to the weakening of the self-concept. The patients, in addition to enduring life with fear, pain, uncertainty, and hopelessness about the future, experienced feelings of rejection, discrimination, humiliation, prejudice, hatred, and other concerns and societal boycotts (32).

Rejection by others was another painful experience of the participants in this study. The majority of them expressed that not only did they deal with the symptoms and consequences of their disease, but also they endured the unkindness and inattention of their friends and colleagues, which further complicated their problems. In this context, the results of two studies showed that some participants felt a sense of rejection and labeling (14, 31), which was consistent with the results of our study. Given the negative effects of stigma in social interactions, patients' narratives showed that they were not willing to disclose their disease. The experience of living with psoriasis is a family secret for them, and no one wants to reveal it. The unveiling of the disease to friends and colleagues was accompanied with concerns about their health, which caused them to experience separation from society. In their statements, patients expressed their unwillingness to share their problem with others because the pressure of this secret not only hurt their current social situation, but also undermined their established relationships (23). Furthermore, the lack of education in the general population is another factor which causes rejection of the patients by the society (33,

34).

The participants also reported feeling a sense of absurdity and futility in the family and society as they noticed their disease, so that their social communications were disrupted. In this regard, Reich et al. (35), by conducting a study on 100 patients with psoriasis, suggest that stigma causes disturbance in social interaction, disappoints the person, creates feelings of hatred, inferiority, isolation and worthlessness in the individual, and reduces the social status of the individual in the family and society.

Low family and social support were experienced by participants of this study. In Hrehorow et al. (24), a study that was performed on 102 patients with psoriasis, researchers also noted that psoriasis patients have low social support. The reasons for this include job loss, the society's attitude towards the disease, and poor support from the families after being informed about the individual's disease.

Nelson et al. (2014), Schmid-Ott (2005), and Vardy et al. (2002) reported that there is no difference between men and women patients with psoriasis regarding stigma in the current study and the society (33, 36, 37). Because of the obvious cosmetic side effects on male and female bodies, psoriasis affects the stigmatization of both sexes equally.

The results of this research are consistent with other studies which suggest that patients with psoriasis suffered more than others from psychosocial problems such as stigmatization and rejection. Hence, there is a necessity for interventions to reduce these problems as well as to further empower the patient. In this regard, improving social relationships and modifying their pattern of life will have potential impacts on the healing process.

One way to deal with these issues is supporting the patients through family and friends. Family, friends, and healthcare workers, especially nurses who spend a lot of time with these patients, are able to emotionally support the patients and provide them with the necessary training. In general, stigmatization and rejection of the patients led them to distance themselves from society, and their separation from those around them caused numerous psychological and socio-economic problems. Due to the effect of psoriasis on all aspects of an individual's life (38), it is expected that problems resulting from stigma and rejection of patients can be eliminated with timely and appropriate measures. Performing further qualitative studies in the future, and better understanding the valuable experiences of patients due to their disease and its associated problems, we can help improve the quality of life in these patients. The results of this study also demonstrated that these patients need greater family, economic, social, and psychological support, psychological counseling, religious expert opinion, and social work. On the other hand, increasing awareness and changing attitudes of society, particularly

those around these patients, seems essential and undeniable. We hope that the findings of this study can be used to produce knowledge for solving problems, change the society's attitude, create motivation in researchers, create a good basis for qualitative research, and finally promote the level of community health by appropriate devotion of research credit and budget. Further qualitative research is needed in this regard to explore the different aspects of psoriasis.

The strength of this study is that it is the first qualitative study showing existing challenges for psoriasis patients in Iran. Among the limitations of this study, one can refer to the participants' refusal to disclose some distressing experiences during interviews, which was sometimes associated with their severe discomfort.

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Footnotes

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