

The Meaning of Coping With Psoriasis: A Phenomenological Study

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Abstract

Background: Psoriasis is a chronic mental and physical disease that leads to many challenges for people along their lives so that its compatibility and acceptance by the patient is hardly possible.

Objectives: The objective of the present study was to describe and explain the experienced coping strategies by patients with Psoriasis.

Methods: The present study was a qualitative phenomenological interpretation, which was conducted on people with psoriasis, who had referred to Imam Khomeini hospital of Ahvaz during June and March 2014. In this study, 15 people with psoriasis were selected based on purposive sampling and they were asked to express their life experiences regarding coping strategies. Data were collected through a deep and unstructured interview, and the method of Diekelmann et al. (1989) was used for data analysis.

Results: After analysis of the texts of interviews, the main theme, which was attempt to cope with disease and four sub-themes namely "disease, the reason for spiritual promotion", "intellectual insight", "supporting behavior" and "concealing disease" were extracted, which indicated the patients' experiences when coping with psoriasis.

Conclusions: The results of the present study showed that people with psoriasis experienced many challenges in order to cope with this disease, and accurate identification of these challenges and real understanding of their experiences by health professionals, and reflecting positive experiences such as spiritual promotion via their disease to other patients are recommended.

Keywords: Psoriasis, Interpretive Phenomenology, Experience, Coping

1. Background

Chronic psoriasis disease is a skin disease with an unknown cause that affects a large number of people every year and leads to many challenges in their lives (1). In this disease, skin cells proliferate rapidly and create a bad appearance for the patient (2). The main cause of psoriasis disease is still unclear and there is no certain cure (3). Global outbreak of this disease has been reported as 1 to 3% (4), and is less than 1% in Iran (5).

Chronic diseases are health and life threatening and create serious crises for individuals and their social life (6). Psoriasis creates more apparent effects that involve different aspects of a person's life (7). This disease can create several mental and physical disorders, adaption to some being almost impossible. However, as this disease occurs more at young age (8), beauty and mental-physical problems associated with it, cause acute mental problems in patients; thus these cases need better understanding of coping strategies (9-12).

The coping includes a set of cognitive and behavioral efforts of a person, which are used to interpret and modify

a stressful situation leading to harm reduction (13). Coping with psoriasis disease and the problems associated with it can affect quality of life positively and negatively. In case of good adaptation, quality of life increases, otherwise problems such as conflicts and family disruption are created (14).

Today, our knowledge about the psoriasis disease is mainly extracted from a few studies that focused on pathophysiology, symptoms and treatment of this disease (15). Problems of the patients are still considered from the physical viewpoint (16). While today it has been proved that these patients require holistic treatment to consider the physical, mental and social aspects of this disease. In a recent research, the need to conduct more qualitative studies was clearly demanded (17-19). Frequent visits of a physician, tests and several medicines (15), despair and depression (20), are all painful experiences for these patients. Identification of the experiences of patients with psoriasis regarding the coping phenomenon will determine the concerns of patients, and in fact with a deep study of these experiences and clearing their covert and overt as-

pects, pathology and better analysis can be addressed. The present study was conducted with an aim to portray the experiences of patients and in fact, it helps us to recognize these experiences in order to promote better care and treatment modalities for patients and also have a new outlook to different aspects of their life. For efficient and effective care, the lived experiences of each person with psoriasis regarding the coping phenomenon should be accurately evaluated. Modern strategies support care with dynamic comprehensive treatment standards (18) and in this regard, it is required to conduct broad studies to explore and explain the experiences of patients with psoriasis disease. Therefore, according to the mental and physical load of disease diagnosis on a person's life and the effect of coping process on their physical and mental well-being, it is supposed that evaluating the coping process, which is experienced with a disease like psoriasis by the patient, is important. By the search of quantitative and qualitative studies in the field of psoriasis in Iran, from the following databases medex, Pubmed, Isc, Cinahl and SID, using the keywords of psoriasis, coping, patients' experiences etc. from 2009 to 2015, it was determined that no study was conducted in the field of patients' adaptation with psoriasis with a qualitative approach. The conducted qualitative studies have often studied other aspects of the experiences of psoriasis patients including mental image (21), anxiety and anger (9), thoughts of suicide (22), depression (23), sexual problems (24) and treatment costs.

2. Objectives

The aim of the present study was to obtain a deep understanding of coping phenomenon in patients with psoriasis.

3. Methods

This study aimed to describe and indicate the experiences of people with psoriasis from the coping perspective. This study was conducted from June to March 2014, using a qualitative method and with interpretive phenomenological approach in the clinic and dermatology department of Imam Khomeini educational hospital in Ahvaz, the only referral center for skin diseases in Khuzestan province and neighboring provinces. Fifteen participants with the following criteria were selected based on purposive sampling: the risk of psoriasis (male or female) for at least six months, willingness to participate in the study, the ability to share the experiences, the ability to understand and speak in Persian language, having an age of 14 years old and above, having no mental disorder and acute physical

illness (according to the evidence available at the treatment site). The disease of these patients was confirmed by a dermatologist and based on diagnostic criteria, and all patients had active records in the clinic and dermatology ward of Imam Khomeini Hospital in Ahvaz. The patients that did not have the inclusion criteria were excluded from the study. The sample selection process continued until data saturation. After obtaining the necessary permits, information was given to the patients regarding the nature and purpose of the study and individuals signed a consent form.

To collect data, unstructured and deep interviews and observations were used. The basic question of this interview was "Please explain what you did to cope with your disease when you were diagnosed with psoriasis?" then, explorative questions were asked to encourage the participants and achieve deeper information. Interviews were done with 12 participants at the department of dermatology, two patients at the clinic and one patient at their home. Time of interviews was between 40 to 70 minutes and number of sessions varied between two and four sessions for each patient (a total of 23 interviews). Participants were asked to determine the time and place of interviews. Interviews were continued to obtain deep data. Interviews were taped with permission of the participants, and immediately after the end of the interview, after multiple listening, the texts of interviews were transcribed and analyzed using the MAXQDA software version 19. Using the experts and specialists' comments allowed the researchers to evaluate and confirm the content at different stages, and determine in depth meanings.

In this study, interpretative phenomenology with an emphasis on the viewpoint and seven-step method of Diekmann et al. (1989) (25) and exploration of experiences of the patients with psoriasis were used. The method of Diekmann et al. (1989) (25) is based on Heidegger's interpretative philosophy and is one of the most common qualitative analysis methods. It also has separate and clearly defined steps and on the other hand, the nature of team-work in the analysis based on the discussed method provides a good opportunity to take more advantages in the presence of professors and experts. This will ultimately increase the validity and accuracy of the research process, which is one of the challenging issues in qualitative researches. Using this method and after the end of each interview, the texts of interviews were transcribed and then reviewed to obtain a general understanding of the text. A brief interpretation was written for each text and steps were taken to understand and extract the hidden meanings. The research team consisted of experts with knowledge about the interpretative analytic method of Heidegger and the subject of the study, who exchanged their com-

ments for the extraction of themes. With the continuation of interviews, the previous subjects became clearer and also new issues emerged. In order to explain, clarify and classify and remove any disagreements and inconsistencies in the interpretations, the process of return to the texts or referring to the participants were regularly continued. In each section and with progress, integration of the interpretive summaries was done, and in order to identify and form the fundamental patterns, this was continued till the contents and obtained themes communicated with each other in the best way.

To confirm the validity and accuracy of the research, validity and reliability were evaluated (26). To ensure the validity, the findings of this research were presented to the participants and they expressed their comments on the consistency of findings with their experiences, also collaborative reflection regarding the themes was conducted by the research team during the different stages of the study. Researchers guaranteed the verification capability of this research by keeping the records at all stages of the research. The interest of researchers in the studied phenomenon, long-term contact with data and also seeking the opinions of others in this field were the other factors of verification capability. In order to determine the verification ability, researchers tried not to make assumption during the data collection and analysis process. In addition, the present study was conducted as a team and with guidance and supervision of experts, which made the reliability of data and the verification capability possible. The present study was approved by the ethics committee of the Ahvaz University of Medical Sciences with the ethics code of 1393.264 in November 2014. In order to comply with ethical issues, before the beginning of the interview, participants were informed about the objectives and importance of the research, and participated in the research after providing an informed consent. A permit was obtained from them to participate in the study and a tape record was used for recording interviews; participants were ensured that the obtained data were solely used for the purpose of the research and was not available for people other than the research team. Participants were also allowed to withdraw from the study at any stage of research and their profiles were kept confidential during and after the research.

4. Results

Interviews with 15 patients with psoriasis (nine females and six males) aged between 18 and 58 years, and an average age of 43 years and an average illness history of 6.3 years, were performed. Demographic characteristics of participants are shown in Table 1.

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

Variable	Frequency (%)
Age, y	
15 - 3	7 (45.5)
30 - 45	5 (33.5)
45 - 60	3 (21)
Sex	
Female	9 (59.5)
Male	6 (40.5)
Marital status	
Married	8 (52)
Single	4 (26)
Widow	2 (13)
Separated	1 (6.5)
Occupation	
Housekeeper	4 (26)
Employed	6 (40.5)
Unemployed	3 (19.5)
Retired	2 (13)
Educational level	
Primary	4 (26)
Secondary/diploma	9 (59.5)
University	2 (13)
Duration of disease	
1 - 5	6 (40.5)
5 - 10	7 (45.5)
10 [U+02C3]	2 (13)

^aValues are expressed as No. (%).

In content analysis of data, more than 850 primary codes were extracted from the total interviews. In later stages, these codes were decreased gradually by removal of similar and overlapping codes and finally four sub-themes emerged. The extracted sub-themes included: disease as the cause of spiritual promotion, intellectual insight, supportive behavior and concealing the disease, all of which were named as the main themes to cope with disease (Table 2) and are presented in this section, separately.

4.1. Disease, the Cause of Spiritual Promotion

The first sub-theme of the present study was “disease, the cause of spiritual promotion”. Patients with severe and chronic disease talked about the importance of development and maintaining positive thinking and attitude, so this can be considered as a strategy for compliance with the disease. According to participants’ belief and according to their religious context, the role of spirituality was clearly identified or implied in compliance with the disease.

Examples of these evidences are given in below:
One of the participants said:

Table 2. The Evolution of the Main Themes

Primary Codes	Sub Theme	Main Theme
Religious beliefs	Disease; Spiritual promotion agent	Attempt to cope with the disease
Submit to the will and power of God		
Disease; cleansing agent from sin		
Dealing wisely with the disease	Intellectual insight	
The effect of individual consciousness on recovery		
Pretending to be healthy	Concealing disease	
Changes in the physical coverage		
Lack of participation in community activities		
Absence from work		
Encouraged to continue treatment	Supportive behavior	
Financial support		
Consolation		
Track the process of treatment		
Making friendship		

“I try to spend time on prayers, I believe in Islam and pray most days and cry when praying. Praying helped me tolerate until now” (Male, 34 years, worker).

Another participant indicated his experience as follows:

“I am a totally rational person and think that God wanted this for me and when I say that this was god’s will, I calm down. God wanted this instead of something worse and he loves me very much. Finally it is said that incurable illness makes the sins clear” (Male, 46 years old, worker).

Another participant said:

“I ask god to please cure my face and my hands. Against this disease, I tried to look at somethings to make me able to see from a higher place to this disease. I try to study more in the field of science and ethics. In regards to my relationship with God, I ask for a cure of my pain from God; science was unable to treat me so I turned to spirituality. I ask him to give me the ability to tolerate this disease or open another path for me” (Female, 52 years old, housewife).

The above sentences, reminds the Dasein spirit that can enter to the concern, anxiety or deep boredom based on the Heidegger view point. These traits mean that I am in a special position in the world and I am not in my usual situation and daily life. However, the point is that Heidegger does not know concern as a negative feedback although this is not a good and easy experience, but makes the per-

son free from routines and can acquaint him with the idea that I have to make something from myself (“despite of this suffering, I tried to seek something to make me able to look at this suffering from a high level, I studied more in science and ethics”)

One of the participants said:

“When I came to the hospital, I said, God I only believe in you and trust that you will really help me” (Female, 26 years old, housewife).

4.2. Intellectual Insight

The second sub-theme derived from the interviews with participants in the present study was “intellectual insight”. Some participants in the present study expressed that, after becoming aware of their disease and continuing their treatment process, they became logical and started to have hopes for the future. Thus, those who believed that this disease does not create any physical and verbal limitations and cannot prevent progression, thought that it is not worth thinking and worrying about, and showed better adaptation to their disease. They said that their disease did not interfere with any of of their social activities and in one case the disease was introduced as the reason of progress in other aspects of his life.

Another participant also said:

“I am a reasonable person and when I said to myself that God wanted this for me, I calm down. I argue with myself and sometimes I cannot think well and try to do more but without any result” (Male, 46 years old, worker).

A participant said regarding this matter that:

“I have had this disease for a few years and it is a part of my life now; I must be reasonable and be patient to obtain results from the treatments. Life and death is controlled by God. God does not work without wisdom. We cannot understand God and only he knows what is right” (Female, 31 years, employee)

4.3. Concealing Disease

The third sub-theme derived from interviews with participants in the present study was “concealing disease”. Concealing disease is one of the most common ways to defend against threatening behaviors of others. Disease concealing from others in the present study included wearing long-sleeve clothing and socks in all conditions and applying make-up.

Another participant said:

“No one knows about my disease and I do not let them know” (Male, 38 years old, Worker).

Also, another participant indicated:

“In the family, only family members know about it and no one knows in the relatives, and as no one knows, it is

not a problem for me but if relatives knew, it was hard as they wanted to ask about it constantly” (Male, 43 years old, unemployed).

Another participant indicated in this regard:

“At the swimming pool, I said it is a fungal disease when others asked, because a couple of my other friends had fungal disease, and they were treated quickly as their disease was really fungal” (Male, 46 years old, worker).

Another participant said:

“I cannot expect others to accept me as I am like this. Right now, ladies and gentlemen at my work place ask me why I am like this and what if it is contagious, and I keep my gloves on to attract their attention less and control my anger” (Female, 47 years old, employee).

Another participant said:

“In a ceremony, I have to wear long-sleeve dresses because of people questions and I often wear a suit to cover my legs and also have no problem in communications, but if anyone thinks that the disease is contagious, I withdraw myself” (Female, 29, housewife).

A participant indicated in this regard:

“I was very sad, because if it is on your hand, you have to wear gloves when you want to go out. If it is on your legs, you have to wear stockings” (Female, 26 years old, housewife).

Another participant said:

“This disease has no specific effect on humans, it is not contagious, yet when you are going to enter a group or want to go to an important place or meet an important person like when I am going to the university where boys and girls are, I have to cover all my face with a lot make-up” (Female, 26 years old, student).

4.4. Supportive Behavior

The last sub-theme in the present study was “supportive behavior”. According to statements by the participants in the present study, first-class family and some friends showed supportive behavior, including financial support, encouragement to continue treatment and verbal expression such as your improvement is clear and new treatment must be effective. Patients knew that this kind of support is effective in the pursuit of effective treatment and disease toleration.

A participant said regarding this matter:

“Family support is very important, they constantly asked me to stay strong and that I was good. If they did not support me, I may have stopped treatment” (Male, 30 years old, worker).

Another participant also said:

“My husband was always with me and came with me whenever I went to my doctor” (Female, 24 years old, housewife).

Another participant indicated:

“My family always sympathized for me; I say what if it happens on my face and he says: don’t worry, it has not happened now” (Female, 28 years old, housewife).

One of the participants indicated in this regard:

“My family sympathized with me. They said that you become well when you are white but it was hard for me, I felt I am alone, when I wanted to go with my friends, I liked to wear short-sleeve clothing but I could not” (Male, 30 years old, worker).

In the present study, finally with the use of statements of the participants in the research and narrative approaches and according to the objective of the study, which was description and explanation of compatibility phenomenon in people with psoriasis, people reported their experiences such as concealing the disease, and disease being the cause of spiritual promotion, supportive behavior and intellectual insight; these sub-themes were ultimately considered as the subsets of attempts to cope with the disease.

5. Discussion

The present study was conducted with an aim to investigate the experiences of people with psoriasis regarding coping phenomenon and the central question was “please explain what you did when you found that you had psoriasis to adapt with it?”

Psoriasis creates several problems for the patients because of its effect on beauty and appearance. One of these problems is the patient’s compliance with the disease and his abnormal conditions that usually makes the person’s relationship with people and the environment difficult. Failure to compromise with the disease causes physical and mental problems and makes the control and treatment of this disease, more difficult (20). Undoubtedly, reasonable adaptation and accepting the reality is the most suitable possible situation. People, who adapt to the disease, actively participate in the process of compliance with this disease, and on the contrary, patients, who do not adapt with their disease, suffer from hopelessness, despair and loneliness (27).

These contradictions and problems can bring about serious problems and make adaptation a complex process. However, the findings based on the experiences of participants in this study showed that after informing people about their disease, it takes a long time for the patient to adapt with his new health condition. This has different stages. In fact, it is a process that ends to self-discovery and acceptance of the situation and new conditions of life by the patient with this disease. This period is very different for different patients depending on various factors such

as mental ability, cognition, knowledge of disease, family conditions and family, social and environmental culture as well as available facilities (28).

The study of Bangemann et al. (28) (2014) in this regard concluded that according to different beliefs about psoriasis, patient's strategies for compliance with this phenomenon are different. Experiences of the participants in this study also showed that each of them had a special interpretation of this phenomenon. For example, a group of patients regarded psoriasis as a result of their behavior, a situation to compensate for the past or a situation to become clear. They were able to establish a more effective peaceful coexistence with this phenomenon and continue their lives with doubled tolerance or effort.

One of the important and effective factors was beliefs and religious attitude of individuals. Religious beliefs were known as a fundamental factor in approaches dealing with the problems and complications of the disease according to the findings. Also, it had a basic role in compliance with the disease for some participants. Patients were able to rely on religious beliefs at any stage of their disease, relieve their psychological problems and achieve relative peace. In other words, diagnosis and problems of this disease affected the patients severely and took away their abilities to think. One of the major factors that helped them to bear these difficulties was religious belief.

Studies showed that there is a highly significant relationship between having spirituality and religious beliefs and the sense of comfort and well-being in the life of patients (29). All these findings correspond with the research results, yet a research, which was conducted by Bewley and Page (29) (2011) did not confirm these findings.

In addition, various studies showed that strategies with a strong religious root are the active ones that help patients refine their thoughts and focus on problems and decision-making in the future (30). In this regard, one of the other effective findings in tolerating problems and compatibility with disease in the present study was participants' attitude towards this phenomenon as a divine test.

Overall, the experience of feeling God in their life by some participants and the belief that God will be always with them, gave them hope for treatment and being healthy, again. The obtained results in this research confirmed the previous researches regarding the useful effects of religious beliefs for positive and constructive coping with the disease (30). Therefore, it is necessary for all stakeholders and specially people in the health care team to turn to religious dimensions of the fight against disease and prayers as an important and effective strategy in relation to patients with psoriasis.

Participants often used avoidance and hiding strategies to escape the gaze of others. However, none of them

had inner satisfaction and showed their ambivalent feelings in words such as "forced veiling" and "even though I don't like gloves" and similar sentences that show ambivalent feelings were more because of the concern of social exclusion, which was mentioned in the study of Bewley et al. (27).

Rapp et al. (2001) (30) mentioned in this regard that coping with a rare chronic disease is difficult. Patients usually try to hide their disease from others. When people encounter a patient with a common disease, they sympathize with them but in case of encountering a rare disease; it is a challenging situation for them from two aspects. The first aspect is understanding the nature of the disease and second, understanding its effects; both of them are effective on the interaction between the patient and others. Coping is not a simple task but a dynamic process that requires various strategies at different times. Strategies have an extensive range, from dealing with risk factors and search for social support to expressing emotions and using religion.

Considering the negative effects of the disease process in the collapse of individual social interactions, stories of the patients showed that patients are not willing to disclose their disease. The experience of life with psoriasis is a kind of family secret for them that no one wants to talk about. Finding out about the disease by friends and colleagues was associated with concern about their health and patients developed a feeling of separation from other people. Patients in their statements preferred not to share this issue with any one because the pressure of this secret not only hurt their current social status, but also destroyed their established relationships.

Social support was experienced in varying degrees. In the study of Hrehorow et al. (31) and Janowski et al. (32), the effect of social support in the compatibility process of patients with psoriasis was mentioned. Instability in supportive behaviors can be directly effective on the quality of patients' lives. Also, family and social support improves the disease process of individuals and reversely, not supporting patients can separate them gradually from their family and society and make them an isolated individual.

Dealing with the disease in a rational and wise manner helps patients recover faster. Participants in the present study indicated that wisely dealing with the disease had a positive effect in the process of disease and could extricate them from thinking about the complications of the disease. Also, in the study of Eghlileb et al. (33) (2007), the findings of the present study were confirmed and the impact of dealing rationally with the disease was mentioned.

Generally, coping with the disease in each level led patients to better adapt with their disease and finally their psychological and socio-economic problems were reduced.

5.1. Conclusion

The results of the present study showed that the patients with psoriasis had variable experiences. Some failed to adapt effectively with these conditions. They did not only experience many challenges, but were always threatening for themselves, their families and others. However, others, who adapted well with the disease due to the supports of their family and having spiritual beliefs, had better experiences and felt accepted in the society.

The findings of the present study as a small image in a large and complex world can be used in order to design and implement effective care for patients with psoriasis in the areas of nursing management, education (including students and nurses), practice (rehabilitation of mental and psychological patients) and nursing research. Also, the generated knowledge in this research can be helpful for other researches to open horizons regarding this phenomenon and can be used as a guide of holistic care of patients with psoriasis. Given that the present study was the first research in this field in Iran, it can be considered as a basic knowledge and a basis for further researches. According to the positive effects of religious beliefs and praying on coping and compatibility with psoriasis disease, the authors of the present study recommend that the personnel of health care team and especially patients consider praying as an important strategy in care and draw their attention to meet this need. This study had some limitations that restrict the use of the findings. The present study was conducted on Iranian Muslim patients and was not applicable for other countries and religions. Therefore, it is recommended for similar studies to be done on other religious minorities in Iran to help the extent of knowledge on this subject. Therefore, similar to other qualitative researches, the findings cannot be extrapolated to the target population.

Nonetheless, there are many complexities and obstacles for adaptation of the patients. Real understanding of the experiences of these people by the health team and reflecting the positive experiences to other patients is always recommended with an appropriate guide and support at various individual, family and social levels. Also, further studies related to different aspects of this phenomenon in other groups and regions of the country are essential.

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