



Experiences of Young Girls with Psoriasis: A Descriptive Phenomenological Study

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Received 2020 January 12; Accepted 2020 January 13.

Abstract

Background: Psoriasis is an inflammatory skin disease with detrimental effects on patients' physical, mental, and social health. Living with this physical skin disorder can pose a threat to patients' identity and bring about unwanted changes to their role, mental image, and lifestyle. Hence, the analysis of different experiences and perceptions of people living with psoriasis can help healthcare managers and policymakers in adopting the most efficient coping strategies.

Objectives: The study aimed to explain the experiences of young girls with psoriasis.

Methods: This qualitative descriptive phenomenological study was conducted using in-depth, semi-structured interviews with 10 young girls with psoriasis who referred to the Dermatology Clinics of Zahedan hospitals in 2018-2019. The participants were selected using purposive sampling and the data were analyzed by Colaizzi's method.

Results: The themes describing the experiences of young girls with psoriasis included the challenging emergence of disease, indefatigability in pursuit of ineffective treatment, social stigma as a community gift to the patients, and fear of uncertain future.

Conclusions: The challenges of the incidence of disease at a young age and insistence on ineffective treatments were highly evident in the experiences of patients. The patients were also concerned about the social stigma associated with the disease, which could pose further challenges to their uncertain future. According to the findings, increasing public awareness of the disease and applying psychological strategies can be effective in addressing the problems of psoriasis patients. Elevating the awareness of families to accompany the patients in treatments can also be another effective measure.

Keywords: Descriptive Phenomenology, Lived Experiences, Psoriasis, Young Girls

1. Background

Psoriasis, a type of psychosomatic disorder, is a skin inflammatory disease with scaly scarlet-colored plaque symptoms in different areas of the body. Having an equal prevalence among men and women, the disease appears approximately 1% to 3% in the general population (1, 2). The 2013 reported prevalence of the disease was less than 1% in Iran (3). The most common type of the disease is psoriasis vulgaris, which manifests as circular plaques in the extensor areas of the body such as the elbows, lower back, and navel area (4). Since the underlying cause of psoriasis is unknown, there is no definitive cure for it (4, 5). During the course of the disease, skin cells proliferate rapidly and bring negative consequences to the patient's appearance (6, 7). Although often seen on the surface of the skin, psoriasis can have dire physical, psychological, and mental con-

sequences for the patients (8, 9).

Since the appearance of the skin in the disease can determine a person's visualization of the self, any pathological changes in appearance can have deleterious psychological consequences (7). Psychologically, the perception of the disease by the patient is based on information from various sources while his beliefs can affect his mental health and ability to adapt to the disease (10, 11). Symptoms of the disease, especially skin and facial ones, can lead to threats to identity and changes in roles, mentality, and lifestyle. Therefore, any major alteration or impairment in performance requires greater physical, psychological, and social adaptation by the patient and his family (12).

Most members of the community usually avoid contact with patients, which is a very frightening experience and can create an inappropriate image of themselves in

their minds. These attitudes, if repeated, can cause anger, shame, and frustration. Ultimately, this might make patients anxious about contacting others and result in their seclusion (13, 14). Given that the skin plays an important role in interpersonal relationships, skin disorders can have significant effects on the appearance of the patients and change people's attitudes towards them (15). Abnormality in the skin can also cause hatred, fear, and even intolerance and people may prevent contact with the affected patients for the fear of infection.

Various studies have reported community and family rejection as the consequences of psoriasis (16-18). In keeping with this, the perceived stigma of patients with psoriasis has been reported about 90.2% in some studies (12, 19). Also, in an investigation of 265 patients with psoriasis in Germany (2014), 32% were depressed due to the complications of the disease. Significant associations have been identified between psoriasis symptoms and the severity of depression, as well (16). In addition, the self-esteem of female patients with psoriasis was rated poor to moderate in the US in another research study (17).

Many patients also experience problems with self-conception and self-esteem, poor psychological adjustment, feelings of shame, stigmatization, and embarrassment due to their appearance (17). In a study reported in 2013, 20% of patients with psoriasis were excluded from barbershops, swimming pools, gyms, or workplace (20). Other investigations have shown that 40% of the patients have difficulty choosing the right clothes. Ultimately, the consequences of psoriasis, sometimes, lead to psychological and mental complications for the individual, which confirms the high prevalence of anxiety and depression among the patients (21). Another factor that greatly impacts the patients' lives is numerous referrals to dermatology clinics for long-term and various treatments that require much time and high costs, which can, in turn, affect their quality of life (22). These patients, like many others with chronic and debilitating illnesses, require lifelong treatment and face numerous psychological, economic, and social problems, each of which may interfere with regular treatment and follow-up procedures.

Considering the above-mentioned issues, identifying patients' experiences and perceptions of the disease can be effective in coping with psoriasis and psychological problems of the patients, as well as adopting appropriate treatment options. Therefore, it is necessary to examine the lived experiences of individuals in their social interactions (23). As no definitive cure has been detected for the disease after many years, nurses and other healthcare providers are expected to help patients and reduce their suffering (24). This clearly requires the attention of healthcare professionals to the experiences of involved patients.

Also, since patients' willingness and motivation to continue treatment may be influenced by their experiences and understanding of the disease, studying the different dimensions of the experiences and perceptions of psoriasis can help healthcare managers and policymakers to assist them.

As evidence suggests, qualitative research on psoriasis is scarce and the experiences of patients have not been recorded. On the other hand, the cultural and social contexts of any society can be influential in shaping the experience and understanding of these patients. Therefore, a qualitative study with a deeper look at the subject in a different socio-cultural setting like Zahedan would certainly yield useful results.

2. Objectives

The current study focuses on the experiences of young girls with psoriasis as a disease with many challenges in their marital life and social relationships.

3. Methods

This study was conducted based on descriptive phenomenology. Phenomenological research rests on the inductive descriptive methodology and originates from the philosophy of phenomenology that focuses on understanding the essence and nature of phenomena. The emphasis of this philosophy is not merely on understanding a certain or a small part of one's behavior, but on perceiving all human practices and experiences (25).

Participants of the study included 10 young girls with psoriasis who referred to clinics affiliated to Zahedan University of Medical Sciences and Health Services. The sample was selected based on purposeful sampling that continued until data saturation. Data collection was deemed complete when no new data or concept emerged from the interviews with participants. In this method of sampling, individuals were selected for their knowledge of the research subject.

The data for qualitative research are mainly collected through observation and interviews. Observation is used when the researcher seeks to understand certain behaviors, activities and their sequences or the environment in which certain behaviors and actions occur (26). In this study, in-depth, semi-structured interviews were held to collect data. The researcher also used the note-taking method to record observations, interactions, communication, environmental conditions, and nonverbal behaviors. After obtaining the necessary permits, the researcher referred to the dermatology clinics affiliated to Zahedan University of Medical Sciences. Having introduced himself to

the hospital authorities, he clarified his research goals, and asked them to introduce young female patients with psoriasis to the study. The inclusion criteria for the study were as follows: young girls with psoriasis, having at least one patch in visible areas (i.e. face and hands) of the body, being over 18 years of age with at least a six-month history of psoriasis, and willingness to share their experiences. The participants were given necessary explanations and their consent for the interview was obtained before the time and location of the interview were agreed upon.

This study was implemented from October 2018 to July 2019. The in-depth, semi-structured interviews were mostly conducted at relevant clinics in Zahedan and only three participants were interviewed at their homes using open-ended questions. The interviews lasted from 60 to 90 minutes depending on participants' willingness. The voices were recorded on tape with the prior consent of the participants before being completely transcribed on paper. The questions centered on life experiences during the illness course (e.g., How did you find out about your illness first? Can you explain it? Describe what happened to you during the illness). All interviews were conducted by the researcher.

Data analysis was performed using the seven-stage Colaizzi method. The first step of the method was to read the full text of the interviews for the purpose of familiarization (26). At this stage, an attempt was made to identify the concepts in the text of the interviews by reading the materials repeatedly. In the second step, i.e. the identification of important statements, the key concepts and sentences were underlined (27). The third step involved allocating specific meaning to the identified statements (26). In the fourth step, the concepts were organized into clusters (26). This step was repeated for each transcript of the interviews and the concepts were arranged into specific categories. Regarding this stage, two points were important. First, the researcher referred to the text of the interviews to validate the extracted themes and second, differences could be identified within or between clusters. These differences and similarities had to be taken into account. Haloyee, as quoted by Colaizzi, recommends that the researcher should ignore data and materials that are not relevant. In the fifth step, the results and themes were incorporated in the form of comprehensive explanations. In the sixth step, an exhaustive description of the phenomenon under consideration was given in unambiguous terms. Finally, the results were verified by the researcher. To this end, participants were asked about the accuracy and consistency of the results with their experiences (26). The transcripts of the interviews were coded and the resulting analysis was reviewed with several colleagues while agreement on the themes extracted was checked before their

recommended comments were applied. The long-term involvement of the researcher with the participants and the findings was another way of confirming the findings. To achieve objective findings, external auditing was used and personal ideas were disregarded (28).

Credibility, trustworthiness, confirmability, and transferability were used to achieve data validity. To increase credibility, the researcher applied continuous observations and benefited from the reports of research colleagues who were asked to randomly select and analyze several interviews and finally compare them with the results obtained by the researcher. Finally, the findings were reviewed by the participants. To gain credibility in the study, the researcher heard, implemented, and analyzed the interviews with a second person.

4. Results

This study aimed to explain the experiences of young girls with psoriasis. The age of the participants ranged from 18 to 34 years and their mean age was 26.8 years.

After analyzing the interview data, the main themes of the study were formulated according to Colaizzi's method as follows: challenging emergence of disease, a tireless quest for futile treatments, social stigma as a gift from the community to patients, and fear of uncertain future (Table 1).

4.1. Challenging Emergence of Disease

This category included subcategories such as the mysterious and vague emergence of disease, the role of stress in exacerbating lesions, the onset of disease with red and inflamed skin spots, and fear of the incidence of psoriasis during adolescence.

The incidence of psoriasis can be different and challenging for each patient. From childhood onwards, the disease may usually manifest itself as primary red spots on the limbs, behind the ears, and other open parts of the body such as flexor areas. Patients' anxiety and stress can cause symptoms to develop further and change. People initially cover them for the fear of being seen, but when they notice that they cannot be kept disguised, their fears reach the highest levels during adolescence. Patients' mental and practical struggle to fight the disease begins after the emergence of the disease and it is a multi-year process that may cover their whole lifespan. In addition to the individual symptoms of the disease for a certain patient, all members of the family might also be affected by it, as if all family members have psoriasis.

In the following, participant No. 1 talked about the mysterious emergence of the disease and her fear of vague spots:

Table 1. Themes, Subthemes, and Meanings

Main Themes	Cluster of Themes	Meanings
The challenging emergence of disease	The role of stress in exacerbating lesions. The mysterious and vague emergence of disease. The onset of disease with red and inflamed skin spots. Fear of incidence of psoriasis during adolescence	<i>Stress and anxiety exacerbated the symptoms. I had a problem in the last couple of months that put me under a lot of stress and after about three days, I saw these damn spots growing and spreading to the extent that my hands and feet were heavily involved. At the onset of the disease, white spots started to appear on my arm until most areas of my body were affected. For me, it especially spread to my nails. The nails changed color first. Then, they got scaly and their front end was in danger of falling off. I didn't think the disease would gradually develop all over my body.</i>
Fear of uncertain future	Problems with marriage. Hereditary nature of the disease. Psoriasis as a compulsory coexistence for the whole lifetime	<i>But the worry I always had was the fear of the future ... For example, if I had a chance to get married, how could I discuss this with my partner? What would he think of me? How would his family handle it at all? ... Worst of all, I was worried about the hereditary nature of the illness. I had to cope with this disease for I've had it for several years ... I was not going to get rid of it!</i>
Indefatigability in the pursuit of futile treatments	The inefficiency of medical treatment. The inevitability of continuing treatment	<i>I went to the same doctor a few years ago. I was visiting him every month. Until I noticed that the results weren't as I expected. The symptoms didn't get any better, so I went to another doctor who almost gave me the same ointments and medications. I was fed up with that up-in-the-air condition! I took the medication for years, but it didn't work out, whereas leaving the treatment unfinished could make it worse!</i>
Social stigma as a gift from the community to patients	Frustration. Fear of teasing. Negative reactions of the community to patients	<i>I would wear a scarf at the height of the disease because the scales became so obvious. I hid the affected areas in my forehead as the plaques were visible on the scarf or dress, so I always had my hand on my scarf. I would tell my mom I look like those having head lice with my hands always on my head! It was very sad! When I was out in my classrooms, I wrapped my scarf over my forehead. Only would some of my friends see my skin and ask me a lot of questions. I would spend some time explaining the problem ... I was scared that they make fun of me or call me names!</i>

“...White spots normally start as dots and then slowly and very slowly grow bigger and bigger. When I go to the bathroom or after it, these spots first become red and inflamed and then get scaly and turn silver.

It first appeared on my legs, especially on my knees, then spread to the upper limbs. Later, it started to grow on my hands. I was trying to ignore it for a month until I accidentally noticed that my sides were getting involved too and the spots were increasing. There were many of them! I was very anxious and here I told myself that I've got to go to the doctor. I was terrified, it was dead scary” (A 29-year-old single woman majoring in accounting).

Participant No. 4 also commented on the challenging emergence of the disease as follows:

“... At my grandfather's funeral, my mother noticed that rash-like spots had grown on my head. They were abnormal; the wet rashes covered my head, and I went ... to the doctor ... After a while, the legions grew rapidly, and my face got involved, especially the frontal area and eyebrows. I was seriously upset and anxious! I couldn't do anything and once I cried a lot in front of the doctor. I was scared ...” (A 15-year-old girl, high school student).

Participant No. 6 gave a unique account of the emergence of the disease:

“... At the beginning of this disease, white spots started to appear on my arm until most parts of my body were covered, especially my nails. The nails changed color first, then the skin became flaky, and later there was the risk of falling off the front part of my nail. It played a key role in its beauty. Imagine whenever you show your hands, ... the others see them ... I suffered

too much stress from this disease. There were fears you could never tell anyone and you had to hide ...” (A 34-year-old girl, single employee).

As for the role of stress in the disease, the same participant also reported:

“Stress and anxiety exacerbated the symptoms. In the last couple of months, I had a lot of stress, and after about three days, I saw these damn spots grow and grow so much that my hands, legs, and feet were heavily engaged ... You know, the origin of these new diseases, like ours, is more mental or psychological. Stress plays an important role in it ...”.

4.2. Indefatigability in the Pursuit of Ineffective Treatments

This category included the following sub-categories: inefficiency of medical treatments and inevitability of continuing treatment.

Appealing to initial solutions as loneliness, waiting for automatic treatment and administration of generic medication cannot change anything in the long run. Over time, the severity of disease reaches a point where it affects the patients' sleep-wake patterns and eating habits. It may also oblige the patient to refer to a doctor. The rarer is the disease, the more problems it creates for treatment. Symptomatic treatment of the disease by doctors may exacerbate patients' conditions so that they can no longer be indifferent to the subject. Failure in successful treatment and even disappointment with the patient might lead to the transfer of the patient to more advanced facilities. Despite the existing inadequate treatments for psoriasis, patients

continue to hope that they will get rid of the disease someday in the future. A person who develops spots from childhood may look for new treatments to get rid of the disease until the last moment of her/his life. In some cases, it can also be tempting to the patient to try a certain treatment option or to refer to a well-known medical doctor for treatment. Despite the inefficiencies of treatment, unsuccessful experiences, and various problems and limitations that therapies create for the patients, they continue to persist with their quest for adequate remedies.

Participant No. 8 explained that:

"... after treatments and follow-ups in Zahedan, there were no positive outcomes. I already told you that they did not give me the right answer, and this made me and my family even more nervous so that my family suggested I go to Mashhad.

We went to see the doctor. He informed me that I had psoriasis based on the resampling already done Once, one of the doctors prescribed an ointment. These ointments were handmade and very expensive. I used it, but it was no good, hence I told the doctor how ineffective they were! Anyway, the doctor told me that he didn't know what type of disease it was! It didn't get better ..." (A 28-year-old single woman).

Participant No. 4 reported on the ineffective medical treatment and inevitability of continuing treatment:

"I got the disease a year ago. The doctor said that it may be psoriasis, which is incurable, and we should just stop the progression ... I cried a lot ... They said the treatment isn't that effective. I felt thunderstruck for a moment ... After a while, I stopped treatment because the drugs didn't have much effect on disease eradication and I didn't even want to search for the drug and treatment options anymore as it was useless; the doctors said so. After some time, patches started to regrow and covered my face. I was very upset, anxious, and helpless. Again, I had to go to the doctor and say the symptoms were increasing more and more ... I had no choice but to refer to the doctor as the situation had gotten worse" (A 15-year-old lady, with one year of continuous treatment history).

Participant No. 3 described her condition as follows:

"I went to the same doctor a few years ago. I used to be visited by him every month until I noticed that the outcomes are not the ones expected and symptoms don't get any better. I changed my doctor who also gave me the same ointments and medications. I was tired of not being able to figure out what to do. Anyway, I took the drug for three years despite its lack of effect ..." (An 18-year-old Sunni resident from the county).

4.3. Social Stigma, a Gift from Community to Patients

This category involves subcategories such as frustrations, fear of teasing, and negative reactions of community members. The participants indicated that some people who did not have enough knowledge of the illness believe that this group of people must have committed a

sin; hence, they deserved to be punished by God in this world. In their lifetime, these patients were ridiculed by their classmates, teammates, and almost everyone in their community. They were given different labels that led to failure in their education, as well as marital and professional life. Therefore, patients had a negative feeling about their illness. Sometimes, during their childhood, religious beliefs would create a special impression of the disease as a chastisement for an already-committed sin, or cause fear among children or adolescents. Such misconceptions were later demystified after reading the scientific sources and realizing the nature of the disease. The lower the cultural and educational level of the society, the more impressionable the community by wrong beliefs. Therefore, believing such wrong or right propositions could influence the patients' lives.

In the following, participant No. 2 comments on the negative reactions by community members:

"When I entered the community, most people, especially my neighbors, started prying. They always told me that your problem is not clear! They would say: nobody knows what her disease is! They mocked me and when I heard this type of idea, I felt too bad. In my daily relations, the neighbors also ridiculed me. This kind of opinion seems easy on the eyes. It can have lots of annoying effects on an individual. As I told you, I got depressed as a result of the disease. I am like all the other sick ones; what's really wrong with me?! What problems have I created for them?" (A 21-year-old woman with a high school diploma from Zabol, Iran).

The same participant elaborated on her frustrations associated with her illness, as follows:

"Even sometimes, they kicked up a fuss about me that was obviously because of my disease, only to exclude me from their company. For instance, when my friends and I wanted to go to the mosque during Muharram or Ramadan to do our religious services, they would make a feeble excuse to keep me away. As a result, I would go back home since their behavior was terribly annoying".

Participant No. 4 emphasized the negative reactions of the community along with the frustration it creates:

"I am a girl from a single-child family. Generally, beauty plays a considerable role in girls' lives. In the school, the students would ask me what those spots on my hands were? They gazed at me and I couldn't do anything. Even once, our healthcare teacher asked me lots of questions. In the end, she ordered me to come to school with my mother. The next day, she asked my mother about the name of my disease. She was worry of the risk of the disease for the other students! I didn't eat anything on that day because of her words! As a result, I became too weak and they took me to a clinic to be administered serum. I didn't like to go to school by any means. For the next educational year, I changed my school because I thought other students might

look at me differently. It was so unbearable to me; I couldn't stay there". (A 19-year-old high school student)

Participant No. 5 described her fear of teasing as quoted below:

"At the height of the disease, I pulled my scarf over my face to hide the spots on my forehead. Because scaly patches peeled off and were clear on my scarf, I always had to keep my hand on my scarf. Once I told my mother, I look like those with lice with such behavior. During the class, I pushed my scarf forward over and over. It was really annoying! Just some of my friends noticed my strange appearance. They would ask me many questions and I would explain my problem to them. I was scared that they may mock me or give me offensive names" (A 20-year-old undergraduate student).

She continued her comments on the fear of teasing by adding that:

"... I had other concerns too. For example, at first, I was terribly frightened that it may be a contagious disease. I was greatly upset about this! I used to tell myself, if any of my friends saw these spots in the self-service of the university, how would she judge me?! ... He would probably inform my other friends".

Below, participant No. 9 also reports her frustration and fear of teasing:

"Last year, we were invited to my cousin's wedding party. My mom asked me not to wear my favorite dress I had. Hence, I didn't want to go to the wedding ceremony, but at last, I was convinced to attend it. However, I got a modest dress because I had some spots on my body which were visible in my newer revealing clothes. I hid the other smaller spots with cream and cosmetics because I didn't want to be embarrassed among my peers. Thank God, no one noticed my problem at the ceremony ..." (An 18-year-old single girl).

4.4. Fear of Uncertain Future

This category covers the following subcategories: marital problems; psoriasis, compulsory lifelong coexistence; hopelessness; youth as the peak time for conflict among attachment, love and secrecy; and the hereditary nature of the disease.

After the incidence of the disease, with frequent referrals to doctors, application of different treatment options, and establishment of the disease, future concerns are raised about issues such as the selection of the right job, marriage, hereditary transfer and effects of the illness on future children, especially female children. The fear of this problem was evident among young girls who were ready for marriage. Concerns about giving birth to a child with the same problem or children's view of their would-be sick mother also engrossed their minds. Given the inherited nature of the disease, they worried that the gene would carry the disease across generations, and could inflict the same serious problems on the receivers. Certain

problems would affect their lives. They would blame their ancestors and complained that their paternal and maternal ancestors' disease was transferred to them.

A successful marriage is associated with socialization and active participation in society. Due to the difficulty in socializing among people with psoriasis, a successful marriage is too difficult for the affected groups. One of the biggest challenges for people engaged with the symptoms from childhood is their constant concern over marriage. For women, this is a more serious problem, as they would prefer to stay single for the rest of their lives than to be frustrated. According to Ericsson et al.'s psychological theory, youth is the peak time for the tendency to be seen and actively participate in society. However, young patients with psoriasis often experience a strong sense of conflict between their desire to be seen and a sense of isolation due to illness. The hopelessness of these patients reveals itself in their future life. Women with psoriasis may also suffer from the life-long outcomes of the disease such as separation and divorce because of the legal defects that consider the given disease a case for fraud in marriage; this can ultimately kill the last glimmers of hope in the patients.

The future prospect of participant No. 6 for herself is depicted as follows:

"... I have not had any chance of marriage ... Of course, it was my own choice, but the illness had its part, as well. Anyway, I will inform the other party about my problem ... It can't be kept under wraps; for sure, I'll tell them myself" (A 34-year-old single woman).

The participant also commented on youth as the time for an ongoing conflict among dependence, interest, and secrecy:

"... I didn't like to go to parties with my coworkers because I couldn't eat any food or sweets offered. In fact, I didn't like to go there because I wasn't interested to explain my problem anymore. I couldn't control many things at parties ... Even some of my friends mistakenly considered it as a type of skin allergy ... I was stuck in a real quandary; despite my interest in staying in touch with them, I was always terrified that the real fact of my disease may be disclosed, so I tried to hide it ..."

Talking on the same topic, participant No. 1 asserted that:

"There are so many ceremonies where some women are met for marriage. However, I had less time to be seen. I had to avoid these parties and hide. When I was alone, I was very upset without knowing who to blame for this disease or for my vague future with it ..."

Talking about her forced coexistence with psoriasis, the same participant concluded that:

"... I have learned to get along with this disease for I've lived with it for several years ... Apparently, we are not going to get rid of it ..."

Participant No. 7 described the future of the disease as follows:

"... But the concern I always had in my heart was fear of the future ... For example, if I had a chance for marriage, how could I discuss this with my partner?... What would he think of me? or how would his family handle this? ... All the worse, I am worried about the hereditary nature of the disease ... that is, this defective gene in my body made it possible for the disease to emerge; but now, I am mostly concerned about the children who are supposed to come to the world after me ... Why should they get infected or deserve such suffering like me? I can't let them be stared at by people or be teased by their behavior ... I really don't know what to say ..." (Long silence of the patient, ...).

She continued:

"... I'd love to inform my would-be partner of my disease before marriage if someone should like to live with me. I don't like to conceal anything because after a while everything would be discovered and nothing can be kept secret anymore. I also know that I wouldn't be able to get on with the stress for secrecy in my life! I even go to the doctor right now because I want the spots to disappear before I get married or perhaps find a cure for the disease. As you know, it's a huge defect and my frustration is much severe than before ..."

Participant No. 2 also talked about psoriasis and her lifelong coexistence with it by saying:

"... I rarely go out of my house. Some people think I got cancer because I've lost my hair... they talk behind my back and it hurts a lot, even more than my illness ... Cancer is easier because you die and it's over! But what should I do?! I have to live with this and burn until the end of my life with this misery ..."

The same participant also shared one of her memories of having met a married woman who also suffered from psoriasis at a doctor's office:

"... the lady I saw at the doctor's office told me that she had even been under pressure from her husband's family. They always gossiped about her and believed that perhaps her kids would be suffering from the same disease. She used to cry a lot. When I heard this, as I was single, I became concerned about my own future life that would be like hers ... Can one really have skin disease and honestly tell her suitor about it?! ... For sure, they won't agree! Nowadays, appearance is very important to boys..."

Participant No. 3 described her future with the disease:

"I mostly worry about the future of my marriage or my future children. Anyway, there is no other way than praying for me. I ask God not to give such a disease even to my enemies because no one can survive it! It's too sad to see that my baby or any innocent child might inherit this annoying disease from me. I feel a pang of conscience; so I am very much afraid of and concerned about the future ... I believe only God can help me ..."

5. Discussion

The results of the study revealed that the challenging emergence of the disease, indefatigability in the pursuit of futile treatments, social stigma as a community gift to patients, and fear of uncertain future are among the important themes in the experiences of young girls with psoriasis.

Young girls' experiences of the challenging emergence of the disease showed that the first symptoms would initiate with the patient's mental involvement and continue to appear in their observable behaviors throughout life. In the case of the emergence of disease during childhood, many dimensions of an individual's behavior would often be affected over the process of development. The first symptoms usually cause great changes in individual as confirmed in some of the studies reported in the following.

Merola et al. examined the prevalence of psoriasis phenotypes among men and women in the USA. The results were as follows: 55% with plaque psoriasis, 52% with scalp psoriasis, 23% with nail psoriasis, and 14% with palmar-plantar. The study also found that palmar-plantar psoriasis had the highest prevalence (29), which was consistent with the results of our study. Lakuta et al. evaluated the relationship between lesion location and depression, anxiety, and social stigma in patients with psoriasis and concluded that the most intensive level of stigmatization was observed when people had lesions on their chest, arms, and hands. The highest anxiety and depression incidence also occurred with lesions on the patient's head and neck, while the negative feeling was mostly experienced with the lesions on the arms and hands, followed by those on the head and neck of the patient. In our study, most women with psoriasis exhibited the highest levels of anxiety and fear regarding lesions on visible parts of their body (30), which is consistent with the mentioned study.

Reporting on an international workshop on the role of stress in patients with psoriasis, Schwartz et al. concluded that the higher the patient's stress, the greater the extent of the lesion. They also reported that stress plays a crucial role in reactivating the disease after a period of silence; a process that was confirmed by focusing on the hypothalamic-pituitary-adrenal axis. It was, therefore, pointed out in the workshop that cognitive-behavioral therapies, supported by extensive studies and effective therapeutic strategies, can improve the psychological symptoms of the disease (31). The results of this study revealed a concordance with the role of stress in the exacerbation of patients' lesions, which were frequently reported by participants with psoriasis. Polenghi et al. explored the experiences of 179 patients with skin psoriasis at dermatology clinics using psycho-neurophysiology and biofeedback techniques.

They showed that 72% of psoriasis patients had been suffering a major stressful incidence approximately one month before the onset of the disease. The patients reported a high level of anxiety and depression (32).

The patient's indefatigability in pursuing futile treatments was another major theme detected by the researcher. In this case, the patient is forced to take action for treatment due to the emergence of the symptoms and involvement of the open areas of the body, and for the family, cultural, and social problems that she might face in his daily life. While aware of the inadequacy of existing therapies, he constantly tries newer medications to mitigate the symptoms. The affected person considers various options to get rid of the disease problems by following different treatments with the hope that one of the options may work out.

In "Health as a Theoretical Concept", Boorse (1977) showed that when an individual's health is affected by a disease, he can encounter many psychological problems. The individual's interaction with the environment is deemed to stand as one of the causes of these dilemmas. One way to get rid of such problems is to treat the disease. Since there is no definite cure for some illnesses, the patients would seek treatments recurrently to find psychological relief. This process may lead to failure but guarantee the patients' comfort (16). The results of the present study confirmed it, as well.

Similarly, Pariser et al. noted that patients reported negative and positive mechanisms that affected their adaptation to psoriasis. One of the negative mechanisms reported was ineffective treatment or lack of medical care. The study also reported factors that may limit medical treatment. The reported limitations include financial problems, lack of knowledge, and lack of attention by clinicians and society to psoriasis, failure to find effective remedies, and unpleasant therapies (33). Participants of our study also reported the same factors and our results were consistent with the above study.

The social stigma was another theme highlighted in the current study. People affected by the illness confronted various ideas in their relations with friends and other members of society. Some views were seriously annoying and increased the severity of the patient's symptoms and problems while they could also change their mindset for the worst. Factors such as the education level and cultural, social, and economic circumstances of the community influenced their points of view, too. The results of data analysis confirmed the presence of social stigmatization and revealed that symptoms picture the affected individuals as marked in society and attract the attention of people to them. Depending on the views of society, the affected ones may face frustration and failure in their lives. In this

regard, the results of a study by Al-Khouja and Corrigan considered a stigma in skin diseases as a form of prejudice about certain groups of individuals by the members of a different culture. People generally treat people with signs of skin disease on their faces according to their beliefs. Stigmatization is also considered the most important barrier to achieving goals among those who suffer from skin disorders. Social stigma consists of community members' discriminatory behavior towards people with skin disorders, which may influence the mental health of affected individuals (34). Halioua et al. conducted a study on increased misconceptions, negative judgments, and discriminatory behaviors towards patients with psoriasis in France and reported that 62% of people had no knowledge of psoriasis and 19.7% had a misconception about the disease. Also, 16.5% believed that psoriasis is a contagious disease and 6.8% thought that psoriasis is a skin disease related to personal health, while 3.2% maintained that it was associated with people with reduced personal hygiene. Finally, 50% of the participants were reported to show discriminatory behaviors to patients and stood as agents of frustration (35). Both studies indicate similar results to our findings in this case.

A study by Chen et al. entitled "stigmatization in psoriasis" found that social stigma is common in psoriasis and has a much greater impact on patients than social and psychological pressures. It also showed that such a negative effect can even be worse than the extent and severity of skin involvement. Stigmatization is higher for psoriasis than other skin diseases. Social stigma has a significant effect on the quality of life of psoriasis patients, as well. Misinterpretations resulting from the lack of general knowledge may lead to associating the disease with a contagious infection and can possibly lead to social rejection (36). Patients with psoriasis can obviously feel the real sense of discrimination in the community as they have to avoid sports facilities, swimming pools, and beauty salons since such occasions might turn into an opportunity for teasing experiences (19, 37). This was also consistent with our results.

The fear of an uncertain future was another important theme identified in the present study. The problem with marriage was one of the sub-themes associated with this major theme. According to the participants, marriage was a dream for every young man or woman, but for a person with psoriasis, it was a real challenge that could affect their whole life. While the types of challenges may differ for males and females, they are greater for young females. Anxiety about and fear of dealing with the opposite sex, which has different perspectives and ambitions, also kept participants' minds busy. These factors also raised many concerns.

In their study of vitiligo as a skin disease, Elbuluk and

Ezzedine found that marital life is affected by it for married patients and it can also highly limit the opportunity for marriage among young singles. Divorce has also been another outcome of the illness (38). The results of a qualitative study by Saeedinezhad et al. on vitiligo patients also showed that these patients might have marital and divorce problems and face difficulty in marriage if they were single (39). The findings of this study are in line with the current study. It is worth noting that vitiligo is a rare disease that has many features in common with psoriasis.

The disappointment was one of the sub-themes of the fear of an uncertain future. This occurred when patients tried all the available options to resolve their problems. Pompili et al. concluded that hopelessness in patients with psoriasis was much frequent than other skin diseases. The probability of suicide or mental illness was also significantly higher in psoriasis than other skin diseases (40). Our results are consistent with the findings of the above study.

Youth as the prime time for contrasting feelings of dependence, love, and secrecy was another sub-theme of the fear of a vague future. According to Erikson's theory, youth is a heyday to be seen and experience attachment, but as psoriasis disrupts the socialization process, younger people may choose secrecy as a strategy to repel these feelings. For Gitte et al., the major dilemma for psoriasis patients was the ambition for concealing their illness and refrain from attending the community (41). This was consistent with the results of the present study, as our participants also stated that they frequently faced the same challenge.

Given that the participants of the present study were only young girls and that their problems and challenges were normally different from those of men, the findings are partly different from other studies. *Compulsory lifetime coexistence with psoriasis and fear of teasing* were relatively new concepts introduced in the present study.

The lack of focus on the experiences of affected men, the absence of all experiences of individual patients in research, and emphasis on a single setting were among the limitations of the study.

5.1. Conclusions

The results of the study emerged from experiences rooted in the present life and future outlook of patients with psoriasis. Based on the reports from young girls with psoriasis, it can be concluded that the members of the family and society do not have sufficient knowledge of the disease, which indicates the necessity of awareness-raising measures.

Also, it is suggested that psychological techniques and strategies be used to assist the patients to come to terms with their disease. This can be carried out by considering

patients' experiences by the members of the healthcare team such as psychiatrists, physicians, and nurses as the key players in boosting patients' morale and improving their body image and self-esteem. With new advances in the treatment of skin diseases, it is expected that financial and family support for the patients would be pursued to guarantee the desired results.

Acknowledgments

This study was extracted from an approved research project at Zahedan Faculty of Paramedicine Sciences. Hereby, we would like to thank all the participants of the study, without whose cooperation this study could not have been conducted. Special thanks are also extended to the respectable authorities of Zahedan University of Medical Sciences for their help and support.

Footnotes

Authors' Contribution: Design of the study, analysis and interpretation of data, and careful correction of the first draft: Fariba Yaghoobinia; drafting and reviewing of the manuscript: Farshid Saeedinezhad; research design and data collection: Asadollah Keikhaei; critical revision: Fatemeh Piri.

Conflict of Interests: The authors declare no conflict of interest.

Ethical Approval: This study was approved by the Ethics Committee of Zahedan University of Medical Sciences (IR.ZAUMS.REC.1398.35).

Funding/Support: The project was funded by the Office of Vice-Chancellor of Research and Technology of Zahedan University of Medical Sciences.

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