

Emotional Turbulence Perceived by Psoriasis Patients

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ABSTRACT

Background: Psoriasis is a chronic inflammatory immune mediated and incurable skin condition characterized by redness, scaling, and thickening of the skin. It can occur in any age group ranging from toddler to elderly and affect both male and female equally. Treatment differs from person to person according to the severity of the skin. Psoriasis itself causes psychological impact leading to self- isolation and stigma.

Aim: The aim of the review is to determine the lived experience of patients with psoriasis facing psychological impact in their life such as self- stigma and social isolation.

Methods: Review search through PubMed, Google Scholar, Medline Plus.

Results: Many patients with psoriasis had undergone rejection from their friends and families where they thought that psoriasis is contagious and can be spread from one person to another person. People were afraid of them and avoided contacting them and will express bad words by asking questions regarding the disease which makes them frustrated and leads to depression, decrease confidence and low self-esteem. This will make the patients embarrassed and lead to isolating themselves from others by maintaining distances and withdraw from social

work. On the contrary, patients adapt to the disease and try to have a positive feeling towards life.

Conclusion: People do not recognize the burden faced by patients with psoriasis including the health care personnel. Understanding their feelings and giving education and counselling according to their experience and needs is important when dealing with them to cope with their disease and tackle their problems to live a better life.

Keywords: Psoriasis, social isolation, and self-stigma

INTRODUCTION

Psoriasis is a chronic, relapsing, inflammatory skin illness that results in elevated, thicker patches of skin out of the body due to an overproduction of cells in the epidermis ^[1]. Psoriasis can strike at any age and affects both men and women equally. Worldwide, 2% to 3% of the population suffers from psoriasis ^[2]. The prevalence ranges from 0.44 to 2.8% in India ^[4]. A qualitative study done by Alireza et al. found that the majority of psoriasis patients experienced social isolation from friends where they do not

want their friends to be near them due to their disease. Many patients experience stigmatization, embarrassment, and rejection by others as there is a common misunderstanding that psoriasis is contagious through body contact. Feelings of shame and lack of self-esteem led to significant disruption in daily life and social withdrawal [7]. According to one study, 90.2% of psoriasis patients experience rejection and shame. 20% of psoriasis patients have been turned away from hair salons, swimming pools, gyms, or jobs because of their condition. Additionally, stigma may interfere with a patient's social life, overall health, and quality of life.

The purpose of the review is to identify the major problems faced by patients with psoriasis due to embarrassment of their skin and rejection by their family and society.

MATERIALS & METHODS

A review was performed by searching the Scopus index, PubMed, google scholar, journals at full text for studies published in English using the key word "Self-stigma, "lived experienced" or "Social isolation". Inclusion criteria included a study population of psoriasis patients showing results of self-stigma and social isolation, which is cited in English language. Study methods were qualitative study using a semi- structured questionnaire where themes and sub- themes were extracted based on the similar experiences shared by the participants.

Several articles have been reviewed where in every article reviewed, a semi- structured questionnaire was used so that the questions can be modified accordingly to the answers. By using a semi structured questionnaire, interview was conducted for 20-30 minutes after consent being taken from the participants. From the answers recorded by the researcher, verbatims were elicited and where themes and sub- themes were extracted accordingly. Participants feel that they are being ignored by friends and family which makes them maintain distance from their loved ones, thus further leads to self-

isolation and low self- esteem. The present review aims to highlight the subjective feelings of patients with psoriasis being isolated from friends, how the disease affected their emotion and experienced self-stigmatization. The authors present the lived experienced of self- stigma and social isolation of patients with psoriasis by with a view of published literature from Medline via PubMed and Google Scholar.

RESULT

The major results vary according from the patients' experience as mentioned below.

Lack of social support

Evidence suggests that patients were not satisfied with their lives and social environment, leading them to hide their disease. Study found that lack of social support was one of the themes of stigma and rejection. Patients had specific references to their feelings of loneliness due to deprivation from natural rights, dependencies, and lack of formal and informal support. 80% of patients with psoriasis have difficulty establishing social contacts and relationships, making it the most difficult aspect of the disease.

An interpretative phenomenological analysis on the lived experienced of Chinese patients with psoriasis by Chan et al. showed that some informants tried to hide their symptoms, stop participating in social activities, and keep their psoriasis a secret, which led to social disengagement or isolation [11]. They have claimed that they had become pickier while meeting new acquaintances or developing deep interpersonal connections.

"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". [11]

"Although physical appearance was not important for me, I would feel embarrassed when other people focused on my bodily condition, especially when I went and had to expose my body in public. Some people know that it is not infectious, but in the

public area (like swimming) when you take off your clothes, I still embarrassed.”

Rejection

In general, over the course of the illness, patients encountered stigma, rejection, lack of support, denial of social rights, isolation, and withdrawal. Psoriasis even affected the work where they would prefer to work from home in order to avoid questions and suggestions from their co-workers. When people see the rash and the skin of psoriasis, they would be afraid of them and stay away from them as that the people think that it is contagious and can infect from one person to another which is a big misperception nowadays. On the contrary, psoriasis is not an infectious disease but is chronic and incurable.

According to Hawro et al. age-related increases in the perception of rejection ($p=0.38$) which among other things emerges as avoidance of social relationships. People with psoriasis experienced a greater sense of rejection the longer the longer their disease has been present ($p=0.33$).

Stigmatization is one of the most common experiences by psoriasis. Ginsburg et al. found that 99 of 100 psoriasis patients experience stigmatization and Gupta et al. reported that 26% of psoriasis patients experience rejection.

Stigmatization leads to social rejection and psychological problems for individuals. As L.R et al. study stated, *“No doctors have been interested in talking about my psychological issues, even though that is how psoriasis bothers me most”*.

A study done by Alireza et al stated that social stigma and rejection was more with psoriasis by conducting a study of the lived experience of patients with psoriasis where one of the participants stated *“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”*.

Another participant stated, *“One of my friends told me: people say you’re infected, for this reason people do not talk to you”*.

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”*.

Self- isolation

Ghorbanibirgani et al. showed that Self-stigma is a condition caused by low self-esteem and feelings of shame and hopelessness due to an illness. Self-stigmatized individuals believe that they possess a specific disease-related trait that is socially unaccepted, leading to a gradual change in their self – image. Their stigmatization is caused by lack of illness acceptance and self- acceptance in general. Self-isolation is one of the most common feelings experienced by psoriasis patients. They isolate themselves and stay alone most of the time.

One participant stated *“When I want to go out, I must 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 feel weak and tell myself I am not useful for anything.”*

Another participant stated, *“Once my friends and family found out about my disease, they gradually look distance from me”* [8].

Informants commonly said that their psoriasis had disturbed their live by stating *“Now, social activities were largely reduced”* and *“I became more solitary, lonely and eccentric.”*

Positive adaptation

Although patients with psoriasis mentioned their negative thoughts towards the disease, some had mentioned how they had benefited and gained throughout the years [11]. Patients with psoriasis are certain that it cannot be cured, so there is no point cursing self, or others and having negative thoughts because of the disease. Instead, it helps them adapt to have a positive feeling towards life, enjoy their present and work to live for themselves although their wish is still that they would be very happy if it is cured.

“There must be ups and downs over the course of an illness. My mood will certainly be affected, sometimes being very irritated and frustrated due to the itchiness, but afterwards I would be okay as I know it will pass. Or sometimes I felt upset about myself and appearance, yet I felt grateful and proud of myself that I have gone through all difficulties. However, I would not deny that I have my own weaknesses, but I have also learned something good about myself”.

“After years I know that is quite normal for people to encounter adversities. Illness is inevitable. I surrendered and I know this is fate. I appreciated that I have a good family who offered support and acceptance to me all along. They tolerated my bad temper when I felt irritated. They would gently remind me “I don’t scratch, okay?” and I would try to stop scratching, though I could not control... Just like the family relationships, there must be something good or bad, it’s just a matter how you perceive.”

DISCUSSION

Psoriasis is a chronic, incurable disease. Once the patients had the disease, they would experience symptoms occasionally, which is worse in winter. The present review met the objectives as patients with psoriasis experience many psychological issues which further affect their daily living and lead to self-isolation and stigmatization. Many individuals reported obtaining unjustified and suitable labels, which cause psychiatric problems or disturbance of their interpersonal connections. One of these issues is the patient’s ability to communicate with friends and relatives, where they are rejected, criticized, and questioned. In addition to living with dread, agony, uncertainty, and lack of hope for the future, the patients also had to deal with feelings of rejection, discrimination, humiliation, prejudice, and hostility as well as other worries and societal boycotts.

Clinical trials have shown that phototherapy is one of the best treatment alternatives, particularly for people who have moderate

to severe psoriasis who have extensive illness. The biochemical processes by which phototherapy improves psoriasis are just now being understood, even though it is already acknowledged as one of the effective choices for the condition [16].

Self-stigma and isolation are common in patients with psoriasis which is due to the thought that people think that it is contagious and can get from one person to another by physically contacting them. Due to this, they will express a lot of stress, and this leads to isolation and distress, which brings down their confidence. They will hide their skin by wearing long sleeves to go out even if it is summer which is a great burden from them. To avoid questions, they will not go out but rather stay inside the house.

Only increased social knowledge of psoriasis may help to improve understanding and increase acceptance of patients of dermatosis since stigmatization is a social issue. Patients with psoriasis should receive psychological counselling to better their quality of life by assisting them in coping with stigma. The psychological impact of psoriasis varies from person to person since all patients react to their illness differently. The health-care team who knows clearly about the disease can give education to the people so that patient with psoriasis have better way to adapt to their living environment.

CONCLUSION

Understanding the feelings of psoriasis patients is one of the important measures need to be taken to decrease the emotional breakdown that can be felt anytime due to their skin breakdown. Many journals show a qualitative study where they explore the lived experience of patients with psoriasis and different themes and sub-themes were extracted which shows that psoriasis patients had undergone many problems due to their skin which further leads to self-isolation, stigmatization, depression and many more. The healthcare personnel including the family members plays and

important role in dealing with them by supporting them physically, mentally, spiritually, and socially.

Declaration by Authors

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