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Perceptions and Lived Experiences of Individuals with Autoimmune Skin Conditions

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Abstract

Chronic skin conditions consist of many physical and psychosocial challenges that influence individual's overall wellbeing and daily life. A qualitative inquiry was carried out to explore how do individuals living with chronic skin conditions (psoriasis, eczema, acne) describe their coping strategies and overall QoL. Using a qualitative approach of IPA, participants with chronic skin conditions were asked to share the psychological and sociocultural issues faced by them. In Pakistan, treatment cost, disease burden, stigma, discrimination and appearance related concerns are some of the serious problems causing distress in these individuals. The study comprised of participants including 12 individuals (4=psoriasis, 4=eczema, 4=acne) were recruited through maximum variation sampling from the dermatological units in Rawalpindi and Lahore. Interviews were transcribed and analyzed using Interpretative Phenomenological Analysis (IPA). The transcripts were coded and themes were derived that revealed 9 emerging themes including; emotional distress, impact on daily life, self-perception/self-image, coping/adaptation, support systems, treatment/management and awareness/education. Almost all individuals reported the need to dispute myths associated with skin conditions, such as spreading disease by touch and communicable or contagious disease.

Keywords: Chronic skin conditions, Distress, Coping strategies, Awareness, Interpretative Phenomenological Analysis

Introduction

Chronic skin conditions such as eczema, psoriasis, and acne vulgaris can significantly impact an individual’s overall QoL, affecting physical, psychological, and social well-being. These conditions often cause symptoms such as itching, pain, and discomfort, which can interfere with daily activities, sleep and productivity (Koo & Lebwohl, 2001). Beyond physical symptoms, chronic skin conditions can lead to emotional distress, anxiety, depression, and social isolation due to visible skin changes and stigma associated with these skin issues (Dalgard et al., 2015). As a result, individuals with chronic skin diseases often face challenges in maintaining a positive self-image and social relationships.

Qualitative studies have revealed that chronic skin conditions such as eczema, psoriasis, and acne vulgaris have profound psychosocial impacts on affected individuals. These studies highlight feelings of embarrassment, self-consciousness, and social isolation, as patients often face stigma and negative perceptions due to visible skin changes (Magin et al., 2006). The constant struggle with symptoms, alongside the emotional burden, contributes to anxiety, depression, and reduced self-esteem (Jowett & Ryan, 2005). Qualitative research thus provides crucial insights into the complex ways these conditions affect individuals' mental health and social well-being.

Research on the perceptions and lived experiences of individuals with chronic skin conditions reveals significant psychological and social challenges. For instance, studies by Magin et al. (2006) and Thompson et al. (2010) highlight that individuals with conditions such as psoriasis, eczema, and acne vulgaris often face stigma, emotional distress, and impaired self-esteem. These studies show that chronic skin conditions can lead to a sense of social isolation, altered body image, and challenges in forming interpersonal relationships. The unpredictable flare-ups and itching associated with eczema can also result in sleep disturbances and a reduced quality of life (Chamlin & Chren, 2005). These experiences often make it difficult for individuals to manage daily activities and maintain relationships. Afzal et al (2023) identified that women with eczema reported low self-esteem, social withdrawal, and emotional distress. Similarly, Helina Fikre et al (2023) found in a qualitative study using IPA, that individuals with different skin conditions experienced significant psychological burdens such as anger, sadness, shame, fear, and hopelessness. Social challenges included stigma, disrupted life, and lack of support. Secondary analysis of 42 interviews with young people diagnosed with eczema or psoriasis revealed that individuals reported feelings of disruption in identity and social relationships. Some participants experienced bullying and social isolation (McNiven & Ryan, 2022).

Another qualitative study employed reflexive thematic analysis to examine the experiences of seven young women with psoriasis, eczema, or acne. Four key themes emerged: embarrassment over appearance-related symptoms, unrealistic beauty standards, changes in appearance affecting personal identity, and lack of support (Rutter & Owen, 2025).

Similarly, a research conducted in Iran, involved in-depth interviews with 15 individuals with psoriasis. The analysis revealed themes of lack of social support, inappropriate labeling, rejection, isolation, and feelings of futility. These findings highlight the profound impact of social stigma on individuals with psoriasis (Ghorbanibirgani et al., 2016).

Ghio et al (2021) conducted a secondary analysis of qualitative data from 28 interviews with individuals aged 13–25 suffering from eczema. Three primary psychosocial needs were identified: the need to feel understood, the desire to feel normal, and the requirement for emotional support. Participants discussed the challenges of visible and invisible symptoms and the impact on their daily lives and mental health. In addition, Kanji (2019) did a survey-based study gathered responses from attendees of the Skin Matters conference. Findings indicated that chronic skin conditions significantly impact daily living and mental well-being. The internet was the most commonly used source of psychological support, and many participants expressed a desire for increased psychological resources.

Bard (2025) discussed the link between psoriasis and social anxiety, highlighting that approximately 15% of individuals with psoriasis experience social anxiety due to fear of judgment based on their skin's appearance. The article emphasizes the bidirectional relationship between psoriasis and anxiety, suggesting that managing stress and seeking support can improve QoL.

Research Objective

A qualitative approach was used to explore the perceptions and lived experiences by using Interpretative Phenomenological Analysis (IPA). This approach is chosen as the purpose of the study to better understand the barriers or challenges faced by individuals with skin conditions. This study also aimed to explore the facilitating factors that might help them to manage with psychosocial issues in their daily lives. This approach attempts to portray an actual picture of the human experiences and bring researcher closer to participant’s subjective explanations.

Research Questions

- How do individuals with skin conditions describe their life?
- What are the challenges faced by these individuals living in a Pakistani society?
- How do they cope with the psychosocial challenges?

Method

A qualitative approach was undertaken to gain a deeper insight and understanding of how individuals living with chronic skin conditions describe their life and what are the psychosocial challenges they faced in daily routine.

Sampling Strategy and Participants

Initially fifteen individuals were approached and finally N=12 who gave consent to share their experiences were recruited using maximum variation sampling. A maximum variation sampling is created by defining key characteristics of variation and then selecting cases that differ as much as possible from one another (Suri, 2011). The sample of N=12 individuals considered appropriate because of the idiographic idea of IPA and took into account the assortment of rich experiential information (Smith et al., 2009). IPA inspecting was in general be purposive and comprehensively homogenous as a small sample size can give an adequate viewpoint given satisfactory contextualization (Smith and Osborn, 2003). As appearance related issue is a sensitive area so ethical considerations including participant's willingness, well-being and confidentiality restricted the researcher to smaller sample size.

Procedure

The interview protocol was developed based on the existing literature on the psychosocial consequences of autoimmune skin conditions. The interview protocol framework was comprised of four phases: ensuring interview questions align with research questions, constructing an inquiry-based conversation, receiving feedback on interview protocols and piloting the interview protocol. The interview questions asked individuals to describe their lives and psychosocial challenges associated with skin conditions. Semi-structured interview comprised of general questions inquiring about their present and future life, coping with the condition, and its impact on their personal and social life. No time duration was set for the interviews to allow a free flow of information. The average time for interview was 20-25 minutes. The interviews were recorded with the participant's permission to be transcribed later.

Results

IPA is distinguished by a collection of similar processes that move from the particular to the shared and from the descriptive to the interpretative, as well as principles that are applied flexibly, depending on the analytic task (Reid et al., 2005). Analysis is sometimes described as an iterative and inductive cycle (Smith, 2004). IPA is not a prescriptive technique; rather, it provides a set of flexible guidelines that individual researchers can alter based on their study objectives (Smith & Osborn, 2003). The IPA method was utilized to analyze data from one-on-one interviews in order to create rich descriptions of participants' perceptions and lived experiences. In the present study, IPA approach was used to evaluate the individual transcripts with idiographic intensity in terms of details (Smith et al., 2009).

The analysis involves reading through all of the transcripts and making comments in the left margin. After thoroughly studying the comments, these depictions were assigned subject headings based on similar qualities and ideas coming from the narratives. Initially, many themes formed, which were gradually joined and arranged based on parallels and common issues to form superordinate themes to be explored as key themes. The key themes showed the researcher's judgements and subjective records. These superordinate themes emerged from themes and subordinate themes that are presented and discussed in detail (see Table 1).

Table 1

Perceptions and Lived Experiences of Individuals with Skin Conditions

Superordinate themes	Themes	Subthemes/subordinate
Emotional Distress	Negative emotions Stress Hopelessness Mood swings Depression	Anger Irritability Distressed Upset Constant worrying Helplessness Feeling unpleasant
Impact on Daily Life	Reduced social interactions Social consequences Stigmatization Discrimination Functional limitations Occupational impact Relationship impact Frequent urges of scratching/itching Better wellbeing/Satisfaction Poor psychological functioning	Inappropriate comments by others Judged by others Rejection from others Avoid social gatherings Staring by others Treated differently Embarrassment Isolation Difficulty in socializing Challenges in daily routine Scratching/itching in public settings Limitations in daily activities Quit job Issues at workplace Negative impact on career Less marital opportunities Disturbed marital life Hopeful Positive mindset Avoid stressor Acceptance Disturbed Dissatisfaction
Self-Perception/ Self-Image	Negative self-evaluation Appearance related concerns Low self-esteem	Self-hatred Inferiority complex Lack of self-confidence Negative self-view Feeling awkward about appearance Body discomfort Concerns about physical

		appearance
Coping/Adaptation	Problem focused coping Religious Coping Emotion focused coping	Comprise with the disease Acceptance of disease Didn't take stress Faith on Allah Recite different verses to heal the skin Follow medication and precautions Distract self to divert mind Sitting alone and isolate to manage emotional responses Social Withdrawal
Support Systems	Positive social support Lack of support	Support from family, friends and peers Ignored by family, friends and relatives
Treatment/Management	Treatment experiences Medication Adherence Treatment needs	Followed proper medication Too expensive to be afforded Need for cure Need for advanced level treatment Need to open specialized centers Need to work on medication efficacy
Awareness/Education	Need to conduct awareness programs Societal change Dispute myths about skin issues Psychological consultation	Lack of awareness in public Need to address society's thoughts and perceptions regarding skin conditions It's not a contagious disease Skin issues have multiple causes Accept individuals with skin problems Provide counseling to the sufferers

Emotional Distress. *It* refers to a broad range of negative emotional experiences that individuals with skin conditions may encounter as a result of their physical symptoms, appearance changes, or social experiences (Dalgard et al., 2015). Emotional distress in individuals with skin conditions is a multifaceted psychological response encompassing a range of negative emotional states. This distress can manifest in various ways that includes, anxiety, depression, anger, frustration, mood swings, irritability, upset, sadness, intrusive thoughts, constant worry, helplessness, feeling unpleasant and so on. These emotional responses can be influenced by the visibility and severity of the condition, the individual's coping mechanisms, and the reactions of others (Picardi et al., 2000). In the present study most of the individuals reported emotional distress as an unmarried man with psoriasis three year ago said;

> *"Too much disturbed. Very disturbed… I have extreme mood swings. I feel constant irritation. For example, if the itching suddenly starts, it becomes very hard to talk to me. I just want everyone to leave me alone. It's really tough. Mood swings are very common with this…. I am experiencing anger issues due to this condition."*

Adding to this emotional distress, a married woman with psoriasis reported;

> *"I am living my life with great difficulty. If the itching starts, I don't know what to do. And what will people think about me? I get these kinds of tensions. I am very hopeless. I am very stressed about this. I am going into a kind of depression because of this. I am very hopeless. If the itching triggers in a public place, what will I do?"*

One of the participant with acne vulgaris told that;

> *"I have a very disturbed life with my skin problem. Wherever I go outside, people make comments, due to which I am always in state of anger and irritation. This is the main reason that my emotional health has not been good."*

Impact on Daily Life

As one of the research question was about the influence of skin conditions on daily life, so superordinate theme emerged as impact on daily life that further divided into social impact, psychological impact, occupational impact and impact on relationships. Participants reported greater psychosocial impact including disturbance, dissatisfaction, poor psychological functioning, reduced social interactions, social consequences such as discrimination, stigmatization, inappropriate comments by others, isolation, embarrassment, difficulty in socializing, judged by others, rejection, staring, avoid social gatherings and so on. In the present study, one of the married participant with acne reported that;

> *"Wherever I go, people make comments about me, and they are negative. Because of which, my mental health has not been good. Current life is that… because I completely stopped socializing with people, and because of that I have become completely mentally disturbed. I am living completely alone. I have a very disturbed life with my skin problem."*

Social consequences were reported by the participants as one of the individual with psoriasis reported that;

> *"People avoid me, thinking that if she has itching, we might also get it. If the itching starts, I don't know what to do. And what will people think about me? It's very difficult to go outside, so I mostly avoid the events.*"

Adding to this, another participant with eczema reported that;

> "*Whenever I go to family gatherings, people stare at me in a very unpleasant way. It becomes a big issue. Overall, I've been greatly affected mentally. I isolate myself and lock myself in my room. I've reduced social interactions. People don't even want to sit next to me. Making friends becomes a problem. People look at me with disgust."*

One of the married man with eczema reported that;

> *"It's not pleasant all the time because once triggered, the itching continues for quite a while. So yes, there's embarrassment on a personal level too. You always worry about how your spouse might feel. It constantly stays on your mind. Absolutely. There is discomfort for the other person, even if they don't show it. We are mature enough to analyze that. In fact, visible discomfort has been expressed by her."*

Adding to this, another married woman with psoriasis revealed that;

> *"My husband and I often have disagreements and fights over this issue. I am very stressed about this. My daily routine is so disturbed that I can only done limited task due to frequent itching or scratching."*

Self-Perception/Self-Image

In the present study, where psychosocial impact was explored, participants' perceptions about themselves were observed as influenced by their social wellbeing. Self-perception refers to the process by which individuals form an understanding of themselves, their traits, behaviors, emotions, competencies, and identities. It involves how people view and interpret their own actions and internal states (Alleva & Tylka, 2021). Individuals reported negative self-evaluation, appearance related concerns, low self-esteem followed by reporting self-hatred, inferiority complex, lack of self-confidence, body discomfort and feeling awkward about appearance.

Adding to this, another married woman with psoriasis reported that;

> "*I am very hopeless. I start hating myself. I am going into a kind of depression because of this. I don't have any confidence now. I have doubts on my capabilities."*

Similarly another married woman with acne reported that;

"In my personal life, because of people's advice, I have developed a kind of self-hatred. *I have started hating myself. The question remains in my mind, why am I existing? So, because of people, I have started hating myself."*

One of the woman also stated that;

"*My personal life gets quite disturbed. When I look at myself in the mirror, I start comparing myself... why am I not like normal people? Why isn't my skin like normal people's skin"? Looking myself in the mirror again and again and cursing myself.*

Coping/Adaptation

Coping refers to the cognitive, emotional, and behavioral strategies individuals use to manage stressors, such as living with a chronic skin condition. Adaptation is the long-term adjustment process through which a person integrates the condition into their daily life, maintaining emotional balance and functional living. In the present study, it was observed that some of the participants tend to adapt with their skin conditions through problem focused strategy including acceptance of disease and follow medication and precautions. Whereas, others used emotional focused and religious coping strategies. An unmarried individual with psoriasis reported that;

"I believe that you shouldn't lose heart over something that is not in your control. Now *my life is not affected by it. I managed my skin issue by following all prescribed medication and precautions, I will follow this method in my future too."*

Adding to this, an unmarried woman with acne reported that;

"*Only consult a doctor and follow their prescribed treatment. You just need to take some precautions. You should consult a doctor. I will make myself mentally stronger. I will stay away from people's unsolicited advice. Someone is suggesting a home remedy, and then someone else is giving some other advice. So, all the people, including me, who are living with this skin problem should only listen to the doctor."*

A married man with psoriasis said that;

"Overcome? Well, there's no choice. I just sit alone. What else can I do? I can't fight with someone… and that too every day. But it's really tough."

Similarly another married woman with psoriasis reported that;

"I just think that may Allah cure this disease as soon as possible. So that my life can become normal again like before. And I get rid of this itching as soon as possible. May Allah make things better. I offer Namaz and recite different verses from Quran to heal my skin."

Support Systems

Support systems help individuals to manage emotional distress, improve self-esteem, encourage treatment adherence, reduce feelings of isolation and stigma and enhance quality of life or overall wellbeing (Aragones et al., 2020). In the present study it was observed that social support was one of the major theme that help individuals to manage with daily life issues and stressors. Whereas, participants with lack of social support tend to experience greater psychosocial consequences. One of the participant diagnosed with psoriasis reported that;

"I have become much better because of the support of my family and friends. Now I don't lose heart over it. I don't care anymore about what people think or say. My family and friends are enough for me."

Another participant with acne vulgaris said that;

"Now I have overcome it. The reason is that my family is very supportive and my friends. I have a lot of support from my family. My friends have been very supportive, saying there's no need to focus on such a small thing. They used to compliment me, saying, you look very beautiful. Your height is so good. Focus on other things. Don't focus on such a small matter. So, Alhamdulillah, my support system is very good."

Moving towards lack of support that influenced the amount of psychosocial impact as one of a married participant with psoriasis stated that;

"My husband is not supportive at all. I don't have friends due to my in-laws family environment."

One ore individual with eczema reported that;

There are certain things one usually shares with friends I can't do that. Nobody supports me in my tough time.

Treatment/Management

Treatment of skin conditions focuses on reducing symptoms, improving appearance, preventing recurrence, and enhancing quality of life**.** Management is a broader term that includes ongoing care, coping strategies, lifestyle adjustments, and psychological support to help individuals live well with a chronic or fluctuating skin condition. One of the individual with psoriasis reported positive treatment experience reflecting satisfied doctor patient relationship as;

"Yes, absolutely. It's helping a lot. The doctor I'm seeing is very good. He guided me well on how to manage this skin problem. He prescribed good medicines and creams. By using them regularly, the condition is improving over time."

Most of the individuals were concerned about treatment cost and its temporary effects. One of the participant with psoriasis reported that;

“If I take medicine, it gets better. As soon as I stop taking medicine, it happens again. Medicines are very expensive. You can’t take them regularly. Even, I can’t take them on regular basis.” As for the future… I hope there will be a more advanced treatment. Medicines with better results should be introduced. I took medicines, they were have only temporary effects. So there is need to work on this domain. There should be good treatment and it should be affordable. So that they don't have to stop the treatment midway.”

Another participant said that;

“In my opinion, first of all, one must follow proper treatment regularly. If you want this condition to be manageable because I haven’t found a proper cure yet things can be managed with proper medication. I believe there should be advanced level treatment centers. Specialized centers should be established.”

Another participant with eczema reported that;

“I am taking medication regularly haven’t skipped any, and I’ve managed to overcome it. Secondly, there should be advancement in medication. As long as you’re taking medicine, the condition stays under control; the moment you stop, it gets triggered again. So the efficacy of medication should be improved.”

Awareness/Education

Awareness refers to the level of knowledge and understanding that individuals (both patients and the general public) have about skin conditions. For patients, education means teaching them how to manage their condition effectively and cope psychologically (Tuckfield et al., 2022). In the present, almost all participants share similar views, emphasizing the role of psychologist to provide counseling and therapies to needy individuals. Also, they were concerned regarding the myths and society’s response towards skin conditions that needs to be fix through awareness.

A married individual with psoriasis share his views as;

“*Awareness should be raised in society. A lot of things are needed… but the most important is that they should be treated like human beings. Not with hatred. People really dislike it. They avoid you… society needs to become more accepting. People should know that those with psoriasis… should at least be accepted. If someone has this issue, they should take it lightly. God forbid, no one should treat it as if it's a contagious disease. I believe people like me need psychological help as well.”*

Adding to this another participant with eczema stated that;

“*I believe there's a need for awareness among people. This isn’t a hyper-contagious disease. It’s not like the germs will spread in the environment around the person. So, showing visible discomfort causes embarrassment for the patient. People think they shouldn't go near such individuals, not eat with them, or use anything they have touched. It’s okay to be cautious,* *but not to the extent that even unaware people become uncomfortable due to obvious signs of avoidance. There should be awareness and sessions related to mental health. People like me should be provided with better social well-being and mental health support."*

Discussion

The current study explored the perceptions and lived experiences of young individuals living with psoriasis, eczema, and acne vulgaris, three of the most prevalent and psychosocially impactful skin conditions. The findings reveal profound physical, psychological, emotional, and social challenges associated with these skin problems, aligning with a growing body of international research emphasizing the psychosocial impact of chronic skin issues on overall wellbeing. Previous studies, showed that individuals with psoriasis often experience feelings of shame, depression, and anxiety due to public visibility of skin lesions (Kimball et al., 2021).

Similarly, individuals with eczema reported significant psychological strain, frequently linked to incessant itching, scratching, anger, irritation, distress, constant worry, helplessness, mood swings and hopelessness (Silverberg & Simpson, 2019). In the context of acne, especially among young adults, appearance-related emotional distress was predominant theme, reflecting findings from Dalgard et al (2015), who demonstrated a strong association between acne severity and negative emotions.

Ginsburg and Link's (2001) found that visible skin conditions can severely impair social functioning and lead to isolation. In particular, those with psoriasis expressed concerns about being perceived as contagious, a misconception that persists despite public health education (Aragones et al., 2020). Acne sufferers frequently noted bullying during adolescence, a finding echoed by Magin et al. (2006), who reported that acne is a significant contributor to adult psychosocial morbidity.

The psychological impact was evident in reports of anxiety, depression, and lowered self-worth. Numerous studies have established a bidirectional relationship between dermatological diseases and mental health, with skin inflammation often exacerbated by psychological stress (Dalgard et al., 2019; Gupta & Gupta, 2003). The participants' narratives confirm that emotional distress not only results from skin conditions but also worsens disease symptoms, creating a vicious cycle (Lavda et al., 2012). Participants discussed significant social stigma attached to visible skin conditions. Misconceptions such as beliefs that psoriasis or eczema are contagious led to experiences of social rejection, bullying, or uncomfortable questioning from others. This is consistent with Shahwan et al. (2021), who found that public misunderstanding about skin diseases often leads to social exclusion and discrimination. Many individuals internalized negative societal reactions, leading to a diminished self-image. These experiences indicating that visible skin conditions can distort body image and self-concept (Gupta & Gupta, 2003; Marron et al., 2022). Acne sufferers, in particular, described themselves as ugly or repulsive, echoing the findings of Magin et al. (2006), who noted that acne vulgaris significantly contributes to negative self-perception during critical developmental periods. Similarly, individuals with psoriasis often expressed feeling dirty or contaminated, terms associated with deep-seated stigma internalization (Ginsburg & Link, 2003). Persistent negative self-evaluation was also linked to decreased life satisfaction and heightened vulnerability to anxiety and depression (Dalgard et al., 2015).

Fortune et al (2002) noted that positive coping strategies such as problem-focused coping is associated with better psychosocial functioning in individuals with psoriasis, whereas emotion-based coping exacerbates distress. An important aspect of the participants' experience was the role of support systems. Those with strong family and peer, support reported better adjustment and lower psychosocial impact. This supports the conclusions of Marron et al (2022), who found that social support acts as a significant protective factor against the mental health burdens of chronic skin diseases. However, gaps in psychosocial support services, especially among dermatology clinics, were noted, echoing Bewley et al (2021) call for integrated psycho-dermatology services. Fortune et al (2021) emphasized that social support is crucial in mitigating stigma's negative effects, yet many individuals with skin conditions struggle to access adequate emotional support from friends, family, or the broader community.

Participants expressed their concerns about treatment/management of their skin conditions. These concerns reflect those found in the literature, where patient dissatisfaction with dermatological care often stems from a perceived lack of holistic management (Cranenburgh et al., 2016). Lastly, the present study underscore the urgent need of awareness or education to combat misconceptions or myths about skin diseases, and psychological consultation to help individuals to mitigate the psychosocial consequences of skin conditions. Public health campaigns promoting acceptance and accurate knowledge about psoriasis, eczema, and acne are therefore essential, as highlighted by Shahwan et al (2021).

Implication

The study highlight the urgent need for integrated dermatological and psychological care**.** Participants' narratives reflect experiences of anxiety, depression, and social withdrawal, which underscore the importance of screening for emotional or psychological distress in dermatology settings**.** Clinicians should consider referrals to mental health professionals when emotional suffering is evident.

Conclusion

Exploring the psychosocial consequences of living with a chronic skin conditions sheds light on how these individuals describe their lives when describing their experiences.

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