Quality of Life of Women Living with Eczema: A Qualitative Study

Zubana Afzal*, Fatima Kamran, & Rafia Rafique
Institute of Applied Psychology, University of the Punjab, Lahore, Pakistan

The present research used qualitative approach to explore 1) how people living with Atopic Eczema perceive their quality of life and 2) which coping strategies they were using to overcome the physical, emotional and social consequences of Atopic Eczema. Participants were recruited through social media sites from different socioeconomic strata, educational backgrounds, and family systems. Twelve participants were recruited and interviewed. Interpretative phenomenological analysis was used and six major themes emerged: "Stigmatization/Social Rejection", "Social isolation", "Social comparisons and self-image", "Perceptions about recovery", "Self-management/ coping strategies" and "Support System". Participants reported social isolation, negative social comparisons, negative self-image, stigma and social rejection. Moreover, participants reported active, avoidant and religious coping strategies and improvement in physical health with the course of treatment. The findings of current study are beneficial for the dermatologists and psychologists to work on the coping strategies and quality of life of women diagnosed with atopic eczema.

Keywords: atopic eczema, quality of life, coping strategies, self- management

Atopic eczema is an inflammatory skin condition that primarily affects children (World Allergy Organization, 2003). Typically, it starts in early childhood and goes into remission before adolescence, however, 25% of these cases continue to have eczema into adulthood (Thomsen, 2014). It manifests as dry and inflamed skin with intense itching, furthermore, a compromised skin barrier function increases susceptibility to infection, allergen sensitization, asthma, and food allergy. Scratching further worsens eczema due to the damage to skin barrier (Brough et al., 2015). A survey involving 559 eczema patients revealed significant limitations in daily activities and a negative impact on their quality of life (Sibbald & Drucker, 2017). Globally, the overall prevalence of atopic eczema is 15 to 30% in children and 2 to 10% in adults (World Allergy Organization, 2017). In Pakistan, it is the most prevalent type of eczema, affecting 26% of the population (Mohamed et al., 2021). While there is no cure for eczema, effective management involves the use of moisturizers/emollients, oral treatments and topical corticosteroids (Apfelbacher et al., 2013). Therefore, a multidisciplinary model is needed to manage the complications of atopic eczema (Jagadeesan et al., 2022).

Research revealed that the severity of disease is associated with poorer quality of life (Birdi et al., 2020). Various studies indicated impairment in physical, psychological, and social quality of life for individuals with atopic eczema (Ring et al., 2019). The stigmatization, social isolation and discrimination that accompany atopic eczema can lead to psychological disturbances such as anxiety, depressive symptoms, and emotional disturbances both in children and adults (Oh et al., 2010). It also affects interpersonal relationships, leading to a negative impact on appearance and changes in people's attitudes (Knackstedt et al., 2020). Individuals with eczema, especially children, face psychosocial challenges, including bullying,

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*Correspondence concerning this article should be addressed to Ms. Zubana Afzal, Institute of Applied Psychology, University of the Punjab, Lahore, Pakistan.
Email: afzalzubana@gmail.com

anxiety, stress, and low self-esteem (Halvorsen et al., 2014; Mizara et al., 2012). Eczema significantly influences self-image and social functioning, contributing to reduced self-acceptance and self-efficacy (Magin et al., 2009). Stigma further compounds the challenges, leading to the rejection and discrimination of individuals with skin disorders (Ghorbanibirgani et al., 2016). Literature reports that the enduring patterns of avoidant and passive coping behavior, like withdrawing from activities during itch attacks, are associated with increased itch levels, more scratching, low quality of life and higher disease-related disability (Amer et al., 2017; Verhoeven et al., 2006). Psychological symptoms such as sleep difficulties and suicidal ideation were also highlighted in recent research (Afzal & Rafique, 2023).

The biopsychosocial view point has become the most heuristic approach to understand the idea of pain and explore how the mind and body relationship influences the experience of people with skin condition. This methodology sees a physical health issue as the consequence of social and psychological functioning and explains factors that increase the intensity of disease. The biopsychosocial way to understanding the burden of atopic eczema has been recognized as the best model to date, in that it embodies the more extensive issues among the social and psychological factors due to skin condition. The biopsychosocial model utilizes physical, social, psychological, emotional and behavioral connections to best elucidate the quality of life of people living with a skin condition (Verhoeven et al., 2008). As per this model, illness perceptions and coping mechanisms can serve as potential mediators of moderators that can enhance or decrease the symptoms of itch (Verhoeven et al., 2008). Considering this model, it is important to gather in-depth information about how different factors affect the quality of life of women.

As discussed, atopic dermatitis (eczema) is one of the most frequently cited skin disorders with a suspected psychosomatic factor. International researches found atopic eczema associated with a number of psychological, social as well as emotional outcomes (Amer et al., 2017; Gray, 2018; Marron’ et al., 2020). There is an established link between atopic eczema and its negative consequences but limited research has been done in young adults (Ghio et al., 2021). As per literature explored, there is lack of qualitative research in Pakistani population on the burden of atopic eczema and limited research on how to overcome these consequences. It is important to understand qualitative exploration to study the role of eczema on psychosocial wellbeing of individuals as qualitative research helps in gaining a comprehensive understanding of lived experiences of the disease or illness and can help the health professionals in the management of eczema.

Objectives of the Study

- To explore how women living with atopic eczema perceive their quality of life.
- To identify the coping strategies that were being used overcome the physical and psychosocial consequences of atopic eczema.

Research Questions

1. How do women perceive their quality of life while living with atopic eczema in Pakistan?
2. What are the coping strategies that are used deal with the consequences of atopic eczema?

Method

Research Design

The study was framed in an interpretive paradigm by using interpretative phenomenological approach to explore the individuals' lived experiences in detail. The current study used semi-structured interviews to analyse the impact of atopic eczema on quality of life of adults with this condition in Pakistan, along with studying coping strategies they use to deal with the physical, psychological and social impact of eczema.

Participants

The women diagnosed with atopic eczema were recruited through social media sites from different socioeconomic strata, educational backgrounds, and family systems. Participants were requested to participate in a semi-structured interview. Twelve women aged 18 to 30 years participated in present study. Demographic information and clinical sheet were collected before the interview.

Inclusion Criteria

- Those who had a clinical diagnosis of atopic dermatitis for at least last 3 months.
- Infection on the "visible" parts of the body (arm, hands, neck, face, feet).
- Participants with moderate to severe eczema.

Exclusion Criteria

- Patients were excluded if they had any significant comorbidity (any other chronic condition).
- Women aged less than 18 and more than 30 years old were excluded in this research because atopic eczema changes with age, however, it has adverse physical, psychological and social consequences in individuals aged 18 to 30 which in turn negatively affect their quality of life (Garmhausen et al., 2013; Sandström & Faergemann, 2004; Son et al., 2018).

Table 1

Characteristics of the Women living with Atopic Eczema (N = 12)

Cases	Gender	Age	Birth Order	Education	Monthly Income	Residential Area	Family System
1	Female (A)	22	Single child	BS	Rs.70,000	Urban	Joint
2	Female (M)	25	Middle born	MPhil	Rs.100000	Urban	Nuclear
3	Female (Z)	21	First born	BS	Rs.50,000	Rural	Joint
4	Female (M)	26	First born	MBBS	Rs.70,000	Urban	Nuclear
5	Female (N)	20	Middle born	BS	Rs.50,000	Urban	Nuclear
6	Female (L)	27	Second born	BS	Rs.80,000	Rural	Joint
7	Female (S)	22	First born	MSC	Rs.100,000	Rural	Nuclear
8	Female (I)	25	First born	BS	Rs.80,000	Urban	Joint
9	Female (K)	22	Last child	BS	Rs.75,000	Urban	Joint
10	Female (H)	25	Middle born	MPhil	Rs.90,000	Rural	Nuclear
11	Female (R)	21	Last born	MBBS	Rs.100,000	Urban	Nuclear
12	Female (H)	20	First born	MPhil	Rs.90,000	Urban	Joint

Procedure

Adult women with the diagnosis of atopic eczema were requested to participate in this qualitative study through social media sites (such as whatsapp, facebook). Semi-structured interviews were conducted to study their experiences related to their quality of life and their management or coping strategies for atopic eczema. All participants were interviewed through telephone call and interviews were recorded with the consent of participants. After taking interviews, researcher transcribed and analysed all interviews using IPA guidelines.

Ethical Considerations

- The researcher explained the nature of the study and asked the participants to sign the informed consent form.
- All the interviews were recorded after the consent of the participants.
- All the women were assured that the obtained data will solely be used for the purpose of the research.
- There were no distress causing questions and comfortable environment was provided.
- Participants had the right to withdraw at any time during research.

Results

Analysis was done by using IPA guidelines and six supper ordinate themes were extracted from interviews in order to get a complete picture about their quality of life and coping mechanisms.

Themes

Participants reported the perceptions about the consequences of eczema on their lives and experience related to coping strategies to deal with consequences of this skin condition. The extracted themes included:

- Stigmatization/Social Rejection
- Social isolation
- Social comparisons and self-image
- Perceptions about recovery
- Self-management/ coping strategies
- Support System

Table 2

Themes and subthemes extracted from Qualitative Data (N = 12)

Themes	Subthemes
1. Stigmatization/Social Rejection	• Rejection • Negative attitudes by others • Social marginalization
2. Social isolation	• Avoid social events • Avoid family and friends gatherings
3. Social Comparisons and self-image	• Perceptions about own self

	• Perceptions about what others perceive
4. Perceptions about recovery	• Improvement in physical symptoms • Gratitude
5. Self-management/ coping strategies	• Active coping to manage symptoms • Distraction to manage symptoms • Negative Coping • Religious coping
6. Support System	• Family and friends support • Role of healthcare professionals

Stigmatization/Social Rejection

Individuals with atopic eczema reported experiencing stigmatization from society that leads to psychological problems. Participants reported that spots on skin lead to stigmatization and social rejection which negatively affects their social, emotional and academic life and productivity. In present study all participants are students and reported social rejection in different environment ssuch as in college, university, home and family gatherings. One participant reported:

"I had blackish blue marks on my hands and my principal told me not to come to college until you are well because the students are very scared to see you and their parents are very worried about them. It can happen to children if they touch it. So at that time I didn't go to college for 6 months then my treatment started and I got much better then I went to college again then my principal said again take more vacations until you are completely fine."

Another participant also shared her negative experience about how she faced negative attitude and rejection from others in the college:

"I used to wear full sleeves to hide it but it was itchier because of full sleeves but I wore it to avoid bullying. My geography teacher used to think that if I touched someone else, it would happen to them too. People are not aware enough to understand."

Participant 3 reported that the visible pigmentation, inflammation and scars are constant reminders of her suffering. Participant felt stigmatised because of her appearance due to visible eczema spots on face and hand.

"I have scars on my hands and arms, which is why most people notice it. Everybody asks me over and over again what it is, how it happened, and gives advice. It seems that everyone stays away from me because everyone thinks that this disease can happen to them."

Participant 4 from a joint family system reported the emotional aspects of social rejection:

"I don't go to the wedding in fear of being noticed by everyone. By the way, my aunt says that if you don't worry, you will get well but when I go somewhere, my aunt says stay at home. She doesn't know I am not worried for health but such comments cause stress obvious."

Social Isolation

Participants reported they lost their interest to engage in social activities due to stigmatization of visible spots on their body which causes psychological distress in them. To reduce stigma-related stress resulting from atopic eczema, they preferred to stay away from such situations where they encountered other people. A participant from joint family system reported low self-esteem and social isolation due to stigmatization:

"*Whenever I go to someone's house in the family, they point out that this is miserable disease etc. Because of their words, my insecurity level gets very high. I look my skin and become so insecure while talking to someone even I can't make eye contact. I feel like he is not talking to me, I feel like he is looking at my skin. I don't like meeting people again. I spend more time at home"*

Participants were concerned about what others thought of their eczema and were anxious about the questions people asked from them. Therefore, they preferred to stay at home instead of going to social events due to fear of people asking questions. Participant 2 described her experience:

"*I try not to go to more family events until my scars heal. Because people will ask questions when they see and I will just be keep answering them all the time, so I don't go."*

Some participants also reported that they were conscious of exposure and intentionally skipped family get-togethers to avoid the stigma by others because of the physical appearance. Participant 3 also stated that:

"I am very sensitive, I think a lot and take tension, so I don't go when there is a wedding like family gatherings - because I don't like myself in front of them. However, if I don't go then my heart aches a lot and then I get angry that I can't enjoy it because all the cousins have fun and I stay at home."

Social Comparisons and Self-Image

Most of the participants were dissatisfied with their appearance because of eczema lesions on their body. They reported negative views about their self-appearance; they shared their experiences where they felt so disheartened and depressed when seeing other women who looked beautiful. Participants' responses indicated that when they compared themselves with others on the basis of appearance it produced negative perceptions about their self-image. A participant shared that eczema impacted her life routine activities such as not being able to do makeup like other girls.

"*I have eczema on my face and hand but I don't have as much stress on my hands as I do on my face. Because of face scars I don't look as pretty as everyone else."*

Another participant compared herself with other age fellows which reduced her social engagement and further impaired her psychological wellbeing. She reported negative perceptions about appearance which were actually making her feel less confident and unable to maintain eye contact. She reported:

"*I can't make eye contact I feel like he is looking at my skin, he's not talking to me, but just looking at the skin."*

Participants reported a sense of shame and guilt related to their appearance and they also compared themselves with others healthy individuals. Because of comparing themselves with others, they become more conscious about beauty and feel embarrassment due to eczema spots on their body parts. So, they tried to hide visibility of eczema to avoid being stared at and judged by others. As a participants said that:

"*I'm ashamed to go out in front of people because my face looks so bad because of the marks on my face"*

Perceptions about Recovery

In present study, all twelve participants reported improvement in physical health (spots, itching) because of course of treatment. Participants showed gratitude and were aware in how they can prevent their eczema from getting worse. As they stated that:

"Yes, I am better than before. Thank God. I am taking this treatment and the rest of the medicine. It is still happening, but God is the healer."

Participants reported their active management strategies to deal with physical symptoms of atopic eczema. They described their awareness about how to control eczema. Because of the information or awareness participants showed positive recovery and improvement in the present condition of eczema. As participants stated that:

"Yes, it is improving. I'm trying to moisturize my skin to get rid of it quickly."

Self-Management/ Coping Strategies

Active coping. Self-management or coping strategies were found to vary according to the management of consequences of atopic eczema in different domains. Participants reported active coping strategies when it comes to managing the physical symptoms of atopic eczema. As participant reported:

"A lot has changed. By the way, now I know that I don't have to itch. I have to apply cream when I have it. It is itchy, but now the self-control factor is a major help."

Distraction. Moreover, two participants also reported distraction as coping strategy for the management of symptoms. Participants try to divert their attention from the symptoms such as itching as a participant stated:

"I try to divert my attention from the itch by watching drama or movie. If it is not continuously itching, then my attention is easily diverted from the itch"

Another participant reported:

"I try not to itch. I avoid it by interacting with others. So, it doesn't spread too much."

Religious coping. Religion was another key coping strategy used by women diagnosed with eczema in this study. Participants reported that religious coping such as praying, surrendering worries to higher power, and trusting God helped in the management of emotional aspects. As one participant reported that:

"What can I say to someone? I just pray to Allah that I will get well soon. The sign will disappear. I get angry with the words of people. People have power to kill others with their words but Thanks to God I am better than before."

Another participant reported:

"*I cry because I have this disease. Then I explain to myself that Allah is always with the patient and He is the giver of health. I pray to Allah - this is how my heart finds peace."*

Support System

Most of the participants reported that they feel supported by their parents, friends and health care professionals. A participant stated that:

"*My family is very supportive. My grandmother makes me read Qur'anic verses on water. Everyone cares about me and I have a friend. She is very dear to me. I feel very good talking to her. In every situation she makes me feel happy."*

Another participant reported positive support from her social media friend with whom she had never met:

"A friend of mine on Facebook, I have never met her, I have never seen her, she is from Karachi, we live far away, we can't meet, but, I tell her everything. She always says don't worry, Allah will give you fastest recovery soon. She suggests me movies, shows to watch, that's how my time goes well."

In this study, only one participant reported that she receives negative comments from her siblings as she stated:

"*When I have a fight with my sister, she also says angrily that your face is bad, it hurts a lot. And those who do not say anything but make me feel I am useless from their gestures.*"

Discussion

The present study explored the quality of life of adult women living with atopic eczema. Participants reported negative consequences that they experience due to their atopic eczema and the precautions or coping mechanisms they use to cope with these negative consequences. The common features which emerged in the present study were stigmatization, social isolation, social comparisons and perceptions about recovery. The majority of participants reported that along with their physical symptoms, they also experienced social rejection from their family and friends which leads to social rejection and interpersonal issues. The results of previous studies also showed a sense of rejection and labelling (Ghorbanibirgani et al., 2016; Mollerup et al., 2013). Furthermore, all participants in this study were women and all of them reported stigmatization in social situation due to atopic eczema. A study by Boehm et al. (2012) highlighted that women with atopic eczema were more stigmatized as compared to men with atopic eczema. Participants reported social isolation due to skin appearance linked with spots of eczema on body parts which actually has negative impact on their social quality of life. Participants reported that to reduce their stress they tried to stay away from such situations where they had to encounter other people. Previous international studies also highlighted that social rejection and stigma badly affect the individuals' social life (Ring et al., 2019), and eczema patients reported negative management of social stigmatization and rejection by isolating themselves from social activities (Mollerup et al., 2013). Marron et al. (2020) also reported that eczema has a considerable effect on appearance and interpersonal relationships of the participants diagnosed with atopic eczema.

Most of the participants with eczema in Pakistan were dissatisfied with their appearance because of eczema. They reported negative views about their self and they shared their experiences where they felt disheartened and depressed when seeing other women who looked beautiful. Participants reported a sense of shame and guilt related to their appearance while they compared themselves with others healthy individuals. It indicated the adverse impact of eczema on their self-image which leads to reduction of desire to be socially active because of negative image about their appearance. Findings of previous studies supported the findings of current study as negative self-image was positively correlated with poor quality of life in individuals suffering from dermatological issues (Potocka et al., 2018). The resulting stigma of atopic eczema negatively affects an individual's self-confidence, emotions, self-esteem and the ability to establish and maintain interpersonal relationships (Ghorbanibirgani et al., 2016; Teichgräber et al., 2021).

Participants described their individual coping strategies to deal with burden of eczema. In present study, self-management or coping strategies were found to vary according to the management of consequences of atopic eczema in different domains. Participants reported active and avoidant coping strategies when it comes to managing the physical symptoms of atopic eczema. Physical symptoms of eczema reported by participants in the present study were intense itching that was severe at night, small bumps that may leak fluid and crust over when scratched, skin burn and red to brownish-grey patches. Participants also reported recovery of physical health related symptoms and improvement in their eczema condition if they adhered to treatment, protected themselves from dust, applied moisturizers and applied home remedies to reduce itching pain (aleo vera gel and ice cubes) as active coping whereas, avoidant coping included distracting the attention from itching and trying to indulge themselves in other activities. These findings are supported by previous studies (Amer et al., 2017; Cowdell, 2018; Mollerup et al., 2013; Sugimoto et al., 2007).

Religious coping was also reported as an important theme. Two participants reported that having faith and prayer helped them in remaining grateful despite their suffering. Previous research showed that religiosity correlates with lower suicide risk and improved psychological well-being and increased perception of social support (Howells et al., 2020; Magin et al., 2009; Siegels et al., 2021). Furthermore, three participants didn’t report the use of religious coping. Moreover, participants reported positive support from parents, friends and health care professionals (dermatologists) which helped them to adapt to eczema and to cope with emotional burden of atopic eczema. Higher social support may have beneficial effects on adaptation to life with atopic eczema (Konrad et al., 2012). This finding is supported by previous studies (Amer et al., 2017; Cowdell, 2018; Mollerup et al., 2013; Sugimoto et al., 2007).

Conclusion

It can be concluded that social quality of life of eczema patients is negatively affected by stigmatization, social rejection, negative social comparisons and negative self-image. Participants reported avoidant coping strategy (social isolation) to manage social impact of atopic eczema. Participants also reported positive perceptions about recovery because of their adoption of active coping to manage physical symptoms of atopic eczema. Moreover, it indicated that religious coping and support from parents; friends and health care professionals play a positive role in reducing emotional burden of this skin condition.

Limitations

The strength of this study was the qualitative exploration of the quality of life of women living with eczema and coping strategies used by them in Pakistani context. There is lack of qualitative research on atopic eczema in Pakistan as per researcher’s knowledge. However, limitation of this study is participants’ hesitation to disclose some distressing experiences during interviews, which was sometimes associated with their severe discomfort. Another limitation of this study is that only women were included in current study.

Implications

The findings of current study are helpful for health care providers and dermatologists. They should provide proper education and awareness about symptoms and cure of eczema which can reduce psychological distress. The findings of current can also guide psychologists about how to improve the quality of life of eczema patients. Moreover, this study is also potentially beneficial for young women who are living with eczema, because it has identified coping mechanisms to manage the physical and psychosocial aspects of atopic eczema. The results of the present qualitative study can be used as a foundation for further research to explore psychosocial issues of eczema in men and in other age groups.

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