

A Qualitative Study on Understanding Psoriasis: Patient's perspective

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Abstracts: This case study was conducted to explore the experiences and personal perspective of psoriasis patients in Pakistan, since there are significant risks of such patients facing psychological problems that remain unaddressed and undocumented. It enables us to focus on quality of life and management with psoriasis for males and females during the time of Covid – 19, as they face adverse physical repercussions in the form of flare-ups due to mental breakdowns or high anxiety levels because of the pandemic. Individuals were approached for interviews, live and through social media for a period of 2 months from January 2021 till February 2021. The data collection method used was in-depth interviews from volunteer participants who were selected through screening questions given prior to interviews. From all the volunteers five were selected and interviewed, from which three participants were taken, one as a pilot study and the other two for the main study within the same age group. The interviews were then analyzed through thematic analysis. Five main themes were deduced from the participant's interviews; fear of stigmatization, quality of life, psychological challenges and impact, relationship paradox and self-management. The results indicated that fear of stigmatization was felt due to psoriasis for the male and female participant. Likewise, quality of life was affected and altered and psychological challenges were faced. However, it was seen that there was a slight gender difference in relationships with others, as it was established that the female flare up levels decreased in comparison to the male due to the level of relationship with family, friends and the society. It was also seen that the amount of learning, confidence and overall self-management increased with the passage of time and the participants developed their own patterns of coping. Thus, even though negative coping is a real possibility, the area of resilience is still an untapped research possibility that can be further studied

Keywords: Psoriasis, Self-Management, Coping Mechanisms, Stigmatization, Physical Repercussions

INTRODUCTION

Chronic diseases have always had lasting dampening effects on people whether it is physical or psychological and these effects have been acknowledged and researched thoroughly worldwide. Psoriasis is one such chronic inflammatory skin disease which when active forms lesions or plaque in patches around certain areas of the body. The skin may become red and inflamed causing itchy bumps or it may dry up and form scaly patches that itch excessively. Psoriasis is an autoimmune disease that causes the body to fight against its own body cells so the T cells become active and attack skin cells causing the immune system to respond and create inflammation. This inflammation causes plaque around the injured/scratched skin (Gardner, 2019).

During the recent outbreak of the novel pandemic known as Covid 19, there has been a country-wide lockdown that started around March 2020 and continued for two months. This was eased in the middle of May for all those individuals under the poverty line who needed to work. There have been

multiple physical repercussions for all the individuals affected by Covid. The entire physical and psychological framework was disrupted.

However, it has also taken a toll on the mental health of affected and non-affected individuals throughout not only the country but also the world. This study was thus conducted and focused on psoriasis patients in Pakistan because they have had time to ponder and postulate their life and its struggle, they may even face physical repercussions in the form of flare-ups due to mental breakdowns or high anxiety levels because of Covid. In this time of psychological vulnerability, all those already facing chronic disease have shown signs of aggravated symptoms during Covid 19's lockdown. Thus the experiences of psoriasis patients are to be explored and determined.

In a study, it was concluded that there are significant risks of psoriasis patients experiencing psychological problems such as poor self-esteem, anger and frustration, anxiety, helplessness and depression along with experiencing the physical complaints of severe itching, irritation, and pain (Heller et al, 2012). Similarly, it was found in a study documenting the mental health outcomes among the asthma patients in Pakistan, that maladaptive strategies of cognitive emotion regulation had a higher relationship with psychological distress (Hussain, Khawar, Amin, Hamdani, Majeed, 2023), indicating that certain diseases cause severe psychological problems among those who are suffering.

This new critical condition in our country intensified the psychological distress crisis. It was seen that every three out of four (75%) adults were suffering from high stress and anxiety levels determined in a study conducted by Aga Khan University. Some of the symptoms of psychological distress included stress, anger, low mood, irritability, insomnia, emotional exhaustion, and depression (Jamal, 2020).

It has been seen that no viable study for psoriasis has been conducted in Pakistan during Covid 19. It has also been determined that there is very few literature studies conducted on the experiences of psoriasis patients. The only study that was conducted was in 2015 (Khawaja et al, 2015).

Thus two objectives were to be studied:

- To explore the difference in experiences of psoriasis patients (with flare-ups) during Covid 19 in Pakistan
- To explore the individual's quality of life and their ways of managing psoriasis

METHOD

The research design chosen is a case study as it is a bounded system that allows in-depth understanding and multi-dimensional exploration of complex issues in real life. A case study is used to explore, explain and describe events in an everyday context (Creswell, 1998).

Participant

Purposive sampling was used as a sampling strategy as the nature of the research being conducted was a case study, thus specific individuals were sought out (Ishak & Bakar, 2014). The individuals were approached online for the purpose of conducting interviews with the help of an interview guide made and approved by the supervisor. A total of 5 interviews were taken, 4 of which were conducted online. Only one female participant agreed to meet live for the interview. It was decided to send each individual a document online which contained the demographic sheet and screening questions which were all closed-ended questions. The female participant was given the demographic and screening document live as she was keen to fill it during the meeting. The individuals who filled the criteria were chosen to participate in the interview from which three of the interviews were taken for analysis. The sample of this study that were analyzed, comprised of two patients, ages 24 and 23 who were diagnosed with psoriasis around the ages 16 and 18 and they also confirmed to have had episodes of flare-ups.

Measures

Demographic information sheet

A demographic sheet was made and provided to all the individuals interested. The sheet entailed closed-ended questions to determine the bio data and other important information of the participant.

Basic screening questions

The screening questions were made to discern which individuals fell into the category of the exclusion criteria made for this research study. These were closed-ended questions to ascertain if the volunteers for participation should give the interview. The screening questions entailed a yes or no category of questions on flare-ups, symptoms and medical-related emergencies along with a diagram so that participants could mark where they experience psoriasis on their bodies to determine the extent of

flare-up levels.

Semi-structured interviews

Once the participants were chosen, they were called for interviews. Interviews were conducted to get detailed insight into the experiences of individuals according to the research study in question. As case study research was used, the required mode to attain data from the participant was in-depth interviews so that the psoriasis patients could elaborate their lives on how they lived and managed with psoriasis (Creswell, 1998).

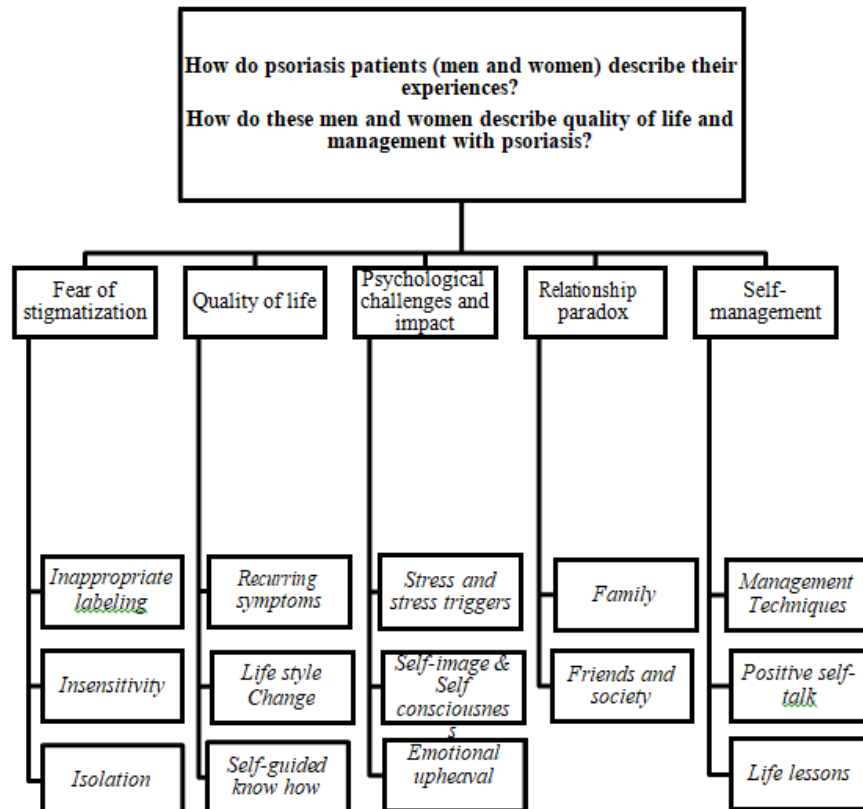
Procedure

For the interviews, the Female candidate was taken first as she responded to the message and wanted to be a part of the study. It was decided that the meeting be held in a public place that isn't crowded, thus the interview was to be conducted early in the morning at a restaurant. The participant arrived and filled out the document which included the informed consent, the demographic sheet and the screening questions. Once that was filled the participant was asked if she needed to ask any question, then after establishing rapport the interview began. The interview was recorded and all nonverbal gestures were noted. The interview lasted 35 minutes and once it was over the participant was asked for feedback and thanked for being a volunteer in the research study.

The male participant also volunteered through a Facebook group and was willing to give an online interview. He was given the form prior to the interview and before it started, he was told to ask if anything was confusing regarding the consent form or the study. Rapport was built, and the interview was recorded but no visual data was collected as the participant stated that he had limited internet data and wanted to conduct the study with clear communication. The participant was thus analyzed using verbal gestures such as the pitch of tone and pauses between sentences. This interview lasted for 31 minutes and then the participant was thanked and also asked for feedback to conclude the interview.

RESULTS

The study indicated five major themes and there assorted subthemes on which the results of the cases were made.



The first theme fear of stigmatization was further divided into three subthemes: isolation, insensitivity and inappropriate labeling. It was seen that according to this theme the participants preferred to be alone rather than among other people to safeguard themselves from being ostracized. The participants further felt as if they were being judged on appearances and needed to try to hide their uncovered areas of the body. Insensitivity: lack of empathy, was always gone unnoticed by people as stated by the participants. It was also determined that they were faced with being labeled by individuals they interacted with daily, due to the nature and expression of this skin disease.

This second theme was extracted from the data coded, which is quality of life, and its subthemes consist of recurring symptoms, self-guided know how and lifestyle change. The participants stated that the discomfort from physical symptoms caused issues in daily life and according to prior studies it was reported that significant symptoms including itching, stinging or burning, pain, and flaky skin effect people's daily activities. It has been seen that according to bio psychosocial approach there is a link between the mind and skin and that there is a high prevalence of psychiatric disorders among skin disease patients. High psychiatric morbidity has been proven to be associated with emotional suffering and lower quality of life (Picardi, & Pasquini, 2007). This indicates that there is indeed a psychological impact of itching, pain and other physical symptoms for people with psoriasis (Globe, Bayliss Harrison, 2009). Thus, the physical nature of psoriasis symptoms has been proven to affect psoriasis patients negatively. It was also seen that self-study is normal when individuals are new to diseases due to the uncertainty and uncharted terrain they enter after experiencing symptoms.

Researches on qualitative studies support that patients expect and require more information on psoriasis than they are given (Bardazzi, 2014). According to monitoring and blunting theory individuals use cognitive processes to reduce impact of stressful stimuli. Mechanism of blunting such as distraction, reconstruction etc are used to help reduce stressors affects. (Cohen, & Lazarus, 1979). This theory accurately depicts how the participants have slowly changed and reconstructed some of their thoughts to cope. Thus life style change and acceptance is the result of coping strategies that patients adapt to with the experiences that are associated with psoriasis.

The third theme; psychological impact was deduced by the codes analyzed. The following subthemes were deduced; stress and stress triggers, self-image and self-consciousness and emotional upheaval. There were lower levels of anxiety overall in the male participant as he did not perceive stress as a cause, even though his flare up levels were higher than the female participant. In another study, patients with psoriasis, those with severe itch had markedly higher scores in anxiety (stress) and depression (Remröd, Sjöström & Svensson, 2015). This indicates that not only does stress increase levels of flare ups but psoriasis itself is a means for increase in stress levels.

It was also seen that the social stigma associated with the disease creates low self-esteem and eventually poor psychosocial adjustment in patients (Kimball et al, 2008). This indicates that stigmatization also decreases self-esteem and is a factor which may lead to poorer psychosocial adjustments in the participants. By using the social comparison theory it can be inferred that individuals find other peoples opinion to be highly informative thus they use those opinions and view themselves accordingly (Festinger, 1954).

This explains why the participant's self-image and self-esteem decreased when they interacted with people as they held other people's opinion to a high standard and also why one participant even in seclusion kept thinking about himself in the negative context. Due to psoriasis being a skin disease, it can predispose patients to psychological issues such as hostility during a flare up (Korman, Zhao, Pike, Roberts, & Sullivan, 2015). This was also the case for the participants who showed signs of anger and frustration due to their disease.

The participants were also more prone to feelings of hopelessness and seclusion due to the nature of their disease and their flare ups which elevated their symptoms further.

This next theme is relationship paradox which has the following subthemes: family, friends and society. It was seen that not only are the psoriasis patients affected by their support system but the support system itself was facing difficulty. In a study that was conducted to determine caregiver stigma, it was found that people taking care of psoriasis patients experienced high levels of stigma which led to higher caregiver burden (Grover et al, 2021). So accordingly, the families of the participants were also facing problems as stated by the participants. It was also seen that according to the level of social support, the participants began to manage their symptoms over time. If we differentiate between both relationships of the participants we can use the relational regulation theory which states that it is more beneficial when individuals have meaningful conversations and do activities of interest together, this is better than conversations on how to cope with stress (Lakey, & Orehek, 2011).

Thus, this confirms that the female participant who spent time with their family was better in managing her symptoms and had less flare ups as compared to the male participant who experienced a lack of warmth.

One theoretical standpoint explains this using the direct effects hypothesis which states that

individuals with high level of social support have better health than individuals with lower social support regardless of stress (Thoits, 1985). According to this theoretical postulation the participants flare up levels do differ on account of the different social support levels received by both; one participant's psoriasis (with family support) being localized to certain regions while the other participant's psoriasis (with less family support) having flare ups all over the body.

The last theme was self-management of the participants, and three further categories of subthemes were deduced; management techniques, positive self-talk and life lessons. According to the participants, they had wide and contrasting management strategies. One study stated that topical treatment is seen to be better than biologic as it is available, less costly, less safety issues and gives the patients the satisfaction of being able to control their disease without expensive therapies and treatments (Segaert et al, 2020). Thus, it can be deduced that usage of topical medication gave a sense of control to the participant that used them frequently.

DISCUSSION

A study conducted on a hundred patients with psoriasis suggested that stigma under the belief that patients' social communication was distrusted led the patients to be isolated (Reich, Welz-Kubiak & Rams, 2014). It was stated in prior studies that the lack of education in the population generally is a factor that causes rejection by the society (Halioua et al., 2016). It was also noted that the position of lesions on the body have an impact and there are negative effects on a sense of stigmatization due to lesion visibility.

Furthermore, it is seen that many psoriasis patients do not accept their body image and self-stigmatize especially if others perceive them in a similar way (Kent & Keohane, 2001). Prior studies have shown that people around psoriasis patients tend to be inattentive and rejecting due to the change in nature of skin thus resulting in fear of being contagious (Bohm et al., 2013)

Wiener's attributional theory may be used to explain this phenomenon. It stated that the more a person is evaluated and held responsible for their condition, the higher the reactions of rejection, hostility and anger (Weiner, 1993).

The general adaptation theory can also help to explain how stress can occur as a reactionary emotion to flare ups. It talks about stress as a dependent variable and through the three stages of alarm resistance and exhaustion; it can come and go depending on the aversive situation or stimuli. However in the case of prolonged or severe stress, there may be physiological complications (Selye, 1956). Thus it adds on the factor that stress if prolonged can heighten and intensify psoriasis symptoms.

The participants were also more prone to feelings of hopelessness and seclusion due to the nature of their disease and their flare ups which alleviated their symptoms even more. It was also seen in another study that hopelessness has been found to have a stronger affect in psoriasis patients (Bewley, Burrage, Ersser, Hansen & Ward, 2014). The hopelessness theory of depression can be used to explain hopelessness. According to Schneider et al. (2012) it states that depressive symptoms occur when an already vulnerable individual experiences negative circumstances. The vulnerable person when stating the negative events as consistent their entire lives are determined to be using the pessimistic explanatory style. Thus according to this theory people with psoriasis who are already vulnerable when faced with a flare up go into hopelessness and may even be afflicted with some depressive symptoms as seen in the participants.

It was seen in a study that three variables that determined social anxiety were disease severity, feeling of inadequacy and patient's degree of perception of social support (Schneider, Heuft, & Hockmann, 2013). Thus this supports that the participants felt the need to seclude themselves as they perceived minimum support from their friends due to bad experiences on occasion. A vast body of research also indicates that social support is a form of protection for the psychological and physical wellbeing of individuals (Cohen, Underwood & Gottlieb, 2000; Picardi et al, 2005). This was seen in the case for one participant who relied on a few people who he trusted to help out when he would be in need. Self – consciousness and social anxiety is mostly developed among individuals suffering with certain illness, as it was also found in a study that students with social interaction anxiety also require the support of adults and support group therapy (Maqsood, Majeed, Anwar, 2019).

One theoretical standpoint explains this using the direct effects hypothesis which states that individuals with high level of social support have better health than individuals with lower social support regardless of stress (Thoits, 1985). According to this theoretical postulation the participants flare up levels do differ on account of the different social support levels received by both, one participant's psoriasis (with family support) being localized to certain regions and the other participant's psoriasis (with less family support) having flare ups in all of his body.

According to another study it was hypothesized and proven that distraction and diverting attention helps to decrease the itching sensation and scratching (Leibovici, Magora, Cohen & Ingber, 2009). This indicates that the distraction methods used by the participants such as going on a drive or

playing with cats helped relieve their symptoms. The participants also deduced that they have a life worth living so they must not stop thriving just because one aspect of it is affected. Schonfeld (1992) determining how self-talk is used as coping for pain and pain management, conducted a study that concluded that the patient was able to control pain, levels of depression and even limited medication for pain. This holds the potential for further research on how positive self-talk may help in coping strategies and to try to apply them.

To further elaborate, Melzack and Patric Wall (1965) proposed the gate control theory which stated that there are ‘gates’ that either block pain signals or allow them to flow. So it can be postulated that one of the factors that helps those gates to remain closed is positive self-talk. Thus it can be seen that positive self-talk does have a role in creating ease in psoriasis symptoms.

Thus it can be seen that positive self-talk does have a role in creating ease in psoriasis symptoms.

It is seen that both participants learnt to be accepting and patient with their disease and a study also promoted this idea as it concluded that patients with a severer disease load had more attention given and were looked after thus they had better acceptance of their illness (Zalewska, Miniszewska, Chodkiewicz & Narbutt, 2007). This indicates that the participants also had high levels of support and thus were able to accept and learn from their disease.

The participants felt the need to have a support group and this is also built on further by a study that determined that group therapy was helpful in coping with psoriasis and that support groups helped reduce feelings of loneliness and enhanced coping (Ginsburg, 1996).

CONCLUSION

The study discussed psoriasis patient’s experiences from their own point of view. It highlighted the effects of psoriasis on an individual’s physical and mental health and how these individuals have learned to cope with their disease. As no prior research of this nature is being conducted in Pakistan during the pandemic of Covid 19, most individuals have had time to ponder, reflect, postulate and reach a better understanding about their lives. This was also the case for psoriasis patients who had deeper understanding and ample time, that otherwise would be taken up due to work. It was concluded that psoriasis does in fact affect the quality of life of patients and there is indeed a gender difference. However it was also seen that with time the participants have learnt to cope with their disease in a multitude of ways. Thus even though negative coping is a real possibility, the area of resilience is still an untapped research possibility that can be further studied and elaborated on.

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