

## Living with Vitiligo in Crisis: A Qualitative Study of Stress and Coping during the COVID-19 Pandemic in Kashmir

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### ABSTRACT

Vitiligo is an autoimmune condition in which the immune system mistakenly attacks the cells that produce skin pigment so that people develop white patches on their skin. It is an idiopathic skin condition and one of the prominent chronic dermatoses having detrimental effect on quality of life of individuals affected with it. With the unprecedented arrival of Covid-19 pandemic, healthcare accessibility was the worst hit and individuals were no longer able to seek medical advice for getting treatment for the condition. This further exacerbated the psychological stress which plays a significant role in the onset, development and progression of Vitiligo. The objective of this study was to understand the relationship between stress and Vitiligo on the affected individuals during the Covid-19 pandemic. Interviews were conducted with individuals affected with Vitiligo in Kashmir. The paper employs a qualitative methodology to understand the relationship between stress and Vitiligo during the time of pandemic and how the affected individuals negotiated with it. Data analysis lead to the following emergent themes: (a) Escalation of negative emotions (distress) during the Covid-19 lockdown (b) Role of Teleconsultation: the new normal and (c) Role of Counselling. The findings confirm that living with Vitiligo is a constant battle. The affected individuals suffer an array of challenges and need acceptance and constant psychosocial support.

**Keywords:** *Vitiligo, Kashmir, psychosocial support, Covid-19 pandemic, stress*

Vitiligo is a chronic depigmentation condition affecting 0.5 to 2% people worldwide (Kruger & Schallreuter, 2012). It is an autoimmune condition in which the immune system mistakenly attacks the cells that produce skin pigment so that people develop white patches on their skin (Grimes, 2016; Mahajan et al., 2019). It is an idiopathic skin condition and one of the prominent chronic dermatoses having detrimental effect on quality of life of individuals affected with it (Al-Mubarak, Al-Mohanna, Al-Issa, Jabak, & Mulekar, 2011).

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Vitiligo is an exemplary case because it is frequently deforming, affects visible areas, has historically been mistaken for leprosy (and still is in many parts of the world), and is frequently misdiagnosed as a benign, purely cosmetic issue despite having a significant negative impact on people's quality of life (Teovska Mitrevska, Eleftheriadou, & Guarneri, 2012). It is an under-recognized organ-specific autoimmune disease of the skin (Van den Boorn et al., 2009). An estimated 1 to 2 million Americans are reportedly impacted by the condition (Nordlund & Lerner, 1982).

The effects of vitiligo can be mentally devastating and have a significant strain on everyday life, despite the fact that it is frequently dismissed as a cosmetic issue (Bergqvist & Ezzedine, 2020). Vitiligo has a substantial psychological impact; people typically experience shame, lack of confidence, social anxiety, loss of self-esteem, concerns with body image, decreased quality of life (QoL), and perceived stigma (Ongenae, Van Geel, De Schepper, & Naeyaert, 2005; Papadopoulos, Walker, & Anthis, 2004; Porter, Beuf, Nordlund & Lerner, 1979).

The condition has a negative impact on people's quality of life because it results in psychological stigmatisation, ostracisation and social prejudice (Juntongjin et al., 2022; Fatima, Das & Jafferany, 2020; Juntongjin, Rachawong & Nuallaong, 2018).

An estimated 1% of the world population regardless of racial groups, sex, and age are affected with vitiligo (Ezzedine et al., 2015). In Western-European countries, vitiligo is typically recognised as a cosmetic dermatological condition; but, in India, where it is also known as White Leprosy or Sweta Kustha, it is considered a serious medical condition with social stigmatisation for the affected individuals (Pahwa, Mehta, Khaitan, Sharma & Ramam, 2013). In common parlance, it is also known as Safed Dagh, Safed Kodh, Phuleri, and Savitra (Chaudhary, Manmohan & Bhanavath, 2022). Because of two factors, the term 'vitiligo' has a particular connotation to individuals from India. The darker skin of Indian patients has been depigmented, and there is a great deal of cultural stigma associated with the condition.

The unpredictable nature of its natural course places a significant strain on the individuals' quality of life (Sampogna et al., 2008). Pathogenesis is complex and poorly understood. As a result, in some cultures, those who have vitiligo are sometimes held responsible for the condition and incurring the disease (Borimnejad, Yekta & Nasrabadi, 2006). The psychological distress of those who are impacted by the condition is also exacerbated by misconceptions regarding the condition, its causes, and its transmission (Alghamdi et al., 2012).

### ***Covid-19 and Vitiligo***

The Corona virus pandemic affected all the sections of the population. Throughout the globe, it had an immense catastrophic impact on the lives of people. The mental health of people was severely affected by the pandemic. It brought along significant psychological issues, such as elevated stress levels, depression, post-traumatic stress disorder, and insomnia, in almost all sections of population. Individuals with vitiligo already had an impaired quality of life and the epidemic made it extremely difficult for them to get medical help, adding to their stress levels (Fatima, Das & Jafferany, 2020).

The pandemic affected the mental health of all sections of population, in particular the vulnerable populations. The pandemic terror, economic losses, and public health measures confining personal freedom triggered the psychiatric disorders (Pfefferbaum & North, 2020).

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People who already have psychological morbidities are at an even higher risk. The problems of individuals affected with Vitiligo were made worse by lack of access to timely follow-up care, missed prescription deadlines and disease flare-ups. With the unprecedented arrival of Covid-19 pandemic, healthcare accessibility was the worst hit and individuals affected with vitiligo were no longer able to seek medical advice for getting treatment for the condition. This further exacerbated the psychological stress which plays a significant role in the onset, development and progression of Vitiligo (Henning et al., 2020).

Thus, with all this mind, the primary objective of this paper was to understand the relationship between stress and Vitiligo on the affected individuals during the Covid-19 pandemic.

### **RESEARCH METHODOLOGY**

A qualitative study was undertaken to the relationship between stress and Vitiligo on the affected individuals during the Covid-19 pandemic and how did they negotiated with it. The analysis present in the paper uses data gathered from twenty interviews conducted with the individuals affected with vitiligo in Jammu and Kashmir. The participants included ten males and ten females. The research questions were explained to them and the interviews were conducted only after obtaining prior oral consent from the participants.

Purposive sampling was employed for the identification of the affected individuals. Owing to the sensitive nature of the topic and the stigma attached with it, it was quite difficult to get their consent to conduct the interview. The researchers, thus, used snowball method to identify individuals affected with vitiligo as well as via friends, colleagues and acquaintances. The participants had the choice of having the interviews conducted in-person or over the phone. Prior to the interview, permission to record the conversation on audio was obtained; in some cases, it was granted; in others, they expressed hesitation. To respect their confidentiality, these interviews were recorded in written form. The semi-structured interviews centred on the stress brought on by the pandemic and how it affected those having vitiligo.

Each interview lasted for approximately an hour, or until the participant felt she had nothing left to say. The researchers took note of the individuals' nonverbal cues, including voice inflections, facial twitches, and other reactions that could not be recorded, such as crying, shaking, or rubbing their hands together in anxiousness.

#### ***Data Analysis***

Interviews with those having vitiligo served as the primary source of information, which was later organised and translated into English. To protect their privacy and anonymity, all of the participants' names that were utilised in the analysis were substituted with pseudonyms. After then, the information was thoroughly categorised with an eye toward discovering emergent themes. Axial coding was utilised to establish overarching themes (Lindlof & Taylor, 2002). Inductive analysis was used. Finally, the "keyness" of developing concepts or how well they addressed a particular study topic was evaluated.

#### ***Emerging themes***

The prominent themes which emerged from the data analysis are (1) Escalation of negative emotions (distress) during the Covid-19 lockdown (2) Role of Teleconsultation: the new normal and (3) Role of Counselling.

### **1. Escalation of negative emotions (distress) during the Covid-19 lockdown**

The participants revealed that Covid-19 lockdown escalated their mental health issues. It further deteriorated their anxiety issues as is stated by one of the participants:

*Covid-19 triggered so much anxiety in me... even thinking about it give me goose bumps... (sighs), my mental health devastated. I was going for therapies already but with the lockdown, I was just shut inside my home... I could do nothing.... (sighs)*

(25 Years, female participant)

Another participant revealed:

*I had several breakdowns during the pandemic. I had no idea that the pandemic would affect me so much. My vitiligo was flaring up.... I could not visit doctors... could not get medicines... I was insane...*

(29 years, male participant)

One of the key causes of progression of Vitiligo is said to be stress which was already escalated during the stressful pandemic. The mental health issues were triggered to a larger extent which further deteriorated the condition of the affected individuals. Thus, the covid-19 induced stress can further escalate the advancement of vitiligo as is confirmed by Rokni et al., (2021).

### **2. Role of Teleconsultation: the new normal**

The participants revealed that the Corona virus pandemic was an altogether new reality. It brought along a new normality in their lives, the emergence of Teleconsultation. One of the participants stated:

*I have survived coronavirus pandemic only through Teleconsultation. Thinking about it now, I feel like I could have died (sighs)...*

(30 years, Female participant)

Technological advancements like telemedicine provide a long-term option for meeting patients' urgent healthcare demands simply at home. It has reduced the risk of direct person-to-person exposure and established itself as a credible source for health treatments during the covid-19 pandemic as is confirmed by Saxena, Srivastava and Chandra (2022). Another participant stated:

*My vitiligo lesions had considerably reduced with the help of medication... then covid-19 happened... my life took a sharp u turn and so did my vitiligo (sighs)... it spread drastically... I could do nothing and had no idea why it happened... could not visit doctors, could not roam out... I was devastated... finally I got to know about a renowned dermatologist who was helping people like me via teleconsultation... that was the sigh of relief...*

(31 years, Female participant)

Teleconsultation proved to be a new horizon for the vulnerable individuals affected with vitiligo. It helped them and supported their healthcare in the catastrophic times of a global pandemic. The utilization of novel digital concepts during the challenging pandemic times helped save lives of people.

### **3. Role of Counselling**

The positive role played by Counselling was a common theme running through all the participants' narratives. They admitted that the only thing that kept them going during the troubling times was being able to express their emotions, with the help of virtual/ online counselling. One of the participants stated:

*I have understood the role of counselling and the immense help it provides only in times of pandemic... I could not have survived without it.*

(22 years, Female participant)

It aided them in coping with the upheaval that had been imposed on the entire population. Counselling undoubtedly played a significant part in helping people deal with the Covid-19 pandemic's effects on their mental and behavioural health.

Another participant stated:

*I think for me counselling was as important as food... Without it, I would have been completely lost. In addition, if I missed a single chance of my online counselling session, I would feel very low. It was actually helping me to live...*

(25 years, male participant)

Counselling helped in creating safer spaces for individuals affected with vitiligo so that they could prioritize their lives and live with esteem and self-worth. These individuals were already susceptible to distress and various other related mental disorders. Counselling helped them in adjusting to the new routine vis-à-vis the pandemic. It helped in addressing the new pandemic-induced mental health challenges as the only viable option in the distressing times.

## **DISCUSSION**

The present qualitative study provides an in-depth understanding of how individuals living with vitiligo in Jammu and Kashmir experienced heightened psychological distress during the COVID-19 pandemic. The findings highlight that stress is not merely a co-existing condition but a significant factor influencing both the progression and lived experience of vitiligo. The study extends existing biomedical understandings by situating vitiligo within a psychosocial and crisis-driven context.

One of the central findings the escalation of negative emotions during lockdown resonates with earlier research that identifies stress as both a trigger and exacerbating factor in vitiligo (Henning et al., 2020). However, this study adds a nuanced layer by demonstrating how pandemic-induced isolation, fear, and disruption of routine care intensified pre-existing vulnerabilities. Unlike general populations, individuals with vitiligo faced a dual burden: managing a chronic stigmatized condition alongside the uncertainty and restrictions of a global health crisis. This aligns with Pfefferbaum and North (2020), who emphasize that pandemics disproportionately affect individuals with pre-existing psychological vulnerabilities.

The study also contributes to the growing discourse on healthcare accessibility during crises. Participants' narratives clearly indicate that disrupted medical services, missed follow-ups, and lack of medication aggravated both physical symptoms and psychological distress. This finding supports previous observations that continuity of care is crucial in managing chronic dermatological conditions. Importantly, the study highlights how the absence of in-person

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consultations was not merely a logistical issue but a source of emotional insecurity and helplessness.

A significant contribution of this research lies in its exploration of teleconsultation as an adaptive coping mechanism. While existing literature acknowledges the rise of telemedicine during COVID-19 (Saxena et al., 2022), this study demonstrates its particular relevance for stigmatized conditions like vitiligo. Teleconsultation not only ensured continuity of care but also reduced the anxiety associated with physical visibility and social judgment. Thus, it functioned as both a medical and psychosocial intervention, marking a shift toward more inclusive and accessible healthcare practices.

Another critical theme emerging from the study is the transformative role of counselling. Participants consistently emphasized counselling as essential for emotional survival during the pandemic. This finding reinforces earlier studies that underline the importance of psychological interventions in dermatological conditions (Papadopoulos et al., 2004). However, this study advances the discourse by showing that counselling, particularly in virtual formats, created safe emotional spaces where individuals could process stigma, fear, and uncertainty. It highlights the need to integrate mental health services into routine dermatological care, especially for conditions with visible manifestations.

Furthermore, the study underscores the intersection of stigma and cultural context. In the Indian and Kashmiri context, where vitiligo is often misunderstood and associated with social stigma, the psychological burden is intensified. The pandemic further limited social interaction, which paradoxically both reduced immediate exposure to stigma and deepened feelings of isolation. This duality reflects the complex ways in which social environments shape illness experiences.

From a social work perspective, the findings emphasize the urgent need for holistic and interdisciplinary interventions. Addressing vitiligo cannot be limited to dermatological treatment alone; it requires integrating psychosocial support, community awareness programs, and accessible digital healthcare services. Social workers can play a crucial role in advocacy, counselling, and bridging gaps between patients and healthcare systems, particularly in resource-constrained and geographically challenging regions like Kashmir.

In conclusion, this study contributes to the limited qualitative literature on vitiligo by foregrounding lived experiences during an unprecedented global crisis. It demonstrates that stress, healthcare disruption, and stigma are deeply interconnected, and that adaptive mechanisms such as teleconsultation and counselling can significantly mitigate these challenges. The findings call for a reorientation of healthcare systems toward more patient-centered, inclusive, and psychosocially informed approaches in managing chronic conditions like vitiligo.

### **CONCLUSION**

The findings confirm that living with Vitiligo is a constant battle. The affected individuals suffer an array of challenges and need acceptance and constant psychosocial support. These individuals have, since times immemorial, been subjected to societal disdain and condescension. They are even socially ostracised and bullied. Vitiligo lesions become the source of their pain and distress. Their lives are complicated by a wide range of concerns and problems caused by the difference in appearance.

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The already dire situation of individuals affected with vitiligo was made worse by the awful catastrophe of the corona virus outbreak. The pandemic increased the susceptibility of the affected individuals who are already at risk to stress and mental health difficulties. The problems of individuals affected with Vitiligo were made worse by lack of access to timely availability of medicines, follow-up care, missed prescription deadlines and flare-ups associated with condition. Those who were affected by the condition experienced worsening mental health problems as a result of the pandemic. Lack of communication or an outlet for their emotions coupled with the panic atmosphere created by the coronavirus pandemic, sparked mental health problems that made their situation worse.

The corona virus mayhem also brought along the emergence of new normalities. It comprised of Teleconsultation and virtual counselling provided by medical health professionals. These frontline workers saved lives of individuals by helping them cope with the adverse unprecedented situation and living altogether new realities. The unfavourable pandemic-induced lockdown was made more manageable for individuals with the condition attributable to the teleconsultation, audio, and video counselling sessions.

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