

## The Psychosocial impact of Vitiligo on children.

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### Abstract

*Vitiligo has a special significance in children, adding to their psychological distress during the formative years. Skin illnesses can have a negative impact on ones self-esteem and social interactions, especially during the vulnerable childhood years. Since vitiligo typically affects exposed body regions, the presence of such lesions might cause severe psychological distress in children. An enormous stigma is associated with the disease in the Kashmiri culture. The aim of the current study is to understand the beliefs about causation and the psychosocial impact associated with the disease, particularly on children, in Kashmir. Semi-structured interviews were conducted with children affected with the condition. Purposive sampling was employed to identify the participants. Each interview was recorded and transcripts were analyzed to identify significant issues and concerns. Participants had a wide range of concerns regarding their disease such as physical appearance, progression of white patches onto exposed skin and the whole body, psychosocial trauma, social restriction, stigmatization and ostracisation.*

**Key words:** *Children, self-esteem, psychosocial impact, qualitative, vitiligo*

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## **Introduction**

Vitiligo is an acquired pigmentary disorder of the skin. The disorder is said to have affected 1 to 2 million Americans (Nordlund & Lerner, 1982). It is the most common depigmenting disorder, affecting about 0.5 percent of the world's population. Over half of the individuals affected with the condition acquire it before they reach the age of 20. There are no obvious differences in frequencies of occurrence according to skin type or race, and both sexes are equally afflicted (Taieb & Picardo, 2009).

Vitiligo represents an emblematic case, this is to say that it is often disfiguring and occurs in visible areas, and has been confused with leprosy in the past (and, in many parts of the world, still is), and it is often misdiagnosed as a harmless, purely cosmetic problem, but it has a significant impact on people's quality of life (Teovska Mitrevska, Eleftheriadou, & Guarneri, 2012).

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 (Grimes, 2016). The disease has a global occurrence. It is an acquired dyschromia of the skin in which there is a loss of epidermal melanocytes. It has a peak onset at 10-30 years with a beginning in childhood or young adulthood (Halder, & Chappell, 2009). As vitiligo frequently involves the exposed parts of the body, the presence of such lesions can lead to significant psychological trauma to the affected children (Al-Mutairi, Kumar Sharma, Al-Sheltawy, & Nour-Eldin, 2005).

Vitiligo as a condition is seen with utmost condescension regarding how it is caused and the alteration in the appearances marked with the skin condition. It is often associated with disdain and stigmatisation of those affected with the condition. This prospective study was thus, carried out to understand the beliefs about causation and the psychosocial impact associated with the disease, particularly of childhood vitiligo, in Kashmir, since there are scarce studies on this subject in Kashmir.

## **Childhood Vitiligo**

Vitiligo affects people all throughout the world, and references to the disorder and various parts of its causes and treatment have been found in published literature since time immemorial (Sehgal & Srivastava, 2007). As an autoimmune pigmentation condition, Vitiligo is marked by white patches on skin caused by the loss of melanocytes in a selective manner. The disease can strike anyone at any age, from childhood to old life (Homan, 2012). In around half of the instances, the condition begins before the age of 20, and in a quarter of the cases, the disease begins before the age of 14 (Handa & Dogra, 2003).

A child's health-related quality of life (HRQL) might be hampered by a chronic disease when they are young (Homan, De Korte, Grootenhuis, Bos, Sprangers, & Der Veen, 2008). A

condition like Vitiligo has a negative psychological impact on those who suffer from it, particularly children, and causes them to underachieve (Hu, Liu, Ma, Yang, & Zhang, 2006), in particular due to the nature of the condition affecting the visible parts of the body and altering appearances. Adolescence, especially, is marked by fast psychological and social development, as well as emotional susceptibility and acquiring a skin condition like Vitiligo, during this period of human development, impacts the overall development of children affected with it.

Negative childhood experiences can impact adult development (Haavet, Straand, Saugstad, & Grünfeld, 2004). Depending on the location and intensity of the disease, the child's age, and his or her particular capacities and social milieu, the visibility of vitiligo may trigger such experiences (Hill-Beuf & Porter, 1984). In young adults with vitiligo, negative childhood experiences of vitiligo are associated with social development issues and HRQL impairment (Homan, 2012).

## **Literature Review**

About 0.5 percent of the world's population suffers from the most prevalent depigmenting illness, vitiligo. More than half of individuals with Vitiligo experience symptoms before age 20. Both sexes are equally affected, and there are no noticeable changes in the incidence frequencies according to race or skin tone (Taeb & Picardo, 2009). 0.1 to 8% of the world's population, regardless of age, race, religion, culture, or gender, are affected by this ailment, which is the most prevalent skin pigmentation disorder (Kruger & Schallreuter, 2015). Vitiligo has been proven to impair Quality of Life in studies utilizing tools that evaluate health-related quality of life (QOL), such as the dermatological life quality index (DLQI) (Ongenaes, Geel, Schepper, & Naeyaert, 2005).

Although vitiligo is not a life-threatening condition, it has a severe psychological influence on quality of life of persons affecting with it (Homan 2012). The condition worsens when it affects sun-exposed regions of the body such as the face, neck, back, and hands. Because of the higher contrast of white spots on their skin, the negative impact is considerably severe for people with darker skin types (Yaghoobi et al., 2011). Vitiligo causes a rapid decline in the quality of life, thus, the affected individuals have to constantly deal with stress, despair, dread, anxiety, social shame, and self-consciousness (Amer & Ghao, 2016; Simons et al., 2018). Individuals with Vitiligo have lower self-esteem than the general public (Porter, Beuf, Nordlund, & Lemer, 1979).

Recently, the importance of emotional and psychological difficulties, associated with Vitiligo, has been highlighted. As a result, the skin condition could be classified as a psychosomatic condition, which means that it affects both the mind and the body.

Physical and psychological factors are both implicated in the emergence, progression, relapse, and remission of Vitiligo. Vitiligo is a major source of suffering for many individuals. As a result of their condition, a lot of people feel ashamed and embarrassed (Taieb & Picardo, 2009).

According to a study, there are more than 15 skin disorders with a global burden in 187 countries, including social integration, emotional condition, everyday life organisation, and the use of medical resources such as consultations and medications (Ahmad, 2017). Among the diseases, 'Vitiligo' is an acquired idiopathic skin condition marked by pigment loss (Al-Mubarak et al, 2011).

The situation is the same all around the world, notably in Asian countries, where getting treatment for both medium and low-income people is even more challenging. Those with Vitiligo face social, economic, emotional, and psychological prejudice not just in their family, but also in their surroundings, due to their dark skin color (Mishra et al., 2014). It is sometimes compared to leprosy, and it has a social and psychological impact on the individual's day-to-day existence (Osman et al., 2009).

Research conducted on Indian patients reveals that vitiligo affects Quality of Life (QOL), with psychiatric morbidity manifesting as anxiety, depression and sleep disturbance occurring in a significant proportion of the individuals affected with the condition (Sharma, Koranne, & Singh, 2001).

In India, the prevalence of persons with Vitiligo is higher than in other Asian countries, ranging from 0.46 percent to 8.8 percent. However, it is found in many places of the world, with rates ranging from 0.1 percent to 8%. (Kruger & Schallreuter, 2012). According to studies, countries with a large population of individuals of dark skin, such as India and Mexico, have the highest occurrence (Kostopoulou, et al., 2009; Pichaimuthu et al., 2011).

Vitiligo is generally acknowledged of as a cosmetic dermatological illness in Western-European countries; but, in India, it is known as 'Sweta Kustha' or 'White Leprosy', and is seen as a severe medical problem, with patients facing social marginalisation (Pahwa et al., 2013).

It is a serious and sensitive skin disorder that has a significant impact on patients' quality of life (QOL), with many of them feeling distressed and ostracised as a result of their condition (Al-Mubarak et al., 2011). The word 'Vitiligo' has a specific meaning in Indian patients for two reasons. The first is that Indian patients have depigmentation on their darker skin, and the second is that the condition has a huge cultural shame attached to it. People have been equating it with leprosy, and those suffering from the condition are discriminated against because they look to be different from regular people. They become the victim of hushed remarks, hostility, insults, or alienation.

In Kashmir, a hospital based study conducted in the Department Of Dermatology, STD and Leprosy of SMHS Hospital (associated teaching hospital of Government Medical College

Srinagar) by Hassan, Hussain, Keen, Hassan, & Majeed (2013) also confirm that Vitiligo is a confined idiopathic hypomelanotic skin condition marked by milky white patches of various sizes and shapes. Locally, the disease is known by different names, in local parlance it is known by terms like '*bizin*', '*chacxhir*', '*dadir*', '*hathir*', and '*badre*' but most of the people agree on '*hathir*' and '*badre*'. It is seen with utmost contempt and disapproval and the individuals suffering with the condition are often marginalized. There are a number of myths associated with the condition. Ironically, a majority of the people believe these stories that have no scientific background and thereby, further add to the psychological trauma these individuals face.

## **Methodology**

It is an exploratory kind of research and thus, a qualitative research method was chosen as it enables the researchers to understand the issues of this part of the population i.e., the children affected with Vitiligo (Creswell, 2008). The researchers conducted interviews with the children affected with the skin condition. The research questions were explained to them and the interviews were conducted only after obtaining prior oral consent from the participants. Permission to audiotape the conversation was requested prior to interview which was granted in some cases and in some cases they showed reluctance and thus respecting their confidentiality such interviews were only recorded in written form.

The interviews were conducted either in the homes of these children or telephonically. Purposive sampling was employed to identify the children. It was quite a task to find children who are ready to speak about Vitiligo owing to the stigma and taboo attached with the condition. We were able to find out the participants mainly through acquaintances and then through snowball technique. Initially the participants showed reticence but after understanding the research objectives and the kind of questions they need to answer they were relaxed and more comfortable. The objectives of the paper were to understand:

- i. The beliefs related to causation of the disorder.
- ii. The psychosocial impact of Vitiligo on the affected children.

## **Sampling**

The sampling of participants in this study is purposive. The researchers conducted interviews of children affected with Vitiligo belonging to the district Anantnag. The reason for choosing the district was the geographical proximity which enabled the researchers to conduct interviews through acquaintances and others through snowballing, who were the residents of the aforementioned district. The findings, thus presented here, pertain only to the sample and are not representative of the larger population.

## **Data Analysis**

Data analysis is the most crucial part of any research. Data analysis summarizes collected data. It involves the interpretation of data gathered through the use of analytical and logical reasoning to determine patterns, relationships or trends (Creswell & Clark, 2007). In this study, primary data was collected by interviewing the children affected with Vitiligo, which was then translated into English by the researchers. The names of all the participants were substituted with pseudonyms, keeping in view the sensitivity of the issue and confidentiality of the participants. The transcript was read, keywords were highlighted, themes were determined based on these keywords and data was analyzed till no new theme further generated. Data analysis was inductive and focused on identifying emerging themes.

## **Emerging themes**

Following are the themes which emerged from the interviews conducted by the researchers:

### **➤ Traumatic Experience**

The quality of life is affected both socially as well as psychologically as a result of Vitiligo. Children are unaware of their condition but the societal misbehavior and condescension affects their psychosocial well-being. These children have to face criticism and discrimination from the very beginning which leaves indelible imprints on their psyche. Since the disorder mostly affects the exposed parts of the body, it becomes a cause of lack of self-esteem and low self-confidence as well as a source of humiliation and embarrassment. One of the participants, Mohsin (name changed) stated:

*I had no idea of my skin condition...as time passed by, my friends and classmates started making fun of my skin and laugh about it.... I started hating my body...*

Ahmed et al (2016) confirms that the presence of white patches of Vitiligo on the exposed regions of the skin, in particular, often becomes a cause of shame and embarrassment for the affected individuals. The presence of Vitiligo patches often hinders their normality of daily lives and adds to it an array of distressing and traumatic experiences. They feel disgusted and less confident as a result of people's gaping expressions.

### ➤ **Stigmatization and Social Ostracisation**

Vitiligo is a social taboo in Indian society and the same exists in Kashmir also. Persons with Vitiligo are often socially restricted, stigmatized and even ostracized. They often become the victims of hushed silences, awkward questions, derogatory remarks and are constantly bullied. The children suffering from Vitiligo, too, become the victims of this societal norm. They are harassed, made fun of and even not talked to. This has far reaching implications on their overall well-being. Arfat (name changed) stated:

*I starting losing friends initially due to Vitiligo as their parents had the notion that they will also get infected, if they touch me, sit beside me, or even talk to me...(sighs), I stopped leaving the house....I am fed up of the surprising looks, constant gazing and contemptely behavior....(sighs)*

Body shaming due to Vitiligo leaves unforgettable impressions on the child's minds. The best of the childhood years are lost to societal discrimination and disdain. Their condition is often treated with awkwardness and pathetic looks. They are a constant victim of disdain and derision.

Another participant, Umair (name changed) stated:

*I first thought it is sun burn but later it turned out to be Vitiligo.... My own friends ghosted me after that, some even laughed about it saying that I resemble cow (sighs)...*

The uneven tone of the skin often becomes the source of indirect abuse as is reported by Khan (2018) and often renders the person suffering with it in deep pain and loneliness. The children are stigmatized and bullied because of a condition they are not responsible for. They are judged only based on how they look, which becomes their identity.

### ➤ **Ignorance about the disease and associated myths**

The lack of knowledge about Vitiligo was also a theme constantly talked about in the interviews by the participants. Without proper awareness about the facts associated with the disease, society ignorantly has linked numerous myths with the disease and this further aggravates the problems of the individuals suffering from Vitiligo. Anam (name changed) said:

*With the onset of Vitiligo people started their own prognosis and diagnosis... my relatives used to keep distance thinking that I have leprosy, some said skin cancer and what not... the myths are countless...and people have the audacity to say it to your face...*

These kinds of comments cause psychological anguish, low self-esteem, and a multitude of other problems. The individuals suffering from the skin condition have to face it on a daily basis.

Another participant, Aqib (name changed) stated:

*My classmates and friends started ghosting me because their parents told them I am mentally disabled due to vitiligo.... (sighs)... some even advised them not to look at me, as it is contagious and one can get affected, even by just looking at the person....*

Another participant, Iram (name changed) revealed:

*People lack the basic knowledge about Vitiligo...I went to a wedding ceremony and nobody was ready to eat with me... (sighs).... It could not get worse...*

The lack of knowledge and ignorance further aggravates the problems these children face and same has been confirmed by Patel (2020). Making a skin issue the reason for embarrassing and shaming a person is tragic and pathetic, and these children are subjected to this insensitive treatment for the rest of their lives. That's also without any of their own fault. Societal ignorance paves way for their life-long distress and exaggerates their trauma.

## **Conclusion**

Children suffering with Vitiligo constitute a vulnerable group largely invisible and often, the victims of gawking looks and constant bullying. They are often stigmatized and psychologically traumatized, while enduring numerous issues pertaining to their skin condition. These children often stay indoors and live their lives in a forlorn manner. There exists a substantial gap in literature vis-à-vis research highlighting the social realities they face in their daily lives. Though clinical and medical research has been conducted on the individuals suffering from Vitiligo, yet the psychosocial context is clearly missing.

These children are susceptible to societal disdain and insensitivity. There is an utmost need to generate awareness about this skin condition, sensitize the general masses about it, and bust out the ignorant myths related to Vitiligo. The children with Vitiligo need not to be isolated and forced to live secluded lives. They, too, have the right to enjoy their childhood to the best extent possible, which can be accomplished by treating them in the same manner as other children.

Various studies have shown that negative childhood events are strongly linked to common adolescent disorders. This is true for both chronic and episodic illnesses, as well as physical and mental ailments (Haavet, Straand, Saugstad, & Grünfeld, 2004). The exposure to negative events during childhood paves way for future illnesses and issues.

Having said that, there is a significant need to understand that Vitiligo is a skin condition and those suffering from it are not untouchables and need to be treated at par normally with other children and not stigmatized. There is a critical need to raise widespread knowledge about Vitiligo and its related aspects among the general public in order to avoid making these children's formative years something that will haunt them for the rest of their lives and a cause of trauma for them.



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