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Lived experiences of stigma among elderly former leper patients in Kashmir, India

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Abstract

This study examines how elderly former leper patients make sense of stigma even after being completely cured. The present study was conducted at leper colony known as Bahrar at Srinagar district of Jammu and Kashmir, India. Literature indicates the presence of stigma associated with a person affected by leprosy but least scholarship is available to establish the relationship between stigma and the leprosy among the cured patients. Thus, this study was to identify the lived experiences of those elderly former leper patients in the context of socio-cultural perspectives. The participants were selected purposively to take part in the study after their consent was received. A total of 10 participants participated in the study. This study adopted interpretative phenomenology to address the lived experiences of living with stigma. From the analysis of the data, two themes were emerged that manifest the stigma present even after being cured which include 1) living a life of untouchables, and 2) the outcast children. The themes that emerged from the data reflects how stigma is deeply rooted in the culture and how institutional discrimination is also one of the reasons that stigma is still prevalent among the former patients.

Keywords: culture, elderly, Kashmir, leprosy, stigma

Introduction

Leprosy, or Hansen's disease (HD), is an ancient bacterial disease that, although treatable, continues to be a severe health concern in many areas of the world. HD is brought on by infection with the bacterium Mycobacterium leprae, which causes a chronic infection in people that mostly affects the skin and peripheral nerves but can also damage the eyes, mucous membranes, bones, and testes. This infection leads in a variety of clinical phenotypes (White & Franco-Paredes, 2015) [34]. Despite the fact that leprosy has been curable since 1940, societies all across the world have long forced afflicted individuals into isolation facilities known as "leper colonies," forcing them to a life of misery. The deformities and disabilities caused by HD, as well as the religious and social connotations attached to the disease or any potential physical changes, have produced and continue to produce stigmatising attitudes and unfavourable beliefs about people with the disease in many regions of the world. Another significant issue that has received little global attention is the provision of services for HD patients (and their families) who reside in communities created as a result of societal stigma or forced isolation. This is because it is not thought to be a significant issue in terms of controlling the disease. Even though HD is now mostly treated as an outpatient condition, there are still many healed individuals who reside in towns, villages, or "colonies" made up primarily of fellow HD sufferers and, frequently, their families. Because of the shame and chronic impairment they have encountered (or fear encountering) outside of these communities, many former patients still reside there. In 1943, Guy Faget, working at Carville Hospital in Louisiana, revealed that sulfone medicines were successful in eliminating M. leprae bacilli (Gelber & Grosset, 2012) [10], although confinement regulations in many nations were in place for many years after this. Mandatory detention persisted in Japan until the middle of the 1990s. The policy choices were frequently affected by societal stigma and problems in offering resources to help the isolated persons reintegrate into society rather than the scientific knowledge of HD as an illness with poor transmissibility (Sato & Narita, 2003) [26].

Leprosy has been dealt strangely by Indian culture in terms of legislation and tradition, a reaction influenced by both scientific understanding and cultural perspectives. With the assistance of several international organizations, including WHO and ILEP, India has made significant strides towards leprosy control. However, the issue still exists, and over the past 20 years, both the prevalence and the drop in new case detection rates have barely altered (Bhat *et al*., 2022) [3]. One of India's biggest problems, as shown by the nearly constant new case detection rate (NCDR) during the past ten years, is the ongoing emergence of new leprosy cases. One of the key contributing causes might be the hurried announcement that India had achieved the leprosy "elimination" aim in 2005, which caused programme designers and healthcare personnel to lose focus and develop a false feeling of security (Rao, 2021) [25]. Anthropologist James Staples outlined the struggles that locals in one such hamlet in India go through on a daily basis, notably in terms of making enough money (White, 2009) [33]. BARRETT (2005) [1], who also conducted ethnographic research among HD patients in India, made note of the ways in which the stigma attached to receiving treatment for HD causes patients to conceal their illness and forgo care; this can lead to severe disabilities and stigma, which makes people decide to move into these HD communities or feel compelled to do so. In a country where the caste system is strongly rooted even if it has been formally abolished, leprosy stigmatization persists, in part because of ignorance. Women, "backward classes" (minority social or ethnic groups defined by the government), and the urban poor are socially marginalised groups that are less likely to seek medical attention. They frequently see elimination efforts as problematic because they fail to take into account their specific needs (Jacob & Franco-Paredes, 2008) [14]. Additionally, stigma is not immediately removed by community outreach programmes or medical awareness of the condition. Only 30% of people in one group who reported having a high level of leprosy knowledge also had a favourable outlook on leprosy sufferers (Raju & Kopparty, 1995) [23]. More research is required to determine the root causes of stigma and the effectiveness of various therapies.

In Jammu and Kashmir which is one of the Union Territories (UT) in India, has a final leper colony in Kashmir, Bahrar, is indescribably beautiful. The colony is unique from any other community in Srinagar: single-storeyed white residences flanked by ancient residual shacks, with a hospital complex at one end. Hospital ward numbers are written on little boards that are attached to the homes in the villages. Moving to the lone leprosy hospital meant leaving behind everything, even blood relations. There are only few empirical studies conducted for the inhabitants of leper colony in Kashmir. However there is no study which would describe their lived experiences of those who have been cured and are in old age. Thus this study offers to examine the lived experiences of former leper patients who are in their old age.

Method

The study aimed to examine the stigma and social discrimination that elderly leper patients still encounter while living in the leper colony Bahrar in the Srinagar area of Jammu and Kashmir, India. Hence, the qualitative method of inquiry was used in this study. Interpretative phenomenological analysis (IPA), which allows the researcher to record actual experiences of leprosy, stigma and social discrimination, was employed to address the study topic. The major reason for employing this approach was to learn more about how elderly, cured lepers integrate their social and personal identities to the occasions and experiences in the setting of leprosy and the problems connected to it. This phenomenological approach comprises a careful examination of the participant's environment in order to probe the personal experiences as the individual perceives them. It does not rely on claims that are objective about the thing or event (Eatough and Smith 2017) [8].

Participants

The participants of the present study are elderly former leper patients who have been cured but still live in the leper colony- Bahrar of Srinagar district Jammu and Kashmir. A purposive sampling method was used to recruit the participants of the study (Palinkas *et al*., 2015) [21]. A study included a total of 10 participants, 05 men and 05 women all of which belong to different villages of Kashmir. All the participants are married and all are dependent on government aid. In terms of classification of a disease, the participants constituted the homogenous group identifying same issues and problems (Pietkiewicz and Smith 2012) [22]. According to Smith *et al*. (2009: 56) [30], "there is no appropriate solution to the question of... sample size" in IPA research. Smaller concentrated samples are typically used to embrace its idiographic commitment. Informed consent was sent to participants in which the purpose of the study was discussed in detail. Only those participants were considered for the study who have crossed the age of above 60 years as the definition of elderly adopted by the government of India in the National Policy on Older Persons,1999 (Department of Social Justice and Empowerment [Ministry of Social Justice and Empowerment Government of India], 2023) [5].

Data Collection

Data was collected through semi-structured interviews. Participants were asked to describe the experiences of stigma and social discrimination. Research questions were formulated using the prior information about the stigma attached with leprosy. The interview began with an opening question, “how long you have been living in this colony and tell us about your experiences of stigma associated with leprosy”. The opening questions were followed by prompts to elicit more information about their experiences. The interviews took place at their residential quarters provided by the government in the leper colony. Each interview lasted for 60-90 minutes and took place in local language Kashmiri. To audio record the interviews, the consent was taken from all the participants. During the field work, field dairy and transcripts were managed.

Data Analysis

The data was analysed with IPA according to the procedures provided by Smith (1996) [29]. The goal was to offer a detailed analysis of participants of this study that were important in the original texts. So, rather than a pre-existing theoretical perspective, connections were established based on the present discourse. Thus the study adopted thematic data analysis. The participants in the qualitative interviews were free to respond however they felt appropriate and to provide as much background information as they were comfortable with. One of the benefits of a qualitative interview is the ability to modify the questions to match the participants' experience, expertise, and comfort levels. After finished, the interviews were verbatim transcribed. Constant reflection and re-examination of the verbatim transcripts was used at all levels of the analytic process to ensure that themes and connections relating to the main source material were retained, with certain topics being deleted and others extended. All topics were represented by excerpts from the original text, although they were not chosen only on the basis of their prominence. Additional considerations include the depth of the specific sections that highlight the themes, as well as how the theme helps elucidate other areas of the narrative

Ethical Consideration

This study followed high ethical standards by keeping the participants' replies anonymous and seeking their consent before conducting research. There was no incorrect information supplied in this research. The interviews were done in such a way as not to exacerbate the depressed older people's sentiments of weakness and despair. They were given full written information, signed a consent form, and were informed that their name and identity would not be revealed and that they may withdraw at any moment. Every data was kept in a secure location. As part of the research, a confidentiality provision was established to send a message to all parties involved that the demographic information of the participants would not be disclosed in any way so that the answer could be recognised. The study does not require approval from ethical board as the findings are specific to study participants only.

Results

The analysis of the data resulted in to two themes which signifies the presence of Stigma associated with leprosy. The two themes include 1) living a life of untouchables, and 2) the outcast children

Living a life of untouchables

Bainson and Van Den Borne (1998) [2] discuss how stigma arises is critical for developing prevention efforts. Stigma linked with leprosy does not emerge instantly, but develops over time in two stages: Stage 1 consists on the cognitive dimension. This reflects the extent to which the sickness has an impact on the person's life. Patients go through the concealability, disruptive, aesthetic, origin, and risk aspects. Stage 2 - the emotional stage in which the individual is socially devalued. Having a stigmatising diseases like leprosy has a negative impact on many aspects of one's existence, including social status, career prospects or jobs, marriage, and family life (Link & Phelan, 2001) [18]. The participants of this study throughout their interviews narrated the stigmatization in terms of how people do not want to communicate with them considering this disease as a source of bad omen. One of the participant narrated

I have been living here from the past 40 years. I am old now. I do not have any other place to go. My family abandoned me to the mercy of God. Since then my family paid a visit to see me only three times. They felt if they visit me they will also be affected with leprosy. The third time they visited to see me was when I was cured. They didn't even touched me and that was most heart-breaking for me

The participants reflected the elements of relationships with their families as it was negative source of their mental wellbeing as well. This type of Stigma occurs when a person believes that he or she is being neglected, and it has been characterised as a process in which some individuals and groups are unjustifiably stigmatised, excluded, and discriminated against (Graham *et al*., 2003) [11]. Some individuals described leprosy-related experiences that included stigma, which can be regarded as the sense of being perceived as different from others. This distinction is produced by the discrimination these people may face when this condition is labelled as a punishment from God, which commonly enhances their perception of not being taken seriously or being worthless. Another participant described stigma as

People think leprosy is a punishment from God but they are wrong. Because of this problem, nobody wants to be with us. No one spent time with us. I am always looked down by the people and by our families as well despite I am completely cured now

The participants manifest the social construction of stigma associated with leprosy. Link and Phelan (2001b) [19] regard stigma as a social construction that emerges when the processes of labelling, negative stereotyping, exclusion, discrimination, and low status coexist in a power position that favours the expression of these processes. For centuries, from a clinical and social perspective, leprosy has been regarded one of the highly visible dermatologic diseases, since people living with leprosy across the world have constantly suffered isolation, exclusion, and stigma. Some of the more disfiguring signs of the disease have often led to "horror and revulsion," and "triggered irrational emotions that have proven difficult to overcome" (Hasnain *et al*., 2019) [13]. The participants narrated that these physical deformities has led people not to make any social contact even after they have been completely cured. All the participants mentioned that the members from the outside colony has let them to live in isolation. Another participant who has been living in the leper colony from past 60 years narrated

I was 20 years old when I was shifted to this colony. Since then I am here. My own family members left me here, not to see again. I have lived my life with this disease but now I am completely cured. I wonder why people treat me differently. Why they don't talk to me? I don't have any one to share my story. I am old now. I need my family members to support me but you know. It is as it is? No one visit here.

The participants shared that their sense of belonging is not like that of normal people as they look different from them. All this physical deformity leads to stigma among the elderly former leper patients. The stigma of leprosy can be characterised as the patient's loss or deterioration of his or her real identity as a person (Thomas, 2023) [32]. Because of the leprous patient's loss of social worth, a negative emotional and cognitive response to leprosy shows in negative conduct towards the leprous patient. This stigmatising process results in prejudice against leprosy patients, as well as a loss of the previous place and value that they occupied and possessed in general society.

The outcast children

Stigma in leprosy is a social interpretation that occurs after labelling, stereotyping, separation, resulting discrimination, and loss of status. In the case of leprosy, the disease is viewed by health personnel based on existing physical signs; the illness is experienced and moulded by the person's socio-cultural factors; and the sickness is perceived by society, which manifests as social stigma (Kaehler *et al*., 2015) [16]. In India, stigma linked with leprosy was shown to be greater in older patients and connected with community members with lower education and socioeconomic level (P. R. V. Rao *et al*., 2008) [24]. When stereotypes are pervasive in a society, they are not only a big component in shaping the stigma, but they are also a major factor in reflecting disease interpretation in a society. The participants of this study revealed that stigma and prejudice will become inextricably linked to their personal and family life. The notion of heredity was strongly ingrained, and when it was considered that leprosy could be inherited, those with the disease (and their children) were avoided. Since leprosy was considered divine retribution, it was stigmatised. As a result it has affected their children, making them outcasts (Jyoti, 2018) [15]. For example one of the participant described stereotypes as

I was married to a fellow leper patient in this colony. We had healthy babies. They go to college now. But once their classmates know about us, they abandon their relationships with our children. Even teachers in their colleges stay away from them.

The community outside of leper colony have indifferent attitude towards the children of participants of this study. Those infected by leprosy, even after being cured, are viewed as inept, useless, and unproductive by the common people. Their children has to face different stereotypes as they move or try to mix-up with the people in the wider community. For instance, one of the participant revealed

My daughter was born in this colony. She completed her college last year. In her college days she faced lot of discriminatory behaviour from the college authorities as well as from her peers. It is time for her to get married but nobody wants to accept her proposal just because she is recognised as the daughter of leper patient.

Other participants narrated the same issue. All the participants mentioned that the word 'Coud'- a kashmiri word to describe leper has been stigmatising effect even on their children. Additional difficulties include being barred from mingling with the community and being barred from public meetings, weddings, marketplaces, and public religious events. People of nearby communities frequently express their displeasure and make hostile gestures at their children. Another participant mentioned

It has been 45 years now since I came here as a patient. It has been a long time. I see my children living a lonely life. They do not have any friends. I cannot do anything about this. Sometimes I cry why my children have to face this because of my disease.

Because of its historical awareness and the associated misconceptions, leprosy has been a social illness. The greater degree of stigma in the older age group and those who have lived in the neighbourhood for a longer period of time shows the amount of stigma prevalent in the community as well as the level of acceptance in the outside community as well.

Discussion

Leprosy is no longer associated with European countries in the social consciousness of western cultures. Although modern leprosy is curable, there are examples of stigma and prejudice in developed countries as well (Grzybowski *et al*., 2016) [12]. In India, while leprosy is curable and early treatment reduces disability, the disease's stigma remains deeply rooted in the culture. The present study attempted to explore the lived reality of stigma associated leprosy among the elderly former leper patients of Kashmir, India. The study was conducted in Kashmir's only leper colony known as Bahrar colony. From the analysis of the data, even after their cure, the participants' struggle with the disease, was emotionally and physically traumatic. They face social exclusion, discrimination and stigma.

The first themes informs how the participants live a life of untouchables. The participants revealed even in their old age, their families do not have a level of empathy for the physical, psychological, and social challenges that people with leprosy endure, they are rarely involved in their personal matters, and there are evidence that they abandoned them even after disease is cured. Meanwhile, because they recognise that leprosy is a disgrace in their family, persons with leprosy prefer to solve difficulties on their own without consulting other family members. This also reflects the presence of internalized stigma among the participants. The reason being the socio-cultural and religious manifestation of the disease. Stigma in leprosy is ubiquitous, ostracising not just the person but also the family. Most traditional Hindu texts, particularly the Manu Smriti, indicate unequivocally that if there is leprosy in the family, no marriage partnerships should be formed. Similarly, there are several references in the Bible that imply leprosy is caused by divine intervention or as a punishment (Sundar Rao, 2015) [31]. The current study was also found to be in consistent with Scambler (2004) [27] that discuss about felt and enacted stigma. The participants of the present study manifested enacted stigma that limited their involvement in everyday activities by family, coworkers, and society as a whole. With leprosy's long history of stigma, any attempt to remove or mitigate stigma would necessitate strong comprehensive techniques that will infiltrate the psychological and social layers of the human psyche and result in needed health-seeking behaviours (Link & Phelan, 2001c) [20].

The second themes informs the impact of parental stigma on the children of the study participants. The analysis of the data manifests the stigma associated with the disease of the parents has also affected and stigmatized their children as well. They experience the hostile behaviour of others. Fear of rejection for their children in the wider community has also been a matter of worry among the participants of the study. Be it a marriage as an institution or educational institutions, the children of these former leper's are facing structural discrimination (Dobener *et al*., 2022a) [6]. Thus, the children of former leper fear Stigma as it has caused widespread social disapproval and includes the negative repercussions of a label imposed on any child (Dobener, Stracke, *et al*., 2022b) [7]. Parental stigma poses distinct psychological issues for families, especially children. Stigma obstructs access to simple but required services and infringes on people's rights. When parents' regular interactions are complicated by socioeconomic inequality, the influence on nurturing habits might be felt. Children of stigmatised parents are subject to stigma-related misery because they begin to experience courteous stigma, which impairs their general development. Living, nurturing, and caring in a stressful setting leads to a variety of negative childhood experiences. These children are more likely to acquire poor ambitions, low self-esteem, addictions, psychiatric problems, and adjustment concerns (Gautam & Bhadra, 2022) [9].

More than 16 million leprosy patients have been treated during last 20 years, and a general drop in new cases has been recorded in numerous nations (KO Web Desk, 2022) [17]. Yet, discrimination against patients and their families continues. Individuals diagnosed with leprosy are deprived of important fundamental rights such as the right to equality, the right to an education, and the right to equal chances in work, marriage, and health care. From this study, it is noted that leprosy's stigma has theological, social, and psychological foundations. It is driven by a lack of awareness of the disease, including misunderstandings about the disease's aetiology, mechanism of transmission, and treatment, as well as dread of the terrible deformities and disfigurements that can arise from untreated leprosy. Negative attitudes against leprosy are not restricted to the uneducated; the highly educated and even medical professionals may exhibit a lack of understanding, such as a lack of awareness regarding reservoirs, modes of transmission, and incubation periods (Dahiru *et al*., 2022) [4]. To address leprosy-related stigma, a multidimensional strategy to dispelling myths and prejudices through awareness development is required. Moreover, treatments are required to address the psychological and social repercussions on impacted individuals, families, and communities.

Limitations of the study

The study focused only on the lived experiences of leprosy among elderly former leper's in Kashmir making generalizability difficult. Since it produces physical abnormalities and disability, leprosy is a very visible illness. Individuals with leprosy can be easily recognised by their features, and they are frequently stigmatised due to the misconception that the disease is easily transferable (Singh, 2012) [28]. Because these aspects are unique to the condition of leprosy, the psychological impacts of the sickness, as well as their interactions with culture and gender, are particularly specialised. Because of the intersection of all of these elements, the current study's conclusions have a very restricted applicability.

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