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# Resistance to Reintegration among Leprosy-Cured Individuals: A Study from Kerala

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***Abstract***

Leprosy is more than a chronic infectious disease caused by *Mycobacterium leprae*. It leads to severe deformities and is a condition laden with stigma. A person diagnosed with leprosy faces challenges in all physical, social, psychological and financial aspects of life. This qualitative study has explored the psychosocial challenges encountered by leprosy-cured individuals at the Kozhikode Government Dermatology Hospital in Kerala, India, and the reasons for their resistance to reintegration. This study adopted a phenomenological paradigm and undertook a theme-based analysis. Data was collected from six participants, three males and three females, who had spent more than 10 years at the hospital despite being cured. The participants were purposively selected and interviewed using a semi-structured interview guide. The study showed that leprosy-cured individuals had permanent physical disfigurements as an outcome of leprosy. The resultant physical impairments and deformities were significant reasons for their isolation and social discrimination. Family members were totally embarrassed by their appearance and stopped them from interacting with others in their social circle. In comparison, they were treated with much more respect and dignity at the hospital, besides having various support services such as monthly pensions, free treatment and free food from government schemes. Even after the completion of treatment, the leprosy-cured individuals were not integrated into their families or communities due to the dread and stigma associated with the disease. Thus the supportive environment at the hospital made them resist reintegration into their homes and communities that were not ready to accept them as normal human beings.

***Keywords***

Leprosy-cured, psycho-social challenges, rehabilitation, resistance, stigma, Kerala

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## Introduction

‘A healthy mind dwells in a healthy body’ is an age-old adage. Health has been a central aspect of any discussion involving wellbeing and quality of life, and is given the most importance by individuals, families, communities and governments. Health is “a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity” (WHO, 2006: 1). Although health is a priority agenda in Millennium Development Goals and in the new Sustainable Development Goals, the intended impact of these global goals is far from being realised. Diseases bring not only physical but also psychological and social challenges. Some diseases in particular are associated with stigma and the person infected is isolated and shunned by society, thus worsening their plight. Leprosy is one such disease.

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae,* which affects the skin and peripheral nerves, causing the formation of nodules or macules that enlarge and spread. Disease progression is accompanied by a loss of sensation with eventual paralysis, wasting of muscles, and the production of deformities. These symptoms may begin within one year, but for some people may take up to 20 or more years to manifest (WHO, 2021). Although the infection readily responds to antimicrobial treatment, the lack of knowledge and community attitudes delay detection and treatment, and can restrict social participation of those affected (Smith, 2013).

Leprosy may be regarded as a social disease because of its recognition throughout history as a curse and the stereotypes attached to it. It is perhaps one among the most stigmatised of all diseases because of the horrifying morphological deformities it causes to the body of the patient. The general image of leprosy even today evokes a picture in the common man’s mind of a “deformed and disfigured person, with ulcers, swollen face, shining nodular skin, depressed nose, shortened digits (fingers and toes), without eyebrows ...they often identify a leprosy-affected beggar in the street, exhibiting his disease, as a classical example of vice incarnate” (Mutatkar, 1979: 237).

Although leprosy can be cured as long as the precise diagnosis is made and treatment is initiated at the earliest with the appropriate medication, people still continue to associate the persons infected with leprosy as ‘cursed’ and are fearful of becoming infected themselves (Ofosu and Bonsu, 2011). While over the years stigma related to leprosy has seen to be decreasing, various aspects of life, including marriage, employment and social interaction, are still affected by the stigma associated with leprosy. This repulsive treatment by society is largely attributed to leprosy and its consequences, specifically the disability and deformity caused by leprosy (Marahatta et al., 2018).

As in the case of HIV/AIDS, leprosy is a disease of stigma. Because of this, individuals affected often do not seek treatment until they develop permanent, visible disabilities (Suzuki et al., 2012). Even though cure is possible, considering that the deformities due to leprosy cannot be reversed, they exacerbate the stigma associated with the disease, thus sustaining the cycle of stigmatisation.

This study aims to understand the psycho-social challenges that the leprosy-cured individuals at the Government Dermatology Hospital, Kozhikode, Kerala, encounter, and the reasons for their resistance to reintegration, despite being cured.

## Review of Literature

Leprosy is an infectious disease that can damage the nerves which may affect the sensory, motor and autonomic functions, resulting in disabilities (Lastória and de Abreu, 2014). In addition to the physical consequences of leprosy, social stigmatisation is a challenge faced by many affected persons, especially since this often remains, even when the medical treatment is completed (Rafferty, 2005; van Brakel, 2003). The studies show that the knowledge of leprosy and its transmission among persons affected and their community members is limited or inadequate (Barkataki et al., 2006; Kaur and Gandhi, 2003).

Inadequate knowledge, if not ignorance and superstitions, are major reasons for persons with leprosy being stigmatised. In general, people are reluctant to establish a matrimonial relationship with a person with leprosy or with their family members, the same also being reflected in their employability (Barrett, 2005; Jacob and Franco-Paredes, 2008; Kaur and Gandhi, 2003). People living with leprosy and its equivalent, enjoy a 'low quality of life and wellbeing' as they experience stigma and discrimination along with physical disability, and are at higher risk of developing mental health problems compared to the general population (van Brakel et al., 2012). The perception of self-stigma and public stigma as well as experiences of discrimination cause the leprosy-cured to feel ashamed and may isolate themselves from society. This perpetuates the stereotype that leprosy is something shameful and needs to be hidden away, thus they avoid any social contact (Arole et al., 2002).

The above literature reveals that although there were studies exploring the challenges encountered on account of leprosy, there have not been many studies on the challenges of leprosy-cured individuals. It is postulated that the stigma not only socially affects the leprosy-cured, but also acts as an impediment to their proper treatment and reintegration. The present study has attempted to understand the psycho-social challenges encountered by leprosy-cured individuals at the Government Dermatology Hospital, Kozhikode, Kerala, India. It also examined the reasons for the leprosy-cured resisting reintegration despite being totally cured, which would give a better insight into their lives. The findings could also bring in better interventions and policy decisions, which may help in improving their quality of life and to plan for their reintegration in a dignified manner.

## Statement of the Problem

In December 2005, India claimed to have attained the elimination figure of less than one case of leprosy per 10,000 people (Sengupta, 2018). Notwithstanding three decades of multidrug therapy, India maintains more than 50 per cent of the leprosy burden of the entire world (Sengupta, 2018). Every year, with over 200,000 cases detected globally, India accounts for more than half of these, according to the World Health Organization (WHO, 2006). Problems of divorce, unemployment and displacement from areas of residence are common in people affected with leprosy (Kaur and Ramesh, 1994). As the people affected with this disease are rejected by the local community and family members, they are forced to stay in ashrams, mandirs, and leprosy sanatoriums. As a result of these problems, patients with leprosy are associated with a high risk of developing psychiatric disorders (Reddy and Bansal, 1984). Studies show that discriminative attitudes towards persons with leprosy were more common in joint than nuclear families. Even if the patients were supported by their families, the disease had definite psychological effects (Kaur and Ramesh, 1994). The fear of social ostracism prevents them from disclosing the disease to the community. In practise, they prefer to leave their homes.

A person diagnosed with leprosy is stigmatised by society. Along with this, they develop self-stigma, where the person with the disease becomes aware of public stigma, concurs with those stereotypes, and internalises them by applying them to their selves. These challenges remain with the individuals even after they are cured of leprosy as most people associate the person with the disease for the rest of their lives, especially because of the visible physical impairments. The literature shows that there has not been enough focus on understanding the psycho-social issues of leprosy-cured individuals, their lives after treatment, reintegration and reasons for them resisting reintegration i.e., resistance to going back to their families and communities to lead a regular life. It is in order to address this gap that the researchers attempted to probe into the lives of leprosy-cured individuals, who continue to stay at the Government Dermatology Hospital, Kozhikode, Kerala, India, in spite of the completion of the course of treatment.

## Methodology

This study is qualitative and is intended to explore the resistance to reintegration found among leprosy-cured individuals and adopted a constructivist paradigm. This phenomenological study was undertaken among leprosy-cured individuals at the Kozhikode Government Dermatology Hospital. The participants consisted of three males and three females purposively selected based on the longevity of stay, and included those who had spent more than ten years at the hospital, despite being completely cured.

A pilot study was undertaken with permission of the authorities of the hospital and ethical clearance was sought. The tool, a semi-structured interview guide developed in consultation with experts and consisting of 17 questions, was modified based on a pre-test. Prior to the interviews, informed consent was obtained from each participant after communicating with them the purpose of the study and affirming that confidentiality would be maintained and the data collected would be used strictly for academic purposes.

The interviews were recorded in the local language (Malayalam) using a voice recorder with their permission to reduce distraction, and later transcribed into English. The contents of the interviews were subjected to thematic analysis. The emergent themes generated and the interpretations made by the researchers were discussed with the respondents in three iterations for the purpose of triangulation of the themes. The study was conducted during the height of the Covid-19 pandemic over the three months, beginning with May, and spread over June and July of 2020. The participants were disposed to cooperate during interviews and group discussions, given the restrictions on mobility during the said period.

## Findings

The themes that emerged in the course of this study could be summarised as ‘unprecedented challenges’, their ‘scary appearance’, ‘rejection by family and community’, and ‘unconditional support’ from the health personnel.

In spite of being medically leprosy-cured, the participants reported encountering ‘unprecedented challenges.’ The visible physical disfigurements and deformations they acquired made them look scary to others. This repulsive appearance translated into self-stigma, which coupled with social stigma, forced them to alienate themselves from society, further enhancing their disability. They were literally hidden or forced to leave their homes which caused them deep psychological trauma.

The participants were grateful and happy with the services provided by the hospital during and even after treatment. The approach from the hospital staff as well as the governmental support received, helped them to lead a dignified life. Even though those staying at the hospital would mean extra work for the doctors and hospital staff, the compassion satisfaction they experienced in providing services motivated the hospital personnel to continue supporting the individuals cured of leprosy. In contrast, the inadequate support from the family, and the absence of dignity and respect evident by the responses of community members due to the stigma associated with the illness, were the major reasons for them resisting reintegration into a community.

## Discussion

### Leprosy-Related Disfigurement

Although the participants were leprosy-cured, they suffered severe permanent physical impairments as a result of the disease. Their family members were embarrassed by their presence at home and would usually force them to stay inside to avoid being seen by others. The family was afraid that their social status and prospects of marriage would be ruined if others knew about the family history of leprosy. The visible features of the disease resulted in a vicious cycle of stigma, which forced them into social isolation, which in turn contributed to psychological distress. One participant explained that:

> "They look at me with horror and disgust...my grandchildren have the horrid expressions on their face when they see me. Whenever someone visits, my children rebuke me to stay inside, so that I don't scare them...My children are also worried about not getting suitable alliances for their children in future because of me."

A study conducted in Delhi revealed that respondents believed that the leprosy-afflicted should be confined to leper colonies away from society. The participants expressed reluctance to establish a matrimonial relationship with a family having a leprosy-afflicted person (Kaur and Gandhi, 2003).

The visible impairments and irreversibility of their physical conditions contributed to them being associated with leprosy for life, despite being cured. The participants had visible impairments such as amputated legs, hands, finger digits, blindness, and disfigurement of ear lobes and nostrils.

These impairments often gave them a different and scary appearance and evoked repulsion, making people avoid contact with them. The loss of body parts not only causes disability, but also gives an impression of inadequacy, thus ruining their prospect of employment. As a participant reported:

> "I wish I could do some work and sustain myself so that I don't have to trouble my family members and I could stay away from them, but I am not in a physical condition to work. Not only that but, who would be willing to give work for a person like me?"

The findings of this study are congruent with the findings of a study conducted by Kaur and van Brakel (2002), which shows that the combination of leprosy, physical impairments and social stigma causes participation restriction, which can lead to the dehabilitation of people affected by leprosy, and some of them may end up as state beggars.

The findings of the present study support the findings of the studies conducted in this area previously (Arole et al., 2002; Barrett, 2005; Marahatta et al., 2018). Despite being leprosy-cured, the permanent impairments largely impacted the lives of individuals. Because of these they are shunned by their family members and their prospects of employment also remained bleak. Hence it is important to tailor interventions that can help the leprosy-cured to utilise their residual capabilities so that they can be independent and lead dignified lives.

## Unconditional Support

The reason for resisting reintegration back into the community is the perceived support. On the one hand they are supported by the hospital staff and the other empathetic residents, while on the other hand, they receive no support from their own families and communities of origin. This is very evident in the reflections of the leprosy-cured who were interviewed. One of the participants recollected:

> "There was a time when I wanted to get cured and go back to my family. They would visit me in the initial days, but gradually they stopped visiting me...Now I have no contact with them. I know that I will not be welcome even in my own home. Here I have people who have been through what I experienced. Here, I am considered as a normal human-being in spite of the way I look. They are my family for life."

This finding contradicts those of a study conducted in Tamil Nadu that shows that family members were found to be willing to support their leprosy affected relatives (Stephen et al., 2014). This may be explained because rural communities are more inclusive when it comes to taboo contexts – transpersons, hijdas, and devadasis. A study conducted in Nepal showed that a good knowledge of leprosy was highly associated with favourable attitudes towards leprosy (Singh et al., 2019). Hence, it is important to educate the community with adequate information regarding the illness and modes of transmission, in order to moderate the perception of both the families of leprosy-cured individuals as well as communities.

### Pull Factors

Given the prolonged duration of treatment and the time away from home, and later being stigmatised and discriminated by their family and community, those with leprosy completely lose touch if not broken away from their families. In sharp contrast, in the hospital they enjoy the company of many other residents with similar issues who interact freely with them without being judgmental or appalled by their very physical appearance. The feeling of security that comes from the hospital, their second home, along with the comfort of staying with other leprosy-cured who can empathise with them, gives them a definite logic for resisting reintegration into the community that treated them as abnormal. However, this fostered dependence on a system is largely a motive against them being re-integrated into normal living back in their respective communities.

### Compassion Satisfaction

Although the workload of the hospital staff has increased with the leprosy-cured individuals staying on despite being completely cured, the compassion satisfaction they received from rendering their services, motivated them to extend their services for this group of individuals as well as making contributions towards welfare funds. As the leprosy cases were very low at the time of the research and plummeting fast, they did not find that residents staying on was an issue, as there was enough space to accommodate any new admission. The finding supports the conclusion of other studies by Lin et al. (2012) and Zinn (1993) in the area of similar diseases where stigma and taboos prevail. It is seen that empathy towards persons living with HIV benefits both service providers and patients. For the patient, interaction with an empathetic health care worker may serve to enhance their sense of self and relieve anxiety and shame. From a doctor's perspective, respectful communication will help to support patients in disclosing their disease status, helping service providers to adopt appropriate self-protective measures.

### Resistance to Community Reintegration

The participants felt very well supported by the hospital staff as well as the various government schemes. All the basic needs of the participants such as food, clothing and shelter, were taken care of at the hospital, hence they did not have to depend on others to meet these needs. In addition to that they also received free and timely treatment for other comorbid and health issues. The hospital staff have helped those with impairments to be listed for disability pensions offered by the government. The government schemes also took steps to provide remunerable work for those capable, based on their residual capacity. A participant added:

> "The staff here take extra effort to make life comfortable for us. I don't think it is part of their job...but they help us by completing procedures for disability pension. All our basic needs are met here...more than anything we are treated with respect. What more can I expect, especially when your own family disowns you?"

A study by Srinivas et al. (2018) conducted in Southern India showed that the health care professionals were knowledgeable about the modes of transmission and management and regarded leprosy as any other disease. They hardly ever discriminated against individuals on the basis of the diagnosis. They wanted to set an example to others by being good role models so that other cadres of health care professionals would learn from them and behave accordingly.

The findings of this study show how the negative attitudes of family members and their community on one hand, and the support of health care staff on the other, are the major reasons for the leprosy-cured individuals resisting reintegration. Various other studies conducted previously also support these findings (Marahatta et al., 2018; Reddy and Bansal, 1984; Srinivas et al., 2018). Although they find temporary relief by staying back at the hospital, it puts an additional burden on the healthcare system. Hence it is important to design interventions to bring about favourable attitudinal changes in the families and communities, besides helping individuals cured of leprosy to lead an independent life in the community rather than in the institution.

## Recommendations

The findings show that the reasons for the persons cured of leprosy resisting reintegration are multifaceted. Any intervention with the leprosy-cured must be tailored to address all aspects of life, namely physical, social, psychological and financial. Proper awareness through psycho-social education of the immediate family and the community of origin is necessary, to tackle the stigma associated with the disease. These significant persons should be provided with a clear picture about the disease to eliminate the derogatory portrayal reinforced by the media or historical texts. Proactive interventions, legislations, and vocational rehabilitation with opportunities for work would equip them to be independent. To this effect, necessary interventions and policy decisions must be made to improve the quality of their lives and assist in their reintegration in a dignified manner rather than spending the rest of their lives in an institutional setting.

## Conclusion

Leprosy is a chronic infectious disease with visible, objectionable impairments. From time immemorial it has been looked upon as a stigma and regarded as a curse. Even though leprosy can be cured with proper treatment, society has still not come to terms with accepting people with leprosy, thus reducing their chances of reintegration and living a life with dignity. This study explored the psycho-social challenges faced by the leprosy-cured and explains the reasons for them resisting reintegration into the community. The findings indicate that leprosy-cured individuals face social and psychological issues along with permanent physical impairment as part of their disease, even after being completely cured. Not being accepted back into their families or communities due to the stigma, coupled with isolation and discrimination from their own loved ones, create psychological distress. Their appearance on account of physical impairments which could be easily rectified by rhinoplasty, forces them into isolation and discrimination and makes them dependent on others to meet their basic needs. The services from the hospital and government schemes such as monthly pensions, free treatment and free food and the friendly and supportive attitude of the doctors and other hospital staff towards them helps them to get through their lives. Being treated with respect and dignity, they prefer to overstay at the hospital. The supportive hospital environment, the company of people with similar diseases, a monthly pension and the surety of meeting their basic needs makes them psychologically resistant to any opportunity of reintegration back into a community that is unwilling to accept them as normal human beings. The same learning generated here could be taken forward by engaging with other phenomena such as persons living with mental illness, HIV/AIDS, victims of acid attacks, victims of human trafficking, victims of substance abuse, and persons in conflict with the law, where stigma and taboos prevail.

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