

Socio-psychological Issues of Adolescents Affected with Leprosy: A Scoping Review

S Ahmad*

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Skin sores, ulcers, nerve weakness, and disfigurement are a few most common leprosy complications when the diagnosis is delayed and not treated timely. The chronic nature of leprosy and the associated risks of deformities make it the most horrifying illness in human history. Although leprosy affects every segment of the population, adolescents and their highly sophisticated social life put them at additional risk and prone to severe socio-psychological problems. This study has systematically collected and reviewed published literature and arranged findings in a single report to provide a comprehensive understanding of adolescents affected by leprosy. Findings indicate that early adolescents are affected mainly compared to children (0-10 years). Household contact is the primary source of infection among adolescents, and changes in daily life, poor wellbeing, the experience of stigma, self-isolation, and reduced social mobility are prominent issues among affected adolescents. Adolescents with one or both parents affected with leprosy showed signs of anxiety, depression, poor academic performance, or dropout. Leprosy among adolescents demands extra attention due to their precarious and unsafe behavioural traits and their comparably extensive peer and social engagements. This review shows that systematic and well planned studies are required on directly or indirectly leprosy affected adolescents to further research relevant issues for defining the problems and finding solutions to various challenges so as to frame effective interventions and policies.

Keywords : Leprosy, Adolescents, Socio-psychological, Stigma, India

Background

Leprosy, caused by *Mycobacterium Leprae*, primarily affects the skin and nerves of patients (Fischer 2017); failure in timely diagnosis and treatment of the disease results in severe bodily disfigurements and disabilities (Guerrero et al 2013). Leprosy is entirely curable (Lockwood & Suneetha 2005), and unlike previous eras, if diagnosed on time and treated well with the recommended MDT regimens, disabilities

are also preventable (van Brakel 2007). Even though medical science has developed ways to reconstruct disfigured and restore the functions of disabled organs in leprosy-affected people (Palo et al 2019). Still, many are left undiagnosed, hiding their illness (Silva et al 2014a) and not taking available treatments due to the fear and social stigma associated with the disease.

Previously, leprosy-affected people faced social rejection, discrimination, debilitation and

[^] Dr Shahnawaz Ahmad, PhD, Office of NASI-ICMR Chair at Rajasthan University of Health Sciences (RUHS), Jaipur-302033 (Rajasthan), India.

Current Address : State Project Coordinator, International Union Against Tuberculosis and Lung Disease (The Union), South-East Asia Office, C-6, Qutub Institutional Area, New Delhi -110016, India.

Correspondence : Dr Shahnawaz Ahmad, **Email :** ishahnawaz@hotmail.com

restricted social mobility (Ahmad & Katoch 2021). These social evils are still not very rare (Seshadri et al 2015) and cause social stigmatisation, limiting the scope of active case finding, timely diagnosis, and treatment; also, it reduces patients' quality of life, personal development and growth (Tsutsumi et al 2007).

The problem of people affected with leprosy is well documented, especially for women (Le-Grand 1997, John et al 2010, Sarkar & Pradhan 2016) elderly (Silva et al 2014b, Oliveira et al 2019) and children (Butlin & Saunderson 2014, Ekeke et al 2014, Oliveira & Diniz 2016). Most studies have included adolescents as part of children. However, adolescents represent a different age group, and issues which require attention are: their social interactions, future aspirations, expectancies from life, education, academic and social engagements, more independent life, a continuous search for self-identity, and a suitable position in the social order of society. These aspects of adolescence (10 to 19 years) make them apart from children (0 to 10 years) and signify the extra attention they require. These issues need to be studied so that the problems could be identified and suitable intervention(s) could be done and help provided to them to overcome the challenges faced by them.

Psychosocial aspects which may play a vital role in their health include such as peer relation, family adjustment, social engagement, educational difficulties, helplessness, dilemma, insecurity; deprivations in daily and leisure activities; self-exclusionary behaviour, academic achievements, school dropout, engagement in household activities; guilt, fear, depression and anxiety, also the quality of love and warmth they receive from their family and relatives. The social interaction and engagement of adolescents are one of the most critical aspects of this age

group; interaction often happens among the peers, in school or community settings, in the family, and between siblings and relatives; and helps in socialisation and shapes overall personality, growth and wellbeing - any glitch in these sociopsychological processes due to illness and disability results in socio-psychological problems. Leprosy is one such illness that reduces affected people's social mobility and interactions and hinders their development and psychosocial wellbeing. Adolescents may be directly be sufferers due to leprosy and or their parents may be leprosy afflicted, thereby adolescents getting the impact of family being affected by social stigma. Hence, it is essential to explore and comprehensively understand the socio-psychological issues of those adolescents affected with leprosy for more informed policy and interventions. This study aims to fill this gap by collecting, reviewing and synthesising relevant published literature in a single report to highlight the relevant issues, problems of adolescents affected with leprosy either directly due to their being a patient/ ex-patient or indirectly due to their parent/ parents being affected from leprosy and facing psychosocial consequences.

Material and Methods

This study has collected, reviewed, and analysed published literature on adolescents affected with leprosy with the objectives –

- (i) to explore the psychosocial problems of leprosy affected adolescents, and also
- (ii) to explore the psychosocial problems of adolescents of leprosy-affected parents.

PubMed database was searched using an advance search building mechanism, for studies on leprosy related psycho-social problems of those between the age group of 10-19 years and relevant keywords (leprosy OR leprosy patients OR

people affected with leprosy AND ((y_10[Filter]) AND (fft[Filter]) AND (adolescent[Filter]))) AND (adolescents OR adolescence AND ((y_10[Filter]) AND (fft[Filter]) AND (adolescent[Filter]))). Only empirical studies that have explored the problem of leprosy among adolescents, published in English and peer-reviewed journals during the last ten years, were considered for review. A total of 824 studies were found in PubMed and extracted in MS Excel format. After initial scrutiny through the title (removed duplication, non-data discussions, and review studies), only 32 were found suitable for the second phase of scrutiny, which was done by reading the abstracts. After the second round of scrutinising, nine studies were found eligible for further consideration; two studies were on clinical-epidemiological aspects of childhood leprosy but had some trivial mention or discussion of adolescents, and seven were relevant to the theme of the present study. Four studies were manually searched using other databases (Research Gate, Google Scholar). In the final stage, 11 articles were thoroughly reviewed, and Table 1 was prepared based on the emerging themes and findings.

Findings and Discussion

Issues, problems and challenges are different words with different meaning. Issues are aspects which need discussion (these may be or may not be problems), problems are things/ issues that are difficult to deal with or to understand and challenges are things that are difficult and need lot of effort to overcome. This review has attempted to understand the type of information available on these aspects.

Socio-psychological problems of leprosy-affected adolescents

Even in this post-elimination era of Leprosy, a large number of children are showing up in

leprosy clinics for treatment (Ramos et al 2018), and those in early adolescent age are the most affected by leprosy. Balai et al (2017) have noted that the ages of affected children ranging from 7 to 14, and a majority (more than 80%) of cases are between 10 to 14 years of age consistently; Chaitra & Bhat (2013) found that the disease is primarily manifested frequently in older children; other studies have similar findings. Household contact is a primary source of infection of leprosy among adolescents (Chaitra & Bhat 2013, Pedrosa et al 2018). Pedrosa and colleagues (2018) have reported from a large-scale sample that in 95.2% of cases of adolescents, contact with family members who previously either had the disease or were still taking medication and treatments was the source of infection.

A large number of adolescents are aware of the early symptoms of leprosy. Pitchaimani et al (2016) reported that 81.5% of their sampled adolescents noticed early leprosy symptoms by themselves in the initial stage; sadly, they delayed treatment-seeking by 7 to 36 months from the first sign notice to the first visit to a clinic for diagnosis and treatments. Studies (Sarkar et al 2012, Srinivas et al 2019) have found that delays in diagnosis and treatment are associated with developing deformities and disfigurements in leprosy-affected people. Santos et al (2012) reported from a Brazil-based sample that leprosy diagnosis is often delayed in adolescents, which causes deformities that hinder not only physical activities but also cause social discrimination and stigma. One possible cause of delay in diagnosis and treatment-seeking is the dependency of adolescents on parents for health-related issues. John et al (2005) reported that despite education and economic engagement, many adolescents depended on their parents to seek required and appropriate treatment for their ill symptoms.

Table 1 : Review of Literature

Study and author	Location	Sample	Notable Findings
Freitas et al 2019	Cuiaba, Brazil	Adolescents, 30 sample size	Adolescents perceive leprosy as a severe and incurable disease that causes fear, shame and social isolation.
John et al 2005	Kolkata, India	Adolescents, 10 to 20 years age group, and 258 sample size	<ol style="list-style-type: none"> Adolescents depend on their parents to seek appropriate care for their symptoms. Adolescents were confused and ashamed of their disability, which affected their social interactions, education, jobs, and marriage; unmarried people were reluctant to marry. Social stigma was quite strong, and there was a general tendency to hide the disease as long as possible. After disclosure, the behaviour and attitude of some family members changed towards affected adolescents, primarily isolated or distant from the affected person. However, parents' attitudes were protective towards their children but not as motivated to seek early medical help. Psychological and emotional problems, helplessness, dilemma, and insecurity were prevalent among affected adolescents.
Pitchaimani et al 2016	Purulia, West Bengal, India	Adolescents and children, 65 sample size.	53(81.5%) adolescents have noticed their early illness symptoms by themselves, and almost half (55.4%) were delayed in seeking treatments by 7 to 36 months.
Balai et al 2017	Southern, Rajasthan, India	Children and adolescents, 32 samples.	The ages of affected children ranging from 7 to 14 years, and most cases (80%) belonged to the 10 to 14 age group.
Chaitra & Bhat 2013	South India	Children and adolescents, 36 cases	The disease seemed to manifest frequently in older children, and in more than half of cases, household contact was the prime source of infection.
Santos et al 2012	Legal Amazon, Brazil	Adolescents and children	Leprosy diagnosis is very late in adolescents and children, which causes deformities beyond physical impairments; leprosy also causes social discrimination and stigma.

Ponte et al 2005	Sobral Municipality, Ceara	31 Adolescents	Leprosy brings significant changes in adolescents' lives that make it challenging to construct their identity.
Pedrosa et al 2018	Amazon region, Brazil	School children, 34,547 cases, less than 15 years of age, with approximately 10 (9.6 year) years of mean age.	95.2% of leprosy-affected adolescents had contact with family members who previously had or were still receiving treatments for the disease.
Yamaguchi et al 2013	Lalitpur and Kathmandu, Nepal	Adolescents (N=102, 11 to 17 years age group)	Adolescents with leprosy-affected parents had higher levels of depressive symptoms, lower self-esteem, and lower emotional wellbeing.
Romero-Montoya et al (2014)	-	-	Disability is higher with increasing age in children and adolescents with leprosy, as the disease's social and psychological effects and stigma are distressing.
Darlong & Govindharaj 2020	West Bengal, India	Adolescents and children.	Parents of leprosy-affected adolescents had a positive attitude and caring behaviour towards their affected sons or daughters.
Marinho et al 2018	Southeast, Brazil	19 adolescents, 12 to 18 years age group	<ol style="list-style-type: none"> 1. Most family members expressed being typical and revealing that the disease did not represent a barrier to expressing affection for the affected adolescents. Family members also reported increased attention, zeal, and concern for the affected individuals in the family. But changes in the daily lives of family members were found, such as the separation of household items and utensils and a ban on touching things due to fear of spreading the infection to other family members. 2. Adolescents cited relevant deprivations in daily and leisure activities due to physical pain, significantly interfering with their daily lives. 3. Adolescents reported withdrawal from social life due to fear of prejudice. The fear of being excluded made some adolescents anticipate exclusionary behaviour by choosing to isolate, interfering with their relationships in certain daily activities.

Parents have positive and caring attitudes and behaviour toward their leprosy-affected adolescents. Darlong & Govindhraj (2020) reported that those parents who participated in their study showed a positive attitude towards their leprosy-affected adolescents. John et al (2005) found that parents were concerned and protective; similarly, Marinho et al (2018) found that leprosy does not create a barrier for other family members to express affection, love, or concern. Still, many have to suffer, as John et al (2005) further add from their findings that after disclosure of the disease, the attitude and behaviour of some family members changed towards affected adolescents; these behavioural changes often include distancing and isolating affected adolescents from other family members.

Lack of understanding is one of the most profound aspects of leprosy among adolescents; many still consider leprosy as an incurable illness. Freitas et al (2019) reported that adolescents perceive leprosy as a severe untreatable, chronic disease that causes fear, shame and social isolation from social and community life. John et al (2005) report that leprosy-affected adolescents feel ashamed and confused, impairing their social interaction, employment, education, and intimate life and relationships, John et al (2005) further added in their findings that even those unmarried had a reluctant attitude towards marrying, and those who were already married hid their illness from their in-laws and other relatives.

According to a study of adolescents conducted by Ponte et al (2005), leprosy has numerous effects on adolescents, including affecting their ability to develop social identity and recognition in the society. John et al (2005) reported that psychological and emotional problems, feelings of helplessness, dilemma, fear and insecurity

are a few aspects that cause decimal wellbeing. Marinho et al (2018) reported that fear, stigma and insecurity lead to a situation when leprosy-affected adolescents themselves are excluded from their social life by anticipating exclusionary behaviour from others.

Socio-psychological problems of adolescents of leprosy-affected parents

Anxiety and depressive symptoms manifest psychological issues among adolescents with family members infected with leprosy (Yamaguchi et al 2013). Yamaguchi et al (2013) have reported from a Nepal-based sample of adolescents belonging to leprosy-affected families that these adolescents have low self-esteem and worry a lot due to the risk and vulnerability to the onset of leprosy. Poor educational attainments and dropping out of school are associated with family members' severe and chronic illnesses (Yi et al 2012, Ampiah & Adu-Yeboah 2009). Leprosy is a chronic disease, and affected people generally live in poverty and poor economic conditions due to jobs loss and low wages employment (Adhikari et al 2013, Majumder 2015, Heidinger et al 2018, Pescarini et al 2018, Nery et al 2019). These are potential reasons behind adolescents' school dropouts and involvement in household activities and economic earnings; the eldest adolescents are also supposed to care for other brothers and sisters.

Limitation

This review only brings out some problems relevant to address psychosocial health of leprosy affected adolescents. Significance will be qualitative rather than quantitative. There could be omission of some relevant studies while narrowing down to a smaller number.

Conclusion and way forward

It appears that previous studies have mainly focused on childhood leprosy and more on clinical

and epidemiological aspects; even though there is vast and varied literature on leprosy, there is little information about adolescents with leprosy and its socio-psychological challenges.

Those surveyed have found that most adolescents know the early signs of leprosy; parents are supportive and protective; family members are caring and have the usual behaviour. Still, a delay in diagnosis and the prevalence of depression and anxiety, social stigma, a tendency to hide the disease, and low self-esteem were seen among affected adolescents. Emotional problems, helplessness, dilemma, insecurity, deprivations in daily and leisure activities, self-exclusionary behaviour, poor academic achievement, school dropout, engagement in household activities, and less social mobility are other aspects manifest in a leprosy-affected adolescent's life. Leprosy among adolescents demands extra attention, requiring more research to explore the issues and frame effective interventions and policies.

This review shows that there is sketchy information about the issues, problems and challenges relevant to the psychosocial health of adolescents whether directly suffering/ have suffered from leprosy and their parents suffering/ suffered from disease in the past. Further, India specific information is extremely limited. Focus has been on some targeted problems of adolescent rather than on analysis of information about issues, then moving to pinpoint problems and then challenges. Impact of adolescents being sufferers of leprosy and their parents facing the consequent problems and challenges deserves separate focus. It is important that these issues are adequately researched in different settings, problems identified, and among the problems challenges are focused that require/ will require extra effort to overcome.

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