



## Psychological consequences of leprosy in children of leprosy affected parents

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**Abstract:** *Leprosy (Hansen's disease) is a chronic infectious disease caused by M. leprae., an acid-fast, rod-shaped bacillus mainly affecting the peripheral nerves, skin, muscles, eyes, bones, tastes, and internal organs of human beings. It is a disease of complex nature that affects the patient's physical, social, and psychological well-being. Leprosy patients are not allowed to contact the community, including their families. Even they face difficulty entering public places and using the public transport system. Leprosy is a stigmatizing condition and can lead to the person affected being rejected and excluded from society. People's misconception about this disease affects leprosy patients and the healthy children of leprosy-affected parents. Due to neglect and hatred, they suffer from social discrimination, injustice, and exploitation. This can affect the shaping of personality as well as the cognitive level of the children. Many studies have been conducted on children of healthy parents, but little has been given to study children of leprosy-affected parents. The suggestion for children of leprosy-affected parents was further given.*

**Key words-** Leprosy, children, and Leprosy-affected parents.

Throughout history, leprosy has been feared and misunderstood. The origin of leprosy is unknown. The disease was first described around 600 BC. In the 1960s and 1970s, there was a debate about the appropriate name for this disease - leprosy, lepra, Hansen's disease, or Hanseniasis. A strong movement developed in some countries to substitute the name Hansen's disease for leprosy. ( Rotberg ,1968;Gramberg,1952;Cochrane , 1970; Lendrum , 1952;Rabello, 1980) Leprosy is probably the oldest disease known to humanity. The word Leper comes from a Greek word meaning scaly. For a long time, this disease was confused with psoriasis, elephantiasis, and Pellagra. In India, Leprosy has been known since ancient times as Kustha Rog and attributed to punishment or curse from God. Leprosy has affected humanity for over 4000 years. Two or three million people worldwide are estimated to be permanently disabled because of leprosy. India has the greatest number of cases, Brazil is second, followed by Burma as the third(WALSH,2007).

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More than 250,000 new leprosy cases are reported annually worldwide. (WHO, 2012). Leprosy (Hansen disease) is a chronic infectious disease by M. bacterium leprae, an acid-fast, rod-shaped bacillus principally affecting the peripheral nerve, mucosa of the respiratory tract, and skin of human beings.

Leprosy may be manifested by skin lesions and loss of sensations associated with neurological changes. It is a disease of complex nature that affects the patient's physical, social, and psychological well-being (Rafferty, 2005). Leprosy is often called a "Social Disease. Numerous social factors." favor the spread of leprosy in the community, such as poverty and poverty-related circumstances ( e.g, overcoming, poor housing, lack of education, lack of personal hygiene) and fear, guilt, and unfounded prejudices regarding the disease. Despite scientific information available about leprosy, this legend is deeply rooted in most people's minds at all levels of society, resulting in social ostracism apparent everywhere ( Park, 2005). Throughout several years, the disease leprosy has been feared.

Pain affects physical and emotional well-being; it leads to social isolation, relationship, psychological problems, and an inability to work. Leprosy patients are not allowed to contact the community, including their families. Even they find it difficult to enter public places and use the public transport system. Leprosy is a stigmatizing condition and can lead to the person affected being rejected and excluded from society (Kaur & Ramesh, 1994). Persons affected by leprosy experience unsympathetic reactions, insults, hate, abandonment, or rejection, aggravating their social stigma and psychosocial problems (Leekasa, Bizuneh & Akem,2004).

Several findings indicate that parental disease also affects healthy children. Over the past ten years, research has suggested that



when children take on caregiving roles in the family, their educational, social, and emotional experiences and Health can often be seriously jeopardized. Such role adoption can occur due to long- or short-term parental illness or disability. (Jo Aldridge and Saul Becker, 1999). Early medical studies tended to highlight the negative impacts of parental illness or disability, often viewing physical and mental impairment as a crisis for the family (Arnaud, 1959; Castro de la Mata et al., 1960; Anthony, 1970; Romano, 1976), and for children within these families (Orvaschel et al., 1980; Cytryn et al., 1982; Schilling et al., 1982; Feldman et al., 1985; O'Neill, 1985). The children of leprosy patients also face negative psychological problems, but they have to face social isolation without fault. This kind of rejection, isolation, and deprivation affects both the physical and mental processes.

**Psychological Impact of Leprosy-** People's misconceptions about this disease affect leprosy patients and the healthy children of leprosy patients. Due to our neglect and hatred, they suffer from social discrimination, injustice, and exploitation. It has also been demonstrated that the school lives of adolescent children whose parents suffer from leprosy are also affected. In 2004 Vishwa Samvad Kendra denoted, "The healthy children of leprosy patients frequently face difficulty in getting access to primary education ." And also, the Anand gram society describes in the report (2003), "Leprosy is not a hereditary disease but unfortunately children of leprosy patients faced considerable difficulties in getting admission into schools ." This can affect the shaping of personality as well as the cognitive level of the children. The psychological impact leads them to many psychological problems such as low self-esteem, low quality of life, depressive symptoms, and other cognitive and health-related dysfunctions. Mahajan, Garg & Gupta (2002) selected a 5-15 years range group of children whose parents were affected with leprosy and stayed away from their parents in the charitable ashram. They were examined for any behavioral changes and signs of leprosy patients. They found that none of these children showed any behavioral changes or signs and symptoms of leprosy. It shows that leprosy is not a transmitted disease or hereditary disease. Only 5 to 10 percent of diseases are infectious. Therefore it is treated as another disease. Yamaguchi, Powel & Jimba (2013) conducted a study to examine the impact of Health-related Quality of Life (HRQoL), depression, and self-esteem in adolescents with leprosy-affected parents and found that the adolescents with leprosy-affected parents had higher levels of depressive symptoms, low levels of

self-esteem, and lower HRQoL compare with adolescents whose parents were unaffected by leprosy. Satish Kumar & N. Parashar (2015) researched to study the Quality of Life and Self-Esteem in the adolescent children of leprosy patients. They found that 60 percent of the sample showed low self-esteem and quality of life, and 40 percent showed average Quality of life and self-esteem. Antony, J. & Broota, A. (1991) found in their study that there was a negative self-concept compared with healthy parents' children. This low self-concept is attributed to parents' negative self-image & shame, social seclusion & societal attitudes. Another study found that the Physical well-being of the KINDLR was lower for adolescents with leprosy-affected parents than for those with unaffected parents (Rao, 2009). The children of leprosy patients gradually became neutral about social event participation; children of leprosy-affected people claimed that they were considered unfit for marriage because they were children of people suffering from leprosy. (Ayuba & Ebseno). The investigation shows that they fear avoidance and devaluation from others. The self-esteem, as well as the physical and emotional well-being of Leprosy patients and their families, are likely to be affected. Sometimes the unit family diffuses when any family members are affected with leprosy, then the members face social isolation, and children are deprived of their parents or mothers/ fathers. (Quinton & Rutter, 1985). These studies indicated that the children of leprosy patients have the negative psychological impacts of leprosy, such as low self-esteem, poor well-being, low self-concept., and so on.

**Psychological consequences-** The reviews mentioned above highlighted negative psychological impacts. These negative psychological impacts are leading them to many psychological problems. The negative



attitude of society toward leprosy patients and their families become the cause of many psychological problems such as anxiety disorder, depressive symptoms, etc. (Singh, 2012). The exclusion from school life poorly affects children because education is the fundamental right of every child and helps to develop a personality. It has also been postulated that the school lives of adolescent children whose parents suffer from leprosy are also affected.

Leprosy is a physical illness, but the affected people suffer from physical pain and face many challenges in society. They are hated by society and face social isolation. These kinds of problems affect not only them but also their healthy children. Leprosy is considered a hereditary disease despite many awareness programs by the Government and NGOs. The children of leprosy-affected parents faced problems getting admission to school and jobs at any private shop. They fear being evaluated in society; it means they suffer from higher social anxiety, low self-esteem, low well-being, and other psychological problems. Thus it is necessary to focus on the children of leprosy-affected parents.

**Conclusion-** Leprosy is not only a disease of a person but also of society. The whole society suffers from superstition about leprosy. These superstitions led them to do negative work or behavior toward leprosy patients. Leprosy patients faced social isolation. They have no permission to do jobs and face economic challenges. Poverty and social discrimination also affect their healthy children. It is the time of modernization means the current society is called modern society, but for leprosy and their families still the tradition. The deep-rooted psychosocial factors cannot be banished overnight, much less by legislation. Most factors are overlooked, and emphasis is laid only on early detection and treatment. Failure to appreciate the importance of the social and psychological factors has failed, of an otherwise well-conceived program. After all, they are also human beings and have the right to get a job, social status, get married, and live a happy married life, strengthening the socio-economic status of their own house and, ultimately, the Nation. (Gupta, 2009).

**Suggestion-**

\* The present study reflects the need for proper implementation of mental health programs for adolescents whose parents are affected with leprosy, and there is the goal of planning programs focused on improving the quality of the environment so that they can have proper living conditions and have proper medical facilities. Also, there is a stigmatization in society regarding leprosy and the stigma attached to the family members.

\* The stigmatization was reduced by spreading awareness about the treatment and precautions related to leprosy, which helps improve the quality of living and self-esteem among adolescents with leprosy-affected parents. (Borus, Lee, Gwadz & Dramin, 2001).

\* Realizing that the children of leprosy patients also need to aspire to higher goals like other children in the society to live independent lives, they were requested to list their expected career goals in life. If these children are motivated by providing accessible and affordable quality education, they are likely to succeed and thereby contribute their quota in nation-building. (Enwereji, et al, 2009)

**Limitations of the study-**

1. The reviews are very few children of leprosy-affected parents describe them.
2. Among these studies, the sample size is small; thus, more is needed to describe the condition.
3. We have to measure many psychological variables on various variables and know what impacts occur.

**Implications-**

\* Leprosy is considered a social stigma and God's curse rather than a disease. No other disease has this much public prejudice, hatred, and social stigma than leprosy and its sufferers. Not only the Parents with Leprosy but their children are also discriminated against in all spheres of life. However, extensive efforts are being made to avoid the segregation of parents with leprosy and their family members and the acceptance of parents with leprosy and their family members in society.

\* The present study will carry out the probable causes of different psychological problems among the children of leprosy-affected parents. If impairment would show, psychological intervention should be applied to reduce the impact of high social anxiety and enhance low self-esteem, emotion regulation,



and well-being. Further, the study would also throw light on the effectiveness of social attitudes towards parental disease, which help to understand the severity of the psychological problem in children of parents with leprosy.

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