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Research Article

Social Identity of Leprosy-Affected People in Puducherry Region: A Qualitative Study

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ABSTRACT

Leprosy is a least communicable disease affecting the human race. It can result in disability and impairments though can be prevented and treated effectively when diagnosed on time. It imposes constraint on the day to day activities and social participation of the affected persons. The result of disease stigma had furthered to the problem of social exclusion. Despite efficient treatments and considerable public awareness the stigma associated with the disease stands as a major issue in many societies. With social pressures such as poverty, illiteracy and unequal allotment of medical resources, the sufferers of leprosy experience increased social inequity. Leprosy had not only affected the physical condition but the status and roles of the individuals were also compromised in many ways. The disability resulting from the disease also declines the economic production of the affected individuals. Hence, the social factors attached with leprosy are studied in order to understand the status and identities of the sufferers. From literature survey on leprosy, it is understood that in spite of several programs and researches being done on the aspect of prevention and rehabilitation of the leprosy-affected people, there are very few studies carried out on the socio-cultural aspect of the community affected with leprosy. There are a number of people with leprosy and its social consequences living in Puducherry; a study on the social implications as a result of leprosy in a qualitative way is hence necessary. A qualitative study with observation and semi-structured interviews is carried out from the leprosy-affected individuals and families, in generating their case studies regarding their roles and status within family and society. Secondary sources were referred simultaneously.

Keywords: Leprosy, Disability, Social Identity, Stigma, Status and Roles, Economic Rehabilitation and Case Studies

INTRODUCTION

The notion of diseases is attached to various cultural reasons. With several social pressures such as poverty, illiteracy, unequal allotment of health resources and improper doctor–patient relationships the sufferers experience increased social stigma and social inequities (Foster *et al.,* 1978; Berreman, 1984; Volinn, 1989; Staples, 2007). The culture, experiences and social structuring related to the illness shape the identity of those being affected. With respect to the diseases that result in disfigurement of the body, the possibilities of being stigmatised by their physical disabilities become severe. Culture tends to attribute several reasons including spiritual, ancestral and social intentions for being afflicted with certain disease like leprosy. Thus, an identity has been falsely created affecting the lives of the victims in spite medically the condition can be cured completely. The role played by an identity becomes very important in any cultural scenario. Especially in the Indian context, the identity of an individual determines the status and roles of them. Identity in basic sense refers to the socially constructed category and the individual's dignity or self-respect (Fearon, 1999). Identity is thus associated with both social and personal aspect, the ways in which the individuals and groups define themselves and are defined by others comprising believes, moral values, physical and behavioural attributes (Hogg and Abrams, 1988; Deng, 1995). To possess an identity means to relate oneself to a particular social status which may also be assigned by other members of the society giving rise to what we call the social identity (Jenkins, 1996). The identity imposed on those affected by certain diseases makes it challenging to lead lives efficiently like a normal person. The identity of those affected by leprosy and lives led aftermath is discussed in the following passages.

LEPROSY–ITS SOCIAL SIGNATURE

Leprosy is a least communicable disease affecting the human race. It can result in disability and impairments though can be prevented and treated effectively when diagnosed on time. It imposes constraint on the day to day activities and social participation of the affected persons (Geetha and Rao, 1999; Rao, 2009). In resource-poor countries, leprosy continues to cause massive disfigurement particularly among most vulnerable population whose lives are weighed by poor hygiene and malnutrition (Ovesen and Trankell, 2010). Despite effective treatments and massive public awareness the stigma associated with the disease stands as a major issue in many societies (Brakel, 2003; Heijnder, 2004). The disability resulting from the disease declines the economic production of the individual along with restricting their social roles (Kopparty, 1998). The result of identity associated with the disease had furthered to the problem of social exclusion (Mull *et al.*, 1989; Douglas, 1991; Nicholls *et al*., 2005; Brakel, 2006). The identity related to leprosy is associated with the fear regarding social restriction, the family and economic issues and disfiguring deformities.

With the implementation of multidrug therapy (MDT), significant improvement in leprosy control has been achieved all over the world (Gopal, 1999). In spite of it, people living with deformity due to leprosy are still found in certain endemic regions. The South–East Asia region accounted for 71% of new cases detected worldwide in 2012 according to the WHO report. According to global statistics, there are 2,20,810 (95%) new leprosy cases reported from 16 countries and only 5% of new cases from the rest of the world and India is 1 of the 16 countries listed in 2012 report for being detected with ≥1000 new cases; having 1,34,752 new case detection (WHO, Weekly Epidemiological Report, 2013).

From literature and history it can be understood that there are preconceived notions and superstitious beliefs associated with leprosy, which exist till today. The identity and stigma attached to leprosy is promoted and sustained through cultural manifestations, societal attitude and other historical constructions. Leprosy does not only affect the physical condition if untreated on time but also the status and roles of the individuals are compromised in many ways. In antiquity people believed (often mistakenly) the leprosy victims were forcibly cast out from families and castigated as a threat to the rest of society. In fact, the identity of those affected with leprosy, such as addressing them as lepers can be considered as a socially excluded category and form of untouchability (Staples, 2007). Indeed, in the English language itself, the word 'leper' has become synonymous with someone shunned and ostracised (Sontag, 1989). Stigma caused by a disease is not because the disease may be fatal but because it is recognised as giving the sufferer a different self-identity and therefore, making one dissimilar from the social norms.

OBJECTIVE OF THE STUDY

To study the social identity created as the result of being affected with leprosy and consequently understand their status and roles.

MATERIALS AND METHODS

A qualitative study with observation and semi-structured interviews was carried out from the cured leprosy-affected individuals along with their families, working at 'Atelier Shanthi' and staying at the quarters provided by Volontariat – a non-governmental organisation. Atelier Shanthi is a weaving centre with a rehabilitation purpose for disabled people in particular cured leprosy-affected persons at Lazar Koil Street, Dubraypet and from aged deformed leprosy patients residing with their families in 'Nicole Durieux' a residential quarter built for them and sponsored by CERTH, India, hospital at Vambakeerapalayam, Puducherry. This study was initiated in generating data to understand the impact of the disease on the sufferers and their families. The case studies of the informants were collected and analysed

which led to the key discussion of this article. This article particularly focuses on the social identity of the leprosy-affected individuals and is developed from five case studies generated from leprosy victims and two case studies about lives led as leprosy victims from the perception of individuals not affected with leprosy.

DISCUSSION

REFLECTING THE THOUGHTS OF LEPROSY VICTIMS

Today, in spite of advanced medical treatment ensuring complete cure, leprosy still imposes an identity on its victims. The following discourse will reflect the thoughts of leprosy-affected people regarding their experience living with the mark of the disease through case studies.

CASE ONE

'One of the respondents, Wasir Ahmed with partially deformed hands and foot, residing alone at the quarters allocated for him by CERTH, an NGO, shares his experience of how it is to live with leprosy identity'.

The perceived stigma prevented him from revealing his condition, not furthering with treatment resulting in disfigurement. Coming from an orthodox Muslim family, he was forcibly sent out of his home soon after knowing his condition. Having visited the CERTH, he was treated and given quarters meant for leprosy-affected people. He runs a small-scale doll-making industry helped by CERTH. He had a school-level French education. In spite of his education and earnings from the doll company, he is disappointed that he could not marry and have a family because of leprosy identity. His friends are cured leprosy affected and physically challenged neighbours. He does not associate with any other outsiders. This shows his feeling of humiliation as leprosy victim. He is unable to cook, hence his blind neighbour helps getting food for him. He manages to ride a bicycle and visit markets in buying his daily needs. However, there are only few places he regularly visits. Despite holding strong faith in his religion, he is unable to visit mosques because of health and personal reasons. He says, 'My thought is mosque and place of worship'. He was born Muslim and wants to die Muslim, his identity according to him.

However, he was introduced by the medical workers and neighbours as leprosy victim, he has earned respect and recognition among his area people through the doll company he runs. He employs three other physically challenged in his company, providing them income. By marketing his products to various places through CERTH, he has earned dignity in spite of physical deformity that imposes restriction in social participation. Even though the economic upliftment has not changed the leprosy-related stigma entirely, he manages to socialise and improvise his lifestyle.

CASE TWO

Rajam is a widow. She got married at the age of 20. Her husband was not related to her and he did not suffer the pain of being affected with leprosy. He nursed her well and never alienated her for the reason that she was affected with leprosy. He died 6 years ago. She mothered two female children and one male child, who had abandoned her due to property dispute. She is now residing in a separate house. She sells fish for her livelihood and also receives an amount of Rs. 1000/- as old age pension. She was infested with leprosy, when she was 10 years old and underwent medical treatment immediately, despite in those days, the moment one is diagnosed with leprosy the stigma associated with it would not allow them to further treatment. Despite treatment she became ill with fever which culminated into physical deformity. Her children and grandchildren too, never hate or distance her due to leprosy.However, in the beginning her relatives and others spoke ill of her condition of being affected with leprosy. She was not in a position to mingle with others due to the social stigma created. She was feared by her family members and this generated within her a feeling of being ostracised. Nevertheless, presently being in the company of similar affected persons she does not feel left alone. The persons who buy fish from her in the market had not shown any sign of abomination looking at her deformed hands. In fact, a medical officer who also had bought fish from her asked her as to whether she was medically treated and advised her to visit him if she would suffer other ailment. She now financially suffers even though she gets the old age pension and the sales proceeds from fish, which most of the time is much less than the purchase price. She wishes that the Government may consider such conditions for additional benefits to substantiate her living.

CASE THREE

Mahalakshmi is a Christian convert widow. She was born in Mumbai, brought up in Chennai; hence she is very fluent in Hindi and Telugu. Her father was a ship captain and she hailed from an affluent family. She was affected with leprosy at a very young age and before she could get treated, the disease had resulted in deformity of her hands and feet. Fingers of her hands and feet were lost due to the severity of leprosy. After being diagnosed with leprosy, her parents stopped taking her to relative's places and to temples, fearing that they might ill treat them. Most of the times, she was excluded from her family happenings due to the impression that being infested with leprosy would pollute it. Even if she was taken to temples, she used to be given bath and cleaned up before going. The feeling of being ostracised in the name of pollution offended her. As a result she lost hope on the ideologies of her religion and her community. She came over to Pondicherry to get treated for leprosy where she got married to a person who was also infested with leprosy at

the age of 25. It is 11 years since her husband died, after which she stays alone in the quarters provided by Atelier Shanthi, where her husband had worked. Here she met with Christian missionaries often, who prayed and encouraged her in living life confidently. However, her relatives treat her well and care for her now; she feels that if she was not affected with leprosy, she would have been in a good job and a better position in the society. In spite of having lost the fingers of her hands and feet, she manages to eat, brush and carry on other basic day-to-day activities comfortably. She only feels poignant that she could not help others but never had felt her deformity restricted her personal lifestyle. Indeed, she feels pleased that all her needs are being taken care of someone or the other. Her piousness enables her to live a worry free life. None speaks ill of her condition, in view of the fact that she stays in the company of other similar people. She tries to help others monetarily whenever possible. In fact the way she lives show others that she feels blessed compared with many other leprosy-affected persons who lack house or people to take care of them.

CASE FOUR

Jayalakshmi, a widow was affected with leprosy at the age of 10 and was brought up mother less. Sooner being diagnosed with leprosy, she was taken by her father to be admitted in a Leprosy Hospital at Saakottai, Kumbakonam. In spite of it the disease resulted in mild deformities of her fingers. She got married to a person who also suffered leprosy with disabled hands and feet undergoing medical treatment in the same Hospital. She had no children as result of leprosy. Her husband died in 2009 after a serious lung problem and later she started living alone. Sister of Jayalakshmi's mother-in-law was affected with leprosy; she had also given birth to nine children who were all well brought up with good health. This set an example and hence Jayalakshmi too did not experience any indifference or mistreat from her husband's family. Indeed she had enjoyed good respect. She is presently working in 'Atelier Shanthi', in the weaving department, earning Rs. 600/- per week after deducting house rent for the quarters set up for such people in colony. In her view, there is a considerable change of opinion among the public about leprosy between the past period (20–30 years ago) and the present. She gets a sum of Rs. 1100/- as old age and differently abled person's pension. She used to get 15kg of rice through public distribution system, which is not available recently from the last year (2012) and this causes hardship in her daily livelihood. She is able to perform her day-to-day activities independently. She appreciates other leprosy-affected people. She says, many of them without fingers and feet work hard and even beg to run their families. There are many people who have successfully brought up their children, educating them. She says that one should learn to lead life with confidence like them.

CASE FIVE

Iyyappan aged 45 was affected with leprosy at the age of 9. He comes from Kumbakonam. He initially suffered fever which resulted in deformities of his fingers. He had undergone medications for 8 years after which he was completely cured. He got married at the age of 30 to a leprosy infested person, a native of Tanjore, whom he met at Atelier Shanthi, where he and his wife work in hand weaving of fabrics. He has one son aged 16 and a daughter aged 15 who are healthy and are studying now. He receives a sum of Rs. 700 per week and also a sum of Rs. 1100 as a pension for the physically challenged person. He finds it difficult to work with this company because of his physical deformity. Though he said, he was not commented nor spoken ill of because of his physical condition, he refused to further talk about his family and other issues related to leprosy. His only aspiration is to bring up his children well, without bearing the mark of being the children of leprosy-affected persons. He was unwilling to continue with the interview saying that it might impose an identity on his children that will affect their carrier and as well earn him a bad name from the organisation that has employed him.

CASE SIX

Following is the excerpt from interview with Sekar who is not a leprosy victim but who had worked together with leprosy-affected people in Atelier Shanthi and stays in the quarters allocated for them. He explains his view about the lives led by the leprosy victims and their identity.

Sekar though is not affected with leprosy stays as a neighbour to those impinged with leprosy. He says that his family never treated them differently and in a way that would hurt them. He feels this impartial mentality and the awareness about leprosy are implanted by the administrators of Atelier Shanthi, organisation started for the wellbeing of leprosy victims. He mingles very casually with those affected with leprosy. He sympathises over their condition of being unable to take care of themselves. He and his family can happily associate with them in all social happenings. He feels that 30 years back, those affected with leprosy were engaged in beggary for their living. Their physical condition made them stay isolated from rest of the society, leaving them uncared. However, by the goodness of those who establish organisations for the welfare of those affected with leprosy, they are given places to stay, provide food and care through its voluntaries. Many of them affected with leprosy now lead a successful life bringing up their children well educated and well mannered, that an outsider could barely discover the condition of their family and parents. His family members had never hesitated to share food or participate in the occasions of those affected with leprosy. Sekar astoundingly says, ‘Those families here, that are affected with leprosy had so far not borrowed

money from us even if it was urgently needed, they manage to arrange it whereby they are evident to show how to live with dignity. In fact they generously lend us money when we are in need'. He dedicates the wellbeing of leprosy-affected people there purely as a successful effort by the management of Atelier Shanthi. Sekar points out an incident that had inspired and amazed him. He talks about a co-worker Emmanuel and his wife, affected with leprosy. Emmanuel worked in checking the fabric pieces in the weaving section of Ateleir Shanthi and his wife worked there as a cleaner. They stayed in the quarters provided for them. They had a son, whom they educated well. He is now working as a Sub-Inspector of Police in Pondicherry and they have now shifted to the police quarters. The determination and hard work of his parents to ensure that his son is well respected in the society had earned them this state of reverence and admiration. Moving from a quarters for leprosy victims to police quarters not only portray the physical transformation but also the transformation of their identity. They are now referred with the designation of their son rather by their physical condition with which they were addressed once.

CASE SEVEN

JesuMary is a nurse employed in Certh India Private Hospital at Wambakeerapalaym. She works amongst the leprosy-affected people from past 28 years. According to her, these days leprosy is just like any other curable and treatable disease. With the introduction of MDT (multidrug therapy) the treatment has become very effective. When patients are treated at early stages, the disease can be cured and the deformities be prevented. In earlier days, treatment for leprosy was very sparse and hence many cases were diagnosed with prolonged infection and deformities. She says, 20 years back the stigma associated with leprosy was so great in India as well in Pondicherry. She has worked under a project funded by Spanish Organisation dealing with identification and eradication of leprosy through Certh India. She says that 25 years back there was 1 leprosy case in a population of 1000 and now there are just 0.1 cases in every 10,000 of a population. Earlier the spread and causation of the disease was unknown and there were several misconceptions like the disease was caused as a result of sin, curse and wrong deeds associated with it. This had led to isolation and exclusion of the leprosy-affected people from their families and society. Those affected with leprosy suffered abomination due to the deformity caused by the disease. People around hesitated to socialise with them fearing the spread of the disease. Later people became aware of the disease through advertisements, T.V shows and street plays. Because of the awareness about the nature of the disease and that it is caused by bacteria and is completely curable when treated, public's acceptance of the leprosy-affected population has grown wider. People who are cured but disabled are found easily socialising in common places like the tea stalls, use public transportations, mingling with rest of the society.

Those who are adversely affected by the disease are considerably low these days. Mortality rate was high 20 years ago, as soon as people were affected by leprosy, they were sent out of their houses. Since they were ostracised by the family and their community they started occupying isolated homes, leprosarium and hospitals for shelter and care. However, these days they stay with their families and undergo medications and treatment and are cured completely. Leprosy in recent days has become a fearless disease. Those days, treatment was not easily accessible and the places of treatment were unknown. But the treatment is affordable, easily accessed in appropriate time reducing its effects on the individuals.

RESULTS

In spite of several programs and researches being done on the aspect of prevention and rehabilitation of the leprosy-affected people, there are very few ethnographic studies carried out on the community affected with leprosy. This article tries to discuss the social consequences of leprosy with reference to the people affected with it in the Puducherry region.

From the first case study, though the feeling of being affected with leprosy is visible from the respondent's interview, economic sustainment through business empowers the person in managing his daily activities, socialising and facing life with assurance. From the income generated, the respondent not only earns the favour of others in fulfilling his requirements but also develops friendly relationship with his neighbours and their families. The identity of the respondent is seen shaped by his business rather by the disease. However, this case depicts the stigma associated with the disease has changed from what is called the enacted to the perceived stigma, fear about the result of having leprosy and its associated feeling of inferiority, shame and unworthiness (Nicholls *et al*., 2005; Tsutsumi *et al*., 2007). The second case study describes the treatment received from the family and society towards a leprosy-affected woman and it portrays the complications faced by the respondent in fulfilling her physical obligations due to insufficient income generated. There is a change in how people treat the respondent and being able to socialise with everyone she meets, she does not feel isolated due to leprosy and the stigma associated has also gradually vanished. The feeling of being unable to seek help from others for the reason that they would claim money in return demands economic rehabilitation. The respondent though is not identified with leprosy socially, the impoverished condition as result of the disease makes her express her condition in order to receive support. Religion plays an important role in every individual's life. People are identified with their religious background. The norms and values attached to it regulate the familial and communal relations. In case of leprosy, religion has become a reason in developing inferior and neglected feeling. Case Study Three explains how being

afflicted by religious norms affects the respondent's dignity where by a religious conversion is opted. Though the respondent displays physical deformity she expresses her identity as a Christian and a well-wisher to others rather sympathise through her condition. However, with reference to Case Study One, though the respondent agonises about being unable to visit mosque, prefers to hold on to Islamism, religion by birth and wanting to be identified as a Muslim. A person may or may not take a special pride about her identity and many times the person believes the identity does not change even if he/she wants it to (Fearon, 1999). Though the signature related to leprosy is burdensome and unwanted, it can be seen influencing the lives of its victims throughout. However, like the mindset of the respondent in Case Study Four which portrays the appreciation towards those leading lives confidently in spite of disease mark, it is the personal choice whether or not to take pride over their identity. Case Study Five talks about those affected with leprosy still facing problems in their job opportunities and economic aspects because of the disease identity. This case reveals the respondent's feeling that if his condition of being victimised with leprosy is known to others it might impose an unacceptable identity on his children. Here the respondent is still conceived by his disease stigma in spite being employed and having a good family. The perception of individuals not affected with leprosy and health care workers about leprosy and lives led as leprosy victims brought out from the interviews are depicted from the below case studies. Though economic instability impacts their living, Case Study Six describes the zeal of those affected with leprosy to lead life with dignity. In this case, a person not afflicted with leprosy records his admiration for the disease victims in how they try to maintain their self-respect through moral living. They possess high principles like not to borrow money even at times of hardships, which earns them others high opinion. Also, from the same case it can be understood that the organisations working for the benefit of leprosy victims plays essential role in changing the preconceived notions about leprosy where by diminishing the identity of the disease and inducing positive attitudes towards them. Case Study Seven illustrates an interview with a medical practitioner who has been working amongst the leprosy-affected community. It reveals the following about the conception of the disease and its relation to its sufferer. Medical advancements and its increased awareness among public plays an important role in reducing the stigma related to leprosy. As discussed by the medical practitioner, the social stigma related to leprosy when compared to past has taken a different course with effective and affordable treatments.

CONCLUSION

From the case studies discussed, it can be clearly understood that the identity of a person gets modified in case he/she becomes susceptible to certain conditions like a disease/a disorder or an illness. Nevertheless, as told by Charles Taylor in

Sources of the Self: The Making of the Modern Identity, the question of identity is often phrased by people in the form: 'Who am I? and who others are?'. Visible changes that have taken place as the result of being affected by a disease or an illness imposes a change inthe identity of that particular person. Though leprosy is a stigmatised disease, the stigma associated with leprosy has gradually declined and the unconstructive attitude towards leprosy victims has changed with the intervention of productive bio-medical practices and knowledge. Many leprosy-affected individuals live with their families these days with not much socially provoked disappointments and arguments. However, the requirements of cured leprosy victims whether institutionalised or not should be noticed and taken care of. In order to completely banish the leprosy identity as a socially unacceptable one, economic rehabilitation with finance schemes from the Government and self-help-based income-generating projects fulfilling the expectation and needs of the leprosy victims will play a major role in upbringing their status in the social category. Hence, it is also recommended that the family members of those affected with leprosy are provided education and job opportunities in order to face the society without the stigma imposed on the family by the disease. Social integration is one of the best ways to counter the isolation of many leprosy-affected people, as said by Frist (2003) since it helps hold one's self esteem. As pointed out by him the move should be from segregated support systems to integrated ones.

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