

Stigmatization in Leprosy: A descriptive study from patients' perspective in Sri Lanka

M.A.J.D. Mallawa Arachchi, A.G.D. Kumari

Leprosy Hospital
Hendala, Sri Lanka

R. Wickramasinghe

Dept. of Basic Sciences
The Open University of Sri Lanka
Nawala, Nugegoda
rachithaw@yahoo.com

N.R. Kuruppu, A.V. Pramuditha Madhavi

Dept. of Nursing
The Open University of Sri Lanka
Nawala, Nugegoda
nipunarandini@gmail.com, avpma@ou.ac.lk

Abstract- The stigma of leprosy is a real phenomenon in many people's lives that affects their physical, psychological, social and economic well-being. The objective of the study is to investigate the stigma in leprosy from patient's perspective. Further this study help to determine how stigmatization affect the social life of patients with leprosy, how stigmatization affect the psychological aspect of patient's life and identify the coping mechanisms employed by patients to manage the stigma. This study was conducted in the central leprosy clinic in National Hospital in Sri Lanka. The data were collected from hundred and thirty two leprosy patients who are being treated in central leprosy clinic. The quantitative approach and descriptive design were used for the study. The tool was researcher administered questionnaire with close ended questions. The data were analyzed using descriptive statistical analysis with Microsoft excel. The results clearly indicated that majority of patients have high level of self-stigmatization in both psychological (60.4%) and social (76.7%) aspects. Therefore, stigma reduction activities should focus on health education and counseling programs while giving multi drug therapy.

Index Terms— Stigmatization, Leprosy.

I. INTRODUCTION

Throughout the recorded health history in the world, leprosy has been one of the most dreaded communicable disease by which people are threatened [16]. By the time the treatment was found to leprosy, many people have already been infected from the disease [5]. Leprosy is a chronic infectious disease if untreated, leads to progressive physical, psychological and social disabilities [6]. According to the world health statistics more than 1000 cases have been reported from sixteen countries in the world during the year 2012. Among these countries, India, Nepal, Nigeria, Philippines, South Sudan, Sri Lanka and united Republic of Tanzania reported more new cases in 2012 than in the previous year [17]. In Sri Lanka, over 2000 new leprosy patients had been identified during the

period from year 2000 to 2013. Six new leprosy patients are being detected in Sri Lanka daily [4].

People with leprosy and related deformities suffer from social stigma and discrimination leading to economic loss [5]. Stigma is not a single phenomenon and can be define as "an attribute that is deeply discrediting, and the stigmatized individual is one who is not accepted and is not accorded the respect and regard of his peers; one who is disqualified from full social acceptance" [8]. Stigmatization in general can consider from two min aspects, e.g. it may be conceptualized in terms of self-stigma (e.g. shame and lowered self-esteem) or public stigma (e.g. the general public's prejudice) that is also associated with social participation restrictions and discrimination [15]. Negative attitude towards people with leprosy act to destroy the patient's psychological and social health. The shame associated with this disease due to its stigmatization can prevent people from seeking treatment until significant disability has occurred [8].

Patients with leprosy who did not follow multi drug therapy and late diagnosed patients remain with permanent deformities and disabilities such as visual problems and changing their external appearance [6]. The associated visible deformities and disabilities of the disease have contributed in turn to the stigma in the society and discrimination experienced by leprosy patients [5] so that it clearly explicit a vicious cycle. Even if patients are cured the stigmatization can remain leading to create obstacles to resumption of a normal life [2].

Given the deformed appearance of the leprosy caused by its complications patients with leprosy by themselves are feared and hesitant to have regular social contacts in addition to the negative social responses they confront [2]. Therefore, social stigmatization in leprosy becomes a complex issue which need to be promptly addressed in order to successfully control and then to eradicate the disease from the society. Given its stigmatized nature, as a global health issue leprosy has drawn the research attention in several countries.

Many studies done in other countries have shown that leprosy and its stigma have a prevailing effect on a patient's life, affecting marriage, employment, interpersonal relationships, leisure activities and attendance at social and religious functions [13]. In Nepal, people with leprosy are often ostracized by their communities, reporting insults, rejection and hate [2]. Scott, (2000) found that one-third of leprosy patients in the study were left by their spouses. This situation is substantiated by a participant's own voice "we can endure losing fingers and toes, eyes and nose but what we cannot endure is to be rejected by those nearest and dearest" [10]. A study of India found that 16-44% of those with leprosy fall in their income because of their disease, bringing them an economic burden, showing another adverse aspect of the stigma [9]. Rafferty (2005) found that younger people who develop leprosy may find it restrict their education. Giving rise to gender discrimination another study has shown that women are more affected by leprosy and its stigma with suffering more isolation, loss of touch, rejection, and having more restrictions on them than men with the same level of disease [18].

While many studies are exploring the social stigma of leprosy, some studies have looked at the stigma of leprosy from a different aspect. Thus, Verma (2010) emphasized that current social stigma in leprosy has reduced and self-stigma among leprosy patients is having a developing trend instead. This is evident by the fact that in an Indian study 49% of breast feeding mothers with leprosy have stopped breast feeding their children assuming by themselves that it is not good to breast feed their children. Another example for rising self-stigma of leprosy is that one third of patients in a study conducted in South Africa were found to have contemplated suicide after they are being diagnosed as leprosy [11].

Developing trend of self-stigmatization among patients with leprosy evident by available literature prompt the researchers' interest to examine the leprosy related stigma from sufferers' own perspective in Sri Lanka context. The study was further focused to examine how participants' social and psychological aspects of life have been affected by stigmatization and coping mechanisms used by participants to cope with disease related stigma.

II. METHODOLOGY

The quantitative approach and a descriptive design were used for the study and the study was conducted at central leprosy clinic in NHSL Sri Lanka. The target population of the study consisted of leprosy patients who are being treated in central leprosy clinic. A convenient sample of 150 patients fulfilled the inclusion criteria and volunteered to participate were selected to the study.

Subjects were included to the sample based on meeting following inclusion criteria; they should have had diagnosed the disease, be mentally sound, and should be free from any auditory problems. Volunteer participation was encouraged throughout the selection process. Individuals with any type of mental impairments or with any type of auditory impairment are excluded from the study.

Data was collected using a researcher administered questionnaire to evaluate the stigma in leprosy patients. Pre tested validated questionnaire was used after modifications. The questionnaire was consisted of four sections. Section I included demographic data such as age, level of education, income and gender. Section II and III included an internationally validated questionnaire called (ISMI)

Internalized Stigma of Mental Illness scale and (EMIC) Explanatory Model Interview Catalogue stigma scale to determine how stigmatization affects the social life of patients and psychological aspect of patient's life. The section IV of the questionnaire was used to identify the coping mechanism employed by patients to manage the stigma. The questionnaire was prepared in Sinhala, English and Tamil languages. Data Analysis was done using descriptive statistics and Microsoft Excel software.

Ethical approval for the study was obtained from ethics review board of the NHSL to conduct the study. Permission was taken from relevant authorities to collect the data. Informed consent of the participants was obtained after explaining them about the study.

Anonymity, confidentiality, and ethical principle of self-determination were maintained throughout the study to assure the privacy and autonomy of participants.

III. RESULTS

Of the total, majority (75.2%) of participants were age between 38-48years and more than half of the patients were female. When considering the social life 98.6% were rejected in getting closer by family members and 92.5% and 88.6% were discriminated and ignored by others respectively (Fig.1). According to the research results, it is clearly indicated that majority (98.6%) of the participants thought that nobody was interested to get closer to them due to leprosy. From this study 89.3% of participants tend to stay away from the society due to leprosy while 86.6% thought that it is better to avoid people from contacts (Fig.2). When considering the psychological aspect 89.7% participants were experienced stress and 73.9% were got embarrassed and ashamed as a result of having leprosy (Fig.3). Getting socially isolated was identified as the most common type of coping mechanism (Fig.4).

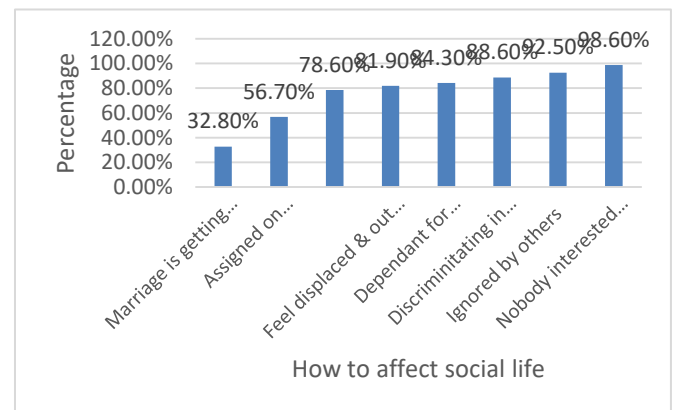


FIGURE 1. EFFECTS ON SOCIAL LIFE

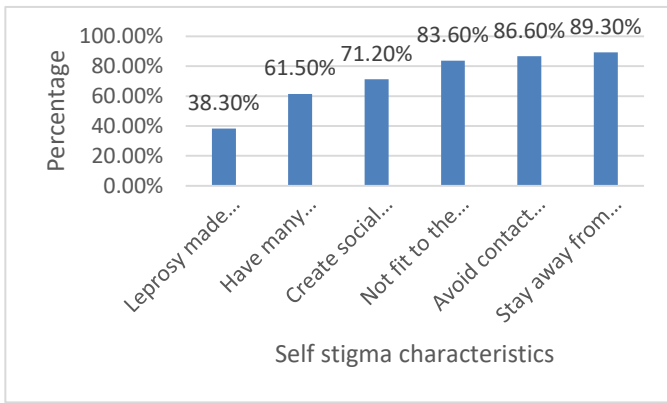


FIGURE 2. SELF STIGMA CHARACTERISTICS

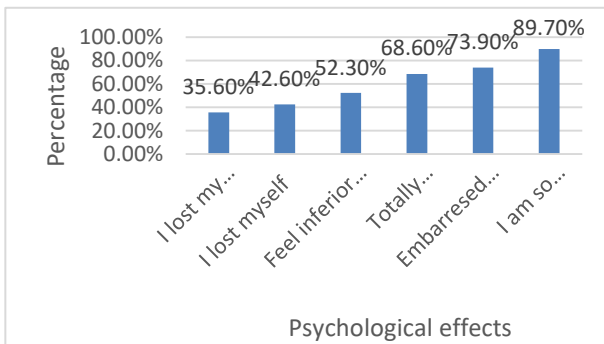


FIGURE 3. PSYCHOLOGICAL EFFECTS FOR LIFE

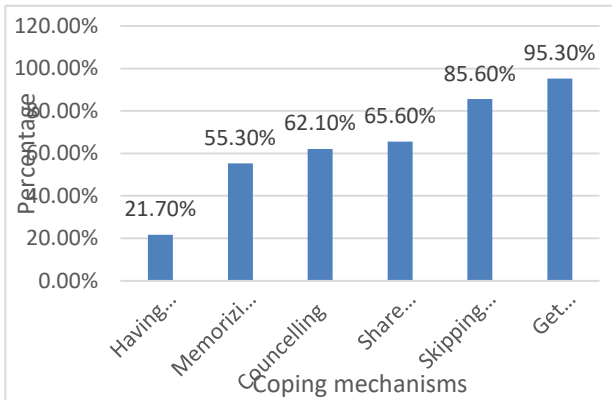


FIGURE 4. COPING MECHANISMS

IV. DISCUSSION

The present study is focused to investigate the leprosy stigma from patients’ perspective. The results clearly indicated that most of the patients have high level of self -stigmatization affecting their both psychological and social aspects of life.

A. Effects of leprosy on social life

Around 75% of participants’ social lives were affected by stigmatization of leprosy. Nearly 88.6% were discriminated at social gatherings while more than 92% were ignored by others. A significant proportion of participants thought that nobody interested to get closer to them. This may be due to negative perceptions and misbeliefs of people about the disease, as well as their unpleasant deformities. In a study conducted by Myint and Ulrich (2001) showed similar results highlighting that many leprosy patients experienced rejection from the societies and are not able to find complement. Similarly Verma et al (2010) observed that their neighbors do not even sit with them after diagnosis/disclose of the disease and most patients do not

visit neighbors’ home due to their rude behaviors. But contradictory results to these findings have been found by Seshadri et.al. (2015) from their study where restriction in community participation was not so prominent. According to the findings of this study, only 32.8% got their marriage late due to leprosy. In similar to that Arole (2002) has indicated that there were very few negative attitudes among family members towards their leprosy spouses. Further they found that even though some of the participants were suspicious of leprosy before their marriage, they tend to get married. Some participants lose their employment because of functional disabilities associated with leprosy or because of negative attitudes of employers or the community. It has a major impact on their economic status as some of them were breadwinners of their family. Similar findings were found by Ebenso (2007) and his colleagues from their study.

B. Psychological effects for life

Present study showed that patients feel ashamed and had to isolate themselves from the society and experiences of discrimination and they think leprosy is something shameful to hidden away. Similar results were found by Verma et al (2010) stating that common reactions after knowing their diseases was anxiety and hopelessness. One of the studies done in South Africa has found that one third of black patients had contemplated suicide when they learned about their diagnosis [11]. Other prominent psychological effects evident from this study were stress and disappointment experienced by participants due to disease. It is a major issue resulting from leprosy highlighting the psychological support needed from family and community.

C. Self-stigma characteristics

When considering the self-stigma characteristics, it was found that more than 89% of patients felt it is better to stay away from the society rather than creating social problems for their families. They may isolate themselves from the society thinking as they are having many health problems due to leprosy thus they are not fit for the society. Similarly Verma et al (2010) found that most of the patients have high level of self-stigmatization rather than the social stigma. Furthermore they found that majority were reluctant by themselves to go to the society.

D. Coping mechanisms

Getting socially isolated (95.3%) and skipping social contacts (85.6%) were identified as most common types of coping methods. Interestingly, 65.6% & 62.1% of patients in this study prefer to get counseling and sharing their feelings with close ones respectively.

V. CONCLUSION

Findings of this study showed that majority of the participants by themselves have restricted their many social contacts by getting apart from the society. This explicitly shows that participants are affected by self-stigmatization rather than being stigmatized by the society. Therefore, stigma reduction activities should be focused on giving psychological support through counseling programs to empowering sufferers to change their own view of their condition. Social awareness programs on leprosy may be another potential remedial action to reduce the social stigma on leprosy.

ACKNOWLEDGMENT

The authors acknowledge all the participants who voluntarily participated for this study,

REFERENCES

- [1] Arole, S., Premkumar, R., Arole, R., Maury, M., & Saunderson, P. (2002). Social stigma: a comparative qualitative study of integrated and vertical care approaches to leprosy. *Leprosy review*, 73(2), 186-196.
- [2] De Stigter, D. H., De Geus, L., & Heynders, M. L. (2000). Leprosy: between acceptance and segregation. Community behaviour towards persons affected by leprosy in eastern Nepal. *Leprosy review*, 71(4), 492-498.
- [3] Ebenso, B., Fashona, A., Ayuba, M., Idah, M., Adeyemi, G., & S-Fada, S. (2007). Impact of socio-economic rehabilitation on leprosy stigma in Northern Nigeria: findings of a retrospective study. *Asia Pacific Disability Rehabilitation Journal*, 18(2), 98-119.
- [4] Epidemiological Bulletin (2013). Available from: http://www.epid.gov.lk/web/images/pdf/bulletin/2013/4th_qeb_2013.pdf [cited 10 March 2017].
- [5] Jopling, W. H. (1991). Leprosy stigma. *Leprosy review*, 62(1), 1-12.
- [6] Joseph, G. A., & Rao, P. S. (1999). Impact of leprosy on the quality of life. *Bulletin of the World Health Organization*, 77(6), 515.
- [7] Myint, T., Thet, A. T., Htoon, M. T., & Win, M. (1991). A comparative KAP study of leprosy patients and members of the community in Hlaing and Laung-Lon townships. *Indian journal of leprosy*, 64(3), 313-324.
- [8] Opala, J., & Boillot, F. (1996). Leprosy among the Limba: illness and healing in the context of world view. *Social Science & Medicine*, 42(1), 3-19.
- [9] Prabhakara Rao, V., Rao, I. R., & Palande, D. D. (2000). Socio-economic rehabilitation programmes of LEPRO India-methodology, results and application of needs-based socio-economic evaluation. *Leprosy review*, 71(4), 466-471.
- [10] Rafferty, J. (2005). Curing the stigma of leprosy. *Leprosy review*, 76(2), 119-126.
- [11] Scott, J. (2000). The psychosocial needs of leprosy patients. *Leprosy review*, 71(4), 486-491.
- [12] Seshadri, D., Khaitan, B. K., Khanna, N., & Sagar, R. (2015). Dehabilitation in the era of elimination and rehabilitation: a study of 100 leprosy patients from a tertiary care hospital in India. *Lepr Rev*, 86(1), 62-74.
- [13] Van Brakel, W. H., Sihombing, B., Djarir, H., Beise, K., Kusumawardhani, L., Yulihane, R., ... & Wilder-Smith, A. (2012). Disability in people affected by leprosy: the role of impairment, activity, social participation, stigma and discrimination. *Global health action*, 5(1), 18394.
- [14] Verma, D. K., Katoch, V. M., Katoch, K., Gupta, S. C., Jain, P., Tomar, S., & Yaduvan, A. K. (2010). A study of social stigma by the neighbors among leprosy patients of Agra and Kanpur districts of UP. *Indian Journal of Community Health*, 22(1), 8-12.
- [15] Weiss, M. G. (2008). Stigma and the social burden of neglected tropical diseases. *PLoS neglected tropical diseases*, 2(5), e237.
- [16] World Health Organization (1996). Global Strategy for the elimination of leprosy as a public health problem. Available from: http://apps.who.int/iris/bitstream/10665/63050/1/WHO_LEP_96_7.pdf [cited 12 August 2017]
- [17] World Health Organization (2013). Global leprosy update, 2013; reducing disease burden. Available from: <http://www.who.int/wer/2014/wer8936.pdf?ua=1&ua=1> [cited 10 July 2017].
- [18] Zodpey, S. P., Tiwari, R. R., & Salodkar, A. D. (2000). Gender differentials in the social and family life of leprosy patients. *Leprosy Review*, 71(4), 505-510.