

## Original Research Article

# Perception of social stigma among patients attending a filariasis morbidity control clinic in South India

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## ABSTRACT

**Background:** The psychological and social stigma associated with lymphatic filariasis can adversely affect productivity and quality of life. This study was carried out to assess the perception of social stigma among patients with lymphatic filariasis.

**Methods:** A hospital based cross sectional study was done on 30 subjects with lymphatic filariasis who attended a filariasis morbidity control clinic in Tamil Nadu. Data was collected using a locally adopted, pilot tested interviewer administered questionnaire derived from explanatory model interview catalogue community stigma scale (EMIC-CSS). Patients were categorized into none, mild, moderate and severe levels of social stigma based on their responses for questions related to stigma assessment. Data was analyzed using Epi-Info. Quantitative variables were presented as mean with standard deviation. Qualitative variables were presented as frequency with proportion.

**Results:** Majority of the study subjects were males (60%), Hindu by religion (73.3%) and belonged to nuclear family (73.3%). The mean age ( $\pm$ SD) was 47 ( $\pm$ 10.9) years. 66.7% of subjects were aged between 46-50 years. Majority (60%) of subjects had mild stigma. 13% had moderate while 3% had severe stigma. 23% of subjects had no stigma.

**Conclusions:** 87% of this study subjects had perceived the social stigma towards lymphatic filariasis. Hence, apart from prevention and treatment measures for filariasis, importance has to be given in context of reducing social stigma towards the disease.

**Keywords:** Lymphatic filariasis, Social stigma, Perception, Discrimination, South India, EMIC-CSS

## INTRODUCTION

Lymphatic filariasis is a chronic and debilitating disease with the potential to cause disability permanently. It is widely prevalent in tropical and sub-tropical countries.<sup>1</sup> Globally, the highest burden of lymphatic filariasis is in the south-east Asian region. Worldwide, this region also accounted for half of the total disability-adjusted life years.<sup>1,2</sup> More than 50% of the population requiring multi drug administration (MDA) is from WHO South-East Asian region.<sup>1</sup> The mental disability, stress and stigma caused by the disease go unrecognized behind the well-

recognized physical presentation of lymphedema, elephantiasis, scrotal swelling and other permanent disabilities.<sup>3-5</sup> They suffer mental, social and financial losses contributing to stigma and poverty. Furthermore, the psychological and social stigma associated with the disease is significant and can adversely affect productivity and quality of life.<sup>3,6</sup> The deformity and the resulting disability caused by the disease appears to be the main reasons for the stigmatization and discrimination.<sup>7</sup> Although morbidity control is one of the main goals of the global programme for elimination of filariasis, the stigmata and discrimination associated with such morbidity also need to be addressed. Stigma is also an

important social determinant of the effectiveness of disease control through its effect on help-seeking and treatment adherence. Furthermore, stigma influences political commitment to disease control. Although that is typically a problem because stigma may encourage neglect, for agencies committed to working on problems that matter, recognition of the serious impact of stigma may encourage them to support disease control. Stigma is a complex construct with a variety of definitions and frameworks. The commonly used scales to assess stigma are EMIC-CSS and the social distance scale (SDS).<sup>8-10</sup> They have adequate cultural validity to assess stigma.<sup>11,12</sup> EMIC measures the patient's fear of discrimination and awareness of negative attitudes as perceived or anticipated stigma while SDS measures the stigma from the perspective of the stigmatized. There are only a very few studies available in the literature with regards to understanding the stigma and discrimination experienced by subjects with lymphatic filariasis. This study is the first of its kind to our knowledge in Tamil Nadu, a part of South India. This study was aimed at assessing the perception of social stigma among patients attending a filariasis morbidity control clinic in Woraiyur, Trichy.

Objective was to assess the perception of social stigma towards lymphatic filariasis among those patients attending filariasis morbidity control clinic in Woraiyur, Trichy.

## METHODS

This hospital based cross sectional observational study was conducted among all lymphatic filariasis patients attending the filariasis morbidity control clinic in Woraiyur, Trichy, Tamil Nadu for 2 months from 1<sup>st</sup> February to 31<sup>st</sup> March 2015. The sampling frame included all patients with lymphatic filariasis attending

the clinic. All the adult patients aged 18 years and were included in the study. Purposive sampling was used. Informed consent was obtained from the patients after explaining the title, objectives, procedure and benefits from the study. Patients who were unwilling to give consent were not included in the study.

After obtaining consent from patients, data was collected using a locally adopted, pilot tested interviewer administered questionnaire (schedule) derived from EMIC-CSS. Patients were categorised into none, mild, moderate and severe levels of social stigma based on their responses for questions related to stigma assessment. The EMIC was developed to elicit illness-related perceptions, beliefs, and practices.<sup>8,9,13-15</sup> It is a 12-item scale with Likert scale response options as follows: (3) "yes"; (2) "possibly"; (1) "uncertain"; (0) "no". EMIC-CSS measures perceived attitudes and behaviour of the respondent regarding the attitudes and behaviour of others in the community. EMIC-CSS includes totally 15 items. It covers areas of life affected by stigma, like concealment, avoidance, pity, shame, being made fun of. It is readily available in various languages. It has been used to investigate stigma associated with various diseases like filariasis, leprosy, depression and various diseases.<sup>9,13,16</sup> It has adequate cultural validity to assess stigma.<sup>11,12</sup> The EMIC-CSS asks how filariasis is considered in the community of the interviewee, while the SDS assesses the personal perception of the interviewee. Used a locally adopted, pilot tested interviewer administered questionnaire derived from EMIC-CSS. The scale included 10 items. It is scored from 0 to 3 for every response-definitely willing (0 points), probably willing (1), probably not willing (2) and definitely not willing (3). The maximum score that could be scored was 30 and the minimum was 0. They will be categorised into 4 groups as no stigma (0-4), mild stigma (5-9), moderate stigma (10-14) and severe stigma (15-30).<sup>8,9,13-15</sup>

**Table 1: Self adopted social stigma questionnaire used in this study.**

Conditions	No	Uncertain	Possibly yes	Yes
<b>Afraid to go to Filarial clinics</b>	0	1	2	3
<b>Feeling lonely</b>	0	1	2	3
<b>Feel guilty because family has the burden of caring for them</b>	0	1	2	3
<b>Keep distance from others to avoid spreading the disease</b>	0	1	2	3
<b>Others refuse to visit your house</b>	0	1	2	3
<b>Uncomfortable to meet new people</b>	0	1	2	3
<b>Not participating in any social functions</b>	0	1	2	3
<b>Asked to stay away from work</b>	0	1	2	3
<b>Decided to stay away from work</b>	0	1	2	3
<b>Did not get support from spouse</b>	0	1	2	3

Data was entered in Microsoft excel and analysis was carried out using Epi-Info statistical software. Distribution of the data was checked for normality. Descriptive analysis was carried out by mean and standard deviation for quantitative variables, frequency and proportion for categorical variables. Bar chart and

pie diagrams were used for representing categorical variables.

## RESULTS

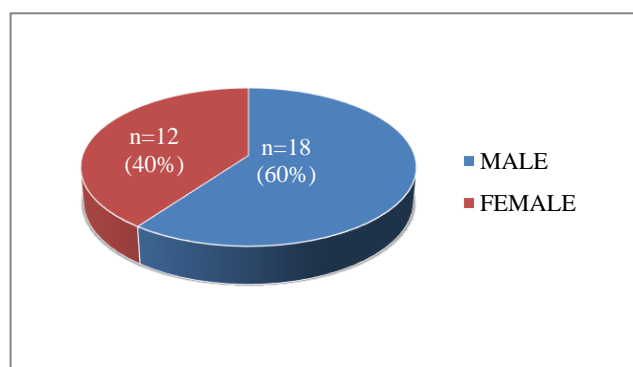
A total of 30 subjects were included in the study.

Table 2 describes the age distribution of the study population. The mean age of the study population was  $47 \pm 10.9$  years. The age of the participants ranged from 33 to 66 years. Majority (66.67%) of the population were in the age group of 46 to 50 years.

**Table 2: Distribution of study population according to age (n=30).**

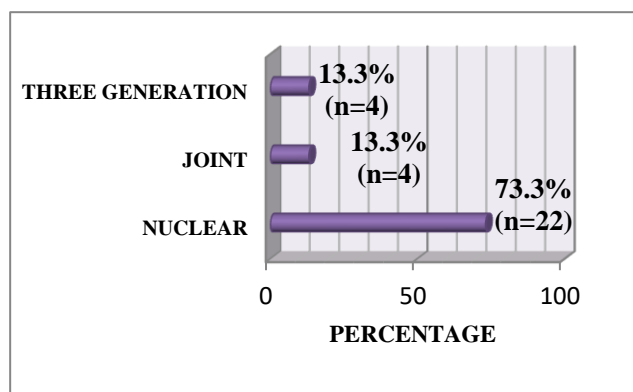
Age group (year)	Frequency	Percentage (%)
31-35	1	3.3
36-40	2	6.67
41-45	1	3.3
46-50	20	66.67
51-55	1	3.3
56-60	2	6.67
>60	3	10
<b>Total</b>	<b>30</b>	<b>100</b>

Figure 1 describes the gender distribution of the study population. Majority (60%) of the study subjects were males.



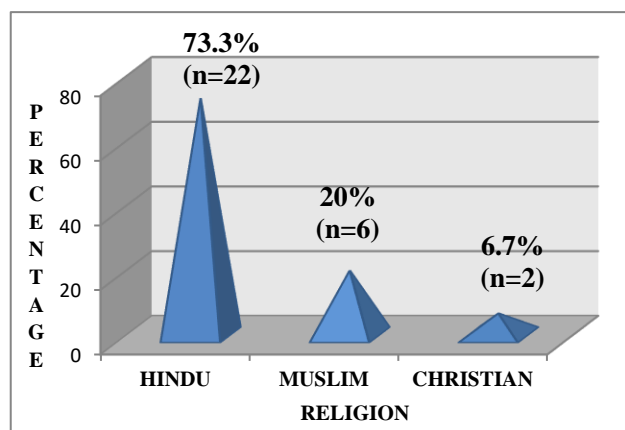
**Figure 1: Distribution of study population according to gender (n=30).**

Figure 2 describes the distribution of type of family in the study population. 73.3% of study subjects belonged to nuclear family. 13.3% were from joint family and another 13.3% belonged to 3 generation family.



**Figure 2: Distribution of study population according to type of family (n=30).**

Figure 3 describes the distribution of religion the study population. 73.3% of study subjects were Hindus. 20% were Muslims and 6.7% were Christians.



**Figure 3: Distribution of study population according to religion (n=30).**

Table 3 describes the level of social stigma perceived by the subjects. Majority (60%) of subjects had mild stigma. 13% had moderate while 3% had severe stigma. 23% of subjects had perceived no stigma.

**Table 3: Levels of social stigma (n=30).**

Levels of social stigma	Frequency	Percentage (%)
No stigma (0-4)	7	23
Mild (5-9)	18	60
Moderate (10-14)	4	13
Severe (15-30)	1	3
<b>Total</b>	<b>30</b>	<b>100</b>

## DISCUSSION

Stigma is a complex construct with a variety of definitions and frameworks. In many health conditions, people are severely affected by health-related stigma and discrimination. 87% of this study subjects had perceived the social stigma towards lymphatic filariasis. Majority (60%) of subjects had mild stigma. 13% had moderate while 3% had severe stigma. 23% of subjects had no stigma. This study was the first of its kind to our knowledge, to quantify the stigma in lymphatic filariasis although many other studies have done an elaborate qualitative analysis.

Lymphatic filariasis is a major health problem in many parts of the tropical world. Lymphatic filariasis is a chronic disease which adversely affects the livelihood, social and marital life of the individual. It can also weaken the marital prospects of the patients' children. The deformity and the incapacitation caused by the disease is the main cause of discrimination based on stigma.<sup>5</sup> Although morbidity control is one of main pillars for the global programme for elimination of filariasis, the

stigmas and discrimination associated with such morbidity also need to be addressed.<sup>1,17</sup> Beyond the physical challenges associated with the disease, the effects of stigma can be profound. Men affected by lymphatic filariasis face challenges in establishing relationships and in securing financial stability, with reports that some patients having been prohibited from trading their produce at local markets.<sup>18</sup> In this study, majority of the study subjects were males (60%). This could be due to the stigma associated with females to even come out of their homes for treatment. There is a continued need for gender-specific psychosocial support groups to address issues particular to men and women as well as a continued need for improved economic opportunities for LF-affected patients.<sup>17</sup> The age of the participants ranged from 33 to 66 years and majority (66.67%) were in the age group of 46 to 50 years. This could be due to their regular attendance in the clinic after a certain stage of disease progression. Relatively younger adults may not go to the clinic regularly because of lack of severe morbidity. In the qualitative study by Abdulmalik et al they observed that many patients with lymphatic filariasis perceived it as a spiritual illness with a religious connect.<sup>3</sup> In this study, majority (73.3%) were Hindus. The association between religious ideas and stigma needs to be explored further in qualitative studies. Studies have acknowledged the restricted marriage prospects of women with lymphedema because of the failure to meet aesthetic standards held by society.<sup>19</sup> A study done in East Nepal reported that the behaviours of rejecting and banishing a wife with leprosy for a second wife was common.<sup>20</sup> The psychological stresses of these exclusions can be severe, particularly in South Asian countries, where to be excluded from a family or community is to be deprived of any sense of purposeful function in life. Obindo et al in their study in Nigeria observed that prevalence of depression was high among individuals with lymphatic filariasis and was associated with low self-esteem.<sup>4</sup> Abdulmalik et al in their study observed that there was a 20% prevalence of depression in 69 subjects with lymphatic filariasis.<sup>3</sup> Person et al in their study on subjects with lymphatic filariasis observed that poverty, poor access to health care resources, limited education, and diminished social support challenged the coping strategies of many women and exacerbated negative consequences of lymphedema-related stigma.<sup>16</sup> Hofstra et al in their systematic review reported that there are similarities in stigma related to the various neglected tropical diseases.<sup>21</sup> They also advocated a joint approach for stigma associated with these diseases. Kumari et al in their study on 201 cases of lymphatic filariasis in Tamil Nadu reported that subjects with lymphatic filariasis are stigmatized and discriminated.<sup>7</sup> Suma et al in their study on subjects with brugian filariasis reported that patients complained the disease eroded their community status and diminished their marriage prospects.<sup>22</sup> Hence awareness of these factors could help in planning suitable disability and rehabilitation management programmes. Stigma is a process that begins when a particular trait or

characteristic of an individual or group is identified as being undesirable or disvalued.<sup>10</sup> The stigmatized individual often internalizes this sense of disvalue and adopts a set of self-regarding attitudes about the marked characteristic including shame, disgust, and guilt.

### Limitations

The cross-sectional design limits the inference of causality of stigma and its associated factors. It was only a single centre study with a small sample size. Hence the validity of our results is questionable. We used a self-adopted questionnaire. We did not validate the questionnaire. So, results of this study may not be applicable to other areas. But the hypothesis created from this study can go a long way in paving the way for further large-scale research and testing the formed hypothesis. A community-based sampling frame would help in improving the external validity of the results. A multi-centre community-based study involving a wider array of population would have been better.

### CONCLUSION

In summary, this study provides evidence on stigma level in a small sample of lymphatic filariasis patients attending a morbidity clinic in South India. The need of hour is that apart from prevention and treatment measures for filariasis, importance has to be given in context of reducing social stigma towards the disease. This study was one of its kind throwing light into this neglected topic for decades. Psychological issues and social stigma are experienced by nearly all people living with lymphatic filariasis. Interventions to promote psychological well-being and social inclusion should be included in all morbidity management programs.

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### REFERENCES

1. Global programme to eliminate lymphatic filariasis: progress report, 2016. *Wkly Epidemiol Rec*. 2017;92(40):594-607.
2. Global programme to eliminate lymphatic filariasis: progress report, 2015. *Wkly Epidemiol Rec*. 2016;91(39):441-55.
3. Abdulmalik J, Nwefoh E, Obindo J, Dakwak S, Ayobola M, Umaru J et al. Emotional Difficulties and Experiences of Stigma among Persons with



- Lymphatic Filariasis in Plateau State, Nigeria. *Health Hum Rights*. 2018;20(1):27-40.
4. Obindo J, Abdulmalik J, Nwefoh E, Agbir M, Nwoga C, Armiya'u A et al. Prevalence of depression and associated clinical and socio-demographic factors in people living with lymphatic filariasis in Plateau State, Nigeria. *PLoS Negl Trop Dis*. 2017;11(6):e0005567.
5. Zeldenryk LM, Gray M, Speare R, Gordon S, Melrose W. The emerging story of disability associated with lymphatic filariasis: a critical review. *PLoS Negl Trop Dis*. 2011;5(12):e1366.
6. World Health Organization Commission on Social Determinants of Health. Closing the gap in a generation: health equity through action on the social determinants of health: Commission on Social Determinants of Health final report. World Health Organization. 2008. Available at: [https://www.who.int/social\\_determinants/thecommission/finalreport/en/](https://www.who.int/social_determinants/thecommission/finalreport/en/). Accessed on 20 September 2020.
7. Kumari KA, Harichandrakumar KT, Krishnamoorthy K, Das LK. The stigmata and discrimination experienced, in southern India, by cases of lymphatic filariasis. *Ann Trop Med Parasitol*. 2010;104(5):421-6.
8. Weiss MG. Explanatory Model Interview Catalogue (EMIC): Framework for Comparative Study of Illness. *Transcult Psychiatry*. 1997;34(2):235-63.
9. Weiss MG, Doongaji DR, Siddhartha S, Wypij D, Pathare S, Bhatawdekar M et al. The Explanatory Model Interview Catalogue (EMIC). Contribution to cross-cultural research methods from a study of leprosy and mental health. *Br J Psychiatry*. 1992;160:819-30.
10. Link BG, Cullen FT, Frank J, Wozniak JF. The Social Rejection of Former Mental Patients: Understanding Why Labels Matter. *Am J Sociol*. 1987;92(6):1461-500.
11. Peters RMH, Dadun, Van Brakel WH, Zweekhorst MB, Damayanti R, Bunders JF et al. The cultural validation of two scales to assess social stigma in leprosy. *PLoS Negl Trop Dis*. 2014;8(11):e3274.
12. Peters RM, Dadun, Zweekhorst MB, Bunders JF, Irwanto, van Brakel WH. A Cluster-Randomized Controlled Intervention Study to Assess the Effect of a Contact Intervention in Reducing Leprosy-Related Stigma in Indonesia. *PLoS Negl Trop Dis*. 2015;9(10):e0004003.
13. Sun Y, Chen G, Wang L, Li N, Srisurapanont M, Hong JP, et al. Perception of Stigma and Its Associated Factors Among Patients with Major Depressive Disorder: A Multicenter Survey From an Asian Population. *Frontiers Psychiatry*. 2019;10:321.
14. Padmanabhan N, Poornima S. A study to assess the stigma related to tuberculosis among directly observed treatment short-course (DOTS) providers and patients on DOTS therapy attending DOTS centres of Mandya. *Int J Community Med Public Health*. 2016;3(10):8.
15. Weiss MG. Cultural epidemiology: an introduction and overview. *Anthropol Med*. 2001;8:5-29.
16. Person B, Bartholomew LK, Gyapong M, Addiss DG, van den Borne B. Health-related stigma among women with lymphatic filariasis from the Dominican Republic and Ghana. *Soc Sci Med*. 2009;68(1):30-8.
17. Cassidy T, Worrell CM, Little K, Prakash A, Patra I, Rout J et al. Experiences of a Community-Based Lymphedema Management Program for Lymphatic Filariasis in Odisha State, India: An Analysis of Focus Group Discussions with Patients, Families, Community Members and Program Volunteers. *PLoS Negl Trop Dis*. 2016;10(2):e0004424.
18. Babu BV, Mishra S, Nayak AN. Marriage, sex, and hydrocele: an ethnographic study on the effect of filarial hydrocele on conjugal life and marriageability from Orissa, India. *PLoS Negl Trop Dis*. 2009;3(4):e414.
19. Wynd S, Melrose WD, Durrheim DN, Carron J, Gyapong M. Understanding the community impact of lymphatic filariasis: a review of the sociocultural literature. *Bull World Health Organ*. 2007;85(6):493-8.
20. Van't Noordende AT, Van Brakel WH, Banstola N, Dhakal KP. The Impact of Leprosy on Marital Relationships and Sexual Health among Married Women in Eastern Nepal. *J Trop Med*. 2016;2016:4230235.
21. Hofstraat K, Van Brakel WH. Social stigma towards neglected tropical diseases: a systematic review. *Int Health*. 2016;8(1):i53-70.
22. Suma TK, Shenoy RK, Kumaraswami V. A qualitative study of the perceptions, practices and socio-psychological suffering related to chronic brugian filariasis in Kerala, southern India. *Ann Trop Med Parasitol*. 2003;97(8):839-45.

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