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Stigma and stigma-induced stress in filarial lymphoedema patients in Puducherry, India

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ABSTRACT

Introduction: The morbidity management and disability prevention (MMDP) strategy for elimination of lymphatic filariasis (ELF) focuses on alleviating the sufferings of about 36 million filariasis patients living in 49 endemic countries. At present, available quality of life questionnaires are not adequate to address the stigma and stress of filarial lymphoedema (FLE) patients. Therefore, a comprehensive and a robust stigma and stress assessment tool needs to be developed.

Methods: We developed 49 item SARI-FLE-Version-2 questionnaire for stigma assessment and 20 item PSS-FLE-Version-2 questionnaire for stress assessment and tested it among different grades of FLE patients. We followed the Likert scale scoring system and conducted a statistical analysis using SPSS IBM version 25.0.

Results: Of the 80 lymphatic filariasis (LF) patients assessed, 35.0%, 42.5%, and 22.5% had grades 2, 3, and 4 LE of the lower extremity, respectively. The developed stigma tool had an excellent internal consistency, as indicated by high Cronbach alpha values for all six domains. There was a significant correlation ($p < 0.05$) between different stigma domains. In three domains (cognitive function, social stigma, and experienced stigma), the mean stigma scores were significantly higher for the grade 4 patients compared to grade 2 patients ($p < 0.02$).

Conclusion: Stigma and stress assessment tools in the form of 49 item SARI-FLE-Version-2 and 20 item PSS-FLE-Version-2 questionnaires are reliable in quantifying the stigma and stress of LF patients. There is a scope to incorporate these tools in the MMDP component of the national ELF program in disease-endemic countries with finer modifications to the local situation.

Keywords: Stigma; stress; filariasis; morbidity management and disability prevention; lymphoedema; Likert scale

INTRODUCTION

Lymphatic filariasis (LF) is a public health concern in Asia, Africa, South America, and the Pacific regions. Estimates at the launch of the Global Program in the year 2000 indicated over 120 million people with infection and about 40 million people with disfigurement and disability by the disease. LF appears to be the second leading cause of permanent and long-term disability in many LF-endemic countries (1). It continues to be a significant public health problem requiring finance and human resources despite implementing the various control measures for two decades. Estimates in 2018 showed that about 893 million people

continue to live in endemic zones that require transmission control measures, including preventive chemotherapy. Although the global filarial infection reduced by 74%, an estimated 51 million were infected in 2018. As on March 2022, 863 million people from 47 countries were at the risk acquiring filarial infection (2) even after the Global implementation of MDA in 1997.

The impact of the mass drug administration (MDA) resulted in a reduction in the number of people infected over a period. However, the transmission control did not reduce chronic clinical manifestations of filariasis (3). About 36 million people, including 15 million lymphoedema (LE) patients, require interventions under the morbidity management and disability prevention (MMDP) strategy of LF elimination in disease-endemic countries. Lymphoedema in its late stages leads to disfigurement and restriction of physical and daily activities. Disfigurement affects the support from the family members and the quality of life (QoL) (4). McPherson observed that dermatology life quality index (DLQI) ranged from 6.7% to 60% among the filarial

lymphedema (FLE) patients (5). A community-based study in Sri Lanka has shown that QoL is much lower in higher grades of LE and the disease affects psychology and physical activity (6). Initially, the QoL studies depended on the general health questionnaire like SF36 and subsequently on 5D3L-Euro QoL and then 6D5L descriptive system. Lymphoedema-specific tool (LE-HRQoL) applied 7D5L illustrative approach. However, these QoL assessment tools did not sufficiently address the stigma and stress to elicit anxiety and depression among filarial LE patients.

Stigma in many LF patients drives patients to suicidal tendencies, especially among women when the patients suffer from multiple combinations of physiological impacts (7). Moreover, in some social settings, the suicidal tendency is extended to family members also. On the other side, low-cost psychosocial interventions significantly benefitted the patients and family members in alleviating the extreme psychological stress and follow-up in improving the QoL of the patients. Therefore, it is desirable to assess LF-related psychological sequences exclusively in the form of stress and stigma assessment to develop specific intervention strategies for improving the QoL of LE patients with disfigurement of the extremities. A few tools explored by other investigators also need to be modified to the local situation. The stigma scale developed by Dadun et al. (8) was considered a simple tool for stigma assessment among leprosy patients. In the present study, we developed stigma and stress assessment tools, translated them into the local language, and field-tested them for application in the national program.

METHODS

We adopted a cohort study design to assess the FLE patients' stigma and stigma-induced stress and envisaged a comprehensive assessment by a structured questionnaire administered by an interviewer.

The study area consisted of urban and rural parts of Puducherry in South India, with a population of about 9.5 lakhs (0.95 million) distributed over 472 km². About 69% are urban, the average literacy rate is 85.4%, and the recorded male literacy is higher than females (91.2% vs. 79.9%). The integrated vector management project was launched in 1981 for 5 years, reducing the infection rate from 8% to 5%. Further, the Government of India initiated a single annual dose MDA program in 2004 (9). Hydrocele and lymphoedema cases identified through the pre-MDA drives are treated at filaria clinics. We prepared a comprehensive list of LE patients from the government primary health centers and treatment centers. For line-listing of the LE cases, the investigators mainly depended on two exclusive filariasis clinics, one at Vector Control Research Center (VCRC) and the other run by the National Vector Borne Diseases Control Program at Puducherry. Both these clinics are funded by government organizations and treatments are provided free of cost. In addition, the authors acquired the list of LE patients detected for other research projects carried out past 5 years. Patients routinely attending the filariasis clinics were listed every week, and clinical reassessment was done for the present LE grading. We contacted other LE patients in and around Puducherry through mobile phones available in the clinical records or

by at least three house visits. All the available patients were listed daily, and area-wise consolidated lists were prepared for easy access for recruitment. We also invited the patients identified in their households to participate in the study and were clinically reassessed for lymphoedema grading by four-grade clinical classification criteria. Briefly, grade-1 is transient edema resolving completely on rest, grade-2 partially resolving, grade-3 lymphoedema with skin thickening (indicates fibrosis), and grade-4 skin thickening with other secondary skin changes. After obtaining written informed consent following the Ethical Guidelines of the Indian Council of Medical Research (ICMR) 2017, participants were recruited in the study by the following inclusion and exclusion criteria.

We included patients either with unilateral or bilateral lymphoedema, aged 18–65 years, body mass index (BMI) up to 40, and willing to participate in the study.

Exclusion criteria are age above 65, BMI above 40, currently suffering from Acute Dermato–Lymphangio-Adenitis (ADLA) episodes, or recently discharged from the hospital. In addition, we excluded the patients who were unwilling to participate or with family members' hesitations and those requiring assistance to respond to the questionnaire.

The Institutional Human Ethics Committee (IHEC) of Annamalai University, Chidambaram, Tamil Nadu, India, approved the study (Approval certificate no is IHEC/0524/2019 issued on 29.11.2019).

Stigma is a common problem in disfiguring diseases, including lymphatic filariasis. Although lymphatic filariasis and podoconiosis of the lower extremities lead to disfigurement and disability, Van't Noordende et al. found that stigma was higher in lymphatic filariasis than in podoconiosis (10). Several studies have demonstrated stigma in leprosy (8, 11, 12), HIV (13, 14), mental health (15), psoriasis (16, 17), and skin disease (18). After reviewing the contents of these stigma assessment tools, we prepared a suitable questionnaire to assess the stigma of the FLE patients based on the Stigma Assessment and Reduction of Impact (SARI) Scale (8). SARI-FLE-Version-1, with 42 items closed questionnaire on six domains, was developed for pilot-testing among FLE patients. Considering the difficulties in administering the questionnaire and the inputs from the patients, we modified each item, suiting the FLE patients in this region. The questionnaire items elicited the response from the participants, and the interviewer recorded the response on a five-point Likert Scale.

We modified the 10 perceived stress scale (PSS) (19), a stress assessment instrument developed in 1983. Again, the PSS-FLE-Version-1 was 20 items closed questionnaire that elicited the response on a five-point Likert Scale.

We tested both SARI-FLE-Version-1 and PSS-FLE-Version-1 among 15 FLE patients. One experienced Medical Officer in MMDP verified the responses, and he carried out necessary modifications in the cases of ambiguity. The final stigma assessment tool, SARI-FLE-Version-2, contained 49 items in six domains; cognitive functions (14 items), social stigma (seven items), experienced stigma (seven items), disclosure concerns (eight items), internalized stigma (seven items), and anticipated stigma (six items), essence only Clinic for FLE. Each item in a domain carried an equal

weight score in a five scores response Likert Scale (Yes=4, mostly=3, sometimes=2, rarely=1, No=0). Similarly, the 20 items stress assessment tool PSS-FLE-Version-2 carried an equal weight score (Very often=4, fairly often=3, sometimes=2, almost never=1, never= 0). Throughout the tool development, the four steps, described under "Process of translation and adaptation of instruments," were followed to translate the questionnaire (20) and its applications among the FLE patients with minimal literacy.

We computerized the data in a Microsoft Excel spreadsheet, and analyses were carried out using SPSS IBM version 25.0 (Armonk, NY, IBM Corp.). We tested continuous variables for normality assumption using the Kolmogorov–Smirnov test. We calculated descriptive statistics such as mean, SD, and range values for normally distributed data. The mean values were compared using the student-t independent/one-way analysis of variance test as appropriate, followed by the Bonferroni *post hoc* test. The frequency of categorical variables was compared using Chi-square/Fishers exact test. We computed bivariate correlation coefficients to assess the linear association between the study variables. For all statistical tests, a two-sided probability of $p < 0.05$ was considered for statistical significance.

RESULTS

In total, 126 FLE patients were line-listed, and 80 (63.5%) from urban and rural areas of Puducherry gave written informed consent to participate in the study. The demographic, socioeconomic, and lymphoedema grade-wise details are presented in Table 1. Among the 80 participants, there was significantly more representation from females (83.8% vs. 16.2%) and the older age groups >50 years (58.8% vs. 41.2%). About 65% of the participants had at least a school education, and 67.5% lived below the poverty line with less than INR 3000 (40.5$) as monthly income. More than two-thirds of the participants (67.5%) had lymphoedema duration of more than 15 years, and 22.5% had grade-4 lymphoedema of the lower extremity.

Internal consistency/reliability using Cronbach's alpha measure was 0.8, indicating excellent internal consistency for all the six domains of the SARI-FLE-Version-2. The consistency coefficients varied from 0.76 for social stigma to 0.94 for cognitive function (Table 2). The Pearson correlation coefficient for the inter-relationship between the six domains of the developed stress questionnaire also showed a significant correlation ($p < 0.01$). There was also a significant correlation between age and the disclosure concern and also the anticipated stigma ($p < 0.05$) (Table 3). Stress assessment by the developed tool PSS-FLE-Version-2 showed no significant difference in the mean stress score for gender and the duration of lymphoedema ($p > 0.05$). However, there was a considerable difference between the grades of LE ($p < 0.001$), as shown in Table 4. Grade-4 lymphoedema patients had a higher stress score than grades 3 and 2. In addition, there was a significant negative correlation between age and stress score, indicating that younger age class patients had higher stress scores in the community ($r = -0.36$; $p = 0.001$). However, the correlation coefficient between the stress scores and LE duration was insignificant ($r = 0.02$; $p = 0.845$).

TABLE 1. Baseline characteristics of study participants

Gender distribution		
Gender	N	%
Female	67	83.8
Male	13	16.2
Age distribution		
Age (years)	N	%
≤40	8	10.0
41–50	25	31.3
>50	47	58.8
Education		
Illiteracy	28	35
Literacy	52	65
Monthly Income		
≤Rs. 3000	54	67.5
>Rs. 3000	26	32.5
Duration of FLE		
Duration (years)	N	%
≤5	5	6.3
6–10	12	15.0
11–15	9	11.2
>15	54	67.5
FLE grade distribution		
FLE grade	N	%
2	28	35.0
3	34	42.5
4	18	22.5

FLE: Filarial lymphoedema

Assessment of the mean score for each domain among males and females by t-test for independent samples showed no significant difference for all six domains (Table 5). We also analyzed the mean stress score in two broad groups (≤50 years vs.>50 years). The mean scores of cognitive function and internalized domains among the age group ≤50 years were significantly ($p < 0.05$) higher than the older age group (>50 years). However, the differences in the mean stress score between the two age groups (Table 6) among the four domains (social stigma, experienced stigma, disclosure concerns, and anticipated stigma) were insignificant. We also observed that the mean scores for the six domains did not differ significantly for lymphoedema duration (Table 7). Figure 1 depicts the mean score for all six stigma domains by different lymphoedema grades. There was a significant variation in the mean stigma scores between the grades of edema among the three domains (cognitive function, social stigma, and experienced stigma). In all these three domains, the mean stigma scores were significantly higher among the grade 4 patients compared to grade 2 patients ($p < 0.02$) (Figure 1).

DISCUSSION

In this part of the project, we developed and validated PSS-FLE-Version-2 and SARI-FLE-Version-2 for the stress and stigma assessment among FLE patients. The developed tools have an excellent internal consistency as assessed by Cronbach alpha and the correlation between stress and different stigma domains. Application of the developed tool indicates that the stigma and stress score is significantly higher in grade-4 FLE patients ($p \leq 0.05$). It is clinically proven that late-stage FLE leads to disfigurement

TABLE 2. Reliability of six domains of Stigma in LF (n=80) assessed by Cronbach's alpha

| S. No.	Domains	Items	Cronbach's alpha	Cronbach's alpha based on standard items
1	Cognitive function	14	0.945	0.950
2	Social stigma	7	0.759	0.853
3	Experienced stigma	7	0.910	0.910
4	Disclosure concerns	8	0.885	0.897
5	Internalized stigma	7	0.842	0.836
6	Anticipated stigma	6	0.865	0.856

LF: Lymphatic filariasis

TABLE 3. Pearson correlation between the patients' characteristics different domains

Domains	Age	Duration	Stress score	Cognitive	Social stigma	Experienced stigma	Disclosure concern	Internalized stigma	Anticipated stigma
Age	1	0.362**	−0.359**	−0.296**	−0.075	−0.102	−0.249*	−0.338**	−0.252*
Duration		1	0.022	0.126	0.127	0.145	−0.051	−0.006	0.053
Stress score			1	0.798**	0.599**	0.559**	0.446**	0.308**	0.573**
Cognitive function				1	0.655**	0.664**	0.458**	0.392**	0.554**
Social stigma					1	0.820**	0.496**	0.345**	0.529**
Experienced stigma						1	0.545**	0.466**	0.488**
Disclosure concerns							1	0.532**	0.478**
Internalized stigma								1	0.368**
Anticipated stigma									1

*Correlation coefficients were statistically significant at $p<0.05$. **Correlation coefficients were statistically significant at $p<0.01$

TABLE 4. Comparison of stress score by gender, duration, and grade of filarial lymphoedema

			Stress score versus gender, LF duration and grade					
Variables	N	Mean	Standard deviation	Minimum	Maximum	t\F	p-value
Gender						0.185	0.854*
Female	67	35.26	12.58	10	63		
Male	13	34.5	16.52	17	80		
Total	80	35.15	13.13	10	80		
FLE duration (years)						0.500	0.683#
≤5	5	28.20	7.79	19	38		
6–10	12	36.25	7.55	25	47		
11–15	9	35.44	10.64	23	55		
>15	54	35.50	14.78	10	80		
Total	80	35.15	13.13	10	80		
FLE grade						11.193	<0.001#
2	28	33.50	11.32	18	55		
3	34	30.56	10.02	10	56		
4	18	46.39	14.90	22	80		
Total	80	35.15	13.13	10	80		

*p-value based on Student's t-independent sample means test. #p-value based on one way analysis of variance test. FLE: Filarial lymphoedema
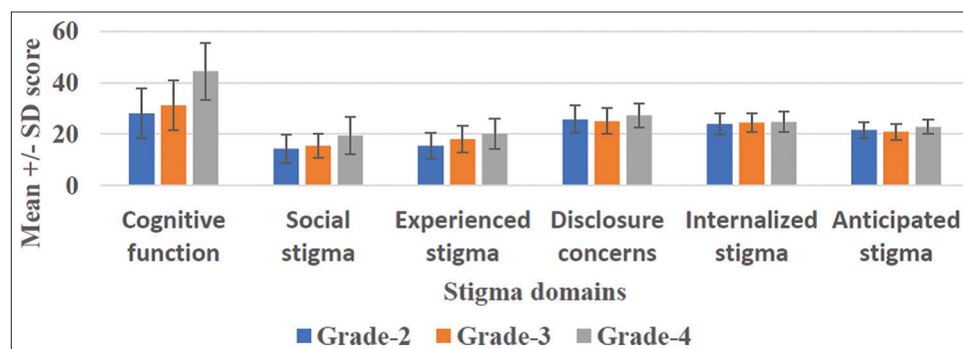
FIGURE 1. Comparison of stigma mean scores by lymphatic filariasis grades and domainse

and disability. Global program to eliminate lymphatic filariasis (GPELF) advocates MMDP to alleviate the suffering mainly through the prevention of ADLA episodes (22, 23), as these acute episodes incapacitate patients

at intervals. Several investigators have demonstrated gross deterioration in the QoL in FLE patients (5, 6, 10, 21). These studies comprehensively assessed the patients on physical, social, and psychological dimensions and suggested that MMDP must also address psychological and social issues of the filariasis patients. However, it is necessary to assess the patients at the micro-level, particularly the psychological domain, and the control programs in most of the disease-endemic countries do not adequately address this issue. Disfigurement and disability due to filariasis lead to anxiety, fear, and frustration (24), particularly among female patients. LF patients develop stigma as they suffer from social disgrace and ridicule by their relatives.

TABLE 5. Comparison of stigma mean scores between the gender and six domains

S. No.	Domains	Gender		Mean	SD	*p*-value*
1	Cognitive function	F	67	32.97	12.01	0.891
		M	13	33.46	10.75	
2	Social stigma	F	67	16.07	5.87	0.733
		M	13	15.46	6.16	
3	Experienced stigma	F	67	17.97	5.53	0.191
		M	13	15.77	5.39	
4	Disclosure concerns	F	67	25.94	5.14	0.578
		M	13	25.08	4.87	
5	Internalized stigma	F	67	24.42	3.91	0.925
		M	13	24.31	3.57	
6	Anticipated stigma	F	37	21.66	2.99	0.771
		M	13	21.38	3.53	

*Test for independent samples. Six domains mean scores were not statistically significant between the genders. M: Male, F: Female

It has been shown that in LF late stages, the patients feel depressed, find themselves a burden to the family and society, and are afraid that the disease affects the marital prospects of the siblings. Therefore, the patients tend to restrict themselves within the family and isolate themselves from social functions. Ultimately, these feelings lead to suicidal tendencies (25).

We assessed the stigma of lymphatic filariasis patients in six domains: cognitive function, social stigma, experienced stigma, disclosure concerns, internalized stigma, and anticipated stigma. Overall, the six domains construct reflects the stigma of FLE patients, and there was a significant correlation between the six domains. Furthermore, the reliability coefficients between the items vary between 0.836 and 0.950, inferring that the assessment of domain scores is consistent and reliable. The developed tools also revealed a significant negative correlation for overall stress score, cognitive, disclosure concern, internalized stigma, and anticipated stigma ($p < 0.01$).

Earlier, a short questionnaire by four domains with 22 items SARI stigma scale by Dadun et al. revealed a high level of stigma suffered by leprosy patients (8). In the present study, we constructed and field-tested six domains of 49 items of a stigma assessment tool to get the in-depth psychological impact among FLE patients and the results revealed no significant difference in mean stigma scores among gender and duration of lymphoedema. However, there was a considerable difference between the grades of edema. The significantly higher stress score among grade-4 lymphoedema patients compared to lower grades corroborates a similar finding in chronic dermatological

TABLE 6. Comparison of stigma mean scores between the age in six different domains

Domains	Age group (years)	*n*	Mean	SD	*F*	Sig*
Cognitive function	≤30	1	28.00	NA	2.443	0.710
	31–40	7	41.14	10.51		
	41–50	25	35.72	13.11		
	>50	47	30.53	10.60		
Social stigma	≤30	1	9.00	NA	0.719	0.544
	31–40	7	16.14	7.29		
	41–50	25	16.88	6.52		
	>50	47	15.62	5.36		
Experienced stigma	≤30	1	9.00	NA	1.110	0.350
	31–40	7	19.00	5.32		
	41–50	25	18.20	6.03		
	>50	47	17.28	5.26		
Disclosure concerns	≤30	1	27.00	NA	0.860	0.466
	31–40	7	28.43	3.73		
	41–50	25	26.08	6.31		
	>50	47	25.23	4.50		
Internalized stigma	≤30	1	26.00	NA	3.379	0.023
	31–40	7	27.43	1.51		
	41–50	25	25.36	3.62		
	>50	47	23.40	3.89		
Anticipated stigma	≤30	1	24	NA	0.822	0.486
	31-40	7	22.71	1.60		
	41-50	25	21.92	3.03		
	>50	47	21.23	3.24		

*Based on one-way analysis of variance test

TABLE 7. Comparison of stigma mean scores between the duration of lymphoedema in six different domains

Domains	Duration (years)	Mean	SD	F	Sig*
Cognitive function	≤5	24.8	6.77	1.34	0.269
	6–10	32.58	5.97		
	11–15	29.78	6.96		
	>15	34.46	13.32		
Social stigma	≤5	10.00	4.00	2.04	0.116
	6–10	15.50	3.99		
	11–15	16.11	3.52		
	>15	16.61	6.43		
Experienced stigma	≤5	12.40	5.60	2.11	0.107
	6–10	17.08	4.62		
	11–15	16.44	2.51		
	>15	18.41	5.87		
Disclosure concerns	≤5	22.00	7.91	1.45	0.235
	6–10	26.25	5.07		
	11–15	27.78	3.49		
	>15	25.72	4.94		
Internalized stigma	≤5	23.6	5.86	0.78	0.972
	6-10	24.5	3.68		
	11-15	24.33	2.50		
	>15	24.46	3.93		
Anticipated stigma	≤5	20.20	3.27	0.648	0.587
	6–10	22.00	3.10		
	11–15	22.44	2.13		
	>15	21.52	3.19		

*Based on one-way analysis of variance test.

conditions such as psoriasis. Furthermore, the stigma score was much higher among patients with a long duration of psoriasis (16,17). It has been well-accepted that stress is a common phenomenon in all chronic illnesses. Community-based studies in leprosy and filariasis showed that stress depends on the disease's socioeconomic conditions, duration, and stage or severity (26,27). A lymphedema-related stigma framework on enacted stigma, perceived stigma, and internalized stigma showed a considerable difference between the Dominican and Ghanaian women, and even access to education was denied to the female filarial LE patients. This was a qualitative study, and the authors suggested extending the study further through a quantitative approach to understand the problem better (28). Results of our study showed that the mean scores of all six domains were not statistically significant between the genders. There was no significant variation in the mean scores between the age groups for the five domains. However, there was a considerable variation in the mean scores between the age groups for the internalized stigma domain. *Post hoc* analysis showed that the mean stigma score among individuals aged (>50 years) was significantly lower than those under 40. The mean scores of the six domains did not differ significantly for the duration of edema. However, the stress score increases with higher grades and in younger age class patients.

Limitations of the study

The primary limitation is that we restricted the sample to 80 FLE cases in and around Puducherry. In addition, each LE case must complete 49 items SARI-FLE-Version-2 questionnaire for stigma assessment and 20 items PSS-FLE-Version-2 questionnaire for stress assessment. Second, depending on the patient's education and understanding, each patient took 25–35 min. Third, 35% of the participants were uneducated, so the health worker administered the questionnaire, and the interviewer's bias could not be eliminated. We allowed 1 month of recall for retrieving the information. However, as the events of stigma and related stress are so painful, a memory for 1 month is unlikely to affect the study outcomes.

CONCLUSION

Leprosy, lymphatic filariasis, and podoconiosis are neglected tropical diseases (NTDs), and the chronicity and the post-infection sequelae lead to disfigurement and disability. In addition, the stigma affiliated with these NTDs affects several dimensions of family and the QoL (13). In filariasis, the negative impact on caregivers' QoL is likely to be profound when the patients suffer from ADLA, and the family members forfeit an average of 6–7 days' wages during these acute episodes (29). Therefore, MMDP advocated by the WHO needs to be further augmented to assess stigma and stress among the diseased and their family members. Control programs need to consider interventions beyond disfigurement, and as suggested by Zhang et al., there must be a long-time commitment (30) to the rights-based approach (31). Internationalized Stigma in Mental Illness (ISMI) scale modified for lymphoedema patients in Ethiopia showed that community-based intervention significantly reduced the stigma among lymphatic filariasis patients (32). Support from Non-Governmental Organizations is essential to identify the gaps in the implementation of control measures and also to fill the gap (33). Governments must incorporate NGOs' role in filariasis elimination, in particular, enhancing drug consumption, and alleviating the physical and psychological impact among FLE patients and their family members. The national filariasis elimination program must adopt a uniform stigma and stress assessment tool to address the psychological impact and plan for suitable community-based intervention. In a large country like India, the tool must be in local vernacular for ease of administration and appropriate to the local social and cultural practices. SARI-FLE-Version-2 questionnaire for stigma assessment and PSS-FLE-Version-2 questionnaire for stress assessment developed by the authors are reliable. These tools can be applied among patients with poor literacy and in different socioeconomic groups. The tools can be modified to the local situation, translated to other languages in the country or elsewhere, and field-tested before incorporation in the national filariasis elimination program.

COMPETING INTERESTS

Authors declare no conflicts of interest.

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