

A New Instrument to Measure Family Support among People Affected with Leprosy: Leprosy Family Support Scale (LFSS)

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Received : 01.10.2020

Accepted : 31.12.2020

This study aimed at developing a scale to measure family support for people affected by leprosy (PAL). A cross-sectional scale development study was carried out in a tertiary leprosy referral centre, Purulia, West Bengal, India. A 10-item scale was developed to measure the family support and administered with a consecutive sample of 416 persons affected by leprosy aged above 18 years, and 71 completed the scale twice within an interval of three to four weeks. Developing the scales involved face and content validity, internal consistency, factor analyses, construct validity and test-retest reliability. Construct validity of the scale was determined by using the Participation Scale (P Scale) and World health Organization Quality of Life (WHOQOL-Bref) scale. Exploratory factor analysis revealed a single factor solution accounting for 82.79% of the total variance. Cronbach's alpha was 0.97, and the test intra-class correlation coefficient was 0.93. The total score of the LFSS scale had a moderate positive correlation with WHOQOL total score ($r = 0.44$, $p = 0.00$) and a significant weak negative correlation with the P Scale ($r = -0.34$, $p = 0.00$). The LFSS scale is acceptable, valid and reliable for measuring the family support of the people affected by leprosy. It is a promising tool that can be easily incorporated into the leprosy programme.

Keywords : Leprosy, Family Support, Stigma, Disability, Scale development, People Affected with Leprosy (PAL)

Introduction

Stigma has an important impact on the lives of people living with leprosy (van Brakel 2003, Tsutsumi et al 2004). Some people do not reveal the disease even to their family members for the

fear of rejection (Seshadri et al 2015, Mishra & Gupta 2010, Scott 2000). Society maintains negative feelings toward people affected with leprosy (Kaur & van Brakel 2002), and they are at greater risk of debilitation from their families,

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especially people with disability, due to the social stigma of the disease affecting the family's standing within the community (Seshadri et al 2015, Kopparty et al 1995). Besides, people faced matrimonial difficulty due to leprosy and divorce or separation among married people (Seshadri et al 2015, Thilakavathi et al 2012, Yadav 2011).

A study from India found that the family members of person affected with leprosy (PAL) were aware that early diagnosis and treatment would cure leprosy completely. However, around one fifth of them expressed their opinions that patient affected with leprosy should be kept away from family members and community (Mandal & Saha 2017). Having a family member affected by erythema nodosum leprosum (ENL) places a considerable financial burden on households in rural India, and households affected by ENL are at risk of being pushed further into poverty (Chandler et al 2015).

In rehabilitation, family support is one of the most important factors in persons affected with leprosy, and it has an impact on the psychological wellbeing of the persons (van Brakel et al 2012, Govindharaj et al 2018). Support that is received from family is an important factor in determining the individual's quality of life. Besides, having a disability needs more support from the family, which requires to be met in order to cope with the situation. Thus, a need was felt to develop a specific tool to assess the family support for the people affected with leprosy. Hence, this study aimed to develop a scale that quantitatively measures the family support among the people affected with leprosy.

Methods

A cross-sectional instrument validation study was conducted among people affected with leprosy to develop a tool to measure family support. The validation study took place in a tertiary leprosy

referral hospital in the district of Purulia, West Bengal, India from April 2017 to June, 2017. This study included all adult person affected with leprosy who were 18 years and above, diagnosed as leprosy at least for a year at the time of interview who were willing to participate and gave written informed consent. Persons who were living in leprosy colony and difficulties in communication were excluded.

Sample size

To achieve adequate power for the various statistical calculations to determine the measurement equivalence, it was estimated that a sample of at least 189 people affected by leprosy was needed in the main quantitative part of the study. Terwee et al (2007) recommended a minimum sample size as corresponds to 7 times the number of items. To achieve an adequate sample size for the reliability calculation, at least 50 repeated measurements are necessary.

The Scale development process

Items: Items were collected through field observation, interviews with experts. Followed items collection, performed item reduction to eliminate items addressing similar issues and converted the items into questions.

Translation: Since the items were prepared in English, it was translated into the Bengali language for appropriate and easiness in interviewing the study subjects. The scale translation procedure was followed as per World Health Organization (2017) guidelines. The English version of the instrument was translated into Bengali by three experts who were with expertise in leprosy treatment and rehabilitation and fluent in both English and Bengali. The Bengali translated version was back translated into English by an independent person who were not involved in the study and checked for comparability with the original English questionnaire.

Validity: To determine the content validity, the developed scale was simultaneously given to three expert health professionals in leprosy rehabilitation to evaluate the tools. The expert panel reviewed the LFSS scale and judged the instrument to be meaningful and relevant to the cultural context. Further, to determine content validity, we purposively recruited five respondents to test the instrument. An informal discussion was held with them about their perceptions on the relevance and adequacy of the concepts and language used in the scale as they related to the concept of family support. Based on their suggestions, the investigator drafted the tool and established the validity of the scale.

Construct validity: Bengali version of Participation scale (P Scale) (van Brakel et al 2006), and World Health Organization Quality of Life (WHOQOL-BREF) scale (WHOQOL Group 1998; Tsutsumi et al 2006), was used to establish the construct validity of the newly developed scale. The P scale used to measure the social participation restriction, and WHOQOL-BREF was used to measure the quality of life. The researcher hypothesized that family support of the people affected with leprosy would be positively correlated with WHOQOL-BREF and inversely correlated with P scale.

Reliability: Test-retest reliability was performed using the interclass correlation coefficient. The coefficients were estimated, considering results above 0.70 as acceptable (Terwee et al 2007).

Scale

The developed final instrument named as Leprosy Family Support Scale (LFSS), which is comprises of 10 items to measure the support in financial, caretaking, emotions, discussing the health issues since last six months from their family. The patients were asked to respond on a 4-point Likert scale, and the items each scoring from 1 to 4 (1 - 'Very little', 2 - 'Somewhat', 3 - 'Good' and 4 - 'Excellent') ranges from 10 to 40.

Procedure

The first author was assigned to recruit participants, describe the study to the respondents, obtain informed consent and performed the interview with assistants of trained field investigators. The scales are administrated by the interviewer. Each respondent's demographic information and clinical information extracted from hospital database, followed by administered LFSS, P scale and WHOQOL. The interviews were conducted in the vernacular language 'Bengali'. The interview was conducted in strict privacy after building rapport with the respondents, and precaution was taken not to avoid the emotional distress of participants. In case of any emotional distress, the interview was terminated. The field investigators administered the scales with five respondents affected by leprosy for testing the developed scale. Followed by a discussion was held with the field investigators and checked the items for consistency, understanding and terminology. After that, the pilot study was carried out and tested the instruments. Finally, the quantitative validation of the study was conducted.

Ethical considerations

Approval of this study was obtained from the Doctoral Research Committee members, Department of Sociology, Bharathidasan University and The Research Committee of Leprosy Mission Trust India, New Delhi. Participation was voluntary and information was collected anonymously after obtaining written consent from each respondent by assuring confidentiality throughout the data collection period.

Data analysis

The data were entered into Microsoft Excel database and analyzed using SPSS. Descriptive statistics were used to describe the demographic and disability profile of the respondents.

Table 1 : Demographic details of the respondents (n=416)

| Status | | Frequency | Percent (%) |
|------------------|----------------------------------|-----------|-------------|
| Gender | Male | 260 | 62.50 |
| | Female | 156 | 37.50 |
| Age | 18 - 30 years | 122 | 29.33 |
| | 31 - 45 years | 147 | 35.34 |
| | 46 - 60 years | 112 | 26.92 |
| | Above 60 years | 35 | 8.41 |
| Education | Primary | 40 | 9.62 |
| | Secondary | 115 | 27.64 |
| | Higher Secondary | 45 | 10.82 |
| | Illiterate | 216 | 51.92 |
| Occupation | House wife | 138 | 33.17 |
| | Labor | 55 | 13.22 |
| | Skilled Labor | 66 | 15.87 |
| | Farmer | 100 | 24.04 |
| | Government, Private and Business | 32 | 7.69 |
| | Student | 25 | 6.01 |
| Family Income | Below Rs. 5000 | 303 | 72.84 |
| | Above Rs. 5000 | 113 | 27.16 |
| Disability Grade | Grade '0' | 182 | 43.75 |
| | Grade '1' | 71 | 17.07 |
| | Grade '2' | 163 | 39.18 |

Reliability analysis and factor analysis was performed for 10 items of the scales. Pearson correlation analysis was performed for construct validity. Independent 't' test and analysis of variance (ANOVA) test was performed for significant among variables on LFSS scale.

Results

A total of 416 persons participated in this study; of this, 38% were females, and 62% were males. The demographic profiles of participants are shown in Table 1.

The total score of the LFSS scale had a mean of 33.46 with a ranged 10-40, 95% CI 32.81-34.11. The distribution of the total score is normal with Kurtosis 1.89 and Skewness -1.23 (Table 2).

Internal consistency

Cronbach's alpha was computed for internal consistency to test the reliability of the LFSS scale. The alpha for the 10 items was 0.97, which indicates that the items from a scale that has good internal consistency reliability (Table 2).

Factor Analysis

Both the Kaiser-Meyer-Olkin (KMO) value (0.942) and the statistical significance of the Bartlett's test of sphericity ($\chi^2=7272.53$; $p=0.00$) supported that the data were appropriate for exploratory factor analysis. Principal axis factor analysis with varimax rotation was conducted to assess the underlying structures for the 10 items of the LFSS

Table 2 : Descriptive statistics of the items of the LFSS (range per item 1-4) and corrected item-total correlation (n=416)

| Items | Mean | Std. Deviation | Corrected Item-Total Correlation |
|--|------|----------------|----------------------------------|
| 1 Supporting travel/medicine expenses for my regular treatment. | 3.43 | .684 | .891 |
| 2 Someone accompany with me when I go to hospital for treatment. | 3.34 | .749 | .897 |
| 3 Giving time to listen my deepest problems. | 2.93 | .943 | .495 |
| 4 Giving a role to me. | 3.34 | .790 | .859 |
| 5 Accepting me even though I had leprosy. | 3.37 | .753 | .917 |
| 6 Having a good time with my family. | 3.42 | .714 | .946 |
| 7 Showing love and care to me. | 3.43 | .711 | .941 |
| 8 If I am sick, I could easily find someone to help for my daily chores. | 3.41 | .732 | .957 |
| 9 Understands my problems. | 3.40 | .728 | .946 |
| 10 Encourage me to do a good job of taking care of health. | 3.39 | .736 | .928 |

Table 3 : Factor analysis of the LFSS (1 factor) (n=416)

| Items | Factor 1 |
|--|----------|
| 1 Supporting travel/medicine expenses for my regular treatment. | .918 |
| 2 Someone accompany with me when I go to hospital for treatment. | .914 |
| 3 Giving time to listen my deepest problems. | .543 |
| 4 Giving a role to me. | .888 |
| 5 Accepting me even though I had leprosy. | .937 |
| 6 Having a good time with my family. | .965 |
| 7 Showing love and care to me. | .963 |
| 8 If I am sick, I could easily find someone to help for my daily chores. | .973 |
| 9 Understands my problems. | .963 |
| 10 Encourage me to do a good job of taking care of health. | .950 |

scale, and the results showed in Table 3. After rotation, the results extracted as a single factor and accounted total variance of 82.79%. The items and factor loading for the rotated factors and all the 10 items were high loaded as a single

factor fitted in the scale.

Floor and ceiling effects

In the LFSS scale resulted no floor and present of ceiling effects. Seven (1.6%) respondents scored the lowest possible score (10), and 120 respon-

Table 4 : Mean total score and 95% CI by demographic variable and disability grade (n=416)

| Status | N | Mean | 95% CI | p value |
|----------------------------------|-----|-------|-------------|---------|
| Gender | | | | |
| Male | 259 | 33.66 | 32.94-34.39 | 0.42 |
| Female | 156 | 33.11 | 31.86-34.36 | |
| Age | | | | |
| 18 - 30 years | 122 | 34.33 | 33.30-35.36 | |
| 31 - 45 years | 147 | 32.50 | 31.41-33.60 | 0.09 |
| 46 - 60 years | 112 | 34.06 | 32.63-35.49 | |
| Above 60 years | 35 | 32.51 | 30.23-34.80 | |
| Education | | | | |
| Illiterate | 216 | 33.17 | 32.14-34.20 | 0.04 |
| Primary | 40 | 32.18 | 30.61-33.74 | |
| Secondary | 115 | 33.43 | 32.37-34.50 | |
| Higher Secondary & above | 45 | 36.04 | 34.58-37.51 | |
| Occupation | | | | |
| House wife | 138 | 32.50 | 31.14-33.86 | 0.00 |
| Labor | 55 | 31.95 | 30.24-33.65 | |
| Skilled | 66 | 35.74 | 34.56-36.93 | |
| Farmer | 100 | 32.93 | 31.64-34.22 | |
| Government, Private and Business | 32 | 35.75 | 34.14-37.36 | |
| Student | 25 | 35.24 | 33.16-37.32 | |
| Family Income | | | | |
| Below Rs. 5000 | 303 | 33.05 | 32.22-33.87 | 0.04 |
| Above Rs. 5000 | 113 | 34.57 | 33.66-35.48 | |
| Disability Grade | | | | |
| Grade '0' | 182 | 34.34 | 33.55-35.13 | 0.06 |
| Grade '1' | 71 | 32.94 | 31.46-34.43 | |
| Grade '2' | 163 | 32.70 | 31.45-33.95 | |

dents (28.8%) had a highest score of 40 for a maximum of 40.

Construct validity

The total score of the LFSS scale had a week positive correlation with the WHOQOL total score ($r = 0.44$, $p=0.00$) and a weak negative correlation with P Scale total score ($r = -0.34$, $p=0.00$).

Test-retest reliability

The final scale was evaluated for test-retest reliability on 71 of the 416 respondents to whom the LFSS scales were administered twice within four weeks. The interclass correlation coefficient (ICC) of the LFSS scale was 0.93 (95% CI .89-.96),

and the mean difference between interviewers was 0.12 ± 2.10 .

Interpretability

The LFSS total mean scores and corresponding confidence intervals of demographical variables and disability grade are shown in Table 4. The variables of education, occupation and family income had a significant mean score difference among the groups. The mean total LFSS score of persons with disability grade '0' (34.34) had a faintly higher mean score than the disability grade '1' (32.94) and disability grade '2' (32.70). However, there is no statistically significance found in disability grade.

Discussion

Assessment of the level of family support is important for the persons with chronic illness, particularly for the persons affected with leprosy because of stigma and discrimination due to the disease (van Brakel et al 2012). The scale development process can be carried out in three basic steps; Item generation, theoretical analysis and psychometric analysis (Morgado et al 2017). In order, this study followed the scientific scale development procedure and developed a new scale to measure the family support among people affected with leprosy and tested in the Bengali language.

Always, there will be challenges when developing a new scale or translation. Also, this study had few challenges when translating to Bengali languages. The meaning of words was discussed with experts during translation and testing the scale. Further, the discussion was held with field investigators who were native speakers, understanding the meaning of the words and tested with the respondents. After the testing, a discussion was held with the respondents, the scale was finalized, and the quantitative interview was conducted.

The scale was developed in statement format so that it can be used by both interviewer administration and self-administration. In addition, items on the scale were prepared in an easy manner to answer by the respondents at the same time, easy to ask by the interviewer. In this study, the final format of the scale has 10 items. The minimum total score is 10, and the maximum total score is 40. There is no missing value on the items, and it implies that the items are understood well by respondents. The internal consistency of the LFSS scale was good, and the Cronbach alpha was 0.97.

The construct validity of the LFSS was supported by the weak positive correlation with the WHOQOL-BREF and the weak negative correlation with the P-scale. Further research should be conducted to investigate the relationship between family support and quality of life. The ICC of the LFSS scale was good (0.93).

This study found no floor and presence of ceiling effects in the overall LFSS using the criteria of Terwee et al (2007). The high proportion of ceiling effects showed that it might be due to positive attitude of the family member towards the persons affected with leprosy. The positive attitude of the family members towards the person affected with leprosy will raise the family support and psychosocial well-being and quality of life will improve.

For interpretation of LFSS scale, the level of family support can be categorized based on the total mean score. Could be used two category method as receiving a low level of family support (1.00 to 2.50) and receiving a high level of family support (2.51 to 4.00).

This study had strength and limitation. This study only validated the LFSS scale in Bengali, India. Cross-cultural validation is needed to ensure that

a scale will produce valid data on what it intends to measure, especially in India because of the multilingual country. Reliability and validity were high, and factor analysis resulted in a 10 item of the scale that possessed good psychometric properties. Test-retest reliability, another important measure of overall reliability, indicated stability over time.

The LFSS scale focused to measures the family support for the people affected with leprosy. We believe that the LFSS Scale is suitable for use as a generic instrument to measure family support. Moreover, it can be used to other stigmatized condition and neglected tropical diseases.

Conclusion

The Leprosy Family Support Scale appears to be a brief and reliable tool that can be used to measure the family support by the persons affected with leprosy. It is a promising tool that can be easily incorporated into the leprosy programme to identify individuals in need of family support to improve their psychosocial wellbeing and quality of life.

Acknowledgements

The authors express sincere thanks to Prof Dr M. Thavamani, Formerly Head-Department of Sociology, Bharathidasan University, Tamil Nadu, Dr Famkima Darlong, Head-Healthcare, The Leprosy Mission Trust India, New Delhi (Formerly, Superintendent, The Leprosy Mission Hospital, Purulia) and The Research domain, The Leprosy Mission Trust India, New Delhi for their guidance and encouragement. We thank Ms Sneha Mahato, Mr Subir Ketiar and Mr Deepraj Mardy for their sincere involvement in data collection. We thank all the persons who participated in this study. We extend our sincere thanks to the staff of the Physiotherapy Department, Purulia Leprosy Mission Hospital, for their support.

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How to cite this article : Pitchaimani G, Sampathkumar S, Darlong J et al (2021). A New Instrument to Measure Family Support among People Affected with Leprosy: Leprosy Family Support Scale (LFSS). *Indian J Lepr.* **93**: 157-165.