

Impact of basic psychological support on stigma and mental well-being of people with disabilities due to leprosy and lymphatic filariasis: a proof-of-concept study

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Background: People with leprosy and lymphatic filariasis (LF)-related disabilities experience higher levels of poor mental well-being compared with the general community. Mental health services are often not available. This study was conducted to provide proof of concept that basic psychological support for people affected by neglected tropical diseases (BPS-N) can be given by peer supporters to reduce stigma, improve mental well-being and participation among clients.

Methods: The BPS-N approach was tested in a quasi-experimental design using mixed methods. To provide psychological support using the BPS-N, peer supporters were selected and trained. They supported people with leprosy- and LF-related disabilities. Preintervention and postintervention, stigma, mental well-being, depression and participation were measured through standard scales within 4 wk of the intervention; differences were tested using standard tests of significance.

Results: After 3 mo of intervention, the mean level of stigma had decreased (30.3 to 24, $p < 0.001$); high mental well-being increased (0% to 13.3%, $p < 0.001$); and moderate to severe depression decreased (88% to 47%, $p < 0.001$). No significant change occurred in participation restrictions (87% to 92%, $p = 0.497$).

Conclusions: Psychological peer support using the BPS-N guideline appears effective in reducing stigma and improving mental well-being and can be operationalised. However, this should be confirmed through a randomised controlled trial.

Contexte: Les personnes atteintes de lèpre et de handicaps liés à la filariose lymphatique (FL) souffrent davantage d'un manque de bien-être mental que le reste de la population. Les services de santé mentale ne sont souvent pas disponibles hors des zones urbaines. Cette étude a été menée pour démontrer que le soutien psychologique de base pour les personnes atteintes de MTN (BPS-N) peut être dispensé par des pairs (dans une logique de transfert de tâches) afin de réduire la stigmatisation et d'améliorer le bien-être mental et la participation des clients.

Méthodes: L'approche du BPS-N a été testée dans le cadre d'un modèle quasi-expérimental utilisant des méthodes mixtes. Pour fournir un soutien psychologique à l'aide du BPS-N, des pairs ont été sélectionnés et formés. Ils sont venus en aide aux personnes atteintes de lèpre et de déficiences liées à la FL. Avant et après l'intervention, les éléments suivants ont été mesurés à l'aide d'échelles standardisées: niveau de stigmatisation, bien-être mental, symptômes dépressifs, et enfin, la participation sociale. Les différences ont été testées à l'aide de tests de signification standardisés.

Résultats: Après 3 mois d'intervention, le niveau moyen de stigmatisation a diminué (30,3 à 24, $p < 0.001$); le niveau de bien-être mental a augmenté (0% à 13,3%, $p < 0.001$) et la dépression modérée à sévère a diminué (88% à 47%, $p < 0.001$). Aucun changement significatif n'a été observé en ce qui concerne les restrictions de participation (87% contre 92%, $p = 0.497$).

Conclusions: Le soutien psychologique par les pairs utilisant la ligne directrice BPS-N semble efficace pour réduire la stigmatisation et améliorer le bien-être mental. Toutefois, cette efficacité doit être confirmée par un essai contrôlé randomisé.

Antecedentes: Las personas con lepra y discapacidades relacionadas con la filiarisis linfática (FL) sufren niveles más altos de malestar mental en comparación con la comunidad en general. Los servicios de salud mental no suelen estar disponibles a nivel periférico. Este estudio se llevó a cabo para proporcionar una prueba de concepto de que el Apoyo Psicológico Básico para personas afectadas por NTDs (BPS-N) puede ser dado por compañeros de apoyo (rotación de tareas) para reducir el estigma, mejorar el bienestar mental y la participación entre los clientes.

Métodos: El enfoque BPS-N se probó en un diseño cuasi-experimental utilizando métodos mixtos. Para proporcionar apoyo psicológico con el BPS-N, se seleccionaron y formaron compañeros de apoyo. Apoyaron a personas con lepra y discapacidades relacionadas con la FL. El estigma, el bienestar mental, la depresión y la participación se midieron antes y después de la intervención, mediante escalas estándar; las diferencias se comprobaron mediante pruebas estándar de significación.

Resultados: Después de 3 meses de intervención, el nivel medio de estigma disminuyó (30,3 a 24, $p < 0.001$); el bienestar mental alto aumentó (0% a 13,3%, $p < 0.001$) y la depresión moderada a grave disminuyó (88% a 47%, $p < 0.001$). No se produjeron cambios significativos en las restricciones de participación (87% frente a 92%, $p = 0.497$).

Conclusiones: El apoyo psicológico entre iguales, utilizando la guía BPS-N, parece eficaz para reducir el estigma y mejorar el bienestar mental. Sin embargo, esto debe confirmarse mediante un ensayo controlado aleatorizado.

Keywords: disability, mental well-being, NTD, peer support, stigma.

Introduction

Leprosy and lymphatic filariasis (LF) are two neglected tropical diseases (NTDs) that mainly affect poor communities in low- and middle-income countries. India accounts for more than 50% of the global new leprosy cases and 40% of the global LF burden.^{1,2} In India, Bokaro District in Jharkhand State is endemic for both leprosy and LF, with a disability rate of 70 and 14 per 100 000 population for LF and leprosy, respectively. (Technical Report submitted to Coalition for Operational Research in NTDs (COR-NTD) at the Task Force for Global Health with support from UKAid, the study funding agency, May 2022.)

Leprosy, caused by *Mycobacterium leprae*, mainly affects the skin, eyes and peripheral nerves, and people affected by leprosy may experience permanent physical disabilities secondary to nerve impairments.^{3,4} LF, caused by filarial worms, impairs the lymphatic system, causing swelling of the scrotum (hydrocele) or breasts and lymphedema of the extremities.⁵ If not diagnosed and treated early, people affected by these conditions may develop irreversible and life-long disabilities.

Affected individuals may experience stigmatising attitudes, discrimination, social exclusion and limited participation in society.^{3,6} Stigma has been associated with reduced health-seeking behaviour, poor health outcomes, unemployment, problems in marriage and fewer social relationships, mental distress, depression and anxiety.^{3,7-12} A variety of stigma-reduction and mental health interventions can be implemented to counter these detrimental psychosocial consequences.^{13,14} In the field of leprosy, peer support strategies have been shown to contribute to reduced stigma and improved social participation among people affected.^{15,16}

People with leprosy- and LF-related disabilities are more likely to have poor mental well-being than the general community. Mental health services are often not available at the peripheral level. This study was conducted to provide proof of concept that basic psychological support for people affected by neglected tropical diseases (BPS-N) can be used by peer supporters (PSs) to reduce stigma, improve mental well-being and participation among clients.

Methods

Research design

The study used a preintervention and postintervention design without a comparison group (quasi-experimental) using mixed methods.

Study population

The study population included people with a leprosy- or LF-related disability, and who were residents of the study area. Excluded were people not willing to participate. For the qualitative study, 10 PSs were involved in one focus group discussion (FGD).

Study site

The intervention study followed a formative assessment conducted in Bokaro (Jharkhand) and Jaunpur (Uttar Pradesh) districts. Bokaro was selected for the intervention based on operational convenience. Chas block was selected out of nine

blocks in the district; it had the highest number of people with leprosy- and LF-related disabilities.

Sample size

We aimed to include 45 people with leprosy-related and 45 people with LF-related disability. A minimum total sample size of approximately 80 was needed to detect a reduction of 50% in prevalence of poor mental well-being, with a power of 80% and a significance level of 0.0517, assuming a 40% prevalence at baseline (so from 40% to 20%).¹⁷ A slightly bigger sample was included to account for drop-out.

Preintervention activities

- (A) Development of the BPS-N guideline ([BPS-N Guidelines.pdf](#), [BPS-N_video.mp4](#)). The study team adapted the WHO Psychological First Aid to make it suitable for use with chronic stress.
- (B) Community/stakeholder engagement. District officials, community leaders, representatives of Association of Persons Affected by Leprosy (APAL), leprosy colonies and village leaders were briefed about the study for facilitating clients' participation. Leprosy- and LF-affected youth were approached about joining the study as PSs.
- (C) A total of 90 people, 45 with LF- and 45 with leprosy-related disability, were randomly selected using a standard randomisation table including the eligible people and stigma, mental well-being, depression and participation scores were collected (N=184) during the formative research in Chas Block of Bokaro district. Eighty-seven provided consent to participate in the study.
- (D) Recruitment of PSs: a total of 10 male and five female PSs were selected from the vicinity of the affected people. Each PS was supposed to support around six leprosy- or LF-affected people. The criteria used to select PSs were: (1) leprosy- or LF-affected; (2) age > 21 y; (3) completed at least class-8 schooling; (4) layperson from the community; (5) knows the community well; (6) well accepted by the community; (7) has good communication skills; and (8) willing to volunteer without remuneration.
- (E) A clinical psychologist with experience of the local community was recruited to train, mentor and supervise the PSs.
- (F) The psychologist was virtually trained on BPS-N by NLR India over 3 d, followed by in-person training of the PS by the psychologist and NLR India for another 5 d. The PSs were trained on the basics of leprosy and LF, the needs of the affected individuals, the available government services, the BPS-N toolkit, communication skills and documentation of their meetings with the clients. A number of mock exercises were performed.

Preintervention data collection

Data were collected within 4 wk before the start of intervention.

Four tools were used for collecting the preintervention and postintervention scores.

1. The SARI Stigma Scale (SSS): the SSS is a standard scale for measuring experienced stigma, disclosure concerns,

internalised stigma and anticipated stigma. It was adapted for use with people affected by leprosy in the NLR SARI Project in Indonesia.¹⁸

2. The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS): the WEMWBS is a standard scale for measuring mental well-being in the general population.¹⁹ Based on a normative sample of 98 community controls (collected during formative assessment), cut-offs were contextualised. Low mental well-being: 14–28 (bottom 15% of normative sample); average mental well-being: 29–44 (16%–85%); and high mental well-being: 45–70 (top 15% of normative sample), as was done in the original UK sample.¹⁹
3. The Patient Health Questionnaire 9 items (PHQ-9): the PHQ-9 is a standard instrument to screen for the presence and severity of symptoms of depression in a primary care setting. The results are used to make a depression diagnosis according to the Diagnostic Manual of Mental Disorders (DSM-IV) criteria.²⁰
4. The Participation Scale Short Simplified (PSSS): the PSSS is a standard scale to measure social and work participation.²¹

The study team translated the SSS and PSSS into Hindi and piloted the translated version among eight leprosy- and eight LF-affected people with disabilities. Adjustments were made to the wording to improve understanding. Hindi versions were already available for the other scales.

The SSS, PHQ-9, WEMWBS and PSSS scales were interviewer-administered in the order mentioned to all clients in the intervention. The responses were registered directly in the tablets used by the interviewer. These scores served as the baseline for determining the impact of the 3-mo pilot intervention.

Implementation of the intervention study

The BPS-N-based intervention was implemented for 3 mo from 6 December 2021 to 5 March 2022. During the intervention, each PS supported clients following the BPS-N toolkit. They were mentored by the psychologist, who also linked them with the district psychiatrist and other health personnel. The PSs themselves linked clients with local health workers. After each meeting with clients, the PSs recorded their observations in a prescribed format. The psychologist met each PS weekly and they held a monthly group meeting with all the PSs. The successes and challenges experienced were discussed and records reviewed. Each PS was paid an honorarium of US\$13 per month as well as a travel allowance for attending monthly meetings.

Postintervention data collection and analysis

Data were collected within 4 wk of the end of intervention. The clients undergoing the complete 3-mo intervention were requested to respond to the SSS, WEMWBS, PHQ-9 and PSSS scales at the end of the intervention. These scores were compared with the baseline scores. The opinions of the PSs were collected through a structured FGD. Ten out of 13 PSs assembled at a common place for the FGD. After collecting written consent, the moderator facilitated the discussion. A notetaker wrote down the important points and recorded the interview. The FGD lasted around 70 min. The quantitative data were analysed using Stata

Table 1. Sociodemographic profile of people with LF- or leprosy-related disability

	Men (N=32)		Women (N=43)		Total (N=75)	
	n	%	n	%	n	%
Residence						
Urban	9	28.1	14	32.6	23	30.7
Rural	23	71.9	29	67.4	52	69.3
Age (y)						
≤24	5	15.6	2	4.7	7	9.3
25–44	2	6.3	10	23.3	12	16.0
45–64	16	50.0	27	62.8	43	57.3
≥65	9	28.1	4	9.3	13	17.3
Mean (SD), range	51.7 (17.1), 15–78		51.2 (14.0), 16–85		51.4 (15.4), 15–85	
Educational level						
No schooling	11	34.4	34	79.1	45	60.0
Primary school	5	15.6	3	7.0	8	10.7
Middle school	11	34.4	3	7.0	14	18.7
High school and above	5	15.6	3	7.0	8	10.7
Marital status						
Currently married	26	81.3	32	74.4	58	77.3
Widow(er)	3	9.4	9	20.9	12	16.0
Never married	3	9.4	2	4.7	5	6.7
Living situation						
With family	21	65.6	32	74.4	53	70.7
In affected people colony	11	34.4	11	25.6	22	29.3

All percentages are column percentages.

v. 15 (StataCorp LLC, College Station, TX, USA). The preintervention and postintervention mean scores were compared and the p values were determined using a statistical paired t test to assess the significance of the changes observed in stigma, mental well-being, depression and social participation scores. Qualitative data were collected to gather insights into the experiences of the PSs on how the intervention impacted their clients' lives. They were analysed manually. Audio recordings were transcribed and merged with the handwritten notes.

Ethical considerations

The study was approved by the Institutional Ethics Committee, Banaras Hindu University, and the Health Ministry Screening Committee (HMSC), Indian Council of Medical Research, Government of India. Informed consent was obtained from the clients before recruitment in the study and before the 3-mo intervention. No monetary benefit was provided.

Results

Sociodemographic characteristics of the participants

The sociodemographic characteristics of the participants are listed in Table 1; 57% were women; 65% were aged ≥45 y.

Table 2 depicts the sociodemographic characteristics of the PSs; 38% were women and 23% were aged ≥45 y.

Seventy-five out of 87 clients (87%) completed the 3-mo intervention. The baseline stigma, mental well-being, depression and participation scores of clients lost to follow-up (12) were similar to those of the clients who completed the intervention (Table 3).

Of the PSs, two men dropped out, leaving 13 (eight men and five women). Although we intended to have equal numbers of female and male clients, more women were available and willing to join in the study area. However, the experience was different with regard to the recruitment of PSs: although we aimed for equal numbers, we were only able to recruit five women and 10 men.

Impact of the BPS-N-based peer support intervention

The FGD showed that almost every PS had observed a transition in people opening up to them. Initially, there was almost no communication from clients. They felt embarrassed, were agitated and were non-responsive about personal issues and health problems. Some PSs even communicated with families to improve involvement in the intervention. After the 3-mo intervention, the clients talked openly, shared their problems and met regularly with people in the community and family. The PSs

Table 2. Sociodemographic profile of Peer Supporters (PSs)

	Men (N=8)		Women (N=5)		Total (N=13)	
	n	%	n	%	n	%
Residence						
Urban	1	12.5%	2	40.0%	3	23.1%
Rural	7	87.5%	3	60.0%	10	76.9%
Age (y)						
≤24	2	25.0%	3	60.0%	5	38.5%
25–44	4	50.0%	1	20.0%	5	38.5%
45–64	1	12.5%	1	20.0%	2	15.4%
≥65	1	12.5%	0	0.0%	1	7.7%
Mean (SD) range	36.7 (17.6) 18–73		28.6 (13.3) 20–52		35.8 (17.5) 18–73	
Educational level						
No schooling	0	0.0%	0	0.0%	0	0.0%
Primary school	0	0.0%	1	20.0%	1	7.7%
Middle school	0	0.0%	0	0.0%	0	0.0%
High school and above	8	100.0%	4	80.0%	12	92.3%
Marital status						
Currently married	5	62.5%	3	60.0%	8	61.5%
Widow(er)	0	0.0%	0	0.0%	0	0.0%
Never married	3	37.5%	2	40.0%	5	38.5%
Caste category						
Others	1	12.5%	1	20.0%	2	15.4%
SC/ST	1	12.5%	2	40.0%	3	23.1%
OBC	6	75.0%	2	40.0%	8	61.5%
Living situation						
With family	6	75.0%	3	60.0%	9	69.2%
In affected people colony	2	25.0%	2	40.0%	4	30.8%

All percentages are column percentages.

Abbreviations: SC, schedule caste; ST, schedule tribe; OBC, other backward caste.

Table 3. Comparison of baseline stigma, mental well-being, depression and participation scores of the lost to follow-up (n=12) and in study (n=75) clients

	Mean preintervention (lost to follow-up) (n=12)	95% CI	Mean preintervention (in study) (n=75)	95% CI	Mean difference	p value*
SSS	30.3	24.2–36.4	30.3	27.8–32.8	0.0	0.9936
WEMWBS	31.3	27.2–35.3	28.8	27.2–30.4	2.5	0.2563
PHQ-9	14.0	12.3–15.7	12.9	11.9–13.7	1.1	0.3270
PSSS	23.8	17.0–30.7	20.1	17.4–22.8	3.7	0.3032

*p value based on t test two samples.

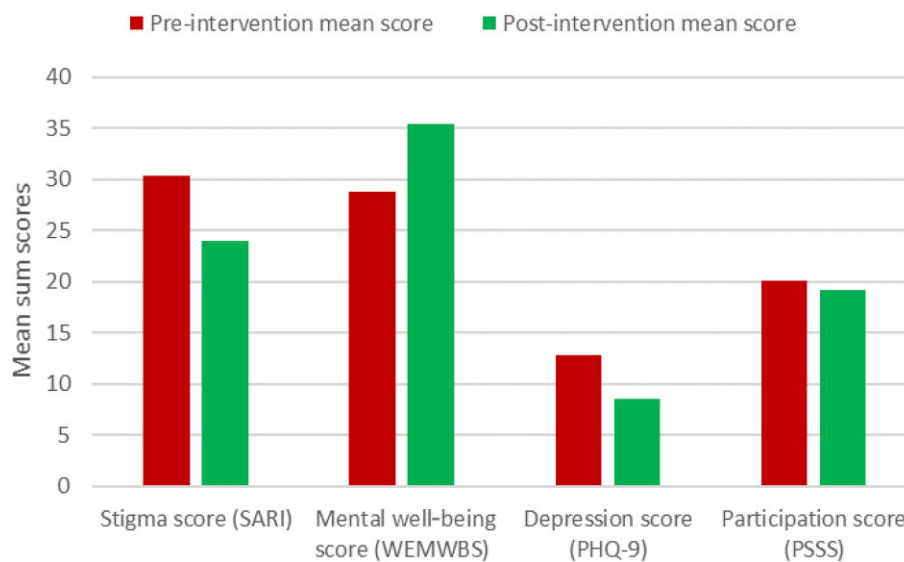
Abbreviations: PHQ-9, Patient Health Questionnaire 9 items; PSSS, Participation Scale Short Simplified; SSS, SARI Stigma Scale; WEMWBS, Warwick-Edinburgh Mental Wellbeing scale.

Table 4. Preintervention vs postintervention comparison in stigma perception and experience, mental well-being, depression and participation among people with LF-related (n=43) or leprosy-related (n=32) disability in Bokaro district

	Mean preintervention	95% CI	Mean postintervention	95% CI	Mean difference	95% CI	p value*
SSS	30.3	27.8–32.8	24.0	20.9–27.1	6.3	4.2–8.4	<0.001
WEMWBS	28.8	27.2–30.4	35.4	33.7–37.1	6.7	4.7–8.6	<0.001
PHQ-9	12.9	11.9–13.7	8.6	7.84–9.36	4.3	3.2–5.3	<0.001
PSSS	20.1	17.4–22.8	19.2	17.2–21.3	0.9	–1.8–3.6	NS

*p value based on a paired t test.

Abbreviations: NS, not significant; PHQ-9, Patient Health Questionnaire 9 items; PSSS, Participation Scale Short Simplified; SSS, SARI Stigma Scale; WEMWBS, Warwick-Edinburgh Mental Wellbeing scale.

**Figure 1.** Comparison of preintervention and postintervention outcomes regarding stigma perception and experience, mental well-being, depression and participation among people with LF-related (n=43) or leprosy-related (n=32) disability.

mentioned that they observed a change in anxiety level among the clients:

Initially my client was irritated and not polite. I tried going to her (keeping quiet) then after the second, or third visit she started talking. She is more of a friend now and also listens if I suggest something to her (PS, female, LF).

Table 4 and Figure 1 show the effects of the peer-support intervention on stigma, mental well-being, depression and social participation levels. After 3 mo of intervention, the mean level of stigma had decreased from 30.3 preintervention to 24.0 postintervention ($p < 0.001$).

In the FGD, the initial fear of stigma was also discussed. Many PSs faced challenges in matching suitable times with the clients;

initially clients found it difficult to believe that someone had reached out to them without any personal gain. Some clients refused multiple meetings within 1 mo for fear of increasing the stigma against them. Gender seemed to be a barrier to discussing personal issues. It took time to connect with clients from different age groups. Just spending time was also soothing to the clients:

I have seen changes in the happiness of women I was talking to. They don't have anywhere to go and stay isolated within the home. They have started interacting and seemed happy after we spoke (PS, female, leprosy).

The mean mental well-being score increased from 28.8 to 35.4 ($p < 0.001$), while the mean depression level decreased from 12.9

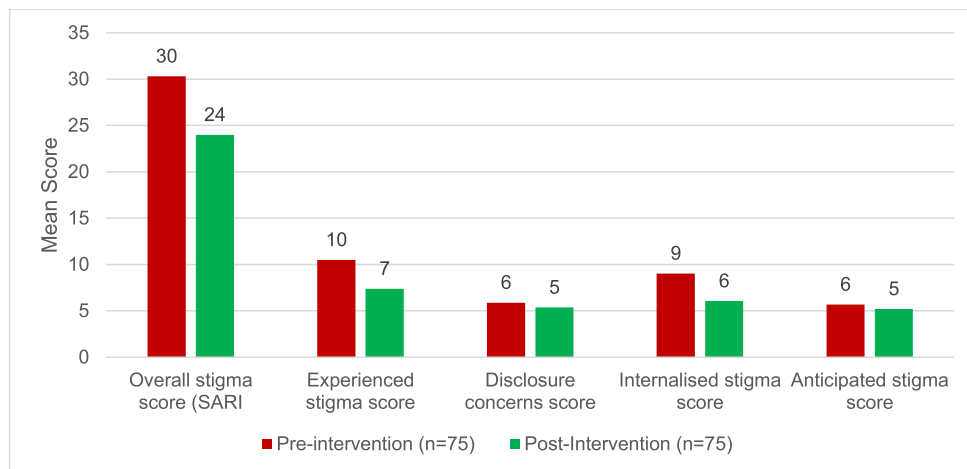


Figure 2. Comparison of preintervention and postintervention outcomes regarding stigma perception and experience among people with LF-related (n=43) or leprosy-related (n=32) disability in Bokaro district, India.

to 8.6 ($p < 0.001$). There was no significant change in the mean score of participation restrictions (20.1 vs 19.2; $p = 0.497$).

Poor mental well-being was clearly noticed by the PSs and shared during the FGD:

We observed that they were very depressed, they would sometimes be seen talking to themselves, praying to God to kill them. We try to counsel them and also see if they have any mental health problem. They have this internal feeling that they are worthless and the society has discarded them, we tried to explain to them that they are a part of society and that they could lead a normal life like others. So, now, they have started to open up about themselves and among the peers (PS, male, leprosy).

Figure 2 shows that the decrease in stigma levels from preintervention to postintervention was limited to experienced stigma (decreasing from 10 to 7) and internalised stigma (from 9 to 6). There was no change in the mean scores of disclosure concerns and anticipated stigma.

Through the focus group it was noted that peer support benefited the client, PS, healthcare providers and the surrounding community. Peer support increased the number of social relationships of the clients. The PSs experienced a sense of empowerment by helping a client. The healthcare providers were able to reach individuals who might not be currently using their services. PSs were able to serve as a liaison between the individual and a psychological health professional, helping them to better understand the needs of the individual seeking services:

Earlier, the issue was that the affected person was not interacting with others. Now they are meeting with the other people and going in the hospital for the treatment without hesitation (PS, male, LF).

Figure 3 shows that the percentage of clients with low mental well-being decreased from 47% to 13%, while the percentage with high mental well-being increased from 0% to 13%.

Figure 4 shows that by the end of the 3 mo the percentage of individuals with moderately severe or severe depression levels decreased from 26% to 0%, while the percentage with no depression or mild depression increased from 12% to 53%.

Figure 5 shows that the percentage of clients with no and mild participation restrictions decreased from 13% to 8% and from 17% to 13%, respectively. The clients with moderate restriction increased from 25% to 35%, while 44% remained with severe restriction. No significant changes were observed in social and work participation.

The PSs themselves also had a positive experience through delivering the intervention; it gave them a sense of usefulness in being able to help others experiencing the same disease:

I always wanted to help the affected persons, but no one helped and guided me, but this programme gave me a platform to help them (PS, female, leprosy).

Discussion

This study was conducted to provide proof of concept that basic psychological support given by PSs can reduce stigma and improve mental well-being and participation among people with leprosy- or LF-related disabilities. The study team included researchers with experience of working on peer education for HIV/AIDS and peer counselling for leprosy.²² They defined criteria for the selection of PSs. However, the context in the study area was different in that a high proportion of leprosy- and LF-affected people had received no schooling (60% of the study participants). It was therefore difficult to recruit PSs with the original criterion of a minimum of class 12 education. It also proved difficult to recruit women as PSs. Important reasons for this were that

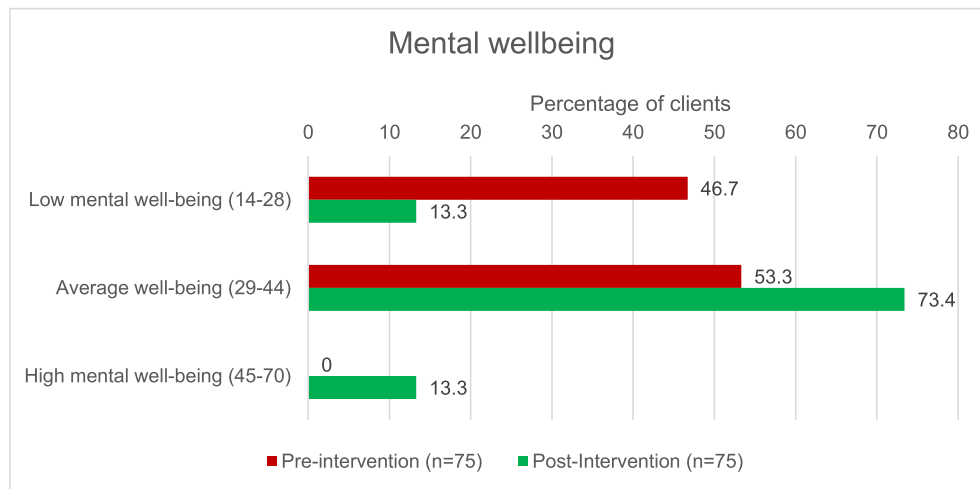


Figure 3. Comparison of preintervention and postintervention outcomes regarding mental well-being among people with LF- or leprosy-related disability (n=75) in Bokaro district, India.

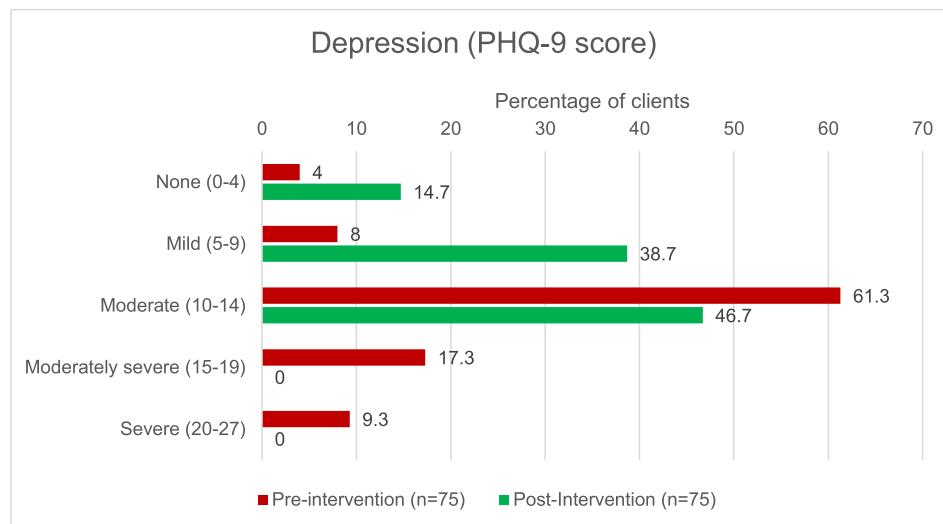


Figure 4. Comparison of preintervention and postintervention outcomes regarding depression among people with LF- or leprosy-related disability (n=75) in Bokaro district, India.

permission was needed from family members and being occupied with household chores.

Sociodemographics of the participants

The study clients were older than the average community member and had a higher percentage of illiteracy (60% had received no schooling) compared with the district demography (census 2011). Many of them lived without family (29%). Besides the stigma and disabilities due to leprosy and LF, older age, illiteracy and living without family are known to be important factors contributing to poor mental well-being.^{23,24} However, the differences between the study sample and the general population will

not have biased the findings of this study, because only within-person comparisons were made.

Impact of the BPS-N-based peer support intervention

The study demonstrated that a 3-mo BPS-N-based peer-support intervention was able to significantly decrease levels of stigma and depression and improve mental well-being levels. However, it may not have been long enough to improve social participation. Lusli et al. found that rights-based counselling by peers was effective in reducing stigma and improving the social participation of people affected by leprosy after 1–2 y of intervention.¹⁶ Topping found peer education to be an effective strategy for

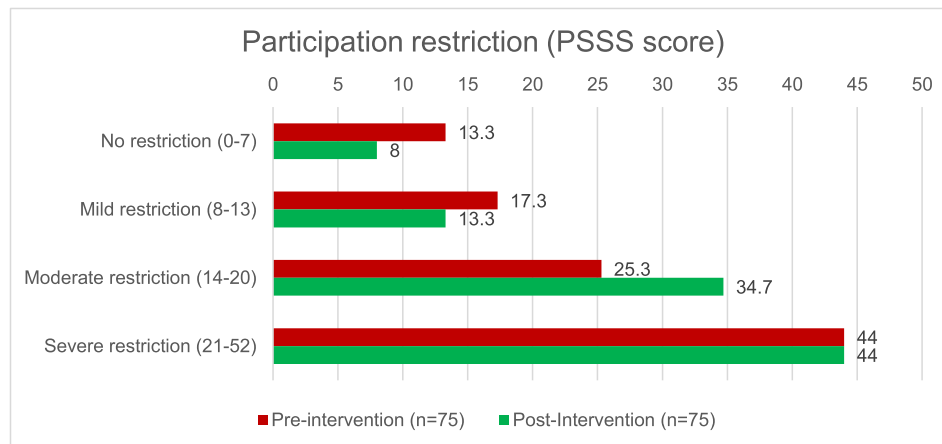


Figure 5. Comparison of preintervention and postintervention outcomes regarding participation among people with LF- or leprosy-related disability (n=75) in Bokaro district, India.

improving mental well-being.²⁵ However, the review did not include any studies addressing mental well-being among people affected by leprosy and LF. The current study showed, through both quantitative measures and qualitative outcomes, that the BPS-N intervention also had a noticeable impact on the clients. Positive experiences were shared by the PSs, showing that clients opened up, stigma was reduced and that they took the initiative in accessing the health and social system. Similar findings were reported by Schafer et al., applying the look, listen, link principle and reporting that ‘It would still help a woman improve her skills, life skills, her confidence’.²⁶

Experiences of Peer Supporters (PSs)

Lusli et al. reported a positive impact of peer counselling on various aspects of stigma, quality of life and social participation of people affected by leprosy.¹⁶ However, they did not measure mental well-being and depression. A study similar to ours among substance users in Egypt found it difficult to recruit female PSs and highlighted the need for proper training of the PSs and self-care.²⁷ Another study on support of homeless people found that peers’ persistence in developing unique experience-based relationships, providing social support, role modelling recovery and peers’ motivations were perceived to be important factors involved in peer support.²⁸ They described how peers benefited from helping, such as undergoing transformative identity developments that helped them to escape homelessness. In our study, PSs experienced a sense of empowerment by helping a client. In a scoping literature review, Fortuna et al. found that major growth and advancements in peer support have occurred through new developments in training, certification, reimbursement mechanisms, competency standards and fidelity assessment.²⁹ Peer support is now a service offered across the world and is considered an indispensable part of mental health services. Our study showed that PSs are able to meet a variety of

clients’ needs, resulting in a positive impact on stigma and mental well-being.

This was a proof-of-concept study testing the newly developed guideline for BPS-N used by PSs. Hence a preintervention and postintervention study was used with a limited number of clients and for a limited time period. The BPS-N for addressing the mental well-being of people with disabilities due to NTDs has been developed and tested for the first time. This is a rich contribution to the existing literature addressing NTDs. The study findings can inform policymakers considering how to initiate or expand mental well-being services to people with disabilities due to NTDs through peer support services. However, the findings of this study need to be confirmed in a randomised controlled trial before they can be recommended. This is the study’s limitation. Researchers may use the findings for conducting studies to test the effectiveness of this peer support approach among people affected by NTDs other than leprosy and LF with and without disabilities. They may also try to standardise the PS approach and study ways to embed peer support in basic health services.

Conclusion

This proof-of-concept study showed that a peer-delivered psychological support intervention is effective in reducing stigma and depression and in improving the mental well-being of people with a disability due to leprosy and LF. However, changes in social participation were only seen in the qualitative study findings. The proof-of-concept evidence will need to be validated by a randomised controlled trial. The study provides the first evidence of the effectiveness of basic psychological support in addressing the mental well-being of people with leprosy- and LF-related disabilities. In settings with limited mental well-being services, this could be an important approach. The frontline workers can also be trained on BPS-N.

Authors' contributions: WvB and HB developed the study design. WvM, CPM, AA and HB led the development of the BPS-N guideline; CPM, WvB, AA, PKN, RvW and HB guided and monitored the study implementation, data collection, analysis and reporting; RvW in particular guided the qualitative component of the study. AA led drafting of the manuscript, AJ assisted in data analysis for the manuscript and MM contributed in review and editing of the manuscript drafts. All authors have read, reviewed and approved the manuscript.

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PPI statement: The leprosy- and lymphatic filariasis-affected people were involved as peer supporters in providing the basic psychological support to their peers with mental well-being issues. The results were disseminated through a national meeting attended by the Association of Persons Affected by Leprosy (APAL). Late Mr. Venugopal, The President, APAL, graced the dais and expressed his opinion on the study findings. He felt poverty plays an important role in stigma and discrimination of the affected.

Competing interests: AA is a Guest Editor of this supplement but had no role in the review of this manuscript.

Ethical approval: The ethical approval for the study was provided by the ethical committee at the Institute of Medical Sciences, Banaras Hindu University, Uttar Pradesh.

Data availability: The data will be available in the COR NTD website, and can also be requested from the corresponding author after all publications from the study.

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