

SHORT PAPER

Effectiveness of Social Skills Training for reduction of self-perceived Stigma in Leprosy Patients in rural India – a preliminary study

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Summary

Objectives: To assess the effectiveness of social skills training in leprosy patients to raise self-esteem and reduce self-perceived stigma.

Design: Five leprosy patients were given 10 day-long group-sessions of social skills training over 3 weeks. Training involved: identification of the emotions and concerns of patients when interacting socially; analysis of positive and negative social interactions and non-verbal and verbal skills training. Role-plays, videos and live models were used. Self-esteem and a reduction in self-perceived stigma were assessed qualitatively before and after training using semi-structured interviews. Assessment of change was scored under the indicators: self-perception, family, wider community and job. Patients were assessed for displaying new ways of interacting with people and changes in expectations for the future.

Results: Qualitative analysis of the interviews before and after training suggested that social skills training could raise the self-esteem of leprosy patients and combat self-perceived stigma. Increase in self-esteem, as evident through the verbal interactions with the interviewers and behavioural changes in the community, were noted in the majority of patients.

Conclusion: Social skills training along with counseling may be able to increase the self-esteem of leprosy patients, and so be a useful part of leprosy rehabilitation schemes to try and combat the stigma of leprosy.

Introduction

Despite the huge advances in treating leprosy over the past decades the stigma associated with the disease has not decreased proportionately in India.¹ Although leprosy is now curable,

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many people affected by leprosy are still branded permanently as 'lepers' and the stigma remains.^{2,3} To truly heal those affected by leprosy it is not enough simply to render patients free from the bacterial disease. Misconceived ideas of leprosy's etiology and method of contagion⁴ are often at the root of leprosy stigma. We need to combat the stigma effectively, both that which is self-imposed⁵ and that imposed by the community.⁶ Leprosy will never be eradicated if patients continue to delay initial presentation for fear of being shunned by society. Even though cured, patients can find it difficult to reintegrate back into society.⁷

A vicious circle ensues, whereby negative social experiences promote negative perceptions and behaviours. By failing to assert themselves as valid members of their communities, as well as willfully consenting to leading socially constrained lives, they are perpetuating and validating the reaction of the community towards them.^{8,9} Self-perceived stigma often, though not always, leads to negative consequences for self-perception.¹⁰ Yet knowledge and research into effective coping strategies for leprosy patients to combat stigma and the lowered self-esteem this provokes is still in its infancy.^{11,12} Self-perceived stigma is dynamic, and therefore susceptible to change.¹³ Support groups and counseling have been shown to reduce stigma.¹⁴

This preliminary study investigates whether social skills training can be used to overcome the decreased self-esteem of leprosy patients, and so promote productive interactions once more in the community.

In this context, where the training focuses on improving positive social interaction thereby improving self-esteem and confidence,¹⁵ stigma is referred to more in terms of its effects in a social context. Weiss defines stigma as a social process or related personal experience characterised by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem.¹⁶

According to Link and Phelan, stigma is a social process that exists when elements of labelling, stereotyping, separating, status loss and discrimination co-occur in a power situation that allows these processes to unfold.¹⁷

In this training programme we aimed to reduce perceived (or felt) stigma: the fear of being discriminated against;¹⁸ and internalised (or self) stigma: the devaluation, shame, secrecy and withdrawal triggered by applying negative stereotypes to oneself.¹⁹

Materials and Methods

Five male leprosy inpatients of similar socioeconomic background (aged between 21 and 56) at the Schieffelin Leprosy Research and Training Centre were selected for the training. All patients had visible skin patches though lacked major deformities.

The purpose of the training and the time involved was explained and all five gave their full consent to participate in the training. They were given 10 days of group-sessions of social skills training over 3 weeks. A social skills training programme was adapted from a social rehabilitation-training programme devised for head and neck cancer patients.²⁰

The sessions were conducted by the first author (a psychologist) and were carried out in the local language, Tamil. Evaluation was done by two postgraduate students in psychology, and a staff member from the occupational therapy department.

The sessions started in the morning and went on until evening with breaks for tea and lunch. Some sessions extended to late evenings, which included practical sessions. Some sessions took more than 2 or 3 days. Sessions on SCARED (which is explained in the sessions

section following) and REACH OUT (which is also explained in the sessions section) each required an extra day. Also tasks in the community such as organizing public meetings needed extra days beyond the 10-day sessions.

EVALUATION

The evaluation was based on: (1) post-interviews, (2) spontaneous remarks by patients during the sessions, and (3) evaluation of the patients' behaviour (practices or tasks at home) after the sessions. They said that they did not have the courage to do these before the sessions.

Semi-structured qualitative interviews were used before and after the training to assess the outcomes of the training. Subsequently, three of them returned after a couple of months and reported improvements, and this data is also incorporated into the results table.

Questions were aimed at analysing the self-esteem of the patients, and as such were based on Rosenberg's Self-esteem Scale²¹ and the Bogardus Social Distancing Scale.²² Interviews were tape-recorded and evaluated independently for changes in self-esteem using the criteria 'New Ways of Interacting with People' and 'Changes in expectations for the future'. Patients were scored depending on how their thoughts, feelings and behaviours had changed with respect to themselves, their family, the wider community and their job.

DETAILS ABOUT THE PARTICIPANTS

Only in-patients were chosen to participate in the group since outpatients would not have been able to come to the hospital for daily sessions because of economic and logistical limitations. Only male participants were chosen, because patients may not have felt comfortable in a mixed group consisting of both males and females. It was also important to select patients who could relate to each other and benefit from each other in the group. Therefore, patients in fairly similar life situations were chosen, with common attributes and problems. Patients were similar in terms of their educational level, employment and similar visible signs of leprosy. An average employment age was chosen (between 20 and 40 years); and a similar educational level (between 5 and 6 years of school) had been obtained by four of the five patients. The one exception had more years of training in business. He was asked to be the facilitator of the group.

Among the five respondents one was from an upper- middle-income group; one from a middle-income group; and three from a lower- middle-income group. None of them were from 'below the poverty line'. Regarding caste, three belonged to upper castes and two were from lower caste groups. As for religion, one was a Muslim, two were Hindus, and two were Christians. All the families had a good status in the community.

In this part of Tamil Nadu the main occupation is agriculture and if the monsoon fails they turn to construction work. Four of the participants were from a farming background but only two were engaged in active farming at present. One was a hairdresser.

All the patients had visible patches and visible symptoms of reactions were treated. However, none of them had any major disfigurements.

TOOLS USED IN THE TRAINING PROGRAMME

- Modelling
- Behavioural rehearsal/Role play

- Independent practice: Target behaviour carried out by participants and self-recording of progress.

CONTENT OF THE SESSIONS

Aim of the Individual sessions:

In social skills training, the group is a therapeutic group with a socializing component.

The group was oriented to the purpose of the training.

During each session, the first few minutes were spent in general discussion on crucial issues related to disease and stigma and warm up exercises and we then moved on to skills sessions.

Session on personal stories

The main focus of this session was to get to know the other members of the group, by each one sharing their personal life story. The focus was on assessing their grief reactions, through comparing how the patients felt currently with the period before they had contracted leprosy, and on sharing information about how a stigmatized person usually feels when interacting with others. An introduction was given about assignments that participants would have to carry out as ‘home work.’

Session on hearing other people’s concerns

This session was to enable participants to open up discussion about things that most immediately concerned the group. Time was given to reflect and discuss.

Session on Introduction to SCARED syndrome

Interaction with others can be very difficult for people with a stigmatizing condition, and studies¹⁵ indicate that anticipating negative behaviour from others can produce defensive or evasive behaviour. This pattern in turn tends to elicit negative behaviour from ‘others’ thus leading to a negative ‘feedback loop.’ The SCARED programme helps the affected person and the ‘others’ to understand how communication can go wrong when stigma is present. Both individuals struggle with communication and behaviour, consequently a negative interaction or avoidance occurs.

SCARED is explained in the session as follows, and is intended to help the participant get in touch with his own feelings and his consequent behaviour.

| | |
|-----------------------|------------|
| The affected Person | |
| Feeling | Behaviour |
| Self-conscious | Shy |
| Conspicuous | Cowardly |
| Angry, anxious, alone | Aggressive |
| Rejected | Retreating |
| Embarrassed | Evasive |
| Different | Defensive |

SCARED for the ‘others’ (family, neighbours, colleagues, and community), is to help them understand their own feelings and behaviour towards those affected by leprosy. In this training we could not involve ‘others’ for logistic reasons, but the group was oriented about ‘others’ feelings and behaviour.

| | |
|--------------------|---------------------|
| Others’ Feeling | Behaviour |
| Sorry, shocked | Staring, speechless |
| Curious, confused | Clumsy |
| Anxious | Asking, awkward |
| Repelled | Recoiling, rude |
| Embarrassed | Evasive |
| Distressed, Dread | Distracted |

Session on Non-verbal communication skills

This session started with a discussion on challenges faced during social interactions such as the fear of contagion and the fear of facing questions. Skills such as confident body language, eye contact, facial expression and posture were taught. The session focused on learning skills on the following aspects:

Eye contact: Group Interaction Exercise (with and without eye contact).

- (1) Two ways of interacting were listed on a flip chart and responses were recorded.
- (2) Ways of listening to their neighbour with and without eye contact were given. Responses of their feelings were listed on the flip chart, discussed and recorded.

Discussion followed on:

- **Posture:** The importance of correct posture and postural exercises were explained, modelled and discussed.
- **Body language:** exercises and modelling
- **Handshake/namaste** (Indian way of greeting): through exercises and modeling.
- **Smile:** through exercises and modeling.

Session on verbal communication Skill

1) Education in the area of skills such as tone of voice, initiating conversations, possible conversation topics, and facing and answering questions were introduced. Activities included role-play. The session encouraged and carried out role-play such as acting like a mouse (i.e. diminutive) or a tiger (i.e. assertive).

This session highlighted the following issues:

To make communication easier by using verbal and non-verbal skills and giving individuals confidence by anticipating questions about their condition and how to answer them successfully.

The following skills were taught

Tone of voice: Through exercise and modelling

Initiating conversation: (a) discussion about the difficulties and advantages in initiating conversation; and (b) the group's ideas were elicited and listed on a flip chart, on the following three ways of initiating conversation.

- What do you and the other person have in common? (Work, children at school, living in the same area, common friends, attending a shared social event)
- Focus attention on the other person (clothes, work, and family)
- Show that you are interested and listening, using the skills learnt (eye contact, nodding, questions, using statements about yourself, being prepared on national and local news to continue the conversation.)

Exercises were given, and discussed along with suggestions on how to keep the conversation going.

This session also explored the reactions normally elicited when people first meet someone with an unusual appearance, and:

- (a) Considered how 'others' might feel when meeting someone with a stigmatising disease.
- (b) Analysed how people's interactions with the patients had changed before and after they had contracted leprosy.
- (c) Helped them to work on answers to questions they feared from others.

Examples on the following ways of answering were discussed in the group:

- Answering with the minimum information about the disease.
- Answering & changing the subject.
- Answering with lots of details.
- Introducing the subject first.

Session on Introduction to skills on REACH OUT

The sessions included:

- (1) Using communications skills
- (2) Recap of SCARED – The resource person reviewed the SCARED model with the group to help pick up the following salient points:
 - People experience uncertainty about unfamiliar situations.
 - Uncertainty leads to lack of skill
 - Lack of skill leads to avoidance
 - Manifestations of avoidance

REACH OUT is a set of skills, where each letter represents a strategy to try. Skills on how to take the initiative, manage intrusive questions and manage staring were taught:

Reassurance: This is about the need to reassure people that there is no reason to feel uncomfortable. Using eye contact, posture and smile, others will get a message that they don't have to behave differently or avoid contact.

Effort: Importance of trying to match the energy and effort of other people to appear interested. The skills to be used here are enthusiasm, voice, tone, and other communication skills such as nodding head or use of the hand.

Assertiveness: Importance of posture, eye contact, body language, and of leading the way and changing communication patterns that are not conveying assertiveness.

Courage: the group is encouraged to take small steps and build on small successes even though it may be difficult.

Humour: To break tension and gives a chance to take initiative in a lighthearted way. It conveys a relaxed state to the other person.

Out There: To shift the focus of attention from you to the other person.

Understanding: To understand the 'others' feelings of uncertainty, their fears and discomfort and about how to behave or respond to this. To understand that this uncertainty is not hostility.

Try Again: Not to give up if failures occur.

Session on video and Interaction with positive models

- (1) This session was comprised of a video of a life story of a person with disability and how successfully she was coping with her challenges.
- (2) Next, a former leprosy affected person who has successfully coped with the challenges of stigma was invited to share his experiences with leprosy. The group interacted with him.

Sessions on practical assignments and tasks

The final part of the training consisted of giving patients opportunities to put into practice the skills they had learnt in a community setting. They were sent to nearby villages to carry out the specific tasks they had earlier hesitated to perform. They were also asked to give talks about leprosy in public meetings in villages. The patients were then invited to assess these experiences using an evaluation form.

Results

Before the training programme, all the patients reported having predominantly negative thoughts regarding themselves. The shame, guilt, anger, fear, sense of helplessness and lack of confidence repeatedly expressed in the initial interviews were replaced with expressions of acceptance, hope, courage and increased self-confidence and assertiveness. As one patient expressed, "I got relief, courage. I walked with my head down, but now I walk with my head up. I came here as a patient, but [am] going back as a normal person. I was like a mad man before coming here, but now I feel I am free and happy". Before training, four of the five had suffered negative responses from their families, yet all professed a new confidence to combat these difficulties in the future. Before the training all the patients were having trouble interacting in the community, but afterwards three of the five had practiced public social interactions in at least one form, such as participating in village plays; visiting shops and tea stalls or discussing what it is like to be a leprosy patient in a forum with physiotherapy students. Four of the five patients were employed, and afterwards four of the five professed a new ambition to seek a new job or find ways of increasing their income, thereby expressing a

Table 1. Self-esteem profiles before and after social skills training

| Subject No. | Age | Deformity grade | Self-perception | Family status | Community status | Job status | |
|-----------------|-----|-----------------|-----------------|--|---|---|--|
| Before training | 1 | 24 | 2 | Hopeless, socially reticent, shameful and had attempted suicide. | Rejected, given no support. | Socially restricted, avoided church and teashops. | Unemployed |
| After training | | | | Courage, sense of hope and confidence in social interactions. | Improved family interactions | Visited church and performed in a local speech and drama production. | New impetus to seek job due to increased confidence. Found a job. Employed |
| Before training | 2 | 37 | 0 | Shy, socially withdrawn and feared rejection. | Had not told family. | Goes out only at night. | No change |
| After training | | | | Increased courage, verbal assertiveness and motivation to face problems. | Scared of transmission. Decided to tell family. | Visited village teashop. Practice in the wider community not yet known. | Employed |
| Before training | 3 | 56 | 2 | Dissatisfied, frustrated and cynical, with a negative world outlook due to his leprosy | Supportive family. Avoids physical contact. | Community rejected him. | Employed |
| After training | | | | New confidence and courage in social interactions | Improved understanding within the family | Performed in public plays. | Increased initiative to generate increased income |
| Before training | 4 | 21 | 0 | Socially reticent, completely hopeless, sense of guilt and fear of rejection | Rejected, discriminated, looked down on him | Socially withdrawn | Lacked initiative to work |
| After training | | | | Increased confidence, hopeful and increased appreciation of his own abilities. | More positive outlook towards the family. | Initiated social interactions with strangers. | Now owns his own teashop |
| Before training | 5 | 47 | 0 | Socially withdrawn and timid. | Discriminative | Withdrawn | Uncomfortable as a barber as he feared rejection |
| After training | | | | Very slight increase in confidence and hope | No change known within the family | Acted in a village play, visited teashops. Practice in the wider community not yet known. | Hoped for increased confidence with clients |

change in expectations for the future. Results suggested that the social-skills training caused an increase in self-esteem, as seen through changes in self-perception and behaviour (see Table 1).

Discussion and Conclusions

This pilot study gives pivotal new evidence that social skills training offers effective coping strategies for targeting self-stigmatisation. From the results it can be concluded that group counselling through social skills training caused patients to confront their negative perceptions, to act in more socially productive ways and have more optimistic perspectives of their future lives. Training in groups rather than individually appeared successful as it enabled patients to practice newly learnt social skills in a safe and trusting environment. Patients could share experiences and provide mutual support. The use of leprosy patients as role models was also found to be highly powerful, and suggests the potential benefit of training ex-leprosy patients as agents of change to combat stigma in society. Group training also may help resolve the problem of the paucity of time available for individual counselling.

LIMITATIONS OF THE STUDY

In studies of this nature it is possible that there may be a sense of obligation or gratitude from the participants either due to their familiarity with the trainers or a sense of compulsion to give only positive responses since they are in a hospital. One way we tried to limit this was to have outside evaluators. For future training sessions it may be better to have bigger groups and, if the participants are literate, they can be asked to write their responses without their names. However, for an illiterate group it may be difficult and interviews have to be done orally. The only way to avoid this is to get evaluators from outside the hospital who are not known to the participants.

As this is only a preliminary study, with a very limited number of patients, the statistical analysis potential is also limited. Furthermore, it is difficult to know how long these changes in attitude towards themselves and their future will last. Follow-up training as 'refresher sessions' may be useful for ensuring sustainability of results.

The ecological validity of the hospital environment is restricted and demand characteristics are also factors that prevent over-extrapolation of results. The results from this preliminary study, however, show importantly that self-perceived stigmatisation can be reduced. This suggests that social skills training would be a valuable part of leprosy rehabilitation schemes. It also highlights the validity of, and need for further research into this area, and suggests the positive impact this knowledge will have in liberating many lives constrained unnecessarily by self-stigma.

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Ethical approval

This study proposal was screened by the Karigiri Research committee and obtained ethical approval.

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Appendix

Participant’s profile

Given below are the excerpts from the qualitative information about a participant (under the categories of family, community and self, collected during the pre training session. (Information below is in participant’s verbatim format)

Story Profile of one participant

Anb (name changed) is one of the youngest members of the group, aged 24, and not married. He is the most educated person in the group, since he had almost finished his graduation in commerce. Anb has had the disease for more than 3 years. He has been hospitalised often for recurrent leprosy reactions.

FAMILY

“My family has told me to keep a distance due to fear of contagion. I have been told not to feed my little nieces, which I used to do before. With regard to eating, earlier I used to serve food myself from the pans but now they serve it for me.

I’m not able to talk freely or boldly with my sister’s husband as before. I have a fear if he would ask about my health. He does not know that I have leprosy. We have not told him because he may even desert my sister if he comes to know that I have leprosy.

I don’t visit my uncle’s houses any more. Some of them know about my disease and I see some changes when I visit them. Earlier when I visit them they used to serve food in a plate but now they serve it in banana leaves.

When guests come home I am told by my family to keep out of the house till the guests leave. Since my family itself is discriminating, I am not able to concentrate on my studies. (He has to complete one paper)

When I ask for money to buy my medicines, my brother says sarcastically “he is going for a big administrative job. He needs money”

My family has a fear that my brother’s marriage prospects may be hindered because of my disease.

Most importantly I could not marry the girl I loved. The father of the girl refused to let her marry me. (In orthodox Indian families a girl cannot marry a boy without her parents’ consent even if she is in love with him). Even the girl refused to accept me when she knew I have the disease. If the girl who knows me well, has refused to marry me, who else will marry me? Even if I marry can I hide the disease from the girl?”

COMMUNITY

“When I go to town, looking at my symptoms, friends ask me what disease I have. When there is a group of people, I want to go [to them], but I am not able to. I also feel difficulties in other public places like sitting in church and going to teashops. So I try not to go where there are people.

When I go to the hair saloon, it’s literally like dying because of the fear they will find out about my disease. I have a reason for this fear because in my regular saloon, they refused to cut my hair. Nowadays I try to cut it myself.

When traveling in the public bus, people who sit near me look at my hands with disgust. Some of them get up and go away to some other seat.

In some teashops, looking at me they say there is no tea, giving some lame excuses like there is no milk.

It’s difficult to go and eat in a hotel because the servers keep staring at me. I am not able to go with courage.

Not able to sit peacefully during the church service. I am uncomfortable because I am worried that some body will say some thing.

I'm not able to concentrate on my studies or the family's farm work.

SELF

"I am very sad about my situation. I don't have much hope for my future life. I am especially worried about my family problems. I don't feel like living anymore.

(He had attempted suicide)

My father has told me that I might as well commit suicide, and that I should not cause any more shame to the family. My family does not want me in the house, and no one visits me during my stay at the hospital. I see my sister once in a while; she gives me money to by food at the hospital.

I am angry and frustrated."

Post training Changes in ANB

New ways of interacting with other people

(The following report is based on the evaluation done immediately after the training and also based on observations and feedback received during the training. The changes that were experienced after their return to their homes are mentioned in the table (page 8). Those were reported during their subsequent visit to the hospital.

During the period with the group sessions, Anb actually tried some new way of interacting with other people. In one of the sessions he told about a good experience he had in church, which he attended during the weekend.

"I went to church. Usually I bend my head, but this time I remembered and held my head up high. Usually I just walk in fast. There is an usher, who follows the people in, and usually I don't wait for this man and I don't look at his face. But this time I looked at his face and I put my hand on the man's back and let the man follow me inside. I felt very good and I think I can do it on other places as well."

This episode indicates that Anb's way of interacting with other people began to change during the sessions. Another important change for Anb was that after the sessions he wrote the script for a skit about alcohol abuse and made a speech about leprosy. He and some of the other patients from the group performed the skit and gave the speech in two different villages as well at the hospital. This included taking initiative, planning, organising, dressing up, acting, and singing for the audience. Furthermore he talked to a group of students at the hospital about leprosy. Both of these experiences were new to him and he felt good having enough self-confidence to speak in public. As he said earlier, the disease had made it difficult for him to stand upright and talk with other people.

Changes in expectations for the future

Anb feels he has benefited a lot from the sessions. Because of what he learned in the sessions, he has now much more courage for going out and facing his problems:

“Something which I liked very much in this training was a thought, that instead of avoiding people I need to just go and face them. Before I was shy and my mind was not free to go anywhere. But now after your teaching I have got the courage to go and face everything “ He had never before considered the importance of looking at people in their eyes and standing upright like he did in the church. Now he feels he is able to do so. During the sessions his perspective on his future relationship with his family has changed as well. As he said in one of the last sessions, he will now try to get a job and prove to his family that he can care for himself. These different statements indicate that Anb has benefited from the intervention programme. However, even after the intervention programme he still has serious concerns about his future. He still worries a lot about his mother and how she treats him, and he is very concerned about how to get a job and earn money, and whether his physical reactions will be cured.

Even though he has already tried out some of the new social skills, he still has concerns whether he will be able to use what he has learned in real life situations:

“Like in yesterday’s role-play, going straight into a marriage hall and talking is not possible immediately, but doing it in a role-play gave me courage. But still it stays as a question whether it will be possible do to it. Madam. V is suggesting that in a social function I should try to volunteer to serve food to guests (An Indian custom where friends volunteer to take up various responsibilities in a wedding even without any one telling them to do) and go forward to do other things. These things are easy to talk but not easy to practice.”

He mentions this specific issue both in the post-interview and several times during the sessions. Because he has not been home yet, it is not possible to tell how he will actually manage in practice in the future. However he seems quite realistic about his own capabilities to change his way of living. As he said in relation to practicing the new social skills: “Maybe we cannot do it 100% but maybe 50%.”

In the near future he expects to continue to arrange village meetings with skits and speeches.

What in the sessions seems to have had an influence?

For Anb the most important aspect of the sessions was the training in showing courage and having eye contact with people instead of looking down and withdraw:

“It was good to learn about courage and eye contact. From Madam V, I had learned to talk with eye contact, when I go out and when people ask any questions. The way I should answer was taught.”

He had especially learned about courage & assertiveness through the different role-plays. The subsequent changes seen after his return to hometown are mentioned in the table in the original paper (page 8).