

Chapter 7

Counselling in Leprosy



Sunil Kumar Gupta

Abstract Counselling encourages the needy person to realize the existence of the problem and helps them to analyse the cause. Also, it helps them in finding a feasible solution. Successful counselling ends with positive change in the thought process, feelings, and activity of the patient. Leprosy is a neglected tropical disease known for stigma and discrimination of the affected. It affects the physical, psychological, social, and economic well-being of the patient. Hence, there is utmost need of counselling for the leprosy patients, their family members, and the community.

Keywords Leprosy · Counselling · Intervention in counselling

Introduction

Leprosy is a neglected tropical disease (NTD) that often results in deformity if not treated at the appropriate time. Leprosy and its deformity are best known to cause stigma and discrimination in low- and middle-income countries like India. The stigma of leprosy is a real development in many people's lives that affects their physical, psychological, social, and economic well-being. There are several causes for this damaging image of leprosy.

The Burden of Stigma and Mental Illness in Leprosy Affected

When diagnosed with leprosy, patients usually attempt to conceal the disease and try to consult from a health centre far away from their homes. Leprosy patients may withdraw communication from their spouses and/or family to avoid negative behaviour. They isolate themselves. Even community members also express their negative

S. K. Gupta (✉)

Department of Dermatology, AIIMS, Gorakhpur, India

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attitudes by avoiding leprosy-affected people, forcing them to leave, gossiping about them, and refusing to share public transport with them. Such behaviours harm the physical, psychological, and socioeconomic status of leprosy-affected people. Psychologically, they may suffer mental stress and anxiety leading to depression and even, in some cases, suicide [1].

A multi-centric, cross-sectional questionnaire-based study was carried out in four leprosy-endemic states of India—Chhattisgarh, Maharashtra, West Bengal, and Tamil Nadu. Disease profiles like leprosy classification, deformity grade, number and size of the patches, and socioeconomic status were collected along with individual data. Of the total 220 respondents, the prevalence of depression and anxiety symptoms was 33% (73) and 19% (42), respectively. The presence of disability (47%) and female gender (46%) was significantly associated with depression. The presence of disability (32%), lower-income group (27%), and low education (22%) was significantly associated with symptoms of anxiety. As the severity of disability increased, the risk of developing depression and anxiety increased [2].

Another semi-structured questionnaire-based cross-sectional study was conducted among 358 persons affected by leprosy above the age of 18 and married who were reporting at the tertiary leprosy referral hospital, Purulia, West Bengal, India. Among the participants, 41% of them were female, 60% were aged between 18 and 45 years, 58% were literate, and 40% of the participants had a physical disability. The participants had multiple feelings of fear, anxiety, and sorrow when first diagnosed with leprosy. The majority (69%) of the participants had fear of the disease. A significant association was present among males and females feeling fear of leprosy, and the female feared more than male [3].

While both men and women were negatively affected in terms of their family and marital lives, women suffered more isolation and rejection. Psychologically, women appeared more vulnerable because they were deprived of personal contact with others in the domestic environment where they were accustomed to receiving their greatest emotional rewards. Women reported that indifference to them by other family members, or seeming negation of their presence, caused them the greatest suffering [4]. Van't Noordende et al. also found that many women affected with leprosy faced fear, abuse, and violence in their marital and sexual relationships [5].

What Does Counselling Mean

“Counselling is a helping process where one person explicitly and purposefully gives his/her time, attention and skills to assist a client to explore their situation, identity and act upon solutions within the limitations of their given environment” [1]. The GATHER (greet, ask, tell, help, explain, return visit) technique can be useful in successful counselling. Counselling services have been proven successful in reducing stigma [6].

While the scope for counselling is quite enormous, it will vary according to the specific need.

Objectives of Counselling

The objective of counselling is to encourage the needy person about the realization of the existence of the problem and help them to think and analyse the cause. Also, it helps to find a feasible solution and work on it to solve the problem. Successful counselling ends with positive change in the thought process, feelings, and activity of the client/patient (Table 7.1).

Counselling in Leprosy

Counselling in leprosy involves various levels from:

1. Leprosy-affected person
 2. Family members
 3. Group counselling
1. *Counselling of leprosy-affected person:* Individual counselling is required on following conditional stages of leprosy:
 - (a) *Diagnosis of leprosy:* Breaking news regarding the diagnosis of leprosy is a very critical time. An empathic behaviour of a treating physician requires a good counselling technique during this stage.
 - (b) *Irregularity in taking anti-leprosy treatment:* Treatment dropout is very frequent in leprosy due to the long duration of treatment and adverse cutaneous drug reaction to multidrug therapy (MDT) drugs. Adherence with MDT in the treatment of leprosy is important to minimize the risk of relapse and avoid the emergence of drug resistance [7].
 - (c) *Developing reactions during therapy:* Leprosy-affected people become more depressed due to lepra reaction. This increases the chance of drug withdrawal. Both situations aggravate the rectory stage. At this time, proper counselling is required.
 - (d) *Poor compliance with self-care:* Due to lack of self-care practices, leprosy patient easily develop trophic ulcers and secondary bacterial infection. Ignoring advice on self-care results in the development of disability or deformity. Regular counselling on self-care is of utmost importance for leprosy patients.

Table 7.1 Counselling process and after effects

Counselling process	Aftereffects of a good counselling
<ul style="list-style-type: none"> • Exploring • Understanding • Action • Interacting • Involving 	<ul style="list-style-type: none"> • Changing how a person thinks • Changing how a person feels • Changing how a person behaves or act

- (e) *Stigma and counselling*: Stigma is known to harm leprosy-affected people emotionally, socially, economically, and spiritually. A preoperative counselling session with the patients helps them reach the realistic goals that they can achieve. They should be told what benefits surgery can offer them and be made aware of the problems which will persist after the operation, such as anaesthesia and analgesia [8]. Group participants are attached with the group members and understand that they are not lonely sufferers. Sometimes role model presentations during group counselling help to raise self-esteem and increase participation in social activity.
2. *Counselling of family members of leprosy-affected people*: The family members of leprosy-affected people should be thoroughly educated about the disease course, treatment duration, lepra reaction, and infectivity. The counsellor should take care of the family image and help to cope with the disease. In the case of a woman with leprosy, her husband and in-laws should be properly counselled about how to give moral support and maintain the marital status without any unlawful act or violence.
 3. *Group counselling*: Group counselling of stigmatized persons help in the common issues to more than one person at a time, encouraging the unity of sufferers, developing compassion for others, understanding the common effects of stigmatization, and beginning to overcome its harmful effects. It also helps to remove the fear of corrective surgery preoperatively [9]. Group counselling can allow those with leprosy to talk about their feelings and experiences to empower one another.

Interventions in Counselling

Counsellors provide psychological support, appropriate education, and coping skills to persons affected by leprosy. Counselling of leprosy patients is essential to enable them to cope with perceived stigma as well as managing severe enacted stigma at home, in society, place of work, or elsewhere. Counselling became more intensive in Grade 1 and for almost all in Grade 2 disability who experienced restrictions in meeting new people, participating in social activities, and indulging in socioeconomic activities. Counselling for such groups of patients required multiple approaches, including in-depth leprosy education for regular treatment, self-care measures, mobilization of coping skills, self-confidence and acceptance counselling, and follow-up counselling for those released from treatment after multidrug therapy [10].

The counselling intervention should be effective in reducing stigma, promoting the rights of people with leprosy, and facilitating their social participation.

Effective communication skills such as listening and asking effective questions were not only important but also difficult to acquire for the lay and peer counsellors.

Sharing personal experiences are highly appreciated by clients and stimulated by a deepened reflection.

The author recommends paying 20–30 min extra time to the patients with leprosy on their every visit either individually or through focused group discussion and look into the following points:

- **Integration:** *Leprosy services should always be integrated into general health services. In this way, the feeling of stigma and isolation is dropped down.*
- **Education:** *Breaking news regarding disease to leprosy-affected people should be in an empathetic manner. Patients with leprosy must know about the disease, its sign and symptoms, and causative agent. All the myths related to leprosy should be clearly explained to the patient. Leprosy-affected people should know the disease course and treatment duration. The patient also needs to be educated about detecting the early signs of lepra reaction. At the same time, all other family members of the patient should be screened for leprosy, and they should also be educated regarding the disease.*
- **Motivation:** *Patients should be motivated regularly for self-care, compliance with proper anti-leprosy treatment, and reconstructive surgery. The patient's spouse and family members should be motivated for acceptance and normal behaviour with leprosy-affected people.*

The training involved identification of the emotions and concerns of patients when interacting socially, analysis of positive and negative social interactions, and nonverbal 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.

Education-oriented counselling and psychological supportive counselling are necessary adjuncts for clinical care and treatment. Client-oriented counselling allows clients to freely express their fears and anxieties and promotes coping skills and confidence [2, 11]. The Stigma Assessment and Reduction of Impact (SARI) scale is a useful tool to assess the stigma associated with leprosy [12].

The counselling intervention is effective in reducing stigma, promoting the rights of people with leprosy, and facilitating their social participation.

All of the healthcare workers should display a good understanding of patients' difficulties and needs and acknowledge the key role of patient education. However, they express several challenges in managing patients due to lack of time, human resources, and training in patient education. Further efforts need to be made to increase patients' general knowledge of the disease to motivate them to seek healthcare earlier and change their perception of the disease to reduce stigma. HCWs need proper training in patient education and counselling for them to acquire the necessary skills required to address the different educational needs of their patients. The counsellor should know what to do and what not to do during counselling (Table 7.2) [13].

Table 7.2 Dos and don'ts in counselling

What to do	What not to do
Great the patient on each visit	Overlook the root cause of the problem
Ask the patient about the problem that needs help	Start counselling prematurely without understanding the basic problem
Encouraging self-respect, teaching how to avoid shame, increasing self-sufficiency, working on self-regard, and explaining the importance of self-care	<i>Enforcing</i> solution/alternative on patient to solve his problem
Helping in the selection of appropriate solutions	Hurting the patient's emotion/feelings
Explaining how to implement the solutions	Using technical and tough words for patient to understand
Regular scheduling for the next session	Time not suitable/counselling in hurry/atmosphere not conducive

Take-Home Message

- Leprosy is a chronic neglected tropical disease, often associated with stigma and prejudice.
- Leprosy-affected people develop fear, anxiety, and depression due to the disease course itself and also due to negative behaviour of the family and society.
- Women are at higher risk to develop psychological morbidity, and their marital lives are also on verge of a break.
- Counselling is an art, and for leprosy patients, it requires different stages starting from diagnosis to psychosocial rehabilitation.
- A counsellor should follow the GATHER technique on every visit by patients.
- Gradually attitudes towards leprosy are changing; however, there is still much to be done to decrease the stigma of leprosy from the community and empowerment of leprosy-affected people, especially women.

References

1. Thakor HG, Murthy P. Counselling of leprosy affected persons and the community. *J Indian Med Assoc.* 2004;102(12):684–7.
2. Bense N, Das P, Rao PS, John AS. Enhancing counselling strategies for leprosy patients through the participation scale. *Lepr Rev.* 2013;84(3):199–208.
3. Correia JC, Golay A, Lachat S, Singh SB, Manandhar V, Jha N, et al. “If you will counsel properly with love, they will listen”: a qualitative analysis of leprosy affected patients’ educational needs and caregiver perceptions in Nepal. *PLoS One.* 2019;14(2):e0210955.
4. Dadun D, Van Brakel WH, Peters RMH, Lusli M, Zweekhorst MBM, Bunders JGF, et al. Impact of socio-economic development, contact and peer counselling on stigma against per-

- sons affected by leprosy in Cirebon, Indonesia—a randomised controlled trial. *Lepr Rev.* 2017;88(1):2–22.
5. Floyd-Richard M, Gurung S. Stigma reduction through group counselling of persons affected by leprosy—a pilot study. *Lepr Rev.* 2000;71(4):499–504.
 6. Govindasamy K, Jacob I, Solomon RM, Darlong J. Burden of depression and anxiety among leprosy affected and associated factors—a cross sectional study from India. *PLoS Negl Trop Dis.* 2021;15(1):e0009030.
 7. Govindharaj P, Srinivasan S, Darlong J. Perception toward the disease of the people affected by leprosy. *Int J Mycobacteriol.* 2018;7(3):247–50.
 8. Nicholls P, Bakirtzief Z, Van Brakel W, Das-Pattanaya R, Raju M, Norman G, et al. Risk factors for participation restriction in leprosy and development of a screening tool to identify individuals at risk. *Lepr Rev.* 2005;76(4):305–15.
 9. Ramanathan U, Malaviya GN, Jain N, Husain S. Psychosocial aspects of deformed leprosy patients undergoing surgical correction. *Lepr Rev.* 1991;62(4):402–9.
 10. Rinehart W, Rudy S, Drennan M. GATHER guide to counseling. *Popul Rep J.* 1998;48:1–31.
 11. Sermrithirong S, Van Brakel WH, Bunbers-Aelen JF. How to reduce stigma in leprosy—a systematic literature review. *Lepr Rev.* 2014;85(3):149–57.
 12. Van't Noordende AT, da Silva B, Pereira Z, Kuipers P. Key sources of strength and resilience for persons receiving services for Hansen's disease (leprosy) in Porto Velho, Brazil: what can we learn for service development? *Int Health.* 2021;13(6):527–35.
 13. Vlassoff C, Khot S, Rao S. Double jeopardy: women and leprosy in India. *World Health Stat Q.* 1996;49(2):120–6.