

SOCIO-CULTURAL ISSUES IN LEPROSY CONTROL AND MANAGEMENT

M L Wong,* P Subramaniam

ABSTRACT

The priority areas in the leprosy elimination programme are early case detection, case holding and consequently, the prevention of disabilities. In some countries, a significant number of cases do not seek treatment or seek treatment late, partly due to socio-cultural beliefs and stigma about leprosy. We review the literature on socio-cultural beliefs and stigma about leprosy and the intervention programmes that address these beliefs and issues. Socio-cultural dimensions should be incorporated into leprosy control programmes to reduce stigma and promote community acceptance of leprosy patients by using the following approaches: (I) conducting qualitative studies on socio-cultural beliefs, (II) designing culturally appropriate messages and integrating them with existing beliefs, (III) involving community leaders, traditional healers and families, (IV) conducting cross-cultural comparison studies and (V) training health staff to be sensitive to patients' concerns and culture.

INTRODUCTION

The goals of the leprosy elimination programme are to increase community awareness and participation; improve the capacity of general health workers in diagnosis and treatment; and detect cases that have remained undetected in the community and cure them by providing free access to multi drug therapy (1). The World Health Organisation has identified the priority areas in this programme to be early case detection, case holding and consequently, the prevention of disabilities. Since 1995, all top endemic countries have implemented the leprosy elimination campaign with the aim of intensifying elimination activities at the grass-root level. Overall, the elimination goal had been successful as could be seen by the marked decline in the global prevalence of leprosy. Among the 122 countries where leprosy was considered endemic in 1985, 107 countries have reached the elimination goal (2).

In some countries, a significant number of cases still remain undetected or are detected late partly due to their delay in seeking treatment. Late case detection may result in deformities, which could have been prevented with timely treatment. In addition, the risk of transmission in a community increases as the infection pool is maintained longer than necessary (3). In addition, a significant proportion still default treatment although compliance with drug therapy is generally good. Many leprosy patients also experience rejection from the society and are not able to find employment (4,5,6) due to the stigma attached to the disease. In short, the social problems encountered in leprosy control and management include patients' delay in seeking treatment, non-compliance with medication or self-care and leprosy stigma. The occurrence of these problems is partly due to the cultural beliefs associated with leprosy. It is important to understand the socio-cultural beliefs and stigma towards leprosy and how they affect health-care seeking behaviour if we want to improve the effectiveness of leprosy control and management programmes.

This paper reviews the literature on socio-cultural beliefs and stigma about leprosy and the intervention programmes that address these beliefs and issues. Based on the review, the authors propose recommendations on how to incorporate socio-cultural dimensions into leprosy control programmes to increase their effectiveness in early case detection, deformity prevention and in improving the quality of life of leprosy patients.

METHODS

A literature search of socio-cultural aspects in leprosy control and intervention programmes on health education was conducted using electronic databases such as the Medline, Social Science Citation Index (SSCI), BIOSIS previews and PubMed. The following key words were used in the literature research: knowledge, beliefs, attitudes, stigma, practices, socio-cultural aspects, health education and intervention programmes. Recent journal articles on Leprosy were also hand-searched for articles relating to socio-cultural aspects and intervention programmes.

RESULTS

C o n c e p t s o f d i s e a s e , i l l n e s s a n d s i c k n e s s i n l e p r o s y

Robinson (7) explains leprosy as three entities (i) the disease of leprosy - biomedical perception; (ii) the illness of leprosy - self perception; and (iii) the sickness of leprosy - social perception. In the event of leprosy, the disease is perceived by the health workers according to existing physical symptoms; the illness is experienced and is shaped by the socio-cultural influences of the person; and the sickness is perceived by the society and is expressed as social stigma (8). This distinction is also defined by Kleinman (9) as follows: “ ‘illness’ is the culturally constituted, socially learned response to symptoms that includes the way we perceive, think about, express and cope with ‘sickness’, while ‘disease’ is the technical reconstruction of sickness into terms of the theoretical system used by health practitioners”.

I l l n e s s b e h a v i o u r o f l e p r o s y p a t i e n t s

Illness behaviour is defined as the ways in which given symptoms may be differentially perceived, evaluated and acted upon (or not acted upon) by different kinds of persons (10). Thus a person, on experiencing numbness of his hand, may do nothing about it or do something about it by seeking treatment from western or traditional health-care facilities. The latter is referred to as health-care seeking behaviour, that is, what people do and where they go on suspicion of illness. The health-care seeking behaviour of people affected by leprosy is influenced by many factors, including the patient’s and the society’s beliefs and perceptions about leprosy; the availability, accessibility, acceptability and affordability of health services, quality of the health-care provider-patient relationship (11,12) and the patient’s socio-demographic characteristics. In a society, which discriminates against leprosy sufferers, patients would conceal their condition and not seek or adhere to the treatment for fear of, or as a result of social rejection.

Previous research showed that health seeking behaviour of leprosy patients typically followed a pattern of home-based care with over-the-counter medications, followed by consultations with traditional healers and finally approaching the local health facility (6,13). Delay in identifying symptoms and presenting for treatment was also found to be higher among females (14). More females than males also resorted to “home remedies” such as fasting and offerings to God, as well as native treatment given by traditional healers prior to seeking medical treatment.

L e p r o s y s t i g m a

Leprosy stigma has been found to be a major factor leading to the delay in patients seeking treatment (15). Goffman (16), defines stigma as an attribute that is deeply discrediting, and the stigmatised individual is one who is not accepted and not accorded the respect, rights and regard of his peers; one who is disqualified from full social acceptance.

The stigma against leprosy seems to be related to the fact that leprosy deforms and disables but seldom kills, so that those who have been crippled, live on, getting steadily worse, their deformities visible to the whole community. The chronic symptoms of untreated leprosy often afflict individuals in their most productive stage of life and limit or prevent them from fulfilling their normal roles in society: they may lose their economic independence as a result of losing their jobs, their physical independence as a result of disabilities, their self esteem as a result of social isolation and generally live a lower quality of life (17).

Persons affected by leprosy experience unsympathetic reactions, insults, hate and rejection from society (4,5,18). The stigmatisation in leprosy is frequently extended to the families having members suffering from leprosy. A study revealed that families with a patient who had deformities faced 10 times higher societal problems than those having patients with no deformities (19).

C u l t u r a l b e l i e f s a n d m i s c o n c e p t i o n s a b o u t l e p r o s y

The stigma against Leprosy is partly due to cultural beliefs and misconceptions about the causes and transmission of leprosy. The cultural beliefs about leprosy are summarised in Table 1. Leprosy has been commonly considered a punishment from God in many cultures (20,21). In India, the Hindus consider deformity resulting from leprosy as divine punishment (22). A similar view is shared in China where leprosy

patients. Croft et al's study (34), in Bangladesh found markedly lower levels (18% - 28%) of prejudice in a rural community, which had received community education (which targeted stigma as one of its educational components) as compared to another rural community without the health education programme. In the village that had not received health education, over 75% of the families reported that they would not share a meal with a leprosy sufferer and 94% cited that they would not permit their son to marry a girl who is cured of leprosy. This village was also more likely to seek traditional healers and "informally-trained" doctors for the management of leprosy.

Another more recent study in Bangladesh (35) also found that overall knowledge in leprosy and positive attitudes towards leprosy patients were significantly higher in a slum area that has received a community health programme as compared to another comparable control slum that has not received the programme. The majority (92%) of the females in the intervention area reported that they would not avoid contact with a leprosy patient.

A culture-specific health education programme in Malaysia that incorporated local cultural beliefs and considered the people's sensitivities, social structure, values and beliefs has also been found to increase their acceptance of leprosy messages and improved their knowledge and attitudes towards leprosy (36).

Some countries are beginning to work with traditional and religious healers to provide care to leprosy patients, probably because many patients consult them first before seeking treatment from western health-care systems. A study in Nigeria showed 59% of the patients consulted the folk-medicine sector as the first step in their health seeking routine (37). Studies in Botswana (6) and Tanzania (33) demonstrated the harmonious co-existence of modern health-care workers and traditional and religious healers even though the latter harboured superstitious beliefs as to the cause of the disease.

CONCLUSION

A review of the literature showed that the stigma, misconceptions and negative attitudes towards leprosy patients are prevalent in most communities, despite medical advances in leprosy treatment. Most misconceptions pertaining to leprosy, in particular the beliefs in heredity, evil spirits and contact with prostitutes as causes of leprosy, were found to be rather similar across wide geographical and cultural backgrounds. In addition, deformities arising as a consequence of untreated leprosy played a significant part in increasing the stigma to leprosy.

Implications for programme planning

Based on the review, recommendations are proposed on how socio-cultural dimensions may be incorporated into leprosy control programmes to reduce stigma and fear about leprosy patients and increase community acceptance of leprosy patients. If the stigma related to the disease is reduced, community members are also more likely to seek early treatment.

Conduct qualitative studies on socio-cultural beliefs: The existing knowledge, attitudes, beliefs and practices of the target population pertaining to the disease should be explored and researched before appropriate awareness programmes are designed and implemented. This is best done through a combination of qualitative methods such as focus groups and quantitative methods such as surveys. Studies should also be conducted among health care providers to assess their beliefs and attitudes on leprosy.

Design culturally appropriate messages and integrate them with existing beliefs: The primary objectives of community health education interventions are to inform the community about the effectiveness of treatment, counteract the stigma and promote integration of affected persons and their families. Misconceptions are difficult to dispel and cultural beliefs are very resistant to change. Thus, it is important to integrate the true facts about the disease, such as its curability and non-infectivity, into the local community's existing beliefs. The campaign should provide accurate knowledge of leprosy by working its way around the misconception rather than denouncing the traditional beliefs outright (1). The challenge for health educators is to get the right mix of traditional beliefs and modern theory of medicine which neither offends the community nor compromises on the accuracy of the message.

Involve community leaders and families: A multi-sectoral approach that involves health professionals, community and religious leaders as well as governmental representatives in all stages of planning and delivery of community health education programmes and other leprosy control activities is recommended to ensure better impact, continuity and wider acceptance of the intended health messages. Spouses should also be involved in leprosy control activities, as they can play an important role in case finding particularly among Muslim female patients who donned the 'purdah' as a religious practice. Children can also play a role in disseminating health messages and influencing family members to seek early treatment.

Consider the feasibility of involving traditional healers: The feasibility and acceptability of involving traditional healers should be explored to encourage lay referral. This is important particularly in communities where a significant proportion of leprosy patients sought traditional healers prior to seeking treatment from health facilities.

Conduct cross-cultural comparison studies: Some communities have been found to be more accepting of leprosy patients than others. Leprosy patients have been found to be better accepted by Malays than the Chinese (38). The communities in Myanmar also did not mind having leprosy patients as their neighbours (4). Cross-cultural studies should be carried out to compare factors that have led to the differing attitudes towards leprosy patients. We can learn from communities with more favourable attitudes and apply and adapt what we have learnt from them to less favourable communities.

Train health staff to be sensitive to patients' concerns and culture: The quality of the health-care provider-patient relationship is an important factor influencing patient compliance with treatment (11,12). It is important to improve the holistic care of leprosy patients at the clinics, hospital or rehabilitation centres, where their psychosocial concerns are also taken into consideration. Other than training health-care providers in management of the disease and side effects from drug treatment, attention should be paid to the training of health-care providers in communication and counselling skills. Health providers must learn to empathise, listen to patients' concerns and respond to them. The paternalistic approach which is often adopted by health-care providers in managing patients in developing countries, is not only inappropriate, but would deter patients from coming for follow-up treatment. Health providers should also learn problem-solving skills to assess the patients' reasons for defaulting treatment or follow-up and act on them. This means that they should be trained on techniques to analyse and motivate behaviour change.

* Associate Professor
Department of Community, Occupational and Family Medicine (MD 3)
Faculty of Medicine, National University of Singapore
MD3, 16 Medical Drive, Singapore 117597
Email: cofwml@nus.edu.sg Fax: (65) 7791489 Tel: (65)8744965

REFERENCES

1. World Health Organization. *Leprosy elimination campaigns*. Weekly Epidemiological Record, WHO, Geneva. 2002; 77: 17-20.
2. World Health Organization. *Leprosy-Global situation*. Weekly Epidemiological Record. WHO, Geneva. 2002; 77: 1-8.
3. World Health Organization. *Action programme for the elimination of leprosy: Status Report*. WHO, Geneva. 1996.
4. Myint T, Thet AT, Htoon MT, Win M. *A comparative KAP study of leprosy patients and members of the community in Hlaing and Laung-Lon townships*. Indian J Lepr 1992; 64: 313-324.
5. Ulrich M, Zulueta AM, Caceres-Ditmar G et al. *Leprosy in women: characteristics and repercussions*. Soc Sci Med 1993; 37: 445-456.
6. Kumaresan JA, Maganu ET. *Socio-cultural dimensions of leprosy in North-Western Botswana*. Soc Sci Med 1994; 39: 537- 541.
7. Robinson I. *Personal narratives, social careers and medical courses*. Soc Sci Med 1990; 30: 1173-1186.

8. Valencia L.B. XIII *Leprosy congress state-of-the art lecture. Social science research on social dimensions of leprosy. Where are we going from here?* Int J Lepr Other Mycobact Dis 1989; 57: 847-863.
9. Kleinman A, Sung LH. *Why do indigenous practitioners successfully heal?* Soc Sci Med 1979; 13: 7-26.
10. Mechanic D, Volkart EH. *Illness behaviour and medical diagnosis.* J Health Human Behav. 1960; 1: 86-94.
11. Bakirtzief Z. *Obstacles to compliance with treatment for Hansen's disease.* Cad Saude Publica 1996; 12: 497-505.
12. Bijleveld I. *Leprosy care: patient's expectation and experience. A case study in Western Province.* Kenya. Amsterdam: Royal Tropical Institute 1977.
13. Mull JD, Wood SC, Gans LP, Mull SD. *Culture and compliance among leprosy patients in Pakistan.* Soc Sci Med, 1989; 26: 799-811.
14. Rao S, Garole V, Walawalker S, Khot S, Karandikar N. *Gender differentials in the social impact of leprosy.* Lepr Rev. 1996; 67:190-199.
15. Bekri W, Gebre S, Mengiste A, Saunderson PR, Zewge S. *Delay in presentation and start of treatment in leprosy patients: a case-control study of disabled and non disabled patients in three different settings in Ethiopia.* Int J Lepr Other Mycobact Dis 1998; 66: 1-9.
16. Goffman E. *Stigma: notes on the management of spoiled identity.* Englewood Cliffs: Prentice-Hall Inc. 1963.
17. Bainsan KA, Van Den Borne B. *Dimensions and process of stigmatization in leprosy.* Lepr Rev 1998; 69: 341-350.
18. Kant VP. *Socio-economic problems of leprosy patients and their relatives in Gujarat state.* Indian J Lepr 1984; 56: 889-899.
19. Kopparty SN, Kurup MA, Sivaram M. *Problem and coping strategies of families having patients with and without deformities.* Indian J Lepr 1995; 67: 133-52.
20. Browne SG. *Some aspects of the history of leprosy: the leprosy of yesterday.* Proc R Soc Med 1975; 68: 485-493.
21. Richards P. *The medieval leper and his northern heirs.* Cambridge: D. S Brewer Ltd. 1977.
22. Muthankar RK. *Society and Leprosy.* Wardha, India: Gandhi Memorial Leprosy Foundation, 1979.
23. Skinsnes OK. *Leprosy in society I. Leprosy has appeared on the face.* Lepr Rev 1964; 35: 21-35.
24. Teckle-Haimanolt R, Forsgren L, Gebre-Mariam A. et al. *Attitudes of rural people in central Ethiopia towards leprosy and a brief comparison with observation with epilepsy.* Lepr Rev 1992; 3: 157-168.
25. Chen PCY. *Human behavioural research applied to the leprosy control programme of Sarawak, Malaysia.* Southeast Asian J Trop Med Public Health 1986; 17: 421-26.
26. Gussow Z. *Leprosy, racism and public health: social policy in chronic disease control.* London: Westview Press, 1989.
27. De Stigter DH, de Geus L, Heynders ML. *Leprosy: between acceptance and segregation. Community behaviour towards persons affected by leprosy in eastern Nepal.* Lepr Rev 2000; 71: 492-498.
28. Cook A. *An urban community's thought about leprosy: A study in Guyana.* Lepr Rev 1982; 53: 285-296.
29. Awofeso N. *Appraisal of the knowledge and attitude of Nigerian nurses toward leprosy.* Lepr Rev 1992; 63: 169-172.
30. Valencia LB. *Socio-economic research in the Philippines with special references to Leprosy.* Southeast Asian J Trop Med Public Health 1983; 14: 29-33.
31. Kumaresan JA, Maganu ET. *Knowledge and attitude of health workers towards leprosy in North-Western Botswana.* East Afr med J 1994; 71: 366- 367.
32. Awofeso N. *Effect of socio-cultural beliefs on patients' perception of leprosy: A gender factor.* Trop Geogr Med 1995; 47: 175-178.

33. Van den Broek J, O'Donoghue J, Ishengoma A, Masao H, Mbega. M. *Evaluation of a sustained 7 year health education campaign on leprosy in Rufiji District in Tanzania*. Lepr Rev 1998; 69: 57-74.
34. Croft RP, Croft RA. *Knowledge, attitude and practice regarding Leprosy and Tuberculosis in Bangladesh*. Lepr Rev 1999; 70: 34-42.
35. Hilary C. *Comparative study of KAP towards leprosy in an intervention and a control group of the community in Bangladesh*. Unpublished Master's Dissertation, National University of Singapore, 2001.
36. Chen PCY, Sim HC. *The development of culture-specific health education packages to increase case finding of leprosy in Sarawak*. Southeast Asian J Trop Med Public Health 1986; 17: 427-431.
37. Van De Weg N, Post EB, Lucassen R, De Jong JTVM, Van Den Broek J. *Explanatory models and help seeking behaviour of leprosy patients in Adamawa state, Nigeria*. Lepr Rev 1998; 69: 382-89.
38. Mymoon A. *A study of KAP with regards to selected aspects of leprosy amongst Chinese and Malay inmates of the National leprosy control centre, Sungai Buloh, Selangor*. Master's Dissertation, University of Malaya, 1990.