

Report of the pre-congress workshop on Social Science and Leprosy titled “Leprosy stigma and its psychosocial consequences”

16th International Leprosy Congress, Salvador, Brazil, August 2002

The two-day Workshop focused on the nature, processes and consequences of stigma, paying specific attention to enacted and perceived stigma. The first objective was to identify ways in which current knowledge may be implemented in the field. The second objective was to identify gaps in knowledge and priorities for research. Participants were professionally involved in the fields of psychology, social psychology, anthropology, medicine, rehabilitation, nursing care, occupational therapy or social research and included representatives from IDEA and Morhan. Many participants have published work relevant to the discussion of leprosy-related stigma.

Problem statement. Leprosy-related stigma is found in countries world-wide, irrespective of whether leprosy is endemic, eliminated or eradicated. In the context of leprosy, stigma is known to have an adverse impact on efforts to achieve early detection, on treatment compliance and on every aspect of leprosy control.

The efforts of researchers and the energies of programme managers have concentrated on treatment and disease control while in comparison the social aspects of leprosy have been neglected. We now have a state of the art cure for *Mycobacterium Leprae*, while stigma continues to permeate society and impact those affected, even to the point of exclusion on the basis of suspicion rather than diagnosis. While physicians make diagnoses and present solutions of MDT, those affected are concerned with the social consequences of the disease, the threat it carries to security, life chances and identity.

A much improved understanding of stigma is essential to all aspects of the care provided for people affected by leprosy. It will direct our provision of counselling and support services. It will allow us to design effective health education programmes and materials. It will inform the evaluation of such interventions. It will highlight the need for rehabilitation interventions and provide effective support for advocacy.

The nature of stigma. Stigma is the response to an undesired “differentness”, a departure from what is considered “normal” by society. Stigma is recognised in a society’s restrictions on an individual in the form of isolation, exclusion, derogatory labelling, devaluation and many other forms of prejudice. It may be physically oriented or a response to blemishes of character or to race. It may result from ideas of culpability or from fears of contamination. Primarily stigma is a cultural phenomenon, an outworking of a society’s world view, something that is learned. Everyone is capable of displaying stigma.

Stigma is deeply discrediting and spoils personal identity. The psychological impact on the affected individual is seen in low self-esteem, fear and loneliness.

Both the stigmatiser and stigmatised see the other as a threat. This results in forms of enacted stigma, the outward expression of prejudice, and in perceived or felt stigma, the fear of such prejudice. In the context of leprosy, stigma is unique in its intensity, inventiveness and ubiquity.

Every leprosy-affected person experiences stigma in some form. Stigma is with us (in society) and therefore a factor for everyone working to control leprosy.

The process and consequences of stigmatisation. Stigma is self-fulfilling, defining the behaviour of stigmatiser to stigmatised and vice versa. These stereotyped behaviours are culturally based and self-reinforcing. The most minor and apparently insignificant blemish may intrude into normal social interactions, undermining the quality of relationship the affected individual might otherwise expect and leading to loss of acceptance. The impact of stigma therefore extends to family members and social contacts, having an impact on the individual, the family and the community.

There are important differences in consequences between men and women, between poor and rich, between young and old, between literate and illiterate, and on those with visible disabilities. Where poverty or physical disabilities are stigmatised the person affected by leprosy may be doubly or trebly stigmatised.

Stigma is seen and learned through language and observation of normal social transactions. It may be reinforced through art, the media, the written word or through ill-conceived promotions by fund-raisers. Stigmatisation may be seen in some forms of religious teaching and in the attitudes resulting from lack of awareness of health workers. In consequence, the views of society remain resistant to developments in science and medicine. The impact on the affected person is to conceal or deny their true status with all that this implies for leprosy control.

Recent research. Studies of stigma in leprosy focus on the impact on the individual and/or on the attitudes and behaviour of community, for example in relation to domestic life, interpersonal relations, major life areas, and community life. Work in Brazil has focused on the formal adoption of the term Hansen's Disease in an attempt to free control activities of the stigmatising connotations of leprosy. Efforts continue to assess the social representations of the disease. Research in Nepal has demonstrated that leprosy is not limited to low status castes. Rather, the status of high caste individuals, their perceived value and their use of the resources available to them enable them to be more effective in concealing or coping with the disease.

Stigma has been demonstrated to encourage delay in presentation and to be a factor in poor compliance and default from treatment. In some situations, individuals known to be on treatment may avoid stigmatisation, their societies with-holding judgement pending the outcome. Certifying cure with RFT-certification is being tested as a means to oppose stigma.

Recommendations I – Implementation of current knowledge

Having reviewed the various research findings regarding leprosy-related stigma, the following recommended actions/strategies were compiled for consideration by all those involved in leprosy work. The list is presented in no particular order.

1. Vertical leprosy programs have reinforced stigma. Thus, government and NGOs should implement an integrated approach to leprosy care and avoid creating programs which make leprosy care (and those involved with it) "special" or different.

2. Including people affected by leprosy as stakeholders in all aspects of leprosy care helps fight stigma. It is essential to involve individuals who have personally faced the challenges of leprosy as resource people (counselors, support groups, health education, fundraising, policy making, program development, board members, etc).
3. Leprosy stigma has been reinforced by negative stereotypes. An effort should be made to promote a positive image of people affected by leprosy (through their art, poetry, writing, achievements, etc) in order to give another view of people with leprosy rather than the negative image that has historically been presented. This should include working with the media and fundraising agencies to avoid negative presentations of leprosy imagery, which only perpetuate stigma.
4. Education about leprosy is key to overcoming stigma. Thus, appropriate education about the basics of leprosy should be targeted at the community, families, and individuals directly affected by leprosy. Education should be particularly aimed at innovative methods to reduce fear and change attitudes/behavior. This may mean the development of appropriate training resources which address stigma. Further, in some places better monitoring and evaluation of current government education systems need to take place in order to ensure the quality of training. Education efforts should avoid using negative images of leprosy as a means to ensure MDT compliance.
5. Counseling services have proven successful in reducing stigma. In some settings, group counseling and support groups have been shown effective for overcoming self-stigma. In other contexts, families have provided essential psychological support. The development of counseling skills is thus important for doctors, family, and every center where leprosy care is being provided.
6. People who have been empowered can better deal with stigma. Empowerment workshops that include people affected by leprosy and community in which they live should be held (perhaps in the context of helping establish disabled people's organizations). Such workshops can also help make people aware of their rights – thus enabling them to fight against laws that enforce or perpetuate stigma.
7. Various civil society members can play a role in reducing leprosy-stigma. These include church/religious groups, which have historically perpetuated stigma through Biblical and other religious imagery that has connected leprosy to sin/moral bankruptcy. Companies can also be engaged in stigma reducing projects, such as developing appropriate shoes, makeup/skin products and other materials which will help minimize the stigmatizing affects of appearing “different” from others in the community.
8. Various programs and methodologies for rehabilitation have been found to help overcome stigma. These include CBR, socio-economic programs, psychological counseling, self-care, and others. Leprosy programs should work to include these strategies in their rehab work.

9. Leprosy can provide valuable lessons for fields of study beyond medicine. Efforts should be made to develop innovative methods of incorporating information about leprosy into diverse educational settings, including university curricula, as it can speak to medicine, human rights, stigma...and several other fields of study.

Recommendations II – Recommendations for research

The Workshop listed some 20 potential areas for research of which the following were identified as priorities:

1. Research to explore the impact of stigma on self-care practices
2. Research on the impact of teaching by major religious faith on leprosy
3. Development of a generic scale to measure stigma - important to bear in mind the different perspectives of service provider, affected individual and society
4. Research to draw on experience with other stigmatised conditions
5. Research into aspects of community-based care – bureaucratic assumptions versus field realities
6. Research on how to develop positive image and self-esteem, enabling affected persons to confront and overcome stigma
7. Research on the impact of MDT on stigma

The following additional action points were identified:

- To publish the Workshop report, possibly along with the papers presented at the Workshop.
- To bridge the language barrier, especially between workers/scientists in Brazil and in English-speaking countries.
- To pool the available literature on social science and leprosy and make it available in a few central locations, perhaps one in Brazil, one in Africa and one in India. Paper databases of photocopied articles should be kept there.
- To encourage people to enlist on the Social Science and Leprosy Network (SSLN), an email forum run from the TLM Research Resource Centre. The moderator is Dr. Robert Pattanayak (<robertp@tlm-india.org>).
- To broaden the literature research to include non-leprosy publications relevant to the topics discussed/presented at the pre-congress workshop.
- To organise training in social science methods.

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