Letter to the Editor

CONCEPT AND IMPACT OF STIGMA ON DISCRIMINATION AGAINST LEPROSY SUFFERERS – MINIMIZING THE HARM

One of the resolutions adopted by the July-August 2004 56th session of the United Nations Subcommission on the Promotion and Protection of Human Rights (www.un.org/news/press/docs/2004/hcrn110/doc.htm) was the call for a working paper on ‘Discrimination against leprosy victims and their families’. The term ‘discrimination’ embraces most, but not all, facets of the concept and impact of leprosy stigma. Goffman defines stigma as an attribute that is deeply discrediting within a particular social interaction. Individuals with a stigmatized attribute fall short of generally accepted social expectations, and are therefore reduced to tainted, discounted individuals. The social hostility that results from such tainted perception of stigmatized individuals is commonly referred to as discrimination.

Of Goffman’s three broad categories of stigma, attributes related to abnormalities of the body are the most relevant to leprosy stigma. The distressing aspect of having the stigmatized condition of leprosy, combined with the stigmatized status of the leprosy sufferer in most societies, may make some sufferers conceal or deny the condition. Such denial and reluctance to take effective treatment may eventually result in preventable deformities. Hence, the concept and impact of leprosy stigma operate in a vicious cycle.

Discriminatory attitudes against leprosy sufferers are commonly based on an enduring feature of a ‘leprosy identity’, conferred by religious, legal, economic, physiognomic, and language issues, as well as the leprosy sufferers’ self-esteem. Such judgment is generally medically unwarranted. Each facet of the socially constructed ‘leprosy identity’ contributes significantly to discrimination.

Adverse religious perspectives on ‘leprosy’ have done much to intensify leprosy stigma. For instance, most biblical references to leprosy in the Bible (e.g. Leviticus 13, v 45; Numbers 5, v 2; and II Kings 26, v 21) create an impression of a dreaded disease associated with sinners. Buddhist teachings on Karma make it acceptable for believers to frame leprosy sufferers as sinners in a past incarnation. Such adverse perceptions invariably apply to the families of leprosy sufferers. In some societies, discrimination against leprosy sufferers appears to be justified on religious grounds, as a demonstration of religious commitment. In addressing this impediment, anti-discrimination advocates need to work with religious authorities to stress the fact that what was termed ‘leprosy’ in most religious texts was in fact a synonym for any disfiguring skin lesion, and that unlike most of these disfiguring lesions, leprosy is curable and, with early treatment, hardly ever results in deformity. Encouraging senior religious leaders to publicly correct past pernicious associations between leprosy and stigma and to promote a positive perception of the disease, constitutes a significant step towards minimizing the harm caused by leprosy stigma, and consequently reducing discrimination against leprosy sufferers and their families.

Legal impediments to reducing discrimination such as the 1907 Japan Leprosy Prevention Law (repealed in 1996), which compelled thousands of Japanese leprosy sufferers to a life of strict isolation, exist in some form in most nations and should be repealed. Such repeal would require a robust exercise of public health advocacy, as leprosy remains an ‘unbounded’ disease in popular imagination.

Leprosy sufferers are generally linked with beggars and other socio-economically deprived cohorts in most societies. Such a perception intensifies discrimination, as leprosy sufferers are equated with parasites on societies resources, and harbingers of filth in the neighbourhoods. Addressing
discrimination related to this issue would require concerted efforts by leprosy workers and sufferers to significantly facilitate the socio-economic rehabilitation of leprosy affected people. Effective surgical cosmetic, and medical management of leprosy deformities are established strategies for reducing stigma and discrimination against leprosy sufferers. Unfortunately, success in the chemotherapy of leprosy is yet to be matched by sufficient capacity and desired outcomes in the management of deformities.

Despite the substantial progress made in the control of leprosy, stigma and discrimination has persisted partly because most languages have framed the word ‘leprosy’ as a synonym for stigma since the Middle Ages, with the result that the stigma associated with leprosy has remained consistently high. The appropriation of the word ‘leprosy’ as a metaphor for stigma has created significant hostility against leprosy sufferers at interpersonal and cultural levels. Strategies such as a change of name to Hansen’s disease have only been partly successful in reducing leprosy related stigma and discrimination. A complementary strategy, successfully piloted by the author in northern Nigeria between 1992 and 1995, is for leprosy workers to assist motivated leprosy sufferers to form ‘Leprosy Sufferers’ Associations’, with members playing prominent roles in activities to promote a positive image about leprosy through their hard work and conscious efforts to be respectable members of mainstream society.

Finally, efforts to minimize discrimination against leprosy sufferers and their families must address the generally low self-esteem suffered by a large proportion of leprosy sufferers and their families. In the author’s experience in northern Nigeria, the majority of leprosy sufferers with visible deformities appear to act as if society’s discriminatory practices vis-à-vis their disease complications are justified. It is important that leprosy sufferers are assisted through education, high quality health care, and vocational support, to develop a high self-esteem, and a high John Henryism – a mind set that perceives just about any obstacle as being surmountable through hard work and a strong determination to succeed. Also, opinion leaders and leading political figures should be encouraged to have personal contact with, especially, deformed leprosy sufferers. As aptly demonstrated by the visit of the late Princess Diana to a leprosy hospital in northern Nigeria, such contacts humanize the condition, improve the sufferer’s self-esteem, and make it more likely that the stigmatized leprosy sufferer would be perceived first and foremost as an individual.

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References