

Leprosy: treating the disease and the social stigma

By Ranjit Shahani*

A series of innovations have made leprosy, one of the world's oldest diseases, nearly history. During the past 2 000 years, we have made huge strides in the diagnosis, treatment and rehabilitation of patients with this disease – but have we come as far in our social treatment of leprosy? In many countries, including India, leprosy continues to be a shameful disease. Patients with leprosy are still forced to live separately from the rest of society, in spite of the fact that the first dose of medication stops the disease from spreading to others. Even cured leprosy patients are not treated as normal members of society. Now that we can effectively treat the disease, we need to help remove the social stigma affecting leprosy patients.

Innovation has revolutionized treatment and availability

The global fight against leprosy is a prime example of using innovation to solve a centuries-old challenge. Pharmaceutical innovation introduced effective treatment. Innovative partnerships between government, global organizations and pharmaceutical companies deliver medicines to patients who need them most. Plastic surgery and other inventive solutions help reintegrate leprosy patients into society. All of these innovations have revolutionized treatment of leprosy, decreasing its global prevalence by 90% since 1985 (from 21.1 per 10 000 inhabitants to less than one per 10 000 inhabitants in 2000). The dramatic reduction in the detection of new cases is largely due to the progress made here in India, where there were 74% fewer new cases from 2001 to 2005. Yet, sixty-four percent of new leprosy cases are registered in India.

Leprosy has a cure: multi-drug therapy (MDT). MDT has been used against leprosy for more than 25 years, and is still the most effective cure for all types of leprosy. The first breakthrough treatment for leprosy was dapsone, discovered in the 1940s and effective to stop the disease. Unfortunately, because of the long treatment duration and extensive use of this single treatment, a dapsone-resistant leprosy developed during the 1960s. In that same decade, two other drugs effective in combating leprosy, rifampicin and clofazimine, were discovered. It was a team of Indian scientists that first formulated a combined therapy using rifampicin and dapsone, intended to avoid drug resistance. In 1981 the World Health Organization (WHO) recommended creating MDT based on these three drugs to effectively combat leprosy without creating resistance.

Because leprosy nearly always affects extremely poor people, access to treatment became the next hurdle after an effective cure was discovered. In 1995 the WHO began a partnership with several companies and governments to distribute MDT free of charge. Novartis is a partnering company in eradicating leprosy, providing MDT to the WHO. The WHO in turn distributes MDT to the Ministries of Health in endemic countries, including here in India. Governments use a network of healthcare providers and nongovernmental organizations to ensure the treatment gets to patients who need it. This innovative access to medicines scheme has been so effective that it has been used as a model for other programs.

A devastating effect of advanced, untreated leprosy is deformity, often leaving patients cast out of their communities and unable to work or care for themselves. A number of devices have been invented to make it possible for recovering leprosy patients to live independently, allowing them to more easily integrate back into society. Through programs like the Novartis Comprehensive Leprosy Care Program, patients in India receive special care to help prevent deformity: ready-made hand and foot splints, grip aids and skin care products. In more extreme cases, the program works with local physicians to help correct deformities using advanced surgical techniques.

Stigma prevents a total cure

In spite of how far we have come in curing leprosy and caring for its victims, common perceptions and social taboos have significantly hindered efforts to de-stigmatize the disease. People believe that even cured leprosy patients are highly contagious, when in fact the first dose of MDT stops the disease from spreading to others.

During the Middle Ages, before scientists discovered the bacterium that causes leprosy, it was assumed that leprosy was highly contagious, and that any contact with someone who had the disease would cause it to spread. In some religious traditions, leprosy was believed to be “unclean.” People with leprosy were forced to differentiate themselves by wearing special clothing and ringing bells or playing horns to warn others that they were approaching. They lived in colonies separated from the rest of society, and were only allowed limited contact with the rest of the world.

In some places, little has changed in 2 000 years. In spite of the fact that now we can effectively treat leprosy, patients with the disease are still widely stigmatized. Humiliation and fear can prevent diagnosis and treatment, leading to more severe manifestations of the disease and causing deformities. Where social stigma persists, patients are compelled to hide their condition and avoid diagnosis, allowing a completely curable disease to worsen to the point of disfigurement. It is a simple lack of understanding that leads people to believe that the disease is highly contagious and incurable, and leads to the stigma that prevents patients from reintegrating back into society.

Stigmatization dehumanizes leprosy patients – these people are ostracized, rejected and scorned. Even cured patients are kept on the margins of society, often without jobs or means to support themselves. They are discriminated against, insulted and avoided. They continue to live in colonies, kept out of their villages and away from their families.

Projects sponsored by the Novartis Foundation for Sustainable Development and Novartis India help recovering leprosy patients with both physical and social rehabilitation. These initiatives offer tools to help prevent and correct deformities caused by the disease and, as important, provide resources to help cured patients support themselves and reintegrate into society. Programs are needed to treat all of the effects of leprosy, physical and psychological, and to give patients a reinforced sense of self esteem, confidence and hope for the future.

An effective treatment and access to treatment are two important pieces of treating any disease, but acceptability of treatment is essential to the WHO's goal of eliminating leprosy. As long as leprosy patients are stigmatized, their willingness to present themselves for diagnosis and treatment will be negatively impacted. Until patients with leprosy are treated as equals, the goal of elimination will remain out of reach.

Regardless of how treatment of leprosy has improved and in spite of efforts made to help patients reintegrate into society, the stigma affecting leprosy patients persists. One of the goals of World Leprosy Day, on January 27, 2008, is to raise awareness of the disease, increasing understanding and correcting misperceptions. If we can progress past stigma and break down myths, we will be able to treat the disease more effectively. This type of innovation – changing people's perceptions – is both the most difficult and most important innovation left in leprosy treatment.

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