

ABSTRACT

A Pilot Exploration of Life With Leprosy in Bangladesh Julia Petras, Laxme Shaw (interpreter)

This pilot study explored the experience of Bangladeshi patients with leprosy receiving inpatient treatment at the Danish Bangladesh Leprosy Mission Hospital (DBLM) in Nilphamari, Bangladesh. DBLM is in a rural district of northern Bangladesh within the Rangpur division. Two patients with leprosy were interviewed as well as a nurse and a physician who work with patients with leprosy. Leprosy (Hansen's disease) is a major public health concern in Bangladesh according to the World Health Organization (WHO). While not highly infectious, it can cause progressive and permanent damage if untreated (1). The stigmatization of leprosy has been cited well in literature but little qualitative research exists regarding the personal impact and meaning of living with the disease. This research explored the lived experience of leprosy in Bangladesh and the role of stigmatization in this disease process. Many patients with leprosy are unable to work independently and carry out activities of daily living due to permanent peripheral nerve damage and resulting deformities of the hands and feet. The inability to eat with their hands and the inability to eat hot foods is a major concern within the cultural context of Bangladesh, which has contributed to stigmatization. There are community misconceptions about leprosy transmission, which results in avoidance of those with leprosy. Many people believe that leprosy is an "evil disease". Family support is strong for these patients but their community often ostracizes the family. Early detection is key in preventing deformities but resources are limited to carryout screenings within communities. Potential solutions would focus on secondary prevention—screening programs for early detection of leprosy so permanent peripheral nerve damage can be avoided. Community education programs can educate the community about leprosy in hopes of diminishing stigma and fostering a suitable environment for re-entry of people with leprosy. Education should emphasize that leprosy is treatable and communicability is relatively minimal. Questions for further research would include: What are some factors that contribute to the public tendency to view leprosy as a "evil disease." Can these factors be ameliorated? How is the management of the disease implemented in the home setting and what are some challenges of at-home management?

¹*Leprosy key facts.* (n.d.). Retrieved from
<http://www.who.int/mediacentre/factsheets/fs101/en/index.html>
