From contagious to chronic: a life course experience with leprosy in Taiwanese women

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Abstract

This study used the narrative analysis method to explore stories told by Taiwanese women who had suffered from leprosy. Twenty-one women from a leprosarium, a long-term care centre, and the community participated in either focus group discussions or individual interviews. The age range for the participants was 54-88, with an average of 68 years old. Physical impairments and disabilities of the participants included skin scars, claw fingers, drop feet, amputated legs, and facial disfigurement. Their stories were analysed in two phases: structural and holistic content analyses. Structural analysis identified four life stages: before being diagnosed, after being diagnosed, living with leprosy, and the future. Holistic content analysis uncovered common themes in each life stage. Findings indicated that stigma was experienced throughout the life course of these women. At this stage of life, these women were facing not only physical impairments and disabilities from the leprosy, but also the usual chronic health problems of the elderly. This study suggests that prevention and treatment of leprosy-related physical impairments and chronic diseases are important.