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Promoting Social Inclusion: Voices from Persons Affected by Hansen's Disease

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Abstract

Hansen's disease or leprosy is one of the stigmatized skin afflictions in human history. The afflicted persons who are clinically cured often received persisting discrimination and suffer the consequences of the affliction. Stigmatization, physical restrictions, economic disadvantage and loss of self-dignity are the main elements to be considered in promoting inclusion to these former sufferers. The idea of social inclusion is initiated by World Health Organization in a five-years global elimination programme for Hansen's disease, the Global Leprosy Strategy 2016-2020. One of the strategic pillars of the programme is to end prejudice and discrimination, and to promote inclusion among the persons affected by Hansen's disease. By using an ethnographic approach that involves in-depth interviews and participant observations, 15 former sufferers and their family members from Kampung Sinar Baru, a village settlement in a sub-district of Kuching, Sarawak, Malaysia have been selected. Findings reveal the impacts of being affected by Hansen's disease on the lives of the former sufferers and their families such as having to separate from the family. Despite that, the affected persons have taken positive initiatives by building their own community in Rajah Charles Brooke Memorial Hospital and eventually, in Kampung Sinar Baru. By highlighting the social impacts of Hansen's disease, inclusion then can be demonstrated by understanding the contexts and social needs of those experiencing Hansen's disease as well as changing negative attitudes and perception towards former sufferers. By letting their voices be heard, it will provide awareness in society about the misconceptions of Hansen's disease, in the hope to build an inclusive society that accepts differences of people.

Keywords: Social Inclusion, Hansen's Disease, Global Leprosy Strategy, Voices, Stigma, Sarawak

Introduction

Hansen's disease, which is known as leprosy is one of the dreaded skin afflictions in human history. In the olden days, it had an image of being a highly contagious, incurable and hereditary disease. It was also believed that the affliction was a result of past sins in previous life or a curse from God(s). Although Hansen's disease has been disappearing and is relatively a 'historical' affliction in most countries, continuous humiliation and stigmatization towards the former sufferers and their family members have led to many initiatives by the state, self-groups and World Health Organization