

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

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To Link this Article: <http://dx.doi.org/10.6007/IJARBSS/v9-i6/5923>

DOI:10.6007/IJARBSS/v9-i6/5923

Published Date: 20 June 2019

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 (WHO) to promote social inclusion. WHO has initiated a global elimination programme for Hansen's disease, "The Global Leprosy Strategy 2016-2020" with the main aim of making "a leprosy-free world" (WHO, 2016, p. viii). There are three strategic pillars in the program: "to strengthen government ownership, coordination and partnership", "to stop leprosy and its complication", and "to stop discrimination and promote inclusion" (WHO, 2016a, pp. 11-13). This study will focus on the latter strategy which is to put an end to all forms of stigma and prejudice towards former sufferers and their families, and to achieve an inclusive society that accepts differences.

While attention has been given to medical studies and statistical data on cases of Hansen's disease in Sarawak, Malaysia (Ninh, 2014; Utap & Kiyu, 2017; WHO, 2016b; Yap, 2009), studies on social aspects of Hansen's disease need to make tremendous progress along with the medical area. Issues on stigmatization, disabilities, economic disadvantage and loss of self-dignity should be considered in bringing inclusion to these former sufferers and their family members into mainstream society. A complete engagement with society does not mean only for surviving after completely recovering from the affliction but also to thrive as members of society. Encouraging participation in society and letting unheard voices speak can ensure equal rights and opportunities regardless of the background. Therefore, the research objectives in this study are (1) to highlight impacts of Hansen's disease on the social life of the former Hansen's disease sufferers and their family members, and (2) to evaluate the inclusion of persons affected by Hansen's disease through the examination of social needs and restrictions imposed on those experiencing the affliction.

Literature Review

Experiencing Hansen's disease

In literatures on Hansen's disease, the affliction is experienced differently from one community to another. In Northern Tanzania, Hansen's disease was believed to be similar to other common illnesses and the sufferers continue living, eating and sleeping with their families and marriages carry on (Waxler, 1981). Contrarily, in India and Nepal the sufferers are divorced by the spouse and ostracized from their family and village because of the high respect place on status, caste, kinship structures and the value of fertility in the Hindu marriage culture (Try, 2006; Vlassoff, Khot & Rao, 1996).

In Asian countries, afflicted persons were expelled to leprosaria in the nineteenth century and some ended up as beggars in cities (Boonmongkon, 1995; Loh, 2009; Raj, 2010; Shieh, Wang & Lin, 2006; Tang & Wong, 2012; Varkevisser et al., 2009; Vlassoff, Khot & Rao, 1996). It was Christian missionaries who introduced a mode of treatment in 'leper colonies' or leprosaria in their colonized countries. It then emerged as a new moral definition of protecting other members of society from the contagion of the disease by segregating the sufferers in secluded asylums. In the leprosarium the sufferers formed their own community based on the sense of belonging, which makes them attached to each other. After completely recovering from the disease and discharged from the leprosarium, some sufferers refused to return to their hometowns due to the social stigma in their communities or had lost contact with their families after a long stay in the hospital. As such, the affected persons remained in the leprosarium, or they made their own village settlement on land provided by the state government (Boonmongkon, 1995; Le, 2016; Loh, 2009; RCBMH, 2015; Schuller et al., 2010; Shieh, Wang & Lin, 2006; Tang & Wong, 2012).

Promoting social inclusion

Social inclusion is increasingly becoming a new global concept to promote an inclusive society. Social inclusion establishes a notion of “a multidimensional, relational process of increasing opportunities for social participation, enhancing capabilities to fulfil normatively prescribed social roles, broadening social ties of respect and recognition, and at the collective level enhancing social bonds, cohesion, integration, or solidarity” (Silver, 2015, pp. 2-3). In other words, it aims to create a comprehensive vision that integrates and includes every person into mainstream society and promoting involvement in all potential aspects in one’s social life. Spandler (2007) sees the notion of social inclusion as “a universal good” and consequently, makes it “difficult to critique because ... it is presented as self-evidently desirable and unquestionable” (pp. 3-5).

Social inclusion, sometimes, could be adversely interpreted as a uniform framework and it often “inadvertently imposes certain choices as more desirable than others” rather than emphasizing social contexts and voices of the individuals on life (Spandler, 2007. p. 8). For instance, the social position of mental health survivors who have been rejected and excluded could never easily be adapted into an inclusive society until the society itself change its prejudiced attitudes towards them (Secker et al., 2005). Similarly, individuals in prisons and asylums who have been separated from broader society would take a longer time to reintegrate into society, to avoid stigmatization from others (Allman, 2013). Hence, the concept of social inclusion should be reflected in the social position of the individuals and as explanations of “why one or more groups merit access to the core or the periphery, [and] to the benefit or at the expense of others” (Allman, 2013, p. 7). The inclusion of persons affected by Hansen’s disease then can be demonstrated by understanding the contexts and social needs of those who are experiencing the affliction. Issues such as persisting discriminations, physical restrictions, economic disadvantage and loss of self-dignity should be tackled prior to promoting inclusion on the afflicted persons into an inclusive society. This provides an opportunity for the affected persons to gradually adapt into norms and expectations of the society, and at the same time, the society itself can change negative perceptions and attitudes towards them.

On the state level, Hansen’s disease has been integrated into the general health care service (Cross, 2006; RCBMH, 2015). Cross (2006) reports that a high level of stigma associated with the communities is shown when a separation of the facility services for Hansen’s disease has been maintained. Cross finds that afflicted persons build their confidence by receiving treatment in the same healthcare building with other patients and when they were given equal attention by health workers in the general health services. Cross (2006) also points out that the “knowledge (of Hansen’s disease) does not change attitudes, but that evidence of inclusive practice might” (p. 370). Similarly, Frist (1996) emphasizes the importance that the engagement of communities and health providers can improve the perspective of society and impact positively on the early detection of cases.

In addition, the empowerment of persons affected by Hansen’s disease is often conducted by self-groups, the state government and healthcare services. However, limitations of these interventions to address the stigmatisation of the disease become complex if the biological explanations of the disease are unlikely connected to the worldview of the community. Cross (2006) argues that giving rational explanations of the affliction may become a common sense to some people, but “in societies where blame is attributed to those affected”, the intervention should be considered with caution (p. 368). This includes “reports of information, education and communication (IEC) campaigns that have claimed to be

successful in reducing stigma”, but the knowledge and surveys that are produced do not pinpoint to the issues of the complex world-view of Hansen’s disease (Cross, 2006, p. 368). As suggested by Cross, IEC is a crucial stigma reduction intervention, but the information and strategies should be multifaceted to include more complex human understanding of the disease. strategies should be multifaceted to more complex human understanding of the disease. Likewise, WHO (1998) points out that people tend to manage their disease based on past knowledge and it varies by sociocultural factors.

Methodology

This section presents the research design related to the methodology in the study. This study was carried out in Kampung Sinar Baru (Sinar Baru Village), a village settlement resided by former Hansen’s disease sufferers and their families in Kota Padawan, a sub-district of Kuching, Sarawak, Malaysia. The village is where most descendants of the afflicted persons can be found in Borneo.

Historically, Hansen’s disease was prominent in Borneo Island between the 1920s and 1980s. Persons contracted with the affliction had experienced humiliation and stigmatization from society. All identifiable afflicted persons who had been diagnosed in general hospitals were then sent to Rajah Charles Brooke Memorial Hospital (RCBMH) for further treatment. RCBMH was the only leprosarium in Borneo at the time. Nobody was allowed to visit the sufferers in the hospital until in the 1970s, when on account of the controlled treatments the hospital permitted children and families to live together in the hospital’s dormitories. As years passed, the residents of the dormitories continued to reside in the hospital because they had nowhere to live outside the hospital, and because of the enormous shame to go back to their hometowns. As a result, the hospital initiated a village settlement, Kampung Sinar Baru, for these remaining former sufferers and their families – to aid in empowering them and at the same time the former sufferers undertake a positive transition to live independently.

This fieldwork was conducted in three months at Kampung Sinar Baru, a village for the affected persons and their families which is in Kota Padawan, a sub-district of Kuching, Sarawak. Through ethnographic fieldwork, in-depth interviews and participant observation were applied to gather the experiences of the former sufferers and their family members on how Hansen’s disease had affected their social life.

During the early weeks of the fieldwork, one of the researchers settled in the village head’s house and spent her time joining various events and ceremonies held by the villagers. Her presence in the ceremonies had helped to make significant progress as many of her newfound acquaintances provided suggestions as to whom she should refer to and whom to avoid during the interviews. She also participated and observed the social activities of the villagers to understand the social order of the village. With the help of the head of village and a former sufferer, she had identified a list of informants and planned for more organised visits to each informant’s home. 15 informants – 10 former sufferers and 5 other informants who are their children or their spouses, were chosen among the villagers of Kampung Sinar Baru. The former sufferers are persons who had been treated in RCBMH and who lived with their spouse in the hospital’s dormitories and then resettled in the village after being discharged from the hospital. The children are the second generation in the family who had also lived together in the hospital’s dormitory with their parents. The informants are at the age of 45 and 75 years old. The interviews were conducted in the Malay language and then translated into English language. The questions that were asked during the interviews included how Hansen’s disease had affected their lives, the challenges in RCBMH and the coping strategies

in dealing and reintegrating into society. This study applied ethical research to protect researchers, informants and institution including confidentiality and anonymity of the informants by using pseudonyms, managing trust relationships with the informants, protecting cultural sensitivity and privacy of the informants in the writing.

Findings and Discussion

Impacts of Hansen's disease on the lives of the former sufferers and their families

Based on the interviews with the informants, there are consequences of being afflicted by Hansen's disease, in spite of that, former sufferers and their families took positive initiatives to build their own community in Rajah Charles Brooke Memorial Hospital (RCBMH) and in Kampung Sinar Baru. This section will explain three key points on its impacts: (1) separation from family, (2) building their own community in RCBMH, as well as, (3) forming independent living after settling in Kampung Sinar Baru.

The first impact on being afflicted by Hansen's disease is experiencing separation from their family members in order to undergo further treatment at RCBMH. This was a way of protecting other members of society from the contagion of the disease that subsequently segregate the afflicted persons. The strict isolation policy affected new born babies and grown-up children who have to part from their parent(s). The children were either sent to the Salvation Army in Kuching or were taken care of by their families and relatives. Complicated cases such as the divorce between wife and husband also occurred, as in the case of one of the informants:

"when my mom was sick [affected by Hansen's disease], her mother-in-law was really furious and asked my dad to divorce my mother immediately, but my dad refused. My mom lived in the Iban longhouse; only my mom got afflicted. My mom's sister also disliked her. So, my mom, my dad and my older sister left the longhouse and moved all the way to RCBM [Settlement]. But the hospital did not allow my dad and sister to live together. They returned back to the longhouse, leaving my mom alone in the hospital which means, my mom and my dad had divorced".

Over the years, during the administration of Generawi Mok in the 1970s, the policy of incarceration was lifted and many families were reunited. Bringing their families into the dormitory has lightened many lives in the hospital. Moreover, some sufferers have built a new family by getting married among themselves in the hospital. One informant explains that she has married a former sufferer without telling her parents about the background of her husband.

In the hospital, the former sufferers and the staff of the hospital then have taken positive initiatives by building their own community and encouraging various economic and social activities. This included a patient-worker programme to empower former sufferers through skills and to provide jobs for the residents. The programme has tremendously been credited for its success in bringing back opportunities into the lives of former sufferers in RCBMH. Seven informants have taken on significant roles as medical staffs during the time when the hospital has had a shortage of nurses, attendants and administrators. Moreover, vocational guidance such as carpentry and crafts making have been taught to the residents for enhancing skills and capabilities of the residents when they are discharged. One of the informants recounts that his father has worked as a carpenter in RCBMH, where some of his furniture can still be seen in some buildings and wards today. In addition, spiritual activities are also openly practised by the residents as various worship buildings have been built around the hospital. In particular, all informants mention that they have turned back to their religions

and believe in God as a way in accepting their fate on being afflicted by this stigmatizing affliction.

In 1980, a survey on the social background of the residents conducted by the medical staff at RCBMH showed that many families were living in the hospital's dormitories. Several attempts had been made to encourage them to return to their respective villages, but all had failed. Most of them had cut off relationships with their families and suffered from permanent physical marks that remarked the social stigma of Hansen's disease to their communities. Ultimately, the hospital initiated a village settlement for these remaining former sufferers and their families. In Kampung Sinar Baru, the former sufferers formed a new identity and empowered themselves with the help of the Malaysian Leprosy Relief Association (MaLRA). Through MaLRA, social and economic aids were given to assist the former sufferers and their families to reintegrate into society. Awareness about the misconceptions of Hansen's disease has also continuously been promoted to society. Thus, Kampung Sinar Baru takes great pride and dignity in its residents who have established new independent living for themselves.

Towards Inclusion in Society

Social inclusion has been emphasized in the Global Leprosy Strategy 2016-2020 in response to the continuous discrimination that remains to humiliate those who have been affected by Hansen's disease. A complete engagement into society does not only mean for survival after full recovery from Hansen's disease but also to thrive as members of society. Encouraging participation as a member of society and letting unheard voices out can ensure equal rights and opportunities regardless of their background. In this section, two aspects will be explained – intervention based on the needs of former sufferers, as well as acceptance and understanding by society.

Firstly, by highlighting the understanding of the social impacts of Hansen's disease, it wisely provides empowerment to former sufferers to meet their own needs. As argued in the literature, issues such as physical restrictions, economic disadvantage, persisting discrimination and loss of self-dignity should be emphasized in promoting inclusion to the affected persons. Hansen's disease is a malady that has not only affected the physical but has also impacted the mental well-being of the afflicted persons and their families. In the cases of former sufferers in Kampung Sinar Baru, physical restrictions and old-age influence their competence to continue labour works that improve their economic households. A good example of intervention by the Malaysian Leprosy Relief Association (MaLRA of Sarawak branch) is to give preference in choosing suitable jobs for the former sufferers. Planting vegetables and fruits is the common choice. MaLRA has provided a non-rigid contract on leasing the net-garden to the former sufferers in a low-rate price. From the onset of the stay in RCBMH until their resettling in Kampung Sinar Baru, MaLRA has provided immense support to the residents and in assisting the welfare of the villagers. It is recommended for the state, self-groups and organizations to take note of wider issues and restrictions of the residents before planning on intervening in the matters of the residents of Kampung Sinar Baru, especially in long-term intervention that needs the full involvement and participation of the residents. This could happen because of the restrictions and limitation of their capabilities to be involved. This issue is not limited to the community of Kampung Sinar Baru but to other communities as well. In sum, promoting an inclusion should be associated with the understanding of the social order and social needs of a particular community.

Ultimately, by understanding the peril of the past lives of the former Hansen's disease sufferers, society needs to change the persisting discrimination and negatives attitudes

towards this age-old disease and to those who had been affected by it. Acceptance and understanding by society are important to reintegrate these affected persons, and to achieve an inclusive society that accepts all differences. Prejudice and discrimination can lead to a never-ending loss of self-dignity of the affected persons. Nonetheless, the changes in perception have been improved among members of society who are educated about Hansen's disease and who are aware of the past lives of these affected persons. Today, the afflicted persons can live with their families as long as they are taking the medication as prescribed by the doctor. By ending the discrimination and prejudice towards the afflicted persons, Hansen's disease should be treated like any another affliction that can be treated and cured. Early treatment is able to save many new cases of Hansen's disease. In addition, campaigns on promoting inclusion and reducing the stigmatization of Hansen's disease need full attention to the complexity of the affliction in one community.

Conclusion

Impacts of Hansen's disease have affected the social life of the affected persons and their families. Issues such as stigmatization, physical restrictions, economic disadvantage and loss of self-identity are the main subjects to be considered to achieve an inclusive society, as promoted by World Health Organization in the Global Leprosy Strategy 2016-2020. This can be illustrated by Allman (2013) and Secker et al., (2005)'s concept of social inclusion, in which the social position of the affected individuals who have been rejected and excluded by society should be reflected to understand their contexts and social needs.

In studying persons affected by Hansen's disease in Sarawak, particularly in Kampung Sinar Baru, a study had shown that most of the descendants of Hansen's disease were experiencing separation from family members, and were living with stigmatization and in economic disadvantage. However, at the same time, they took positive initiatives to build their own community and to find a life within it. This is shown in the various social and economic activities in the hospital. The activities continue after they have taken residence in Kampung Sinar Baru. Restoring self-respect is the first step to complete their basic human rights, in the hope to be reintegrated into society.

In promoting social inclusion, this study suggests that reintegration should be examined by looking at social needs and restrictions of those who are experiencing the affliction. For instance, a good intervention that has been provided by MaLRA to the former sufferers is based on their capabilities and competence which involves planting that requires a non-rigid contract of leasing the net-gardens. It is recommended for the state, self-groups and organizations to take note of wider issues and restrictions of the residents before planning on interventions, especially on more complex human understanding of the Hansen's disease and physical restrictions of the afflicted persons. Furthermore, society needs to change its attitude and perception towards this age-old stigmatized affliction and to those who had been affected by it. Reintegration of the afflicted persons and their families cannot be achieved without the acceptance and understanding of the members of society. An inclusive society is a society that accepts all differences without prejudice and discrimination against certain groups of people.

Acknowledgement

The authors wish to acknowledge the following institution and individuals that had been supporting and guidance for this study.

1. UNIMAS Zamalah Graduate Scholarship for providing financial support during the period of research.
2. Pak Ngui, Mak Limah, Pak Yanchi, Madam Kong, Mak Bani and all the informants for their assistance and openness to share their experiences .

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