

## Economic Access of Lepers

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### ABSTRACT

Leprosy is a disease that has a high social stigma. The stigma of leprosy is associated with its physical defects that seem frightening and disgusting. Thus, lepers have limited economic access. This research used a qualitative approach through multi-method data collection, such as 1) literature study, 2) institutional survey, 3) observation, and 4) in-depth interviews with informants. This research was conducted in three provinces, namely, Sampang Regency, East Java Province; Kupang City, East Nusa Tenggara Province; and Makassar City, South Sulawesi Province. Results show that lepers in the three study areas overcame their limited economic access through the organization of the Self Care Group (*Kelompok Perawatan Diri*). In the Self Care Group, lepers receive life skills training that can overcome barriers to economic access to produce various commodities matched with their physical capabilities independently. This life skills training is supported by the local government, health department, and social department. Civil society organizations play an important role in the advocacy for human rights and economic empowerment of lepers in Indonesia.

Keywords: Stigma, Leprosy, Economic access, Empowerment

## 1. INTRODUCTION

In 1873, Armauer Hansen succeeded in identifying *Mycobacterium leprae* as the causative organism of leprosy. The mycobacterial infection mainly affects the skin and peripheral nerves (Entezarmahdi et al., 2013). The delay in diagnosis and treatment causes deformities and impairments and results in permanent organ damage and hinders daily life activities in any circumstance. Upon its appearance, deformities include scars, claw fingers, or paralysis.

Historically, leprosy is a disease that has a high social stigma. This social stigma remains a global phenomenon even in modern society (Yadav, 2011; De Groot et al., 2011; Ebenso, 2012). According to Yadav (2011), this social stigma is derived from the deformities caused by leprosy, which resulted in significant differences in appearance between the lepers and the people around them. Buckingham (2002), Miyasaka (2009), and Sermittirong and Van Brakel (2014) noted that leprosy is negatively perceived as a curse or the consequences for the wrong deeds of their ancestors.

In the past decade, curative systems for leprosy has been focused on to prevent further effects with the potential to raise several social problems (Buckingham, 2002; Yadav, 2011; Singh et al., 2012; Peters et al., 2013; Sermittirong and Van Brakel, 2014; De Souza et al., 2016). First, the social problem is derived from the social stigma, which is the main reason for excluding or rejecting lepers from the community. Second, the social exclusion of lepers leads to restrictions in social relationships, prohibitions from public domains, and denial of economic access. Third, the restrictions lead to the powerless condition of lepers to help themselves, thereby making them a burden to the entire community (Sekarningrum et al., forthcoming in 2017).

At the individual level, leprosy causes psychological problems that result in the inability of individuals to cope with daily life. A leper is trapped in self-stigma as a consequence of the negative social construct of leprosy in the community. These individuals perceive themselves as different, punished, cursed, and guilty for being a leper, thus closing their interaction channels with other people. Moreover, their access to public economic domains is also restricted.

Stigma and self-stigma reduce the ability of a person to connect to the community and his/her opportunity to experience a good life. The community rejects lepers for certain reasons, that is, avoiding the disease, perceiving that the affected individual brings disgrace to their descendants, and assuming that the disease is the result of negative metaphysical aspects (e.g., magic, curse, or sin). These reasons resulted in the practice of punishing a leper. According to Foucault (1995), a punishment is a substantial endeavor to ensure discipline and order within the community. In the context of leprosy, Foucault's idea of punishment would be viewed as torture for people living with leprosy. Lepers have limited economic access and are prohibited from working as ordinary human beings. This rejection from society results in impoverished living conditions for lepers and will continue to be a burden for the individual and the community if no assistance is provided.

In fact, several empowerment programs have been established for lepers to provide them with life skills training, to release them from community restrictions, and to ensure that they can support themselves. These empowerment programs were established by the government as part of the national leprosy eradication policy. In Sampang-Madura, the public health service officer is involved in empowerment programs for lepers, in addition to essential public health services. The public health service officer endorsed the development of community-based rehabilitation (CBR) considering the impoverished living conditions of lepers in the community.

In Kupang and Makassar, empowerment programs for lepers also involve civil society organizations (CSOs). Many CSOs established CBRs to empower lepers (Cornelieje et al., 2008; Jacob and Paredes, 2008; Lusli, 2015). CBR members consist of former lepers who finished their treatment course and have dedicated their lives to the advocacy of helping lepers. In Kupang, where lepers live in an inclusive environment, empowerment programs increased the capacity of CBR members. Lepers are given limited access to public domains and provided the same opportunity for economic access. In Makassar, lepers live in specific areas defined as the leper village of Dangko. The CBR aimed to eliminate the limitations of lepers to enable them to support themselves and land a productive work to alleviate their economic situation. In other circumstances, many of the CBR volunteers conduct peer counseling to people living with leprosy (Kim and Free, 2008; Maticka-Tyndale and Barnett, 2010; Lusli et al., 2015, Yusar, 2016).

Therefore, empowerment programs for lepers are part of the heuristic action to ensure economic access through CBR, although the stigma on lepers still impedes them

in social participation at certain levels. The empowerment programs established by the government and the CSOs offer a new hope for lepers to live a good life and play a positive role in developing the communities where lepers live in.

## 2. RESEARCH METHODOLOGY

This research was conducted from October 2016 to December 2016. The qualitative approach was used to obtain an in-depth comprehension of the economic access of lepers. Data were obtained using multiple methods, such as literature study, institution survey, direct observation, and in-depth interview with key informants. This study was conducted in leprosy communities in three provinces of the Republic of Indonesia, namely, Sampang-Madura, East Java Province; Kupang, East Nusa Tenggara Province; and Makassar, South Sulawesi Province.

Of the three locations, Sampang-Madura and Makassar have endeavored to ensure economic access of lepers through the Self Care Group (*Kelompok Perawatan Diri* [KPD]). In Sampang-Madura and Makassar, many lepers exhibit deformities of their hands or feet and impairment of their body parts, such as hands or feet, thereby resulting in difficulties in accomplishing economic activities. In Kupang, only a few lepers manifest deformities and are categorized as disabled persons. In addition to public health service, the local government initiated the Self Care Group for lepers in Sampang-Madura.

In Kupang, lepers show minimal deformities and are slightly stigmatized in their community. Thus, their economic access is normal and they are allowed the same opportunity to work in the public economic domains. In urban Makassar, lepers are empowered by the Self Care Group established by the CSO, which advocates for their human rights and economic access and provides lepers with life skills training. Lepers in Makassar are able to craft wood into toys or recycle rubbish into plastic bags or wallets through the empowerment programs and are able to find work, such as parking service attendants, and do not end up becoming beggars.

## 3. RESEARCH FINDING AND DISCUSSION

### 3.1. Economic Access of Lepers in Sampang-Madura

Leprosy was characterized as a chronic disease by Frieden (2010, in Hossain et al., 2016: 183) who noted that chronic diseases increase the living standards of a community compared with infectious diseases. *Mycobacterium leprae* can be found in various places, not only in the low-quality environment but also in the high-quality surroundings.

The social participation of lepers depends on the acceptance of the entire community. According to Cornielje et al. (2008), social participation is affected by the social system. Less acceptance from the community means that lepers are restricted in their public life. In many places where lepers experience restrictions in their society, they also experience impoverishment, that is, the condition where they could not meet their necessities.

Sampang-Madura is categorized as exhibiting massive stigma for people affected by leprosy. The term *judem* places lepers at the lowest level in their social strata. In *judem*, a person is stigmatized according to the deformities of their fingers, hands, and feet and the impairment of their body parts. Lepers will experience rejection from their community,

and their presence in the public domains will be prohibited by the conservative religious values imposed on many generations.

In addition to their duty as a public service officer, the health service officer initiates the development of an empowerment group for lepers and the provision of medical treatment and life skills training to enable them to adjust to their deformities. The health service officer, along with an ex-leper, conducts these programs covertly to prevent other people from intervening, which may hinder their actions. In general, A CBR in Indonesia is defined as an empowerment care group or *KPD*. In the beginning, lepers in Sampang felt ashamed to show themselves, indicating the effect of massive stigma in their community. The *KPD* was transferred from one place to another approximately four times to avoid the negative perception from the community.

The health officer directs the lepers to become productive, to be able to work, and to adjust to their deformities. The health officer subsequently cooperates with the social officer in providing life skills training to ensure that lepers are able to adjust to their physical condition to support this action. The government also supports the lepers in Sampang by conducting skills training in raising livestock, such as chicken and goats. They were also trained to build cages for their livestock. They crafted these cages not only for their livestock but also to become commodities, which they could sell in the local market. Thus, the lepers gained access to a particular economic domain.

In Sampang, the *KPD* managed by ex-lepers, supported by the local government, provided a loan worth two million rupiahs as their initial capital for developing their livestock cage business. In line with their ability to build livestock cages, the loan successfully assisted the lepers in earning income by themselves. Thus, the physical limitation of the lepers was no longer a handicap for them to be economically productive. Lepers are currently independent and are no longer a burden to their family. Moreover, male lepers may be able to raise their own family and regain their position as the breadwinner of the family. In Sampang-Madura, lepers are dominated by males of productive age.

In the 2017 fiscal year, the progress shown by the *KPD* resulted in the trust from the local government and the increase in productivity and income of the lepers. The local government entrusted the manufacture of spring mattresses for local hospitals to the *KPD*. The empowerment of the lepers to craft many goods is perceived as the success indicator of the *KPD* in training lepers to gain access to the public economic domains and become independent of other people.

### **3.2. Economic Access of Lepers in Kupang**

Different from lepers in Sampang, the lepers in Kupang did not experience the stigma or discrimination from their society. In Kupang, lepers have an equal opportunity to people who do not suffer from leprosy. Moreover, the religious values of people enabled them to accept lepers more easily in Kupang than in Sampang. The parish network efficiently finds the lepers and quickly takes them to the health service office. In this condition, lepers have the same economic access as ordinary people around them.

Meanwhile, empowerment programs for lepers implemented by the CSO, which consists of ex-lepers, are called *Perhimpunan Mantan Kusta* (Permata). Permata focused on advocacy for lepers to receive medical treatment and encourage them to interact with other people. Permata members also developed a database of lepers in Kupang. They obtained information from the parish network to reach lepers to provide them with health

services or refer them to the health officer for immediate treatment. This program successfully prevented the development of deformities in lepers for them to live a normal life.

### **3.3. Economic Access of Lepers in Makassar**

The urban nuance of Makassar's society has a moderate attitude toward lepers. Minimal attention is focused on lepers who have become beggars. These beggars are perceived as disabled persons without identifying the causal factor of their disability. Makassar's inhabitants focus minimal attention on the existence of lepers around them, except on the designated leper community in a certain area of the urban Makassar.

During the Dutch colonization of Makassar, lepers were isolated in an area near the leprosy hospital, namely, the Dangko village. This leprosy community still exists, with a massive change in its inhabitants. Currently, the Dangko village is not only an exclusive area for lepers but also many other people who are unaffected by leprosy. However, from the point of view of other inhabitants of Makassar, the Dangko village is a shelter for lepers and is negatively perceived as a community for beggars.

In the Dangko village, empowerment programs for lepers are organized by the CSO, namely, the Permata organization, which is the same as the group in Kupang. Permata empowered the Dangko inhabitants to assert their human rights and trained them to gain the ability to live through the KPD. In Makassar, the CBR or the KPD is under the guidance of the Permata. In the Dangko village, ex-lepers conduct peer education and counseling for persons who are newly affected by leprosy. They also share their experiences of being a leper. The ex-lepers also motivate the persons who are newly affected by leprosy to receive medical treatment immediately to prevent deformities.

Members of Permata coach lepers on specific life skills to be able to operate home industries to alleviate their economic situation. In the Dangko village, microbusiness joint venture groups are operated by the inhabitants. Plastic wastes scattered around Dangko are utilized by this group to produce certain goods, such as plastic bags, wallets, or thin containers. They organized themselves into different divisions of workers, that is, the males collect the plastic wastes; males and females wash the plastic wastes; and the females sew the plastic wastes into goods.

Under the direction of the KPD and Permata, certain Dangko inhabitants work as wood crafters. They build wooden toys using manual equipment, such as hand drills, jigsaw, or hammer, to shape the wood into toys. The KPD collects the toys and sells them outside the Dangko village. The toys were even sold to the United States based on an order from a tourist.

The Makassar municipal government also provides support for the lepers. They employ ex-lepers as parking attendants who assist the local government in raising funds for the city through parking tickets. The ex-leper deposits the money from parking tickets to the local government and receives their salary from this occupation. The local government also employs ex-lepers as street cleaners who receive a monthly salary as freelancers. Thus, the cleanliness of the city is maintained, and the ex-lepers obtain the benefits provided by the local government.

In a few cases, the private sector also employs ex-lepers as janitors. The ex-lepers work for offices as outsourced employees and receive a salary for their work. The private sector that employs ex-lepers is a party who demonstrates a thorough understanding of

leprosy and avoids placing a stigma on leprosy. Therefore, they do not discriminate persons with disabilities or persons who have a different appearance.

Open access to the economic domains enables lepers to provide for themselves and their families. Thus, they are able to send their children to school and ensure the continuity of their children's education. This condition results in an improved quality of life for lepers and ensures a bright future for their descendants.

#### 4. CONCLUSIONS

Lepers can gain access to the economic domains and can live normally as other individuals. This condition requires the absence of stigma to lepers. Equal economic opportunity can be achieved by eliminating the stigma and providing an equitable and inclusive atmosphere. Thus, lepers will be able to attain the benefit of socioeconomic equity for them to work in the economic domains without fear of other people's negative perceptions.

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