Social Exclusion and Impoverishment of Lepers

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ABSTRACT

Indonesia ranks third in the number of leprosy cases recorded, after India and Brazil. Social exclusion is a reality that lepers face. This research used a qualitative approach with multi-method data collection, such as literature study, institutional survey, observation, and in-depth interviews with informants. This research was conducted in three provinces, namely, 1) Sampang Regency, East Java Province; 2) Kupang City, East Nusa Tenggara Province; and 3) Makassar City, South Sulawesi Province. Results of this research show that lepers in Sampang Regency, East Java Province experience serious social exclusion and impoverishment; lepers encounter barriers to economic access leading to poverty. The religious and cultural factors in the local community support the inhibition of economic access, which is the determinant factor for developing social exclusion, thereby resulting in the impoverishment of lepers in Indonesia.

Keywords: Social exclusion, Poverty, Leprosy, Leper

1. INTRODUCTION

Many scholars agree that leprosy is the oldest disease known. Leprosy can be traced in ancient Egyptian archaeological evidence or in European medieval folklores. Khapre et al. (2013: 1) stated that leprosy originated from India in the 600 BC period. In 1873, Amauer Hansen identified *Mycrobacterium leprae* as the causative organism for leprosy. Thus, leprosy is also called Hansen morbidity. Leprosy is one of the most misunderstood and feared diseases and is recognized as the oldest human disease (Yuasa, 2015: 9).

Leprosy is a chronic infectious disease that mainly affects the skin and peripheral nerves and rarely other organ systems. This disease does not target a particular age or gender. Therefore, poor living standards and inadequate nutrition make people susceptible to leprosy. The behavior of individuals also contributes to the continuous transmission of leprosy, because many people are still unwilling to seek medical care even after being diagnosed; this behavior is due to misconceptions, stigma, and superstitions (Sileshi, 2015: 31). Leprosy still exhibits a high rate of disability despite a significant reduction in the global prevalence of the disease; however, its determinants are unfair, and many of these determinants are amendable (Entezarmahdi et al., 2013). Leprosy remains to be a serious problem in many developing countries, with 213,899 new

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cases detected globally in 2014, representing a new case detection rate of 3.78 per 100,000 population (Global Leprosy Update, 2014 in Tiwari and Richardus, 2016: 2–3). Lepers initially suffer from anesthetic sense and paralyzed limbs and eyes. Then, lepers experience disability in using their body parts, such as hands or feet, thereby seriously interfering with the work life of lepers.

Over the century, leprosy is perceived as a public health problem. De Souza et al. (2016: 197) argued that leprosy is still endemic in certain developing countries in Asia, Africa, and Latin America, although leprosy is no longer a health problem in developed nations. For these developing countries, leprosy is considered a neglecting disease, which becomes the priority of health domains. Peters et al. (2013: 1) indicated that efforts on leprosy focus on curing the disease, controlling its spread, and preventing impairment. These efforts are conducted because leprosy is one of the world's most important causes of permanent disability; this disease not only results in secondary lesions, such as wound, shortening, finger erosion and clubbing, keratitis, and blindness, but also causes skin damage, paralysis of face and hand muscles (secondary to motor neuron nerve damage), and damages and scars in the legs (anesthetic) (Entezarmahdi et al., 2013).

Similarly, leprosy is perceived as a social problem rather than merely a medical disease (Yadav, 2011: 201). The problem is not only in the disease itself but also in the implications of leprosy for the lepers themselves and the people surrounding them. Leprosy may cause psychological problems and social distress apart from physical distress. Leprosy may lead to individuals' inability to perform their daily social function. The basic knowledge of the perceptions of persons with the disease is crucial in regulating any communicable disease. However, people have developed inaccurate notions regarding leprosy, which is similar to any other disease; lepers are ostracized by their families and society (Singh et al., 2012: 68).

Historically, lepers are perceived negatively, such as being cursed, performing sinful acts, or being the consequences of their ancestors' wrong deeds or *karma* (Buckingham, 2002; Miyasaka, 2009; Yadav, 2011; Ebenso et al., 2012; Singh et al., 2012; Sermittirong and Van Brakel, 2014; Entezarmahdi, 2013; O'Dell, 2015). In the modern society, the social stigma to lepers remains a global phenomenon (Yadav, 2011; De Groot et al., 2011; Ebenso, 2012). Lepers experience rejection from people around them, including their family members, thereby restricting their social participation and common rights, such as working, religious, and health facility rights.

Yadav (2011) explained that deformity stages and social stigma demonstrate a positive relationship. Physical disabilities and deformities are important causes for the socioeconomic deterioration of lepers. Owing to social stigma, people might continuously separate lepers from the population; therefore lepers lose the opportunity to gain access to economic domains, such as the working life. Thus, this scenario may cause a burden to the whole population. Stigma leads to social consequences, such as participation restriction. It can be defined as "the coexistence of the following components: labeling, stereotyping, isolation, status loss, and discrimination in a context where power is present" (De Groot et al., 2011: 169).

2. METHODOLOGY

This research was conducted in leprosy communities in the following three provinces of the Republic of Indonesia: 1) Sampang, Madura, Jawa Timur Province, 2) Kupang, Nusa Tenggara Timur Province, and 3) Makassar, Sulawesi Selatan Province.

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Among these locations, the highest rate of social exclusion on lepers was recorded in Sampang, where many lepers suffer visible deformities. The values of the conservative Islamic tradition also enforced social exclusion that leads to impoverishment. In Kupang, Nusa Tenggara Timur, an inclusive behavior was observed because people are open-minded and are following Christianity values that require them to care for lepers. In urban Makassar, lepers moderately live an inclusive life because the civil organization advocates that lepers assert their human rights.

In this research, the sociodemographic profile highlighted that the poor socioeconomic conditions in Sampang-Madura, Kupang, and Makassar, in addition to biological determinants, are factors that contribute to leprosy infection. This research found that low educational level is directly related to low family income, thus resulting in poor housing conditions, hygiene, nutrition, and the lack of access to health service, which consequently promotes appropriate environmental conditions for *Mycrobacterium leprae* infection or the spread of leprosy to susceptible individuals.

Compared with the two locations (Kupang and Makassar), the massive marginalization of lepers is a serious problem in Sampang-Madura, leading to the burden of economic life for the population. Most lepers belong to the lower-class minimally educated people, which appearances were concealed from the public because of stigma. In the context of the social exclusion and impoverishment of lepers, this research investigated the case of Sampang-Madura through cross-sectional observations, which comprise four factors, such as 1) the stigma on leprosy, 2) the social exclusion of lepers, 3) the impoverishment of lepers, and 4) the socioeconomic burden for the population.

This research was conducted from October to December 2016. The qualitative approach was constructed to gain an extensive comprehension of the social exclusion and impoverishment of lepers. The data were obtained through multiple methods, such as literature study, institutional survey, direct observation, and an in-depth interview with key informants.

The present research was conducted on Sampang residents in the areas of Camplong district. The key informant was the health officers in Camplong Public Health Service (Puskesmas Camplong) who provided the comprehensive information not only in the medical service for lepers but also in the socioeconomic and cultural information related to leprosy cases in Sampang, such as stigma and working life of lepers. The significant information described the difficulty experienced by lepers in maintaining a decent job, because of not only the deformity caused by leprosy but also the people's inability to accept the lepers; this scenario was due to the structural tension on the population. The information from the health officer indicated that lepers with deformity were interviewed to discuss their life story in the terms of socioeconomic aspect. Lepers revealed that the difficulties they face when attempting to find a decent job are mainly due to the deformity from leprosy and the rejection from the people. This scenario resulted from the lepers' lack of access to economic domains within the population.

3. SOCIAL EXCLUSION AND THE IMPOVERISHMENT OF LEPERS

3.1. Stigma on Leprosy in Sampang-Madura

According to previous research, leprosy as a chronic disease randomly exists in various environments. This finding was contrary to Frieden (2010, in Hossain et al., 2016: 183) who noted that chronic diseases replace infectious diseases in connection to the rise in the living standard. Our findings show that people can still acquire leprosy even in a

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good quality living environment. Furthermore, the existence of *Mycrobacterium leprae* is still unpredictable.

Compared with the leprosy cases in Kupang and Makassar, leprosy in Sampang-Madura is more complicated in the medical and socioeconomic life. Lepers in Sampang-Madura delay in diagnosis and treatment, thereby leading to primary and secondary deformities that mainly cause social stigma from the population. Ebenso (2012) stated that the most common attitudes revealed by the study are devaluation, distancing, hatred, rejection by family, exclusion, and labeling. People label others by their appearances; whoever appears differently is at risk of stigma from people around them.

Cultural factors, such as belief system, norms, and values, force people to stigmatize lepers as a *judem*. The term *judem* refers to the terrifying physical appearance of lepers with secondary deformity and is derived from religious values that are perceived as the permission to judge lepers as disgusting humans by the mistakes from previous generations. The belief that people without leprosy have the right to punish lepers by alienating these lepers from their population. However, many lepers still lack acceptance from their neighborhood.

In many cases, lepers in Sampang-Madura residence may be banished by their family due to the disgrace lepers may cause the family. Families with members who are affected by leprosy conceal this condition from their neighbors because of stigma for leprosy. A conservative Islamic monk argues that lepers must be banished from the society because lepers may harm the entire community. In addition, this monk argues that leprosy is caused by the lepers' parents who had sexual intercourse during the mother's monthly period. This belief represents a fallacy and ignorance about leprosy.

In terms of the subjectivity of lepers in Sampang-Madura, Kupang, and Makassar, this research found the similarity in subjective reasoning, which builds a sign of self-stigma. Lepers usually feel fear, embarrassment, low self-esteem, and isolation or feeling different. De Groot (2011) explained that self-stigma occurs when lepers have stigmatized their condition and have become ashamed of their illness due to the attitudes of other people toward leprosy and/or the deformities lepers may have. This process affects lepers and influences them to start applying the negative stereotype that people are concealing and develop a negative self-image. A correlation frequently exists between actual discrimination and self-stigma at an individual level (De Groot, 2011).

The monk, as a religious leader has an ultimate position in the cultural experiences of the people in Sampang-Madura. His utterance is constantly followed by the community as a truth and cannot be disproven. In the context of stigma, the monk plays a major role in preserving the stigma against lepers. The community transmits "the faith" by punishing lepers in many ways, such as marginalizing or alienating and separating lepers from the entire community as the consequence of the lepers' condition. Then, these "punishments" lead to the social exclusion of lepers, a scenario that is implied to the whole aspects of the lepers' life and can unwittingly become an economic burden to the community.

3.2. Social Exclusion of Lepers

Lepers experience social exclusion when the lack of acceptance of lepers' existence is pulled into social stigma, which may cause a massive human right problem by marginalizing or alienating lepers. Marginalization and alienation are considered a way of separating lepers from their communities. These actions are influenced by the appearance of these lepers because lepers with deformities receive devaluation from the

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community directed by cultural or structural values. Thus, Byrne (2005) emphasized that lepers in Sampang-Madura and Makassarare are considered different by individuals and communities due to their disability or difference in structural values in the society. Meanwhile, lepers are not considered different by individuals and communities who value religious beliefs and consider that all human being are equal despite their deformities.

In Sampang-Madura, lepers experiencing social exclusion are precluded from participating and accessing information, economic domain, sociability, and resources, indicating that lepers exhibit multidimensional disadvantages that lead to social consequences, such as restricting participation (De Groot et al., 2011). Lepers as a *judem* are often prohibited from accomplishing daily activities within the community, secluded from interaction with other people, and deprived of access to public health service and economic domains.

The social exclusion in Sampang-Madura is mainly derived from the conservative Islamic values, which allow people to punish lepers. The most common action of this form of punishment is separating and isolating lepers from the entire community. This isolation probably hinders lepers in accessing medical treatment that results in serious deformity, which restricts the ability of lepers to work similar to any other person. Lepers carry their disability and become economically unproductive. The society prohibits lepers from accessing public economic domains, such as public works or employers in industrial enterprises, although lepers can still work despite disabilities.

In this research, we found that most lepers do not work in the public sector. Lepers can only work in grass fields to feed their livestock, because lepers often suffer discrimination from their community. Consequently, lepers in Sampang-Madura live in poor condition and posit the lowest level in the economic strata with the lack of access to public work domains. In Makassar, we found that lepers are mentally and physically disabled and often end up as beggars. Kaur and Van Brakel (2002: 347) defined dehabilitation as the loss of former place or role in society, causing loss of dignity, job or position, and lead to physical displacement. In terms of social exclusion, this restriction is the direct effect of impoverishment on lepers; an exception to this restriction is the case in Kupang, where lepers are fairly accepted by their community that values religious beliefs.

3.3. Impoverishment of Lepers

In Sampang-Madura, chronic social exclusion makes lepers unproductive in economic terms, such as occupation or work. The deformity on the hands and feet of lepers is a considerable handicap for daily work, thus denoting that leprosy makes an affected individual economically dependent on others, who are not handicapped, while working. Most lepers are from the lower social class, and lepers on the lower class households exhibit difficulty in meeting daily needs in any circumstances. This scenario may be the reason these lepers are alienated by their families to reduce the burden of the household.

In Sampang-Madura and Makassar, lepers are excluded from social relations at certain levels that lead to other deprivations and further limit the living opportunities for lepers; this situation results in the capability deprivation from economic domains that lead to the decline of the socioeconomic capacity of lepers. This result relates to the social stigma that mainly implies restrictions to the access of lepers to economic domains. Most lepers cannot land a permanent job nor gain a decent salary to raise their family.

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Furthermore, impoverishments continue as lepers are excluded from the community that allows lepers to live in many limitations. These difficult conditions force lepers to work with their disability alone without depending on other people.

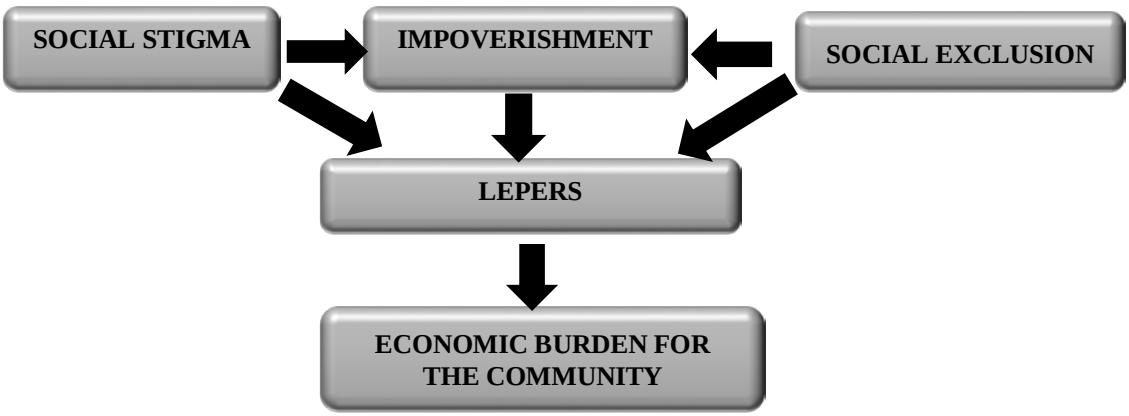
The combination of social stigma and exclusion leads to dehabilitation of lepers, thereby situating lepers in a state of poverty. In Sampang-Madura and Makassar, all lepers have physical deformities that limit their economic activities and then lead to the socioeconomic dehabilitation, which may affect the economic circumstances.

3.4. Socioeconomic Burden For The Population

Based on evidence found in this research, most lepers are males, who are within productive ages. Cultural values subject males in assuming the role of raising their families. Therefore, male lepers, who are incapable of working for their families, will cause an economic burden to the society.

Moreover, rejections of lepers unwittingly decline the role of males as the breadwinner for their family. The unemployment of males may cause a burden to the society although females in large number may also work to raise their family. The productive age groups must bear these lepers apart from their households. In addition to meeting household necessities, additional expenditure should also be spent on the cost of care for lepers.

In this research, the communities we observed in both locations are likely to be in the lower class of socioeconomic strata; the existence of leprosy causes a burden to the economic life of people living in poverty. Hence, the existence of leprosy within the community threatens economic growth. Poor economic growth can hinder the improvement of people's quality of life, which brings other deprivations in social life, such as deprivations in education, health, and environments.



4. CONCLUSION

Leprosy is a health problem with an impact that can be a socioeconomic problem, which can hamper the development of a society. This research shows that social stigma and exclusion exhibit a positive relationship, which results in a burden for the socioeconomic development of the society. Social stigma and exclusion are the important causes for socioeconomic deterioration. Therefore, essential actions, such as educating the society by imparting knowledge on leprosy and establishing a sympathetic attitude

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toward lepers to eliminate social stigma and create social inclusion in the community, are required. Owing to these efforts, lepers might seek early medical services to prevent deformities. Similarly, lepers should also be provided with several life skills as their productive economic activity for these lepers to earn a living and avoid burdening their family and their society.

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