ORIGINAL RESEARCH

Exploring the Complexities of Leprosy-related Stigma and the Potential of a Socio-economic Intervention in a Public Health Context in Indonesia

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ABSTRACT

Purpose: *This article explores the complexities of leprosy-related stigma and the potential effectiveness of a socio-economic intervention in Cirebon District, Indonesia.*

Methods: *A qualitative approach was adopted. 53 people affected by leprosy were interviewed, and 17 focus group discussions were conducted among people affected by leprosy, community and religious leaders, and health providers and other key persons who were all purposively selected.*

Results: *People affected by leprosy face major socio-economic consequences. This was confirmed by key persons. Several opportunities for a possible socio-economic intervention were perceived, as also the barriers. People affected by leprosy are constrained by certain aspects of the health system (e.g., the health providers' negative attitudes), views in society (e.g., misunderstandings about the condition, stigma), and the physical and social consequences of the disease (impairments, feelings of shame). Study participants identified strategies to deal with these barriers, as well as specific activities for a socio-economic intervention; in particular, the training of staff responsible for implementation.*

Conclusion and Implications: *Socio-economic interventions in the field of leprosy need to anticipate the barriers and develop strategies to deal with*

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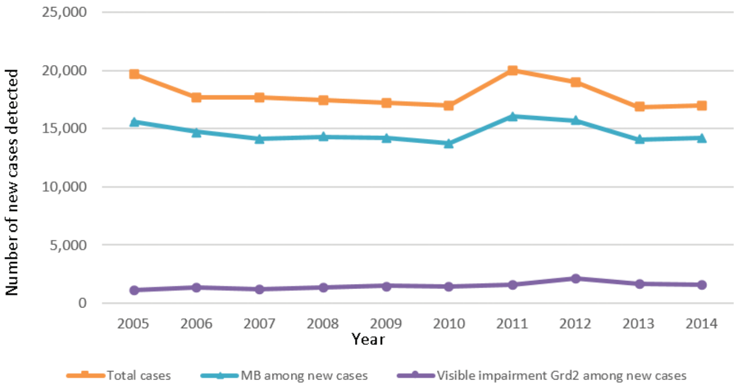
them. Cooperation between people working in the health system and those in the welfare / financial system is needed, to improve the quality of life of people affected by leprosy.

Key words: *Health system, socio-economic status, knowledge, beliefs, qualitative study, Cirebon.*

INTRODUCTION

Although the prevalence and incidence of leprosy has declined over the last 20 years, the South-East Asian Region is still the biggest contributor to the number of new cases reported (World Health Organisation, 2015). Indonesia officially eliminated leprosy in the year 2000, reaching a prevalence level of <1/10,000 population (MOH Indonesia, 2007). However, the WHO (2015) reported that Indonesia still occupies a 3rd place in terms of the leprosy burden, with an average of 17,000 new cases per year, of whom about 9% have grade 2 impairment at the time of diagnosis. Although some provinces have reported a decrease in new cases detected, Figure 1 shows that a more or less constant number of new cases continue to be detected every year, indicating that Indonesia faces major challenges in reducing the incidence of leprosy.

Figure 1: Number of new cases detected in Indonesia 2005 – 2014 (MOH Indonesia, 2007; WHO, 2015)



* WHO classifies persons affected by leprosy in one of two groups, paucibacillary (PB) and multibacillary (MB) leprosy, by counting the number of skin lesions. Paucibacillary if the person has five or fewer lesions, and multibacillary if there are more than five or if a positive skin smear is found.

Leprosy-related stigma can negatively affect the diagnosis (e.g., delayed presentation of symptoms), treatment (e.g., refusal or discontinuation of the multi-drug therapy -MDT) and management of the disease (van de Weg et al, 1988; Nicholls et al, 2003; Heijnders, 2004a; Barrett, 2005; Brown, 2006). The often poor attitudes of health professionals, identified in several countries, contribute to this situation (Awofeso, 1992; Briden and Maguire, 2003; Nicholls et al, 2003; Iyor, 2005). Leprosy-related stigma has many more far-reaching consequences as it can negatively influence an individual's prospects for education, employment, marriage, family life, religion, housing and, in this way, one's quality of life (Calcraft, 2006;Tsutsumi et al, 2007; Rao et al, 2008; Rao, 2010; Schuller and van Brakel, 2010).

Various interventions have been implemented to address leprosy-related stigma. Most of them attempt to deal with the causes, such as lack of knowledge or awareness (Brouwers et al, 2011; Nsagha et al, 2011), negative attitudes of the community (Brown, 2006), and negative attitudes and behaviour in the health system (Arole et al, 2002). Another very different approach is not to focus on the causes of stigma but to strengthen the capacities of individuals (WHO, 2011), which may lead to improved self-esteem, well-being, and enhanced participation in socio-economic life, and consequently reduce stigma. Socio-economic interventions (specifically, microcredits, business training and so on) are an example of the latter approach.

Improving people's socio-economic status seems to be a 'short-cut' solution to reduce the impact of stigma. Based on the findings from other studies on leprosy (Ebenso et al, 2007; Velema et al, 2008) and also evidence from the field of HIV/AIDS and disability (Verma, 2009; Wagner et al, 2012;Tsai et al, 2013) the authors of the current study hypothesise that a socio-economic intervention can improve the quality of life of affected people and reduce stigma. A person affected by leprosy who receives a microcredit may feel acknowledged and appreciated as a human being with capabilities. He or she may feel proud to be eligible and trusted with a microcredit. As Velema et al (2008) wrote, "A 'side-effect' of these socio-economic interventions is the enormous boost in self-esteem that many clients get out of it".

The start-up of a business would require the development of new skills and involvement in new activities. This requires interpersonal contact with family members, neighbours and community members. This contact may alter previously held assumptions that lead to stigma, and this in turn may change the attitudes of family members, neighbours, community members, and perhaps even health professionals. Improved financial independence is likely to improve one's status and further enhance social interaction. This hypothesis is in line with the arguments put across by Tsai et al (2013) who developed a strong case for considering livelihood interventions as a compelling stigma-reduction strategy for HIV-infected persons. However every new approach aiming to reduce stigma is at risk of failure because of the many barriers that may arise during the implementation of the intervention. A socio-economic intervention might also fail due to the many problems that persons affected by leprosy encounter, such as stigma, health problems, weaknesses of the health care system, and so on.

Objective

This study aimed to explore and analyse the barriers that exist and how they can be dealt with in the process of the implementation of a Socio Economic Development (SED) intervention.

METHODS

Study Setting

This study is part of the Stigma Assessment and Reduction Impact (SARI) project that was implemented in Cirebon District of West Java in Indonesia. Cirebon was selected as the study area because it has a high burden of leprosy, with more than 250 new cases detected every year, making it the third worst-affected area of West Java.

Study Design

An explorative study design was used, aiming to represent three perspectives – of persons affected by leprosy, healthcare providers and key persons in the community. 53 persons affected by leprosy were interviewed, sometimes together with a caregiver or family member. Also, 17 focus group discussions (FGDs) were conducted with key persons from financial, business and social institutions in Cirebon District, community members, community leaders, religious leaders, teachers, health workers, mothers of children affected by leprosy (child cases) and adults affected by leprosy.

Participants

A purposive sample of people affected by leprosy was selected from Health Centres (HCs) in 10 sub-districts, using data provided by the District Health Office (DHO). The aim was to get a broad perspective; thus, people varying in age, sex, health status, socio-economic status and education were selected. Health workers and leprosy officers were chosen from data obtained by the DHO; teachers were selected from schools in the study area; religious leaders were selected through faith based organisations, and community leaders through villagers; financial, business and social institutions in Cirebon District were identified and key persons from these organisations were invited.

Data Collection

Interview guidelines were developed for in-depth interviews and FGDs. For affected persons and the community, the themes explored were leprosy, stigma, participation, socio-economic impact of leprosy and their expectations. For FGDs with health workers, the themes were selection and training of leprosy officers, the health system, treatment of leprosy, perceptions of and beliefs about leprosy in the community, attitudes and behaviour of health staff towards persons affected by leprosy and other challenges in the field of leprosy, along with possible solutions. For community and religious leaders, the questions addressed their perceptions of leprosy (according to their religion) and the perceptions of others, and their suggestions to reduce adverse impacts of the disease. For key persons from financial, business and social institutions, the questions related to what an SED intervention could look like, anticipated problems in implementing a micro-credit programme and strategies to deal with them. Organisations and people who could fulfil a role in an SED intervention were also identified.

Data Analysis

Content and thematic analyses were applied. First, all participants were put into three groups- healthcare providers, key persons in the community and people affected by leprosy, and a contextual text segmentation was then conducted using open-ended codes to identify similar concepts. Second, similar concepts were gathered into similar content themes. Finally, a triangulation among participant groups was conducted and all the interviews were reviewed to validate the content and to minimise the risk of bias. These processes were conducted manually.

Ethical Considerations

The study was approved by the ethics committee of Atma Jaya University in Jakarta. Informed prior consent was obtained from all participants and the study team guaranteed the confidentiality of the data they provided.

RESULTS

This section starts with an analysis of the socio-economic consequences of leprosy. Next, barriers in relation to i) the health system, ii) knowledge, beliefs and attitudes in society, and iii) emotional, psychological and physical consequences of leprosy, are explored and analysed. For each barrier, possible solutions suggested by the study participants are analysed and described. These are then translated to conditions and more specific strategies to deal with the discussed problems in order to increase the likelihood of a successful SED. Finally, an analysis of the feasibility of realising an SED intervention by local organisations is given.

Characteristics of Study Population

In-depth interviews were conducted with 34 women and 19 men affected by leprosy. The youngest interviewee (interview conducted together with caregiver) was 9 years old and the oldest was 80 years old (mean age was 38.5 years). Occupations varied from unemployed to self-employed (such as farming, fishing or selling food), unpaid work as domestic labourer or helping in the family business, and paid employment. Almost half of the participants had completed only elementary schooling or had dropped out before completion. Community and religious leaders were between 40 and 60 years of age, while healthcare providers were between 25 and 54 years of age, with experience ranging from 1 to 20 years.

Socio-economic Consequences of Leprosy

The interviews and FGDs revealed the negative impact of leprosy on the social participation of affected people within their community and family. Some of them had lost their jobs due to leprosy. For example, one informant resigned out of fear that colleagues would find out about the leprosy. Several others - who have small shops or food stalls - reported that it was difficult to sell products once neighbours knew about their leprosy status. Some of them went far away from their own village to sell their products in places where nobody knew about their condition. The consequence of reduced earnings was the increase in their out-of-pocket expenses for treatment and care. This had pushed some families into poverty, and some of them had ended up begging, stealing or trapped in debts or loans.

> *"I couldn't walk, so scary. I went home right away and I did not want to go work anymore"* (Female, FGD with affected people).
>
> *"I have one patient and she is doing business for food and beverage. Every time I visit her, she told me not ever to tell anyone about her disease"* (Male, FGD with leprosy officers).

Table 1 gives an overview of the social and economic consequences for people affected by leprosy.

Table 1: Perceptions on Social and Economic consequences of Leprosy

Social consequences	Economic consequences
- Use of degrading words	- Hard to find job
- Rejection	- Loss of job
- Avoidance	- Poverty
- Gossip	- Low income
- Ignorance	- Lack of money for living
- Broken family relationship	- Begging
- Broken social (neighbour) relationship	- Stealing
- Dropping out of school	- Debt
- Isolation	- Cannot sell food
- Concealment	- Spend money for care/treatment
- Divorce	

People affected by leprosy mentioned that it is very important to improve their economic status by being employed or self-employed. Some even considered it more important than their health. As one interviewee said, "Well … I'd like to have a better life, financially". Others said:

> *"It is difficult if we do not have money... rice, money, any kind of help is good"* (Interview with a person affected by leprosy).
>
> *"Help in funding.... I don't have money to start a business... If I have enough money, I feel free"* (Male affected by leprosy, In-depth interview).

Interestingly, some people affected by leprosy and some community members mentioned that a better socio-economic status would improve their self-esteem and reduce stigma.

> *"There are many things I need. Groceries I need, money I need… to avoid people mocking, we have to run a business"* (Female affected by leprosy, Interview).
>
> *"The main issue is that the majority of the people affected by leprosy are poor. They need money for medication. Even the patients that are already cured, they still need money for re-socialisation"* (Male, FGD with community and religious leaders).
>
> *"With financial aid of some sort, it could give them the passion to live their life again"* (Male, FGD with community and religious leaders).

Several respondents mentioned solutions to address the socio-economic problems of people affected by leprosy. Community and religious leaders suggested grants or micro-credits as a possible solution, and thought that local banks might be interested in this specific group. They said that it is essential that people affected by leprosy are willing to change. In addition, they highlighted the need for training in skills and some entrepreneurs (also some who had been affected by leprosy) offered their help. Participants also mentioned the possibility of establishing support groups. Key persons from several financial, business and social organisations noted that close collaboration and support from the local government offices (e.g., health, social welfare) would be beneficial to integrate the available resources to support people affected by leprosy. Also, people affected by leprosy were interested in socio-economic activities. Some said that they had been entrepreneurs earlier and already possessed certain qualities and skills needed to run a business. One participant in a FGD explained:

> *"Why the people affected by leprosy are commonly poor? First, people who are affected by leprosy are usually limited in mobility. So they are not capable to work as an employee in a company. A company also wants a normal healthy employee. So people affected with leprosy are best directed to become an entrepreneur. But they need skills to do that. Now these skills are what we should think about together. (...) If they have skills, they should be financially prepared to perform a business. Also if possible we create a market. After that they should be monitored and directed. (...) Well, this is only my advice"* (Male, FGD with community and religious leaders).

However, there were also worries. During a FGD with key persons from several financial, business and social organisations, doubts were raised about the feasibility of creating an SED intervention for this target group. According to the participants, starting and running a profitable business is in itself a difficult endeavour. For people affected by leprosy who face so many different health, social and financial problems, this is even more difficult. Supporting the start-up of such a business seemed to them a very high risk that no bank would be willing to take.

To sum up, people affected by leprosy face major socio-economic consequences because of their disease. Improving the socio-economic situation is, not surprisingly, a key concern of theirs. They even believe that improved socio-economic status would improve their self-esteem and reduce stigma. Key persons confirmed this and perceived several opportunities for a socio-economic intervention. However, there were also fears. Hence it is important to be specific about the problems clients face in the different areas of their lives, and to develop strategies that could be implemented by financial institutions or others.

The next section addresses the problems in the health system and society that are related to the affected individual.

Barriers in the Health System - and suggested Strategies

Barriers - Treatment of leprosy is available at primary health services such as sub-district HCs and village Satellite Health Centres (SHCs). All services are supposed to be free of charge, including the MDT treatment. Most sub-district areas are supervised by a single leprosy officer, which means that leprosy officers work on their own most of the time. Other health workers at the HC sometimes ignore issues related to leprosy or even have a negative attitude towards the disease. Sometimes other health workers refuse to shake hands or treat a person affected by leprosy.

> *"I mean if it is clear that the patient has leprosy as diagnosed by the laboratory, when I am not there –because I am in the field– nobody* [other health professionals/ colleagues] *serves the patient. They have to wait until I return to the HC... I want at least they take note of them or serve them"* (Male, FGD with leprosy officers).

> *"In reality, there are several officers who still are afraid to be infected. The important thing is, thank God that I am healthy until now"* (FGD with leprosy officers).

Salaries of health staff were described as low and the budget for the leprosy work that had to be done was described as limited. Leprosy officers mentioned several constraints such as feeling unwanted by the HC, boredom because of being a leprosy officer for too long, fear of being infected and worry about exclusion by family members.

Participants affected by leprosy mentioned that there was sometimes a misdiagnosis. Instead of leprosy, the initial diagnosis was diabetes or arthritis. This means that the start of treatment can be delayed, increasing the risk of disability and prolonging the risk of infection in the community. Also, several people affected by leprosy said that they did not receive information about the cause, ways of transmission and contagiousness of the disease from the leprosy officer. In a few cases, people affected by leprosy had to pay for the seemingly free leprosy services. Observations in the study area revealed problems in referral. Sometimes the person affected by leprosy sought treatment for reactions (a serious complication of leprosy) at the district hospital. Health insurance is available for clients, which helps them to receive treatment and care in these hospitals. The district hospital, however, was sometimes full and the person affected by leprosy had to be referred elsewhere. In general, the quality of the case management in hospitals is often limited due to the lack of knowledge about leprosy and leprosy reactions, health workers' attitudes, and lack of coordination with the referring HC where the person affected by leprosy used to obtain treatment.

Strategies: The health system needs to be strengthened at different levels. Leprosy workers proposed to improve the coordination between programmes, enhance leadership, increase the attention towards leprosy, advocate for more money for the leprosy programme (for example, so that community socialisation can be organised more frequently and leprosy officers can attend leprosy training routinely), provide knowledge about leprosy to all health staff during training and increase feelings of shared responsibility among them.

Strategies for the implementation of an SED intervention:

An SED intervention is more likely to be successful if staff of the organisation that aims to implement it would acknowledge the failures in the health system and the many problems people affected by leprosy have experienced in the process of getting diagnosis and treatment. This information could be used for designing a training course for the clients. Staff of an organisation that implements an SED intervention or affiliated partner could:

- Facilitate access to social insurances if the client is eligible but not yet a beneficiary.

- o Provide correct and complete medical information (cause, ways of transmission, becoming cured) to clients affected by leprosy if they have not yet been informed by a health professional.
- o Be aware and supportive if clients need to re-visit the health clinic for check-ups, new treatment or when they experience leprosy reactions or any other complication.

Barriers related to Knowledge, Beliefs and Attitudes in Society - and suggested Strategies

Barriers: Many of the study participants lacked a clear understanding of leprosy. In general there was a lack of knowledge about its causes, symptoms and treatment. When the researcher first mentioned the word, some community members wondered whether leprosy still existed. Most community members perceived leprosy as a disease that causes bodily impairments and deformities, but some perceived it mainly as a skin disease.

> *"Their hands get smaller, after a long time their legs shrink and finally become a stump, it is mostly like that"* (Male, FGD with community).

Various perspectives about the causes of leprosy were mentioned at the in-depth interviews and FGDs. Some respondents mentioned black magic or heresy, a belief that deters seeking treatment from health services. The perspectives were grouped in three categories: spiritual, biological and environmental. An overview of the perceived causes is given in Table 2. Most of them believed that leprosy is an infectious disease that is difficult to cure. Some did not know that it could be treated.

Table 2: Overview of Community Responses on Causes of Leprosy

Spiritual	Biological	Environment
Challenge/test from God	Bacteria	Poor hygiene (e.g. contact with dirty objects, poor sanitation)
Destiny (it has been written)	Heredity	Direct contact with people affected by leprosy or by sharing utensils, dishes and meals with or from a person affected by leprosy
Punishment for immoral behaviour or not following community norms (e.g. forbidden sex, bad conduct to parents)	Blood deviant	Pollution

Emotional hygiene (good heart)	Weakening of immunology	Contact with animals
Curse	Similar blood type	Infected from daily activities (e.g. working in factory)
Black magic or heresy	Genetic problem	
Karma	Under-nutrition	
Chance from God to help others	Food consumption (e.g. certain items like shrimps)	
Conviction that you will be infected		

Strategies: Participants in this study suggested education and raising awareness as possible ways to improve community awareness. They emphasised that mass education alone would not be sufficient, and a more direct and contextualised approach would be needed.

> *"It* [government] *only tries to cure the affected people, but it does not make any publication* [education] *for the whole community, saying that the disease is not dangerous, that people do not need to avoid the affected"* (Male, FGD with people affected by leprosy).
>
> *"I think that we need real information about leprosy, not only from TV or other media. If we know about it directly from the counselling* [normally by a health provider] *we will know a lot of things about it"* (Female, FGD with teachers).

Strategies for the Implementation of an SED Intervention:

An SED intervention is more likely to be successful if staff from the implementing organisation acknowledge the lack of knowledge about leprosy and negative attitudes that prevail in society. Staff of an SED intervention or affiliated partner could:

- Train the clients affected by leprosy in coping strategies (e.g., explain to a person who is sharing incorrect information that leprosy is not very infectious, and is no longer infectious once treatment has started).
- Provide medical information about leprosy and address worries of group members who know that one of their group is, or has been, affected by leprosy.

Barriers related to Emotional and Physical Consequences of Leprosy - and suggested Strategies

Barriers: Leprosy has an emotional and physical impact on the affected person. Fear, shyness, shame and shock were the emotional consequences mentioned in the interviews, while loss of sensation, hurt, bleeding and weakness were some of the physical consequences. Both were the cause of stigma. One respondent referred to leprosy as a "secret" disease and explained that this is because "it may cause shame". Table 3 shows the emotional and physical consequences of leprosy that triggered all types of stigma - internalised stigma, experienced and anticipated stigma - in affected people, and negative attitudes and enacted stigma in leprosy officers.

Table 3: Perceptions of Emotional and Physical consequences of Leprosy

Emotional consequences of Leprosy	Physical consequences of Leprosy
Shy	Wrong diagnosis
Shame	Losing sensitivity
Depression/anxiety	Hurt/pain
Shock	Swollen
Low self-confidence	Wound
Hopelessness	Bleeding
Fear of dying	Smelly
Helplessness	Body weakening
Sadness	Dark skin
Anger	White/pink spotted
Loneliness	Stiff skin
Fear of impairment	Itchy skin
Fear of infecting others	Impairment
Worry about partner leaving	Under- nutrition
Worry about not finding a partner	
Feeling unclean	
Feeling disgusting	
Feeling ugly	
Insecure	
Tired	

Strategies: Community leaders mentioned that stigma could be reduced through empowerment, but it depends on the mindset and commitment of people affected.

> *"A strong motivation and commitment from the leprosy affected and the community is needed to reduce stigma and discrimination"* (Male, FGD with community and religious leaders).
>
> *"People affected are expected to change their mindset so that they can empower themselves and even help others"* (Male, FGD with community and religious leaders).

Strategies for the implementation of an SED intervention:

An SED intervention increases the likelihood of success if staff from an organisation that implements it or an affiliated partner could give a brief counselling to increase knowledge, create a positive self-image, discuss coping strategies and increase self-esteem. This requires careful selection of staff and dedicated training in counselling.

Feasibility of realising an SED intervention by Local Organisations

As stated earlier, there were serious doubts whether a local financial or social organisation would be willing to accept leprosy clients as a target group for microcredit. This client group would be considered a high risk for the bank. By analysing the problems that clients face and finding ways to mitigate these problems, the risk might be considerably reduced. The results above show the expected problems and strategies to deal with them. These concrete strategies for a microcredit programme were discussed with organisations in Cirebon District and were found acceptable. A variety of organisations were interested in an SED intervention. For example, one was a microcredit bank that was interested in including people affected by leprosy in their standard services (mainstreaming). Another was a DPO that was ready to learn how to develop a tailor-made socio-economic intervention. Both organisations were willing to deal with the barriers identified in this study. They were willing to offer training to staff and clients.

DISCUSSION

This study revealed the varied and serious socio-economic consequences of leprosy in Cirebon District. Many people affected by leprosy are coping with poverty. Some became poor after the diagnosis, while those who were already poor sank further into poverty. The often devastating impact of leprosy on the socio-economic life of affected persons has also been found in Nepal and India

(Calcraft, 2006; Rao et al, 2008; Stevelink et al, 2011). Calcraft (2006) wrote that “the loss of income is a very serious matter” in a developing world context, especially because of the lack of formal and informal safety nets.

This study also found broad support in Cirebon District to improve the socio-economic position of people affected by leprosy. Although the barriers described in this study are local, in relation to the health system, society and the consequences of leprosy, many of them are found in other countries also (Nicholls et al, 2003; Heijnders, 2004b; Barkataki et al, 2006; Varkevisser et al, 2009). Poverty was generally seen as an inhibitor for realising good health and quality of life, as also for creating opportunities for economic development. Specifically, the idea of facilitating entrepreneurship was supported broadly. There were, however, doubts regarding the difficult life conditions of people affected by leprosy that could prevent most of them from becoming successful entrepreneurs. By analysing these life conditions in detail and discussing the results with key persons in the community, strategies were suggested to strengthen a purely financial intervention by adding a variety of training programmes.

Ideas relating to this strengthened SED intervention were discussed with key persons from different local organisations and were positively received. It also became clear that different strategic options were available. Existing financial organisations could specifically target people affected by leprosy, and add training and support programmes to their current services. Existing social organisations could add a financial component to their services. An implementing organisation could either provide all the necessary interventions themselves or they could link up with other organisations (such as governmental offices, DPOs, NGOs, faith-based organisations) or people (e.g., individual entrepreneurs).

Literature in the field of disability describes these variations. The study of Fiasse (2011) on microcredit schemes for people with physical disabilities in Afghanistan suggests adding awareness programmes to a microcredit programme in the community, in order to change attitudes and promote sustainability. The study of Nuwagaba et al (2012) on accessibility of microfinance by people with disabilities in Uganda suggests that both the providers of microfinance and the beneficiaries need to attain the right knowledge, skills and attitudes. Studies on leprosy have also highlighted the possibilities of networking with and referring to local organisations and collaborations with the government and general public (Withington et al, 2003; Ebenso et al, 2007).

On the basis of this analysis, it was concluded that conditions were favourable to implement an SED intervention. Yet it is important to remember that achieving socio-economic empowerment is not simple: it takes time, effort and commitment on the part of the people affected and the community. Opala and Boillot, in their 1996 study on leprosy in Sierra Leone, noted that "behaviour can change incrementally as new practices are given old interpretations, but because world view is a logically consistent whole, it is not nearly so amenable to piecemeal change". Furthermore, Dalal (2006) in his study in India mentioned that it is difficult to realise attitude change. However, it was promising that the programmes in this study described role reversals and discussions about abilities, instead of disabilities. It was clear that many strategies to deal with the problems can only be realised in the long term with inputs from the health sector. The knowledge and expertise in this sector is continuously improving and cannot easily be generated in other sectors. Increased networking between sectors is very important and is an effective way of dealing with complex social problems in which monodisciplinary approaches are no longer sufficient. In addition, a socio-economic intervention needs to be supported by other interventions to make a better impact (Cross et al, 2011; Tsai et al, 2013). It should be reinforced with approaches such as counselling, contact and advocacy.

Limitations

The limitation of this paper is that it is based on data from an exploratory study that addresses a broad range of barriers in relation to leprosy-related stigma. Each of these barriers would benefit from a more in-depth analysis of causes and dynamics which, it is to be hoped, will be done in the future. Also, the findings presented in this paper are specific to the study area and might not apply to other areas in Indonesia or elsewhere.

CONCLUSION and IMPLICATIONS

In the development of new interventions – for dealing with stigma or poverty as well–the barriers for implementation need to be taken into consideration. More importantly, strategies to deal with the barriers that were identified need to be developed. For introducing an SED intervention, there needs to be cooperation between actors in the health system and those in the social welfare and financial systems. This route for improving the quality of life and reducing stigma of people affected by leprosy has potential and appears to hold promise.

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The authors declare that they have no competing interests.

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