CHAPTER 3

EXPLORING THE COMPLEXITIES OF LEPROSY-RELATED STIGMA AND THE POTENTIAL OF A SOCIO-ECONOMIC INTERVENTION IN A PUBLIC HEALTH CONTEXT IN INDONESIA

ABSTRACT

Aim: This chapter explores the complexities of leprosy-related stigma and the potential effectiveness of a socio-economic intervention in Cirebon District, Indonesia. Methods: We adopted a qualitative approach by interviewing 53 people affected by leprosy, and conducting 17 focus group discussions among people affected by leprosy, community and religious leaders, and health providers and other key persons who were all purposively selected. Results: The study shows that people affected by leprosy face major socio-economic consequences because of their disease and that improving their socio-economic situation is a key concern. Key persons confirmed this and saw several opportunities of how a socio-economic intervention could look like, but there were also worries. People affected by leprosy are still constrained by aspects of the health system (e.g. the health providers’ negative attitudes), views in society (e.g. misunderstandings about the condition, stigma) and due
to the physical and social consequences of the disease (impairments, feelings of shame). Participants of this study identified strategies to deal with these barriers and also attempted to identify specific activities for a socio economic intervention; especially trainings of staff responsible for the implementation is key. **Conclusion and implications:** Socio-economic interventions in the field of leprosy need to anticipate the barriers and develop strategies to deal with them. A cooperation between actors in the health system and those of the welfare/financial system are needed. This route for improving the quality of life of people affected by leprosy looks possible and very promising.

**Keywords:** health system, socio-economic status, knowledge, beliefs, qualitative study, Cirebon

### 3.1. INTRODUCTION

Although the prevalence and incidence of leprosy has declined in the last 20 years, the South-East Asian Region is still the biggest contributor to the number of new cases reported (WHO, 2015). Indonesia officially eliminated leprosy in 2000, reaching a prevalence level of <1/10,000 population (MOH Indonesia, 2007). However, the WHO reported that Indonesia still occupies a 3rd place in terms of the leprosy burden, with an average of 17,000 new cases per year, among whom about 9% have grade 2 impairment at the time of diagnosis (WHO, 2015). Although some provinces have reported decrease in new cases detected, Figure 3.1. shows that Indonesia still detects a more or less constant number of new cases every year, indicating that the country faces major challenges in reducing the incidence of leprosy.
Figure 3.1. 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 (Barrett, 2005; Brown, 2006; Heijnders, 2004a; Nicholls, Wiens, & Smith, 2003; van de Weg, Post, Lucassen, De Jong, & Van Den Broek, 1988). The frequent poor attitudes of health professionals identified in several countries contribute to this situation (Awofeso, 1992; Briden & Maguire, 2003; Iyor, 2005; Nicholls et al., 2003). 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 thus ones quality of life (Calcraft, 2006; Rao, Raju, Barkataki, Nanda, & Kumar, 2008; Rao, 2010; Schuller & van Brakel, 2010; Tsutsumi et al., 2007).

Various interventions have been implemented to address leprosy-related stigma. Most of them attempt to deal with its causes, such as a lack of knowledge or awareness (Brouwers, Brakel, & Cornelije, 2011; Nsagha et al., 2011), negative attitudes of the community (Brown, 2006), and negative attitudes and behaviour in the health system (Arole, Premkumar, Arole, Maury, & Saunderson, 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, wellbeing, and enhanced participation in socio-economic life and consequently reduced stigma. Socio-economic interventions (specifically, micro-credits, 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 in leprosy (Ebenso et al., 2007; Velema, Ebenso, & Fuzikawa, 2008), and also evidence from the field of HIV/AIDS and disability (Tsai, Bangsberg, & Weiser, 2013; Verma, 2009; Wagner, Rana, Linnemayr, Balya, & Buzaalirwa, 2012), we hypothesize that a socio economic intervention can improve the quality of life of people and reduce stigma. A person affected by leprosy who receives a micro-credit may feel acknowledged and appreciated as a human being with capabilities. He or she may feel proud to be eligible and trusted with a micro-credit. As Velema et al. (2008) write “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 will require the development of new skills and the involvement in new activities. The activities will require interpersonal contact with family members, neighbours and community members. This contact may break previously held assumptions that lead to stigma, and it in turn may also change the attitudes of family, neighbours, community members, and perhaps even health professionals. An improved financial independence is likely to improve one’s status and further enhance social interaction. This hypothesis is in line with the arguments brought across by Tsai et al. who developed a strong case for considering livelihood interventions as a compelling stigma-reduction strategy for HIV-infected persons (Tsai et al., 2013). But every new approach aiming to reduce stigma is at risk of failure because of the many barriers that may occur during the implementation of the intervention. Also, a socio-economic intervention might fail due to the many problems that persons affected by leprosy encounter due to stigma, their health problems, and weaknesses of the health care system and so on.
3.1.1. Aim

To explore and analyse the barriers that exist and how they can be dealt with in the process of the implementation of an SED.

3.2. METHODS

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.

An explorative study design was used aiming to represent three perspectives – of persons affected by leprosy, health care providers and key persons in the community. We interviewed 53 persons affected by leprosy sometimes together with a caregiver or family member. Also 17 FGDs 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 were conducted.

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

Interview guidelines were developed for in-depth interviews and FGDs. For people affected 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 field of leprosy and possible solutions. For community and religious leaders, the questions addressed their perceptions of leprosy (according to their religion) and the perception 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 the how an SED intervention could look like, anticipated problems for implementing a micro-credit program and strategies to deal with them. Also organisations and people that could fulfil a role in an SED intervention were identified.

The study applied content and thematic analysis, first grouping all participants into three groups of health care providers, key persons in the community and people affected by leprosy, and then conducting a contextual text segmentation to identify similar concepts using open-ended codes. 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.

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

### 3.3. RESULTS

This section starts with an analysis of the socio-economic consequences of leprosy. Then 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 realizing an SED intervention by local organizations is given.

3.3.1. 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 eldest 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 aged between 40 and 60 years, while health care providers were aged between 25 and 54 years, with experience ranging from one to 20 years.

3.3.2. Socio-economic consequences of leprosy

The interviews and FGDS show that the social impact of leprosy directly hampers the participation of affected people in their community and family. The study revealed that some informants lost their jobs due to leprosy. For example, one informant resigned because of fear colleagues would find out about the leprosy. Several other informants - who have small shops or food stalls - reported that it is difficult to sell products, once neighbours know about their leprosy status. Some informants found a location far away from their own village to sell their products where nobody knows about their condition. Negative economic consequences resulted from reduced earnings of those affected and increased out-of-pocket expenses for treatment and care. This situation pushed some families into poverty. Some end up begging, stealing or becoming 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.” (FGD with affected people, female)

“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.” (FGD with leprosy officers, male)
Table 3.1. shows an overview of the social and economic consequences of leprosy for people affected by it.

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

People affected by leprosy mentioned that it is very important to improve their economic status by being employed or self-employed, and 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.” (In-depth interview with a person affected by leprosy, male)

Interestingly, some people affected by leprosy and 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.” (Interview with person affected by leprosy, female)

“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-socialization.” (FGD with community and religious leaders, male)

“With financial aid of some sort, it could give them the passion to live their life again.” (FGD with community and religious leaders, male)

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 a 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 before and already possessed certain qualities and skills needed to run a business. One participant of an FGD explains:

“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 is 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.” (FGD Community and religious leaders, male)
However, there were also worries. During an 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. Starting and running a profitable business is, according to the participants, 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 of such a business seemed to them a very high risk that no bank was willing to take.

In summary, 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 these people. They even believe that an improved socio-economic status would improve their self-esteem and reduce stigma. Key persons confirmed this and saw several opportunities of how a socio-economic intervention could look like, but there were also worries. Specifying the problems clients face in the different realms of their lives and developing strategies that could be implemented by financial institutions or others is thus important. In the next section we will address those problems in the health system and society that are related to the individual affected.

3.3.3. Barriers in the health system and suggested ways forward

**BARRIERS**

Treatment of leprosy is available at primary health services such as sub-district HC 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.” (FGD with leprosy officers, male)
“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 also 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 they were initially diagnosed with diabetes or arthritis. This means that the start of treatment is delayed, increasing the risk of disability and prolonging the risk of infection in the community. Also several people affected by leprosy said they did not receive information about the cause, ways of transmission and contagiousness of leprosy from the leprosy officer. Also in a few cases people affected by leprosy had to pay for the seemingly free leprosy services. Observations in the study area showed 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 the patients which helps them to receive treatment and care in these hospitals. The district hospital, however, was sometimes fully occupied and the person affected by leprosy had to be referred elsewhere. The quality of the case management in hospitals in general is often limited due to the lack of knowledge about leprosy and leprosy reactions, health workers’ attitudes, and lack coordination with the referring HC where the person affected by leprosy used to obtain treatment.

**STRATEGIES**

The health system needs to be strengthened on different levels. Leprosy workers proposed to improve the coordination between programmes, enhance leadership, increase the attention for leprosy, advocate for more money for the leprosy programme (for example so that community socialization can be organized more frequently and leprosy officers can attend leprosy trainings routinely), provide knowledge about leprosy to all health staff during a training and increase feelings of shared responsibility among health staff.
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STRATEGIES FOR THE IMPLEMENTATION OF AN SED INTERVENTION

An SED intervention is more likely to be successful if staff of an organisation that aims to implement such an intervention acknowledges the failures in the health system and the many problems people affected by leprosy have experienced in relation to getting a diagnosis and treatment. This information could be used for the design of a training 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.
- Provide correct and complete medical information (cause, ways of transmission, becoming cured) to clients affected by leprosy if they have not yet received this from a health professional.
- Be aware and supportive if clients affected by leprosy need to re-visit the health clinic for check-ups, new treatment or when they experience leprosy reactions or any other complication.

3.3.4. Barriers related to knowledge, beliefs and attitudes in society and ways forward

BARRIERS

Many participants in the study lacked a clear understanding of leprosy. In general there was a lack of knowledge about its causes, symptoms and treatment. Some community members wondered whether leprosy still existed when they heard the researcher first mention the word. Most community members perceived leprosy as a disease that causes bodily impairments and deformities, but some perceive 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.” (FGD with community, male)

Various perspectives on the causes of the leprosy were mentioned in 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 3.2. Most believed that leprosy is an infectious disease that is difficult to cure. Some did not know that it can be treated.

<table>
<thead>
<tr>
<th>Spiritual</th>
<th>Biological</th>
<th>Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Challenge/test from God</td>
<td>Bacteria</td>
<td>Poor hygiene (e.g. contact with dirty objects, poor sanitation)</td>
</tr>
<tr>
<td>Destiny (it has been written)</td>
<td>Heredity</td>
<td>Direct contact with people affected by leprosy or by sharing utensils, dishes and meals with or from a person affected by leprosy</td>
</tr>
<tr>
<td>Punishment for immoral behaviour or not following community norms (e.g. forbidden sex, bad conduct to parents)</td>
<td>Blood deviant</td>
<td>Pollution</td>
</tr>
<tr>
<td>Emotional hygiene (good heart)</td>
<td>Weakening of immunology</td>
<td>Contact with animals</td>
</tr>
<tr>
<td>Curse</td>
<td>Similar blood type</td>
<td>Infected from daily activities (e.g. working in factory)</td>
</tr>
<tr>
<td>Black magic or heresy</td>
<td>Genetic problem</td>
<td></td>
</tr>
<tr>
<td>Karma</td>
<td>Under nutrition</td>
<td></td>
</tr>
<tr>
<td>Chance from God to help others</td>
<td>Food consumption (e.g. certain items like shrimps)</td>
<td></td>
</tr>
<tr>
<td>Conviction that you will be infected</td>
<td></td>
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</tbody>
</table>

**STRATEGIES**

Participants of this study suggested education and raising awareness as possible ways to improve community awareness. They underlined that mass education alone will not be sufficient and that a more direct and contextualized 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.*” (FGD with people affected by leprosy, male)
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“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.” (FGD with teachers, female)

**STRATEGIES FOR THE IMPLEMENTATION OF AN SED INTERVENTION**

An SED intervention is more likely to be successful if staff from an organisation that implements an SED intervention acknowledges the lack of knowledge about leprosy and negatives 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 about the infectiousness of leprosy to others that leprosy is not very infectious to and that it is no longer infectious after treatment has started)
- Provide medical information about leprosy and address worries of group members who are aware that one of their group members is or has been affected by leprosy.

### 3.3.5. Barriers related to emotional and physical consequences of leprosy and the way forward

**BARRIERS**

Leprosy has an emotional and physical impact on the person affected. Fear, shyness, shame and shock were emotional consequences mentioned in the interviews, while losing sensation, hurt, bleeding and weakness were some of the physical consequences. Both were able to cause stigma. One respondent referred to leprosy as a “secret” disease and explained that this is because “it may cause shame”. Table 3.3. shows the emotional and physical consequences of leprosy that triggered all types of stigma; internalised stigma, experienced and anticipated stigma in people affected, and negative attitudes and enacted stigma in leprosy officers.
### Table 3.3. Perceptions of emotional and physical consequences of leprosy

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

Community leaders mentioned that stigma can be reduced through empowerment, but this depends on the mind-set and commitment of people affected.

“A strong motivation and commitment from the leprosy affected and the community is needed to reduce stigma and discrimination.” (FGD with community and religious leaders, male)
“People affected are expected to change their mind-set so that they can empower themselves and even help others.” (FGD with community and religious leaders, male)

**STRATEGIES FOR THE IMPLEMENTATION OF AN SED INTERVENTION**

An SED intervention increases the likelihood of success if staff from an organisation that implements an intervention 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 a dedicated counselling training.

### 3.3.6. Feasibility of realising an SED intervention by local organisations

As stated above, there were serious doubts whether a local financial or social organisation would be willing to accept leprosy clients as a target group for micro-credits. This client group would be considered a high risk for the bank. By analysing the problems the clients face and finding ways to mitigate these problems this 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 found acceptable. A variety of organisations were interested in an SED intervention. For example, one was a microcredit bank who was interested in including people affected by leprosy in their standard services (mainstreaming). Another was a DPO who was ready to learn how to develop a tailored made socio economic intervention. Both organisations were willing to deal with the barriers identified in this study. They were willing to offer trainings for staff and clients.

### 3.4. DISCUSSION

This study showed the variety and seriousness of the socio-economic consequences of leprosy in Cirebon District. Many people affected by leprosy in this study are dealing with poverty. Some moved into poverty, while others who were poor before
being diagnosed were driven further into poverty. The sometimes devastating impact leprosy has on the socio-economic life has been found for instance in Nepal and India (Calcraf, 2006; Rao et al., 2008; Stevelink, Van Brakel, & Augustine, 2011). Calcraf wrote that “the loss of income is a very serious matter” in developing world context, especially because of the lack of formal and informal safety nets (Calcraf, 2006).

This study also showed that there is a broad support in Cirebon District to improve the socio-economic position of people affected by leprosy. Although the barriers in relation to the health system, society and the consequences of leprosy described in this study are local, many of them are found in other countries also (Barkataki, Kumar, & Rao, 2006; Heijnders, 2004b; Nicholls et al., 2003; Varkevisser et al., 2009). The poverty of the people was generally seen as an inhibitor for both realising good health and quality of life and for creating opportunities for economic development. Specifically, the idea of facilitating entrepreneurship was supported broadly. However, doubts were raised that the difficult life conditions of people affected by leprosy would 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 related to this strengthened SED intervention were discussed with key persons from different local organisations and these were positively received. It became clear also 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. Also an implementing organisation could 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).

In the field of disability, these variations are described in the literature. The study of Fiasse on micro-credit schemes for people with physical disabilities in Afghanistan suggests adding awareness programmes to a micro-credit programme in the
community to change attitudes and promote sustainability (Fiasse, 2011). Also the study of Nuwagaba et al. on accessibility of microfinance by people with disabilities in Uganda describes that both the providers of microfinance and the beneficiaries need to attain the right knowledge, skills and attitudes (Nuwagaba et al., 2012). Also in the field of leprosy, studies have highlighted the possibilities of networking with and referring to local organisations and collaborations with the government and general public (Ebenso et al., 2007; Withington, Joha, Baird, Brink, & Brink, 2003).

On the basis of these analyses it was concluded that sufficient conditions for success were in place to start with the implementation of an SED intervention. But it remains important to realise that achieving socio-economic empowerment is not simple: it takes time, effort and commitment on the part of people affected and the community. Opala and Boillot, in their study on leprosy in Sierra Leone, note 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” (Opala & Boillot, 1996). Furthermore, Dalal mentioned in his study in India that it is difficult to realise attitude change (Dalal, 2006). However, the fact that the programmes in this study described role reversals and discussions about abilities, instead of disabilities, are promising. 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 improved 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 have a better impact (Cross, Heijnders, Dalal, Sermrittirong, & Mak, 2011; Tsai et al., 2013). It should be reinforced with approaches such as counselling, contact and advocacy.

The limitation of this chapter 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 we hope will be done in the future. Also, we like to stress that the findings presented in this chapter are specific for the study area and might not apply to other areas in Indonesia or elsewhere.
3.5. CONCLUSION AND IMPLICATIONS

New interventions – also for dealing with stigma or poverty – need to take into account in their development the barriers for implementation. More importantly, strategies to deal with the barriers identified need to be developed. For introducing an SED intervention, cooperation between actors in the health system and those of the social welfare and financial system needs to be explored and organised. This route for improving the quality of life and reducing stigma of people affected by leprosy looks possible and very promising.
REFERENCES


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PART II

VALIDITY OF SCALES TO MEASURE STIGMA