CHAPTER 6
DEALING WITH THE COMPLEXITY
AND ASSESSING THE IMPACT OF A
SOCIO-ECONOMIC INTERVENTION ON
REDUCING LEPROSY-RELATED STIGMA
IN CIREBON DISTRICT, INDONESIA

ABSTRACT

Background: The consequences of leprosy go beyond the physical, social and psychological, as leprosy can drive persons affected and their families into poverty or deepen their poverty. Can a socio-economic intervention improve the socio-economic status and reduce stigma? This chapter describes the impact of an intervention that uses a twin-track approach (two micro-credit models) to reduce leprosy-related stigma in Cirebon District, Indonesia. Methodology/Principal Findings: This study is part of a larger study i.e. the Stigma Assessment and Reduction of Impact (SARI) project. A randomized-controlled mixed-methods intervention study design was used to test the effectiveness of three interventions. In this chapter we focus on the clients affected by leprosy that were involved in the socio-economic development (SED) intervention. In the quantitative part of this study three scales were used. Data from 30 SED clients and 57 controls were analysed. In the qualitative part of this study 20 in-depth
interviews with SED clients and 7 focus group discussions with key persons were held and 65 profiles of the clients were written and analysed. The qualitative data shows that the socio-economic status of 44 out of 65 SED clients (67%) improved. The clients also reported a higher self-esteem, improved interaction with neighbours and less stigma than before, however disclosure concerns remained an issue. Quantitative data shows that the median family income increased by 25%. Also the three scales indicate a positive effect of the intervention on stigma reduction (e.g. SARI stigma scale mean difference total score between the pre and post assessment for SED clients versus the control group was 8.5 versus 5.6).

Conclusions/Significance: A socio-economic intervention seems a promising effort to reduce leprosy-related-stigma. The potentials for sustainability and the high interest of the target group are especially favourable. Future socio-economic interventions can built upon the findings of this study.

6.1. INTRODUCTION

Leprosy is a communicable disease and as many other NTDs it has various adverse effects on the person affected. The disease can have physical, social and psychological impacts to people who experience it. These adverse effects are interconnected. A physical impact such as a deformity of hands and/or feet can cause or increase stigma towards people affected and their family, reducing someone’s self-esteem, which results in negative feelings and emotions (Heijnders, 2004; Tsutsumi et al., 2007; Van Brakel et al., 2012). However, the consequences go beyond the physical, social and psychological, as leprosy can drive persons affected and their family members into poverty or, if they are already poor, deepen their poverty.

The relationship between leprosy, stigma and poverty has been explored by various scholars (Ebenso et al., 2007; Tsutsumi et al., 2007; Velema, 2008). Leprosy can lead to stigma and this stigmatization lies at the basis of two distinct dynamics, both of which have negative consequences. First, stigmatization is usually followed by rejection, exclusion and discrimination from society, but sometimes also from family members and loved ones (Chapter 2; Heijnders, 2004; Nicholls, Wiens, & Smith, 2003; Peters et al., 2014). Secondly, people affected by leprosy sometimes
initiate the isolation themselves because of a fear of infecting others or because internalized feelings of being less worthy are paramount (Chapter 2, Heijnders, 2004; Nicholls et al., 2003; Peters et al., 2014). As a result of these dynamics, people affected by leprosy might be fired, lose their customers or may decide to resign or close their business. This has a negative influence on the financial situation of the household (Calcraft, 2006). In a way there is a double burden: poverty and leprosy both produce stigma.

Not surprisingly, people affected by leprosy see benefits in a socio-economic intervention (see Chapter 3). In one of our previous studies a participant affected by leprosy made a direct link between running a business and less mockery (a manifestation of stigma). She said “There are many things I need. Groceries I need, money I need… to avoid mockery, we have to run a business” (Chapter 3.3.2). A key person in the same study provides a different reason why a business is important; he said that financial aid of some sort “could give them [people affected by leprosy] the passion to live their life again”. Similarly, Velema et al, mention that clients of a socio-economic intervention can have an enormous boost in self-esteem (Velema, Ebenso, & Fuzikawa, 2008). They also notice that activities such as selling products at a marketplace changes dynamics among people in their community and as a result these community members might perceive people affected by leprosy more positively (Velema et al., 2008). Recent studies show similar effects. Abera & Shanko (2000) found in their study in Ethiopia on leprosy that 86% of the participants who received a small loan reported a considerable improvement in attitudes of community members and family members. Likewise, Ebenso et al. (2007) concluded, based on their study in Nigeria, that socio-economic rehabilitation can lead to more social interaction and change community attitudes.

This is all very promising, but there are at the same time important challenges for creating a sustainable socio-economic intervention for people affected by leprosy (Briden & Maguire, 2003; Croft & Croft, 1999; Nicholls et al., 2003; Pati, Lyngdoh, 2010). Challenges include certain characteristics of people affected by leprosy (e.g. low self-esteem, ashamed, internalized stigma), a lack of knowledge about leprosy of different actors, and negative views in society that may affect the business. As a result, there are serious doubts whether a local financial or social organisation would be willing to accept leprosy clients as a target group for micro-credits.
The rationale is that setting up a business with a micro-credit is difficult enough without the additional barriers of being affected by leprosy; giving loans to people affected by leprosy is considered too much of a risk. (Indeed, often socio-economic programmes for people affected by leprosy revolve around providing grants instead of loans (e.g. (Jayadevan & Balakrishnan, 2002; Velema, 2008; Withington, Joha, Baird, Brink, & Brink, 2003), making socio-economic rehabilitation expensive and non-sustainable.) At the same time, in order for a socio-economic development intervention to be sustainable beyond the project duration, working together with established local actors/parties and using an integrated approach are seen as a key prerequisite (Devadas, n.d.; Ebenso, Idah, Anyor, & Opakunmi, 2010). This thus poses a challenge to the current project. Sustainability should be a ‘built in’ criterion of the intervention design. Some concrete suggestions on how to deal with these challenges are also provided in the literature. Even more than in regular micro-credit programmes, for programmes targeted at people affected by leprosy Abera & Shanko (2000) highlight the importance of investing in a good relationship between the client and the credit provider (e.g. regular follow up visits, give advice) when a micro-credit is given. In addition, Ebenso et al. (2007) describe the importance of involving key persons in the community, connecting to the local government bodies, and including people with general disability. It is thus not straightforward to develop a sustainable socio-economic intervention that is successful in dealing with the above challenges and that contributes to income generation and stigma reduction. A combination of an exploratory study, baseline study, implementation phase and final survey was carried out to meet this challenge.

The aim of this study is to assess how effective a SED intervention is in improving the socioeconomic status, reducing leprosy-related stigma, and in facilitating a social transformation in people affected by leprosy in Cirebon District, Indonesia. Secondary aim is to explicate the factors that have contributed to the observed changes, giving insight into how the intervention accommodates the challenges of developing a SED intervention that is sustainable beyond the project duration. Three research questions were formulated. What is the impact of the SED intervention on the socio-economic status of the clients (family income, business condition) and how is this achieved? What is the impact of the SED intervention on stigma (different types) its effects (participation restrictions and quality of life), and how is this achieved? What is the impact of the SED intervention on a transformation in the lives of the clients and how is this achieved?
6.2. THEORETICAL FRAMEWORK: STIGMA AND SOCIO-ECONOMIC TRANSFORMATION

To distinguish between different types of stigma, Weiss extended the hidden distress model of Scambler (Weiss, 2008). He categorized stigma into two groups: stigmatized and stigmatizers with different types of stigma in each perspective. In the stigmatizers, Weiss distinguished between enacted, endorsed and accepted stigma. While in the stigmatized, internalized stigma, perceived stigma, and experienced stigma were found (Weiss, 2008). These latter types are important in this chapter. Perceived stigma refers to a person with a stigmatized condition who behaves or feels a certain way due to anticipated responses from others. Internalized or self-stigma is the stigma people apply to themselves due to negative views about the self which could lead to feelings of shame and guilt. Finally, enacted stigma is often called discrimination. Recognizing all these types of stigma could help in the development of appropriate programs for stigma reduction.

A model developed by Pati and Lyngdoh shows how a microfinance intervention can lead to economic transformation and social transformation (Pati, Lyngdoh, 2010). Economic transformation, in this model, described, among others benefits, as having an access to income and savings, economic decision-making and household property. A positive economic transformation can result in increased well-being and this is then the start of a so-called ‘social transformation’. Indicators of a social transformation are, among others, changes in satisfaction (e.g. vision in life, planning the future), capacity (e.g. networking, socialization, life skills), decision making, health, travel and mobility, recognition and acceptance (Pati, Lyngdoh, 2010).

Figure 6.1. Socio-Economic Transformation Model (Pati, Lyngdoh, 2010)
6.3. METHODS

6.3.1. Study design

This study is part of the SARI project. The aim of the SARI project is to assess the effectiveness of three different stigma reduction interventions. For ethical reasons these interventions were implemented in pairs. In this chapter we focus on the socio-economic development intervention. For this project a cluster-randomized controlled intervention study design was selected. A mixed methods approach was applied to measure the impact of the intervention on economic aspects and social aspects such as stigma, participation and quality of life. A baseline survey was conducted at the end of the year 2011 and a final survey was conducted at the beginning of 2014. This allows us to assess an impact up to two years after the start of the intervention, which is a relatively long-term impact. The research team consists of senior researchers, PhD students and local research assistants.

6.3.2. Study area

This study was conducted in Cirebon District, West Java, Indonesia. Cirebon District has a population of 2,6 million people. It is known as an area with a high leprosy burden as there are around 250-300 new cases per year, ranking third in terms of new leprosy cases detected in West Java. Cirebon District has 57 PUSKESMAS (Community Health Centres) in 40 sub districts. Leprosy treatment has been integrated in the primary health care and is provided cost free in the Community Health Centres. The provincial annual report of 2012 showed that there were 308 new leprosy cases detected, of which 9% were children cases and 16% has grade 2 impairments (which means visible impairments on hands/feet/eyes) in District Cirebon (Provincial Health Office, 2013). The District Health Office of Cirebon reported that in 2012, 33 of 57 Community Health Centres had a leprosy prevalence of more than 1/10.000 population in their area (Cirebon, 2012).

6.3.3. Study population

The main study population comprises of persons affected by leprosy who participated in the SED intervention, those who participated in other stigma-reduction interventions (counselling and contact, for more information see (Peters
et al., 2015) and a control group that was not involved in an intervention. Also key informants such as family members of SED clients, health professionals and micro-credit providers were part of the study population.

6.3.4. Research methods and sampling

Assessing a complex concept such as stigma is challenging and the quality of the evaluation depends, among others aspects, on the availability of a good set of qualitative and quantitative methods (Cross, Heijnders, Dalal, Sermittirong, & Mak, 2011; Nyblade, 2006; Van Brakel, 2003). Six quantitative and qualitative methods were used to assess the impact of the SED intervention. Each method assesses the socio economic status and/or stigma and its impact and together we expect them to provide a comprehensive picture of the impact of the intervention. Different sample techniques were used for the different research methods.

**QUANTITATIVE METHODS**

First, the demographic information of people affected by leprosy was collected. Variables included sex, age, education, marital status and disability grade. To assess socio-economic status, the work status and income details were collected. Data on the repayment of the loan that people affected by leprosy received in this study were obtained through the annual reports of the implementing organisations. Socio-economic development interventions are expected to not only improve socio-economic status of participants but, through economic transformation, also to increase well-being. In order to study well-being we applied scales to measure changes in stigma, participation restrictions and quality of life.

- **SARI Stigma Scale (SSS)** is based on the Berger Scale (Berger, Ferrans, & Lashley, 2001) which was developed for HIV AIDS related-stigma measurements. The SSS has adequate cultural validity to measure leprosy-related stigma among affected people who speak Bahasa Indonesian in Cirebon District, Indonesia (Chapter 3). The SSS has four domains: Experienced stigma (7 items), Internalized stigma (6 items), Disclosure concerns (4 items) and Anticipated stigma (4 items). The SSS asks if a certain situation/experience/feeling occurs (e.g. feel unclean, feel guilty, regret having told anyone) and if so how frequent (scoring 0 = no, 1 = rarely/hardly, 2 = sometimes, 3 = always/often).
• The Participation Scale Short (PSS) is the shorter version of the Participation Scale which measures restriction in social participation and was developed in India (Stevelink, Terwee, Banstola, & Van Brakel, 2013; Van Brakel et al., 2006). It has been validated in several countries (Ebenso & Velema, 2009; Rensen, Bandyopadhyay, Gopal, & van Brakel, 2010; Stevelink, Van Brakel, & Augustine, 2011) and has been used in Indonesia before (Van Brakel et al., 2012). The PSS asks whether the interviewee takes part in, for example, family discussions, household work, casual recreational activities, as peers do. The scale has 13 items and a scoring from 0 to 3.

• WHO Quality of Life BREF (WHOQOL-BREF) was developed by the WHO and consists of 26 items which are grouped in 4 domains; Physical health, Psychological health, Relationships and Environment. This scale has been validated, and is widely used, in many countries including Indonesia (Salim, Sudharma, Kusumaratna, & Hidayat, 2007; Skevington, Lofth, & O’Connell, 2004; Trompenaars, Masthoff, Van Heck, Hodiamont, & De Vries, 2005).

The SARI project established a cohort to assess the impact of stigma-reduction interventions and a small sample of this cohort (the SED clients) will be analysed in this chapter. The SARI project estimated that to achieve adequate power for the quantitative assessment, it required a sample size of 600 people affected by leprosy. To reach this number, we invited at least 10 affected people per Community Health Centre for an interview. Data of people affected by leprosy was provided by the District Health Office Interviews that were done in a language different than Bahasa Indonesia were excluded. All people affected by leprosy (including those that spoke a language different than Bahasa Indonesia, but excluding those that lived in a control area) were offered participation in the interventions of the SARI project. During the final survey the scales were repeated.

**QUALITATIVE METHODS**

Three different qualitative methods were used.

• IDI were conducted with SED clients. The interviews explored the changes SED clients experienced in their (i) financial situation, (ii) social situation, (iii) household situation (iv) health and (v) general well-being. Most interviews were conducted at the SED client’s house and some were conducted in the SARI office (request from SED client).
• FGDs were conducted with different key informants including SED clients, family members of SED clients, leprosy workers, employees from the micro-credit providers and the research assistant. These actors all provided insights in the situation of the SED clients. Generally the following topics were discussed: (i) financial situation, (ii) social situation, (iii) household situation (iv) health and (v) general well-being, as well as evaluation questions about the intervention itself.

• Profiles of SED clients were written by research assistants. The research assistants compared the situation regarding the socio-economic status (of the household and of the business) and stigma before and after the SED intervention. Special attention was paid to being afraid of leprosy, feelings of shame, ideas on concealment/disclosure, willingness to interact with community members.

The participants of the IDI and FGDs were purposively selected, aiming for diversity in terms of age and gender. Table 6.1 provides an overview of the research methods used during the baseline and final survey.

<table>
<thead>
<tr>
<th>Approach</th>
<th>Research methods</th>
<th>Phase</th>
<th>#</th>
<th>Study population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quantitative</td>
<td>SARI Stigma Scale (SSS)</td>
<td>Baseline &amp; Final survey</td>
<td>143</td>
<td>SED clients and people affected by leprosy who lived in the control and counselling/contact area</td>
</tr>
<tr>
<td></td>
<td>Participation Scale Short (PSS)</td>
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<td></td>
<td>WHO Quality of Life BREF (WHOQOL-BREF)</td>
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<tr>
<td>Qualitative</td>
<td>In-depth interview</td>
<td>Final survey</td>
<td>20</td>
<td>SED clients</td>
</tr>
<tr>
<td></td>
<td>Focus Group Discussion</td>
<td>Final survey</td>
<td>43</td>
<td>SED clients (2x), family of SED clients, leprosy workers, SED providers (2x), research assistants</td>
</tr>
<tr>
<td></td>
<td>Profile participant SED</td>
<td>Final survey</td>
<td>74</td>
<td>SED clients</td>
</tr>
</tbody>
</table>

The participants of the IDI and FGDs were purposively selected, aiming for diversity in terms of age and gender. Table 6.1 provides an overview of the research methods used during the baseline and final survey.
6.3.5. Analysis

Quantitative data entry was entered using EPI Info versions 3.5.4 and transferred into Stata version 12.1 for analysis. Descriptive such as means, median, interquartile range (IQR), standard deviation (SD), 95% confidence interval (CI) were used to describe the data. Paired t-tests were conducted to evaluate significance between pre and post interventions. A p-value of 0.05 was considered significant. Besides reporting the total scores of the scales we will also present the analyses of items or domains. This is because some items / domains are more relevant for an SED intervention than others. For instance we expect a larger change in the internalized stigma domain of the SSS scale compared to the experienced stigma domain.

For the interviews and FGDs, this study applied content and thematic analysis. First, a contextual text segmentation was conducted to identify similar concepts using open-ended codes. Second, similar concepts were gathered into similar content themes. Finally, triangulation among methods was performed and all the interviews were reviewed to validate the content and to minimize the risk of bias. Observation data from profile participants was used to describe the minimal change of stigma and socio economic improvement. For the analyses of the profiles, SED clients were grouped into groups of high stigma, moderate stigma and low/no stigma (indicators such as fear, shame, and interaction with neighbours were used). Family economic condition was based on the ability to fulfil daily needs such as food and school fee. The business condition was based on the status of the business in terms of size and growth.

6.3.6. Ethics

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

6.4.1. Overview of the SED intervention of the SARI project and how it is embedded in the local system

Following our discussion of the challenges associated with SED interventions for people affected by leprosy, we can conclude that simply including these people in regular micro-credit programmes without adjustments is not so promising. At the same time, mainstreaming people with a disability into regular services is the dominant discourse within contemporary disability practice (Albert, 2006; Jones & Webster, 2006; Miller & Albert, 2005) and not only contributes to inclusion of people with a disability in mainstream society, but also contributes to the sustainability of an intervention. Considering, on the other hand, the specific needs of people affected by leprosy, a so called twin track approach is often promoted (DFID, 2000). Indeed, the SED intervention that resulted from experimentation and implementation in the SARI study is characterised by a twin track approach and a portfolio of different activities embedded in different organisational settings.

On the one hand, the SARI project tried to mainstream people affected leprosy into existing microfinance business entities. The SARI project collaborated with an organization called Koperasi Mitra Dhuafa (KOMIDA) and the local government. On the other hand, an alternative micro financing and capacity building activity was started; through a DPO named Forum Komunikasi Difable Cirebon (FKDC). Three other smaller activities were started; livestock and skill training, both in collaboration with the District Social Welfare Office (DSWO) and individual loans from a family member or friend with individual support through the DPO. In Table 6.2, an overview of the five types of socio-economic activities is provided.
The KOMIDA model is based on a well-known and frequently applied Grameen system which was developed in Bangladesh (Hossain, 1988). KOMIDA was established in 2004 and started services in 2005 to support earthquake/tsunami victims in Aceh, Indonesia. Now KOMIDA supports more than 210,000 clients, especially women in several provinces in Indonesia (KOMIDA, 2016). When KOMIDA opens a new office they normally send a team to the villages to inform and ask permission of the community leader and to raise awareness for the program. To become a KOMIDA member, candidates should register and propose a plan on how to use the money.

Then a survey is constructed by KOMIDA to assess the financial situation of the participant, such as the house condition, and what business they would like to run. Microcredits are given in a group of 5 - 10 persons. Before the micro-credit is given there is a five-day (10 hours) training for commitment building (e.g. building trust) and developing a business plan. After this initial training there are weekly meetings to pay back the credit and provide support. If one member fails to pay back the other group members should cover it. KOMIDA clients are also obliged to join a saving group. KOMIDA works with an interest rate, which will help to pay for the management of the microfinance scheme. It also charges 1% of the total credit for life insurance, to ensure the family will have no debts if a participant passes away. Anticipating on the challenges of including people affected by leprosy in the programme, the SARI team offered a training about leprosy (medical and social aspects) to KOMIDA. People affected by leprosy that lived in areas in Cirebon District which KOMIDA worked were invited by KOMIDA staff and the research assistants of the SARI project to start or join groups. These were not groups with only people
affected by leprosy; normally there were one or two persons affected by leprosy in one group. The research assistants of the SARI project motivated potential clients and prepared them through counselling (e.g. providing medical information about leprosy, listening to worries and challenging unhelpful assumptions, providing encouragement).

FKDC started the alternative model for microfinance and capacity building. FKDC is a local DPO in Cirebon District that had just moved from an informal organisation to a formal one. FKDC staff received different trainings from SARI and Community Based Rehabilitation (CBR) consultants on running a micro-credit programme and also on personal development skills (e.g. strengths, weaknesses, opportunities and treats (SWOT) analysis, fund raising and proposal development, financial administration and dealing with emotions). The director and several board members of FKDC are research assistants of the SARI project and lessons learnt from working with KOMIDA were taken into account in the new model. The difference between the FKDC model and the KOMIDA model is that the FKDC model is less regulated/strict and that there were monthly pay back meetings instead of weekly. In addition, a gathering with members of the DPO and micro-credit participants takes place once in every three months for coordination and mentoring. The process of FKDC is simpler than KOMIDA’s, the clients just have to apply for a microcredit and propose a plan on how to use the money. In 1 day (instead of 5) the payment system is explained. The FKDC team assesses the (financial) situation of participant such as house condition, what business s/he runs, and the condition of the neighbourhood. FKDC prioritizes people affected by leprosy and people with disabilities; the proportion of people with leprosy is about 60%, people with disability 20% and proportion of general members should be not more than 20%. FKDC staff know the beneficiaries personally and provide support during the process. FKDC also works with an interest rate as this will help to pay for the management of the microfinance scheme. KOMIDA and FKDC both provided microcredit loans with a maximum amount of IDR 1 million for the first year. If needed, participants can receive another loan of IDR 1.5 million in the second year and IDR 2 million in the third year. The participant receives the new loan only when certain conditions are met, such as having paid back the first loan and a commitment to attend meetings regularly with other members.
Three other smaller socio-economic related activities were started. First, a collaboration was started with the DSWO. They have a programme to support people affected by a chronic disease. They provide financial or material support (usually in the form of a grant, for example a goat) and together with the SARI team they provided skill trainings for income generation (e.g. sewing, handicraft, making broom, electronics). Secondly, there was an individual support model. The SARI team found that many people affected by leprosy felt insecure about having a debt from a formal institution. They were afraid to fail to pay back the loan and be drawn in debt. Since they did not want to deal with loans from the formal sector, the SARI team encouraged them to have microfinance support from their trusted friends, parents, brother, or other relatives. The process of individual support was initiated by the outreach workers. They motivated people affected by leprosy and people with a disability to start or to continue their business. The outreach worker would help the participant to identify the type of business they wanted to start and to find a trusted source for capital. Together the outreach worker, participant and trusted sources would then discuss the possibility to execute the plan. The business started when the trusted sources fund agreed about the proposed business.

6.4.2. Participants of the SED intervention

About 369 people were involved in the different SED-related activities, including 110 persons affected by leprosy, 251 community members and 8 persons with disability. In total, 66 persons affected by leprosy accessed 71 units of micro-credits (some received more than 1 credit). In total, 40 received a micro-credit from KOMIDA, 20 from FKDC and 11 from a friend or relative. Also, 21 persons affected by leprosy received a goat and 52 participated in different skill trainings. Table 6.3. provides an overview of the activities and the number of people involved. Most SED clients already had their own business or had a business before at some point in the past. From 325 SED clients, 34% use their credit to work as a food vendor, 24% used it to open a small shop to sell goods and groceries, 23% used it to work in farming or selling farming product, 11% used it to sell cloths and the others 8% used it for varies reasons such as making crafts, services electronic or motor cycles, and recycling
waste. The data shows that most SED clients in this study were successful in paying back the loan. In total, 78% of the SED clients succeeded to pay back within the agreed timeframe, 19% managed to pay the loan back with some additional time, and only 3% failed to repay.

<table>
<thead>
<tr>
<th></th>
<th>Micro credits</th>
<th>Livestock (goats)</th>
<th>Skill training</th>
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<tbody>
<tr>
<td></td>
<td>KOMIDA</td>
<td>FKDC</td>
<td>Individual</td>
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<tr>
<td>Persons affected by leprosy</td>
<td>40</td>
<td>20</td>
<td>11</td>
</tr>
<tr>
<td>Community member</td>
<td>242</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>Persons with disabilities</td>
<td>-</td>
<td>8</td>
<td>-</td>
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<tr>
<td>Total</td>
<td>282</td>
<td>32</td>
<td>11</td>
</tr>
</tbody>
</table>

### 6.4.3. Characteristics of the study population

After the baseline and final survey, the SARI project had a cohort with paired data of 237 persons affected by leprosy. Among these, 29 (12%) were SED clients, 57 were controls (24%) and 57 (24%) were from the counselling/contact area. The demographic characteristics of the respondents are shown in Table 6.4. In this table the demographics of the interviewees, the participants of the FGDs and the profiles are also displayed. In total, seventy-four profiles were written, but only 65 were complete and of use to the analysis.
### Table 6.4. Characteristics of study participants

<table>
<thead>
<tr>
<th></th>
<th>Quantitative</th>
<th>Qualitative</th>
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<th>FGD</th>
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<tr>
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<td>Cohort (n=237)</td>
<td></td>
<td>Profile</td>
<td>In-depth</td>
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<tr>
<td></td>
<td>SED clients</td>
<td>Control</td>
<td>observation</td>
<td>interview</td>
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<tr>
<td>n</td>
<td>29 (12%)</td>
<td>57 (24%)</td>
<td>57 (24%)</td>
<td>65</td>
<td>20</td>
<td>43</td>
</tr>
<tr>
<td>Sex (male)</td>
<td>13 (45%)</td>
<td>37 (65%)</td>
<td>38 (67%)</td>
<td>29 (44%)</td>
<td>5 (25%)</td>
<td>29 (67%)</td>
</tr>
<tr>
<td>Age (mean/range) in</td>
<td>33</td>
<td>38</td>
<td>33</td>
<td>43 (17-70)</td>
<td>20 - 70</td>
<td>20 - 60</td>
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<tr>
<td>years</td>
<td></td>
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<tr>
<td>Marital status</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(married)</td>
<td>12 (41%)</td>
<td>23 (40%)</td>
<td>21 (37%)</td>
<td>Mostly</td>
<td>Mostly</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>married</td>
<td>married</td>
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<tr>
<td>No schooling</td>
<td>1 (3%)</td>
<td>5 (9%)</td>
<td>1 (2%)</td>
<td>4 (6%)</td>
<td>2 (10%)</td>
<td>-</td>
</tr>
<tr>
<td>&gt; Junior high school</td>
<td>28 (97%)</td>
<td>52 (91%)</td>
<td>56 (98%)</td>
<td>61 (94%)</td>
<td>18 (90%)</td>
<td>30 (70%)</td>
</tr>
<tr>
<td>&gt; College/ University</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>13 (30%)</td>
</tr>
</tbody>
</table>

### 6.4.4. Economic transformation: Impact of SED on socio-economic status of the clients

Data shows there was an improvement of about 25% in the median family income when we compare to pre and post intervention (from IDR 750 thousand to IDR 1 million). The mean improvement in family income among SED client was higher (IDR 554,000) than among people affected in the control area (IDR 363,000) and in the contact/counselling area (IDR 175,000).

### Table 6.5. Median family income pre and post intervention (IDR in Thousands)

<table>
<thead>
<tr>
<th></th>
<th>Pre</th>
<th>Post</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Median</td>
<td>IRQ</td>
</tr>
<tr>
<td>SED clients</td>
<td>26</td>
<td>750</td>
<td>500</td>
</tr>
<tr>
<td>Contact / counselling area</td>
<td>47</td>
<td>600</td>
<td>700</td>
</tr>
<tr>
<td>Control</td>
<td>50</td>
<td>650</td>
<td>500</td>
</tr>
</tbody>
</table>

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The profiles show that in general there is an improvement in the socio-economic condition of the family and an improved socio-economic condition of the businesses the clients were running. Table 6.6 shows that 44 out of 65 clients (67%) have an improved economic condition in the family compared to the time before they joined the SED activities. They can more easily fulfil their daily needs such as buying food (e.g. rice and proteins). The profiles also show that the socio economic condition of the families of 14 out of 65 clients (22%) remained stable and in 7 out of 65 (11%) decreased. Table 6.6 also shows the status of the economic condition of the business. Referring to the growing business in total, 39 out of 65 (%) clients reported that the economic situation of their business improved after having received microcredit, in terms of selling more products and having more customers. Twenty-two out of 65 reported stable business conditions or no big changes and 4 out of 65 (6%) failed to set up or improve the business due to sickness, death, or having a baby.

Table 6.6. Change in family and business economic condition pre and post intervention based on profiles (n=65)

<table>
<thead>
<tr>
<th></th>
<th>Improved</th>
<th>More or less stable</th>
<th>Decrease</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family economic condition</td>
<td>44 (67%)</td>
<td>14 (22%)</td>
<td>7 (11%)</td>
<td>65 (100%)</td>
</tr>
<tr>
<td>Business condition</td>
<td>39 (60%)</td>
<td>22 (34%)</td>
<td>4 (6%)</td>
<td>65 (100%)</td>
</tr>
</tbody>
</table>

The analyses of the interviews and FGDs are in line and show that SED clients who received a loan used it for starting or strengthening their business and as a result earned more money for their daily needs and reported increased well-being. The data also showed that many SED clients joined saving activities related to the microcredit scheme, improved their assets (e.g. TV set, closet) and property, and had more power in decision making in household issues.

“We can use [the profit] for daily needs and for school... My wife can open a business. We opened a Rujak [traditional fruit and vegetable dish] shop.” (FGD 2 client SED)

Interviewer: How much income did you get from that IDR 200,000 capital? 
Interviewee: Yah, IDR 50,000 [US$ 4]  
Interviewer: You got IDR 50,000? [US$ 4]  
Interviewee: If it’s afternoon I earn IDR 25,000 [US $2].
Interviewer: ... So if its morning and afternoon you got IDR 75,000 [US $6] per day, right, is it enough for your family daily needs?
Interviewee: Thank God, it’s enough.
Interviewer: Is it the same between now and before, sir?
Interviewee: It’s different.
Interviewer: What is the difference, sir?
Interviewee: Yes, capital increased, more progress. (IDI S-CS18-Male-50)

“I became happier. I have more money. I can go to the market to sell something. I used to only stay at home and have no activity. I have a capital so I can go to the market. So I have a happy feeling.” (FGD 1 client SED)

“I save at school [micro credit group meeting]...I save at home too. I save the change from the money spent on daily needs.” (IDI S-CS01-female-35)

6.4.5. Changes in well-being: Impact of SED on stigma, the effects of stigma and quality of life

Socio-economic development interventions are expected to not only improve socio-economic status of participants but, through economic transformation, also to increase well-being. In this project we studied changes in well-being through measuring changes in stigma, participation restrictions and quality of life. The data of the profiles shows that many of SED clients had a high level of stigma before they joined the intervention activities. The high level of stigma was reflected in being scared for leprosy, low self-esteem and limited interaction with community members. The profiles show there is an improvement in the way SED clients see themselves and their relationship with others. Most SED clients moved from a high level of stigma to a moderate level of stigma (see Figure 6.2.). This means they were not afraid of leprosy anymore, were more comfortable to tell someone about their disease (though some were still afraid of disclosure), were less ashamed for their disease, had an improved self-esteem and were more willing to interact with neighbours (some still hesitated). A few profiles describe clients with very limited or no stigma.
The analysis of the scales shows there is a significant improvement in the SSS and PSS total scores of SED clients when we compare the baseline assessment with the final survey. In SSS there was a decrease of 8.5 points between pre and post intervention (p-value 0.004) and in the PSS an decrease of 3.6 points (p-value 0.0074). The difference in the WHOQOL-BREF is the going in the right direction (4.3 improvement in quality of life, but this difference was not statistically significant).

Comparing the scores of SED clients with the control area and the contact/counselling area shows that the scores of SED clients differed more (sometimes are almost twice as high) than the scores in other areas. Interestingly, the WHOQOL-BREF score appeared to have reduced in the control area (2 points), but this was not statistically significant.
### Table 6.6. Total score of SSS, PSS and WHOQOL-BREF pre and post by area intervention

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>Pre</th>
<th></th>
<th>Post</th>
<th></th>
<th>Difference</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>SSS</td>
<td></td>
<td>Mean</td>
<td>CI 95%</td>
<td>Mean</td>
<td>CI 95%</td>
<td>Mean</td>
<td>CI 95%</td>
</tr>
<tr>
<td>SED clients</td>
<td>29</td>
<td>19.01</td>
<td>14.05</td>
<td>24.02</td>
<td>10.59</td>
<td>5.95</td>
<td>15.23</td>
</tr>
<tr>
<td>Contact counselling</td>
<td>57</td>
<td>17.30</td>
<td>13.90</td>
<td>20.69</td>
<td>10.75</td>
<td>8.19</td>
<td>13.31</td>
</tr>
<tr>
<td>Control</td>
<td>57</td>
<td>15.42</td>
<td>12.47</td>
<td>18.37</td>
<td>9.79</td>
<td>6.88</td>
<td>12.70</td>
</tr>
<tr>
<td>PSS</td>
<td></td>
<td>Mean</td>
<td>CI 95%</td>
<td>Mean</td>
<td>CI 95%</td>
<td>Mean</td>
<td>CI 95%</td>
</tr>
<tr>
<td>SED clients</td>
<td>29</td>
<td>8.44</td>
<td>4.34</td>
<td>12.55</td>
<td>4.89</td>
<td>1.46</td>
<td>8.32</td>
</tr>
<tr>
<td>Contact counselling</td>
<td>57</td>
<td>6.41</td>
<td>4.51</td>
<td>8.31</td>
<td>3.59</td>
<td>1.76</td>
<td>5.42</td>
</tr>
<tr>
<td>Control</td>
<td>57</td>
<td>5.42</td>
<td>3.80</td>
<td>7.04</td>
<td>4.05</td>
<td>2.19</td>
<td>5.92</td>
</tr>
<tr>
<td>WHOQOL-BREF</td>
<td></td>
<td>Mean</td>
<td>CI 95%</td>
<td>Mean</td>
<td>CI 95%</td>
<td>Mean</td>
<td>CI 95%</td>
</tr>
<tr>
<td>SED clients</td>
<td>28</td>
<td>82.59</td>
<td>78.20</td>
<td>86.99</td>
<td>86.91</td>
<td>82.04</td>
<td>91.78</td>
</tr>
<tr>
<td>Contact counselling</td>
<td>50</td>
<td>84.16</td>
<td>81.17</td>
<td>87.14</td>
<td>85.34</td>
<td>85.05</td>
<td>91.62</td>
</tr>
<tr>
<td>Control</td>
<td>55</td>
<td>85.83</td>
<td>83.36</td>
<td>88.30</td>
<td>83.83</td>
<td>81.32</td>
<td>86.35</td>
</tr>
</tbody>
</table>

1 Paired t-test

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**IMPACT ON DIFFERENT TYPES OF STIGMA AND DISCLOSURE CONCERNS**

We will now focus on the domains, individual items of the scales that are particularly interesting in relation to the SED intervention and present more qualitative data. Further analysis of the SSS data shows that the SED intervention had an impact on different types of stigma and on disclosure concerns. Figure 6.3 illustrates the largest improvement took place in the Internalised stigma domain and in the Disclosure concerns domain. The Experience stigma score reduced slightly (0.59 point or 21%) after the intervention, the Disclosure concern score reduced 2.79 points (50%), the Internal stigma score reduced 3.83 (56%) and finally the Anticipated stigma score reduced 1.24 points (32%).

![Figure 6.3. Mean of the four domains scores of the SSS for the SED clients pre-post intervention (n=29)](image-url)
The reduction of domain disclosure and internalized stigma is much higher compared to two other domains. Similar findings were found when analysing the qualitative data, but more importantly it provided insights into how this change was achieved. The trigger that started the cycle of increased self-esteem and therefore increased participation is the moment the person affected by leprosy was offered participation in a micro-credit scheme. Research assistants of the SARI project and KOMIDA staff went to the house of the SED candidate and shared knowledge about leprosy (e.g. leprosy is curable, the symptoms will disappear and impairment can be prevented) and information about the SARI project and the micro-credits schemes (e.g. no collateral and gathering with others). They also motivated and encouraged them to improve themselves through the microcredit. The clients felt accepted by the research assistant and realised there were people who still pay attention to them. The provision of knowledge about leprosy, information of the microcredit programme and motivational advice changed the way they saw themselves. The increased self-awareness that they can improve their life themselves was powerful. By joining economic activities or becoming self-employed they gained the appreciation and respect of the family members and neighbours. It increased their own self-esteem, which then in turn influenced other aspects like participation. Gaining more self-esteem, confidence, and less shame encouraged some of the SED clients to disclose their leprosy status or to worry less about a possible disclosure. Of course, in some cases it is not possible to conceal due to impairments. Some quotes to illustrate these changes

“My husband has changed. He used to be quiet, didn’t interact or have friends but after SARI came, he has changed. He interacts and doesn’t hide himself anymore.” (FGD family counselling-SED client)

Interviewer: What do you feel after you joined [the SED activity]? 
Interviewee: Maybe I’ve become better, more courageous. Basically I’ve been better than before. 
Interviewer: Do you still have any bad feelings about leprosy? 
Interviewee: I used to, but now I don’t think about it too much. 
Interviewer: Did you ever talk to anyone else [about your disease]? 
Interviewee: Some people, yes. 
Interviewer: What do you talk about?
Interviewee: About the disease – the symptoms, the medicines, how to treat it, etc. we basically explained to everyone about what leprosy is? (IDI S-CS09-female-43)

**IMPACT ON PARTICIPATION RESTRICTION IN WORK AND OTHERS**

Further analysis of the PSS data shows that participation in economic life improved; restriction to find work reduced, restrictions to work equality reduced, however restrictions in economic contribution remained similar (see Figure 6.4). Also on some other items of the PSS improvements were found.

![Figure 6.4. Mean score selected individual items of the PSS by pre and post intervention (n=29)](image)

Many SED clients mentioned in the IDI and FGDs that the increased self-confidence helped them to increase their participation in life. And in a same way, the increased participation increased their confidence further. It is a cycle. In order to run their business SED clients joined a training, met other beneficiaries of micro-credits, needed to buy products at the market or shop. These activities helped them to interact again with their neighbours. One quote to illustrate this:

“When I had leprosy, I felt numbness so I never went out of the house. After SARI came to my house, I became confident and capable to socialize with other people.” (FGD 2 client SED)
IMPACT ON QUALITY OF LIFE

Additional analysis of the WHOQOL-BREF domains shows that most change occurred in the Psychological health (see Figure 6.5.). In Figure 6.6., details of some of the changes in individual items (less negative feelings, more money, better quality of life in general) are shown. The quantitative part of the quality of life will be addressed in the next section on social transformation.

Figure 6.5. Mean domain scores WHOQOL-BREF by pre-post intervention (n=29)

Figure 6.6. Mean scores selected items of WHOQOL-BREF by pre-post intervention (n=29)
6.4.6. Social transformation: Re-integrating of people affected by leprosy with the community

Following Pati & Lyngdoh (2010) the SARI project started from the hypothesis that a microfinance intervention may lead to economic transformations in the participants, which affects their well-being, and finally this may result in overall social transformation. Indeed we saw that the SED intervention positively impacted the socio-economic status of people affected by leprosy and their family and led to a reduction in stigma, less participation restrictions and a better quality of life. Now we are interested in knowing whether a social transformation did occur and if so what it was that set this transformation in motion. We looked at indicators identified by Pati & Lyngdoh (2010) described earlier in the IDIs and FGDs: satisfaction of life, decision making, health, travel and mobility, recognition and acceptance and capacity (see Table 6.7.). Some participants of this study mentioned they are now happier and more satisfied with their life. Being capable of fulfilling their daily needs and knowing more about their disease were important reasons. Several participants – also females as shown in the quotes – said they are involved in managing the household expenditure and this was easier and more common if the women contributed to the income. Many people affected by leprosy remained concerned about their leprosy status (e.g. afraid for relapse, afraid not being cured) even after being declared cured by a health professional and released from treatment. Data shows that SED clients are more aware of the importance of medical adherence and felt more confident to visit the health care centre if they had questions about their disease. The travel and mobility of SED clients improved as they were less restricted than before. SED clients, for instance, encouraged themselves to interact with members in their community and to be involved in community activities. Data shows there was also an increased recognition and acceptance from household members, family members and the wider community. People affected by leprosy worried less about attitudes of neighbours or potential clients. People seemed to be nicer to SED clients and showed more respect. It implies that anticipated stigma and experience stigma reduced. Increased capacity of people affected by leprosy led to major changes in self-confidence. Overall, the IDI and FGDs show that there are indicators for a social transformation.
The evidence for social transformation as portrayed in Table 6.7. shows that economic transformation, increased well-being and social transformation are intricately interwoven and mutually connected. Table 6.7. confirms the socio-economic transformation model by showing for instance that increased income can lead to satisfaction with life (well-being), which in itself amounts to social transformation. But we also see that more confidence, for instance through increased knowledge, can lead to an increased role in financial decision-making (social transformation), which in turn can lead to improved economic status. This suggests that rather than a linear model from microfinance intervention to social transformation, the SED intervention for people affected by leprosy may intervene on any point of the cyclic process connecting economic transformation, increased well-being and social transformation. Increased confidence and self-esteem seem to be underlying key factors contributing to socio-economic transformation of people affected by leprosy.

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Quote</th>
<th>Examples of what set things in motions:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction</td>
<td>“Well, I am happy now, yeah. My husband and I earn enough [money]”</td>
<td>- Being capable to fulfil daily needs</td>
</tr>
<tr>
<td>of life</td>
<td>(IDI S-CS01-female-35).</td>
<td>- Knowing and sharing correct medical information about leprosy</td>
</tr>
<tr>
<td></td>
<td>“I am very happy because I can talk to many people and tell them about the correct understanding of leprosy – that it is curable and cannot infect easily.”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(IDI S-CS14-female-33)</td>
<td></td>
</tr>
<tr>
<td>Decision</td>
<td>“My husband once wanted to buy something. I told him not to buy it now, because we need to buy a window for our house. When he wanted to buy a sofa, I said to him to buy it in credit, because sometimes we have people coming by our house.”</td>
<td>- For women it helped if they contributed to the income themselves.</td>
</tr>
<tr>
<td>Making</td>
<td>(IDI S-CS11-female-33)</td>
<td></td>
</tr>
<tr>
<td>Indicators</td>
<td>Quote</td>
<td>Examples of what set things in motions:</td>
</tr>
<tr>
<td>-----------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Health</td>
<td>“I think it is going better now. I didn’t take medication very diligently, but now I always take it. It’s like I have motivation”. (In-depth-S-CS16-male-37)</td>
<td>the increased confidence of SED clients helped them to visit the healthcare provider for advice</td>
</tr>
<tr>
<td></td>
<td>“I was afraid of getting infected again. But [now after visiting the doctor] I understand that once we had medication leprosy will be over. It cannot infect me again. So I am calm after I understand.” (IDI S-CS06-female-35)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“They [health providers] told me not to worry, that the disease would be cured. They counselled me by telling me that I was not the only one suffering from the disease. There were many other people who sought medication for the same disease.” (IDI S-CS05-female-26)</td>
<td></td>
</tr>
<tr>
<td>Travel and mobility</td>
<td>“Well, I used to be staying at home. Then I thought that it would be better if I join any kind of social gathering rather than staying at home.” (IDI S-CS05-female-26)</td>
<td>Realisation that clients can change take action themselves</td>
</tr>
<tr>
<td></td>
<td>“Yes, I was invited to become the administrator for national election booth but I gave it to my husband and I became election witness.” (IDI S-CS06-female-35)</td>
<td></td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Indicators</th>
<th>Quote</th>
<th>Examples of what set things in motions:</th>
</tr>
</thead>
</table>
| Recognition and acceptance | “I used to get scared when having the disease. I thought nobody would be willing to buy my merchandise. It turns out that I was wrong, they still want to buy it.” (IDI S-CT06- male-60) | - Respect because of business  
- Awareness of wrong assumptions                                                                 |
|                         | “We have two groups [for micro-credit gathering]. We were asked to move one group to another house. But they refused: “No, I don’t want. It is more enjoyable to be in this house. I don’t want to move” [house belongs to people affected by leprosy]. (FGD 2 client SED) |                                                                                                                                                          |
|                         | “Yes, all my neighbours became nicer to me and respect me. ... If there is something like cake, they share it with me. They are nicer and more friendly.” (FGD 2 client SED)                                      |                                                                                                                                                          |
| Capacity                | “I had no ability to start anything in the past, but now I can start my small business.” (IDI S-CT02- female-21)                                                                                   | - Increased capacity (e.g. because of trainings) to run a business                                                                                       |
|                         | “I used to be very down. I was very poor, I hardly had anything to eat. Now, I have built [renovated] a house in the last 2 years. My children’s school fees are paid. My economy is getting better.” (FGD 1 Client SED) |                                                                                                                                                          |
Currently microcredits are becoming more and more common in Indonesia. Various organizations such as the Indonesian government (e.g. Bank Negara Indonesia, Bank Rakyat Indonesia, Bank Mandiri), private formal financial institutions (e.g. KOMIDA), faith-based organisations (e.g. Zakat center, Rumah Zakat) and Non-Governmental Organizations provide micro-credits for small-scale businesses (Farida, Hermanto, & Nunung, 2015; Mustapha, Jung, & Zapata Veronica, 2007; Okten & Osili, 2004). Marginalized people such as people affected by leprosy and people with disability are often not seen as potential beneficiaries by formal and informal credit market systems (Mustapha et al., 2007). There are a few examples of a specific focus on the most vulnerable groups in society (e.g. poorest of the poor, persons with disabilities), but these examples are exceptional and the programmes are facing serious challenges. In general, many vulnerable groups experience constraints to access the credit (Farida et al., 2015). This study was set up to realise a ‘proof of principle’ that people affected by leprosy-related stigma could under certain conditions be reliable clients of a micro-credit programme.

Rather than one uniform SED intervention, the SARI SED intervention comprises a portfolio of different activities. Two different micro-credit schemes and some other socio-economic activities were implemented in the SARI project. Both schemes tried to deal with the barriers such certain characteristics of people affected by leprosy and the lack of knowledge (Chapter 3) and opened up opportunities to improve the social economic status and facilitate a social transformation of people affected by leprosy. The different activities respond to the various needs of people affected by leprosy and are aligned with the locally available resources and programmes, enhancing its sustainability. A strong point of the SED intervention is indeed that it is the only intervention of the SARI project that is still running three years after the implementation of interventions in the study area stopped. Currently, KOMIDA is still recruiting for micro-credits – though to our knowledge not very actively – people with disability and people affected by leprosy. Similarly, the DPO also managed to maintain their micro-credit and related activities. The skills of the DPO personnel have improved substantially over time. Good networking of the DPO with local stakeholders continued and has resulted in various activities for people affected leprosy and people with disability.
The main purpose of the SED intervention was to improve income generation and reduce stigma and its impacts, such as participation restrictions and a lower quality of life. This study confirmed what Ebenso et al. (2007), Velemma et al. (2008) and Wagner, Rana, Linnemayr, Balya, & Buzaalirwa (2012) found earlier, which is an effect of SED on the socio-economic status. Leprosy-related stigma has been studied in-depth, but how to reduce it has received less attention (Cross et al., 2011a; Cross, Heijnders, Dalal, Sermittrong, & Mak, 2011b; Heijnders & van der Meij, 2006). Velemma et al. performed a literature review in 2008 and found 7 programmes that provided socio-economic support to people affected by leprosy (Velemma et al., 2008). These SED interventions aim to improve the socio-economic status and do this mainly through the promotion of self-employment (e.g. tailoring, cycle repair). Velemma et al.’s review (2008) suggests that a well-structured socioeconomic intervention might lead to persons affected by leprosy becoming self-employed, have more material well-being and in some cases become self-supporting. Similarly, the median income of SED clients in this study shows an improvement, which was higher compared to the control area. It proved that SED intervention could improve socio-economic status of participants.

This intervention described in this study indicates that SED can lead to less stigma, fewer participation restrictions and an improved quality of life. Stigma was reduced both in the intervention as well as in the control area, however mean differences were higher in the intervention area compared to the control area. The level of participation restriction was reduced in both areas, but in the intervention area the difference was significant, which was not the case in the control area. The quality of life of people affected in intervention area was significantly increased, which is a promising result as quality of life decreased in the control area. Qualitative data also shows that there is often a change in the level of stigma. These findings are in line with other similar studies: Shumin et al found clear evidence that loans have positive social and psychological effect on people living with HIV/AIDS (Shumin, Diangchang, Bing, Lin, & Xioulu, 2003). Gheeta et al. found in India that an improved socio economic status improvement quality of life (Joseph & Rao, 1999). Chien found a relationship between self-esteem and quality of life among people with schizophrenia (Chien-Yi Ow & Lee, 2015). A study by Rao et al among people affected in India, illustrated that an increased expectation is bound to lead to changes of people’s perception of their quality of life (Joseph & Rao, 1999). Furthermore, the result indicates that people affected by leprosy become more satisfied with their life,
have more life aspirations for the future, are more aware their health, access health services, are more involved in decision making, and experience more recognition and acceptance from people around them. We conclude that these are indicators for a social transformation as defined by Pati & Lyngdoh (2010).

The process of developing and implementing the SED intervention of the SARI project, incorporating views, expectations of the persons affected by leprosy and establishing meaningful collaborations with the District Health Office, DSWO and other organizations took time. However, it was needed to create a sustainable intervention that was embedded in the local context. All organizations were willing to cooperate and to support the activities with their resources. In the end, the long-term impact of intervention is the network between the different actors.

The main limitation of this study is that it has some characteristics of a pilot study, although it was not set up that way. The number of SED clients was, for instance, lower than expected and needed to draw a firm conclusion. We believe that our findings are, nevertheless, important to share to the NTDs community as future SED programmes can and should build upon the findings described in this chapter to contribute to socio-economic transformation of people affected by leprosy and NTDs as well as other marginalised and/or stigmatised groups.

6.6. CONCLUSION

In this study we report on the development, implementation and assessment of an SED intervention. Although the number of participants was lower than anticipated, the assessment shows many positive results in terms of socio-economic status, stigma, participation and quality of life. The results of this study are promising and add to the understanding of SED interventions. This study demonstrates something else that is imperative, namely that it has great potential in terms of sustainability. The pledge to “leave no one behind” was a key feature in the discussions leading the Sustainable Development Goals (UN, 2015). This study shows that with moderate support a lot is possible for those that have been left behind before. A socio-economic intervention, if embedded and integrated, can provide support to those who are stigmatised by others and themselves.
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