CHAPTER 1
INTRODUCTION

Why do I have such a disease like leprosy?

I did not know that it was this kind of disease. I thought that it was just a common skin rash. I cannot socialize with other normal friends; I cannot play with them any more.

Almost everyone avoided me. My neighbours and my friends avoided me when I suffered from leprosy Maybe they were afraid of being affected. I was insulted because I had leprosy. It made me feel ashamed myself.

I feel sad, embarrassed, disappointed and my feelings are hurt ... I don’t have any confidence because people tease me.

She can’t stand me with my condition, and asked me to divorce her, so I divorced her, and since then we live in separate houses.

My office asked me to leave until my leprosy is cured; when I finished my medication they didn’t want to employ me anymore because of my leprosy. (SARI Exploratory study, 2011)

All the above phrases are responses from people affected by leprosy to a question we asked them during the interviews in the exploratory study: ‘What is the impact of leprosy on your life?’ The responses were more complicated than expected. Leprosy is – from a public health perspective – a communicable disease caused by Mycobacterium leprae that, since the 1970s, be treated effectively with multi-drug therapy (MDT). Without giving it much thought one could argue that the disease could be eliminated if people sought care and received the right treatment. These interviews, however, made me realize that leprosy is not just a communicable disease or a common and straightforward public health problem.
CHAPTER 1

Leprosy is an ancient disease and perceptions of what kind of disease it is have been shaped in people’s minds for generations. There are various legends, myths and ideas concerning the level of infectiousness, whether people affected can be cured, the causes of the impairments, and how people affected should be treated (e.g. exiled). Not surprisingly, some people affected by leprosy prefer to conceal their illness. From a public health perspective this is problematic as it leads to delay in seeking treatment. Besides increasing the risk to infect other people, the delay can cause impairments and disability that in the long run might increase stigma.

Leprosy can have a range of negative consequences on people who are affected by the disease and stigma is only one of them, though often perceived as one of the most severe. The consequences vary from the physical to the psychological and social impact. The interviews show that people affected by leprosy have to deal with the skin lesions, numbness and muscle weakness, that they were shocked, afraid, ashamed, embarrassed and disappointed with themselves because of their disease, and they also experienced disrespect, segregation, exclusion and discrimination from others. These consequences are the day-to-day reality for people affected by leprosy. Consequently, those affected, and often also their family members, experience major social-economic challenges.

In this thesis I will explore the complexities of leprosy-related stigma and study how a socio-economic development (SED) intervention can reduce it in an appropriate, effective and sustainable manner. There are several promising interventions that might be able to reduce health-related stigma, though evidence is scarce and varies across studies (Heijnders & van der Meij 2006; Sermrittirong et al. 2014; Cross et al. 2011a; Brown et al. 2003; Hanisch et al. 2016). One of them is SED. This approach is different from others as it does not focus on the causes of stigma, but aims to strengthen the capacities of individuals, which may lead to improved self-esteem, regained dignity, wellbeing, and enhanced participation in socio-economic life, and consequently reduced stigma. The socio-economic intervention looks promising, but we need to realise that leprosy-related stigma is a complex problem that is not easy to manage.

This thesis is part of the Stigma Assessment and Reduction of Impact (SARI) Project that ran from 2010 to 2014 in Cirebon District, Indonesia. This project was an
intervention study. Three different stigma-reduction interventions were designed and their effectiveness was tested. Three PhD students were involved, who worked in a larger team on the design and implementation of the study. Each student focused on one of the interventions. I focused on the socio-economic development intervention, Mimi Lusli focused on the counselling intervention and Ruth Peters focused on the contact intervention. We worked closely together to understand the complexity of leprosy-related stigma and to create synergies in the research work undertaken.

This chapter begins with a section on leprosy, stigma and poverty and stigma-reduction interventions. I then introduce the aim of this thesis and the relevant theoretical concepts. Then I present the research questions and describe the research design of this thesis. The chapter ends with an outline of the thesis.

1.1. LEPROSY AND STIGMA

Leprosy is often described as an ancient disease. This is because leprosy or a disease similar to leprosy was recorded in several old documents, for example, religious scriptures, sacred books, medical documents, possibly from as early as 1400 BC (Brown 1975; Skinsnes 1973; Yawalkar 2009; Bennett et al. 2008). The first authoritative publication on leprosy was published in 1847 by Danielssen and Boeck (1848). They described the characteristics of leprosy and clearly distinguished it from other diseases. They described leprosy as a specific chronic granulomatous disease of peripheral nerves and dermis caused by an unknown specific micro-organism. In 1873, Hansen discovered the causative agent of the leprosy: Mycobacterium leprae (Hastings 1994; Ghosh & Chaudhuri 2015).

The understanding and control of leprosy have progressed greatly over the years. Significant efforts have been made to find a cure, and in the 1970s MDT was discovered. A few years later the World Health Organization (WHO) provided MDT protocols that recommend a combination of rifampicin, clofazimine, and dapsone

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1 Scholars disagree on the exact years and documents.
in the treatment of leprosy. In the 1990s, a global programme to eliminate leprosy was implemented (Rafferty 2005). Since 2000, the number of new cases reported has reduced around the world.

Currently, there are more than 200,000 new leprosy cases detected worldwide each year (WHO 2015). The new case detection rate per 100,000 population varies per WHO region; in the African regions it is 2.44, in the Americas, 3.75, and in South-East Asia, 8.12 (WHO 2015). The global grade-2 disability rate, also known as the rate of visible impairment at the time of diagnosis, is 0.25 per 100,000. In the African regions this is 0.36, in the Americas 0.23, and in South-East Asia 0.45 (WHO 2015). In 2010, a global commitment was made to reduce the occurrence of new leprosy cases with grade-2 disability to less than one per million population, and to have zero child cases with grade-2 disability by 2020 (WHO 2015).

Although Indonesia officially eliminated leprosy in 2000, reaching a prevalence level of <1/10,000 population (MOH Indonesia 2007), WHO reported that Indonesia still occupies third place in terms of the leprosy burden, after India and Brazil. Indonesia has an average of 17,000 new cases per year, among whom about 9% have grade-2 impairment at the time of diagnosis (WHO 2015). An integrated leprosy programme at community health centres (sub-district level) all over Indonesia has been implemented. MDT is provided free and the centre staff are trained in leprosy. Some provinces have reported a drop in the new cases detected, however, in general 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. The question is why this disease is difficult to eliminate.

Various studies have reported that leprosy is a disease that has many negative consequences for the people who are affected by it. Leprosy can have physical, psychological and social consequences that can lead to disability and a reduced quality of life (Rao et al. 2008; Joseph & Rao 1999; Van Brakel & Officer 2008; Tsutsumi et al. 2007). Physical consequences include the impairment of hands and feet, loss of sensation, pain, wounds and muscle weakness. Psychological consequences include negative emotions and feelings, such as fear, embarrassment, shame and shock (Tsutsumi et al. 2004; Tsutsumi et al. 2007). Social consequences include exclusion and discrimination (Heijnders 2004b; van Brakel et al. 2012; Nicholls et al. 2003).
Stigma plays a major role in these consequences (Van Brakel et al. 2006; Sermrittirong & van Brakel 2014; Nsagha et al. 2011; Stevelink et al. 2011). Stigmatization can happen when people see a deviation from normative assumptions of acceptable states of being for oneself and others (Scambler 2009). Various causes of leprosy-related stigma have been identified. These include beliefs about the causes of leprosy, fear of contagion, fear of impairment, the idea that leprosy is a death sentence and the bad odours resulting from chronic wounds (Rafferty 2005; Rao 2010; Sermrittirong & van Brakel 2014). As a result, family members, community members but also health professionals and the public apparatus may start to treat people affected by leprosy differently (e.g. less acceptance, more distance) (Nicholls et al. 2003; Rao et al. 2008; Chen et al. 2004; Briden & Maguire 2003; Kaehler et al. 2015). Also people affected by leprosy might start feeling differently about themselves (e.g. low self-esteem, feeling less worthy) (Heijnders 2004b; Yamaguchi et al. 2013). Impairments can worsen stigma, but also people affected by leprosy even without impairments may face stigma (Plagerson 2005; Peters et al. 2012; Heijnders 2004a). Moreover, leprosy-related stigma not only influences the person affected but often also the family (Withington et al. 2003; van Brakel et al. 2012). This is called courtesy stigma (Goffman 1963). The adverse effects of leprosy are strongly interconnected. As a result of stigma, people affected by leprosy often decide to conceal their illness. This might hamper their treatment and in the end can have an impact on the control of leprosy. The variety of causes and consequences and the connections between them make stigma a complex concept and one of the reasons why it is challenging to eliminate leprosy.

1.1.1. The potential of an SED intervention to reduce stigma

Interventions to reduce health-related stigma have been implemented in different countries and for different conditions, such as HIV/AIDS (Brown et al. 2003) and mental illness (Rüsch et al. 2005; Hanisch et al. 2016). Some studies have been conducted to address leprosy-related stigma (Sermrittirong & van Brakel 2014). Evidence on the effectiveness is, however, scarce (Heijnders & van der Meij 2006; Brown et al. 2003).

A socio-economic intervention is believed to affect people positively in two ways, through improving economic welfare and through social interaction (Pati &
Lyngdoh 2010). A few socio-economic interventions have been made in the field of leprosy to improve socio-economic status, such as micro credit, capacity building, skill development and grant funding (Veilema 2008). The effect of a socio-economic intervention was explored in the study undertaken by Ebenso et al. (2007) in Nigeria. The study indicated that such interventions can lead to greater self-esteem and wellbeing. Studies show that any efforts to improve the socio-economic status of people affected by leprosy are complex. Almost every new approach aiming to reduce stigma is very likely to face challenges due to the complexities of leprosy-related stigma, which might in the end undermine the effectiveness of an intervention. The main aim of this thesis is to increase insights into leprosy-related stigma and in how it can effectively be addressed through an SED intervention.

1.2. THEORETICAL CONCEPTS

This section presents the key theoretical concepts used in this thesis including stigma, participation, quality of life, poverty, stigma-reduction, the twin-track approach and social transformation.

1.2.1. Stigma

The feelings and experiences such as shame, devaluation, withdrawal, exclusion, isolation, and discrimination of people affected by leprosy can be described as stigma. The concept of stigma in this thesis includes what Goffman described as ‘negative’ attributes that are deeply discrediting (1963:3). Goffman’s concept and theory were advanced by many scholars, resulting in a better understanding of the concept from different perspectives and settings. Stigma is frequently associated with (chronic) diseases and in this context it is therefore called health-related stigma. Health-related stigma has received wide attention from many researchers working on different diseases such as HIV/AIDS, mental illness, epilepsy, and from perspectives such as social anthropology, psychology and medical science. Health-related stigma is defined by Weiss as:

A social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group [identified with a particular health problem]. (Weiss 2006:280)
Scambler (2009) developed the ‘hidden distress model of epilepsy’ and distinguished between ‘felt’ and ‘enacted’ stigma. Weiss (2008) extended this model and distinguished six types of stigma, three from those who stigmatize and three from those who are stigmatized. Those who stigmatize may show accepted, endorsed and/or enacted stigma. Endorsed stigma refers to supporting exclusion but refraining from being actively engaged in it, while accepted stigma means not endorsing it, but not speaking out against the process. Enacted stigma is often called discrimination. Those being stigmatized may exhibit anticipated, internalized and/or experienced stigma. The latter refers to the experience of discrimination. Anticipated stigma refers to a person with a stigmatized condition who behaves or feels a certain way due to anticipated responses from others. Finally, internalized or self-stigma is the stigma individuals attach to themselves. Internalized stigma is defined by Livingston and Boyd as:

> A subjective process, embedded within a socio-cultural context, which may be characterized by negative feelings (about self), maladaptive behaviour, identity transformation, or stereotype endorsement resulting from an individual’s experiences, perceptions, or anticipation of negative social reactions on the basis of [their leprosy status]. (Livingston and Boyd, 2010:2151)

Internalized stigma is connected to self-esteem. Self-esteem refers to people’s appraisal of their own value. Self-esteem is an internal, psychological monitor of something that is very important to people – namely self-belongingness (Leary & Baumeister 2000). Robinson et al. (1990) described self-esteem as an evaluative component of a broader representation of self. Self-esteem can refer to the overall self or to specific aspects of the self, such as how people feel about their social standing, or physical features (Heatherton & Wyland 2003). Individuals that experience stigma and have low self-esteem often limit their interaction with the community (i.e. participation restrictions), which can in turn negatively affect their quality of life.

1.2.2. Impact of stigma on participation and quality of life

People all over the world participate in family life, education, work, community life, religious activities, politics and so on. One of the social consequences of health-related stigma is a participation restriction in these areas (Brouwers et al. 2011;
Brakel et al. 2012; Resnik & Plow 2009). Stevelink et al. (2012:1597) note that ‘the precise nature and level of this participation may vary from person to person and culture to culture, but otherwise, “social participation” is a global phenomenon’. The International Classification of Functioning, Disability and Health (ICF) identifies several key facets of disability and ‘participation’ is one of them. The three main dimensions of the ICF model are: body structure and function, activity (and activity limitations) and participation (and participation restrictions). Participation is described by WHO as ‘involvement in life situation’ (WHO 2002). The restrictions in participation are defined as ‘problems an individual may experience in involvement in life situations’ (WHO 2002). Several researchers have tried to measure of participation in different contexts (Van Brakel et al. 2006; Noonan et al. 2009; Heinemann et al. 2010; Brouwers et al. 2011; Resnik & Plow 2009).

Quality of Life as described by WHO is an individual’s perception of their position in life in the context of the culture and value system in which they live, and their relation to their goal, expectation, standard and concern (WHO 1996; Skevington et al. 2004). WHO identified four domains: physical health, psychological health, social relationships and environment (WHO 1996). Many researchers have measured quality of life related to the chronic disease (El-Badri & Mellsop 2007; Brouwers et al. 2011; Tsutsumi et al. 2007). However, the consequences of leprosy go beyond the physical, social and psychological, as it can drive persons affected and their family members into restricting participation in ways that can lead to poverty.

1.2.3. Interactions between stigma and poverty

Not surprisingly, leprosy and stigma can drive those affected into poverty or deepen existing poverty. The relationship between leprosy, stigma and poverty has been explored, among others, by Velema (2008) Ebenso et al. (2007) and Tsutsumi et al. (2007). Figure 1.1 offers an overview of the relationships between leprosy, stigma and poverty. How leprosy can lead to stigma has been explored above. Here I will explain how leprosy and stigma can lead to poverty.

![Leprosy, Stigma, Poverty Diagram](image-url)
Low self-esteem, self-isolation, exclusion and rejection by community members will have a negative impact on expenditure, earning capacity and thus the financial situation of the household (Calcraft 2006). As Withington mentioned, it will affect the socio-economic status of people affected by leprosy including their family (Withington et al. 2003). Although MDT is often provided for free, people affected by leprosy often still face direct and indirect health expenditure. A study in India showed that indirect costs accounted for 65% of total household costs for some cases (Chandler et al. 2015). Evidence is scarce, but children and young adults affected by leprosy may be refused education or decide to (temporarily) stop going to school (Nicholls et al. 2003). Employment can also be adversely affected by leprosy-related stigma (Calcraft 2006; Stevelink et al. 2011; Rao et al. 2008). Employees affected by leprosy might be dismissed by their manager or resign. Those with their own business might lose customers who shun interaction once they know about their leprosy status, and risk going bankrupt. Or they might anticipate negative consequences and close their business without anybody knowing about their illness. This situation, in some cases, has devastating effects on the social welfare of the people affected and their families (Shumin et al. 2003) and creates socio-economic problems for the family.

Leprosy and leprosy-related stigma can make people poorer, and, consequently, if it affects self-care, visits to the clinic or treatment adherence, can also worsen the physical consequences of leprosy. In addition, poverty can also worsen the stigma. In a way there is a double burden, because poverty is also stigmatized in itself (Somma et al. 2008). The poor have less power and gain less respect in the community (Withington et al. 2003).

1.2.4. Levels for stigma reduction

Stigma does not operate on one level. Heijnders and van der Meij identified five levels at which stigma can manifest itself (Heijnders & van der Meij 2006). These are also the five levels at which stigma-reduction interventions should be aimed (see Table 1.1.). Moreover, to be successful, interventions should be oriented towards multiple levels (Brown et al. 2003; Cross et al. 2011a; Link & Phelan 2001; Heijnders & van der Meij 2006).
Table 1.1. Stigma-reduction strategies at different levels (Heijnders & van der Meij 2006; Peters 2015)

<table>
<thead>
<tr>
<th>Levels for stigma reduction</th>
<th>Stigma-reduction interventions at this level aim to:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intrapersonal</td>
<td>Change individual characteristics such as knowledge, attitudes, behaviour, and self-concept; improve self-esteem, coping skills, empowerment and economic situation.</td>
</tr>
<tr>
<td>Interpersonal</td>
<td>Establish relationships between members of the patient’s interpersonal environment (family, work environment, friendship network).</td>
</tr>
<tr>
<td>Community</td>
<td>Increase knowledge regarding health conditions and stigma, increase community development skills and develop support networks within specific groups.</td>
</tr>
<tr>
<td>Organizational and institutional</td>
<td>Change to modify health and stigma-related aspects of an organization.</td>
</tr>
<tr>
<td>Governmental and structural</td>
<td>Enforce the protection of rights of people affected with a stigmatizing illness.</td>
</tr>
</tbody>
</table>

1.2.5. Stigma-reduction strategy

Leprosy-related stigma has been studied in-depth, but how to reduce it has received less attention (Heijnders & van der Meij 2006; Cross et al. 2011a; Cross et al. 2011b). Fortunately, increasing attention is now given to leprosy-related stigma-reduction strategies. Various leprosy-related stigma-reduction interventions have been undertaken and studied by researchers in different countries and settings (Weiss & Ramakrishna 2006; Heijnders & van der Meij 2006; Cross 2006; Cross et al. 2011; Cross et al. 2012; Peters, et al. 2015; Sermrittirong et al. 2014). The last systematic literature review about stigma-reduction interventions was conducted by Sermrittirong et al., who describe five strategies to reduce stigma: integrated services, community education, counselling, socio-economic rehabilitation and changing the name of the disease (Sermrittirong et al. 2014).
Most of these interventions attempt to deal with the causes of stigma, such as a lack of knowledge or awareness (Brouwers et al. 2011; Nsagha et al. 2011), negative attitudes in the community (Brown 2006; Varkevisser et al. 2009) and negative attitudes and behaviour in the health system (Arole et al. 2002). The SARI project, however, attempts to understand leprosy-related stigma and address stigma at different levels. Three different interventions were selected by the SARI project. Each of them has been described as promising in the literature on health-related stigma (Brown et al. 2003; Ebenso et al. 2007; Heijnders & van der Meij 2006). The first stigma-reduction intervention is ‘counselling’. The purpose of the counselling is to reduce stigma, but also to increase and expand people’s view of life, enlarge their repertoire of coping resources, and create the possibility of making choices for change in themselves, the situation and the environment (adapted from Yeo 1993). The second stigma-reduction intervention is ‘contact’. Contact refers to ‘all interaction between the public and persons affected, with the specific objective to reduce stigmatizing attitudes’ (Heijnders & van der Meij 2006). The third one is SED. In this intervention persons affected by leprosy are helped to find paid employment, offered vocational training, or offered some form of self-employment (e.g. microcredit) (Velema et al. 2008). All three interventions come to the fore in this thesis (Chapter 7), but the focus is on the SED intervention.

SED is a promising intervention, though evidence of its effectiveness is still scarce. A unique feature of SED interventions is that they do not focus on the causes of stigma such as lack of knowledge or altering negative attitudes. Instead, this intervention strengthens the capacities of affected individuals (Ebenso et al. 2007). Velema et al. undertook a literature review in 2008 and found nine programmes that provided some sort of socio-economic support to people affected by leprosy (Velema 2008). These SED interventions aim to improve the socio-economic status, mainly through the promotion of self-employment (e.g. tailoring, cycle repair), but also through support in housing and education. The SED intervention was selected based on experiences elsewhere that SED has the potential to improve people’s financial situation, self-esteem, respect/status in the community, acquisition of new skills and access to public institutions (Ebenso et al. 2010; Ebenso et al. 2007; Velema et al. 2008). Two concepts/theories relevant for the SED intervention specifically are described below.
CHAPTER 1

TWIN-TRACK APPROACH

The so-called ‘twin-track’ approach is a combined approach (see Figure 1.2) that is both disability-specific (it addresses special needs) and aimed at mainstreaming disability in general development (it treats disability as a cross-cutting issue). It was developed in the United Kingdom by the Department for International Development (DFID) to achieve greater equality for women (DFID 2000). The framework took into account women’s needs and rights in mainstream development co-operation, as well as supporting specific initiatives aimed at women’s empowerment (DFID 2000). The framework was also perceived to be very relevant for the work related to disability and has been widely adopted by development and disability-related organizations and translated into their activities. It is believed that the twin-track approach can ‘help provide an enabling environment for people with disabilities to achieve greater livelihood security, greater equality, full participation in the life of the community, and more independence and self-determination’ (DFID 2000). In the field of leprosy, a ‘twin track approach’ – ‘in which on the one hand, people affected by all kinds of disabilities receive mainstream services and are involved in mainstream development, while on the other hand special programmes are developed for people with particular types of disability where special needs are identified’ (p.31)– was recommended by Cornielje et al. (2008).

A twin-track approach

Addressing inequalities between disabled and non-disabled persons in all strategic areas of our work

Supporting specific initiatives to enhance the empowerment of people with disabilities

Equality of rights and opportunities for persons with disabilities

Figure 1.2. Twin-track approach (DFID 2000)

SOCIO-ECONOMIC TRANSFORMATION

A model developed by Pati and Lyngdoh (2010) shows how a microfinance intervention can lead to economic and social transformation (see Figure 1.3). Economic transformation, in this model, is described as having access to income and
savings, economic decision-making and household property among other benefits. A positive economic transformation can result in increased wellbeing and this is then the start of a so-called ‘social transformation’. Indicators of a social transformation include 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 1.3**: Socio-Economic Transformation Model (Pati & Lyngdoh 2010)

### 1.3. RESEARCH DESIGN

#### 1.3.1. Main research question and sub-questions

The main research question of this thesis is: **How is leprosy-related stigma understood and how can it be addressed with a SED intervention in an appropriate, effective and sustainable manner?**

This question can be divided into several sub-questions that correspond to different parts of this thesis.

Part one of this thesis is concerned with understanding leprosy. Leprosy can mean different things to different people. The question ‘what is leprosy?’ was therefore central in the beginning of this study. My colleagues and I put this question to people affected by the disease, but also to key persons in the community such as teachers, religious leaders, and health workers in an exploratory study. The aim was to reveal these different meanings, but also gain insight into the experiences, knowledge, feelings and emotions towards leprosy and people affected by leprosy, as these were important for the design of stigma-reduction interventions.

**Sub-question 1**: How is leprosy understood and what are the experiences of people affected by leprosy and other key persons in Cirebon District, Indonesia?
Almost every new approach aiming to reduce stigma is very likely to face challenges due to the complexities of leprosy-related stigma, which might in the end undermine the effectiveness of an intervention. Barriers could be the lack of knowledge about the causes and treatment of leprosy, severe emotional and physical impacts on individuals, a sub-optimal healthcare system, and/or the negative attitudes of healthcare providers. Hence, it was important to identify possible barriers in the study area and to find ways to deal with them.

**Sub question 2: What barriers exist and how can they be dealt with in the process of the implementation of SED?**

The second part of this thesis is about tools to measure the concept of stigma. This is important to be able to determine the effectiveness of the interventions. Different tools are needed to measure the experiences in different actors involved (i.e. stigmatized and stigmatizers). Measuring the level of health-related stigma using a quantitative approach has been done in different countries and different settings (Van Brakel 2006). In this study several tools were used, three of which had not yet been validated in the study area. One scale – the Berger HIV Stigma Scale – has frequently been used in the field of HIV/AIDS, but not yet in the field of leprosy (the adapted version is called SARI Stigma Scale (SSS)). In addition, the Social Distance Scale (SDS) and the Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CSS) needed to be validated.

**Sub-question 3: What is the cultural validity of the SSS among people affected by leprosy and of the SDS and EMIC-CSS among community members in Cirebon District, Indonesia?**

The third part of the thesis is concerned with the effectiveness of the SED intervention, but also with the effectiveness of the other interventions of the SARI Project. Based on the exploratory study a SED intervention was developed and implemented in a participatory way. The intervention aimed to create a social transformation.

**Sub-question 4: How effective is a SED intervention in improving the socio-economic status, reducing leprosy-related stigma, and in facilitating a social transformation in people affected by leprosy in Cirebon District, Indonesia?**
The SARI Project was initiated to develop and test the effectiveness of three stigma-reduction intervention strategies in the field of leprosy. Each intervention targeted a different level (intrapersonal, interpersonal and community), though effects were also expected on other levels. Three combinations of interventions are tested ‘Contact – Counselling’, ‘Counselling – SED’ and ‘SED – Contact’ for their effectiveness.

**Sub-question 5: What is the overall impact of the three pairs of leprosy-related stigma-reduction interventions in Cirebon District?**

Table 1.2 gives an overview of the study questions and shows in which chapters these questions are addressed.

<table>
<thead>
<tr>
<th>Research question</th>
<th>Chapter</th>
</tr>
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<tbody>
<tr>
<td>1. How is leprosy understood and what are the experiences of people affected by leprosy and other key persons in Cirebon District, Indonesia?</td>
<td>2</td>
</tr>
<tr>
<td>2. What barriers exist and how can they be dealt with in the process of the implementation of an SED?</td>
<td>3</td>
</tr>
<tr>
<td>3. What is the cultural validity of the SSS among people affected by leprosy and of the SDS and EMIC-CSS among community members in Cirebon District, Indonesia?</td>
<td>4</td>
</tr>
<tr>
<td>4. How effective is an SED intervention in improving the socio-economic status, reducing leprosy-related stigma, and in facilitating a social transformation in people affected by leprosy in Cirebon District, Indonesia?</td>
<td>5</td>
</tr>
<tr>
<td>5. What is the overall impact of the three pairs of leprosy-related stigma-reduction interventions in Cirebon District?</td>
<td>6</td>
</tr>
</tbody>
</table>
1.3.2. Research approach

In order to study and address the complex and persistent negative social experiences of people affected by leprosy and assess the effect of interventions, this study applied the transdisciplinary Interactive Learning and Action (ILA) approach. This approach brings together a wide range of opinions and draws on the knowledge of a broad set of actors.

The concept of transdisciplinary research, which dates from the 1970s, seeks to address the perceived mismatch between academic knowledge and the kind of knowledge required to respond to social problems (Hoffmann-Riem et al. 2008:3). Transdisciplinary research is:

*A new form of learning and problem-solving involving co-operation between different parts of society and science in order to meet complex challenges of society. Transdisciplinary research starts from tangible, real-world problems. Solutions are devised in collaboration with multiple stakeholders.* (Klein et al. 2001:7)

Unlike monodisciplinary, multidisciplinary and interdisciplinary research, transdisciplinary research deliberately integrates the ‘experiential knowledge of societal actors in the research and problem solving process’ (Cummings et al. 2013:11). Of the four types of research, transdisciplinary research has the highest form of integration (Stock & Burton 2011), and five of its widely shared features include responding to real, persistent global problems, involving multiple stakeholders, integrating different forms of knowledge, combining knowledge production and social problem solving, and the iterative process that follows emergent design (Cummings et al. 2013).

The transdisciplinary ILA approach was developed during the 1980s and 1990s by Bunders and Broerse (1991) in order to support more inclusive agricultural, health

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2 The research approach, research setting, description of the SARI Project, timeline and ethical considerations as described below including some of the tables and figures were developed by the three PhD students of the SARI project. These aspect have been described before in Ruth MH Peters doctoral thesis (Peters 2015). Section 1.3.2, 1.3.3, 1.3.5, 1.3.6, and 1.3.9. in my thesis draw heavily on her text.
and biotechnological innovations through interactive multi-stakeholder processes. It has been successfully applied and adapted in different fields and countries, including Bangladesh, the Netherlands, South Africa and Zimbabwe (Swaans et al. 2009; Caron-Flinterman 2006; Zweelhorst 2004; Betten et al. 2013). Its main characteristics are that beneficiaries participate actively from the outset, and that it promotes mutual trust and learning and integrates different forms of knowledge in a shared vision. The approach is roughly structured around five phases. The first three are called the reconnaissance in which a broad view of the issue and its characteristics is obtained prior to planning and implementation of interventions (see Figure 1.4.). Comprehensive description of this approach draws heavily on Peters (2015).

Figure 1.4. Action–research spiral (Kemmis & McTaggart 1988:154)

1.3.3. Study area and selection sub-districts

In 2011, Kabupaten Cirebon (Cirebon District) in Indonesia was selected as the area of research and project implementation. It has a relatively high number of new leprosy cases annually and – according to national experts – more leprosy-related stigma than in other districts, which no other initiatives address. Cirebon District is located on the north coast of West Java, bordering Central Java (see Figures 1.5. and 1.6). It covers an area of about 990,36 km² (Susanto 2012).
Figure 1.5. Location of Indonesia, the square shows West Java

Figure 1.6. West Java, location Cirebon District
Administratively, the district comprises 40 kecamatan (sub-districts), 412 desa and 12 kelurahan (both administrative villages) (Susanto 2012), which are in turn divided into dusun (hamlets), formerly rukun warga (RW) comprising a number of households or rukun tetangga (RT).. It was decided to separate the 40 sub-districts into an exploratory study area and an intervention/control area in order to ensure that the study-related activities (such as interviews) did not affect the baseline study. For the exploratory study, the 10 sub-districts selected were either fairly remote or had relatively few cases of leprosy. The remaining 30 sub-districts were randomly allocated to a paired intervention or control area (care as usual area) see Table 1.3 and Figure 1.7. The reason for pairing interventions was because of research findings suggesting that a combination of interventions is needed to address stigma (Heijnders & van der Meij 2006; Cross et al. 2011a).

<table>
<thead>
<tr>
<th>Exploratory study</th>
<th>Counselling Contact</th>
<th>Contact SED</th>
<th>SED Counselling</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ciwaringin</td>
<td>Pasaleman</td>
<td>Beber</td>
<td>Greged</td>
<td>Arjawinangun</td>
</tr>
<tr>
<td>Kaliwedi</td>
<td>Lemahabang</td>
<td>Babakan</td>
<td>Sumber</td>
<td>Ciledug</td>
</tr>
<tr>
<td>Karangwareng</td>
<td>Losari</td>
<td>Pabuaraan</td>
<td>Klangenan</td>
<td>Jamblang</td>
</tr>
<tr>
<td>Karangsembung</td>
<td>Astanajapura</td>
<td>Pabedilan</td>
<td>Sedong</td>
<td>Pangenan</td>
</tr>
<tr>
<td>Mundu</td>
<td>Depok</td>
<td>Gempol</td>
<td>Waled</td>
<td>Panguragan</td>
</tr>
<tr>
<td>Palimanan</td>
<td>Weru</td>
<td>Kedawung</td>
<td>Surenenggala</td>
<td>Plered</td>
</tr>
<tr>
<td>Susukan</td>
<td>Genung Jati</td>
<td>Kapetakan</td>
<td></td>
<td>Plumbon</td>
</tr>
<tr>
<td>Susukan Lebak</td>
<td>Tengah Tani</td>
<td></td>
<td></td>
<td>Gegesik</td>
</tr>
<tr>
<td>Talun</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gebang</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
1.3.4. Study population

The main study population of this study are people affected by leprosy and community members in Cirebon District. Community members include key persons such as health professionals, teachers, religious leaders and community leaders. For specific information about the study population, sample size and selection, I refer to the relevant chapters in this thesis.

1.3.5. SARI Project

This study is part of a larger project, the SARI Project (see Table 1.4 for an overview of the SARI team), which began in 2010 and was funded by the Netherlands Leprosy Relief (NLR), American Leprosy Missions (ALM), Sasakawa Memorial Health Foundation (SMHF) and effect:hope (formerly The Leprosy Mission Canada). The project’s main aim was to measure and compare the effectiveness of three stigma-reduction interventions: counselling, contact and SED. These three interventions address stigma primarily at the personal, interpersonal and community levels (see Box 1.1), each of which can have an impact on the other, as illustrated in Table 1.5.
<table>
<thead>
<tr>
<th>Name</th>
<th>Organization</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prof. Irwanto</td>
<td>Universitas Indonesia</td>
<td>Principle investigator/ Promotor</td>
</tr>
<tr>
<td>Prof. Joske F.G. Bunders</td>
<td>VU University Amsterdam</td>
<td>Principle investigator/ Promotor</td>
</tr>
<tr>
<td>Dr. Wim H. van Brakel</td>
<td>VU University Amsterdam and NLR</td>
<td>International coordinator/ co-promotor</td>
</tr>
<tr>
<td>Dr. Marjolein B.M. Zweekhorst</td>
<td>VU University Amsterdam</td>
<td>Social scientist/ co-promotor</td>
</tr>
<tr>
<td>Dr. Francisia S.S.E. Seda</td>
<td>Universitas Indonesia</td>
<td>Social scientist/ co-promotor</td>
</tr>
<tr>
<td>Dr. Rita Damayanti</td>
<td>Universitas Indonesia</td>
<td>Social scientist/ co-promotor</td>
</tr>
<tr>
<td>Dr. Beatriz Miranda-Galarza</td>
<td>VU University Amsterdam</td>
<td>Post-doctoral</td>
</tr>
<tr>
<td>Ms. Mimi Lusli</td>
<td>Universitas Indonesia</td>
<td>PhD student</td>
</tr>
<tr>
<td>Mr. Dadun</td>
<td>Universitas Indonesia</td>
<td>PhD student</td>
</tr>
<tr>
<td>Ms. Ruth M.H. Peters</td>
<td>VU University Amsterdam</td>
<td>PhD student</td>
</tr>
<tr>
<td>Mr. Yando</td>
<td>Universitas Indonesia</td>
<td>Administrator</td>
</tr>
<tr>
<td>Mrs. Yanti</td>
<td>SARI project</td>
<td>Local administrator</td>
</tr>
<tr>
<td>Mrs. Siti</td>
<td>SARI project and FKDC</td>
<td>RA</td>
</tr>
<tr>
<td>Mr. Rohman</td>
<td>SARI project and FKDC</td>
<td>RA</td>
</tr>
<tr>
<td>Mr. Solihin</td>
<td>SARI project and FKDC</td>
<td>RA</td>
</tr>
<tr>
<td>Mr. Oni</td>
<td>SARI project and FKDC</td>
<td>RA</td>
</tr>
<tr>
<td>Mr. Mujib</td>
<td>SARI project and FKDC</td>
<td>RA</td>
</tr>
<tr>
<td>Mr. Hasan</td>
<td>SARI project</td>
<td>RA</td>
</tr>
<tr>
<td>Mrs. Christine</td>
<td>SARI project</td>
<td>RA</td>
</tr>
<tr>
<td>Mr. Harry</td>
<td>SARI project</td>
<td>RA</td>
</tr>
<tr>
<td>Mr. Hadi</td>
<td>SARI project</td>
<td>RA</td>
</tr>
<tr>
<td>Mr. Ulum</td>
<td>SARI project</td>
<td>RA</td>
</tr>
</tbody>
</table>
### Table 1.5. SARI interventions and the primary (dark grey) and secondary level (light grey) they target

<table>
<thead>
<tr>
<th>SARI Interventions</th>
<th>Intra-personal</th>
<th>Inter-personal</th>
<th>Community</th>
<th>Organizational and institutional</th>
<th>Governmental and structural</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counselling</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SED</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contact</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Box 1.1. Brief descriptions of the three stigma-reduction interventions of the SARI Project

Socio-economic development (sometimes also called socio-economic rehabilitation)
The SED intervention was based on experiences elsewhere that SED will improve people’s financial situation, self-esteem, acquisition of new skills and access to public institutions (Ebenso et al. 2007; Velema et al. 2008; Ebenso et al. 2010). Through improvements in economic and living conditions, SED positively influences social interaction, which often results in positive changes in attitudes towards affected people. These in turn make it easier for an affected person to participate in community activities. Perceived stigma and self-stigma are expected to decrease. A twin-track approach was adopted to integrate people affected into mainstream business and to develop a customized intervention for people whose debts prevent them from seeking loans from formal financial organizations. Persons affected by leprosy enrolled in the SARI Project were offered loans, business training and/or other assistance to improve their livelihoods. They were encouraged to form groups in the community and appoint group leaders. Loans and other assistance were channelled through these groups, using the locally popular microfinance system. Two organizations managed the intervention: KOMIDA, a mainstream microfinance bank with stringent membership and repayment conditions, and the Disability Forum, a disabled people’s organization (DPO) in Cirebon that used a revolving loan fund and had more flexible repayment conditions. Other organizations like the District Social Welfare Office were involved other activities such as training.

Contact between community and persons affected by leprosy
The contact intervention is based on evidence from the field of mental health and HIV that contact with affected persons challenges negative stereotypes and reduces negative attitudes and behaviour among those taking part in the intervention (Brown et al. 2003; Brown et al. 2010). We organized so-called ‘contact events’ to create ‘contact’ (or a dialogue, interaction) between people affected by leprosy and community members at a local level, e.g. in schools, village halls and mosques (Peters et al. 2015). The research assistants of the SARI Project together with persons affected by leprosy were responsible for organizing the events and for ensuring that these fitted into and made optimal use of the local social structures and context. Based on an exploratory study conducted in Cirebon District, testimonies were chosen as the direct method, and participatory videos and comics made by people affected by leprosy as the indirect method to create this contact. The rationale for these choices was that they would optimize involvement of affected persons, enabling them to share their own stories and messages, that the testimonies and the development of participatory videos and comics on their own were expected to be empowering experiences for the participants, and that the development process would be relatively inexpensive, thus facilitating scale-up of the interventions. Providing medical information about leprosy was a key element during the contact events.

Counselling
The counselling intervention was selected because of experiences mainly in the field of HIV-related stigma (Cartoux et al. 1999; Sweat et al. 2000; Brown et al. 2003). Those living in the study areas allocated to the counselling intervention were offered the Rights-Based Counselling Module. This counselling practice and module was developed and adapted during the course of the project and integrates three different types of counselling (individual, family and group) and comprises five sessions (Lusli et al., in preparation). The module used elements of cognitive-behavioural therapy, is knowledge-based, because of a need for more factual knowledge about leprosy, and is rights-based because, as a result of stigma and discrimination, rights of persons affected are often violated. A professional counsellor provided the initial counselling, but the main implementation was by so-called peer and lay counsellors. These peer counsellors, selected from among previous counselling clients, and lay counsellors, e.g. staff from a local disabled person’s organization, were trained during a two-week course (Lusli et al. 2015). After the training, the peer and lay counsellors gave counselling to persons affected by leprosy under the supervision of a professional counsellor (Lusli et al. 2015). The counselling intervention actively involves persons affected by leprosy, and is low cost, because it is undertaken by volunteers. This increases the feasibility of replicating the intervention elsewhere.
1.3.6. Timeline

The SARI Project follows the five phases of the ILA approach. Since it aimed to measure the effect of the interventions, a baseline and final survey were organized. The instruments that were going to be used during the baseline and final survey were tested during the pilot and validation study before the start of the baseline. See Figure 1.8 for the timeline of the SARI Project.

![Timeline of SARI project](image)

Figure 1.8. Timeline of SARI project

1.3.7. Overview research methods

Measuring the concept of stigma is not easy, but observing and measuring stigma is crucial to the scientific understanding of it (Link et al. 2004). In this thesis stigma is assessed from two perspectives: the individuals who experience stigma (stigmatized) and the individuals who stigmatize (stigmatizers). The thesis uses mixed methods, as advanced by Van Brakel (2006). The mix of methods gives the opportunity to simultaneously generalize from a sample to a population and to gain a richer, contextual understanding of the concept of stigma and its reduction.

The exploratory study aimed to gain insights into the everyday experiences of people affected by leprosy and the perceptions of key persons in the community. In-depth interviews (IDI) and focus group discussions (FGDs) were used. The validation study aimed to assess the cross-cultural validity of three scales: SSS, SDS and EMIC-CSS. The framework for this cross-cultural validation study (see Figure 1.9) was developed using the model for cultural validity testing of Stevelink and van Brakel (2013) who integrated Herdman's model (Herdman 1998) with measurement...
property standards of Terwee et al. (2007). The effectiveness study aimed to assess the effect of the SED, counselling and contact intervention. Methods used included three different scales: SSS, PSS, and WHO-QOL BREF. Different software packages were used for data management and analyses. For specific methodological approaches and data analyses I refer to the relevant chapters in this thesis.

<table>
<thead>
<tr>
<th>Equivalence</th>
<th>Definition and when it achieved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conceptual Equivalences</td>
<td>Refers to how the underlying concept(s) of the scale are conceptualized in the new context and culture. It is achieved when the same relationship to the underlying concept(s) exists in both cultures, primarily in terms of domains included and the emphasis placed on the different domains.</td>
</tr>
<tr>
<td>Items Equivalence</td>
<td>Explores whether items are equally relevant and acceptable. It is attained when items estimates the same parameters of the concept(s) under study.</td>
</tr>
<tr>
<td>Semantic Equivalence</td>
<td>Is concerned with the language. It is achieved a similar meaning of words and concepts is tranferred and when similar effect on respondents is obtained.</td>
</tr>
<tr>
<td>Operational Equivalence</td>
<td>Concerns with the suitability of the questionnaire format, instructions and mode of administration. It is attained when these do not affect the result.</td>
</tr>
<tr>
<td>Measurement Equivalence</td>
<td>Acceptability of the psychometric properties, and is reached when the psychometric properties of the adapted version are acceptable.</td>
</tr>
</tbody>
</table>

Figure 1.9. Framework for this cross-cultural validation study (Stevelink et al. 2013; Herdman 1998)

Table 1.6 provides an overview of the data collected. Different software packages were used for data management and analyses. For the qualitative data analyses I used N-Vivo 9 and 10, for the quantitative data entry I used Epi Info for Windows, version 3.5.3, for the quantitative data analysed I used Stata 12.1 and SPSS 21. For specific methodological approaches and data analyses I refer to the relevant chapters in this thesis.
### Table 1.6. Overview research methods

<table>
<thead>
<tr>
<th>Study</th>
<th>Methods</th>
<th>Population</th>
<th>Chapter</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Exploratory study</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>53 IDI (series of 3)</td>
<td>Persons affected by leprosy or caretakers of persons affected by leprosy</td>
<td>2-5</td>
<td></td>
</tr>
<tr>
<td>17 FGDs (2-12/group, in total 97)</td>
<td>Persons affected by leprosy, neighbours, community and religious leaders, mothers, teachers, health professionals</td>
<td>2-5</td>
<td></td>
</tr>
<tr>
<td><strong>Validation study</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 FGD</td>
<td>Persons affected by leprosy</td>
<td>4, 5</td>
<td></td>
</tr>
<tr>
<td>20 testing EMIC-CSS, SDS and SSS</td>
<td>Persons affected by leprosy and others</td>
<td>4, 5</td>
<td></td>
</tr>
<tr>
<td>&gt;100 piloting EMIC-CSS, SDS and SSS</td>
<td>People affected by leprosy and community members</td>
<td>4, 5</td>
<td></td>
</tr>
<tr>
<td>292 validation +93 test retest SSS</td>
<td>People affected by leprosy</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>72 validation + 46 test retest EMIC-CSS and SDS</td>
<td>Community members</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td><strong>Effectiveness study</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>53 Semi-structured interviews</td>
<td>Participants participatory SED</td>
<td>6, 7</td>
<td></td>
</tr>
<tr>
<td>Notes workshops/meetings</td>
<td>SARI team and stakeholders</td>
<td>6, 7</td>
<td></td>
</tr>
<tr>
<td>65 Profile observations</td>
<td>People affected by leprosy SED client</td>
<td>6, 7</td>
<td></td>
</tr>
<tr>
<td>2 SED reports</td>
<td>Research assistant</td>
<td>6, 7</td>
<td></td>
</tr>
<tr>
<td>17 FGDs</td>
<td>SED client, FKDC staff, KOMIDA staff, Leprosy officers &amp; programmer</td>
<td>6, 7</td>
<td></td>
</tr>
<tr>
<td>Survey EMIC-CSS and SDS</td>
<td>Community members</td>
<td>6, 7</td>
<td></td>
</tr>
<tr>
<td>213* (baseline)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>375* (final survey)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Survey SSS, PSS, WHO QoL BREF</td>
<td>People affected by leprosy</td>
<td>6, 7</td>
<td></td>
</tr>
<tr>
<td>394* (baseline)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>237* (final survey)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* After omitting files due to missing values or to a language other than *Bahasa Indonesia*. 
1.3.8. Validity of the data

In this study, multiple strategies were used to enhance the validity of the data. The strategies comprised the following:

Methodological triangulation: to understand leprosy-related stigma and to assess the impact of the interventions a mix of methods – sometimes several qualitative methods and sometimes quantitative and qualitative methods – were applied.

Investigator triangulation: multiple researchers were involved in the design of the study, the data collection, analyses and interpretation of the data.

Member checking: in the exploratory study three extra FGDs were organized to check the accuracy of the data and preliminary results.

Feedback: at several moments in the projects feedback was provided by researchers and practitioners not involved in the project. The SARI Project has a Steering Committee with five international members who met four times – twice in the Netherlands and twice in Indonesia – during the course of the project. Two independent researchers undertook a mid-term review. Finally, representatives from donor agencies attended presentations and discussions at which feedback was given.

Cross-culturally validated tools: the main tools used to assess the impact of the interventions were piloted and cross-culturally validated during the course of the SARI Project (see also Chapter 4-5).

Recorded data: audio recorders were used to record the data and these were transcribed and translated into English.

Saturation: in the SARI Project, saturation of the data was sought as much as possible. Interviews and focus group discussions were generally conducted until no new issues arose.
1.3.9. Ethical considerations

The study presented in this thesis was approved by The Ethics Committee of Atma Jaya University, the Sub-Directorate for Leprosy and Yaws, the Ministry of Health, Provincial Health Office, West Java and the District Health Office, Cirebon District. The study guaranteed the confidentiality of the information provided by the participants. Only the researchers directly involved in the data collection and analysis had access to data records. If required, only anonymized information was made available to others.

Participants were given detailed written and/or oral information about the SARI Project prior to the start of the data collection and/or enrolment in the interventions. The control area in this study is a care as usual area. Recruitment was undertaken in close collaboration with health professionals at the community health clinics, who frequently paired up with the RAs during home visits. Written informed consent was obtained from participants, who had the right to decide whether they wanted to participate in the study and could resign at any point (self-determination).

As far as possible, interviews were conducted in private locations away from other participants, health professionals, family members and other researchers. Research assistants were trained in how to conduct an interview and they also learned how to deal with emotions that might arise as a result of encountering and sharing the sometimes harsh and painful experiences that being affected by leprosy evoked. Sometimes interviewees preferred to talk about ‘skin disease’ or ‘my disease’ rather than leprosy, and their preferred term was used throughout the interview. The interviewers were instructed to address any questions the interviewee might have about leprosy at the end of the interview. Occasionally, interviewees being treated for or cured of leprosy were unaware that they were affected by the disease. The health professional responsible had not told them they had the disease when they were diagnosed and started treatment but referred, for instance, to a skin disease. Depending on the context, the RAs informed the person that they were or had been affected by leprosy and provided the necessary information or continued the interview using the interviewee’s preferred terms. The interviewees were offered no incentives other than a small token of appreciation such as a drinking mug or
t-shirt, in particular if they were interviewed more than once. No incentives were provided to participants in the interventions. For the lay and peer counsellors and the participants of the two participatory video activities in contact and counselling intervention an exception was made in order to compensate for lost earnings.

1.4. OUTLINE OF THESIS

In the previous section, I have described the problem, the main theoretical concepts and the research design.

Part 1 is concerned with understanding of leprosy-related stigma and barriers for the implementation of stigma-reduction interventions. Chapter 2 provides insights into the experiences of persons affected by leprosy and the meaning they and key persons give to leprosy. Chapter 3 describes the barriers for a SED intervention and how to deal with them.

Part 2 is about the validity of scales to measure stigma. In Chapter 4 I describe the cross-cultural validation of adaptation of Berger HIV stigma scale for measuring aspects of leprosy-related stigma. Chapter 5 describes the cross-cultural validation of two instruments to assess aspects of community stigma: EMIC and Social Distance Scale.

Part 3 is concerned with the implementing and assessing the impact of stigma-reduction interventions. In Chapter 6 the impact of the SED intervention is assessed. In this intervention we applied a twin-track approach to microcredit and income-generating skills to people affected by leprosy. In Chapter 7 the impact of three interventions among people affected by leprosy in the intervention area is detailed.

Part 4 focuses on the discussion, conclusions and reflections. In Chapter 8 I will draw the final conclusions regarding the design, implementation and assessment of stigma-reduction interventions. The implications of the findings presented in this thesis are discussed and placed in a broader context.
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