Returning the rights of people affected by leprosy-related stigma through counselling: developing, implementing and assessing a rights-based counselling module in Cirebon district, Indonesia

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No. 978-602-60299-0-4

Design
Eriando Rizky Septian

Printing
Mandaka Mitra Media

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ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad Doctor aan de Vrije Universiteit Amsterdam, op gezag van de rector magnificus prof.dr. V. Subramaniam, in het openbaar te verdedigen ten overstaan van de promotiecommissie van de Faculteit der Aard- en Levenswetenschappen op maandag 21 november 2016 om 13.45 uur in de aula van de universiteit, De Boelelaan 1105

door

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geboren te Jakarta, Indonesië
promotor: prof.dr. J.F.G. Bunders-Aelen
copromotoren: dr. M.B.M. Zweekhorst
               prof.dr. Irwanto
I would like to thank Visio for providing financial support for editorial services and all editors for helping me write this thesis.
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Chapters 2 to 8 are based on articles that have been published in, accepted by or submitted to international peer reviewed journals. I have maintained the 'we' form in the co-authored articles.

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<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<td>ALM</td>
<td>American Leprosy Missions</td>
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<td>CBR</td>
<td>Community-Based Rehabilitation</td>
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<td>CBT</td>
<td>Cognitive Behavioural Therapy</td>
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<td>CHC</td>
<td>Community Health Centre</td>
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<td>CRN</td>
<td>Counsellor Reflection Notes</td>
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<td>DFID</td>
<td>Department for International Development (United Kingdom)</td>
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<td>DHO</td>
<td>District Health Office</td>
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<td>DPO</td>
<td>Disabled People's Organisation</td>
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<td>EMN</td>
<td>Evaluation Meetings notes</td>
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<td>FCN</td>
<td>Family Counselling Sessions Notes</td>
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<td>FGD</td>
<td>Focus Group Discussion</td>
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<td>FKDC</td>
<td>Forum Komunikasi Difabel Cirebon</td>
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<td>GCN</td>
<td>Group Counselling Sessions notes</td>
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<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>ICESCR</td>
<td>International Covenant on Economic, Social and Cultural Rights</td>
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<td>IDI</td>
<td>In-Depth Interviews</td>
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<td>ILA</td>
<td>Interactive Learning Approach</td>
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<td>LC</td>
<td>Lay Counsellors</td>
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<td>MDT</td>
<td>Multi-Drug Therapy</td>
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<td>MoH</td>
<td>Ministry of Health</td>
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<td>NFC</td>
<td>Notes of Family Counselling</td>
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<td>NGO</td>
<td>Non-Governmental Organisation</td>
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<td>NLCP</td>
<td>National Leprosy Control Programme</td>
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<td>NLR</td>
<td>Netherlands Leprosy Relief</td>
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<td>PCN</td>
<td>Personal Counselling notes</td>
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<td>PHO</td>
<td>Provincial Health Office</td>
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<td>PPRBM Solo</td>
<td>Community-Based Rehabilitation Development and Training Centre Solo</td>
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<td>PRN</td>
<td>Participant Reflection Notes</td>
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<td>PSS</td>
<td>Participation Scale Short</td>
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<td>RA</td>
<td>Research Assistant</td>
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<td>RBCM</td>
<td>Rights-Based Counselling Module</td>
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<td>RT</td>
<td>Rukun Tetangga or neighbourhood groups</td>
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<td>RW</td>
<td>Rukun Wanga or hamlet or community groups</td>
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<td>SARI project</td>
<td>Stigma Assessment Reduction of Impact project</td>
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<td>SD</td>
<td>Standard Deviation</td>
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<td>SED</td>
<td>Socio-Economic Development</td>
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<td>Acronym</td>
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<td>SMHF</td>
<td>Sasakawa Memorial Health Foundation</td>
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<td>SSS</td>
<td>SARI Stigma Scale</td>
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<td>STEP</td>
<td>Stigma Elimination Program</td>
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<td>TLMC</td>
<td>The Leprosy Mission Canada (now effect:hope)</td>
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<td>TR</td>
<td>Tape Recordings</td>
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<td>UDHR</td>
<td>Universal Declaration of Human Rights</td>
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<td>UI</td>
<td>Universitas Indonesia</td>
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<td>UN CRPD</td>
<td>United Nations International Convention on the Rights of Persons with Disabilities</td>
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<td>UN</td>
<td>United Nations</td>
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<td>WHO</td>
<td>World Health Organization</td>
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<td>WHO-QOL BREF</td>
<td>World Health Organization Quality of Life instrument</td>
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Chapter 1

Introduction

‘Can I be cured?’, ‘Have I been cured?’, ‘Why can I not be close to my grandson?’, ‘Why do they ban me from feeding my baby?’, ‘Why do they look at me?’, ‘Why am I dismissed from my job?’, ‘I am ill, I do not have any rights, right?’ , ’Do I have rights to talk at home?, ’I am an affected person, may I go to school? And may I go to work?’

These were some of the questions I was asked when I interviewed people affected by leprosy in Cirebon District, West Java, Indonesia. I was really surprised; I was expecting to hear stories of shyness, shame and perhaps discrimination and exclusion, but did not expect to hear how leprosy-related stigma brutally infringed on people’s rights.

Leprosy is an infectious disease which affects primarily the skin, superficial peripheral nerves, the eyes, and certain organs. Since the 1970s leprosy is effectively treated by multi-drug therapy (MDT). If not treated in time, leprosy can lead to nerve damage that can result in sensory, motor and autonomic nerve impairments, which in turn may lead to the typical chronic wounds, disfigurement and in some cases blindness. Impairments on hands and feet – if they have appeared – will not disappear. But most harmful is the leprosy-related stigma. People affected by leprosy tend to stigmatize themselves and they are stigmatized by others. It is a cycle. I also heard stories of hope and a will to continue life. The people affected by leprosy that were interviewed wanted to do what other people were doing. But they were weak and passive and so I wondered how they could feel enough energy and spirit to make the changes in their life, to change themselves and the people around them that stigmatize them.

It brought back memories of the time I was diagnosed with retinitis pigmentosa. When my doctor stated that my eyes could no longer see, I stigmatised myself. I felt no confidence and felt unsafe. In particular I was ashamed, worried, and feared living with blindness. People stigmatised me by looking at me, gossiping about me and avoiding me. All because of my blindness. More sadness came when I dropped out of school, when I lost good friends and when I stayed at home, taking medicine (see Reflective note for more details).

The central themes of this thesis are leprosy, stigma and counselling. Leprosy has long been a stigmatised disease in society. The stigma can have negative effects on an individual’s quality of life. Stigma-reduction is important and really necessary to help people deal with health-related stigma. Studies suggest there are promising approaches to deal with stigma reduction (Cross, Heijnders, Dalal, Sermrittirong, & Mak, 2011a, 2011b; Heijnders & van der Meij, 2006; Graham Scambler, Heijnders, & van Brakel, 2006). Counselling is mentioned as one of the potential effective stigma reduction interventions (Brown, Macintyre, & Trujillo, 2003; Heijnders & van der Meij, 2006). However research on leprosy-related stigma and counselling, specifically in
Indonesia – which ranks third in number of new cases after Brazil and India – is still lacking. Ultimately, the counselling aims to guide and aid people affected by leprosy to feel hope, take initiatives and experience less internalized stigma. In this thesis, I seek to understand under what conditions counselling is an effective intervention strategy to reduce leprosy-related stigma.

The research described in this thesis is part of the Stigma Assessment Reduction of Impact (SARI) project that ran from 2010 to 2015 in Cirebon District, Indonesia. In this project the effectiveness of three stigma-reduction interventions was studied. Three PhD students worked together in a larger team on the design and implementation of this study. Each PhD student focussed on one of interventions. Mr. Dadun focussed on the socio-economic development (SED) intervention, Dr. Ruth Peters focussed on the contact intervention, and I focussed on the counselling intervention. We worked closely together to understand the complexity of leprosy-related stigma and create synergies in the research work undertaken.

This chapter begins with a section in which I describe the problem of leprosy-related stigma and introduce the main aim of this thesis. I then introduce the theoretical concepts relevant for this thesis, followed by the research questions and research design. This chapter ends with an outline of the thesis.

1.1. The subtlety, brutality, persistence and complexity of leprosy-related stigma

Leprosy and leprosy-related stigma are for many affected people huge and complex problems. Despite the fact that nowadays effective medication is available to cure leprosy, and that as a result, major achievements in the control and management of leprosy have taken place, new leprosy cases are found every day in countries such as Brazil, India, Indonesia, Nepal, Ethiopia, Nigeria and Sri Lanka. In 2014, there were 213,899 registered cases in the world and the new case detection rate was 3.78 per 100,000 population (WHO, 2015). In Indonesia, there were 17,025 new cases in 2014 (see Box 1.1.). These people suffer, both due to the ailments and the stigma related to the leprosy. Both influence their lives enormously. Stigma manifestations and effects on people affected by leprosy may differ depending on the severity of impairments, a person's sex, social status and age (Vlassoff et al., 1996; Try, 2006; Rao et al., 1996; Shale, 2000; Zodpey et al., 2000; Oliveira, 1997; Morrison, 2000; van Brakel et al., 2012; Varkevisser et al., 2009; Raju and Reddy, 1995; Heijnders, 2004b, 2004a; Boku et al., 2010; Leekassa et al., 2004; Opala et al. 1996).
Box 1.1. Leprosy in Indonesia

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

Leprosy limits the opportunities available to people affected by leprosy in terms of education, employment, marriage and family life, health care, housing and even religion (Nicholls et al. 2003; van Brakel et al. 2012; Schuller & van Brakel 2010; Try 2006; Vlassoff et al. 1996; Raju & Reddy 1995). For example, leprosy may have a negative effect on marriage opportunities and can lead to divorce. There is also evidence that schools have been known to refuse entry to children affected by leprosy (Nicholls et al., 2003). Leprosy also has an adverse influence on employment prospects and opportunities to run businesses (Calcraft, 2006; Rao et al., 2008; Stevelink et al., 2011). People affected by leprosy can lose their jobs or might be refused employment, while the self-employed sometimes lose customers (van Brakel & Miranda-Galarza 2013). When people with leprosy become unemployed, they are no longer able to support their families, losing familial and community respect. In addition, they might not be permitted to take part in religious activities (Rao et al., 2008).

Shame can also stop people from seeking treatment (Rafferty, 2005). Delay in seeking treatment can lead to deformities and disabilities. In turn, deformities and disabilities reinforce stigma, perpetuating the vicious cycle. Patients being treated for leprosy may decide to stop attending clinics or stop taking their medications (non-compliance) because they refuse to accept their health status or because they are frightened of being rejected by the community. Even when they are cured, stigma can continue to hinder the resumption of normal life. Negative perceptions of leprosy can continue to represent a barrier to reintegration in family life, employment and communities (Rafferty, 2005).

Leprosy and leprosy-related stigma have been found to cause anxiety, emotional stress and depression (van Brakel 2006; Leekassa et al. 2004; Tsutsumi et al. 2004; Tsutsumi et al. 2007; Weiss et al. 1992) and can lead to suicide, attempted suicide and suicidal ideation (Behere, 1981; Leekassa et al., 2004; Nishida, Nakamura, & Aosaki, 2006). For example, a study in Ethiopia found that suicidal ideation was three times higher in leprosy patients than other patients (Leekassa et al., 2004). People affected by leprosy may also try to hide the disease to prevent negative reactions from others (Heijnders, 2004; Kaur & Ramesh, 1994; Vlassoff et al., 1996). Although this might avoid stigma, it can also place an additional strain on the person affected by leprosy (Pachankis, 2007). We therefore conclude that leprosy-related stigma effects many aspects of the daily life of people affected by leprosy and has considerable psychosocial effects.
Family members, neighbours and friends of persons affected by leprosy can also be stigmatized in a phenomenon known as ‘courtesy stigma’ which can lead to social and economic losses (Barrett, 2005) and reduced marriage opportunities (van Brakel et al. 2012; Schuller & Brakel 2010; Try 2006). In efforts to cope with this, persons affected by leprosy might decide to isolate themselves to protect their family or even to leave home (Harvinder Kaur & van Brakel, 2002; Try, 2006). Related stigma, thus, poses challenges for people affected who live their daily life in seclusion, feel worried about their condition and are uncertain about the role they can play in their family and in their community. But there are also challenges for people associated with the person affected by leprosy. What can the family do? How can they assist?

Why is it that stigma is that subtle, brutal, persistent and complex? Decades of stigma research have been helpful in analysing the causes and the complexity and relations between them. Many factors contribute to the stigma of leprosy, and these vary across continents and communities. In each community, there is a complex mix of reasons why leprosy is a feared, shameful and stigmatizing disease. Some of the more common reasons that cause stigma are, among others, beliefs about the causation of leprosy, idea that leprosy is a death sentence, fear for contagion and disability and deformities (See Box 1.2.). The question is, do these insights on the causes help to deal with the problem of stigma? What is needed to change the status quo and improve the quality of life of the persons affected, their family and the community? What is needed to reduce shame and increase their participation in social economic life? Although insights on the causes are of tremendous value, they do not specify the exact route to follow in order to reduce stigma.

**Box 1.2. Six main causes of leprosy-related stigma (Rafferty, 2005; Rao, 2010; Sermrittirong & van Brakel, 2014)**

**Beliefs about the causes of leprosy.** Some groups believe that leprosy is a judgment of God, or the Gods, for wrongdoing. People with leprosy are avoided as they are seen as sinful, and those around them do not want to incure that wrath.

**Death sentence.** Another factor feeding in to the folklore of leprosy is that until the 1940s, there was no effective cure. This meant that contracting leprosy was a death sentence, with disability and deformity progressing until one finally succumbed.

**Fear of contagion.** Leprosy is often perceived as a very infectious disease, but sometimes also as a genetic disease. In the past - in certain epidemiological settings - leprosy ran in families to the extent that many authorities considered it an inherited rather than an infectious disease. So marriage into a leprosy family was forbidden.

Disability and deformity. In some forms of leprosy, there is a characteristic facial appearance that marks out a patient as having the disease as the skin becomes ridged and thick and the nose wider.

**Odor.** Some patients with leprosy may have a distinctive odor caused by infected ulcers. This smell can be nauseating and is made worse in cases where communities do not allow people with leprosy to wash in communal water.

**Self-stigmatization.** People with leprosy may become ashamed, possibly because of local attitudes and deformity, and may isolate themselves from society, thus perpetuating the idea that leprosy is something shameful to be hidden away. Patients may find it difficult to value themselves and have a positive self-image. The self-loathing associated with leprosy can be permanent, persisting after the disease is cured.
Several options for stigma reduction have been described: Community-Based Rehabilitation (CBR) in India (Gershon & Srinivasan, 1992; Raju, Rao, & Mutatkar, 2008), self-care groups in Ethiopia (Benbow & Tamiru, 2001), and SED in Nigeria and Nepal (Cross & Choudhary, 2005; Ebenso et al., 2007). But one of the most promising interventions is counselling (Brown et al., 2003; Heijnders & van der Meij, 2006). Counselling is defined by Yeo (1993) as a collaborative process in which the counsellor or psychologist facilitates the expansion of people's view of life. But also enlarges their repertoire of coping resources and enables them to make choices for change in themselves, the situation and the environment (Yeo, 1993). A pilot group counselling for people affected by leprosy has been described as an efficient and productive method in Nepal (Floyd-Richard & Gurung, 2000). Examples of counselling for stigma reduction can be found in the field of HIV/AIDS and mental health (Brown et al., 2003; Dewing et al., 2013; Rajaraman et al., 2012; Seaton, 2003; Thornicroft, Brohan, Kassam, & Lewis-Holmes, 2008). But many questions remain. How to reach people affected by leprosy? How to deal with their characteristics? And most importantly how to develop and implement an intervention that is effective in creating a life more full and fulfilling?

The overall aim of this thesis is to understand conditions under which counselling is an effective intervention to reduce leprosy-related stigma.

1.2. Theoretical concepts

This section presents the core concepts used in this thesis – stigma and counselling – and the way to assess its impact.

1.2.1. Stigma

The concept of stigma has changed over time. At first, stigma was seen more as a physical attribute (Goffman, 1963). Nowadays, the emphasize lies much more on stigma as a social process and thus goes beyond the individual body (van Brakel 2003). I will use a frequently applied definition of health-related stigma that acknowledges this focus. Health-related stigma is:

* 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)

To differentiate between different types of stigma, Weiss (2008) extended the Hidden Distress Model of Scambler (1998). He identified six types of stigma. There are three types in the so-called ‘stigmatizers’: accepted, endorsed and enacted. There are also three types in the persons that are stigmatized: anticipated, internalized and/or enacted stigma. For this thesis the types of stigma in the ‘stigmatized’ are important (Jacoby, 1994; Scambler, 1998). The latter refers to the experience of discrimination, and is also called experienced stigma. Anticipated stigma, also called perceived
stigma, is the fear of being discriminated against. Finally, internalized or self-stigma is the stigma people apply to themselves. Livingston and Boyd defined internalised stigma 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)

It is an internalized perception of being devalued or ‘not as good as’ another individual, and is seen as a source of anguish and unhappiness (Scambler 1998).

1.2.2. Purpose of the counselling and assessing the impact of 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). These last elements are expected to reduce stigma in an indirect way. To assess whether this purpose is achieved, stigma itself needs to be assessed.

It is not easy to assess a complex concept as stigma (Cross et al., 2011a). In this thesis I apply mixed methods to get an in-depth understanding of the effects of the counselling and to be able to generalize the findings (see next section), and make use of tools that are (or could easily be) validated for the local context and that would allow me or future researchers to compare the results with studies in other countries. With the help of three scales – SARI Stigma Scale (SSS), Participation Scale Short (PSS) and WHO Quality of Life –BREF (WHO-QOL BREF) – it is possible to get an idea of (changes in) stigma, participation restrictions and the quality of life of people affected by leprosy. Table 1.1. gives the relationship between the purpose of the counselling and the concepts used to assess whether this purpose is achieved.

Table 1.1. Aims of counselling and concepts to measure the impact

<table>
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<tr>
<th>The counselling specifically aims to:</th>
<th>Impact is measured with concepts of:</th>
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<tr>
<td>Reduce stigma</td>
<td>Stigma (internalized, anticipated, enacted and disclosure concerns) → SSS</td>
</tr>
<tr>
<td>Increase the expansion of people’s view of life</td>
<td>Participation restrictions → PSS</td>
</tr>
<tr>
<td>Enlarge their repertoire of coping resources</td>
<td>Quality of life → WHO-QOL–BREF</td>
</tr>
<tr>
<td>Create the possibility of making choices for change in themselves, the situation and the environment</td>
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To justify the choice of the concepts ‘participation’ and ‘quality of life’, some studies that have explored and assessed the relationship between these concepts and stigma are discussed here. Studies in India, Philippines and the Netherlands have shown that leprosy and in particular
leprosy-related impairments can negatively affect someone’s participation in life (Boku et al., 2010; Slim, Van Schie, Keukenhkamp, Faber, & Nollet, 2010; Stevelink et al., 2011). In Indonesia this association was studied and confirmed. A study of van Brakel et al. showed that 60% of the people with a leprosy-related impairment experience participation restrictions (van Brakel et al., 2012). Quality of life is another well-known overall measurement. The effect of leprosy or leprosy-related stigma on quality of life is interesting but has been hardly studied and when it is done the results are mixed. Brouwers et al. did not find a significant association in a multivariate analysis on data from East Nepal (Brouwers, Brakel, & Cornielje, 2011). In contrast, Tsutsumi et al. did find an association between perceived stigma and QoL in Bangladesh (Tsutsuni et al., 2007). By assessing stigma, participation restriction and quality of life we hope to get a broad impression of the impact of the counselling intervention. Although not designed to assess the effect of interventions, existing scales that measure the concept of stigma, participation (restrictions) and quality of life allow us to measure the impact of the counselling practice in a quantitative manner. Also in the qualitative assessment I will focus on these concepts.

1.2.3. Characteristics of the counselling approach

In order to deal with the complexity of leprosy-related stigma, the theoretical framework of this study combines several approaches. The counselling developed in this study makes use of cognitive behavioural therapy (CBT) and is also knowledge-based, rights-based and low cost. Each element is elaborated below.

*Cognitive Behavioural Therapy*

CBT (Dobson, 2010; Glickman, 2009; Kuyken, Padesky, & Dudley, 2009; Taylor, 2006) is a counselling approach with a variety of counselling practices and different aims, including empowering those affected. It is ‘solution-focussed’, ‘action-oriented’, relatively brief in nature and deals with problems clients face in their daily life (Dobson, 2010; Glickman, 2009; Kuyken et al., 2009; Taylor, 2006). A number of studies describe the contribution of CBT in empowering clients to improve their self-awareness, self-image, self-confidence and capacity for taking initiatives and making change (Corrigan & Calabrese, 2005; Glickman, 2009; Hall & Tarrier, 2003).

*Knowledge-based*

The counselling approach is knowledge-based, because knowledge plays a very important role in dealing with misunderstandings with regard to causes and consequences of leprosy (Croft & Croft, 1999; van der Broek, O’Donoghue, Ishengoma, Masao, & Mbega, 1998). Some medical aspects of leprosy are described in Box 1.3. Next to the use of knowledge as medical information in counselling, knowledge is also important to tailor the CBT towards the characteristics and conditions of the clients and their environment. For the design of stigma reduction interventions, Yang et al. underline the importance of taking into consideration the ‘everyday lives and the actual difficulties that stigmatized individuals face’ (2007:1533). Hence, these everyday
experiences and difficulties need to be known so that interventions can be tailored to the local circumstances.

**Box 1.3. Medical aspects of the disease leprosy**

The disease leprosy is caused by *Mycobacterium leprae*. *Mycobacterium leprae* causes a chronic granulomatous infection of the skin and peripheral nerves. The period of incubation varies, but is on average believed to be between two and five years (Hastings, 1994). Diagnosis is clinical and is made when the patient has at least 1 of the following cardinal signs specified by the WHO: hypopigmented or erythematous macules with sensory loss; thickened peripheral nerves; or positive acid-fast skin smear or skin biopsy with loss of adnexa at affected sites. Leprosy affects primarily the skin, superficial peripheral nerves, the eyes, and certain organs (e.g., the testicles). A disseminated skin condition is often the reason patients seek care, although they may also complain of numbness and other types of paresthesia or systemic signs such as fever and weight loss (Eichelmann et al., 2012).

In the 1970s MDT was introduced to treat leprosy. Since, 1995 MDT is provided free to persons affected in leprosy-endemic areas (WHO, 2005). Transmission of the disease to others is unlikely after MDT is started (WHO, 2009). A common side-effect of the medication is the temporary darkening of the skin due to the clofazimine component in MDT.

Important complications of leprosy are immunological phenomena called leprosy reactions. A person affected by leprosy with an anaesthetic hand or foot needs to be examined periodically and repeatedly, and taught about appropriate footwear and how to care for the feet and hands. Leprosy should not be a life-threatening disease. When death occurs, it is the result of secondary infections (pneumonia and tuberculosis), amyloidosis, and/or kidney failure (Eichelmann et al., 2012).

**Rights-based approach**

In 1948, the United Nations General Assembly adapted the Universal Declaration of Human Rights (UDHR) as a common standard of achievement for all peoples in all nations (UN, 1948). Covenants were made such as the International Covenant on Economic, Social and Cultural Rights (ICESCR) which is concerned with labour rights, rights to social security, right to family life, right to an adequate standard of living, right to health, right to education and right to participate in cultural life (UN, 1966). Conventions such as the Convention on the Rights of Persons with Disabilities were also developed. The purpose of this convention is ‘to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity’ (UN, 2006) (For more information on disability see Box 1.4. and for more information on leprosy and rights see Box 1.5.).

A rights-based approach is used to remind the client that even though they have or had an illness they retain their dignity and have the right to eat, drink, make friends, love, share their opinion, make decisions, have medical treatment and ask questions to health professionals about their disease as declared in the human rights formulated in 1948 (UN, 1948). Discussions about rights are used to facilitate the process of change in which stigma is reduced and to explore opportunities for a fulfilling life. Dishonouring someone’s dignity and inequality due to illness are violations of human rights.
Box 1.4. Disability

The WHO (2011) highlights that about 15% of the world population has some form of disability. It is important to have a clear understanding of the concept of disability which has changed over time. Shifts have occurred for example in the move from a medical model to social model, from a charity model to the human rights framework, from an individual approach to community approach, and from exclusion to inclusion. The WHO (2012) describes disabilities as an umbrella term covering impairments, activity limitations and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual while executing a task or action, while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives. Moreover, people with a disability have the same health needs as non-disabled people, but people with disabilities often face barriers in accessing the health and rehabilitation services they need (Disabled World, 2009).

Box 1.5. Rights and leprosy

On the 18th June 2008 the United Nations Human Rights Council unanimously adopted a resolution on ‘The elimination of discrimination against persons affected by leprosy and their family members.’ This historic resolution was sponsored by 59 member states and made specific reference to key earlier documents, namely the UDHR (UN, 1948) and the ICESR (UN, 1966). The 17th International Leprosy Congress in Hyderabad in 2008 highlighted the increasing importance of the issue of leprosy and human rights with workshops, presentations and plenary sessions on the topic. And yet, stigma and discrimination remain widespread for people affected, their families, and communities. Negative attitudes are perpetuated through ignorance, fear, laws, the media and social exclusion. Health workers, in spite of their knowledge, may often be the worst offenders. In many countries laws remain that cite leprosy as grounds for divorce, non-inheritance or travel restrictions (Soutar, 2008).

Low cost

Counselling is often provided by professionals, but can also be given by peer and lay counsellors (LC) which significantly lowers costs, and therefore might be a more sustainable stigma-reduction intervention (Kagee, 2013; Sanjana et al., 2009). Lay and peer counselling have often been applied in the field of HIV/AIDS (Fylkesnes et al., 2013; Grinstead & Straten, 2000). Studies have shown that the roles and responsibilities of lay and peer counsellors within the health system and in a wider context need to be clear to improve effectiveness (Grinstead & Straten, 2000; Rohleder & Swartz, 2005).

1.2.4. Types of counselling

Three different types of counselling are identified in the ILEP counselling guideline: individual, family and group counselling (ILEP, 2011). Each type of counselling has its own dynamics (ILEP, 2011). Individual counselling takes place in a safe and private setting. This type of counselling can help an individual to understand and express his/her own thoughts and feelings about living with the condition. In family counselling the focus lies on relationships and dynamics within the family. Within the group counselling, peer support can be facilitated; personal stigma-related issues can be shared, members can support one another for example by discussing solutions to problems experienced.
1.3. Study design

1.3.1. Research questions

The main research question of this thesis is: Under what conditions is counselling an effective approach to reduce leprosy-related stigma in Cirebon District, Indonesia?

The main research question is divided into three study questions.

1. How is leprosy and leprosy-related stigma understood, experienced and dealt with by people affected by leprosy in Cirebon District, Indonesia?
   a. What meaning do people affected by leprosy give to their disease and the stigma attached to it?
   b. What aspects from the field of disability, personal knowledge and mind-sets of different actors involved might help in dealing with leprosy-related stigma through counselling?

The purpose of this first study question is to increase understanding of leprosy-related stigma in the study area by studying the perspectives of people affected by leprosy and other key persons including the health service providers. These insights will inform the counselling practice.

2. What are the characteristics of a counselling practice for clients affected by leprosy-related stigma in Cirebon District Indonesia?

Although counselling is considered to be one of the most promising stigma-reduction approaches, it is not evident that it is effective under the conditions of clients affected by leprosy-related stigma in Cirebon District. The purpose of this second study question is to develop a counselling practice based on an understanding of the characteristics of the target group and their environment.

3. What is the impact of a rights-based counselling intervention on leprosy-related stigma in Cirebon District, Indonesia?

The purpose of the third study question is to assess as accurately as possible the varied impacts of the counselling practice. Evidence is needed to inform policymakers, scientists and society at large about the effects of the intervention and the possibilities for scaling up. Table 1.2. gives an overview of the study questions and shows in which chapters these questions are addressed.
Table 1.2. Overview research questions and corresponding chapters of the thesis

<table>
<thead>
<tr>
<th>Research question</th>
<th>Chapter</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How is leprosy and leprosy-related stigma understood, experienced and dealt with by people affected by leprosy in Cirebon District, Indonesia?</td>
<td>2</td>
</tr>
<tr>
<td>2. What are the characteristics of a counselling practice for clients affected by leprosy-related stigma in Cirebon District Indonesia?</td>
<td>3</td>
</tr>
<tr>
<td>3. What is the impact of a rights-based counselling intervention on leprosy-related stigma in Cirebon District Indonesia?</td>
<td>4</td>
</tr>
</tbody>
</table>

1.3.2. Research approach

The transdisciplinary, Interactive Learning and Action (ILA) approach was applied to this study to assess the effects of the counselling interventions on the social life of people affected by leprosy. Transdisciplinarity is defined by Klein et al as research that responds to "tangible real-world problems" by devising integrated solutions "in collaboration with multiple stakeholders" (Klein et al. 2001:7). This approach is fundamental to the present study as it enables researchers to take into account the complexly interconnected factors - familial, social, political, economic and medical - that determine the quality and experiences of the lives of those affected by leprosy.

As Hoffmann-Riem et al observe, transdisciplinarity became a prominent approach in research in the 1970s following the 'mismatch between knowledge production in academia, on the one hand, and knowledge requests for solving societal problems, on the other' (Hoffmann-Riem et al. 2008:3). In contrast with inter- and multidisciplinarity, a transdisciplinary approach to research is defined as a new form of knowledge production and problem-solving involving co-operation and coalitions between different parts of society and science in order to meet complex challenges of society. This model for research emphasises the experientiality of making knowledge about real and actant-based social situations. This approach is characterised by its responsiveness to real and protracted global problems, its involvement with multiple stakeholders, the entanglement of different forms of knowledge and the iterative process of research design (Cummings et al. 2013).

The ILA approach, employed in the present study, was developed in the 1980s and 1990s by Bunders and Broerse (1991). It has been proven to be effective in its application and adaptation in various locations and empirical fields such as Bangladesh, the Netherlands, South Africa and Zimbabwe (Betten, Roelofsen, & Broerse, 2013; Caron-Flinterman, 2006; Swaans, Broerse, Meincke, Mudhara, & Bunders, 2009; Zweekhorst, 2004). As shown in figure 1.1, the research interventions can be described and depicted by successive cycles of planning, action, observation.
and reflection, re-iterated until the revised plan satisfies and corresponds appropriately to the thematic concerns.

Figure 1.1. Action research spiral (Kemmis & McTaggert 1988:154)

1.3.3. Study area and selection

Kabupaten Cirebon (Cirebon District) has shown, statistically, increasing number of leprosy cases each year. Furthermore, it has proved to be more prone to leprosy-related stigma in relation to other neighbouring districts, with very low or close to none incentive to deal with the problem. For this reason, it has been chosen as the case study and the research field for the present project (Figure 1.2 and Figure 1.3). Covering an area of 990.36 km2 (Susanto, 2012), its terrestrial features range from flat and plain land in the north to mountainous and more rugged areas in the south. Agriculture is the predominant form of land management and distribution, including products such as rice, sugar cane, peanuts, cassava, vegetables and maize. Among one of the most well known terrestrial features in West Java, where the Cirebon district is located, the active volcano Mount Ciremai can be mentioned. The four most common languages in this region are the national language Bahasa Indonesia, Sundanese, Javanese and Cirebonese.
There are 40 sub-districts (kecamatan), 412 desa and 12 kelurahan, which are two forms of administrative divisions in the district (Susanto, 2012). These regional units are further portioned out into smaller areas called dusun (hamlets), which branch out even further into what are called rukun tetangga (RT), each containing a number of households. In this study the function of either an exploratory study area or interventionist/control area has been assigned to each of the 40 kecamatans. This has been done in order to avoid the confounding of, and the interference between research activities, such as interviews and baseline studies. Correspondingly, 10 sub-districts were chosen as sites for the exploratory study, and the rest were randomly assigned various roles. The choice of the first 10 sub-districts was mainly influenced by their remote locations or their low figures of leprosy cases. The other 30 sub-districts were assigned the role of paired interventions or control areas, as charted in Table 1.3 and Figure 1.4. The reason behind
making interventions in pairs was mainly informed by the observations that such analyses and field studies on stigma needed to be addressed in a comparative fashion incorporating a combination of, as opposed to a single track of, interventions (Cross et al., 2011a; Heijnders & van der Meij, 2006).

Table 1.3. Allocation of 40 sub-districts in the SARI project

<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>Pabuanan</td>
<td>Klangenan</td>
<td>Jamblang</td>
</tr>
<tr>
<td>Karangsebung</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>Dukupuntang</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gebang</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 1.4. Exploratory study and intervention areas of the SARI project
1.3.4. SARI project

This research is part of the SARI project, launched in mid-2010 and funded by Netherlands Leprosy Relief (NLR), American Leprosy Missions (ALM), Sasakawa Memorial Health Foundation (SMHF) and effect:hope (formerly, The Leprosy Mission Canada). The principle goal of the SARI project was to carry out a comparative study of the ways in which the three forms of stigma-reduction interventions, i.e. counselling, contact and SED, could be effective on personal, interpersonal and community levels. The effectiveness of these forms of interventions have proved to be interdependent. For instance, while contact intervention was mainly in correlation with the community level, it showed certain influences on the intra and interpersonal level of stigma as well.

Table 1.5. Team members SARI project

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prof. Irwanto</td>
<td>Universitas Indonesia</td>
<td>Principle investigator/ (co)-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-doc</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>Research assistant</td>
</tr>
<tr>
<td>Mr. Rahman</td>
<td>SARI project and FKDC</td>
<td>Research assistant</td>
</tr>
<tr>
<td>Mr. Solihin</td>
<td>SARI project and FKDC</td>
<td>Research assistant</td>
</tr>
<tr>
<td>Mr. Oni</td>
<td>SARI project and FKDC</td>
<td>Research assistant</td>
</tr>
<tr>
<td>Mr. Mujib</td>
<td>SARI project and FKDC</td>
<td>Research assistant</td>
</tr>
<tr>
<td>Mr. Hasan</td>
<td>SARI project</td>
<td>Research assistant</td>
</tr>
<tr>
<td>Mrs. Christine</td>
<td>SARI project</td>
<td>Research assistant</td>
</tr>
<tr>
<td>Mr. Harry</td>
<td>SARI project</td>
<td>Research assistant</td>
</tr>
<tr>
<td>Mr. Hadi</td>
<td>SARI project</td>
<td>Research assistant</td>
</tr>
<tr>
<td>Mr. Ulum</td>
<td>SARI project</td>
<td>Research assistant</td>
</tr>
</tbody>
</table>
1.3.5. Overview study population and research methods

The main study population of this study are people affected by leprosy, but also family members of counselling clients, health professionals, lay and peer counsellors, RAs and other key persons play a role in this study. Three distinct phases can be identified: exploratory study, pilot study and effectiveness study (see Table 1.6.). A range of both qualitative and quantitative research methods have been applied in this study.

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. Different research methods were used in this phase such as in-depth interviews (IDI), focus group discussions (FGDs), written reflections and notes of meetings.

The pilot study aimed to assess the needs of the clients and to test different types of counselling. Different research methods were used in this phase including Tape Recordings (TR) of counselling sessions, Counsellor Reflection Notes (CRN), Notes of Family Counselling (NFC) and Notes of Group Counselling (NGC).

The effectiveness study aimed to assess the effect of the counselling intervention. Methods used were, among others, three different scales: SSS, PSS, and WHO-QOL BREF, but also Participant Reflection Notes (PRN). 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 1.6. Overview research methods applied for this thesis

<table>
<thead>
<tr>
<th>Study</th>
<th>Methods</th>
<th>Population</th>
<th>Chapter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exploratory study</td>
<td>53 IDI (series of 3)</td>
<td>Persons affected by leprosy or caretakers of persons affected by leprosy</td>
<td>2, 4, 8</td>
</tr>
<tr>
<td></td>
<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, 4, 8</td>
</tr>
<tr>
<td></td>
<td>7 IDI (series of 3)</td>
<td>Persons affected by leprosy</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>7 IDI (series of 3)</td>
<td>Disabled persons</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>3 FGD (9-13 /group, in total 31)</td>
<td>Persons affected by leprosy and disabled persons</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>4 written testimonies</td>
<td>RAs</td>
<td>7, 8</td>
</tr>
<tr>
<td></td>
<td>12 interviews</td>
<td>Lay counsellors</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>2 FGD (4-12 /group, in total 16)</td>
<td>Disabled RAs, LCs</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Notes meetings/ workshops</td>
<td>SARI team and stakeholders</td>
<td>8</td>
</tr>
</tbody>
</table>
### 1.3.6. Validity

Several strategies were used to enhance the validity of the data.

1. **Methodological triangulation**: to assess the impact of the counselling intervention, but also for most other studies in this thesis mixed methods were applied. Sometimes several qualitative methods and sometimes quantitative and qualitative methods were used.

2. **Investigator triangulation**: multiple researchers were involved in the design of the study, the data collection, analyses and interpretation of the data. Workshops were organized to discuss preliminary findings with the RAs to deepen understanding and enhance interpretation.

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

4. **Feedback**: feedback was provided by researchers and practitioners not involved in the project. There was, for instance, a Steering Committee who met four times during the course of the project, a mid-term review commenced by two independent researchers and presentations for representatives of donor agencies.
Cross-culturally validated tools: the tools used to assess the impact of the counselling intervention were valid or piloted and cross-culturally validated during the course of the SARI project.

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

Prolonged fieldwork: I have been in Cirebon frequently and for an extended period of time.

Saturation: in the SARI project, saturation of the data was sought as much as possible. Interviews and FGDs were generally conducted until no new issues arose.

1.3.7. Ethical considerations

The present study has been endorsed and ethically confirmed by The Ethics Committee of Atma Jaya University, the Sub-Directorate for Leprosy and Yaws, the Ministry of Health (MoH), Provincial Health Office, West Java and the District Health Office (of?) Cirebon District. Throughout the course of this research, the confidentiality of the information provided by the participants has been assured by limiting the access to data records to the researchers who were directly involved in the project. If any exceptions have been made, it was made sure that the data was available only anonymously. Before the phase of data collection and registrations in the intervention activities, all participants were informed about the SARI project. The control area in this study is a care as usual area. In collaboration with health professionals at the community health clinics, registrations and recruitments were performed carefully so as to avoid any health issues among the participants, who had the freedom not to join or to resign at any point during the interventions. Written consents to participate were received from each participant. As for the interviews, it was made sure that they were questioned in private locations separated from other participants, professionals, researchers and family members, as far as it was allowed or made possible. Well-trained research assistants (RAs) were recruited and mobilised in the areas. They were well equipped with psychological techniques in order to be able to deal with harsh reactions, emotional expressions and encountering painful experiences. For example, the RAs would often opt for the use of the words preferred by the participants, e.g. 'skin disease' or 'my disease' in lieu of leprosy. Sometimes, participants who were being treated did not know about the fact that they are inflicted by leprosy. In such cases, the health professional in charge must have decided not to inform the patients about the name 'leprosy' and used skin disease instead. The RAs thus had to decide according to the context whether to inform the participants of his/her disease and provide the necessary information or continue using the surrogate wording. The only incentives offered to interviewees, especially those that were interviewed more than once, were in the form of small tokens of appreciation like a drinking mug or a t-shirt. No incentives were provided to participants of the interventions. In the case of lost earnings for the
lay and peer counsellors and the participants of the participatory video activities, exceptions were made and they were duly compensated.

1.4. Outline of this thesis

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

**Part I** is concerned with the counselling intervention. Chapter 2 provides insights into the experiences of persons affected by leprosy and the meaning they and key persons give to leprosy. Chapter 3 focuses on dealing with stigma from the side of persons affected by leprosy and disabled people. Chapter 4 charts the development of a counselling practice and module in which stigmatized individuals are involved as lay and peer counsellors. Chapter 5 portrays the initial experiences with counselling as a stigma-reduction approach based on the perspectives of the lay and peer counsellors. In Chapter 6 describes the analyses of the impact of the counselling intervention. Impact

**Part II** is concerned reflections on the research process. Chapter 7 provides insights and emphasizes the importance of personal knowledge in stigma-reduction. Chapter 8 reports the analyses of the start-up of the SARI project and focuses on the different mind-sets that emerged between or within scientific and social stakeholders on key concepts including disability, stigma and research.

**Part III** provides the discussion, conclusions and a short reflection. In Chapter 9, I will draw the final conclusions regarding the design, implementation and assessment of the counselling practice. The implications of the findings presented in this thesis are discussed and placed in a broader context. A reflective note will conclude this thesis.
References


Peters, R. (2015). 'I am not shy ... so I don’t have leprosy, right?': understanding and assessing leprosy-related stigma and the effect of stigma-reduction interventions in Cirebon District, Indonesia. VU University Amsterdam.


Part I
Developing and implementing a counselling practice
Chapter 2
The meaning of leprosy and everyday experiences: an exploration in Cirebon District, Indonesia

Abstract
It is imperative to consider the meaning of leprosy and everyday experiences of people affected by leprosy and key persons in the community if one aims to make leprosy services more effective, which appears necessary in Indonesia given the large numbers of new cases detected annually. However, little is written in the international literature about the experiences of people currently being treated for leprosy, those cured or other key informants. This chapter analyses the narratives of the people by drawing upon IDIs with 53 participants and 20 focus groups discussions. The participants were purposively selected. We provide insights into the experiences of people and the meaning they give to leprosy, highlight aspect of aetiology, spirituality, religion, darkening of the skin and sorcery. We also examine experiences of seeking care and focused on the impact of the disease in particular on the elderly and children. In conclusion, the continued need for implementation of leprosy services in Indonesia is very evident. The diversities in people's experiences with leprosy indicate a demand for responsive leprosy services to serve the diverse needs, including services for those formally declared to be ‘cured’.
2.1. Introduction

Over the last decades, efforts in the field of leprosy have focused on curing the disease, controlling its spread and preventing impairments. From a global perspective the results are impressive and commendable with a decline of the number of new cases and the reduction of the proportion with severe visual impairments at diagnosis (WHO, 2012). For some countries, among others Indonesia, the picture is not yet so notable. Also for implications beyond the medical scope such as stigma the road is still long (Bennett, Parker, & Robson, 2008; Ebenso et al., 2007; Stevelink, van Brakel, & Augustine, 2011).

Leprosy has been associated with stigma throughout history (Heijnders, 2004; Jopling, 1991; Rafferty, 2005; Skinsnes, 1964; van Brakel, 2003). Manifestations of stigma, including self-stigma, social exclusion and discrimination, although nowadays more subtle with less ostracism, remain a reality for many people affected (van Brakel et al., 2012). To help leprosy services become more perceptive towards issues surrounding leprosy-related stigma and reduce its impact it is necessary to understand stigma from the perspective of the people affected and their family members. Also the views of key persons in the community, such as neighbours, teachers, religious leaders and health workers, should be considered. 'The human face of leprosy' edited by Gokhale and Sohoni (Gokhale & Sohoni, 1999) in 1999 already emphasized the need for such stories.

Several studies related to leprosy have been executed in Indonesia focussing on biomedical aspects (Hatta et al., 1995, 2009; Matsuoka et al., 2007), risk factors (Bakker et al., 2005, 2006; van Beers, Hatta, & Klatser, 1999), case finding (Louhenapessy & Zuiderhoek, 1997; Schreuder, Liben, Wahjuni, van der Broek, & De Soldenhoff, 2002) and gender (Varkevisser et al., 2009). Although these studies on leprosy are valuable in their own discipline, we identified a lack of knowledge in the published international literature on the experiences of people currently undergoing treatment or already cured and other key informants in Indonesia and elsewhere.

Hence, the SARI project, of which this study is a part, decided to undertake an exploratory study into these experiences and perceptions, prior to starting a participatory process of designing and implementing stigma-reduction interventions. The main research questions of this study were: How is leprosy understood and experienced in people affected by leprosy and key persons in the community and what implications do these understandings of leprosy and experiences have for leprosy services?

This chapter starts with a brief overview of leprosy control and epidemiology followed by a concise analytical framework. After the materials and methods, this chapter highlights the human face of leprosy behind the statistics and tries to do justice to the diversity of experiences and the local belief system in the study area. In line with this, our results will be presented according to five main themes that emerged from the analysis: i) giving meaning to leprosy, ii) aetiology, iii) seeking care, iv) understanding healing and cure and v) impact of leprosy. The views and
experiences of people with leprosy and other key persons in the community members are compared, underlining those that are relevant for the improvement of leprosy services and reduction of stigma.

2.2. Brief overview leprosy control and epidemiology in Indonesia

Indonesia presently has the third highest level of leprosy infection in the world, after India and Brazil (WHO, 2012). Twelve, of the in total thirty-four, provinces in Indonesia have new case detection rates above 10/100,000 population, West Papua has a rate above 100/100,000. Indonesia has a long history of leprosy control. In 1655, the first leprosy asylum was built on one of the islands in the bay of Jakarta and over two centuries the number of asylums increased until 45 (Susila, 1984). In 1932, the compulsory isolation of leprosy cases was abolished (Susila, 1984) and the implementation of several national control programs followed. Already in 1969, the government started to integrate leprosy control in the general health services (Hasibuan, 1999). Currently, the second strategic plan for the National Leprosy Control Programme (NLCP) 2011-2015 is implemented (MoH Indonesia, 2011).

We will focus on the epidemiology of leprosy in Cirebon District, as this is the area of research for this study and put the numbers in the context of the provincial (West Java) and national figures. Last year, the District Health Office of Cirebon reported 320 new leprosy cases (15.2/100,000 population). As shown in Figure 2.1., the number of new leprosy cases on national level showed a flat pattern until 2010. Last year, the MoH of Indonesia reported 23,000 new leprosy cases (9.5/100,000 population); an increase of 35% compared to 2010. We are not aware of any recent changes in the leprosy services that can account for this increase. Part of the explanation for the increase at the national level could be increased case detection activities conducted by the NLCP, particularly in some high-endemic and/or remote and difficult to reach areas.

Of the new cases in Cirebon District, 18 (5.6%) had visible impairments (also referred to as ‘grade-2 disabilities’); this percentage has been gradually increasing over the years, but decreased slightly since 2009. Similar trends can be seen on national and provincial level see Figure 2.2. The figures suggest a rather late case detection, but the reduction is promising and indicates that the current leprosy control programmes are making progress. Figure 2.3. shows a varying, but declining percentage of new cases among children particularly in Cirebon District. This indicates progress in the reduction of recent leprosy transmission. Data on the percentage of women among new registered cases was only available from 2008 until 2011 at national level. After an initial increase, the number has declined from 39.8% in 2009 (6,877 cases) to 34.6% in 2011 (7,968 cases).
Figure 2.1. 10-Year trend of new case detection rate in Indonesia, West Java and Cirebon District in 2002-2011 (data is merged from District Health Office Cirebon 2012; MoH Indonesia 2012)

Figure 2.2. 10-Year trend of % visible impairments among new cases in Indonesia, West Java and Cirebon District in 2002-2011 (data is merged from District Health Office Cirebon 2012; MoH Indonesia 2012)

Figure 2.3. 10-Year trend of % children among new cases in Indonesia, West Java and Cirebon District in 2002-2011 (data is merged from District Health Office Cirebon 2012; MoH Indonesia 2012)
2.3. Analytical framework

The experiences of people affected by leprosy are conceptualized in diverse ways. Concepts of social exclusion, discrimination and stigma are frequently used. In particular for the concept of stigma several conceptual frameworks have been developed (Corrigan, Markowitz, & Watson, 2004; M. L. Heijnders, 2004; Joachim & Acorn, 2000; Jones, 1984; Link & Phelan, 2001; Scambler, 1998; Weiss, 2008), often taking Goffman's now classic work on a 'spoiled identity' (Goffman, 1963) as point of departure. One commonly used conceptual framework is the one of Weiss (Weiss, 2008). Weiss extended the Hidden Distress Model of Scambler (Scambler, 1998) and distinguishes six types of stigma; three from perpetrators and three from those who are stigmatized. Perpetrators exhibit accepted, endorsed and enacted stigma; the latter is often called ‘discrimination’. Those being stigmatized exhibit anticipated (or perceived), internalized (or self-stigma) and enacted (or experienced) stigma (Jacoby, 1994; Scambler, 1998). To make productive use of our results and, in particular with future leprosy services and interventions in mind, we use conceptualizations of Weiss where appropriate.

2.4. Materials and methods

2.4.1. Study area

Cirebon District located on the North Coast of West Java, was selected as the area of research and project implementation because it has a high number of new cases annually and has accordingly local experts higher leprosy-related stigma in comparison to other districts. Cirebon has a vibrant history and not surprisingly, is known as a cultural melting pot; it has absorbed influences from Hindu, Buddhist, Islamic, Sundanese, Javanese, Chinese, and Dutch cultures. This is also reflected in the name Cirebon (originally Caruban) what literally means ‘mixed’. In 2011, Cirebon District had 2,405,475 inhabitants and comprised 40 kecamatan (sub-districts), of which 10 were selected for this exploratory study.

2.4.2. Research team

Six RAs assisted the four main researchers with conducting interviews and FGDs. The RAs all come from Cirebon District and speak the local languages Sundanese, Javanese and Cirebonese, in addition to the national language, Bahasa Indonesia. Some RAs have either a disability or have been affected by leprosy themselves. They received training in social research (1 week) and CBR (3 weeks). During data collection, meetings with the whole team were held at the office to share experiences, challenges, feelings and stimulate learning. These meetings were initially held daily and later on weekly basis. This was done to develop a common understanding of the local situation, build a strong connection with the research, improve research skills and improve the approach.
2.4.3. Sampling and selection

The Community Health Centre (CHC) have provided the contact details of people affected by leprosy. The RAs have played an important role in updating the list, identifying potential participants and inviting them to be part of the study. The participants were purposively selected, based on characteristics such as age, gender, religion and role in the community.

2.4.4. Data collection methods

To understand the variety of experiences of people currently under treatment for leprosy or already cured, interviews were conducted in June and July 2011. Each participant was interviewed three times. This was done to build trust and help participants feel confident to talk about the issues they faced in daily life. In total, 53 (times three) interviews were conducted, of which nine were with children. The interviews were conducted with single participants and in pairs of interviewers. The interviews commenced in an exploratory manner and then progressed towards more in-depth enquiry. Topics addressed in the interviews were: i) general information, ii) life history, iii) economic situation, iv) social situation, v) health situation, and finally vi) leprosy. In addition, different visualisation techniques were used. For example, body maps were employed to investigate the participants' perception and implicit knowledge of their own bodies and the connection with the disease. This made it possible to interpret the aetiology of leprosy. Photographs of the families were used to open an intimate space for a dialogue about family issues. In addition, throughout the data collection period, several informal interviews took place; these were also considered during the analyses.

To understand the perspective of the community twenty FGDs were conducted. Participants were neighbours of those who had leprosy, community and religious leaders, mothers of children affected, teachers and health workers. Each FGD had between 4-12 participants. The FGDs were conducted in June and July, October and November 2011. The majority of FGDs took place in the SARI office but, when it was considered to be more appropriate, a meeting room in the District Health Office or a local hotel was arranged. Each FGD was designed slightly different but the purpose was the same: to collect information from different informants about the situation of people affected by leprosy and their families in Cirebon District. The common themes were: i) understanding of leprosy, ii) stigma in the community, iii) main issues in the community, iv) current strategies and v) recommendations for strategies to reduce stigma. A community map was chosen as visualisation technique to explore the main problems that affect their communities in general and specifically related to leprosy and the relationships among them.

The results presented below draw on these interviews and FGDs, but do not represent a complete analysis of the available data. The interviews and FGDs were recorded, transcribed and translated into English. The transcripts were entered and analysed in QSR NVivo 9. First, data was coded and
memos were made to find themes, clusters and patterns. To organize, compare, summarize and finally draw conclusions several models were formed.

2.4.5. Ethical considerations

Permission for the study was approved from the relevant government offices. Written consent was obtained from individual study subjects. Incentives such as travel expenses were refunded, lost earnings compensated and/or sometimes a small present (t-shirt, mug) was given to the participants as a token of appreciation.

2.5. Results

2.5.1. Giving meaning to leprosy

Two terms, lepra and kusta were commonly used by our informants to designate leprosy which has been confusing for many participants. The first is derived from India where leprosy most probably originates from. The name ‘Kushtha’ was derived from ‘Kushnati’ which is believed to mean ‘eating away’ in Sanskrit (Yawalkar 2009:12). The second word lepra, is derived from the Greek word Λέπρα [léprā or lepros] and was used by physicians to refer to a scaly skin disease (Bennett et al., 2008). Some participants believe to two terms mean the same, while others believe that these terms identify a difference in the severity of the disease. Several of the participants were of the opinion that there are different types of leprosy. Sometimes a connection is made to diabetes; one community leader even stated that leprosy and diabetes are the same (FGD 2 community leaders).

Leprosy as a health issue is understood in different ways, which is illustrated by the variety of answers given to the question: ‘What is leprosy?’ Participants often initially responded that they did not know what leprosy is and some questioned the interviewer. For example, they said: ‘I want to ask … Is it true that leprosy can affect children genetically?’ (FGD 2 community leaders) or ‘I heard that all of their fingers will come off. Is that true?’ (Interview 7: female, age 36).

When participants shared their views about leprosy, they often referred to it as a skin disease, emphasising the contagious nature of the disease and impairments of hand and feet. They described the characteristics of leprosy as followed: ‘red or white rash’, ‘face got red’, ‘lumps’, ‘swollen ear’, ‘this vein … is hard’, ‘you cannot feel anything when you are pinched’, ‘feet a little bit open’, ‘lesions’, ‘skin will peel off’, ‘hands shrank’ and ‘permanently damaged body function’. Additional symptoms that were frequently mentioned by people who had suffered from leprosy themselves were ‘hot’, ‘itchy’ and ‘pain’. A teacher compared leprosy to a ripe mango:

\[I\text{ thought the lesions had become as ripe as fruit. The rash was pretty ripe in my opinion; it's just like the black freckles on ripe mango.}(\text{FGD 6 teachers})\]

Interestingly, sometimes concepts as shame and low self-confidence were perceived symptoms indicative for having leprosy, as shown by the following quotes.
As far as he knows about leprosy: the face become pale, become introvert and did not want to join in their activity. (Interview 13: male, 62)

I am not shy and I do not have a low self-confidence, so I do not have leprosy right? (Informal interview 1: male)

What also stands out in terms of characteristics is the darkening of the skin as a side effect of the MDT. People affected by leprosy said that sometimes it is the dark skin and not so much the leprosy that makes them feel inferior. Also, the dark skin triggered friends and neighbours to ask questions which made people affected feel uncomfortable. One participant lied during job interviews by saying that he loves playing kite and that his skin is dark because of that. As a side note, in general in Indonesia a lighter skin is perceived to be more beautiful or ‘cleaner’ than a darker skin as also illustrated by the response from a mother whose son was affected by leprosy.

I was surprised because he [her son] became so dark-skinned. He was so clean before, but he became so dark. ... He was so dark, really really dark. (Interview 3: female, 45)

2.5.2. Aetiology

The reported ideas on aetiology vary. Firstly, participants think it is an infectious disease that can easily spread through direct contact with the person affected. This also implies that, in their perception, breathing the same air, shaking hands, eating food prepared by a person affected, carrying the deceased body of a person affected or using the same personal objects such as glasses, towels and clothes, could potentially transmit the disease. However, this perspective is not shared by all participants as some think it is not contagious. Participants also referred to the importance of having the same blood or same blood type, some consider this to be a prerequisite for infection.

Three related quotes:

Mother: I used to be free from the disease but I got infected through my neighbour.
Interviewer: Ooo, I see.
Mother: Yes...it is my mistake... He keeps coming to my house to play, so the disease infected us. (FGD 4 mothers of children with leprosy)

Teacher: Even in Eid Mubarak we do not shake hand...
Interviewer: So when you meet a patient of leprosy, and you know that the person affected by leprosy, you will not shake their hand when they want to?
Teacher: Not really. Well, coincidentally, the person always keeps himself inside the house... he understands it somehow. (FGD 6 teachers)

Leprosy is like...like what I have. It does not seem contagious. If it were contagious, my children would be affected. (Interview 9: male, 36)
The next category is other biological reasons such as heredity: some believe this is the case as they have seen other members of the same family suffering from leprosy. Others mentioned through ‘breastfeeding the baby’, derived from the observation that the baby’s skin can turn darker if the mother who is breastfeeding is still on treatment. The third category of causes relates to poor hygienic conditions such as swimming in a dirty river. The fourth refers to ‘logical explanations’ related to certain activities. For instance, since some of the people affected work with goats, work in construction or have eaten chicken, a link between the animals, the cement or eating chicken has been used to explain the cause of leprosy. The final category refers to the supernatural and moral aspects of life. Many people affected by leprosy believe leprosy is a challenge from God. People thought that God could be involved in allowing the bacteria to attack the body of the person, but with the purpose of making them stronger internally and in their faith. In contrast, a moral cause is involved when human deeds are seen as a reason for contracting leprosy. Some key person in the community perceived leprosy as a punishment from God. A specific example mentioned as a cause for leprosy was having sexual intercourse with a woman while she has her period. Destiny was also mentioned, for example by a teacher, who said he knew persons who passed away because of leprosy, but also clarified that death comes because it is written and hence should be perceived as destiny. In some cases people believe sorcery is involved. These thoughts on aetiology do not exist in isolation: people could believe that there is a divine will but at the same time they know that there is a scientific explanation. A quote to illustrate this point:

*I think an illness is divine will. But there is a cause of an illness.* (FGD 5 religious leaders)

### 2.5.3. Seeking care: perspectives on diagnosis and treatment

Most participants affected by leprosy have consulted the CHC for their health problem. A few noted that they faced barriers to reach the CHC. Two participants for instance needed medical treatment but did not have enough money to pay the public transport from their house to the CHC.

In the CHC some doctors or leprosy workers did not immediately diagnose leprosy but for instance thought the person was suffering from ‘scabies’, ‘a sweat allergy’ or ‘a skin fungus disease’. When the disease did not get better, participants returned to the clinic to find out they were actually suffering from leprosy. Likewise, leprosy workers shared that also people affected by leprosy sometimes underestimate the severity of the symptoms for example they think it is ‘only wormhole’ and as a result delay a visit to the clinic (FGD 20 Leprosy workers).

Some doctors and leprosy workers diagnosed the disease correctly, but decided not to share the diagnosis with the patient. This happened, for example, with a 29-year-old woman (interview 43). During her consultation the doctor told her she was suffering from a general skin disease, despite that she kept asking, the doctor did not want to tell her more but advised her to take free medicine every day for one year and to collect it monthly at the CHC. Other leprosy workers
decided to share the diagnosis, but participants regularly preferred to hide their disease from neighbours, friends, family members and in some cases their spouse. They also ask leprosy workers to be discrete. Nevertheless, this does not automatically mean people around them did not find.

The initial encounters between a doctor or leprosy worker and newly diagnosed patient are important. Stigmatizing attitudes and behaviour of doctors and leprosy workers can have an enormous impact on the people affected as illustrated by the first quote. The second quote of a leprosy worker confirms that several health workers are afraid to contract the disease.

*The moment the leprosy worker did not want to shake my hand, I had the feeling leprosy cannot be cured and that people will not be friendly with me anymore.* (Informal interview 2: male)

*The health worker still feels afraid, nervous ..., actually there are still many [health workers] that feel so...* (FGD 12 leprosy workers)

The CHS usually executes a certain procedure that includes a contact survey (finding new cases) and socialisation (raising awareness) when a new leprosy case is found. The importance of pictures and the use of simple and the right local language were emphasized by a leprosy worker. Another one described the procedure:

*If we find the leprosy patient, we usually come to their house and deliver understanding to them or to their family as well as the society around them ... So it is describe on what is leprosy and how to cope with it...that is we usually do in the field...* (FGD 12 leprosy workers)

An older woman (interview 18: age 74), however felt disappointment with the socialising procedure of the leprosy worker as it made neighbours actually more afraid and as a result they avoided her. In contrast, some persons affected by leprosy said they benefited from these visits (interview 1: male, 20; interview 45: male, 21; interview 3: female, 45). They said they were visited routinely at home by leprosy workers who gave counselling to increase confidence and to provide information to their family, who supported them in daily and community activities.

Several participants sought assistance outside the CHC. Some went first to a pharmacy for general medicine, which is common practice according to a participant. Some went directly to a hospital for which assistance from the head of the village is needed. In addition, several participants went to a *dukun* who can fulfil the role of traditional healer, spirit medium and occasionally sorcerer. Reasons that were given were curiosity, believe that the cause is sorcery and accessibility. One participant did not gain from it as illustrated by the following quote.

*Some friends advised me to go see a dukun... There is one neighbour ... took me to see a dukun ..., I forgot her name, she is not solving or healing my illness but asking for more money. Since then I never went to dukun again.* (Interview 18: female, 74)
Some participants deny the disease and are quite persistent in this; hence they were also reluctant to seek care. One community leader explained that it is because they feel embarrassed and are afraid of negative responses from others in the community as illustrated by the following quotes:

*Based on my first experience, someone suffers from this illness and until right now she is been denying it as leprosy. She was asked to go to the hospital but she did not want to go. And one day people from Health Department came to her house and she still with her persistence.* (FGD 20 leprosy workers)

*One of the affected people does not want to admit that he suffers from the disease even though his fingers come off. He does not want to find any medication. He is very ashamed.* (FGD 2 community leaders)

*But if one gets leprosy, rumour has it; they are reluctant to have treatment. I once asked ... 'have you consulted to the health centre?' and he answered, 'No way. People will be looking at me.' He feels so much embarrassed. ... Even though he is not sure whether he has leprosy ... He started to keep himself away from the neighbour even they had not known at the moment.* ... (FGD 2 community leaders)

### 2.5.4. Understanding healing and cure

Different words are used by the people affected by leprosy to describe that they are ‘cured’, ‘healed’ or ‘cleaned’. Several participants emphasize the importance of God in a cause of the disease as described earlier, but also in getting cured as shown by the following quotes.

*Every disease has its remedy and it depends on God's mercy.* (Interview 28: female, 20)

*Well, if God listens, then my prayers will be granted and it means I am healed.* (Interview 29: male, 36)

Some people affected clearly indicated that even after being declared ‘cured’, doubts remain. Some, for example, want a second opinion and others constantly keep an eye on their body or the body of the family member. Interesting are the interviews where the participant, also the ones without impairments, say in the beginning state that s/he is cured but when the interview continues and the interviewer asks about their hopes for the future, indicate the hope to be cured.

### 2.5.5. Impact of living with leprosy

Leprosy made people affected live with spots, scars, a dark skin and sometimes sensory loss and physical deformity. Some participants as a result refer to their ‘broken body’. Moreover, some of the participants experienced leprosy reaction after declared cured which caused pain, cramps and/or paraesthesia that made them continue feeling bad. All of those physical impacts challenged their life, and also influenced their emotions, and social and economic situation.
Sadness, frustration, loss of confidence, devaluation of their own capacity, stress and hopelessness were some of the emotions described due to the leprosy. A few people affected told us that they have considered ending their lives. A teacher describes it as follows:

*If they have a high spirit to survive, undergoing treatment, they will live longer... But if they keep hiding and staying away from the sunlight, it is possible for them to get depressed and die... because of depression.* (FGD 6 teachers)

We noted an interaction between self-isolation and being isolated by the community. Several people affected became reserved, shy and ashamed and isolated themselves, but at the same time, several family members and people in the community also isolated people affected. Key persons in the community have a variety of views about what is the cause of isolation:

*It is like anyone with this rare disease. People do not really isolate that person but it is that person who isolates him/herself from the society. Most of the people with leprosy tend to act that way.* (FGD 6 teachers)

*Interviewer: Do all people isolate the affected?*

*Community leader: Well, yeah. People affected are usually isolated and I feel sorry about it.* (FGD 2 community leaders)

We tried to understand the reasoning behind isolating somebody. We heard quite shocking examples of isolation: a child lived, ate and slept in a separate room, spouses that do not sleep together anymore and a mother who distanced herself from her children. However, often there are underlying reasons of protection and care illustrated by the following quote:

*Interviewer: What will you do if you are affected by leprosy?*

*Woman: I will isolate myself. ... Yes, because I do not want to infect my children.* (Interview 7: female, 36)

The economic situation of the persons affected and their family deteriorates. Some participants were physically not able to do the work that they used to do such as making furniture. Some were fired because of leprosy such as a cleaner in the hospital, while others resigned themselves as suggested by family members. Furthermore, people in the community avoided being customers of street vendors, in **warung** (small restaurant) or small shops, because of fear of being infected by touching the objects or eating the food that is sold by persons affected by leprosy. A community leader said that also farmers face problems, because their feet stand in the same water during rice planting and people are afraid to be infected. The socio-economic status of the household in affect influences for example other activities such as education.

The impact can remain for a long time, even after being declared cured. One participant (Interview 35: male, 41) who has impairment due to leprosy said that most people more saw him as a body rather than as a human being. However, also some participants without any visible signs...
are affected for a long time. Some shared to have remained feelings of shyness and limited motivation to participate in social activities.

Elderly and children are important subgroups but are often forgotten. The elderly affected by leprosy interviewed have expressed feelings of sadness because of the lack of care they receive. Their situation is often aggravated by the absence of their family either because most of their relatives have died or because they were rejected when the leprosy started. Moreover, issues as loneliness, dependence on others, other health issues and often an alarming financial situation kept surfacing during our conversations with the elderly.

Schooling is highly valued in Indonesian society, but the majority of the children affected by leprosy stopped attending school temporarily or permanently. Several reasons to discontinue school were mentioned and these can be categorized into feeling i) embarrassed, ashamed and shy, ii) peers making fun of them and taking distance and iii) fear of being insulted.

Some of the respondents have said that it is impossible to think that they would be only sad or only happy all the time; there are some good moments accompanied by some other that are not so good. ‘Leprosy has made us stronger’, one of them said. When the disease has been cured, there is also the feeling of being strong enough to overcome problems. Several of the participants have expressed they have gained strength from their spiritual beliefs. Religion and spirituality was reported by the respondents as either a way of searching for health and protection or as a way of finding acceptance of their situation. There are also many family members, friends and neighbours who are not afraid to be infected and who support and care for the people affected, for example:

*Interviewer: What kind of supporting did your husband gave it to you?*

*Woman: … Hmm like this: do not feel sad or do not feel discouraged… you are not alone. (FGD 18 people affected)*

### 2.6. Discussion

The findings regarding the meaning of leprosy show an confusion around the concepts *kusta* and *lepra* and an overall lack of knowledge of the illness, its causes and ways of transmission. Moreover, the images and perceptions about leprosy already internalized or newly acquired give rise to feelings of fear. The perception that leprosy is a very infectious disease that can be transmitted by touching the same objects leprosy-affected persons have touched is worrisome. Hence, increasing knowledge about leprosy in people affected, community members and health workers remains an important goal for leprosy services, and although it not the sole answer to stigma, it is an essential prerequisite (Cross, Heijnders, Dalal, Sermrittirong, & Mak, 2011; Heijnders & van der Meiij, 2006; Thornicroft, Brohan, Kassam, & Lewis-Holmes, 2008). Several initiatives try to address this, for instance, the World Health Organisation has indicated key messages for the public and for people affected (WHO, 2009).
In addition, the importance of the darkening of the skin, an inevitable but temporary side-effect of the MDT component clofazimine, should be underlined. This study indicated that it sometimes brought people in uncomfortable situations wherein they were questioned about their condition. It influenced their ideas about their own or others’ beauty and cleanliness. A study in Brazil illustrated the connection made between the dark skin and racial ideas by this illustrative quote: ‘Before, I was only a leper. But now, I’m going to be a nigger leper’ (Nations et al. 2009:1219). This study also described the negative impact darkening of the skin can have on the intake of the medication. The topic is not yet well studied, but seems an important subject to improve leprosy services.

Several challenges prevailed in relation to seeking care, recognizing the symptoms, making the correct diagnosis, sharing the diagnosis with the patient and the treatment. Noticeable is the power and influence of the leprosy workers and hence also the destructive impact of any stigmatizing behaviour from their side on the people in their care. White described this as ‘iatrogenic stigma’ or stigma produced by a patient’s encounter with health workers (White, 2008). Here lies a great opportunity for the improvement of leprosy services for example through trainings. Since power is a dynamic concept it can be used in a positive manner as several leprosy workers already do.

Quite a few respondents raised the aspect of sorcery as a cause of leprosy and consequently the role of the dukun. This was found in other countries such as Nepal, Nigeria, Sudan (el Hassan, Khalil, & El-Hassan, 2002; Varkevisser et al., 2009). In the Indonesian context it makes sense to perceive them as relevant and valuable stakeholders for leprosy services, but again more research is needed on their knowledge, views and approaches.

A recurring and thus overarching theme is ‘spirituality and religion’. It seems to help people affected by leprosy and community members give meaning (e.g. a challenge, punishment) to leprosy, as well as offer strategies to cope with the illness. Religion has been proved to play a major role for other stigmatized illnesses such as HIV/AIDS (Cotton et al., 2006; Zou et al., 2009). This theme provides opportunities for leprosy services, but first raises questions regarding the current role of religious leaders and what role they could play in the future. Further research is needed that specifically addresses these questions.

It is clear that, according to the participants’ life experiences, leprosy as a disease evokes feelings and experiences that are described as stigma (Weiss, Ramakrishna, & Somma, 2006). On the side of the stigmatized it is easy to recognize the anticipated, internalized and enacted stigma in the narratives from the participants. For example, in the reasons to discontinue school all three can be seen: i) embarrassed, ashamed and shy (internalized), ii) peers making fun of them and taking distance (enacted) and iii) fear of being insulted (anticipated). Likewise, the accepted, endorsed and enacted stigmata perpetrated by stigmatizers are easy observable. Remarkable is that some
people perceived shame and a low self-esteem as symptoms rather than a result of leprosy. This shows the solid ties between leprosy and stigma. It is important to note that stigma has lasting effects on people already declared cured according WHO standards, even those without impairments or any other visible signs, as there are millions of people worldwide with this status. In spite of the fact that the current concept of stigma already comprises a variety of aspects, it is important for staff in leprosy or rehabilitation services to be aware of the wide range of experiences of people. Leprosy services need to be responsive to the diversity of experiences and the needs of people currently in treatment and those already cured.

The two-way relationship between disability and poverty, that can become a vicious circle, has been extensively described (WHO, 2011; Yeo, 2005) and can be recognized in our narratives. Delayed health seeking due to poverty increases the risk of visible skin lesions and impairments, whereas our data show that having leprosy clearly has a negative influence on the socio-economic status of a household, as also confirmed in other studies (Calcraft, 2006; Kumar & Anbalagan, 1983; Mitra, Posarac, & Vick, 2013). This is an important pointer for leprosy services to address.

Although there are more negative than positive experiences, the positive ones are valuable as these can help stop reinforcing and potentially break down stereotypes and assumptions about leprosy. Leprosy could be seen as a paradoxical predictor of personal development. Positive experiences are, to our knowledge, sparsely described in the scientific literature. A notable exception is the STEP project that actively tried to transform the image of persons affected by leprosy to that of positive change agents (Cross & Choudhary, 2005a, 2005b). Fortunately there are some accounts in non-scientific literature such as (sometimes romanticized) autobiographies and a collection of publications to dignify and inspire1.

Finally, sub-groups that need specific attention are elderly and children, but also women and families. Little is written about these groups and their needs. We hope to address these sub-groups in more detail in another publication, but also encourage others to take these topics forward.

2.7. Conclusion

The continued need for implementation of leprosy services in Indonesia is very evident, with a focus on early detection of new cases, prevention of impairments and equal access for women. We conclude that the experiences of persons affected by leprosy, those under treatment and those that have completed treatment and have been declared cured, are diverse and go well beyond

1 Such as a Quest for Dignity: Personal Victories Over Leprosy/Hansen’s Disease by International Association for Integration Dignity and Economic Advancement 1997, Dignity Regained by Sasakawa Foundation, No footprints in the sand: a memoir of Kalaupapa by Nalaielu and Squint: my journey with leprosy by Ramirez.
leprosy as an infectious disease or medical issue. A majority of respondents related strongly to the prevailing stereotypes about the disease and the related social stigma and discrimination.

Leprosy services continue to be needed and should be strengthened and made more responsive to the diverse needs of affected persons where possible, including to some of those formally declared ‘cured’. In addition, this study emphasizes the work that still needs to be done in terms of raising knowledge and awareness. Health workers need a greater understanding of their own power and sometimes stigmatizing behaviour. Specific interventions are needed to reduce stigma in the health services. The impact of the temporary darkening of the skin due to clofazimine should not be underrated. Other stakeholders in the community, such as religious leaders and traditional healers, need to be involved in attempts to reduce stigma. The impact of leprosy on the socio-economic situation should not be underestimated. There is some evidence that interventions to improve people’s socio-economic status help to reduce stigma. This is currently being tested in the SARI Project. Positive images, experiences and role models should be used to break down existing stereotypes depicting people affected by leprosy as pitiful and disgusting. Specific attention is needed for specific groups as children, elderly and families and women. Leprosy services should take into account the wide diversity of meanings and experiences of people affected by leprosy and key persons in the community. This study shows that this can uncover important clues to make leprosy services more effective and appropriate.
References


Chapter 3
Dealing with stigma: experiences of persons affected by disabilities and leprosy

Abstract
Persons affected by leprosy or by disabilities face forms of stigma that have an impact on their lives. This study seeks to establish whether their experience of stigma is similar, with a view to enabling the two groups of people to learn from each other. The study was undertaken as part of the SARI Project in Cirebon District, Indonesia. Accounts of experiences of the impact of stigma were obtained using IDIs and FGDs with people affected by leprosy and by disabilities not related to leprosy. The analysis shows that there are a lot of similarities in impact of stigma in terms of emotions, thoughts, behaviour and relationships between the two groups. The main difference is that those affected by leprosy tended to frame their situation in medical terms, while those living with disabilities described their situation from a more social perspective. In addition, most individuals respond with passivity and withdrawal from social relationships beyond the family, but some individuals take a more active, positive stance illustrating coping strategies. In conclusion, the similarities offer opportunities for interventions and the positive attitudes and behaviours can be modelled in the sense that both groups can learn and benefit. Research that tackles different aspects of stigmatization faced by people affected by leprosy and related impairments could lead to inclusive initiatives that help individuals to come to terms with the stigma and to advocate against exclusion and discrimination.
3.1. Introduction

With an estimated total of 19,000 new leprosy cases in 2012, Indonesia has the third highest number of new leprosy cases after India and Brazil (WHO, 2012). The provinces of East Java, West Java, Central Java and South Sulawesi each report over a 1,000 new cases a year. Stigma has an important impact on the lives of people living with leprosy (Cross & Choudhary, 2005; Meima, Van Veen, & Richardus, 2008; Tsutsumi, Izutsu, & Islam, 2004; van Brakel, 2003). Studies have found that even people who are cured of leprosy can still remain trapped in the vicious circle of disease–impairments stigma and also face discrimination (Hosoda, 2010). In 2008, the Transformasi Lepra Indonesia Foundation undertook research among people affected by leprosy who were living at home. Most had limited education, were unemployed and lived in poverty. In addition, their families and communities had rejected them, as was apparent from their low participation in family and community events. Everyday discrimination was common; people affected by leprosy, for instance, were not allowed to use the same household utensils as other family members (YTLI, 2008).

The meaning and connotation of the word stigma has varied considerably over the centuries. Today, the term refers to a personal attribute which marks a person as different from 'normal people', that is 'abnormal' with all its negative connotations, namely exclusion from 'normal' society (Goffman, 1963). Some studies have supported the idea that illnesses are stigmatized because of the limitations they entail and the negative social attitudes they generate (Fife & Wright, 2000; Sontag, 2001). According to Fife & Wright (2000:51) 'the specific nature of stigma associated with serious illnesses' depends on three elements: blaming the individual for the illness, the threat the illness represents to others, and the threat that it represents to individual competence. These elements are linked to a classical concept of stigma as an individual attribute, marking the difference between that person and those regarded as 'normal' in a specific environment (Goffman, 1963; Stafford & Scott, 1986). Such a marker, or as Link & Phelan (2001) call it, a 'label', can affect the person who is stigmatized (Corrigan, Kerr, & Knudsen, 2005; Herek, 2007; Livingston & Boyd, 2010; Ritsher, Otilingam, & Grajales, 2003).

There has been considerable research on the effect of stigma on the lives of people with various diseases and disabilities. This has led to the development of a range of stigma-reduction interventions for various target groups worldwide (Link & Phelan, 2001; Scambler, 2006, 2009; Van Rie et al., 2008). Despite this research, few interventions have been developed for people affected by leprosy specifically. This raises the question whether the interventions developed for other target groups could also be effective in reducing the stigma faced by people who are affected by leprosy. In order to assess whether these interventions could have an effect, we first need to know whether the impact of stigma on the lives of people who are affected by leprosy and those who are affected by other diseases or disabilities not related to leprosy, is similar or
different. The research question addressed in this chapter therefore is, to determine the differences and similarities of the impact of stigma on the lives of people with leprosy and other diseases and disabilities living in a Cirebon, Indonesia.

In this chapter we describe the first phase of the SARI Project in Cirebon District, Indonesia. The SARI project aims to assess the effectiveness of stigma reduction interventions in people affected by leprosy. The first phase of the project consisted of an exploratory study, in which we compared stigma experienced by people affected by leprosy and those who have visual and physical impairments not related to leprosy.

3.2. Theoretical Framework: impact of stigma

ILEP (2011) explored the impact of stigma on the lives of people who have health problems, such as leprosy. The identified four domains in which stigma impacts on the lives of people: emotions, thoughts, behaviour and relationships. These domains are interconnected and manifest themselves in different degrees, at different moments and in different contexts (ILEP, 2011). The first domain, contains feelings such as ‘as fear, grief, depression, shame, guilt, anxiety, low self-esteem, hopelessness and anger, or inability to express such feelings’ (ILEP, 2011:7). The second domain describes the impact on thoughts in particular the ‘negative and pessimistic thoughts and beliefs about self, the world and the future’ (ILEP, 2011:7). Emotions and thoughts influence the way people react and behave and can result in lack of confidence, avoidance, withdrawal from social life and self-isolation. These elements are part of the third domain: behavior. Finally, the strength of the person’s social support network, and the attitudes of those in the network are important in the experience of stigma. The impact on the final domain; relationships, is described as ‘rejection, forced isolation and restricted social participation’ (ILEP, 2011:7).

3.3. Method

The participants of this study were purposively selected. We tried to get a broad group in terms of sex, age and marital status. Inclusion criteria were adults (between 20 - 65 years old) affected by leprosy and with disabilities (mental and intellectual disabilities were excluded). A qualitative approach was applied employing IDIs and FGDs. IDIs were used to gain insights into the ways participants deal with stigma in their daily lives. Interviews lasted 45–60 minutes and took place in the homes of the participants. Fourteen participants (seven affected by leprosy and seven by disabilities) were interviewed on three occasions. First, the concept of stigma (or equivalent feelings and experiences) were discussed with the participants. Next, the four main domains of the theoretical framework (impact on emotions, thoughts, behaviour and relationships) were used to explore the impact of stigma experienced by the participants.

The first FGD was organized in the office of the SARI project and had 13 participants; seven persons affected by leprosy and six with disabilities. In this focus group we also focussed on the four domains. From this focus group and the interviews we learnt that views on leprosy,
disability, causes and being cured strongly influenced the impact on thoughts. In addition, coping strategies were strongly impacting behaviour. Therefore, in the next two focus groups we elaborated on these concepts. The second focus group consisted of nine persons affected by leprosy and was held in SARIs office. The third focus group consisted of nine persons with disabilities and was held at the social office in sub-district Lemah Abang.

The interviews and FGDs were recorded and transcribed. The data was analyzed by the author of this thesis, who is a person with a visual disability. Besides, electronic data she used Braille to make notes and find themes, clusters and patterns. The analyses focused on comparing the two groups: persons affected by leprosy and persons with disabilities in the impact of stigma faced in daily life on feelings, thoughts, behaviour and relationships.

The participants gave their informed consent to be involved in the study and were also advised that the results would be published. They received no remuneration. Transport costs were covered when needed. The study was approved by the relevant offices; Ethics Committee of Atma Jaya University; Sub-Directorate for Leprosy and Yaws, MoH, Public Health Office, West Java and District Health Office, Cirebon District.

3.4. Results

3.4.1. Stigma

Bahasa Indonesia does not have a precise equivalent of the word stigma. Participants used different, but largely common, terms to describe their feelings and experiences. Tables 3.1. and 3.2. present a list of different terms used by the study participants.

**Table 3.1. Terms related to the concept of stigma used by people affected by leprosy**

<table>
<thead>
<tr>
<th>Indonesian</th>
<th>English equivalent</th>
</tr>
</thead>
<tbody>
<tr>
<td>cap</td>
<td>label</td>
</tr>
<tr>
<td>tanda</td>
<td>mark</td>
</tr>
<tr>
<td>beda</td>
<td>difference</td>
</tr>
<tr>
<td>sakit</td>
<td>sick</td>
</tr>
<tr>
<td>menular</td>
<td>contagious</td>
</tr>
<tr>
<td>dikucilkan</td>
<td>isolated</td>
</tr>
<tr>
<td>dijauhi</td>
<td>avoided</td>
</tr>
<tr>
<td>sial</td>
<td>unfortunate</td>
</tr>
<tr>
<td>aneh</td>
<td>staring</td>
</tr>
<tr>
<td>dihina</td>
<td>insulted</td>
</tr>
<tr>
<td>menjejek</td>
<td>ridicule</td>
</tr>
<tr>
<td>diasingkan</td>
<td>excluded</td>
</tr>
</tbody>
</table>
Table 3.2. Terms related to stigma used by people affected by disabilities

<table>
<thead>
<tr>
<th>Indonesian</th>
<th>English equivalent</th>
</tr>
</thead>
<tbody>
<tr>
<td>tidak normal</td>
<td>abnormal</td>
</tr>
<tr>
<td>beda</td>
<td>difference</td>
</tr>
<tr>
<td>rusak</td>
<td>broken</td>
</tr>
<tr>
<td>sakit</td>
<td>sick</td>
</tr>
<tr>
<td>merepotkan</td>
<td>burden</td>
</tr>
<tr>
<td>aneh</td>
<td>staring</td>
</tr>
<tr>
<td>menular</td>
<td>contagious</td>
</tr>
<tr>
<td>kasihan</td>
<td>pity</td>
</tr>
<tr>
<td>terbatas</td>
<td>limitation</td>
</tr>
<tr>
<td>kurang</td>
<td>incomplete</td>
</tr>
<tr>
<td>dipisahkan</td>
<td>separated</td>
</tr>
<tr>
<td>diasingkan</td>
<td>excluded</td>
</tr>
</tbody>
</table>

The participants discussed stigma, as understood in the terms given in Tables 3.1. and 3.2. An overview of the impact of stigma as discussed by the participants is presented in Table 3.3. The various elements are divided according to the four domains of the framework. In the sections below we elaborate on the differences and similarities between the two groups.

Table 3.3. Elements of impact by stigma divided by emotions, thoughts, behaviour and relationships

<table>
<thead>
<tr>
<th>Emotions</th>
<th>Thoughts</th>
<th>Behaviour</th>
<th>Relationships</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afraid</td>
<td>Death</td>
<td>Moving away</td>
<td>Rejection</td>
</tr>
<tr>
<td>Worry</td>
<td>No hope</td>
<td>Passive</td>
<td>Separation</td>
</tr>
<tr>
<td>Mourning</td>
<td>No future</td>
<td>Self-isolation</td>
<td>Restriction in social participation</td>
</tr>
<tr>
<td>Shy</td>
<td>Isolated</td>
<td>Keep silent</td>
<td>Discrimination</td>
</tr>
<tr>
<td>Guilt</td>
<td>Feeling sick</td>
<td>Do not want to look for help</td>
<td>Stop relationships</td>
</tr>
<tr>
<td>Anxious</td>
<td>Not being accepted</td>
<td>Protected by family</td>
<td>Withdraw</td>
</tr>
<tr>
<td>Inferiority</td>
<td>Contagious</td>
<td>Stay at home</td>
<td>Reject invitation</td>
</tr>
<tr>
<td>Doubt</td>
<td>Avoided</td>
<td>Do not want to meet people</td>
<td>No contact</td>
</tr>
<tr>
<td>Angry</td>
<td>Burden</td>
<td>Hiding</td>
<td>No social role and responsibility</td>
</tr>
<tr>
<td>Sad</td>
<td>Limitation</td>
<td>Instability</td>
<td>No friends</td>
</tr>
</tbody>
</table>
3.4.2. Impact on emotions

Both groups expressed being identified as ‘different’, because of leprosy or their disabilities. They shared feelings of being shy, sad, confused, afraid and powerless in the face of the stigma and discrimination they faced from the outside world. They also talked about feelings of guilt and about hiding from others, by staying at home for instance. Some voiced feelings of being a burden to their family. The participants explained that, since they believe what people say is true, they prefer to keep their feelings locked inside and not share them with others:

*Why should I share my feelings with my family if I feel they do not care for my feelings? If I share them with people they will avoid (dijauhi) me even more.* (Person affected by leprosy 1 IDI)

The two groups were aware of the negative emotional impact that stigma plays in their everyday life. They expressed the belief that stigma is generated by their families and communities. A common argument was that they would like to overcome their feelings of self-stigma, but found it impossible to do so because of strong social pressures:

*We are shy and have doubts about participating in daily life activities. We prefer to remain silent about our negative feelings, not because of us but because the community puts a label (cap) on us.* (Person with disability 3 IDI)

Although there are generally similarities between the perceptions and experiences of stigma of the two groups, the group affected by disabilities argued that they accepted themselves as having abnormal bodies but that they were not sick:

*I am ashamed of my hand. My hand is abnormal but I am not sick since I can still do my daily activities, manage a small business in front of my parent’s house. But I am often shy and feel uncomfortable using my hand when I serve and interact with customers.* (Person with disability 2 IDI)

The group affected by leprosy see themselves as patients suffering from a disease: some continued seeing themselves this way even after the leprosy officer from the community health
service had declared them cured. Apparently, the remaining deformities or pain were responsible for a persistent self-image as a 'sick person'. As some participants explained:

*It cannot be that we are cured; we always feel pain in our muscles. We have skin patches and they never go away.* (Person affected by leprosy 7 IDI)

*See my left foot, it is crooked, it is abnormal and it is sick.* (Person affected by leprosy FGD1)

*I always wonder when my left foot is going to be cured and become a normal foot again.* (Person affected by leprosy 7 IDI)

### 3.4.3. Impact on thoughts

All participants were concerned about negative comments from others because of their different appearance: skin patches, physical deformity and disabilities. They themselves, as well as their families and community members, regard their different appearance as something negative, labelling it, and marking/characterizing them by it. This may have a negative impact in their lives, limiting and restricting their social participation, making it difficult to assert their rights and satisfy their basic needs. For instance, both groups have faced challenges in finding a job. As one of them explained:

*When I attended an interview for recruitment the interviewer noticed the skin patch on my face. I told them I am cured from leprosy, but they did not trust me. I even showed them a formal letter from the community health services but they rejected me.* (Person affected by leprosy IDI 1)

Another participant added:

*I have to earn money for my children. Before I got leprosy, I worked as a cleaner, washing clothes, sweeping floors and cooking. A few months ago, I was finally cured from leprosy, but nobody wants me to work in their house; people avoid me and ridicule (mengejik) me because of my crooked hand.* (Persons affected by leprosy FGD 2)

People with disabilities told similar stories. Indeed, both groups complained about experiencing rejection. One participant affected by disabilities expressed his frustration:

*Business communities have a prejudice regarding my impairment. When I applied for a job, they spontaneously label me saying I look as somebody who is looking for charity.* (Persons affected by leprosy IDI 1)

Another participant commented:

*When I showed my application, the employer did not look at it but he looked at my body and said ‘You are sick. We cannot accept employees like you. Our company does not have experience working with a person with impairment. You could be a burden for us.’* (Person with disability FGD3)
The participants reported dealing with their own negative thoughts, provoked either by what people think and say about them or by what they think about themselves. The participants affected by leprosy explained that the lack of social relationships could be due to their status as sick people:

*We know we are sick because people have told us so. As sick persons, we have no friends, no hope and no future.* (Person affected by leprosy FGD1)

*My disease is never going to be cured, so sick persons like me cannot work.* (Person affected by leprosy IDI 4)

One of the participants with disabilities said:

*We look different in our daily life, and people see our difference as something abnormal that might not be accepted wherever we are.* (Person with disability FGD3)

A participant with a visual impairment shared another experience:

*I am always avoided by people. When I try to participate in community activities, people say that I am an unfortunate person.* (Person with disability FGD 3)

Although all participants described feeling isolated, those affected by leprosy strongly see themselves in the role of a sick person. Persons with disabilities, on the other hand, seem to struggle more often with being seen as abnormal. The participants reported different understandings of leprosy, disability, causes and being cured, as shown in Table 3.4.

**Table 3.4. Understandings of leprosy, disability and cure**

<table>
<thead>
<tr>
<th>People affected by leprosy</th>
<th>People affected by disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Indonesian</strong></td>
<td><strong>English</strong></td>
</tr>
<tr>
<td>Leprosy</td>
<td>Disability</td>
</tr>
<tr>
<td>Rematik</td>
<td>rheumatic</td>
</tr>
<tr>
<td>Bercak</td>
<td>skin patch</td>
</tr>
<tr>
<td>mati rasa</td>
<td>loss of sensitivity</td>
</tr>
<tr>
<td>bengkok</td>
<td>crawling hands</td>
</tr>
<tr>
<td>Putus</td>
<td>falling apart fingers</td>
</tr>
<tr>
<td>Luka</td>
<td>wound</td>
</tr>
<tr>
<td>pegallinu</td>
<td>pain</td>
</tr>
<tr>
<td>gatal</td>
<td>itchy</td>
</tr>
<tr>
<td>kambuh</td>
<td>reaction</td>
</tr>
<tr>
<td>ke puskesmas selama</td>
<td>once a month take medicine from the community health service</td>
</tr>
<tr>
<td>---------------------</td>
<td>---------------------------------------------------------------</td>
</tr>
<tr>
<td>rutin minum obat</td>
<td>take medicine routinely</td>
</tr>
<tr>
<td>dinasehati terus</td>
<td>be continually advised</td>
</tr>
</tbody>
</table>

**Causes**

<table>
<thead>
<tr>
<th>kotor</th>
<th>dirty</th>
<th>virus</th>
<th>virus</th>
</tr>
</thead>
<tbody>
<tr>
<td>guna-guna</td>
<td>magic</td>
<td>dari lahir</td>
<td>from birth</td>
</tr>
<tr>
<td>kutukan</td>
<td>curse</td>
<td>keturunan</td>
<td>genetic</td>
</tr>
<tr>
<td>keturunan</td>
<td>genetic</td>
<td>kecelakaan</td>
<td>accident</td>
</tr>
<tr>
<td>alergy</td>
<td>allergy</td>
<td>tidak bisa sembuh dan sudah nasib</td>
<td>cannot cure, destiny</td>
</tr>
<tr>
<td>Cured</td>
<td></td>
<td>dosa</td>
<td>sin</td>
</tr>
</tbody>
</table>

| sembuh berarti tidak ada bercak, pegal linu dll | cure means no skin patch, no pain etc. | tidak ada pengobatan | no medical treatment |
| sembuh berarti stop minum obat | stop taking medicine | tidak perlu berobat, ke dokter, ke puskesmas | no need to see doctor, no need to take medicine from community health service |
| diterima | be accepted | dipandang bila punya uang, kerja/usaha, status sosial, dekat dengan pemerintah dan tokoh masyarakat | be recognized if having money, job/business, social status, close with government and community leader |
| bisa beraktivitas (kerja, sekolah, ke pasar, ke sawah dll) | can perform activities (work, school, market, farm etc) | | |

### 3.4.4. Impact on behaviour

All participants shared feelings of pessimism and a lack of motivation. As one of the participants affected by leprosy said:

*I do not know what I should I. I prefer to sit or walk around the house. If my family asks me for help, I help; if not, I usually just sit.* (Person affected by leprosy FGD1)

In particular, most of the participants affected by leprosy agreed: 'We do better keeping our silence and staying away from people.' The participants affected by disabilities shared this attitude. As one person stated: 'I do not want to do anything, I have given up. I prefer sitting or sleeping rather than starting any activity or doing something.' Stigma leads people to become passive and generates attitudinal barriers to undertaking action.
The group affected by leprosy said they prefer to keep silent and do nothing, as they feel that pursuing any activity will bring negative comments from the people around them:

*Keeping silent is better than doing something. Being labelled (cap) cannot be stopped and I cannot stop people labelling me. Meeting people, for me, means being insulted (dihina).*

(Person affected by leprosy IDI 6)

Another participant added:

*When we [people affected by leprosy] are bored, we go to the kitchen and wash some dishes, but our family members shout at us and we get insulted (dihina). So we do not do it again, because doing activities is more isolating (dikucilkan).* (Person affected by leprosy FGD 2)

Some of the participants affected by leprosy justify their passiveness by their idea of being ill:

*We are ill. Going to the community health services, getting and taking our medicine regularly, meeting the health officers if we are in pain and asking for medical treatment. This is enough. Just to do these actions is enough.* (Person affected by leprosy FGD 2)

People affected by disabilities face stigma, which they feel has to be accepted, although they also feel anger and sadness:

*I am sad about my abnormal body. People always tell me to see a doctor, to have medical treatment and stay at home. I am really angry but I cannot take any initiative.* (Person with disability IDI 3)

A participant with visual impairment expressed frustration:

*Self-isolation is the best choice. I cannot stand people staring (aneh) at me, feeling pity for my body.* (Person with disability FGD 3)

Both groups were aware that they will struggle with stigma throughout their lives and that they should adopt strategies to cope with it (see Table 3.5).

**Table 3.5. Strategies to cope with stigma**

<table>
<thead>
<tr>
<th>People affected by leprosy</th>
<th>People affected by disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Indonesian</strong></td>
<td><strong>English</strong></td>
</tr>
<tr>
<td>Diam</td>
<td>silence</td>
</tr>
<tr>
<td>menjauhi</td>
<td>being far from people</td>
</tr>
<tr>
<td>tidak berdekat</td>
<td>not being close</td>
</tr>
<tr>
<td>menghindar</td>
<td>avoid</td>
</tr>
<tr>
<td>menolak ajakan</td>
<td>reject invitation</td>
</tr>
<tr>
<td>berpindah</td>
<td>not moving</td>
</tr>
<tr>
<td><strong>Indones</strong></td>
<td><strong>English</strong></td>
</tr>
<tr>
<td>diam</td>
<td>silence</td>
</tr>
<tr>
<td>cuwek</td>
<td>do not care/ignore</td>
</tr>
<tr>
<td>di rumah</td>
<td>staying at home</td>
</tr>
<tr>
<td>dengan teman sesame</td>
<td>being with peers</td>
</tr>
<tr>
<td>terlibat</td>
<td>participate in activities</td>
</tr>
<tr>
<td>ke belajar dan berlatih</td>
<td>studying and training</td>
</tr>
</tbody>
</table>
3.4.5. Impact on relationships

The group affected by leprosy and the group affected by disabilities reported facing social exclusion due to stigma. They experience social barriers. Although the participants have said they consider themselves to be part of their families and society, they simultaneously feel rejected by them due to their appearance: skin patches, physical deformity and other visible impairments.

The results show that social barriers were more evident when they were away from home: looking for a job, running a business, shopping or just being outside their local neighbourhood. As shared by one of the participants affected by leprosy:

"Once, I felt really disappointed when I met my neighbour. When I greeted him and offered him my hand, he rejected my hand without replying my greeting. Then he went inside his house and closed the door on me. He is a strange neighbour and what makes it even sadder is that he works in a community health service." (Person affected by leprosy IDI 2)

Most of the participants affected by leprosy said they experience social barriers when they go outside the home and that they prefer to avoid any social contact when possible:

"If there are no urgent matters, we prefer staying at home. From our experience it is better to not make contact with people. People surrounding us expressly avoid us and they continually label us as patients with a contagious disease." (Person affected by leprosy FGD2)

"For me, there is not any benefit in interacting with people. Many times I have tried to start social relations by smiling and saying 'hi' to people, but they still look at me as an enemy." (Person affected by leprosy IDI 1)

One of the participants with a visual impairment added:

"I am lonely although I live with my family. I feel like a member of my family but I am isolated by them. They discriminate me. They don't let me participate in preparing the food and cleaning the house." (Person with disability FGD 3)

In their daily social life, both groups are aware of the stigma that is elicited when they try to establish social relations. People spontaneously reject them when they try to participate either in family life or in their respective communities.

For the group of people affected by leprosy, stigma may mean the end of all social encounters:
It is impossible having social interaction with others. I am ill, I must be cured, get my hand back first, then I can go out. I believe people do not want to be friends with a sick person with a crawling hand like me. (Person affected by leprosy IDI 2)

One person affected by disabilities, argued that it is mainly the quality of the relationships that suffers. As one participant said:

My right hand is amputated. When I want to shake the hand of another woman with my left hand she looks at me and takes a step back. Shaking hands with left hands is abnormal. I am disabled and this makes it difficult for me to build social relations with people who are normal and shake hands with their right hand. (Person with disability FGD 3)

Furthermore, people affected by leprosy mentioned their social relations are often restricted to the medical context, namely with patients and health professionals:

I am happy that the leprosy officer sometimes visits me at home, but I feel disappointed. He just comes to check whether I take the medicine regularly or not. I need people I can talk to. (Person affected by leprosy IDI 5)

Predictably, persons affected by leprosy thought they would be better able to build social relationships once they were cured, while people affected by disabilities thought that expanding their social network depended on being ‘normal’.

3.4.6. A perspective on coping strategies

Participants also shared some views showing that they can develop coping strategies to live with stigma. Some felt that the process of coming to terms with their condition made them more at ease with themselves.

There is no choice but just to be patient. I try enjoying life. (Person with disability IDI 3)

Sometimes participants have found that coming to terms with their condition is a good way to empower themselves. These participants show their desire to fulfil their needs such as getting food, medicines or a job. Furthermore, persons affected by disabilities have struggled, trying to get access to work or to develop their own businesses. For instance, two participant with a physical impairment said:

I am not sick and I run a business repairing electronic devices. I am abnormal, that is right, nevertheless I work as many other people do ... Frequently, I challenge people by saying I am not sick, I am just abnormal. Even with this abnormal condition, I can still work and even earn money. (Person with disability FGD 3)

Basically I need to work. Having a job is my right. I must contact people for getting a job and earning money. I can ignore people who discriminate me. (Person with disability FGD 3)

And a participant affected by leprosy noted:
I have the rights to live so I need food and drink for my life. I need money to buy that, so I need to work. (Person affected by leprosy FGD 2)

3.5. Discussion and conclusions

This chapter started with providing a detailed overview of how stigma is expressed in the language of Bahasa Indonesia, which might be a useful resource for other researchers and health professionals working with stigma in the Indonesian context. In this study, stigma experienced by people affected by leprosy and those with disabilities had negative impact on their emotions, thoughts, behaviours and relationships, thus the four aspects of the framework (ILEP, 2011). Categorizing stigma experiences within these four domains was not always easy, as some experiences could fit in more than one domain.

Although the persons in this study differ in their type of illness and disability and the duration of impairment (from birth or attained at some point in their lives due to accident or illness), the experiences between the two groups demonstrate considerable similarity. Social exclusion and rejection come to the front in each domain and in both groups. Hence, these are likely two important concepts. In Indonesia, for disability similar experiences were described in the study of Kusumastuti, Pradasani, & Ratnawati (2014). For leprosy, similar findings were provided in Chapter 2 and Schuller & van Brakel (2010). The study of Schuller & van Brakel (2010), for instance, compared the experiences of women with disabilities due to leprosy and due to other reasons in Indonesia. They found that all women with disabilities experienced stigma, but that those caused by leprosy were worse off. It seems that stigma is most likely to be a generic phenomenon in this context. This is in line with van Brakel (2006) who found, that peoples’ experiences with stigma and the consequences of stigma are remarkably similar among different health conditions and across cultures and countries.

Similarities in the experiences with stigma brings opportunities for interventions. People with different stigmatized conditions can perhaps benefit from the same interventions. As a group they can learn together about the challenges stigma brings. In addition, their thoughts on ‘difference’ and behaviours as ‘social isolation’ might improve by the interaction with a different group of people in similar circumstances. This was already happening, on a very small scale, with participants in our study. People affected by leprosy and with a disability met during the FGD and due to the dialogues they seemed more able to respect differences and accept each other and oneself.

The most notable difference in the experiences of stigma between the two groups is that people with leprosy were more likely to frame their condition as relating to ‘sickness’ – even after they were cured – and those with disabilities were more likely to frame their condition as ‘abnormality’. The group affected by leprosy mostly understood leprosy as a contagious, chronic and an incurable disease. Participants demonstrated negative attitudes that seem, in part, the
result of false perceptions and limited knowledge about leprosy and disabilities, both in society as a whole and by the participants themselves. This was also described by others (for instance Varkevisser et al. (2009)). Such perceptions in people affected by leprosy constitute a form of self-stigmatisation. These findings illustrate the importance of interventions that can challenge deeply held beliefs and assumptions about, for instance, 'difference', 'illness' and 'disability'. Counselling might be an example of such an intervention. Unfortunately, little is known about counselling in the field of leprosy. Floyd-Richard and Gurung conducted a pilot study with group counselling in Nepal that showed positive results (Floyd-Richard & Gurung, 2000).

One additional finding of this study is particularly interesting and relevant. While stigma has undoubtedly many harmful consequences, our study shows that some individuals have developed various coping strategies and are aware of their rights, found employment and in this way contributed to the family income. From these people we can learn in particular, when we develop interventions. Coping strategies have also been the focus in the study of Heijnders (2004). They specifically looked into health seeking and adherence to medication. Although their focus was different they in a similar fashion concluded that listening more carefully to those affected by leprosy is important if we want to improve leprosy services. The desire to contribute to the family income as expressed by participants in this study could be addressed by the development of socio-economic interventions as for instance done by Ebenso et al. (2007). Skills people develop in such an intervention can help generate money and provide a living, which might make people around them view them more positively.

In conclusion, we argue that there are many similarities in the stigma experiences of persons affected by leprosy and persons with disabilities. The most importance difference we found was that those affected by leprosy tended to frame their situation in medical terms, while those living with disabilities described their situation from a more social perspective. The similarities between the two groups and the coping strategies depicted by some persons offer opportunities for interventions. Research that tackles different aspects of stigmatization faced by people affected by leprosy and related impairments could lead to inclusive initiatives that help individuals to come to terms with the stigma and to advocate against exclusion and discrimination.
References


Chapter 5
Lay and peer counsellors to reduce leprosy-related stigma: lessons learnt in Cirebon, Indonesia

Abstract

Objective: Counselling has been identified as a promising strategy to reduce stigma. Lay and peer counsellors have provided counselling in various fields, but this has not yet been studied in the field of leprosy. The SARI project in Cirebon District, Indonesia took up this endeavour. This chapter describes the initial experiences based on the perspectives of the lay and peer counsellors and aims to provide lessons learnt for future initiatives.

Methods: The selection of lay and peer counsellors was based upon pre-defined criteria such as completed junior high school and level of confidence. This study draws on the notes of seven monitoring and evaluation meetings and 21 group discussions the main researcher facilitated with the lay and peer counsellors and the notes written by the lay and peer counsellors on the sessions with their clients.

Results: In total, 198 people affected by leprosy were offered counselling by the 11 lay and 12 peer counsellors; 145 accepted this offer. The other 53 either did not need counselling or did not want to participate, for example, due to worries about disclosure. Effective communication skills such as listening and asking effective questions were important, but also difficult to acquire for the lay and peer counsellors. Sharing personal experiences was highly appreciated by clients and stimulated a deepened reflection.

Conclusion: Challenges related to concealment and effective skills exist, but some people affected by leprosy and others can become effective counsellors making it at the outset a challenging but nevertheless promising intervention.
5.1. Introduction

How can we reduce leprosy-related stigma and its impact? Can something so deeply embedded in how people think and act be changed at all? And if so, who should change first, people at the receiving end of stigma or those who stigmatize. And finally, who wants and is able to bring about this change? In this chapter we describe the process of implementing a promising, new approach to leprosy-related stigma namely lay and peer counselling.

In the review of strategies to reduce stigma Heijnders and van der Meij (2006) conclude that counselling interventions which concentrate on the individual and community level are among the most promising strategies. Counselling is defined by Yeo (1993) as a collaborative process in which the counsellor or psychologist facilitates the expansion of people’s view of life; enlarges their repertoire of coping resources; and enables them to make choices for change in themselves, the situation, and the environment without destructive consequences to the self or to others. Several studies have shown that counselling as a stigma reduction strategy is effective in the field of HIV/AIDS, stroke, mental health and leprosy (Chan et al., 2005; Corrigan & Calabrese, 2005; Evans, Matlock, Bishop, Stranahan, & Pederson, 1988; Floyd-Richard & Gurung, 2000; Hall & Tarrier, 2003). It is thus possible to change something so deeply embedded as stigma, answering the first two questions posed above.

Perhaps even more relevant are some of the other conclusions of Heijnders and van der Meij (2006). According to them, interventions should aim first at empowering affected persons who then can take an active role in stigma reduction (Heijnders & van der Meij, 2006). From these conclusions we can take two points. First, it provides a possible answer to the ‘who should change first’ question, being people affected by leprosy. Second, it states that empowered affected people can take an active role in stigma reduction, although, as noted earlier in their conclusion, they should not carry the burden alone. This means that the final question of who wants and is able to bring about this change in stigma, can be partly answered: empowered people affected by leprosy can become agents of change in their communities.

So how can people affected by leprosy and others be involved in a counselling intervention? An interesting development is the training and involvement of LCs. Lay counsellors do not have a professional or academic counselling qualification, but have acquired a basic training in communication skills. Lay counsellors may be staff from non-governmental organisations (NGOs), disabled people organisations (DPOs), or health workers, but may also be peers. The term ‘peer counsellor’ is used to refer to LCs who themselves share a personal experience with the client, for example by having the same disease, condition or disability. To our knowledge, lay and peer counsellors have been sporadically involved in the field of leprosy, but this has not yet been formally studied. The aim of this chapter is to draw out lessons from a pioneering study of involving lay and peer counsellors in a leprosy oriented stigma reduction project, the SARI project.
in Cirebon District, Indonesia. Specific questions addressed are: what challenges emerge in the different counselling phases: beginning, middle and end phase? And, to what extent are the lay and peer counsellors in the SARI project effective counsellors?

First, we will briefly discuss current experiences related to counselling in the field of leprosy, introduce the SARI project and describe the counselling intervention in more detail. In the Results section of this chapter we describe the process of the counselling work starting with establishing the first contact with the client and concluding with the final session. This chapter does not focus on the development of the counselling module, the selection and training of lay and peer counsellors or on the clients' perspectives. These will be reported elsewhere.

5.2. Counselling for stigma reduction in the field of leprosy

Stigma is a complex construct. It is often described as an undesirable or discrediting attribute (Goffman, 1963), but has several other definitions that are more comprehensive. Weiss describes health related stigma 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’ (Weiss et al. 2006:280). In comparison, Link and Phelan define stigma as ‘the co-occurrence of its components – labelling, stereotyping, separation, status loss, and discrimination’ – and further indicate that for stigmatization to occur, power must be exercised (Link & Phelan 2001:363). Both these definitions show that the concept of stigma consists of several interrelated components that jointly influence the life of a person affected.

Counselling can target some of these components. The most important resource available in the field of leprosy is a guide on lay counselling produced by ILEP (2011). In addition, the author is aware of two studies that address counselling in the field of leprosy (Floyd-Richard & Gurung, 2000; Thakor & Murthy, 2004). We summarize the key points from these sources. First, an effective counsellor has, according to the ILEP guide, ‘a combination of attitudes and personal qualities, skills, and knowledge of the health condition, the cultural/social context, and good ethics’ (ILEP, 2011). Attitudes and personal qualities include empathy, non-judgemental, respect, intent to empower and self-awareness. Skills include listening, observing, non-verbal communication, asking effective questions, reflecting and handling emotions. Second, the counselling process is divided in three distinct phases in the ILEP guide. These are the beginning, in which a safe and private setting is created and rapport is built, a middle phase, characterized by listening, observing, identifying needs, setting goals and stimulating actions, and an end phase with a gradual phasing out (ILEP, 2011). Third, the ILEP guide notes that although counselling focuses on the individual it can be valuable to initiate family and group counselling. Thakor & Murthy (2004) also mention these two groups and an example of group counselling is described in the study of Floyd-Richard & Gurung (2000). Fourth, Thakor & Murthy (2004) note that
education is key to overcoming stigma but Floyd-Richard & Gurung (2000) critically add that health education alone will not heal stigma. Key messages include, according to Thakor & Murthy (2004), that leprosy is curable, is caused by bacteria (not a sin or curse), that deformity does not mean a person still has the disease and that affected people can live completely normal lives. Fifth, the value of peers is mentioned. The ILEP guides describes peer counsellors as people ‘who themselves have personal experience of health-related stigma and have come to terms with the challenges it brings’ (ILEP, 2011). Floyd-Richards & Gurung (2000) refer to a mentor who has gone through the changes him or herself. Some other points relate to the importance of support and continuing training and personal development for the counsellors, counselling ethics, in particular confidentiality, and the importance of a referral system (ILEP, 2011). Based on these resources and others (see chapter 4) the counselling intervention was developed as described below.

The SARI project aims to assess the impact of three interventions to reduce stigma in and against people affected by leprosy in Grebon, Indonesia. The three interventions are: counselling, establishing ‘contact’ between people affected by leprosy and community members, and SED through activities such as micro-credit. The project is executed by the SARI team, which is an inclusive team in the sense that people with disabilities and affected by leprosy are part of the SARI team (either as researchers or as research-assistants). In 2011, a mixed-methods study was executed to describe the baseline situation with regard to leprosy-related stigma and in 2014 an end survey will be executed to assess the impact of the interventions. The project is also participatory as persons affected by leprosy and other key persons were actively involved in the design and implementation of the activities.

The counselling intervention aims to decrease stigma and reduce the negative psychological effects of stigma in people affected by leprosy by helping them to have a positive image of themselves, build their knowledge of leprosy, disability and human rights, increase self-awareness, self-confidence and self-advocacy to fulfil their rights and needs. Lay and peer counsellors are the counselling providers. In this study an effective lay or peer counsellor is characterized as a person who is confident to meet and communicate with clients and their families, is able to create a friendly atmosphere, has a positive attitude and has personal experience of the disease or has a connection with people affected by leprosy. The lay or peer counsellor uses active listening, showing empathy and trying to understand the client, and asks probing and reflective questions in their conversation with the clients. An effective counsellor also has knowledge about leprosy, disability and human rights. He or she uses these knowledge and skills to motivate and empower the clients to be self-confident in what they do.

Nine components can be identified in the design and implementation of the counselling intervention:
An exploratory study was executed by the four researchers and 10 RAs of the SARI project to understand the everyday experiences of people affected by leprosy and to receive input for the counselling intervention (May 2011 – November 2011).

A short 3-day training on the basics of counselling was provided to the RAs of the SARI project by a qualified counsellor who has more than 10 years’ experience (December 2011).

A pilot was executed to assess the need of clients, to test different types of counselling (individual, family, group), assess the approximate duration of each type of counselling and decide on the number of sessions needed. During the pilot 62 persons affected by leprosy received counselling from the author of this thesis assisted by the RAs. The RAs of the SARI project selected clients for the pilot who had potential to become peer counsellors. From 274 people affected by leprosy who participated in the baseline and lived in the counselling area they selected 62 clients based on criteria such as: i) completed junior high school, ii) self-confidence to meet people, and iii) communication skills. In addition, the counsellor also selected potential candidates for the lay and peer counselling training (January – April 2012).

Design of the SARI counselling module in which the content for five counselling sessions, including individual, group and family counselling was developed (October 2011 – April 2012).

The first training course for lay and peer counselling was given to the RAs of the SARI project and previous clients of the pilot. The aim of the training was to build capacity to be a lay or peer counsellor by developing basic counselling skills and attitudes (such as listening, probing, empathy, advocacy) and by increasing knowledge and awareness. The content was built around four topics; leprosy, stigma, counselling and rights. The participants theoretically and practically learned about how to facilitate counselling during 14 days of training (4 hours of training per day, so 56 hours in total). Interactive training methods were used and self-study and an assignment were required (practicing in providing counselling for a minimum of 10 hours to friends or family) (April – May 2012).

Start of the counselling provided by the lay and peer counsellors from the first training, in teams of three. The participants of the baseline study living in the counselling intervention area and newly diagnosed persons in these areas could potentially become counselling clients. Information about which persons are affected by leprosy and their addresses were provided by the leprosy workers at the CHCs. They were visited at their homes. Typically, five counselling sessions were offered: two individual, one family, two group. There was continuous supervision through group meetings and team discussions to improve the counselling skills and overall capacity of the lay and peer counsellors. These were organized on a monthly basis (June 2012).
A second training course for lay and peer counsellors was organised to increase the number of lay and peer counsellors. Minor changes in the content were made including more attention to practice. The newly trained lay and peer counsellors selected from their client group people affected by leprosy for the second course, based on the same criteria. In addition, SARI decided to work more closely together with a local DPO. Leprosy is one of the causes of impairments and disability and in order to increase the chance of sustainability of the counselling intervention a close collaboration seemed beneficial. Some disabled members of this DPO were also selected for the second training. For similar reasons, 14 leprosy workers from the CHCs joined the training. The skills they gained during the training can be used in their daily work but they did not become LCs of the SARI project (August 2012).

Second training course of lay and peer counsellors, same as before (September – October 2012).

The newly trained lay and peer counsellors joined the group of existing lay and peer counsellors. Together the lay and peer counsellors offered counselling to 198 clients and provided counselling to 145 clients (June 2012 – March 2013).

5.3. Methods

This study took place in Cirebon District which is located in the province of West Java near the provincial border with Central Java. Due to its location, people in Cirebon speak different dialects and have absorbed influences from different religions and cultures. The counselling intervention is implemented in 15 sub-districts.

This study is an exploration of involving lay and peer counsellors in the reduction of stigma and its impact in the field of leprosy. It is based on the perspectives of the lay and peer counsellors of the SARI project. The data was collected between April 2012 and March 2013. Demographic information such as age, education, marital status, religion, profession of the lay and peer counsellors was collected by filling in a short questionnaire. This was already done during the lay and peer counselling training. The author of this thesis wrote notes on seven monitoring and evaluation meetings, each lasting on average three hours, in which all the lay and peer counsellors together shared experiences and difficulties from the field, reflected on their skills and attitudes and discussed clients’ stories. Notes were also taken of 21 team discussions in which small teams of three lay and peer counsellors had in-depth discussions and reflections on their work, skills and attitudes. These also lasted about 3 hours each. During the meetings and workshops lay and peer counsellors narrated the conversations that had taken place with the clients in the field. These experiences are presented in the Results section. In addition, the lay and peer counsellors were instructed to write notes on the same day as the counselling session in notebooks or directly in a Word file on clients’ responses to the counselling, difficulties in providing the counselling, the
team work and on meaningful experiences while facilitating counselling. Sections from these notebooks are also presented in the Results section. All notes were written in Bahasa Indonesia and analyzed by the author of this thesis. Based on these notes and her own observations she assessed whether the lay and peer counsellors were or became effective counsellors as defined earlier. She read and re-read the notes many times to find themes and patterns. She then categorized similar experiences, issues and phenomena, discussed these with the team and drew out lessons learnt.

5.3.1. Ethical considerations

Permission for the study was given by the relevant government offices and by the Ethics Committee of Atma Jaya University, Jakarta. In the SARI project most people affected by leprosy were met for the first time at the CHCs during the baseline study. They were asked whether they would be interested to join the SARI project as a participant. If they answered positively, they were visited at home. Some others were visited directly at home. Confidentiality was key, so the SARI team discussed the leprosy status of the person with nobody except with the person themselves. If a person affected did not want to join the counselling intervention they were not visited again. If family members or neighbours asked questions they were given an evasive answer. The team rationalized that one visit by one or two persons unknown in the neighbourhood would not create suspicion, but that repeated visits could give rise to questions. Written consent to participate in this study was obtained from individual clients and lay and peer counsellors. Sustainability of the intervention after the SARI project is concluded was considered important, hence our collaboration with a local DPO, CHCs and the DHO.

5.4. Results

5.4.1. Introducing the lay and peer counsellors of the SARI project

In total, 27 people started the lay and peer counselling training with the intention to become lay or peer counsellors. Four decided to resign during the training for different reasons; pregnancy, job opportunity, realisation there were no financial benefits (although this was clearly mentioned before the start of the training) and because of the reservations of a spouse who was afraid she would be excluded if neighbours found out about the leprosy history of her husband. Table 5.1. provides the demographic information of the 11 LCs (six physically or visually disabled and five non-disabled) and 12 peer counsellors (those affected by leprosy) of the SARI project.
Table 5.1. Demographic information of lay and peer counsellors (n=23)

<table>
<thead>
<tr>
<th>Demographic characteristic</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>15 (65)</td>
</tr>
<tr>
<td>Female</td>
<td>8 (35)</td>
</tr>
<tr>
<td>Age years</td>
<td></td>
</tr>
<tr>
<td>18 - 25</td>
<td>8 (35)</td>
</tr>
<tr>
<td>26 - 35</td>
<td>9 (39)</td>
</tr>
<tr>
<td>36 - 45</td>
<td>6 (26)</td>
</tr>
<tr>
<td>Religion</td>
<td></td>
</tr>
<tr>
<td>Muslim</td>
<td>23 (100)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>14 (61)</td>
</tr>
<tr>
<td>Single</td>
<td>8 (35)</td>
</tr>
<tr>
<td>Widower</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Elementary school</td>
<td>7 (30)</td>
</tr>
<tr>
<td>Junior High School</td>
<td>5 (22)</td>
</tr>
<tr>
<td>Senior High School</td>
<td>6 (26)</td>
</tr>
<tr>
<td>Higher education/university (* those attending)</td>
<td>5 (22)</td>
</tr>
<tr>
<td>Profession</td>
<td></td>
</tr>
<tr>
<td>Involved in the SARI project as research assistant (RA) since 2011 (received training on CBR and social research)</td>
<td>8 (35)</td>
</tr>
<tr>
<td>Other job e.g. housewife, farmer, teacher, running small business, repairing mobile phones, handicraft activities</td>
<td>14 (61)</td>
</tr>
<tr>
<td>Jobless</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Involved in activities of a DPO in Cirebon</td>
<td>15 (65)</td>
</tr>
<tr>
<td>Disability or leprosy</td>
<td></td>
</tr>
<tr>
<td>With a physical disability due to polio, car accident or burns</td>
<td>5 (22)</td>
</tr>
<tr>
<td>With visual impairment</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Affected by leprosy (with leprosy-related impairment)</td>
<td>12 (52)</td>
</tr>
<tr>
<td>3 (13)</td>
<td></td>
</tr>
<tr>
<td>Compensation for counselling work</td>
<td></td>
</tr>
<tr>
<td>Paid (RAs)</td>
<td>8 (35)</td>
</tr>
<tr>
<td>Unpaid (compensation for travel expenses only)</td>
<td>15 (61)</td>
</tr>
<tr>
<td>Key person in community e.g. religious leader, community leader, teacher, source of information for neighbours</td>
<td>12 (52)</td>
</tr>
</tbody>
</table>

All peer counsellors had finished the MDT and hence were cured from leprosy. Three have a leprosy-related impairment. In total eight, are RAs of the SARI project who have received more
training on leprosy, CBR and social research compared to others. The figures clearly illustrate the
diversity of the group in variables such as age, education, profession and involvement in a DPO. It
also shows that in March 2013, 20 lay and peer counsellors were still active; two passed away and
one person found a permanent job that he could not combine with his peer counselling work.

5.4.2. Beginning phase: to create a safe and private setting

During or after the first meeting of the lay or peer counsellor and the client, the client will
determine whether he or she will start the counselling process. Hence, the first meeting is
important. Visiting potential clients for the first time at their homes was a new activity for most of
the lay and peer counsellors. During the meetings and group discussions physically disabled LCs
reported that making the first contact and encouraging potential clients to participate in the
counselling intervention was a challenge for them. Some of the potential clients appeared to have
suspicions and assumptions about disabled people. Some clients assumed that the disabled
person was at their house to ask for a donation. The following field experience was shared by a LC
during a group discussion:

   Lay counsellor with physical disability: Hi, good afternoon. May I have some time?
   Client: Sorry, are you debt collector? Are you here for a donation? Are you salesman?
   Lay counsellor: Can I introduce myself first, my name is (...) and I am one of the lay counsellors
   at SARI project
   Client: What? You are a person with a physical disability, why do you want to meet me?
   (Group discussion notes 12)

Potential clients of peer counsellors affected by leprosy were, in contrast, generally willing to
discuss the possibilities of joining the counselling intervention when they heard that the
counsellor was a person affected by leprosy, as shown by this section from the notebook of a peer
counsellor:

   In the beginning, I found it difficult [to encourage the client to start counselling] but after the
   client knew I have been cured of leprosy, he changes his attitude, he does not see me as a
   stranger, but we can enjoy having a conversation. (Notes LPC16)

In total 53 persons affected by leprosy out of 198 (27%) that were approached by the lay and
peer counsellors did not see a need to start the counselling. In one case, a request was made for a
lay or peer counsellor of the same sex by the husband of the client. Of these 53 people, 14 had
been cured of leprosy for a long time, had no visible signs and led an everyday life without stigma.
Eighteen did not want to start counselling because it did not offer any direct material or financial
benefit, such as food or money, to them. Twenty-one people decided not to start the counselling
because they were afraid it would create or increase stigma from the community or family.
However, this does not mean that all those who concealed their illness decided not to start
counselling, as some (14 in total) saw the benefits of counselling and decided to go for it. The
perceived need for counselling was not related to the person’s treatment status (on treatment or cured) or impairment status (with or without impairment).

5.4.3. Middle phase: with individual, family and group counselling

Counselling skills

The notes of the meetings and team discussions show that applying counselling skills during the individual, family and group counselling sessions was challenging for the lay and peer counsellors. This became apparent to them during the first sessions with the clients. For instance, one peer counsellor told during a team discussion (notes meeting 5) how a client felt insulted and humiliated, because the counsellor assumed too quickly that the client could not read. Peer counsellors had more difficulty with the counselling skills of listening and probing than the LCs. Peer counsellors preferred to talk and share more instantly their knowledge and experiences, whereas for LCs the skills of listening and probing developed naturally as they wanted to first understand the characteristics of the client.

In order to improve counselling skills, the problems of counsellors making assumptions were addressed during the next meeting with all lay and peer counsellors. Over time, the lay and peer counsellors increasingly realized that clients preferred to be listened to compared to being advised, as this increased the confidence of the client in the conversation. In addition, they noted that asking questions deepened the reflection of clients. Consequently, the lay and peer counsellors realized they needed to enhance their counselling skills and several managed to do this. For example, one of the peer counsellors had a client who was losing his vision due to leprosy and experienced sadness and seemed depressed. After listening to the client, the peer counsellor explained the importance of self-care and motivated the client to use glasses. However, the peer counsellor observed that the client seemed more stressed than before. After asking questions and listening some more, the peer counsellor learned that the client did not want others to know he was losing his vision due to leprosy and thought that by wearing glasses others around him would know and stigmatize him. This information helped the peer counsellor address the client differently. Instead of providing information, the peer counsellor encouraged the client to reflect on the use of glasses and the client started to perceive glasses as a protective tool, in contrast to a tool that would create stigma. By applying a combination of skills, such as listening, asking effective question, observing, motivating and providing information, a change was brought about (Notes LPC 8).

By March 2013, the author of this thesis had assessed the skills of the counsellors. She found that the counselling skills of nine lay and peer counsellors could be described as effective, while the counselling skills of the other fourteen counsellors were assessed as weak and still in need of improvement. What are the common characteristics of the lay and peer counsellors in these two groups? Both groups are mixed in terms of demographics: men and women, different ages and
different levels of education. Of the nine effective lay and peer counsellors, three are peer counsellors and six are LCs. Of the eight RAs, five became effective LCs but three did not. The most likely distinguishing factor was that many of the lay and peer counsellors with effective counselling skills had more experience and active involvement with community activities in the past. For instance, one young peer counsellor helped organize social activities at his school. Another, a LC with a physical disability, helped disabled people organize themselves, and yet another LC is a religious leader and therefore was used to working with people.

Enhancing knowledge

Providing basic knowledge on the disease leprosy turned out to be an important element of the counselling sessions. Most persons affected by leprosy had a lack of basic knowledge, for example, related to the cause of the disease and mode of transmission. Based on the meeting and group discussion notes again the difference in the quality of the counselling skills came to the foreground. Some of the counsellors simply provided information to the clients. For instance, a peer counsellor met a client, asked a question and waited for the client's answer. Even though the answer of the client was an unexpected answer and required further probing, she just asked another question without making a link to her client's situation or client's previous answer. The nine lay and peer counsellors, whose counselling had been assessed as effective, agreed amongst each other that they did not just give information, but helped the clients thoroughly process the information and its implications (notes meeting 2). This was seen as an effective strategy and this management of information was therefore given extra attention during meetings and team discussions.

Peer counsellors seemed to be effective in sharing knowledge because of the credibility gained from their personal experience with the disease. This is illustrated by the following story from the field shared during a group discussion. The peer counsellor told the clients during a group counselling:

> Last time, I was an affected person like you. I thought I had this disease because of curse and magic. After I participated in SARI training on lay and peer counselling, I get knowledge on what leprosy is. It [my understanding] is totally wrong, it is because of a bacteria. Not a curse and not magic. Knowledge on leprosy made me aware and understand that leprosy can be cured and that it is not easy to transmit to people. I am now here sharing my knowledge to you. What do you think? (Notes group discussion 11)

There were similar stories from female peer counsellors and pregnant clients who worried about transmission of the disease.

> She [my client] was really worried because of her pregnancy. I listened to her worries. Her understanding is that her disease is a genetic disease and could transmit to her baby. She was thinking about having an abortion. I gave her information on the cause of leprosy. That is not
genetic disease, but because of a bacterium. The knowledge that she got from me helped her think more positively, reduced her readiness to have an abortion and she made a self-commitment to keep her pregnancy. (Notes LPC8)

Sharing (personal) experiences related to stigma: Peer counsellors have been through similar experiences with stigma as their clients. Sharing these experiences helped the clients realize they are not alone with their disease, increased trust further, stimulated reflection, and helped the clients develop a positive self-image. One example from a family counselling session:

Peer counsellor: I am a person affected by leprosy like you, but I could not just stay with no work. I am not an individual human being, I am part of my family and community, and I do not want to be a burden for them. With my health condition, I am not an ill person forever and ever, I have been cured so it is time for me to go back to work to earn money for myself and for my family. (Notes meeting 6)

The physically disabled LCs experienced stigma similarly to persons affected by leprosy. When they interacted with clients this parallel strongly supported their counselling work. Often they had more experiences of impairments and disability aids which allowed them to share different experiences. One example comes from an individual counselling session:

Lay counsellor: It seems, you are a very surprised to see me?
Client: Yes, I am wondering, with your impairment, are you not afraid to be stigmatized by the community when coming to my house?
Lay counsellor: May I say that you seem to feel stigmatized by the community when you go out? According to you, what make communities stigmatize you?
Client: I think twice if I want to go out... Communities around me stigmatize and look at my crooked fingers due to leprosy.
Lay counsellor: Look my fingers, same with your fingers. Crooked fingers because of burns, but it does not limit me to go out, to meet people, to work, earn money and have opportunities, and I can get all of those things within the community. Those are my rights! If people look at me, I take initiative to closely contact and introduce myself by shaking hand with my crooked fingers by this, stigma can be reduced. What do you think? (Notes group discussion 10)

For the five LCs without a disability or leprosy history, sharing personal experiences was different as they have not lived through a similar experience. They, however, shared stories of people affected by leprosy or with a disability that they got to know personally:

I am aware, I am not experiencing leprosy, so when I do counselling, I should bring a successful life story of a person affected by leprosy, it helps to encourage the client to be more confident, to go out and enjoy life with his family and the community. (Notes LPC5)
Awareness of rights and advocacy

The discussion on rights was an important element of the counselling sessions. Rights are addressed in individual counselling sessions, but they are discussed in more depth during the group counselling sessions. The client’s realisation that they have rights, and that a disease such as leprosy does not change that, has been shown to be powerful. The LCs who are involved in the work of the DPO were already aware of rights and were some steps ahead of the other lay and peer counsellors. Others learned and increased their awareness about rights through training on this issue. The importance of rights resonated closely with their own experience or fitted with the experience of clients, so it was relatively easy to reach the same level as the ones already involved in the work of the DPO. Much experience from the field related to rights, but also this exchange from an individual counselling session is illustrative:

*Lay counsellor*: Many times, I hear you mention yourself as a suffering person, what makes you suffer? (...)
*Client*: I do not know, I just hear in the health care centre, the health worker explains to me that I suffer from leprosy, I have a spot in my face. (...)
*Lay counsellor*: According to you, can a suffering person work? What do you think about a suffering person?
*Client*: Crying, feeling sad, doing nothing, not able to work, whimpering in pain
*Lay counsellor*: Do you like that person?
*Client*: So I am not a suffering person..., since I cannot just sit without activities, I want to make my life busy, my rights?
*Lay counsellor*: Yes you are right; you have rights. (Notes LPC11)

Diverse needs

During the individual, family and group counselling sessions, clients discussed a variety of needs and struggles. Foremost was their financial situation, but also medical care, continuation of study and participation in social activities. In some cases, the counsellors took an active role and assisted the clients by going beyond providing counselling (e.g. mediation), sometimes using rights as an advocacy tool:

*Through counselling I [peer counsellor] got to know that the client needs medical treatment but he is shy, afraid and has little confidence to go to the community health services. Thanks to the peer counsellor who has assisted him [to the CHC] he got medical treatment. (Notes LPC23)*

*I successfully helped my client to reclaim her right to go to school again. (...) The school did not allow her to go to school. (...) She faced stigma at school that made her feel shy and she had no confidence to meet friends and teachers. Through counselling, session by session, I listened to her feelings and thoughts. (...) When I asked her if she wanted to go to school, she smiled, and*
asked me to bring her to meet the headmaster and teachers. After consulting on her health condition with her leprosy officer and her parents, I tried to meet the head master in her school. In the first meeting, I lobbied by giving an explanation of her health condition and asking the school for her opportunities. During the second meeting, I accompanied her to talk with her head master and her teachers. (...) The school opened up and changed their mind. They welcomed her back to school. (Notes LPC5)

There also were needs that went beyond the aims of stigma reduction of the counselling provided by the SARI project. In one case, the client talked about the violent behaviour of her husband towards her. In this case the LC, who is also a religious leader, was on his own able to make a profound change in his client’s life, as shown here:

She openly and freely shared her violence experience to me. She was kicked and hit by her husband for a long time, she kept silent in her heart. (...) After 5 sessions of counselling, she said to me ‘I have faith in you; you made me dare to talk’. (...) During counselling sessions, I listened to her and clarified information that she gave to me by inquiring more. I strengthened her capacity. My counselling skills and my spiritual experience were useful to help my client show her spirit and confidence living a peaceful life with her husband. (Notes LPC15)

Another case tells the story of a client who was considering suicide because he felt tired by the medical treatment, visiting hospitals and spending a lot of money without being cured. The counselling motivated him to seek help at the CHC. Supported by his family he went there and started to take his medication routinely again. At the end of the counselling sessions he thanked the LC for opening his mind and appreciating the treatment from the CHC again. He feels better and in more relaxed in daily life. In these examples, had the LCs not have been successful, the client would have been referred to a professional counsellor or psychiatrist.

Location and logistics

The distance between clients was one of the challenging factors for the lay and peer counsellors while facilitating counselling in the field. Public transport is available but takes a lot of time and is less frequent after 6 p.m., a time when many clients were at home and preferred to have a counselling appointment. Therefore the availability of motorcycles was important. Flexibility in arranging the time to meet the clients was shown to be important for both the lay and peer counsellors and clients. Lay and peer counsellors have said that they value such flexibility as it, for example, can allow them to be both a teacher in a school and a lay or peer counsellor. Others said they often provide counselling after office hours or on Sundays in order to fit in with the schedule of the clients. However, there were some challenges regarding time management such as clients who preferred to meet more frequently or longer than feasible for the lay and peer counsellors. Two examples:
I have a dilemma, my client asked me to stay longer as she needs friends, she needs to talk, she also needs to be listened to. I do not want to make my client sad, but on the other hand, I should be back home as soon as possible, otherwise my husband will be angry with me and I do not have time to take care of our child at home. (Notes LPC8)

Today, my client complained to me that I seldom visit her and when I facilitated the counselling I felt ignored by her. (Notes LPC7)

The lay and peer counsellors reported during the fourth meeting that most clients preferred not to use their house for group counselling. On the one hand, the clients were worried and felt uncomfortable when their house was visited by many new people, especially if they had leprosy-related impairments. This was particularly relevant when the client did not want his or her neighbours to know that he or she currently is or once was affected by leprosy. On the other hand, the clients were eager to have group counselling since they knew from the lay or peer counsellor that in a group they could meet ‘friends’ who have or had the same disease. In search for an alternative location, most clients also refused to use a CHC for group counselling. For some clients this was due to mistreatment and stigmatisation by health workers. There were, however, also 42 clients who did not mind having the group counselling session in their house, allowing clients from other villages to come to their house.

5.4.4. Ending phase and gradual phasing out

Of the 145 clients that started the counselling provided by the lay and peer counsellors, 56 decided to skip one session or stopped the counselling prematurely. Table 5.2 provides an overview showing how many clients joined which sessions and how many skipped one session or stopped along the way.

<table>
<thead>
<tr>
<th>Session</th>
<th>Counselling type</th>
<th>Number of clients</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Individual counselling</td>
<td>145</td>
</tr>
<tr>
<td>2</td>
<td>Individual counselling</td>
<td>145</td>
</tr>
<tr>
<td>3</td>
<td>Family counselling</td>
<td>98</td>
</tr>
<tr>
<td>4</td>
<td>Group counselling</td>
<td>127</td>
</tr>
<tr>
<td>5</td>
<td>Group counselling</td>
<td>89</td>
</tr>
</tbody>
</table>

Several reasons why clients decided to discontinue the counselling were identified by the lay and peer counsellors. First, some clients were rarely at home due to a job in another district or city which made it difficult to commit to the counselling. Second, some family members of clients prevented a continuation of the counselling because they were worried about potential stigma from neighbours, for instance gossiping, that might result in their affected family members being avoided. Third, some clients felt that fewer sessions were enough to suit their needs, for instance
their need for information about leprosy. They were ‘bored’ by the conversation due to the repetition of topics. Finally, some clients did not want to continue, because they did not obtain material or financial support. Some clients were embarrassed to talk openly about their wish to stop the counselling, which could be difficult for the lay and peer counsellors as shown by this quote:

We know the client is inside the house, he or she hides and asked family members to say that he or she is not at home (...) We wonder why they must lie, we expect that they would like to meet us to receive counselling, we feel disappointed, but we should think from clients’ perspective why they did, for us, it is better if the client talks, he or she does not want to be disturbed by receiving a counselling session. (Notes LPC10)

In total, 69 clients needed and asked for more than five sessions. Mostly individual sessions were added, but for some young people affected, more group counselling was considered beneficial. The number of sessions that were added depended on the individual needs of the client, but were up to 12 sessions in total. A group of women that joined group counselling developed into a handicraft group. Sometimes a different and more long-term relationship was established as illustrated by this quote:

What was particularly meaningful for me, is that when the counselling sessions were finished, my client and I had developed a relationship as friends. When I am out and pass the client’s house, I drop by and have a chat with him. (Notes LPC16)

5.5. Discussion

For several health conditions there is an urgent need for stigma reduction activities (Cross, Heijnders, Dalal, Semriritrong, & Mak, 2011; van Brakel et al., 2012). With this study we contribute by describing the initial experiences of a novel strategy in the field of leprosy, namely providing lay and peer counselling. Our findings provide insights on involving lay and peer counsellors in reducing stigma and its impact. Findings come from the whole counselling process: from the first knock on the clients’ door to the conclusion of the counselling. They also depict experiences from various lay and peer counsellors: some affected by leprosy, physically or visually disabled and others neither affected nor disabled. Eight key lessons learnt can be abstracted from our findings and these are compared to the findings of other studies.

First, the initial contact between lay or peer counsellor and client is an important moment as at this point the clients determine whether counselling could be of benefit and hence if they want to start counselling or not. Creating a safe and private setting and building rapport as mentioned in the ILEP guide (2011) are indeed key. This study showed that encouraging potential clients to participate was the most challenging for LCs with a physical disability due to some initial assumptions about disabled people. To our knowledge very few studies and guidelines address
the potential stigmatisation of lay and peer counsellors by possible clients. We would like to underscore the importance of this type of stigmatisation and believe more attention to this is needed. For instance, awareness needs to be raised in the training of lay and peer counsellors and in the work of the supervisor so that the lay and peer counsellors learn how to anticipate and deal appropriately and effectively to this stigmatisation. Interestingly, later on in the counselling process, the disability of counsellors often became an advantage as it helped stir deeper reflection in clients.

Second, this study showed that people affected by leprosy who have concealed their illness often reject the counselling or stop along the way due to a worry about disclosure and possible stigmatisation from family or community members. This is an important finding as these clients are, among others, the persons you would like to reach. They may feel a psychological burden due to the secrecy and have a highly internalized stigma and therefore would most likely benefit from counselling. However, counselling provided at their homes may indeed draw unwanted attention and this could lead to involuntary disclosure, which then could eventually create or increase stigma. One could wonder if the home-based approach fits these clients’ context and if counselling at a more neutral place may be more appropriate. There is a contradiction here, because going out of the house might be another challenge for this group. The study of Baiden et al. (2007) on community acceptance of LCs, also found a fear for stigmatisation and discrimination of clients as a result of disclosure. Likewise, counsellors in a study in Botswana noted that clients’ fear of stigmatization was a barrier to effective counselling (Buvalda, Kruijthoff, de Bruyn, & Hogewoning, 1994). Privacy and guaranteeing confidentiality to avoid stigma due to involuntary disclosure are extremely important and should be the priority in a counselling intervention, as also noted by Baiden et al. (2007).

Third, sharing knowledge about the disease leprosy, going beyond the simple dissemination of information, was one of the main tasks of the lay and peer counsellors in this study. Peer counsellors seemed to be the most effective as the clients trusted and could relate easily to the information from peers. Other studies have critiqued the focus on education in lay counselling. For example, information-giving and advice were often used as strategies by the counsellors in the study of Dewing et al. (2013), as illustrated by the title of their paper ‘It’s important that you take your medication everyday okay?’ Also Richter et al. (2001) write that HIV counselling services in South Africa are based primarily on an educational model. However, in the context of Cirebon District, the lack of knowledge regarding basic facts about the disease was also described in Chapter 2 and its effect on stigma is important. Information-giving thus remains one of the key activities of the lay and peer counsellors.

Fourth, imparting knowledge is not, however, the most important of the necessary skills for counsellors. These are listening actively and showing empathy, asking effective questions, sometimes in a reflective or challenging manner, and motivating the client to have self-confidence
and self-empowerment. After the initial 14 day (56 hours) counselling training, the lay and peer counsellors in this study needed to further enhance their counselling skills in practice. From this study we can learn that developing effective counselling skills (as described earlier) was challenging for the lay and peer counsellors. In particular, peer counsellors had the tendency to start sharing and advising too soon, whereas clients preferred to be listened to rather than to be advised. Through continuous supervision nine out of 23 (39%) managed to develop effective counselling skills over about one year’s time. This number is lower than expected. The author of this thesis believes about half of the 14 with current weak counselling skills still have the potential to become effective lay or peer counsellors, but the others will most likely stay at the level they are at right now. We need to emphasize here that this group will still be a valuable resource for leprosy services, even if not as a lay or peer counsellor. That becoming an effective counsellor is challenging is also addressed in the study of Dewing et al. (2013) who evaluated counselling delivered by LCs in Cape Town. They found that the counselling practice was not consistent with the approach to counselling in which they were trained, disregarded its core principles and at times applied inappropriate strategies such as moralising, warning and confrontation. An important implication of ineffective counselling skills of lay and peer counsellors is that clients may reject counselling or not enjoy the counselling they received, for example when the counselling is more a question and answer session than a genuine conversation. Also, if the skills of providing information are weak, the client might be confused by unclear information. This might explain why some clients in this study preferred to stop after the second, third or fourth session. In addition, in this study some clients brought up issues (violence, depression, suicidal thoughts) that were beyond the scope of SARI counselling, so a good referral system as also mentioned in the ILEP Guide (2011) is important.

Fifth, three out of the nine effective counsellors are peer counsellors. They feel a high responsibility towards their peers among others regarding the sharing of knowledge about leprosy. The peer counsellors in the SARI project gained important knowledge about leprosy by joining the project and they are keen to share this knowledge. ‘If we do not help our peers, who will?’ one peer counsellor recently said. This responsibility, the lived experience and high trust among clients and peer counsellor increases the potential of peer counsellors compared to LCs. A dedication to their work and a motivation to help people was also found in the study of Sanjana et al. (2009).

Sixth, the training and supervision provided in the SARI project can be described as intense. However, this was certainly needed as still 14 lay and peer counsellors did not manage to become effective counsellors. As several other studies have done, we also underline the need for a long term commitment and good selection (including criteria as ‘experience with community work’ and ‘confidence to meet and interact with people’), training in counselling skills and ethics, on-
going support and supervision, trainings to review and refresh knowledge and skills of LCs (Dewing et al., 2013; Msisuka et al., 2011; Sanjana et al., 2009).

Seventh, the lay and peer counselling strategy unfortunately does not reach all in need and does not address all needs. Hence, multiple strategies like education, contact, SED and addressing different sources such as community members, family, and health workers remain needed to reduce leprosy-related stigma further. If there is an interest at national level in implementing a lay or peer counselling intervention, we envision in the Indonesian context that the MoH creates the capacity at Provincial and District levels to manage these tasks and responsibilities. Sustaining the counselling services over a longer time might mean that people who initially did not dare to engage with counselling may be willing to do so once community stigma has been reduced.

Finally, we believe that more research is needed in this field and recommend that others study specific elements systematically and in-depth such as how the training process could be improved in order to increase the number of effective counsellors, the perspectives of the clients on the counselling and possibilities for its integration with existing structures and organisations. The author of this thesis and her colleagues are part of the SARI team and the author of the paper on which this chapter is based, which is also the author of this thesis, is responsible for the execution of the counselling intervention. This role can provide unique insights, but also lead to bias in writing. Discussions among the SARI team and author about the findings lead to a more accurate and critical understanding on the role of lay and peer counsellors to reduce stigma in persons affected by leprosy.

5.6. Conclusion

In the first paragraph of this chapter several questions are stated, of which the last one was: ‘Who wants and is able to bring about the reduction of leprosy-related stigma?’ This chapter has shown that some, but not all, empowered people affected by leprosy can be effective counsellors in their communities. The process of involving lay and peer counsellors in reducing stigma and its impact in the field of leprosy is challenging due to people’s desire to conceal their condition and the difficulty of developing effective counselling skills in the counsellors. Observing and analysing the different steps of the lay and peer counselling also showed the great potential of this approach, in particular the credibility of the knowledge and personal experiences lay and even more so peer counsellors can share. We conclude that lay and peer counselling holds much promise as an effective and appropriate strategy for stigma reduction in leprosy.
References


Chapter 6
The impact of a rights-based counselling intervention in Indonesia to reduce stigma in people affected by leprosy

Abstract

Background: This chapter assesses the impact of a counselling intervention on reducing leprosy-related stigma in Cirebon District, Indonesia. The unique features of this intervention are its rights-based approach, the underlying Cognitive Behavioural Therapy (CBT) model, the three types of counselling and the lay and peer counsellors who were involved.

Methodology/principal findings: Mixed methods (e.g. three scales, interviews, focus group discussions and reflection notes) were used to assess the impact of the intervention, which ran over a two-year period. There was a control area with no interventions. The study participants were people affected by leprosy and other key persons (e.g. family members). The sample size differs per method, for example, data regarding 67 counselling clients and 57 controls from a cohort, and notes from 207 counselling clients were examined. The notes showed that most clients faced stigma on a daily basis, whether internalized, anticipated and/or enacted. A significant reduction was found between the before and after total scores of the SARI Stigma Scale (p-value < 0.001), Participation Scale Short (p-value < 0.001) and WHO Quality of Life score (p-value < 0.001) among the counselling clients. While there is also an effect in the control group, it is much larger in the intervention group. Qualitative data indicates that knowledge and rights trigger change. Clients took steps to improve their life such as re-connecting with neighbours, helping in household activities and applying for jobs. Challenges include the wish to conceal their condition.

Conclusion/significance: The findings show that the counselling intervention was effective in reducing stigma, promoting the rights of people with leprosy and facilitating their social participation. More research is needed on how to create a more sustainable intervention, preferably structurally embedded in the health or social services.
6.1. Introduction

“My parents have always hidden my disease from me. I was eager to know, but nobody wanted to tell me. Even my health worker [did not tell me]. I was angry at myself. People around me just asked me to take rest and stay in my bedroom.” (Girl 15 years old, Cirebon District, Indonesia)

The girl quoted above wanted to know what disease she had. Her parents and the health professional, however, decided that it was better not to tell her. The girl was affected by leprosy, which remains a stigmatized condition worldwide. Persons or their family who are affected by a stigmatized condition often try to conceal it (Heijnders, 2004; Vlassoff et al., 1996; Peters et al., 2014). There are, however, costs to concealment: the burden is carried alone, managing concealment is onerous and not being informed might evoke negative feelings and emotions in the persons involved (as happened with this girl) (Pachankis, 2007). Disclosure, on the other hand, can also have negative consequences. Family or community members who know that someone around them is affected by leprosy might want to care, show kindness and support the person, but more often people are worried about infection and tend to distance themselves. Many studies in countries ranging from Bangladesh to Brazil, India, Indonesia, Nepal, Nigeria and Paraguay have shown that leprosy and leprosy-related stigma specifically can lead to negative feelings and emotions, restricted participation, discrimination, and thus a reduced quality of life (Heijnders, 2004; Tsutsumi et al., 2007; Tsutsumi et al., 2004; van Brakel et al., 2011; Nicholls et al., 2003; Varkevisser et al., 2009; Peters et al., 2013; Rao et al., 2008). Not surprisingly, the stigma attached to the disease is often a greater concern for those affected than the disease itself (Rafferty, 2005; Barret, 2005).

There is an increased awareness among researchers, policy makers and practitioners of the importance of addressing leprosy-related stigma. Reducing stigma will improve the lives of the people affected and will also assist in disease management and control. Of the many stigma-reduction interventions that have been identified, counselling has been described as a promising approach (Heijnders et al., 2006; Brown et al., 2003). Counselling is defined by Yeo (1993) – a counsellor from the tradition of Cognitive Behavioural Therapy (CBT) – as a collaborative process in which the counsellor or psychologist facilitates the expansion of people’s view of life; enlarges their repertoire of coping resources; and enables them to make choices for change in themselves, the situation, and the environment without destructive consequences to the self or to others. Though promising, it is not easy to reduce leprosy-related stigma through counselling. Stigma is a complex problem. Its multiple causes are often deeply rooted in societal norms and values (Rafferty, 2005; Sermittirong et al., 2014; Rao, 2010). Moreover, the dynamics and interconnections between the causes and consequences of stigma can erode the effect of any intervention (Link et al., 2001). Studies have shown that interventions need to be context-specific, multi-targeted and oriented at different levels, but it remains unclear how this can be achieved by
single interventions (Heijnders et al., 2006). For a counselling intervention, specifically, the added challenge is often the lack of professional counsellors.

Recently, a new counselling practice named the Rights-Based Counselling Module (RBCM) has been developed in Cirebon District, Indonesia (paper submitted). The approach imports human rights principles into the counselling sessions, especially the right to healthcare, to help empower the clients. Based on an exploratory study that aimed to understand the characteristics of people affected by leprosy and the views of the community, a draft module was developed, and piloted with 62 clients. The module applies CBT principles, integrates three types of counselling (individual, family and group) and is knowledge- and rights-based. The idea is that five counselling sessions can trigger clients affected by leprosy to move from a seemingly hopeless situation into a space where they feel hope, take initiatives and experience less internalized stigma. A unique feature of this intervention is that stigmatized individuals are trained and involved as lay and peer counsellors.

Lusli et al. (Chapter 4) concluded that RBCM seems a promising approach to reducing leprosy-related stigma. It might be asked, however, whether offering three types of counselling is too ambitious, whether lay and peer counsellors are appreciated as counsellors, whether an awareness of rights is as powerful as anticipated, whether an emphasis on knowledge – which is often critiqued in the field of stigma reduction (Cross et al., 2011) – will work, and what are the likely challenges. This study aims to assess the effect of this counselling intervention on stigma experienced by people affected by leprosy in Cirebon District, Indonesia.

6.2. Theoretical framework

In the past, stigma was primarily considered an attribute; a legacy of Goffman’s seminal work (Goffman, 1993), or of its interpretation. The current emphasis lies much more on stigma as a social process and thus goes beyond the individual body (van Brakel, 2003). A well-known definition of health-related stigma that we employ in this study is:

… 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. (Weiss et al., 2006)

To distinguish different types of stigma, Weiss (2008) extended the Hidden Distress Model of Scambler (Scambler, 1998), and identified three types for those who stigmatize and three for those who are stigmatized. This chapter focuses mainly on the types of stigma faced by those who are stigmatized: anticipated, internalized and/or enacted (Scambler, 1998; Jacoby, 1994). The latter refers to the experience of discrimination, and is also called experienced stigma. Anticipated or perceived stigma is the fear of being discriminated against. Finally, 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. It is an internalized perception of being devalued or "not as good as"
another individual, and is seen as a source of anguish and unhappiness (Scambler, 1998). A different categorization of stigma is based on three levels: structural, social and individual (Livingston, 2010; Bos et al., 2003; Corrigan et al., 2005; Herek, 2007), and this paper considers the social level (interpersonal) and individual level (intrapersonal).

It is not easy to assess a concept as complex as stigma (Cross et al., 2011). We decided to assess experiences of stigma, and two aspects that are negatively affected by it: participation and quality of life. Studies in India, the Netherlands and the Philippines have shown that leprosy and, in particular, leprosy-related impairments, can negatively affect one's social participation (Slim et al., 2010; Stevelink et al., 2011; Boku et al., 2010). This association was studied and confirmed in Indonesia. Van Brakel et al. (2012) found that 60% of the people with a leprosy-related impairment experience restrictions on their participation. Quality of life is another well-known overall measurement. The effect of leprosy or leprosy-related stigma on the quality of life is interesting but has been little studied, and when it has, the results are mixed. Brouwers et al. (2011) did not find a significant association in a multivariate analysis on data from East Nepal, while Tsutsumi et al. (2007) did find an association between anticipated stigma and quality of life in Bangladesh. By assessing stigma, participation restriction and quality of life we hoped to gain a broad impression of the impact of the counselling intervention on stigma.

6.3. Methods

6.3.1. Study design
This study is part of the Stigma Assessment and Reduction of Impact (SARI) project conducted in Cirebon District, Indonesia (2010-2015). The SARI project aimed to assess the effectiveness of three stigma-reduction interventions in persons affected by leprosy in Cirebon District, West Java, Indonesia: counselling, contact (Peters et al., 2015) and Social Economic Development (SED). The SARI project is a cluster-randomized controlled intervention study and uses the Interactive Learning and Action approach (Bunders et al., 1991) as a guiding methodology.

6.3.2. Research team
The SARI team is interdisciplinary and inclusive – the scientific staff comes from a range of disciplines and several team members are affected by leprosy or have a disability. For instance, the author of this chapter has a visual disability, the principal investigator uses a wheelchair, and four of the ten local research assistants have a disability or have been affected by leprosy. The SARI team works closely with local, provincial and national Health Offices and with a local Disabled People’s Organisation (DPO).

6.3.3. Study area
Cirebon District was selected as the study area because it has a relatively high number of new cases annually and – according to national experts – a higher level of leprosy-related stigma than in other districts and no interventions to address this. Thirty sub-districts of Cirebon District
were randomly allocated a paired intervention or became a control area where no interventions were made. The interventions areas included: (i) ‘Counselling – Contact’; (ii) ‘Contact – SED’; (iii) ‘SED – Counselling’; and (iv) ‘Control’. The baseline study was conducted in 2011, the counselling intervention ran from January 2012 to December 2013 and the final survey was made in the second quarter of 2014. This enables us to assess a relatively long-term impact.

6.3.4. Study population

The study population included people affected by leprosy living in the area where the interventions were offered. Data was also collected regarding current counselling clients, their family members, health professionals, lay and peer counsellors and SARI’s research assistants to get a rich perspective on the effect of the intervention and to enhance the validity of this study.

6.3.5. The counselling intervention

The counselling intervention was developed during the first year of the project and the idea was that it would address stigma primarily at the individual, and secondarily at the social level. An exploratory study was conducted (see Peters et al., 2014; Peters et al., 2013; Lusli et al., 2015) and based on its findings a counselling practice was drafted and piloted, which led to the Rights-Based Counselling Module (RBCM) (see Box 6.1.). This module can be managed by lay and peer counsellors. The SARI project selected 28 people as potential lay and peer counsellors, including the project’s ten research assistants. They attended 56 hours of RBCM training, and eventually 23 became a counsellor (15 men and eight women; ten were affected by leprosy, six have a physical disability, one has a visual impairment and six had no disability or leprosy). They worked in teams of three and were supervised by the first author (ML) (for more details on the selection, training and perceptions of lay counsellors see Chapter 5).
Box 6.1. Rights-Based Counselling Module (paper submitted)

Counselling is given by Lay and peers counsellors

**Key principles**
1. Each client, whatever his or her condition, wants to change his/her life for the better and he or she should decide what actions/ solutions are needed to bring about this change.
2. Each client needs to be listened to, appreciated and acknowledged.
3. In a relaxed, though energetic, fun and joyful atmosphere, the client will be comfortable and more open and trust will come more easily.
4. Medical knowledge about leprosy is an essential prerequisite for the rest of the counselling process.
5. Awareness of rights is the basis for developing confidence, making changes in life and participating in society.

**The 5C framework**
The 5C framework describes five important counselling skills (confirmation, clarification, confrontation, compromise and commitment) and puts these skills in a certain order.

<table>
<thead>
<tr>
<th>Session</th>
<th>Main topic</th>
<th>Type counselling</th>
<th>Timing</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Assessment of situation and trust building</td>
<td>Individual</td>
<td>30-45 minutes</td>
</tr>
<tr>
<td>2</td>
<td>Knowledge, rights and dealing with stigma</td>
<td>Individual</td>
<td>30-45 minutes</td>
</tr>
<tr>
<td>3</td>
<td>Knowledge and solutions in the family context</td>
<td>Family</td>
<td>30-45 minutes</td>
</tr>
<tr>
<td>4</td>
<td>Learning from each other and action</td>
<td>Group (4-6 clients)</td>
<td>45-60 minutes</td>
</tr>
<tr>
<td>5</td>
<td>Sharing and strengthening action</td>
<td>Group (4-6 clients)</td>
<td>45-60 minutes</td>
</tr>
</tbody>
</table>

In total, 260 persons affected by leprosy were offered counselling: 62 during the pilot phase and 198 during RBCM phase. The counselling offered during the two phases was broadly similar in terms of counselling types and style, but adjustments in, for example, the number of sessions, were made to make it more appropriate and therefore more effective. Of these 260 persons, 53 (20.4%) decided during the first session that they did not need or want to receive counselling. Reasons given by these 53 persons included no or limited stigma and fear for disclosure. The remaining persons became the counselling clients (n=207). The number of sessions and type of counselling differed by client and depended on their needs and wishes (see Table 6.1.).
Table 6.1. Number of counselling sessions given to clients by the author of this thesis during the two phases

<table>
<thead>
<tr>
<th>Phase</th>
<th>Counsellor</th>
<th>Module</th>
<th>Session</th>
<th>Counselling type</th>
<th>Number of clients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pilot</td>
<td>The author of this thesis</td>
<td>Draft counselling module</td>
<td>1</td>
<td>Individual</td>
<td>62</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2</td>
<td>Individual</td>
<td>62</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td>Individual</td>
<td>57</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4</td>
<td>Individual</td>
<td>42</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5</td>
<td>Family</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>6</td>
<td>Family</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>7</td>
<td>Group</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>8</td>
<td>Group</td>
<td>6</td>
</tr>
<tr>
<td>RBCM phase</td>
<td>Lay and peer counsellors</td>
<td>RBCM</td>
<td>1</td>
<td>Individual</td>
<td>198</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2</td>
<td>Individual</td>
<td>145</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td>Family</td>
<td>98</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4</td>
<td>Group</td>
<td>127</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5</td>
<td>Group</td>
<td>89</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>&gt;5</td>
<td>Individual</td>
<td>42</td>
</tr>
</tbody>
</table>

6.3.6. Research methods

Mixed methods were used to get an in-depth understanding of the effects of the counselling and how these were achieved (see questions in introduction) and to still be able to generalize the findings. Three scales were used: the SARI Stigma Scale (SSS), Participation Scale Short (PSS) and the World Health Organization Quality of Life instrument (WHO-QOL BREF). The SSS aims to assess stigma and is based on the HIV Stigma Scale developed by Berger et al. (Berger et al., 2001). The scale has 21 items (score 0–3, min-max total score 0–63) and four domains: experienced stigma (min-max total score 0–21), disclosure concerns (min-max total score 0–12), internalized stigma (min-max total score 0–18) and anticipated stigma (min-max total score 0–12). The cross-cultural validity of the SSS was tested in Cirebon District and found to be adequate for the Bahasa Indonesia-speaking population (Dadun et al. submitted). The Participation scale assesses participation restrictions and is based on the Participation domain of the International Classification of Functioning, Disability and Health (van Brakel et al., 2006). The validity of this scale has been tested and found to be adequate in several Asian countries (van Brakel et al., 2006; Stevelink et al., 2011; Rensen et al., 2010). A shortened version of the Participation scale, the Participation Scale Short, has 13 items (score 0–5, min-max total score 0–65) (Stevelink et al., 2012). This is the version we applied. The WHO-QOL BREF instrument is a shorter version of the original WHO-QOL instrument, comprising 26 items (score 1–5, min-max total score 26–130).
which measure the broad domains of physical health, psychological health, social relationships and environment. The validity has been tested and was found to be adequate in an Indonesian-speaking sample (Salim et al., 2007). Some of the domains and items of these scales are more relevant than others. Of particular interest are, for instance, the SSS internalized stigma and the psychological health domain of the WHOQOL-BREF.

Applying multiple instruments can be quite burdensome for respondents. If the interviewer noted that a respondent was tired and not so keen on continuing the interview, they were instructed to drop the WHO-QOL BREF. Based on a sample-size calculation and an anticipated loss to follow-up it was decided that 600 people affected by leprosy had to be part of the quantitative part of the baseline. Health professionals invited people affected by leprosy (currently in treatment or cured) to different health clinics for an interview.

In addition, in-depth interviews (IDI) and Focus Group Discussions (FGD) were applied using purposive sampling to ensure adequate representation of men and women, different age groups and intervention areas. For the IDI in the final survey, clients whose lay or peer counsellors expected positive outcomes as well as those with limited or no positive outcomes were selected. We aimed for 80 interviews for the baseline and 25 for the final survey. As many paired interviews as possible were conducted (same interviewee for baseline and final survey). The IDIs aimed to gain insight in the extent of stigma in people affected by leprosy before and after the intervention. The topics addressed were: leprosy history, feelings, family and friends, community, economic condition, and future. The FGDs aimed to assess the impact of the counselling after the intervention. Different groups of participants joined these discussions including counselling clients and their family members, health professionals, lay and peer counsellors and research assistants. Topics of the FGD were changes that occurred due to counselling, influence of the type of counselling, role of the type of counsellor and strengths and weaknesses of the counselling.

Finally, two types of notes were prepared. The Participant Reflection Notes (PRN) were written at the end of the counselling and aimed to identify the benefits of counselling for the clients. Clients received nine questions to guide their reflections (e.g. changes experienced, remaining expectations from counselling). These notes were not written during the pilot but only during the implementation of the RBCM. The Counsellor Reflection Notes (CRN) aimed to provide insight into the types of stigma the client experiences, if and what changes occurred during the counselling sessions and how counselling might have contributed to these changes. Table 6.2 provides an overview of all the methods.
Table 6.2. Overview research methods applied in this study

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Participation Scale Short (PSS)</td>
<td>x</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>SARI Stigma Scale (SSS)</td>
<td>x</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>WHO-Quality of Life (WHO-QOL BREF)</td>
<td>x</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>In-depth interviews (IDI)</td>
<td>x</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Focus Group Discussions (FGDs)</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Participant reflection notes (PRN)</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Counsellor reflection notes (CRN)</td>
<td></td>
<td></td>
<td>x</td>
</tr>
</tbody>
</table>

6.3.7. Data management and data analyses

The interviews and FGDs were recorded, transcribed and translated into English. This data was analysed by ML. The quantitative data was entered into an Epi Info for Windows database (version 3.5.3) and analysed using Stata 12.1 by RP. Demographic variables included sex, age (in years), married (yes/no), education, disability grade (0/1/2) (using the WHO leprosy disability grading system (Who, 2009). This chapter addresses the impact of the counselling intervention as a whole and not the impact of its individual activities. Therefore, all participants who were part of either the pilot counselling given by ML or of the RBCM given by lay and peer counsellors were combined in one group for the main analysis. To investigate the effect of the interventions, we calculated means, SD, and performed simple regressions (t-test, paired t-test, Wilcoxon matched-pairs signed-ranks test). P-values less than .05 were taken as significant.

6.3.8. Ethical considerations

Permission to undertake the study was obtained from the relevant government offices. Written informed consent was obtained from individual study participants. The control area in this study was a “care-as-usual” area.

6.4. Results

6.4.1. Socio-demographics study participants

Scales were administered in 523 people affected by leprosy living in the study area during the baseline. For the final survey only people affected by leprosy whose interview was administered in Bahasa Indonesia and whom we were able to interview again were included. This resulted in 237 matched observations (see Figure 6.1.). Given the number lost to follow-up we compared the 237 observations with those who could not be interviewed again to see if there were any systematic differences that might indicate bias (Table 6.3.). No significant differences were found.
As shown in Figure 6.1., of these, 111 (57+54) people affected by leprosy lived in the areas where counselling was offered. In total, 67 of the cohort joined the intervention: 23 received counselling during the pilot from ML (of which seven were selected and also became peer counsellors) and 44 received counselling from lay and peer counsellors using the RBCM. Of the 67 clients, 18 also participated in SED-related activities (received microcredit, attended a training or received livestock) and 34 lived in areas where events were organised that aimed improve negative community perspectives and attitudes. The socio-demographic characteristics of the participants of the counselling intervention are shown in Table 6.4. Also more detailed information about the differences between male and female (the men affected by leprosy in this cohort are less often married and have a higher level of education) are provided.

**Table 6.3.** Socio-demographic characteristics people affected in cohort

<table>
<thead>
<tr>
<th>Variables</th>
<th>Cohort (n=237)</th>
<th>Observations not part of cohort (n=119)</th>
<th>P-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female; n (%)</td>
<td>97 (40.9%)</td>
<td>37 (31.9%)</td>
<td>0.098</td>
</tr>
<tr>
<td>Male; n (%)</td>
<td>137 (59.1%)</td>
<td>82 (68.1%)</td>
<td></td>
</tr>
<tr>
<td>Age (in years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mean (SD)</td>
<td>36.5 (14.0)</td>
<td>34.2 (13.5)</td>
<td>0.143</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married; n (%)</td>
<td>162 (68.4%)</td>
<td>77 (65.3%)</td>
<td>0.557</td>
</tr>
<tr>
<td>Single; n (%)</td>
<td>75 (31.6%)</td>
<td>42 (34.7%)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No education; n (%)</td>
<td>17 (7.2%)</td>
<td>6 (5.0%)</td>
<td>0.190</td>
</tr>
<tr>
<td>Primary school; n (%)</td>
<td>143 (60.3%)</td>
<td>63 (52.9%)</td>
<td></td>
</tr>
<tr>
<td>Secondary school; n (%)</td>
<td>77 (32.5%)</td>
<td>50 (42.0%)</td>
<td></td>
</tr>
</tbody>
</table>

*Overall group differences, based on t-test for continues variables and X2 statistics for categorical variables.
Table 6.4. Socio-demographic characteristics counselling clients from the cohort

<table>
<thead>
<tr>
<th>Variables</th>
<th>Cohort (n=67)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>Female; n (%)</td>
</tr>
<tr>
<td>Age (in years)</td>
<td>mean (SD)</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married; n (%)</td>
</tr>
<tr>
<td>Education</td>
<td>No education; n (%)</td>
</tr>
<tr>
<td></td>
<td>Primary school; n (%)</td>
</tr>
<tr>
<td></td>
<td>Secondary school; n (%)</td>
</tr>
<tr>
<td>Disability grade</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
</tbody>
</table>

Seventy-seven IDI were conducted during the baseline and 24 during the final survey; five were paired. Of these 77 IDI, 38 were with women and 39 with men; mean age was 32 (youngest was 16 and eldest was 70). Of the 24 IDI in the final survey, 14 were with women and 10 with men;
the mean age was 44 (youngest was 18 and oldest was 70). There were nine FGD in the final survey with a total of 64 participants (see Table 6.5. for a detailed overview). PRN were written by 145 clients and CRN were written by ML and 12 lay and peer counsellors on the counselling sessions of 207 clients (five went missing).

<table>
<thead>
<tr>
<th>Table 6.5. Overview FGDs</th>
</tr>
</thead>
<tbody>
<tr>
<td>FGD ID</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5</td>
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<tr>
<td>6</td>
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<tr>
<td>7</td>
</tr>
<tr>
<td>8</td>
</tr>
<tr>
<td>9</td>
</tr>
</tbody>
</table>

6.4.2. Different types of stigma at the start of counselling: internalized, anticipated and enacted

The CRN notes show that most clients faced daily internalized, anticipated and/or enacted stigma. Usually they faced combined types of stigma, but often one type was dominant. According to the CRN of the 202 clients 93 (46%) dealt mostly with internalized stigma, 54 (27%) mostly with anticipated stigma, 38 (19%) mostly with enacted stigma, while 17 (8%) experienced no stigma.

Those facing internalized stigma mentioned that they felt shame, were worried, felt dirty because of the lesions on their face and body, feared impairment, and had lost confidence. As a result, some of them opted to conceal their disease from their family, decided to stop working, preferred to stay at home, did not want to meet people and rejected invitations. About 5% of them admitted to having had suicidal thoughts. Most of those who experienced anticipated stigma feared being excluded and/or suffering discrimination. These clients wondered whether leprosy can be transmitted and whether it can be cured. Again a wish to conceal was found in this group. Those who experienced enacted stigma said they were treated badly by family and community members, which restricted their participation in their daily lives. Some had to stop going to school, lost their job, and lost their family and friends. Table 6.6. provides sections from the CRN notes to illustrate how each type of stigma manifested itself. Occasionally the counsellors concluded that the client experienced little or no stigma. While these clients also faced negative attitudes they dealt with
these in a very positive way, they were full of spirit, accepted their disease, did not care about what others said about them and had sufficient medical information about leprosy.

**Table 6.6.** Pieces from CRN connected to types of stigma

<table>
<thead>
<tr>
<th>Type of stigma</th>
<th>CRN notes</th>
<th>Client</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internalised</td>
<td>‘He is ashamed of his disease so he hides himself and sleeps all day in his bedroom’ (CRN12.103)</td>
<td>Male, 17 years</td>
</tr>
<tr>
<td>Internalised</td>
<td>‘She is very ashamed of her disease and she wants to commit suicide’ (CRN2.9)</td>
<td>Female, 47 years</td>
</tr>
<tr>
<td>Internalised</td>
<td>‘He is feeling useless, ashamed of himself (...) he is hiding from people’ (CRN7.82)</td>
<td>Male, 30 years</td>
</tr>
<tr>
<td>Anticipated</td>
<td>‘He feels despair because he believes that his disease is not curable, he is worried that he cannot support his children’ (CRN2.8)</td>
<td>Male, 58 years</td>
</tr>
<tr>
<td>Anticipated</td>
<td>‘He was afraid his health condition would get worse (...) he was afraid people would mock him’ (CRN8.90)</td>
<td>Male, 30 years</td>
</tr>
<tr>
<td>Anticipated</td>
<td>‘She feared being avoided by her husband, she lied when she took medicine, she said it was for an allergy’ (CRN5.56)</td>
<td>Female, 30 years</td>
</tr>
<tr>
<td>Enacted</td>
<td>‘Due to leprosy he stopped going to school, his friends rejected him (...) they did not want to sit near him’ (CRN2.10)</td>
<td>Male, 18 years</td>
</tr>
<tr>
<td>Enacted</td>
<td>‘He was excluded by people in the farm, they made him stop working there, he was frustrated’ (CRN1.3)</td>
<td>Male, 58 years</td>
</tr>
<tr>
<td>Enacted</td>
<td>[Because of leprosy] ‘she was asked by her mother-in-law to get a divorce’ (CRN12.138)</td>
<td>Female, 39 years</td>
</tr>
<tr>
<td>No/ limited stigma</td>
<td>‘He is fine, his friends know about his disease, he is not afraid since he still has his friends for hanging out together’ (CRN4.42)</td>
<td>Male, 25 years</td>
</tr>
<tr>
<td>No/ limited stigma</td>
<td>‘She is okay meeting and talking to her neighbour, she does her daily work without worry, she has been cured for a long time’ (CRN7.84)</td>
<td>Female, 34 years</td>
</tr>
</tbody>
</table>

This categorization is a simplification of the clients’ complex reality. As mentioned, most clients dealt with a combination of types of stigma at the same time:

“I am ashamed of my body, keeping silence is better. If I go for work, people will exclude me and stop me from doing the work because I am dirty and my disease is a danger for them. I am afraid that people will reject me.” (IDI8, Man, 52 years)

I feel disappointed, I have leprosy. I blame myself, it will kill my future. When I go out, my neighbours always discriminate and avoid me, I am sad I do not have neighbours, I am afraid to feel alone.” (IDI21, Woman, 55 years)

This analysis of the qualitative baseline data shows that stigma is a real, important and complex problem for many, but not all, people affected by leprosy.
6.4.3. Impact of the counselling intervention

**Total scores of SSS, PSS and WHOQOL-BREF**

The analysis of the SSS, PSS and WHOQOL-BREF data shows that there are large and significant differences between the total scores at baseline and at the final survey in the counselling clients. The SSS total reduced from 21.55 to 12.00 (p-value <0.001), the PSS from 9.51 to 5.86 (p-value <0.001), and the WHOQOL-BREF increased from 80.19 to 86.74 (p-value <0.001) (see Table 6.7). Comparing the counselling clients with the control group revealed large differences at baseline. The counselling clients experience more stigma (SSS total score of 21.55 versus 15.42), more participation restrictions (PSS total score of 9.51 versus 5.42), and have a poorer quality of life (WHOQOL-BREF total score of 80.19 versus 85.83) compared with the controls. In the controls a significant reduction between the baseline and final survey SSS total scores (p-value <0.001) and a nearly significant reduction in PSS total scores (p-value 0.052) were found. The differences in the counselling clients are, however, much larger than those found in the controls. The mean different SSS score was -9.55 in the counselling clients and -5.63 in the controls, which is not significant (p-value 0.086). Likewise, the mean different PSS score was -3.65 in the counselling clients and -1.36 in the controls (p-value 0.091).

The WHOQOL-BREF scores show a different picture. First, in the control group we found a reduction in WHOQOL-BREF total score between baseline and final survey (p-value 0.264), and an improved quality of life in the counselling clients. The mean difference in the controls was -2.00 and in the counselling clients, 6.54. This difference was significant (p-value <0.001).

**Table 6.7. Univariate difference between baseline and final survey and between counselling clients and controls**

<table>
<thead>
<tr>
<th></th>
<th>Baseline (2011) Mean (SD)</th>
<th>Final survey (2014) Mean (SD)</th>
<th>P-value</th>
<th>Difference Mean (SD)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SSS total score</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Counselling clients (n=67)</td>
<td>21.55 (13.51)</td>
<td>12.00 (11.02)</td>
<td>&lt;0.001*</td>
<td>-9.55 (12.69)</td>
<td>0.086</td>
</tr>
<tr>
<td>Control (n=57)</td>
<td>15.42 (11.11)</td>
<td>9.79 (10.97)</td>
<td>&lt;0.001*</td>
<td>-5.63 (12.39)</td>
<td></td>
</tr>
<tr>
<td><strong>PSS total score</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Counselling clients (n=67)</td>
<td>9.51 (1.43)</td>
<td>5.86 (1.27)</td>
<td>&lt;0.001*</td>
<td>-3.65 (1.02)</td>
<td>0.091</td>
</tr>
<tr>
<td>Control (n=57)</td>
<td>5.42 (0.82)</td>
<td>4.05 (0.95)</td>
<td>0.052*</td>
<td>-1.36 (0.83)</td>
<td></td>
</tr>
<tr>
<td><strong>WHOQOL-BREF total score</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Counselling clients (n=67)</td>
<td>80.19 (1.14)</td>
<td>86.74 (1.4)</td>
<td>&lt;0.001*</td>
<td>6.54 (1.65)</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>Control (n=57)</td>
<td>85.83 (1.25)</td>
<td>83.83 (1.28)</td>
<td>0.264*</td>
<td>-2.00 (1.77)</td>
<td></td>
</tr>
</tbody>
</table>

1. Wilcoxon matched-pairs signed-ranks test
2. Paired t-test
3. Two sample t-test
We tested if there was an effect of several key variables (sex, age, education, marital status and disability grade) on the total scores. We found a significant effect of the variable of sex on the SSS and the PSS and decided to present the results separately (see Table 6.8.). First, at baseline the women were worse off, with a higher SSS total score (greater stigma) and a slightly higher PSS score (more participation restrictions). Second, the counselling intervention reduced stigma and participation restrictions more in women than in men: -13.35 for women and -6.28 for men in the SSS total score (p-value 0.022) and -6.00 for women and -1.69 for men for the PSS total score (p-value 0.034).

Table 6.8. Results SSS and PSS presented separately for men and women counselling clients (n=67)

<table>
<thead>
<tr>
<th></th>
<th>Baseline (2011) Mean (SD)</th>
<th>Final survey (2014) Mean (SD)</th>
<th>P-value¹</th>
<th>Difference Mean (SD)</th>
<th>P-value²</th>
</tr>
</thead>
<tbody>
<tr>
<td>SSS total score</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women (n=31)</td>
<td>23.16 (2.53)</td>
<td>9.81 (1.72)</td>
<td>&lt;0.000</td>
<td>-13.35 (2.05)</td>
<td>0.022*</td>
</tr>
<tr>
<td>Men (n=36)</td>
<td>20.17 (2.1)</td>
<td>13.89 (1.99)</td>
<td>0.009</td>
<td>-6.28 (2.16)</td>
<td></td>
</tr>
<tr>
<td>PSS total score</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women (n=31)</td>
<td>9.63 (1.58)</td>
<td>3.63 (1.11)</td>
<td>&lt;0.000</td>
<td>-6.00 (1.26)</td>
<td>0.034*</td>
</tr>
<tr>
<td>Men (n=36)</td>
<td>9.42 (2.28)</td>
<td>7.72 (2.09)</td>
<td>0.020</td>
<td>-1.69 (1.47)</td>
<td></td>
</tr>
</tbody>
</table>

1. Wilcoxon matched-pairs signed-ranks test  
2. Two sample t-test

We also analysed the data separately for the pilot clients and the RBCM clients (see Table 6.9.). The n per sub-group is too small to draw firm conclusions but we can see some trends. The differences in the SSS, PSS and WHOQOL-BREF are broadly comparable between pilot clients and RBCM clients; the difference is slightly larger in the pilot clients. The group with a different outcome is the pilot clients who eventually became peer counsellors. They have a larger reduction of the SSS total score, but a smaller reduction in the PSS and WHOQOL-BREF.

Table 6.9. Detailed results SSS, PSS and WHO-QOL-BREF for counselling clients by subgroup (n=67)

<table>
<thead>
<tr>
<th></th>
<th>Baseline (2011) Mean (SD)</th>
<th>Final survey (2014) Mean (SD)</th>
<th>Difference Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SSS total score</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Counselling clients (n=67)</td>
<td>21.55 (13.51)</td>
<td>12.00 (11.02)</td>
<td>-9.55 (12.69)</td>
</tr>
<tr>
<td>Pilot clients + Peers(n=23)</td>
<td>19.60 (2.83)</td>
<td>9.04 (1.57)</td>
<td>-10.56 (2.56)</td>
</tr>
<tr>
<td>Pilot clients only (n=16)</td>
<td>18.69 (3.62)</td>
<td>9.13 (1.60)</td>
<td>-9.56 (3.32)</td>
</tr>
<tr>
<td>Peers counsellors only (n=7)</td>
<td>21.71 (4.49)</td>
<td>8.86 (3.88)</td>
<td>-12.86 (3.81)</td>
</tr>
<tr>
<td>RBCM (n=44)</td>
<td>22.56 (2.04)</td>
<td>13.54 (1.85)</td>
<td>-9.02 (1.96)</td>
</tr>
</tbody>
</table>
The large and significant differences found between baseline and final survey in the counselling clients will now be explored in more detail by analysing the domains and items from the scales and by making use of the qualitative data.

Understanding the impact on stigma in more detail

Before exploring the differences we should underline that the counselling had limited or no impact on some clients. The qualitative data shows that these clients had either long been cured or were less affected by stigma than others. From the FGDs and IDIs it became clear that they nevertheless did enjoy the company of the counsellors.

“I have been cured for a long time, but I like that you come and visit me. During your visit, I have a friend to chat with, and through some visits I just get information related to my health. It is good to remind me.” (IDI11, Woman 55 years)

“The visit that you call counselling, I like it. I enjoy your company rather than being alone at home. Please come whenever you want.” (FGD3 Elderly clients)

To understand stigma at the individual level we used the four domains of the SSS. Significant or nearly significant differences were found between baseline and final survey in the experienced stigma domain (p-value < 0.011), disclosure concerns domain (p-value < 0.001), internalized stigma domain (p-value < 0.001) and the anticipated stigma domain (p-value 0.054) (see Table 6.10.).
Table 6.10. Mean SSS domains scores for counselling clients (n=67)

<table>
<thead>
<tr>
<th>Domain</th>
<th>Baseline (2011) Mean (SD)</th>
<th>Final survey (2014) Mean (SD)</th>
<th>P-value¹</th>
<th>Difference Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experienced stigma</td>
<td>3.25 (0.62)</td>
<td>1.76 (0.49)</td>
<td>0.011*</td>
<td>-1.49 (0.55)</td>
</tr>
<tr>
<td>Disclosure concerns</td>
<td>6.00 (0.48)</td>
<td>3.33 (0.39)</td>
<td>&lt; 0.001*</td>
<td>-2.67 (0.55)</td>
</tr>
<tr>
<td>Internalized stigma</td>
<td>6.79 (0.51)</td>
<td>3.36 (0.40)</td>
<td>&lt; 0.001*</td>
<td>-3.43 (0.51)</td>
</tr>
<tr>
<td>Anticipated stigma</td>
<td>4.25 (0.53)</td>
<td>3.04 (0.36)</td>
<td>0.054</td>
<td>-1.21 (0.55)</td>
</tr>
</tbody>
</table>

¹ Wilcoxon matched-pairs signed-ranks test

We studied in detail the changes that occurred in the Internalized stigma domain. Reductions were seen in all areas, but mainly in the items that ask about “embarrassment” (from 46.2% who often or sometimes felt embarrassed to 29.9%), in “feeling unclean” (from 57.7% who often or sometimes felt unclean to 31.4%) and in “feeling not as good a person as others” (from 52.2% who often or sometimes felt this to 29.9%) as shown in Figure 6.2.

Figure 6.2. Changes in the ‘Internalized stigma’ domain of the SSS before and after counselling (n=67)

The psychological health domain of the WHOQOL-BREF is relevant in this context, showing a significant difference (p-value 0.014) between the baseline and final survey (see Table 6.11.). The
biggest improvement was in the item “negative feelings” (going from 54.4% who never or seldom felt negative feelings to 73.1%), but there were also improvements in “ability to concentrate” and “enjoy life” (see Figure 6.3.). The findings on “accepting bodily appearance” were reduced, but the positive effect is partly hidden because two categories were merged. Before the intervention 33.3% indicated they were “mostly able” to accept their physical appearance and this was reduced to 7.5%, but 5.3% were “completely able” to accept their physical appearance which rose to 22.4%.

Table 6.11. Mean WHO-QOL-BREF domains scores for counselling clients (n=67)

<table>
<thead>
<tr>
<th>Domain</th>
<th>Baseline (2011) Mean (SD)</th>
<th>Final survey (2014) Mean (SD)</th>
<th>P-value*</th>
<th>Difference Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical health</td>
<td>22.23 (0.41)</td>
<td>24.16 (0.48)</td>
<td>0.001*</td>
<td>1.93 (0.55)</td>
</tr>
<tr>
<td>(min 0, max 21)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological health</td>
<td>19.26 (0.35)</td>
<td>20.77 (0.38)</td>
<td>0.014*</td>
<td>1.51 (0.45)</td>
</tr>
<tr>
<td>(min 0, max 21)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social relationships</td>
<td>9.63 (0.21)</td>
<td>10.02 (0.21)</td>
<td>0.199</td>
<td>0.39 (0.30)</td>
</tr>
<tr>
<td>(min 0, max 21)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Environment</td>
<td>23.25 (0.40)</td>
<td>25.00 (0.49)</td>
<td>0.005*</td>
<td>1.75 (0.60)</td>
</tr>
<tr>
<td>(min 0, max 21)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. Paired t-test

Figure 6.3. Changes in psychological health domain of the WHO-QOL-BREF before and after counselling (n=67)

(* % of respondents that answered never or seldom)

The paired IDI at the baseline and during the final survey provided in-depth insights into the impact of the counselling intervention on stigma. The differences between feelings, emotions and experiences before the counselling (e.g. sadness, embarrassment, shame, fear and isolation) and
after (e.g. confidence, happiness, knowledge, comfort, understanding) are illustrated in the Table 6.12.

### Table 6.12. Before and after results of five clients paired IDIs.

<table>
<thead>
<tr>
<th>Interviewee</th>
<th>Before receiving counselling (baseline 2011)</th>
<th>After receiving counselling (final survey 2014)</th>
</tr>
</thead>
<tbody>
<tr>
<td>IDI10: male, 19</td>
<td>‘I do not want to meet people as they gossip on me’</td>
<td>‘I do not care what people are saying’</td>
</tr>
<tr>
<td></td>
<td>‘I am fully confident going out and meeting many people’</td>
<td></td>
</tr>
<tr>
<td>IDI2: male, 22</td>
<td>‘I hide my disease as people always treat me as an ill person’ (…) ‘I am sad’</td>
<td>‘I completely know my disease … I feel ok now to talk to people’</td>
</tr>
<tr>
<td></td>
<td>‘I am aware even though I still have medical treatment, … I have to do something for my future’</td>
<td></td>
</tr>
<tr>
<td>IDI7: female, 44</td>
<td>‘I feel embarrassed because of the spot in my skin’ (…) ‘I feel dirty’</td>
<td>‘I feel happy … I met a woman who has the same disease as me’</td>
</tr>
<tr>
<td></td>
<td>‘I am back to do my daily works without confusion and wondering’</td>
<td></td>
</tr>
<tr>
<td>IDI12: female, 45</td>
<td>‘I always excuse using cosmetics to cover the spots on my face’ (…) ‘I am ashamed of it’</td>
<td>‘I am ready and I am feeling comfortable going out without worrying about the spots’</td>
</tr>
<tr>
<td>IDI15: female, 33</td>
<td>‘I am afraid my disease will transmit to my family’ (…) ‘I isolate myself’</td>
<td>‘I understand my disease well’</td>
</tr>
<tr>
<td></td>
<td>‘I am confident to explain my disease to other’</td>
<td></td>
</tr>
</tbody>
</table>

The PCN, CRN, IDIs and FGDs show similar changes. In general, the counselling clients were less shy and ashamed because of their disease and moved from a negative self-image towards a more positive one. The notes also show that clients experienced less worry or fear of meeting people or encountering people who stare or gossip. Finally, the notes show that clients were less affected and more capable of responding positively to experiencing discrimination and social exclusion. Clients realised they had the power to bring about these changes themselves. Also family members became aware of their role. Some quotes from the IDIs and FGDs illustrate this attitudinal change:

“A client (…) always locked himself in the house because he was afraid of the insults from his neighbours, but after he received five full sessions of RBCM, he was able to change his mind. He positively dealt with his feelings, he was not afraid to meet and talk with his neighbours anymore. When I visited him he told me that he was appointed as an event organizer.” (FGD9 research assistant)

“After we received counselling we became more confident and independent. I am now positive about myself, since negative feelings and thoughts are bad for my future.” (FGD4 clients with impairment)
“Counselling really helped me and gave me personal motivation. Before receiving counselling, I locked myself inside the house and I stigmatised myself as a useless person. However, after receiving counselling, I am aware that my understanding of leprosy was wrong, I understood that leprosy cannot be cured, today I learned that leprosy can be cured.” (IDI1, Man 46 years)

Changes also occurred at the social level. A stimulating and supportive family environment was created, mainly through family counselling. The CRNs show that during this counselling family members became involved. The medical information about leprosy was very important in helping family members be intimate again.

“From the family counselling, we learned and we are completely sure now that leprosy is a disease that can be cured and is not contagious after having routinely taken medical treatment. The peer counsellor convinced us to change our perspective, to not fear to touch him and to include him in our family activities.” (FGD6 family members)

The clients became more confident to take action and participate in their family. For instance, they started to ask questions (e.g. whether they could help with household chores, asked if somebody wanted to accompany them to the community health service) and family members in general responded positively to these changes:

“My husband is now very active, out from his hiding place, full of spirit, helping me to make and sell crackers. I am really amazed that my husband wants to deal with many people without fear and worry.” (FGD6 family members)

“Due to counselling, I [now] prefer meeting people to do some work rather than just passively staying at home. I asked my father whether I can work with him on the farm taking care of the chickens. At noon, I visit my friends, joining with them to do community activities such as weekly praying, doing social events. I particular become more confidence trying to sell credit vouchers for mobile phones.” (IDI17, Man 23 years)

Counsellors energetically encouraged the clients gradually to get involved in reducing stigma by participating in daily activities and to take initiatives. By getting out of the house, visiting the market, buying something at a shop, greeting neighbours, the clients realised that not everybody was looking at them (often nobody) or deliberately excluding them. Jobs, education, family relationships are important areas through which to increase participation, as illustrated in these quotes.

“When I have a conversation, I agree that I should talk and I should reduce stigma. Leprosy has gone, stigma must stop, and I must get a better life. Counselling has motivated me to be
brave to have an opinion and to take a decision to continue my study for my future career.” (PCN57, Man 19 years)

“Confidently I go out from home to participate in a social event, and people do not avoid me, they want to sit beside me, my perception was absolutely false.” (PCN62, Man 47 years)

“After I received counselling, at the last session, I changed my mind, I cannot sit for a long time. Seemingly there is high energy in my life that encourages me to do something. A few weeks after full counselling sessions, I re-opened my food shop in front of the house (...) The shop gives me money and gives me my life back. With the money, I can buy daily needs. So I have a better family life. (...) Moreover, I have the feeling of being equal when I talk with my mother-in-law, she does not compare me again with her other daughter-in-law. We can also spend our time going on picnics.” (PCN126, Woman 33 years)

The study participants sometimes talk about an improvement in their life in general. They use words as a “better life” or get “my life back”.

6.4.4. How was this impact reached?

Stigma was an important problem for many people affected by leprosy in Cirebon District and the counselling intervention had a positive impact on their lives. How was this impact achieved and how did the different aspects of the intervention (raising knowledge, awareness of rights, involvement of lay and peer counsellors, combination of individual, family and group counselling) contribute to the changes? In the introduction several questions were raised, which we address here.

Does an emphasis on knowledge work?

Clients made clear in the PCN how much they benefited from the medical information they received during the counselling. During one of the first sessions, clients’ deeply held beliefs were challenged. The PCN and CRN show there was time to share and discuss information and clients felt free and at ease to ask questions and to confirm that they had understood the information correctly. Key aspects were learning about the causes of leprosy, infectiousness and the ability to be cured. Instead of perceiving themselves as infectious and uncured, they understood and believed that they were cured and no longer infectious. This was perceived as a “miracle”, which created a space and momentum for change. Many said that this knowledge was the main reason why stigma reduced.

Is the awareness of rights as powerful as anticipated?

The space and momentum for change that was created through the new knowledge was strengthened with an awareness of rights, emphasised in each of the three types of counselling session. The realisation that persons affected by leprosy enjoy the same human rights as everyone else was powerful. Not only were their rights as a patient addressed, such as having access to
information and treatment, but also the right to be part of family and community life, including having an education and employment. From the CRN we can deduce that clients who are aware of their rights are more confident and less afraid to take initiatives than those without this awareness.

“Counselling has made me aware of my rights to go out, to make friends, to enjoy daily activity without feeling afraid and worried.” (IDI3, Man 28 years).

What challenges emerged?
Although the lay and peer counsellors attended 56 hours of training, practised ten hours of counselling and had 12 hours of booster training, they still had limited experience and needed intensive supervision initially. At times it was not easy for them to manage clients’ conditions and characteristics (e.g. introvert/silent clients, clients who were bored, clients with a strong personality, clients who requested financial support), particular family behaviour (e.g. a family that rejects the client or is worried about reactions from others), creating commitment for the next session and seeing the RBCM not as a mere blueprint. In their FGD, health professionals identified two of these as potential obstacles to effective counselling. Another challenge was the wish of persons affected by leprosy or their family to conceal the illness. Some clients preferred their own house as the location for counselling, but others did not.

“I do not need to talk, I prefer staying away and keeping quiet. Even my wife, she does not need to know about my disease and my problem.” (IDI 8, Man 52 years).

“Our privacy is disturbed, and too many visits also make us more afraid of our neighbours.” (FGD2 Young clients)

“I do not mind if you come and talk to my husband, but not too often and not too many people.” (FGD6 Family members)

Counsellors’ inexperience and some clients’ wish to conceal their condition may well have influenced the effectiveness of the counselling provided in the SARI project.

Are lay and peer counsellors appreciated as counsellors?
Clients were also asked which type of counsellors they preferred. Eighty-two of 163 participants (50.3%) preferred peer counselling, 63 (38.7%) preferred leprosy workers, and 20 (12.3%) preferred the lay counsellors from a DPO. Reasons for choosing a peer counsellor were sharing similar life experiences, not feeling alone with the disease, feeling more free to talk, feeling motivated and having a role model. The benefits of peer counsellors were also described in the CRN. The counsellors noticed that they became a role model for their clients. Just by doing their job (seeking out clients, meeting new people, sharing information, sharing experiences without feeling worried or ashamed) they displayed confidence and this stimulated and motivated the clients to see things more positively than before.
“My client was surprised that a person affected by leprosy came to her house. She stayed at home all the time, her family did not allow her to go out even though she has been cured for a long time. The arrival of the peer counsellor directly motivated her. Spontaneously she went out from home to the market, that she had been missing year after year.” (FGD 7 Lay and peer counsellors)

Some clients preferred a leprosy worker because of their expertise regarding leprosy and medication. Some wanted to make sure they were receiving the proper medical treatment, while others were quite explicit about not wanting to be counselled by a leprosy worker because of the medical focus:

“A health worker only works for medical treatment asking to routinely take medicine without understanding our feeling, our thought and our other needs beside medication.” (FGD 3 Elderly clients)

Reasons for preferring counselling from a lay person involved in a DPO were feeling part of the wider community, feeling inspired by people with disabilities and the information beyond the disease (leprosy, medication and treatment) on topics such as jobs, microfinance and fun/social activities.

“We can share job opportunities, also we can get information about microfinance to run a business. By having a business and job, we do not care about stigma, we care about our work.” (FGD5 Clients who also joined the SED intervention)

Is three types of counselling (family, individual and group) not too ambitious?

Each type of counselling brought something different to the process. What worked best depended largely on the individual situation and the client’s needs. Family counselling was most appreciated. Seventy-eight of the 163 RBCM clients (47.9%) wrote in their PRN that they had benefited most from the family counselling, which is very high given that only 98 clients received it. A health professional thought that this was because the family is in contact with the “patient every day, every minute, every second”. In the FGD family members and clients mentioned as reasons that counselling increased knowledge of leprosy and encouraged family members to accept, support and perhaps most importantly involve clients in family and community life:

“Because of the family counselling my wife understands me and gives me support, she talks to me more frequently, asks me to do some household tasks.” (FGD4 Clients with impairments)

“After we had family counselling, we stopped avoiding our family members who have leprosy, we are not afraid to be close and talk to them, we are aware that they are part of our family and rather than excluding and avoiding them, we ask them to help us.” (FGD6 Family members)
In total, 52 of 163 (31.9%) clients wrote that they received most benefits from individual counselling because of a feeling of comfort, confidentiality, the secure environment, space to talk and be listened to, receiving spirit and motivation to do things, communicating and advocating for rights:

"I choose individual counselling, I need confidentiality, talking more freely and more openly."
(IDI15, Woman 33 years)

"By individual counselling, I feel there is a person who pays attention and cares for me, feeling (...) [of being] listened to." (IDI24, Woman 43 years)

Last, for 35 of 163 participants (21.5%) group counselling created the greatest benefit, although only 89 clients received group counselling. Reasons mentioned were sharing and learning from each other, being motivated by others and by the group support:

"Really, group counselling helped us to reduce our negative feeling by talking and sharing."
(FGD1 Clients women)

The next quote comes from the same girl who was quoted at the start this chapter and illustrates nicely the added value an integration of three types of counselling brings:

When the counsellors came to visit me I was really happy. ... The conversations with the counsellors reduced my lonely feelings. Through family counselling, my parents and I are not worried anymore. (...) Conversation in the group really opened my mind. The knowledge on leprosy - that is my disease - makes me feel more released. ... I have confidence to explain if people around ask me about the spot on my skin. The disease may attack my body but it does not make me lose my rights. I am not ashamed if people look at me and I am not sad if people avoid me. I ignore them and I am comfortable and able to study till high education, so later people will not look at me negatively. It is better people know rather than hide it. After I explain my disease confidently, gossiping disappears. It is my action for my future." (PCN89, Girl 15 years)

The findings show that integrating three types of counselling contributed to its effectiveness. The counselling skills and attitudes that the lay and peer counsellors needed for each type overlapped somewhat, but there were also important differences (e.g. facilitating a peer group versus individual counselling). This integration is ambitious, but not too ambitious, and seems essential to achieve the impact desired.

6.5. Discussion

This chapter showed that the counselling intervention was highly effective in reducing internalized stigma, creating hope and stimulating action in people affected by leprosy in Cirebon
District, Indonesia. In the literature, counselling is often identified as a promising stigma-reduction approach (Heijnders et al., 2006; Brown et al., 2003) and this study confirms this.

Can only five counselling sessions be effective? In this study, heightened knowledge became the first trigger for change. Perceiving oneself as cured and not infectious can be described as a “miracle”. Here an interesting link can be made with the Brief Solution Based Therapy (BSBT) (a CBT variation), developed by Berg, Shazer and colleagues in the late 1970s (Shazer, 2007). In this approach clients are asked to imagine their life if a miracle had happened overnight. These imagined changes are taken as a starting point to find out how much of a miracle has already happened in their daily life. In the BSBT the miracle is a mental construction – a means to envisage a preferred situation. In the case of clients affected by leprosy-related stigma, knowledge about their cure functioned as genuine miracle, not an imaginary dreamlike one. So knowledge has played an essential role and an important trigger in the progress of the counselling.

The second trigger was awareness of rights. These triggers, combined with increased understanding and support from family members and real-life role models who shared their experiences, proved to be a powerful approach. Frequently, five sessions were enough to set a larger process of change in motion. The key elements of the counselling sessions thus were its i) knowledge-based approach; ii) rights-based approach; iii) CBT-based approach; iv) the integration of three types of counselling; v) lay and peer counsellors providing the counselling; vi) energetic and optimistic counselling style that combines depth and pace. Individual elements have been studied before. Floyd-Richard and Gurung (2000) have, for instance, shown that group counselling can be effective for people affected by leprosy. Peters et al. (2014) recommended that leprosy services should make better use of support in particular from a spouse or parents. But to our knowledge these and other elements have not previously been integrated in one brief and energetic counselling approach.

Some specific findings need further explanation. For instance, we found a change in the control area. This can be partly explained by time (we assume that some people affected by leprosy learn to live with their disease and the stigma), the data collection (which is also a form of intervention), and the attention to leprosy and stigma at district level due to the SARI project. The difference at baseline between the counselling group and the controls can be explained by bias. Only people with more severe problems would seek counselling. People with no problems were either not even offered counselling, or are likely to have refused. The control group included everyone. Some clients we offered more than just counselling and this might lead to an overestimation but also an underestimation of the results. The findings also suggest that the counselling intervention had a different impact on the pilot clients who became peer counsellors. There was a greater reduction of stigma, which is not surprising given that they joined numerous relevant activities (e.g. counselling training, regular meetings) and because of their new role and status as peer counsellors. In contrast, their perceptions regarding participation restrictions and
quality of life did not improve at the same pace. It could be that their ‘peer group’ changed and that their wishes and needs in terms of quality of life evolved. We are measuring perceptions and these can alter when the context changes. This should be kept in mind when applying scales that assess perceptions. We also found that counselling had different impacts on stigma and participation restrictions on men and women. Studies have shown that women and men experience stigma differently (Vlassoff et al., 1996; Rao et al., 1996; Morrison, 2000; Try, 2006), so it follows that an intervention will also have differing effects. Our hypothesis is that women and men undergo a different kind of change: through counselling men are inspired to take action and do things (e.g. talk to neighbours, find a job), whereas women go through an internal change process (e.g. change their perceptions). This would explain the difference on the SSS, but less so on the PSS. We are not aware of other studies that have found a different impact of counselling on stigma among men and women. Future research could focus on understanding the reasons in more depth and perhaps also tailor interventions accordingly.

The results are positive, but there remain important challenges. The intervention is not appropriate for everyone affected by leprosy – some people with presumably high levels of stigma refused the intervention, and the wish to conceal the disease was another barrier. So multiple interventions to address all needs are needed, a case which has also been argued for by others (Cross et al., 2011; Heijnders et al., 2006; Cross et al., 2011).

We recommend future research in several directions. This study showed that some people affected by leprosy are dealing well with stigma without the need of interventions. Studying why this is could lead to valuable insights for reducing stigma. Negative effects due to a lack of knowledge (e.g. self-isolation, fear, worry) could have been prevented had health professionals provided medical information at the time of diagnosis or during the treatment phase. While ignorance is a major challenge to health care in general and in the field of leprosy specifically (Nicholls et al., 2003; Briden, 2003; Chen et al., 2004; Iyor, 2005), it should remain a central topic in leprosy research. The qualitative data shows that there is an impact on stigma in the family context. It would have been useful to test this effect with quantitative measures, but more research in this field is needed. The selection, training and supervision of the lay and peer counsellors was crucial. They required specialist knowledge and it was still difficult for some counsellors to become effective (Lusli et al., 2015), pointing to the need for more research on how to improve the selection and training of lay and peer counsellors. A counselling intervention needs to be sustainable, and since this intervention proved to be less sustainable than we hoped it will be vital to strengthen effective links between health professionals and lay and peer counsellors. Studies could help to establish how this can be achieved.

The key elements of the counselling seem to be appropriate to address leprosy-related stigma not only in Indonesia, but also elsewhere. During the design of the counselling intervention costs
were considered, as we realised that a costly intervention would not be sustainable in a context were resources and time are scarce. In general, the execution of the intervention is inexpensive because of the involvement of lay and peer counsellors who live near the clients. Some costs are involved and some time investments need to be made for example for the training and supervision of the lay and peer counsellors. The intervention is relatively easy to replicate and scale up, so that lay and peer counsellors could play a key role in nationwide programmes to combat leprosy-related stigma. Lay counsellors need to be trained not only in understanding human rights and appropriate counselling skills but also to observe a code of conduct in dealing with marginalized and vulnerable clients. To enable them to assist their clients effectively, the lay counsellors should also receive a clear (written) mandate from the health authority to facilitate clients’ access relevant to public facilities including the social protection schemes currently promoted by the local and central government. The findings of this study are also relevant for other stigmatized conditions. Several Neglected Tropical Diseases (NTD) are associated with stigma (e.g. Buruli ulcer, lymphatic filariasis, onchoceriasis, leishmaniasis and Chagas disease) and so have negative effects on an individual’s quality of life (Weiss, 2008; Scambler, 2009; Person et al., 2009; Stienstra et al., 2002). The value of counselling will depend on identifying similar triggers for change. For example, the knowledge element regarding HIV/AIDS could be that the condition is not as infectious as people often believe, or in the field of NTD that some diseases can be treated or managed with medication.

### 6.6. Conclusion

Rafferty (Raferty, 2005), stated that “if patients are cured, the stigmatization can remain an insurmountable obstacle to the resumption of a normal life”. This study shows that the obstacle is not insurmountable. The findings demonstrate that the counselling intervention is effective in decreasing stigma, promoting the rights of people with leprosy and in facilitating their participation in family and community life. We recommend its application on a larger scale. More research is needed to create a more sustainable implementation of the counselling, preferably structurally embedded in the health or social services.
References


Part II
Input from the research process of the SARI project for counselling
Chapter 7

The power of personal knowledge: reflecting on conscientization in lives of disabled people and people affected by leprosy in Cirebon, Indonesia

Abstract

An epistemological shift can be brought about by recognizing the importance of personal knowledge of disabled people and its transformative social potential. This chapter describes the conscientization process among disabled and leprosy affected RAs and LCs of the SARI project in Cirebon, Indonesia. Conscientization or critical consciousness refers here to the awakening of the individual regarding his or her individual and social situation which provokes individual and collective change. A significant factor in this process relates to the newly assumed role of staff in the SARI project. Findings from the literature on personal knowledge, its conceptualization and the role of conscientization are first presented, including the political nature of personal knowledge and its significance for social change as well as personal knowledge in the context of disability. Narratives portray practice as the materialization of personal knowledge and affirm the value of reflection, experience, intention, context and geographies of power when searching for individual and social conscientization. The conclusion reflects on the importance of conscientization of personal knowledge and its contribution to the field of disability and social change and, briefly, to the field of knowledge management for development.
7.1. Introduction

*We can know more than we can tell.* Michael Polanyi

This popularized phrase of Polanyi (Polanyi, 1962a) lies at the heart of personal knowledge theory. The emphasis placed on the ‘person’ when creating any kind of knowledge helped to challenge the hegemony of neo-positivist empiricism that, for many years, characterised social research production. Neo-positivist empiricism denies individuals their own personal knowledge, granting control to experts with their supposed objectivity. Medical epistemology, for example, is based on the premise that disease is something objective and ‘separated from the individual’s experiences of the material reality of their everyday lives’ (Popay & Williams, 1996: 760).

Feminist, disability and other social movements claim that personal knowledge needs to be taken seriously, and that no theory which attempts to explain oppressive situations should be developed without involving the individual.

This chapter affirms that the disability field needs to recognize disabled people as holders and producers of knowledge (Barnes, 2003). This recognition, however, has not extended to the field of leprosy which is still dominated by medical epistemology. We claim that an epistemological shift can be brought about by recognizing the importance of personal knowledge of disabled people and its transformative social potential. This chapter describes the *conscientization* process among disabled and leprosy affected RAs and LCs of the SARI project in Indonesia.

*Conscientization* or critical consciousness refers here to the awakening of the individual regarding his individual and social situation which provokes individual and collective change.

SARI is an action research study aiming to reduce the impact of leprosy related stigma. In 2011 people affected by leprosy and disabled people were invited to become SARI RAs and LCs. The project acknowledged the difficulties of attaining a high response to the recruitment call because statistics from Indonesia indicate that few disabled persons and even fewer numbers of people affected by leprosy have access to formal and higher education. However, keeping in mind the principles underpinning an emancipatory disability research that demands inclusion of multiple voices and multiple knowledges (Barnes, 2003; Brown, 2005), the project continued with this enterprise. Recruited staff have been involved in a learning-through-interacting process (Gertler, 2003) and have become aware of how their personal knowledge has catalysed social change.

The main focus of this chapter is to look at the process of *conscientization* of personal knowledge as a transformative means. Personal knowledge represents the embodied unique capital of each individual and when marginalized social groups become conscious of such capital, it can provoke changes in both individual and collective life. The SARI project serves as a case study. First, findings from the literature on personal knowledge, its conceptualization and the role of *conscientization* are presented, including the political nature of personal knowledge and its significance for social change as well as personal knowledge in the context of disability. The
chapter continues with a general description of SARI and the methodology used for the present chapter. Following this, a description of the process of conscientization as experienced by SARI’s RAs and LCs and its impact beyond the initial aims of the SARI project is provided. The conclusion reflects on the importance of conscientization of personal knowledge and its contribution to the field of disability and social change.

7.2. Personal knowledge and embodied consciousness

Knowing has to do with an embodied consciousness (not just a consciousness). (Sontag, 2012)

Knowledge is a concept with multi-layered meanings (Nonaka, 1994). The definition of being ‘solely objective and detached from the involvement of the subject’ has been contested by considering knowledge as a discursive formation (Foucault, 1980) in which its creation has a personal mark. The work of Michael Polanyi (Polanyi, 1962a) is of considerable relevance because it criticises the notion of ‘complete objectivity’ of knowledge which denies the individual’s role in its creation. Polanyi recognises that knowing is personal, and this includes scientific knowledge, and that every act of knowing involves a deep personal commitment:

[...] into every act of knowing there enters a passionate contribution of the person knowing what is being known and that this coefficient is no mere imperfection but a vital component of his knowledge. (Polanyi, 1962:268)

Supporting the diverse production and diffusion of knowledge, Polanyi makes the distinction between explicit and tacit knowledge. Individuals are the primary repositories of tacit knowledge and explicit knowledge is transmitted formally and systematically by individuals. However, both exist synergistically. In this chapter, tacit knowledge is defined as personal knowledge. Personal knowledge is created when ‘rediscovering the perception of the world’ (Merlau-Ponty, 1962), as body and mind interplay when producing it. Due to the complexity of personal knowledge and the overwhelming importance society attributes to technical performance, personal knowledge has been reduced to ‘mere experience’. It is important at this juncture to highlight the distinction between personal knowledge and personal experience. Personal knowledge extends beyond personal experience: it is the product of an internal process which includes intentionality, experience and reflection (Dewey, 1988; Turner & Bruner, 1986). Experience is an integral component of personal knowledge, rendering it authentic, irreducible and irreproducible (Benjamin, 1968). Other components such as individual skills (Polanyi, 1962b) and dialogue with other knowledges (Brown, 2005) are also relevant to personal knowledge. The embodiment of personal knowledge implies dealing with discourses of power embedded in socio-cultural contexts (Foucault, 1980; Gertler, 2003; Haldin-Herrgard, 2003). In this process, difficulties regarding its recognition, codification and transfer into practice emerge as the result of its being:

...so practical and deeply familiar to them [individuals] that when people are asked to describe how they do what they do they often find it hard to express it in words. (Tsoukas, 2005:142)
On the one hand, Polanyi (1962b) recognizes such complexity when stating that personal knowledge ‘is not really known by the knower’ and some sort of consciousness is essential for its transference into practice. Conversely, Nonaka (1994) proposes that transfer of personal knowledge into practice is facilitated by intention, autonomy, fluctuation and individual’s commitment (Gertler, 2003; Nonaka & Lewin, 2013; Polanyi, 1962a; Tsoukas, 2005). Although we agree with both positions, we argue, transfer of personal knowledge demands consciousness or, as we will call it here, conscientization. We state that consciousness of personal knowledge leads an individual, emancipated from ‘technical formulas for action’ (Haldin-Herrgard, 2003:136) to assume his or her role as knowledge producer. ‘Geographies of power’, the significance of contexts (Gertler, 2003) and, the importance of reflection play a relevant role in such processes of consciousness. Contexts influence its development and implementation. Power relationships are integral to ‘interaction-transference of knowledge’ (Haldin-Herrgard, 2003). Reflection transforms experience into a significant interaction between an individual and environment. Nonetheless, only when conscientization of personal knowledge is ‘experienced’ by an individual, can personal and collective change occur (Dewey, 1988; Freire, 1998).

7.3. Conscientization, personal knowledge and change

In 1969, ‘the personal is political’ became representative of liberation movements that emerged around the world calling for the emancipation of oppressed social groups including women, black people, workers, homosexuals, indigenous peoples and the disabled (Hanisch, 2006). It demanded social consciousness and simultaneously secured personal knowledge as a source of change, emphasizing that ‘personal problems are political problems’ and that ‘there is no individual solution for them but collective solutions’ (Hanisch, 2006:4). In this context, the concept of conscientization, or critical consciousness, borrowed originally from Franz Fanon’s ‘conscienciser’ was revived by Paulo Freire and implemented in areas of educational and social development. To Freire (1998), knowledge emerges when individuals are conscious ‘that they are in the world and with the world’ (:15) implying that transformative power lies in the self. In this sense, a liberating path of learning relies both on personal experience and existing knowledge. Thus, conscientization, refers to the process of deepening one’s understanding of self and society through learning and reflection (Horton & Freire, 1990). It ensures individuals contextualize personal difficulties in their larger social, cultural and historical settings and provoke change when recognising their own knowledge.

Conscientization of personal knowledge materializes only when ‘practice’ happens (Freire, 1984, 1998) and leads to serious social change when the individual appears as a ‘producer and owner of knowledge.’ In practice, inimitability of personal knowledge crystallizes the uniqueness of individuals as a sort of ‘aura’ (Benjamin, 1968). ‘Without practice
(performance) there is no knowledge, at least it is difficult to know without practice’ (Horton & Freire, 1990:98).

Recognizing the contribution of Freire, we argue that having knowledge is not enough as individuals need to be conscious and confident about it. In doing so, we claim that reflection plays a determining role in this process and that there is no conscientization without reflection. Reflection emerges as the result of a complex, conflictive relationship between processes of knowledge production and various contexts where the individual exists (Alvesson & Sköldberg, 2009). Reflective thinking and personal inquiry, Adorno (1974) argues, have relevance in any learning process. When individuals, especially those who are socially excluded, become conscious of facts that construct their reality by critically reflecting on them, consciousness of change is echoed in their surroundings. Therefore, exploring personal knowledge regarding social change would promote individual and collective conscientization. It would transform the relationships of people with the inner self and the collective self.

7.4. Personal knowledge, disability and leprosy

The transformative potential inherent in conscientization is recognizable in the disability field and in the case study presented in this chapter. For more than 50 years, the disability movement has demanded the recognition of knowledge that is produced as a result of being disabled. Claims from disability activists and theorists (Barnes, 2003; Devlieger, 2005; Goode, 1994; Goodley, 2004; Oliver, 1990) that disability is socially, culturally and phenomenologically constructed have challenged the dominant medical epistemology and demanded recognition of disabled people as knowledge holders and producers. This demand (see: Crow, 1996; Morris, 1992; Thomas, 1997) has materialized as emancipatory research (Barnes, 2003; Oliver, 1990). The inclusion of personal experience of disabled people as an emancipatory principle is increasingly recognized, however, the means to enrich this with personal knowledge, is still ‘gossip in the corridors’ (Rabinow, 1985). Studies of participatory and emancipatory disability research have underscored the need for implementing methodologies that facilitate researchers’ understanding of disabled people’s lives. More importantly, the principle of working together to encourage transfer of their knowledge to others (Gleason, 1989; Goode, 1994; Klotz, 2004) could be translated into a first call for exploring personal knowledge. A few initiatives have promoted the training of people affected by leprosy as community agents and RAs (Beise, 2012; Cross & Newcombe, 2001; Cross & Choudhary, 2005) and yet little is reported about exploring personal knowledge and its impact on individual and collective social change.

In an era where efficiency and success supposedly depends on mechanical reproduction of explicit knowledge (Benjamin, 1968), the elaboration of unique and innovative knowledge depends on the use of individual personal knowledge (Gertler, 2003; Haldin-Herrgard, 2000; Polanyi, 1962a). Barriers disabled people face in being recognised as ‘innovative creators’ reflects
the challenge society faces when attempting to understand ‘other minds’ (Polanyi, 1962b).
Furthermore, the difficulty disabled people encounter in becoming aware of the value of their personal knowledge is a response to these barriers. Understanding how personal knowledge is produced, appropriated and shared will facilitate a move from solely valuing personal knowledge as ‘experience’ to seeing it as an important component of emancipatory disability research.

7.5. Approaching personal knowledge through the voice of disabled and people affected by leprosy

Having established the value of the recognition and transfer of personal knowledge, this chapter explores the contribution that the personal knowledge of disabled people and people affected by leprosy offers to development projects. It positions the SARI project as a case study and source of analysis. SARI emerged in 2010 as a collaborative action research study between the Athena Institute of the VU University Amsterdam and the Disability Studies Centre at the University of Indonesia (UI). The project aims to implement three CBR interventions to reduce the impact of stigma that people affected by leprosy face in Cirebon, Indonesia. These interventions comprise: counselling and individual empowerment; contact with the community; and SED. Exploratory validation of instruments, pilot and base line studies was previously performed. The interdisciplinary team comprises of the author of this thesis and two PhD students; nine RAs, including one affected by leprosy and three who are disabled; and 14 LCs of whom four are disabled and ten are affected by leprosy. Methodologically, SARI employs an ILA which involves an on-going learning process accompanied by continuous training.

The authors of this chapter are senior researchers, including the author of this study. As trainers and researchers, we have witnessed the changes that the SARI team members have experienced by becoming more aware of their own knowledge. This chapter emerged from processes of dialogue and reflection established between the authors and the SARI team members. Incorporating the narratives of the team members has facilitated understanding of personal experiences, personal knowledge and learning processes in which the SARI team and participants are involved. Four written testimonies of the RAs and 12 tape recorded interviews with the LCs collected in 2012 supported the analysis made in this chapter. Testimonies were approximately 12 pages in length each and the interviews lasted up to 90 minutes. Additionally, two FGDs were organized in 2013, one with the four disabled RAs (two men with physical impairments, one woman with a visual impairment and one man affected by leprosy) and one with 12 LCs (four men with physical impairments and eight people affected by leprosy of which six were women). The FGDs were taped recorded, lasted about three hours each, and were conducted by the author of this thesis in charge of the counselling intervention. In total 16 people between 21 and 30 years of age participated in this study over a two year period. The interviews and FGDs were facilitated
by the RAs who also participated in the elaboration of the questionnaires and in reflection meetings to discuss the data collected.

The implementation of qualitative methods for the research responded to the demand of a ‘politics of recognition’ (Bauman, 2001) of disabled participants as citizens and producers of knowledge. Notes of the observations taken place during weekly sessions in the field, fieldwork visits and different training workshops have also been incorporated. Data was collected in Indonesian and translated into English. Semantic issues were taken into consideration when translating. The Indonesian team has helped to minimalize those issues. Analysis of data was developed using Nvivo with four points of focus: previous knowledge; knowledge acquired during engagement in the project; knowledge shared; and effects this process has had in their lives. The analysis was validated with both groups and changes were incorporated into the document. We make no apology for the extensive quotes that permit examination of material on which concluding observations were based. Neither the method of selection nor the numbers of participants enable observations to be generalized. Additionally, terminology used in this chapter ‘people affected by leprosy’ and ‘disabled people’ respond to a social model of disability. The term *kusta* (leprosy) appears in some quotes as it is frequently used in Indonesia and by the participants.

7.6. Personal knowledge and conscientization: stories from the field

The theoretical framework of this chapter elaborated on the definition and characteristics of personal knowledge and the relevance of conscientization for its recognition and transfer into practice. Through the voice of RAs and LCs involved in SARI, we consider the characteristics of personal knowledge, the difficulties facing the recognition of personal knowledge and the changes experienced. The narratives portray practice as the materialization of personal knowledge and affirm the value of reflection, experience, intention, context and geographies of power when searching for individual and social conscientization. Three stages are developed here to show the continuum of conscientization of personal knowledge.

7.7. Background and the first stage: the role of context and difficulties recognizing personal knowledge

SARI was set up, among various reasons, because ‘leprosy [is] one of the major causes of preventable disability’ (Brakel, 2007) and initially involved a comparative study of the stigma experience of people with physical impairments and people affected by leprosy. It soon became evident that this was a complex ambition requiring a different approach. The decision was made to recruit disabled people and people affected by leprosy to work in the project, taking a different methodological and content angle than was originally envisaged. A female psychologist with visual impairments was accepted as a PhD candidate (the author of this thesis) and a professor with physical impairments from the UI holds the position of Principal Investigator in Indonesia. A
CBR organization from Solo led by disabled people was designated to select and train the candidates. The position for six RAs was widely advertised in Cirebon. The job description included data collection, assisting the PhD students on the field, implementation of the interventions and contact with the community. Among the 54 applications, only five were disabled people and two were people affected by leprosy.

The low number of disabled applicants and of applicants affected by leprosy for positions within SARI, despite the explicit call for them to reply, reflects their marginalised position within Indonesia. These groups tend to be overlooked behind the label of a ‘hard to reach group’ (Beresford 2002). There are more than 3 million people with different types of impairments in Indonesia (Susenas 2009) but only a small percentage of disabled people are able to gain access to education. The gap in primary school (35% of disabled children and 85% of non-disabled) and secondary school (17% of disabled children and 75% of nondisabled) attendance rates in Indonesia is significant (WHO, 2011:207). No provision is made for students with disabilities within the higher education system and no significant data is available on tertiary education participation of disabled persons in Indonesia (Steff, Mudzakir, & Andayani, 2010). Furthermore, the situation of people affected by leprosy and their access to education is not included in the statistics. Three of the five disabled applicants, among whom there was only one woman, were selected. Unfortunately, there were no suitable candidates affected by leprosy.

For the recruited staff, the selection process was highly significant. For the project, selection was a mere administrative procedure but, for them, it was the starting point of a journey into confidence. The RAs and LCs belong to low income families, 13 are married and three are single. The majority has attended secondary school. Most of their household income is derived from services, such as technical, retail, construction and housework. Two are founders and members of a small DPO in Cirebon. Early reports revealed negative previous life experiences in which discriminatory practices prevented access to education and difficulties in the work place. This led some to start their own businesses. They were unconscious of the knowledge they had acquired during this time to the extent that they expressed feelings of low self-esteem and insecurity about their ability to perform in this role:

*Even though I had only finished primary school, I encouraged myself to apply. I was a bit ashamed when I applied because the applicants should have mostly finished a bachelor degree; even the disabled applicants. I was feeling as the only one who was a primary school graduate, the others were middle school [12-15 years] or secondary school graduates. I let that thought go and just put it in God's will. I was accepted in SARI Project while my other disabled friends with higher education were rejected. I don't know why. It must have been something they saw in me. I proudly can say now I work as a RA in SARI Project.* (RA2)
Some less confident female candidates attending the interviews embraced this process as a way of proving capacity and willingness to work. Moreover it was an expression of their search for independence despite their impairment and poor education:

*I read the advertisement and initially I was not confident because the requirements listed English skills. But I was given the support of my sister and I thought this could be my last chance to get a job because it is very difficult to find one especially with my condition of disabled and having only middle school, plus being above 25 years old. So I decided to apply with the aim that I no longer depend on my husband. I wanted to prove my husband that I can be independent without a husband, I do not want to be a weak woman who is just resigned to depend on a man. So I hoped that once accepted in SARI, I would show what I know and what I can do. I had the faith that this would be the gate for me to become a formidable woman and not being under the shadow of a husband.* (RA1)

A different approach was taken in the recruitment of LCs. This recruitment took place few months after the implementation of a base line study. From the study, candidates were identified, based on their willingness to work, availability and skills. Later, Puskesmas (Health Centres) officers joined the training for counsellors as well as four members of the Disability Forum, a new DPO of people with physical impairments. Their tasks included counselling people affected by leprosy and their families, collaboration with counselling community activities and reporting to the instructor (the author of this thesis). Similar to the RAs, the LCs expressed that they entered the project feeling helpless, embarrassed and with little confidence about their contribution. The experience of disability and leprosy placed them in a paradoxical position. Some of them acknowledged their experience regarding expertise on medication and social effects of leprosy and disability but were shy and lacked confidence about their knowledge and performance. Phrases such as ‘I am shy because of kusta... I do not have enough confidence to meet people... I just know about the medication but I do not know what kusta is... I am afraid of people who know I have kusta’ were commonly mentioned when the counselling training started. They also attributed little importance to the knowledge, experience and intentionality they had. All recruited staff indicated they wanted to share their experience, gain confidence and join a social cause. But, overall, they expected to obtain knowledge about leprosy and to deepen their understanding of the way people have treated them. Their fears and lack of confidence blurred the importance of the path they have already walked. One of the LCs explained:

*Before I joined SARI Project, I was reluctant to discuss anything about leprosy. It was almost like a trauma. I didn’t want to hear anything about leprosy. It made me remember when my friends were avoiding me and the society outcast me; even someone actually said how ‘disgusting’ I was. ..I think I only have little knowledge especially on leprosy. I always thought leprosy was a scary disease; it is not only about losing your health but also losing your friends*
and losing your confidence. I thought that my knowledge was not enough to become a counsellor... But I needed help and I wanted to learn. (LC affected by leprosy 1)

Becoming conscious: technical training, personal experience and new roles. Topics inclusive of research methods, disability, leprosy and human rights and CBR approaches, were included in the training of RAs and LCs. RAs also attended the counselling training in order to implement the intervention. The process was described by the LCs 'as a learning process where they began to recognize their own knowledge and experience'. They were also overwhelmed by difficulties such as language barriers, different backgrounds of participants and the topic of leprosy itself and by the presence of foreign and disabled instructors.

During this process the participants acquired technical knowledge or expert knowledge (Brown, 2005) which provoked reflection on their own life in many ways. Attaining technical knowledge reconfirmed their own knowledge or eliminated beliefs regarding disability and leprosy. This enhanced personal confidence and certainty regarding their situation and their performance when sharing their knowledge with the communities. The majority mentioned that learning more facts about leprosy and disability helped them become more reliable community workers. Additionally, being reliable was a source of pride due to the importance of their work.

Recognizing their own knowledge about leprosy, disability and methods of research, something that other people in the community lacked, was also a source of pride and courage. Receiving a certificate from SARI at the end of their training was an affirming action, acknowledging the technical knowledge they acquired and reinforcing their public credibility and recognition.

Issues of power/knowledge relationships were also raised. Feelings of contradiction and hopelessness emerged, when discussing issues with authorities or professionals. After receiving training on how to conduct interviews and FGD, RAs were asked to organize different focus groups with school teachers and religious leaders. Organizing and facilitating meetings with people of higher educational attainments confronted them with fears and feelings of inferiority and doubts about their knowledge. This happened due to two factors. First, Indonesia's highly hierarchical society is reinforced by gaps in cultural, social and economic capital of people. Second, barriers that disabled and people affected by leprosy face regarding education and access to information is a vicious circle that situates them in unequal positions and perpetuates hierarchical relationships in production of social research (Barnes & Mercer, 1997).

The presence of disabled instructors helped them to overcome such fears. It generated feelings of admiration, courage and initiatives for the future:

*When I started the training, I was amazed by the experts in SARI Project, especially when they explained the material to increase our skills in performing the project's activities. It was all educational and also very well constructed. But I was so amazed when the instructor was also a disabled person... At that point I committed to follow the training until the end. I*
accompanied Oni [a fellow RA] in the training. I hoped Oni could gain knowledge in SARI Project because I believed that this was the place to gain knowledge and skills. That knowledge, I thought, can be used for FKDC [Forum Komunikasi DAS Cidanau = Cidanau Catchment Communication Forum] to move forward. I also thought I can make connections with the government, seek information and organize activities to increase the resources of our disabled friends. (RA 3)

Having a blind instructor had a significant impact on their learning and increased their level of commitment:

Interviewer: You also interact with me but I am blind. Do you have problems in interacting with me? [...] during the training sessions or when working with me?
LC2: I don’t think so. On the contrary, I am proud of you because with your disability you work better than me. I was surprised when I realized that you are blind but you can write and use a laptop. It motivates me to work better.

These quotes do not imply that the relationship between the disabled staff is always positive and exempt of stressful moments. Ward & Simons (1998) report difficulties facing of collaboration of non-disabled and disabled individuals when doing disability research, and these difficulties may also be experienced by disabled individuals. Some participants have shared anecdotes of situations when describing physical and environmental aspects about the participants to the author of this study who is blind. This resulted in embarrassment and tension that could have been easily misunderstood as unwillingness to collaborate. Moments of frustration have also emerged when some participants have faced the failure of society to accommodate their needs; this source of frustration is also recognised in the literature Oliver (1992). Examples included the difficulties of having an adapted motorcycle, being dependent on others to move from one place to another and, on some occasions, having to cancel appointments. Oliver (1997:812) also argues that ‘employing disabled researchers can have serious resource implications which have yet to be addressed properly by main players funding disability research and, indeed, the research establishment which receives the grants.’

Recognizing themselves reflected in other stories and witnessing others’ living conditions provoked conscientization of personal knowledge among the team members. Both groups explained that attendance in the training and close encounters with people affected by leprosy and disabled people immediately resonated in their own bodies and lives:

In short I joined the training. Once I got there, I was surprised because none of the participants had normal physical condition. Even the instructor had had polio. There, I could laugh out loud and let go of my burden. I felt that this is my world. I was motivated when I saw that there are people who live in difficult conditions, but didn’t complain. I said to myself, if those...
people can do things, than I also can do it. I was ashamed remembering how I locked up myself at home for years. (RA1)

I knew about the discrimination against people affected by leprosy and disabled people but it never occurred to me, why? If I received an insult, I used to take it and never questioned why. But in SARI, it made me question the discrimination. I learned about discrimination and I realized we have rights. (RA2)

Meeting people who had had similar experiences and were in similar circumstances was able to contribute to demystification of their ideas about their condition and simultaneously gave them a sense of relief and acceptance of their skills. They became more confident of their own knowledge through reflecting on the situation of others:

And it turns out that there are more people who are affected by leprosy, not only me. I used to think that I was the only one who had leprosy. There are many out there. [...] I feel more open minded now. I think, well, if others can be confident, why can’t I be confident too? (LC 5)

I know how they feel. I used to be one of them (I had leprosy), so I know their stories. We share the same feelings. So because I know, I tell them to keep the courage, don’t give up. We can be cured. Reduce your feel of embarrassment because mostly they are ashamed of themselves. I know that. (LC3)

Based on this experience, participants strongly recommend active involvement of people affected by leprosy or disabled people in projects addressing leprosy and disability to avoid purely medical approaches. Reasons for this included better understanding of feelings of people involved, empathy as well as a sense of equality:

Interviewer: Do you think that a counsellor should be someone who has had leprosy?
LC4: I think it would be better if they are people who been affected by leprosy. That is my opinion, because people will feel better if they talk to someone who has had leprosy too. It can push them to follow treatment as soon as possible. But I don’t mean it is bad if a counsellor is not a person with leprosy. It is good to show people that they [people affected by leprosy] can help to reduce the stigma on the people who are affected by leprosy.

I think it would be better if people affected by leprosy are involved in every activity. People would accept counselling more easily if things are explained by people who have experience [of leprosy]. People would trust them more and will be more enthusiastic. (LC6)

7.8. Experiencing change: knowledge, reflection and consciousness

In Islam, Allah will not change the condition of people if they don’t want to change themselves. (LC6)
Freire asserts knowing should relate to, ‘speaking the word to transforming reality, and to man’s role in this transformation’ (Freire, 1972). In this sense, RAs and LCs experienced a transformative effect at both an individual and community level during this process of *concientization* of their personal knowledge. This was described in terms of gaining knowledge, respect and status, whilst simultaneously witnessing changes in their wider environment. RAs explained their transformation from ‘uneducated and incapable’ to ‘reliable community facilitators’. They consider that reflection has offered them a different perspective on their own contribution when working with people, as well as access to new knowledge:

*When you gave me a job as a facilitator, at first I was nervous. My hands were shaking and I did not know what to say or what to do. But now I am grateful that I am no longer nervous. I also gained knowledge on computing and on how to organize concepts. I mean, when I performed an activity with people I never reflected on it with them and just did it. But now I learned about planning and concepts. I learned so many things with the other RAs and the friends affected by leprosy.* (RA1)

They also place greater importance on their own knowledge and skills, and what they can mean to others in their communities:

*I think my knowledge now can make the difference. Once I was asked by several ladies in my neighbourhood about my job. They asked me why I wanted to join people who are affected by leprosy. I took that as an opportunity to explain it to them. I told them that leprosy is not a curse, it is curable and I am someone who already has been cured. I think the knowledge I have gained and shared with the community is useful in reducing stigma towards people affected by leprosy. It is because now that people have knowledge and understand the people who are affected by leprosy, they will no longer be afraid to interact with them.* (LC7)

The knowledge learned whilst implementing research methods and interventions has helped them to recognize the value of action research:

*I learned from you that SARI implements both research and interventions. While other organizations only perform research SARI can help reduce the stigma with action. Sari counsels both the people affected by leprosy and the society, so when the people affected and disabled people move on with their life the society can accept them too. I only knew that disabled people are given trainings but that is not enough if they do not try to change the society to accept them. So that is what we learn, to do both.* (RA2)

Knowledge was also perceived of in terms of skills they acquired. The majority summarised these skills as feeling confident and free to talk in public; sharing their stories; finding addresses and approaching people; discussing issues with authorities; independently solving problems; having more patience and understanding that people have different characters; organizing public events; conducting interviews and focus groups discussions; and asserting their rights and demands.
The recognition and acquisition of knowledge improved the respect and status of SARI team members. They have been welcomed to spaces where their knowledge is valued and they transfer their knowledge in their own way in the houses of clients, health centres and community centres. The majority of LCs talked about the development of positive attitudes in the community and new relationships as a result of their new role:

I am happy because I gained more friends. I became more open, especially to those who are affected by leprosy. We can share things, tell stories. I sometimes share thoughts with my clients. We just tell each other stories. (LC8)

The biggest effect is in my study on campus. I became some sort of senior among the students. If they have a problem, they usually come to me; they share thoughts with me about their family or their daily life. There are so many changes in me after I joined SARI. (LC2)

Their new roles have led to the generation of new knowledge, have given them a new perspective on self as well as encouraging them to share knowledge with others. During training and implementation of the interventions, they attributed meaning to their new roles. According to some, this goes beyond the title of RAs or LCs. A LC described communities as perceiving a LC as ‘someone who is really useful for the society.’ They also explained their function has evolved within an accepting and familiar environment. After the LC’s focus group, it was mentioned that being a LC ‘has to do with promoting change’:

A RA can be considered as the front line of a project. He/she determines the success of the research. Being an RA is not a simple job. We have to be very sharp in dealing with situations. The RAs also have to develop relationships with the clients [SARI participants] and also other stakeholders so the research can be performed well. An RA is also the liaison between the researchers and the subjects researched so the research will have a good result. (RA2)

Opportunities for reflection have been an important part of the role of SARI team members. Fieldwork and individual issues, urgent cases needing referral, problems encountered during the collection of the data, and administrative problems are always discussed during weekly or monthly meetings. Data collection always involved group reflection and discussion of problems, successful events and funny anecdotes. A similar process was followed during implementation of the interventions, resulting in a constant questioning their role within the project and their communities. The two groups also explained that, as part of their job, they felt responsible for spreading reliable information about leprosy and dealing with difficult situations faced by people affected by leprosy and disabled people:

By receiving this certificate it means that I have received a mandate. Because not everybody can receive this certificate [...] I received the certificate from SARI Project and the Health Office, which means I have to implement the mandate that has been given to me. I have to make a contribution to the society on the leprosy issue. (LC8)
Collective knowledge, as well as increased awareness of their own personal knowledge, has had a positive impact on themselves and their families:

*I am also more aware about my own health and hygiene. My family has gained knowledge on leprosy. They used to think leprosy was a curse but I explained that it is not a curse and we have the cure for that. Every time my family knows someone who has leprosy symptoms, now the first thing that they do is report it to me.* (RA3)

*There are many changes. In family, I became a better brother and know how to treat my younger siblings.* (LC2)

*I got married [laughing].* (RA2)

Personal changes related to their socio-economic situation were discussed. This was especially highlighted by some of the female participants:

*Honestly this has really helped us. My husband works but has an irregular income. I still have debts, but now they have already reduced. Working in SARI also helps me to give my parents money. My children’s education is also paid from my salary, not from my husband. He actually never took care of my children’s education.* (RA3)

*It is the first time I go out of my house. Now I understand leprosy is just a normal disease so I’m not afraid. Now I travel a lot [laughing]. I went to [a colleague’s] house by car, it was so far. I changed public transport four times, imagine that! I didn’t know [that] neighbourhood until I went to her house. My husband supports me and my family too but I think now they do not like it because I am pregnant and need to rest.* (LC4)

They are also aware that their transformation and *conscientization* about issues of discrimination and suffering could lead to collective change. Both groups expressed pride as ‘instruments of change’ through their transformation. Reflecting on their own knowledge, they conclude that individual change can serve as a catalyst for further change:

*My parents used to be worried about my future; I used to be a closed person because of leprosy. Now, I changed. I became more active and energetic. My parents like me now better than whom I used to be. I am just like another normal person. Then I feel so many contributions from my clients. I see that they have also changed from not taking care of themselves into being willing to take medicines, accept treatment and make recommendation to neighbours who also could have leprosy.* (LC10)

Other examples of changes observed within their environment include people affected by leprosy going out the house, being less concerned about what people think of their physical condition, taking care of themselves and their families, making friends, making decisions about their lives, accepting people with impairments and skin patches, talking in public, managing their own money, and even falling in love. These changes were challenging and difficulties mentioned had to
be solved before change could occur. Difficulties included: people affected by leprosy being denied the opportunity to grow as a result of discrimination; families hesitant to collaborate due to fears or over protection; and lack of information. Additionally, some reported little support and misunderstanding from their husbands and wives about their role in the communities.

Team members increasingly recognise the transformative process and, in the words of one counsellor, the ‘personal call’ of their jobs. Increasingly, they have become activists. For example, some RAs have taken action to strengthen the work of a small, recently established DPO, by changing the organization’s name to one with a more human rights perspective, making it more inclusive by inviting people affected by leprosy to be involved and developing socio-economic projects based on the knowledge they have gained in SARI:

*I will use my personal knowledge in the future by integrating both, my experience before I worked in SARI and the knowledge I received in SARI to reduce stigma and discrimination towards disabled people. To increase our livelihood, we need to fight for our rights as a disabled people to achieve equality as citizens of the country. To achieve all of that, FKDC have become partners with Social Office to use skill training programs for disabled person both in the region and in the province. We have also started to study how to perform advocacy. My hopes for the future would be that there would be a strong organization helping us [FKDC] to achieve all of that.* (RA2)

7.9. Final reflections: personal knowledge as means for individual and social change

*It is of extreme importance [...] to give back to man the childish audacity that years of verbal submission have taken away: the audacity to say: I am here.* Simone de Beauvoir

In the narratives summarized above, disabled people and people affected by leprosy reflect the positions of many other social groups placed in disadvantaged power positions. Their narratives recount how they are taking the audacity to say ‘we are here’ as holders and producers of knowledge. At that very moment, they are becoming conscious of their personal knowledge. The main argument of this chapter is that although such people are not initially aware of being holders of knowledge, individual and collective awareness of the importance of their personal knowledge can be created by interventions, involving a process of awakening. SARI provided a space for learning and teaching; intentionality was a key ingredient; other knowledges interacted; personal experience was valued; and reflecting, creating new knowledge and sharing/interacting with others became possible. Furthermore, it is evident that when recognizing and reflecting on difficulties faced during the process, awakening is possible. This did not occur instantly but rather through a continuous process of reflection, internalization, interaction and sharing. It could be said that tacit knowledge is converted to explicit knowledge through observation, imitation and
practice (Tsoukas, 2005) but also it needs the recognition of personal experience valuing the contextualized difficulties involved.

Personal knowledge has been commonly mistaken as experiential knowledge while experiential knowledge is only one component of personal knowledge. In this chapter, personal knowledge is described as a continuous process that integrates different types of knowledges (individual, institutional, experiential, expert, community) that requires the uniqueness of each individual, their skills, their experience and the possibility that the context offers them for conscientization. The process of collective consciousness demands dialogue and exchange of knowledge between different social actors as producers of knowledge including those considered to be disadvantaged. In doing so, there is also a transformation of the relationships of social research production (Barnes, 2003; Oliver, 1990). This chapter calls for greater value to be placed on personal knowledge within the field of disability and leprosy. The core of such exploration has to be the individual and the unique and irreproducible knowledge that individuals can create and transfer (Benjamin, 1968; Polanyi, 1962a). This chapter has analysed personal knowledge from the perspective of disabled and affected by leprosy SARI staff, reporting the transformative process. (Adorno, 1974:70) affirms:

Knowledge may broaden, only where it persists by the individual, so that its isolation is disassembled by this insistence.

Thus, although the focus of this chapter is on personal knowledge of disabled persons and people affected by leprosy, it is relevant to a wide number of development interventions because the challenge facing the recognition of personal knowledge is a barrier to development and empowerment of individuals and communities worldwide. By this emphasis on personal knowledge and conscientization, it is supporting the field of knowledge management in its understanding of the role played by personal knowledge in conceptions of multiple knowledges (Brown, 2010).
References


Chapter 8

Learning from a leprosy project in Indonesia: making mind-sets explicit for stigma-reduction

Abstract

International attention for disability recognizes that it plays an important role in persistent poverty. Leprosy can cause preventable disability. Stigma associated with leprosy has often greater implications for people affected than physical impairments. The SARI project in Indonesia, employs an action research methodology to develop stigma reduction interventions. By exploring the different mind-sets of the stakeholders in the reconnaissance phase of the project, the project identified differences in aspirations, attitudes to research and conflicting intrinsic models of disability. The differences in mind-sets are not symptoms of failure but, rather, should be actively sought out.
8.1. Introduction

There is a growing awareness of the strong links between disability and poverty. The disability framework published by the UK Department for International Development (DFID, 2014) in November 2014 highlights the over-representation of people with disabilities amongst the persistently poor with 20% of the people living under USD 1 per day having a disability (DFID, 2014). Some one billion people globally have a disability with more than 80% of them living in developing countries. According to the DFID framework, people with disabilities often face significant levels of discrimination and stigma in their everyday lives: they are not visible in society, are prevented from participating in their communities, and less likely than others to be able to leave poverty. There is increasing international attention for disability with the ratification of the United Nations International Convention on the Rights of Persons with Disabilities (UN CRPD) (UN, 2006) by 152 countries. As a result of increasing attention, new disability projects are emerging and existing projects are changing their focus towards disability inclusion.

Leprosy is an important cause of ‘preventable disability’ (van Brakel et al. 2012). If not treated in time, leprosy causes disabilities by damaging skin and peripheral nerves, leading to typical chronic wounds and disfigurement and, in some cases, blindness. These impairments are avoidable with early diagnosis, proper treatment and adequate (self-)management. Although leprosy is no longer a health problem in developed countries, it continues to affect millions of people in large parts of Asia, Africa and Latin America. Despite the fact that it is preventable, some 215,656 new leprosy cases were reported in 2013 (WHO, 2014). Indonesia – with 16,856 new cases in 2013 – ranks third after India and Brazil on the list of countries with the highest number of recorded new cases (WHO, 2014).

In common with a number of diseases of poverty, such as tuberculosis and HIV/AIDS, leprosy is a stigmatized condition. For many people affected by leprosy, the stigma is the hardest part of the burden to bear, even harder than the disabilities themselves (Rafferty, 2005). Leprosy-related stigma has been shown to adversely influence marriage, employment, educational opportunities, friendship and often results in a high burden of emotional stress and anxiety (van Brakel 2006), as well as having an adverse effect on treatment seeking and adherence. The importance of stigma is recognized in the social model of disability which considers that disabled people are disadvantaged not because of their impairment but because of the limitations imposed on them by social, economic, cultural and environmental barriers, including stigma (Albert, 2004). The UN CRPD also specifies various manifestations of stigma as violations of human rights, recognising the non-medical implications of the disease. In efforts to reduce stigma, the perceptions, ideas and opinions of stakeholders should be the starting point for any development project. As Yang and colleagues have argued:
Rather than prescribing interventions without knowledge of their local effects, focused interventions based on observation of the everyday lives and the actual difficulties that stigmatized individuals face may better address how stigma threatens what is fundamentally at stake. (2007:1533)

The study described in this chapter is part of the SARI project that is designing and implementing interventions for people affected by leprosy in Cirebon District, Indonesia. As mentioned above, Indonesia one of the countries with the highest level of new cases of leprosy. Several provinces in Papua, Sulawesi and Java have new case detection rates of above 10/100,000 (MoH Indonesia, 2012). In 1969, Indonesia integrated leprosy control in the general health services giving a primary role in leprosy detection and treatment to leprosy workers at the CHCs. In 2011, Indonesia ratified the UN CRPD. Given the prevalence of leprosy in Indonesia, a grant proposal for the SARI project was written by a small team of Dutch researchers experienced in the field of leprosy and stigma reduction. The SARI proposal was approved for funding in 2009 and the project started in mid-2010. This chapter describes the first reconnaissance phase of the project in which mind-sets related to leprosy were explored and the further stages of the project were designed. Such an exploration is an important part of any effort to reduce stigma facing people with disabilities because it will help to design interventions that are appropriate, sustainable and effective. In describing this process, the chapter describes methodologies and experience which can be applied to other development projects.

The first section of this chapter is concerned with leprosy and stigma, focusing on the importance of mind-sets which are the focus of this chapter. Next, the action research methodology is reviewed. The different phases of the SARI project are described, followed by an analysis of the different mind-sets to leprosy and disability among the stakeholders. Finally, lessons for other development projects are provided.

8.2. Leprosy and stigma

Goffman (1963) describes stigma as an attribute that is ‘deeply discrediting’ (:3) and that reduces the bearer ‘from a whole and usual person to a tainted, discounted one’ (:3). This individualistic approach to stigma has been replaced by new conceptualizations, such as those of Link and Phelan (2001), Parker and Aggleton (2003) and Weiss et al. (2006) which increasingly focus on process, structure and power. Link and Phelan define stigma as: ‘co-occurrence of its components – labelling, stereotyping, separation, status loss, and discrimination – and further indicate that for stigmatization to occur, power must be exercised’ (2001:363). In addition, Weiss describes health-related stigma 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’ (Weiss et al. 2006:280).
Different interventions to reduce stigma related to leprosy have been developed and tested for their effectiveness (Brown, Macintyre, & Trujillo, 2003; Heijnders & van der Meij, 2006). Stigma reduction interventions are however not self-evident and putting an emphasis on stigma through interventions can re-enforce or amplify it. Therefore, it is important to have a comprehensive understanding of stigma and the real needs of the people that experience it prior to the design of interventions. This involves realising that stigma is consciously and unconsciously shaped by a diversity of actors and operates at different levels (micro, meso and macro). To be successful, stigma reduction interventions should be multi-targeted and oriented at multiple levels (Cross, Heijnders, Dalal, Semmrittirong, & Mak, 2011; Heijnders & van der Meij, 2006). In every intervention, a change in the perceptions and behaviours of multiple actors will be needed. This is not a quick and easy process because leprosy and stigma share a very long history: leprosy has long been a disease that evokes shame and disgust (Rafferty, 2005).

Despite this background, stigma reduction is possible. Recent studies have highlighted the potential of ‘counselling’, and bringing into ‘contact’ stigmatized and stigmatizers in the field of HIV/AIDS and mental health (Heijnders & van der Meij, 2006). There is also some evidence supporting SED targeted at people with leprosy (Ebenso et al., 2007). Findings demonstrate that people affected by leprosy are sometimes stigmatized by health professionals (Semmrittirong & van Brakel, 2014). Reducing stigma does, therefore, require attention to the mind-sets which are responsible for stigma.

According to Chambers (2010), mind-sets comprise ‘a person’s mental orientation, predispositions and ways of construing, framing and interpreting experience’ (page 7). Mind-sets are informed by:

- Training, education, professional norms, ideology and personal life experiences.
- Paradigmatically, it interacts with (influences and is influenced by) concepts and ontological assumptions, values and principles, methods, procedures and processes, roles and behaviours, and relationships. (page 7)

Within the factor personal life experiences also one’s personal, perhaps, lived experience with disability and illness falls. These factors together determine how one perceives disability and stigma. Individuals are shaped in a given society through processes of socialisation in different groups and are often unaware of this. Each individual – thus also each stakeholder in a leprosy and disability projects – has his or her own knowledge, predispositions and ways of constructing, framing and interpreting experience (Chambers, 2010).

**8.3. Approach**

The SARI project adopted the ILA methodology which is an action research methodology. Action research was needed in the case of this project because it represented a very novel approach so
we needed to adapt what was being done along the way. The ILA methodology was suitable for a number of reasons: it facilitates the exploration of multi-stakeholder input and, in particular, stakeholders’ perceptions, options and ideas which are of key importance when developing interventions aiming to reduce stigma. Moreover, it is a transdisciplinary research methodology with which the research team is experienced.

Transdisciplinary research emerged in the 1970s in response to ‘a mismatch between knowledge production in academia, on the one hand, and knowledge requests for solving societal problems, on the other’ (Hoffmann-Riem et al. 2008:3). Transdisciplinarity has been defined as:

*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)

The main difference from mono-, multi- and interdisciplinary is that in transdisciplinary research spans boundaries of scientific disciplines transgress ‘by including experiential knowledge of societal actors in the research and problem solving process’ (Cummings et al. 2013:11). Regeer and Bunders add: ‘in the course of the interaction implicit knowledge is made explicit, and new knowledge is construed, shared and tested’ (2009:14).

The ILA approach has supported diverse multi-stakeholder processes aimed at inclusive agricultural, health and biotechnological innovation. It was developed during the 1980s and 1990s by Bunders and Broerse (1991) at the Athena Institute, VU University Amsterdam. The ILA approach has been applied in different fields and in several countries, including Zimbabwe, South Africa, Bangladesh and the Netherlands. Key characteristics of the ILA approach are the active participation of beneficiaries from the start, an emphasis on relationships of trust, mutual learning and knowledge integration. The process is guided around the development of a shared vision and facilitated by a transdisciplinary team.

The ILA approach is structured around five phases. The first three phases are called *reconnaissance* in which a broad view of the issue under concern and its characteristics is obtained prior to the two planning phases. The phases comprise:

1. Exploratory phase: a research team is established. A preliminary overview is obtained of the developments in the scientific field, the relevant stakeholders and their perspectives, as well as the problem context.

2. In-depth phase: the aim of this phase is to identify and analyse the problem perceptions, opinions and ideas of the different stakeholders.

3. Integration phase: the perspectives of the different stakeholders are compared and, as much as possible, integrated.
(4) Prioritization and action planning phase: stakeholders address conflicts and seek consensus on priority issues, common goals and plans of action.

(5) Implementation phase: the plans are put into practice in learning-action spirals in which the observations and reflections on a previous action, leads to a new plan and action for the next cycle. The learning-action spirals are based on the action research spiral (Kemmis & McTaggart, 1988:154) see Figure 1.1. (see Chapter 1).

8.3.1. Data collection and analysis

This chapter focuses on the key activities during the first three phases of the SARI project. The exploration and analysis of these activities are based on qualitative data. Data were collected using a variety of research methods between July 2010 and January 2012. Notes were taken of informal interviews and discussions; numerous meetings of the SARI team; and the workshops with health workers. The RAs of the SARI project also wrote their personal reflections. Finally, interviews and FGDs of the in-depth phase were analysed when they facilitated an increased understanding of constraints and new plans. The narratives and notes were analysed with NVivo 10 by the author of this thesis. First, an analysis was made of the most important constraints, challenges and resistance that the SARI team faced during reconnaissance. These were then clustered, stakeholders involved were identified and the ways the SARI team engaged with these were considered. Discussions among the author and her SARI colleagues about the results led to a more accurate understanding of the learning cycles, decreased the influence of bias of individual team members and helped to draw general conclusions. Permission for the study was given by the relevant government offices. Written informed consent was obtained from individual study subjects, such as, SARI team members and leprosy workers.

8.4. The SARI project

Consistent with the ILA methodology, the first three phases of the SARI project are described in more detail below. Following this description the mind-sets of the SARI team are explored, demonstrating how various mind-sets within the team needed to be addressed before interventions to reduce stigma could be introduced.

8.4.1. Exploratory phase: June 2010 – April 2011

The first key activity was to establish the interdisciplinary research team: the SARI team. The researchers who had written the proposal developed this interdisciplinary team by selecting researchers from the VU University and Universitas Indonesia with experience in research on disability, leprosy and stigma. By January 2011, the SARI team consisted of three PhD students, one post-doctoral researcher, four senior researchers and two professors, from a variety of scientific disciplines including medicine, epidemiology, public health, psychology, disability studies, sociology, development studies and communication. The next step involved the
identification of relevant stakeholders by the interdisciplinary team: NGOs, DPOs and other key informants in the field of disability and leprosy. These key stakeholders were not involved in the development of the original SARI proposal. This is undesirable, but often the reality in grant applications.

In January 2011, a kick-off workshop took place in Jakarta at which the SARI team met other key stakeholders. A preliminary overview was presented of the developments in the scientific field, perspectives of the stakeholders, as well as the problem context. The participants at the workshop discussed their expectations of the SARI project which helped to create a shared vision and to develop relationships of trust.

The SARI team also aimed to find a local partner to implement the interventions. The CBR Development and Training Centre Solo (PPRBM Solo), with a substantial track-record in CBR, expressed interest in becoming SARI’s local partner. In the following months, a field office was established at the study site and RAs from the local area were hired. In order to create active participation of the beneficiaries from the start, the project aimed to hire people affected by leprosy or disability. In March and April 2011, RAs were trained in CBR, social research and the ILA approach. In April 2011, the first workshop was organized for stakeholders from the District Health Office (DHO), Provincial Health Office (PHO) and the CHCs in Cirebon District. The main goals of the workshop were to: introduce the SARI project and, in particular, the ILA approach, gain an understanding of stakeholders’ activities, perspectives, needs and problem context; and seek the support of stakeholders in facilitating this project.

8.4.2. In-depth phase: May – November 2011

The main goal of this phase of the project was to identify and analyse the problem perceptions, opinions and ideas of the different stakeholders in order to design effective, appropriate and sustainable stigma-reduction interventions. The three types of interventions that were going to be implemented had been determined in the project proposal, based on the promises described in the literature. These included counselling, establishing contact between people affected by leprosy and community members, and socio-economic interventions for people affected by leprosy. However, the precise process was left open in the proposal and depended on local input.

To determine how these interventions would be established, the RAs collected information from people affected by leprosy and key persons such as health workers, religious leaders, community leaders and teachers in the local communities through 53 IDIs and 20 FGDs.

In this phase, the initial study design of the SARI project was adapted. It was decided to implement paired interventions, namely counselling & contact; SED & counselling, and contact & SED, and to have a control area without interventions. In order to assess the effect of the interventions a mixed methods approach was selected. The qualitative and quantitative assessment of stigma was equally valued, contrasting with the standard procedure in which
qualitative assessment supports and has a lower status than quantitative assessment. The initial number of scales was reduced. Scales are quantitative instruments intended to give a numerical result that indicates the severity or extent of the phenomenon measured. Leaving three scales for persons affected and two for community members (with an estimated time needed from each interviewee of 20-40 minutes). The RAs received extensive training and supervision on how to deal with emotions that might arise as a result recalling experiences with stigma.

The six new RAs hired during the in-depth phase received training on leprosy and research methods which was also used as refresher training for the others. In addition, executing the daily work and coming into contact with people affected by leprosy gradually changed the perspectives on leprosy among all RAs. As an illustration, one RA married a person affected by leprosy. During the daily, weekly or bi-weekly meetings among the team, the sometimes distressing stories of discrimination, social exclusion, isolation and internalized stigma were discussed. This created an engaged group of RAs. Indeed, the RAs regularly stated that they valued the social aspects of their work.

8.4.3. Integration phase: October 2011- November 2011

The perspectives of the different stakeholders were compared and, as much as possible, integrated during several workshops. In October, a workshop for health workers from the CHCs was organized to provide them with an update of the SARI project and to have some discussions on preliminary findings and observations. Another workshop was organized to learn about and integrate knowledge on the three interventions. Other potential stakeholders from Cirebon District were invited if it was thought they could make a valuable contribution to the design of the interventions: researchers from local universities, artists from the kraton (royal palace), staff from micro-credit organisations and faith-based organisations, and health workers and religious leaders involved in counselling. In November 2011, proposed interventions were presented and discussed with national stakeholders such as the donors, NGOs, DPOs and MoH in Jakarta.

In parallel, other activities were organized such as validation and baseline studies with mixed methods (quantitative scales and qualitative interviews) with about 600 people affected by leprosy and more than 250 community members. In November 2011, the RAs started the preparations for World Leprosy Day (held in January 2012) to increase public awareness of leprosy. This marked the end of reconnaissance and the start of the next phases which are outside the scope of this chapter: prioritization and action planning, and implementation. After the reconnaissance phase, the SARI project moved into the next phases of the project in which the content of the interventions was designed and the implementation started. Twenty-three people affected by leprosy or disability were trained as counsellors for clients affected by leprosy. People affected by leprosy made videos and comics about their lives and these were shared and
discussed with community members during events in villages. Micro-credits, disbursed by a bank and later by a DPO, were provided to stimulate SED.

8.5. Findings – making different mind-sets explicit

The ILA methodology made it possible to make differences in mind-sets (pre-conceptions, opinions and ideas) explicit. In the SARI project, mind-sets on the nature of research, participation, leprosy, stigma, disability and sustainability differed between groups of actors (for example between the SARI team and the DPO), but also within groups of actors (between SARI team members or between health workers). Most of the SARI team members were not involved in the initial development of the proposal and, as a result, their knowledge, views and expertise were not reflected in the overall design of the project. In addition, as mentioned above when describing the development of the team, the team members came from different scientific disciplines with their own epistemology and ontology.

8.5.1. Aspirations

The first workshop demonstrated the different aspirations of the team. A rich and diverse account of visions and dreams collected during the first workshop illustrates this:

- I want to know how we can measure the effect of interventions.
- I hope that we will learn how this project can help to reveal the knowledge of disabled people.
- I hope we can make persons with disabilities able to help themselves.
- I hope to develop a group of people affected by leprosy with experience in participatory research so that they can participate in future research.
- I hope that disability will become a priority for the government. (Notes workshop)

All the visions and dreams were brought together in a document that represented the SARI teams’ common vision.

8.5.2. Approaches to research and scientific validity

There were different expectations and views within the team on the execution of the SARI project as an action research project. In particular, team members had different opinions on what is a scientifically valid study and on the balance between a scientifically valid study and ethical considerations. The team members considered whether the SARI project should implement single interventions because this allows studying the effect of the intervention more precisely or whether interventions should be combined because other studies indicated that combined interventions work best. They also considered whether it is possible to measure the concept of ‘stigma’ and how should this could be done. How much data should the SARI project collect in the form of questionnaires, scales and interviews to allow assessment of outcomes in a scientifically valid way? Would this approach would be ethically appropriate, given the emotional burden on the participants?
There were also different expectations and views between the SARI team and health professionals. SARI’s action research methodology, in which the results from the in-depth study determined the plans, research methods and the content of the interventions, seemed new for the health professionals, who were clearly used to more top-down, structured and standardized study designs. Health professionals of the workshop raised questions about what would happen after four years (the project time span) giving the impression that they had experience with projects coming and going without having a sustainable impact. SARI’s project team explained that the project aimed to create sustainable interventions but that the ideas on how to do this were on purpose not yet clearly defined, because they had to be based on the experience of the first stages of the project. Subsequently, health workers presented a wait-and-see attitude.

Discussions during the first workshops facilitated increased understanding of expectations, intentions, worries and personal interests. The team increasingly understood that it was important to take diverse views into account when designing the interventions, focusing on finding middle ground, balancing contrasting needs and interest, and putting people first. Theoretical discussions on the concept of stigma and on the comprehensiveness, complexity and importance of power and structure led to a better understanding of the various points of view among the team members.

8.5.3. Different attitudes to interventions and timing

During the reconnaissance phase, it became clear that the SARI team and PPRBM Solo had different attitudes to the interventions. PPRBM Solo would have preferred to start the implementation of the interventions as soon as possible and considered that there was too much emphasis on the design and execution of the studies. The SARI team was keen to start the interventions but placed greater value on a more considered transdisciplinary approach. Moreover, PPRBM Solo desired a clear logical framework for the project; the SARI team found this difficult to deliver because of the action research methodology. These and other differing perspectives made it difficult to continue the partnership. During dialogues in the SARI team, and between SARI and PPRMB Solo, a different form of collaboration satisfying both partners was found: PPRMB Solo took on the role of CBR consultant and trainer.

8.5.4. Models of disability

Health workers, important stakeholders in the SARI project, were found to have different attitudes to leprosy than members of the SARI team. For example, they often consider leprosy to be a medical and social problem, reflecting the medical model of disability rather than the social model which underpinned the SARI project. This is illustrated by the following statements from health workers:

*The [leprosy worker] must be highly dedicated to the work. We select those with high dedication, because they will deal with the stigma. They deal with people [affected by leprosy]*
who have no confidence in themselves. (…) That is why they (…) should understand the psychology of patients. (FGD 11 head CHC in-depth phase)

In my opinion, [people affected by leprosy] do not want to start the treatment because they are shy and also they feel okay. When they know they are infected by leprosy, I am sure that they will feel down. The most important thing we, as puskesmas [CHC] officers, have to do is socialisation; we should do this as much as we can. (FGD 20 leprosy worker in-depth phase)

So, this leprosy programme is not like the main programme. It is not like the number one programme. (…) And the fund is too limited. I pity the leprosy personnel! (FGD 11 head CHC in-depth study)

These quotes illustrate that the health workers often had a different approach to leprosy because they had a medical model of the diseases and also they did not see it as a priority. This understanding was important because it helped the SARI team and health workers to understand their differences in approach.

8.5.5. Approaches to people affected by leprosy

Health workers and the SARI team often had different attitudes to people affected by leprosy which became evident when efforts were made to employ people affected by leprosy and with disabilities in the project as RAs. In response to the efforts to employ people affected by leprosy, one health worker stated:

_There was no candidate, they were still sick._ (Comment from health professional informal discussion)

In contrast, the SARI team perceived people affected by leprosy in treatment and ‘cured’ as capable of work. This fundamentally different perspective did not help to facilitate the hiring process. The SARI team learned from the leprosy officers that some seemingly suitable candidates, eager to find work, were not comfortable with applying for vacancies due to a low self-esteem. One person affected by leprosy from a neighbouring district was, however, eager to join the training. The SARI team started the training sessions with eight candidates; three with a physical disabilities and one affected by leprosy.

Additional staff were hired after the first training during the in-depth study that started in June 2011. Connections to the beneficiaries and stakeholders were established which made it easier to find additional candidates for the position of RA. A religious leader that had attended a FGD and a person affected by leprosy who had been interviewed joined the project. The latter told that it had been difficult to find a job.

_‘I was shy, sad, ashamed, and angry and it was really hard to find a job. Companies where I applied asked: ‘Why is your face and body black?’’_ (Comment person affected by leprosy during workshop)
One of the main issues that complicated the relationship between SARI and the CHCs was the attitudes of a few leprosy health workers from CHCs and the power dynamics that were involved. Some people affected by leprosy complained about disrespect for privacy, scanty attention, negligence and soliciting of payments by health workers for medication that is supposed to be free, while others were very positive about their relationship with and the care provided by the leprosy workers. Leprosy workers discussed some of these issues during FGDs:

*Sometimes puskesmas [CHC] officers still have stigma about leprosy.* (FGD 20 leprosy worker in-depth study)

*The medicine is free, however only some patients can get it for free! This thing [requesting payment] was done by irresponsible individuals. ... I disagree with that.* (FGD 20 leprosy workers in-depth study)

Another source of tension emerged a few months later. Some CHCs staff asked for monetary compensation for attending World Leprosy Day 2012, an event organized by the RAs of the SARI project. There was no money budgeted for this event and, consequently, the SARI project depended on local sponsors for it to take place; the RAs themselves contributed small sums. The request for compensation from leprosy workers was annoying and frustrating for the RAs, and underlined the difference in perspective.

**8.6. Lessons for other development projects**

From a development management perspective, the reconnaissance phase of the project in which there was considerable interaction between different stakeholders and the opportunity to discuss their different opinions was very valuable because these differences could have posed serious problems later on. In the ILA approach, these differences are actively sought by asking stakeholders' views, dreams, worries and expectations during workshops or informal meetings.

**8.6.1. Power issues**

There were power dynamics within the project team: the powerlessness of people affected by leprosy and internalized acceptance of this; power of health workers over people affected by leprosy; and also the powerlessness of health workers to effect change. The notion of power relations is fundamental to stigma and discrimination (Link & Phelan, 2001; Parker & Aggleton, 2003). Eyben (2006) notes that unequal power relations remain largely unnamed and unchallenged within development processes. Being aware of power and finding ways to achieve equity, for instance by inviting people affected by leprosy to official meetings and giving them space to share their story and ask questions, was believed to make a difference.
8.6.2. Establishing relationships

Challenges, constraints and resistance are traditionally perceived as something negative and something that need to be eliminated in development projects. The evidence from this project shows that differences in mind-sets should be viewed through a more positive lens because they provide feedback and represent windows of opportunity for learning. The SARI project dealt with these challenges in three ways: discontinuation of a collaboration; continuation in a different form; and increased engagement. There may be good reasons to choose the first two options. Although it was unfortunate that the SARI project could not make the partnership with the PPRBM Solo work, differences in mind-sets and other challenges proved insurmountable. This demonstrates the point that it is sometimes important to defend key principles and discontinue or adapt collaboration in order to create a stronger base for future work. In the SARI project, discontinuation or continuation in a different form were only used occasionally. More frequently, greater engagement offered the way forward as in the case of the SARI team’s interactions with health workers and participants. By engagement, we mean establishing relationships through understanding the array of viewpoints and possible underlying assumptions.

8.6.3. Willingness, flexibility, methods and time are key resources for engaging

A sincere willingness to understand the other and one’s own organisation and project team was also essential in the SARI project. This willingness increases, we believe, when the complexity of disability and stigma are acknowledged and when the value of transdisciplinary research is appreciated. The SARI cases shows that flexibility of the ILA approach is helpful when plans are being adapted. Methods that helped to create relationships comprise dialogues, workshops, FGD and also informal meetings. In the SARI project, establishing relationships took time. A conscious effort should be made to allocate sufficient time to relationship building and not rushing into interventions.

8.6.4. The learning process is a way to prepare and improve an organisation

The experience of the SARI project shows that a new project needs to build on the following: involvement of appropriate stakeholders in the form of people and organisations; an awareness of power dynamics; the development of relationships within a team and between the stakeholders; and appropriate structures for learning and reflection. If these are put in place, a better set of interventions will be developed with better implementation, providing a strong basis for future work in the field of disability.
8.7 Conclusions

In this chapter, we have shown that an intervention project guided by the ILA approach, an action research methodology with transdisciplinarity as a key principle, can contribute to addressing complex and persistent issues such as stigma, discrimination and social exclusion. By exploring the different mind-sets of the stakeholders, the project was able to identify differences in aspirations, attitudes to scientific validity and ethics of research, different expectations in terms of interventions and timing, conflicting intrinsic models of disability, and diverse attitudes to people affected by leprosy. Although these differences represented a challenge to the project, making these differences explicit meant that the project was able to deal with them and that it did not reproduce attitudes and approaches to leprosy and disability which would have undermined its objectives. Indeed, these differences are not symptoms of failure but, rather, should be actively sought out and investigated. This approach is radically different from the practice of seeking to ignore or suppress divergence.
References


Part III
Discussion, conclusion and reflection
Chapter 9
Discussion and conclusions

This thesis started with a list of questions that people affected by leprosy asked me during interviews. ‘Can I be cured?’, ‘Have I been cured?’, ‘Why can I not be close to my grandson?’, ‘Why do they ban me from feeding my baby?’, ‘Why do they look at me?’, ‘Why am I dismissed from my job?’, ‘I am ill, I do not have any rights, right?’, ‘Do I have rights to talk at home?’, ‘I am an affected person, may I go to school? And may I go to work?’ The lack of knowledge and the limited awareness of rights reflected in these questions were important themes throughout my thesis.

This chapter presents the conclusions of the research, which was guided by the following main research question: *Under what conditions is counselling an effective approach to reduce leprosy-related stigma in Cirebon District, Indonesia?* The results described and conclusions drawn in the previous chapters already provide an answer to the sub-questions formulated in the introduction. I will highlight and discuss the main findings here. Next, the answer to the main research question is given and elaborately discussed. After that the validity is described. I also provide policy recommendations and give directions for future research.

9.1. Summary of findings and conclusions

1. How is leprosy and leprosy-related stigma understood, experienced and dealt with by people affected by leprosy in Cirebon District, Indonesia?

From the summary table below (see Table 9.1.) we see that the causes of leprosy mentioned by affected persons and other key persons show there is a lack of medical knowledge on leprosy. This is in line with findings from other studies (Nicholls, Wiens, & Smith, 2003; Opala & Boillot, 1996; Sermrittirong & van Brakel, 2014). This finding points to the importance of including medical knowledge in the counselling sessions. The social and emotional consequences of leprosy-related stigma are diverse and severe. van Brakel (van Brakel, 2006) noted that ‘the consequences of stigma are remarkably similar in different health conditions, cultures and public health programmes’. This study confirms that there are indeed many similarities, but it remains very important to understand the local context in order to tailor the knowledge component of the counselling so that it resonates with the experiences and perceptions of the counselling clients.
Table 9.1. Summary perceived causes and the social and emotional consequences of living with leprosy

<table>
<thead>
<tr>
<th>Causes</th>
<th>Impact living with leprosy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Challenge/test from God</td>
<td>Rejection</td>
</tr>
<tr>
<td>Destiny (it has been written)</td>
<td>Avoidance</td>
</tr>
<tr>
<td>Curse</td>
<td>Gossip</td>
</tr>
<tr>
<td>Black magic or heresy</td>
<td>Ignorance</td>
</tr>
<tr>
<td>Karma</td>
<td>Broken family relationship</td>
</tr>
<tr>
<td>Bacteria</td>
<td>Broken social (neighbour) relationship</td>
</tr>
<tr>
<td>Heredity</td>
<td>Dropping out of school</td>
</tr>
<tr>
<td>Weak immune system</td>
<td>Isolation</td>
</tr>
<tr>
<td>Similar blood type</td>
<td>Concealment</td>
</tr>
<tr>
<td>Genetic problem</td>
<td>Divorce</td>
</tr>
<tr>
<td>Poor hygiene (e.g. contact with dirty objects, poor sanitation)</td>
<td></td>
</tr>
<tr>
<td>Direct contact with people affected by leprosy</td>
<td></td>
</tr>
<tr>
<td>Using utensils (e.g. dishes, towels) from a person affected by leprosy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social consequences</td>
</tr>
<tr>
<td></td>
<td>Emotional</td>
</tr>
<tr>
<td></td>
<td>Shy</td>
</tr>
<tr>
<td></td>
<td>Shame</td>
</tr>
<tr>
<td></td>
<td>Depression/anxiety</td>
</tr>
<tr>
<td></td>
<td>Shock</td>
</tr>
<tr>
<td></td>
<td>Low self confidence</td>
</tr>
<tr>
<td></td>
<td>Hopelessness</td>
</tr>
<tr>
<td></td>
<td>Fear of dying</td>
</tr>
<tr>
<td></td>
<td>Helplessness</td>
</tr>
<tr>
<td></td>
<td>Sadness</td>
</tr>
<tr>
<td></td>
<td>Anger</td>
</tr>
<tr>
<td></td>
<td>Loneliness</td>
</tr>
<tr>
<td></td>
<td>Fear of impairment</td>
</tr>
<tr>
<td></td>
<td>Fear of infecting others</td>
</tr>
</tbody>
</table>

Due to the disability movement, the work of DPOs and the UNCRPD (Mji, Maclachlan, Melling-Williams, & Gcaza, 2009; UN, 2006; Yeo & Moore, 2003), people with disabilities seem one step ahead in term of awareness of rights compared to people affected by leprosy. Chapter 3 indicates the way people with disabilities feel empowered by realising their rights. A counselling practice is likely to benefit from these experiences of people with disabilities. Emphasis on rights to participate in social and economic activities is therefore an important element of the counselling.

Chapter 7 shows the importance of the experiential knowledge of people affected by leprosy, peer counsellors and other key stakeholders. Experiential knowledge is shown to be key in the empowerment of people affected by leprosy-related stigma, their families and communities. But there is also a challenge; people affected by leprosy have valuable experiential knowledge but at the same time often have misconceptions about the disease (e.g. causes, infectiousness).

Misconceptions can also been seen in the field of HIV/AIDS and maternal health (Miltenburg et al., 2013; Tenkorang, 2013). People affected by leprosy first need to be made aware of these negative, disruptive and self-limiting misconceptions. The shift in knowledge and thinking that takes place, becomes the ‘new’ knowledge. This knowledge can then effectively be used by peer counsellors. For example, a peer counsellor could say ‘I also used to think that leprosy was very infectious, but now I know that it no longer spread when medication is started.’ Then the peer counsellor could ask the client: ‘Do you take your medicine?’ and if this is the case, it is confirmed that the client is no longer infectious.
Chapter 8 describes the mind-sets of researchers, health professionals and other key persons on leprosy and stigma, and shows that prejudice against people with leprosy-related stigma is widespread. These prejudices need to be acknowledged and addressed in the counselling practices. Other studies have also shown the sometimes stigmatizing attitudes of health professionals and others (Awofeso, 1992; Briden & Maguire, 2003; Chen, Zhang, Liu, & Liu, 2004; Iyor, 2005; Nicholls et al., 2003). Seldom are the underlying reasons explored. In this study understanding the reasons helped to deal with differences and to build a relationship that was needed for the implementation of the counselling intervention.

2. What are the characteristics of a counselling practice for clients affected by leprosy-related stigma in Cirebon District, Indonesia?

The exploratory study showed the interrelatedness and complexity of the issues at stake. It influenced the development of the counselling practice in four ways as described in Chapter 4. Firstly, many problems people affected by leprosy face are rooted— as stated before—in a lack of knowledge about their disease and the consequences of this disease. An effective counselling practice provides knowledge quickly and efficiently. In the literature, the effectiveness of knowledge in the reduction of leprosy-related stigma is seriously questioned (Brown, 2006; Cross, Heijnders, Dalal, Sermrittirong, & Mak, 2011a; Opala & Boillot, 1996; Raju & Kopparty, 1995). In contrast, this study shows that knowledge is very important.

Secondly, in order to deal with the passiveness, and feelings of guilt and low-esteem, an optimistic and energetic counselling style seems the most appropriate (see Box 9.1.). Such a style is described as motivational interviewing (Rollnick, Miller, & Butler, 2008; Rubak, Sætbaek, Lauritzen, & Christensen, 2005). With its empathic, supportive and yet directive style, motivational interviewing aims to provide conditions under which change can occur. It supports self-efficacy and generates confidence.

Thirdly, the finding that human rights are violated justifies the rights-based approach. People affected by leprosy might feel relieved by having an increased awareness of their rights. It also might create a sense of freedom, which enhances their options for changing their life. Rights are often applied in the context of advocacy (UN, 2008). The noteworthy aspect of this study is that rights are used to reinforce the feeling that people affected by leprosy are human beings and that they have rights in their own environment (within their family, within their neighbourhood). Rights are not used at a macro level to change policies and structures, but they are mainly used as a tool to increase self-confidence and simulate small initiatives for advocacy at a micro level.

Finally, problems with stigma manifest themselves at many levels and in different ways. Instead of focussing on individual, family or group counselling alone, an approach with a combination of these three types seems necessary. To our knowledge this is the first time that a counselling module for leprosy has been developed that integrates these three types in one module. More
often, one type of counselling is selected as was done in the study of Floyd-Richard & Gurung (2000).

<table>
<thead>
<tr>
<th>Box 9.1. Summary of the Rights-Based Counselling Module</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Key principles</strong></td>
</tr>
<tr>
<td>1. Each client, whatever his or her condition, wants to change his/her life for the better and he or she should decide what actions/solutions are needed to bring about this change.</td>
</tr>
<tr>
<td>2. Each client needs to be listened to, appreciated and acknowledged.</td>
</tr>
<tr>
<td>3. In a relaxed, though energetic, fun and joyful atmosphere, the client will be comfortable and more open and trust will come more easily and rapidly.</td>
</tr>
<tr>
<td>4. Medical knowledge about leprosy is an essential prerequisite for the rest of the counselling process.</td>
</tr>
<tr>
<td>5. Awareness of rights is the basis for developing confidence, making changes in life and participating in society.</td>
</tr>
</tbody>
</table>

**The 5C framework**

The 5C framework describes five important counselling skills (confirmation, clarification, confrontation, compromise and commitment) and puts these skills in a certain order. In Bahasa Indonesia the framework is called the 5K framework. It comprises of Konfirmasi, Klarifikasi, Konfrontasi, Kompromi and Komitmen. These counselling skills are not new and have been discussed in literature (Belkin, 1984; Egbochuku, 2010).

- **Confirmation**: information and experiences shared by the client need to be confirmed and verified.
- **Clarification**: information from the client needs to be clarified to make it clear and understandable.
- **Confrontation**: a client should be challenged during a conversation to build knowledge, create rights awareness and to develop confidence; this helps create momentum for finding solutions and making change. The counsellor should confront the client during the counselling process with his/her own statements that have been confirmed and clarified earlier.
- **Compromise**: clients should be encouraged to compromise, to see things from a different perspective and to acknowledge exceptions.
- **Commitment**: clients should commit to an alternative solution and take action.

3. What is the impact of a rights-based counselling intervention on leprosy-related stigma in Cirebon District Indonesia?

The impact of the intervention is evident from the changes in scales and the narratives (see Chapter 6). The key role of the lay and peer counsellors is described in Chapter 5. Below, a shortened version of the main findings is provided, elaborated with some comments. In Table 9.2, the strong reduction of stigma, improvement in participation and quality of life is shown. In Figure 9.1, the reduction of internalized stigma is visualized. Table 9.3. shows the change in knowledge about leprosy, confidence and hope for the future. The impact of the counselling module is significant especially taking into account the short duration of the counselling. The result led to the recommendation to scale up this intervention, taking into account new local conditions, as it can significantly reduce the fear, shame and passiveness of many people affected by leprosy-related stigma.
Table 9.2. Univariate differences for three scales between baseline and final survey to assess effect of the counseling intervention

<table>
<thead>
<tr>
<th>SARI Stigma Scale total score</th>
<th>Counselling clients (n=67)</th>
<th>Baseline (2011) Mean (SD)</th>
<th>Final survey (2014) Mean (SD)</th>
<th>Difference Mean (SD)</th>
<th>P-value</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>21.55 (13.51)</td>
<td>12.00 (11.02)</td>
<td>-9.55 (12.69)</td>
<td>&lt;0.001*</td>
<td>Strong significant reduction of stigma</td>
</tr>
<tr>
<td>Participation Short Scale total score</td>
<td>Counselling clients (n=67)</td>
<td>9.51 (1.43)</td>
<td>5.86 (1.27)</td>
<td>-3.65 (1.02)</td>
<td>&lt;0.001*</td>
<td>Significant improvement in participation in family and social life</td>
</tr>
<tr>
<td>WHO Quality of Life - BREF total score</td>
<td>Counselling clients (n=67)</td>
<td>80.19 (1.14)</td>
<td>86.74 (1.4)</td>
<td>6.54 (1.65)</td>
<td>&lt;0.001*</td>
<td>Significant improvement in quality of life</td>
</tr>
</tbody>
</table>

1. Wilcoxon matched-pairs signed-ranks test
2. Paired t-test

Figure 9.1. Changes in the ‘Internalized stigma’ domain of the SSS before and after counselling (n=67)
Table 9.3. Before and after results of five clients paired IDIs.

<table>
<thead>
<tr>
<th>Interviewee</th>
<th>Before receiving counselling (baseline 2011)</th>
<th>After receiving counselling (final survey 2014)</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>'I do not want to meet people as they gossip about me'</td>
<td>'I do not care what people are saying'</td>
<td>Increased confidence</td>
</tr>
<tr>
<td>19 years</td>
<td></td>
<td>'I am fully confident going out and meeting many people'</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>'I hide my disease as people always treat me as an ill person'</td>
<td>'I completely know my disease ... I feel ok now to talk to people'</td>
<td>Increased hope and</td>
</tr>
<tr>
<td>22 years</td>
<td>'I am sad'</td>
<td>'I am aware even though I still have medical treatment, ... I have to do something for my future'</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>'I am afraid my disease will transmit to my family'</td>
<td>'I understand my disease well'</td>
<td>More knowledge about leprosy</td>
</tr>
<tr>
<td>33 years</td>
<td>'I isolate myself'</td>
<td>'I am confident to explain my disease to other'</td>
<td>Increased confidence</td>
</tr>
</tbody>
</table>

9.2. Overall conclusion

Heijnders & van der Meij (2006), Cross et al. (2011a, 2011b), Brown et al. (2003) have all highlighted the potentials of counselling in stigma-reduction and stated that it is a promising approach. The thesis now shows that counselling is indeed effective, and more importantly, under what conditions the intervention is effective. In this research we can now distinguish between conditions formulated in Chapter 1 of this thesis and conditions that were identified during the process. During the process it became clear that the research design and counselling approach had to be adjusted on the basis of the exploratory and pilot study and according to the realities of people affected by leprosy in Cirebon District. In many cases this understanding led to dilemmas in how to implement the counselling practice. These dilemmas were in most of the cases not solved by choosing one of the possible directions, for example, focussing on deep feelings in the counselling or by focussing on concrete problem solving activities. In most cases dilemmas were dealt with by organizing smart combinations of the options.

In the following paragraphs I will elaborate on each of these conditions, but I will start by describing one of the most important ones which is integration. It is not only important that conditions are fulfilled, but it is also crucial that they are fulfilled in an integrated way. All of the conditions formulated in the Chapter 1 turn out to be needed, but are on their own not sufficient. For example, knowledge on causes and the treatment of leprosy is extremely important, but not a sufficient condition for realising effective counselling.
9.2.1. Conditions based on theory / Chapter 1

In Chapter 1, I suggested that counselling could be effective if it was CBT-based, knowledge-based, rights-based and low-costs, and included three types of counselling. These approaches turned out to be very effective and especially when they were integrated with each other.

I will now provide three examples. The first example illustrates the integration of CBT, knowledge and rights. Clients had asked ‘Can I be cured?’ and ‘Am I cured?’. The medical knowledge provided by the counsellor dealt with the huge uncertainty of the clients. The counsellor could explain how MDT cures people affected by leprosy. This knowledge was often not believed in the beginning because it was taken for granted that they had an illness. By providing medical explanation that leprosy is caused by a bacteria that is killed by the MDT and by answering all the clients questions the clients started to believe this fact. They felt relieved, very happy and considered it to be a ‘miracle’. Here an interesting link can be made with the Brief Solution Based Therapy (a CBT variation) which has been developed by Berg and Shazer in the late 1970s (Bannink, 2007; Shazer & Dolan, 2007). In this CBT approach clients are asked to imagine how their life would look like if during the night a miracle had happened. In the therapy these imagined changes are taken as a starting point to find out how much of a miracle has already happened in their daily life. In this Brief Solution Based Therapy the miracle is a mental construction – a tool to envision how a preferred situation could look like. In the case of clients affected by leprosy-related stigma, knowledge about the cure which often had already happened functioned as a real miracle that had happened in reality. So knowledge and its effects on the client has played an essential role in the progress of the counselling. This miracle which had happened in reality created a space which allowed them to consider their rights. Now other questions that worried them like ‘Can I feed my baby?’, ‘Can I be in the neighbourhood of my grandson?’, ‘Can I work?’ were not difficult to answer and speeded up the progress in terms of improving their quality of life. Yes, CBT, knowledge and rights were necessary conditions, but on their own not sufficient.

The second example is the integration of the low cost of the counselling, knowledge and rights. In order to realise a low cost counselling, lay and peer counsellors were involved in this research. However, also here synergy between the different conditions was created. The LCs were not only inexpensive professionals, were not only trained in medical knowledge, but also had experiential knowledge about health-related stigma. They were able to link questions to their own experiential knowledge but could perhaps even more importantly act as role models. In this situation they were not only talking about rights, but also executing, living their rights by visiting places and people, taking initiatives and responsibilities.

These results go beyond what is stated in the literature. Rafferty (2005) states that counselling can help people affected by leprosy cope with their disease and avoid self-stigmatization. However, he argues that individual counselling can be a slow process that benefits some clients. He suggests that group counselling is a better way forward as it ensures that people affected by
leprosy do not feel alone and it might help them overcome the damaging effects of stigmatization. Instead of individual counselling or group counselling, the counselling practice described in this thesis shows the effect of an integration of individual, family and group counselling.

A third example. As stated in the beginning that people affected by leprosy were often weak and passive, but also wanted to do what other people were doing like preparing food and cleaning the house, caring for family members. In the adopted counselling style homework was given to make a start with fulfilling these needs. The homework was for example talk to your family, explain that you are cured and ask them to involve you in tasks in the household. To make the counselling brief and effective the family counselling was based on this homework. In this way, it was stimulated that the clients take initiatives themselves and become more and more active, that the counselling sessions are integrated. Perhaps most importantly the achieved integration led to an anchoring of the results of the counselling in terms of insights, acquired knowledge, increased self-esteem and a positive self-image were not only integrated in one session, but also built on in successive counselling sessions.

9.2.2. Conditions emerged during the process

During the process, different dilemmas emerged relating to the number of sessions, location of the counselling and counselling style, and these needed to be addressed.

I had to make decisions regarding the number of sessions and wondered how brief can brief counselling be? Would 15 sessions be necessary or could 8 or perhaps even 5 sessions be enough. Also I needed to decide the most appropriate (e.g. private, safe and comfortable) location for the counselling? For one client this might be his/her own home, for another, this might be the clinic or a public space. How provocative, directive, energetic can an effective counselling style be? Counselling needs to be needs oriented, but which needs and who’s needs should it address? For every dilemma different routes could have been taken, but in practice, always a smart solution was looked for to realise the benefits of the different routes. Again the smart solutions found were also integrated.

9.2.3. Final remarks

In the literature there is the discussion on whether being cured is a sufficient condition for dealing with stigma. Rafferty (2005), for examples, states that ‘if patients are cured, the stigmatization can remain an insurmountable obstacle to the resumption of a normal life. Negative perceptions of leprosy still can be a barrier to the process of reintegration into their families, jobs and wider society’ (:121). Most of us would agree with him, however this research shows that the obstacle is not insurmountable. The counselling approach described in this thesis shows that stigmatization can be reduced, participation in family and social life can be increased and a better quality of life can be reached. But most importantly it shows that hope for a better future can be generated.
In every culture there are different ways to deal with stigma. Weiss (2008), for instance, describes a compensation program for people affected by leprosy who have been imprisoned in Japan. All these examples are important to reduce stigma, although Weiss also shows the limited scope of these programs if compared to the extensiveness of the stigma problem which we can find everywhere. Weiss (2008) distinguishes between public and private places. Public settings include, according to him, schools, workplaces, and clinical health services; more private settings include social functions, family and household relations, and other interpersonal interactions. The counselling practice described in this thesis has the potential to address stigma at different places. Discussions of the experiences and interactions of the counselling clients in these different places formed an essential part of the counselling usually approached from the perspective of how they could cope better.

With regard to the different theoretical characteristics of the counselling approach described in Chapter 1 and the emerging characteristics, we can now draw some conclusions regarding the relationships between the different characteristics. In the examples given above it is clearly shown that the different approaches should not be dealt with separately but in an integrated approach see Figure 9.2.

![Figure 9.2. The integration of elements of the Rights-Based Counselling Module](image)

In Chapter 1 the shifts from the medical model toward the social model and from the charity model to the human rights framework are described. This thesis shows how important these shifts are and the thesis can be seen as an exercise to facilitate and embed these shifts in day-to-day realities of people. Although this thesis brings an important contribution to the fight for a more social model towards disability and for a human rights framework, the fight is far from over.
9.3. Validity

9.3.1. Internal validity

In this section, I will reflect on the role of the researcher and the research methods. I was involved in the design, implementation and evaluation of the counselling module, which makes researcher bias an important issue. Several strategies were used to reduce researcher bias such as investigator triangulation, as multiple researchers and RAs were involved in the design of the study, data collection, analyses and interpretation. Another important aspect of the internal validity is the methods used. For our qualitative data, we piloted our list of main questions prior to commencing the study to ensure that the items were suitable for our population. Also all the scales had been validated before or were validated as part of the study.

9.3.2. External validity

The key elements of the counselling (e.g. knowledge, rights, energetic counselling style) seem to be appropriate to address leprosy-related stigma in other districts and provinces in Indonesia but also elsewhere. The counselling intervention is relatively easy to replicate and scale up. An (short) exploratory study will still be needed to tailor the approach to the local circumstances.

The findings of this study are relevant not only for the field of leprosy, but are also of importance for others stigmatized conditions. Several diseases such as HIV/AIDS, tuberculosis, mental illnesses, but also Neglected Tropical Diseases such as Buruli ulcer, lymphatic filariasis, onchoceriasis, leishmaniasis and Chagas disease are associated with stigma and as a result have negative effects on an individual’s quality of life (Person, Bartholomew, Gyapong, Addiss, & Borne, 2009; Scambler, 2009; Stienstra, Van der Graaf, Asamoa, & Van der Werf, 2002; Weiss, 2008). The value of counselling for these diseases will depend on whether similar triggers for change can be identified. For example, in the field of HIV/AIDS the knowledge element could be that HIV/AIDS is not as infectious as people often think it is or in the field of neglected tropical diseases that some diseases can be treated or managed with medication.

9.4. Limitations of this study

The previous chapters already provide a clear picture of the limitations of this study. There are two additional limitations that I like to highlight here. First, the study area - Cirebon District - consists of 40 sub-districts and is 1,071,05 km². Due to the size it was difficult to effectively manage the counselling activities (e.g. trainings, supervision) and time, and this might have influenced the quality of the intervention and research somewhat. Although this can be perceived as a limitation, it is also the reality in many sub-districts and provinces in Indonesia. Many other sub-districts are even less accessible. A second limitation is language. Many different languages are spoken in Cirebon District (e.g. Cirebonese, Javanese, Sundanese). The scales that we applied were only validated for the national language Bahasa Indonesia. Also, I speak Bahasa Indonesia.
but I am not fluent in the other languages. Providing counselling was sometimes challenging and might have led to some misunderstandings in communication. Again, this will be reality in many sub-districts and provinces in Indonesia. So it is also important and a value that I came across this challenge in my study.

9.5. Policy recommendations

Oliver (1992) has argued that research in the field of disability has often failed to provide information that has been useful to the policy making process. In this section I provide some policy recommendations based on the study described in this thesis. As Oliver also stated leprosy is not only a medical and a welfare issue, it is also a political issue. Therefore I believe the knowledge generated in this thesis where people affected by leprosy and with disability were closely involved should be considered by policy makers. I believe that the most important conditions at the policy level for realising stigma reduction through counselling are:

1) Increased interest and awareness of the social aspects of leprosy among policy makers

2) Willingness of policy makers to involve people affected by leprosy or with a disability as experts in the service provision (e.g. as lay and peer counsellors)

To address the needs for empowerment of people affected by leprosy through counselling intervention, trained lay and peer counsellors will have a crucial role due to limited availability of professional counsellors and related disciplines. When engaging lay and peer counsellors, however, we should prepare them not only in understanding human rights and appropriate counselling skills but also on codes of conduct in dealing with marginalized and vulnerable clients. To enable them to assist their clients effectively, the lay and peer counsellors should also receive a clear mandate (written) from the health authority to facilitate clients to access relevant state facilities including the social protection schemes currently promoted by the local and central government. The establishment of strong linkages between the formal health system and a lay and peer counselling system will be crucial.

9.6. Future research

This section presents recommendations for further research based on the findings of this thesis. First, the study of Heijnders and van der Meij (2006) shows that multi-level and multi-target group interventions are needed to reduce health-related stigma. Research on the intrapersonal, interpersonal and community level has now been done, but there is less or even no research on organisational/institutional and governmental/structural level. More research on interventions that specifically target these levels is needed. An exploratory study could identify the needs and potential strategies for these levels. In addition, tools would be needed that can assess a change in stigma at these levels. Eventually, organisations and people at these levels could and should
become key players in the fight against leprosy-related stigma. If changes on all levels occur, the change is more likely to last.

Secondly, the new counselling approach – the RBMC – has been developed and applied in Cirebon District, Indonesia. Since this approach was shown to be effective in this context, it could be a very promising approach for other areas. Short exploratory and pilot studies are needed in other areas affected by leprosy-related stigma to tailor the RBCM to different local contexts in Indonesia such as Madurai, Sulawesi, Nusa Tenggara, Papua, Sumatra and Bali. Then it would be good to test the effectiveness of the RBCM in these areas.

Thirdly, I would like to prioritize the development of valid instruments and qualitative perhaps participatory methods that assess concepts that are influenced by counselling in more depth. For example instruments to assess awareness of rights, social interaction, social inclusion, self-esteem and family relations/stigma. New instruments could be developed or existing instrument can be adapted to the context of Indonesia and people with stigmatized conditions. Also finding better ways to synergize quantitative and qualitative methods that assess or aim to understand stigma are needed.

Fourthly, a study that focuses solely on how this intervention can be made sustainable and embedded in the local system and structure is highly relevant. An in-depth understanding of the organizations in villages (e.g. DPOs), capacity of villages, health care system, budgets, regulations and so on is needed. Also research on how to establish a referral system to professional counsellors is important. In addition, it might be interesting to explore the possibilities and effectiveness of a lay and peer counselling system for health-related stigma in general and not only leprosy specific (HIV/AIDS, tuberculosis, mental illness, disability due to diabetes, stroke).
References


Reflective note

Reaching a dream by becoming a blind PhD candidate

I started losing my sight at the age of ten and became totally blind when I was 17 as a result of retinitis pigmentosa. As a blind adult, I struggled to cope with a different way of living. It was hard. I was on–off about accepting my new identity. When the doctor told me after seven years of medical care that my eye condition is incurable, I was so angry – not with myself, but with the doctor: ‘Why did he never tell me openly and clearly? The doctor only ever asked me to take medicine routinely’. I was amazed. My eyes are my own but the doctor never discussed what I endured in my body. I was tired and frustrated with the doctor’s words.

I could not run away from the reality of a life without sight, my new life, my new identity as a blind person! I learned to perform as a blind girl. I was ashamed of myself, reading by touching and walking with a white cane. I was a burden to my family, depending on them. I was worried about my future. I wondered, ‘could I do anything for myself?’, ‘could I do something for my family and others?’, ‘I want to do this, but my blindness limits me!’, ‘I want to do that, but again my blindness restricts me!’ I did nothing!

This fact was not only new for me, but also for my parents, brothers and sister. This new condition was born in my family, disseminating from home to my extended family, also to my neighbours and my family relations. Once people knew, stereotyping, labelling and gossiping attacked my personal life. A strong expression says that ‘blind persons are nothing’. On the one hand, this made me feel weak, but on the other it burned my spirit to be strong, to prove to people that the expression is not true. I needed to change the way I met and talked to people. They would ask me ‘why are you blind?’ Rather than helping, supporting and assisting me as I needed, people would take pity on me, saying ‘stay at home, you are ill, go to this doctor or see that doctor’. I’d be angry, without knowing with whom. I kept silent and talked less, although people seemed to talk and look at me more. It was a sign. I should talk, so people would stop. A big question came to me ‘what can I do?’ I did not have enough confidence, but I tried once, and cried when I started to introduce myself by saying, ‘I am blind, please read for me’. I was still weak; I felt I did not have the strength to speak up. But after saying this, I felt a certain release.

I visited a special school, and I met peers. I realised I was not alone. With the help of my peers, I learned to become confident and comfortable with my blindness. Experiencing it has taught me that being blind does not mean one cannot see, but that the blind can see in a different way. I see with my hands, ears and other parts of my body. So without eyesight, I can still survive. The
hardest part, however, has been dealing with people's words, perceptions and mind-sets, their attitudes towards those who are not the same as them.

I thanked the people who had said that 'blind people are ill people and do nothing'. I dealt with and embraced these negative words which pushed me to study in order to empower myself by going to school and obtaining higher education. I believed education could bring light to the blind world. In particular, I trusted that with a higher level of education people can recognise and listen to blind people, and will treat blind people honourably.

I have no vision but I have visions. My visions established my dream. I successfully achieved my bachelor's degree in education and counselling. I have two master's degrees: the first in public administration from the University of Indonesia and my second in international communication from the University of Leeds. Determined that I wanted to do something following my education, I wrote and published articles, books and some training modules on disability and inclusive education. I have been active in DPOs. I have also established organisations focusing on the disability movement with a mainstreaming disability strategy. Since 1994, I have been teaching and facilitating knowledge on disability in regard to certain topics such as education, law, transport, counselling, theology, social sciences and politics, health, business and economy. In addition, I still work as a counsellor. Human rights and practical knowledge-based approaches are my counselling skills.

When my colleague from the Center of Disability Study at the University of Indonesia suggested a PhD programme at VU University Amsterdam, it seemed like a dream! PhD research on leprosy with the Stigma, Assessment and Reduction of Impact (SARI) Project in Cirebon District, Indonesia. When I received the project description, for me, everything was new: stigma?, leprosy? I wondered about leprosy since it was really new for me. And as a blind person, I would never see the characteristics of the disease. I heard and knew about it without seeing. How could I deal with this work? True, in the early years of my blindness, I dealt negatively both with myself and with people around me. For instance, I was worried that people knew I am blind and that when I went to school, they would reject me because of my blindness. I was not confident walking with white cane. I did not know that what I experienced was stigma.

As a blind researcher on leprosy-related stigma, with my knowledge on the topic still wanting, many questions came to my mind. What is leprosy? Is it contagious? Dangerous for my health? How contagious? How do people contract leprosy? Can it be cured? And, along with these questions, many feelings, fears, dilemmas and doubts. I therefore really needed accessible signs for when I should shake hands, or when and where I should sit, when I should eat and drink, what the condition of the patients is, or the condition of the house. My thoughts and my feelings were always uncertain when I worked.
I needed knowledge, and that knowledge assured me that leprosy is a disease just like other diseases. Knowledge put an end to my negative thoughts and feelings about leprosy. I kept optimistically doing research visits and interviewing people affected by leprosy. Importantly for me, I took care of my health too. I did not care about people's words and behaviour. With this understanding and mind-set, I did not mind where and when I worked, and particularly who I worked with in the leprosy field. I confidently shook hands, I safely sat beside, I talked comfortably, and I enjoyed the food and drinks that were provided by people affected by leprosy.

I realise now with wonder that I have become a more positive person, and that my senses are more active. I know where a person is sitting from their voice, I can form an impression and expression of what people are doing. I can feel the atmosphere by the sense of my skin. I can sense the leprosy condition by smell. Other parts of my body and other senses jumped in to replace my eyes. I have been working as usual without seeing.

By conducting this research, I had more understanding of leprosy and stigma. Coming to my discourse that leprosy is only a disease, it can be cured, there has been free and effective medication for leprosy, that it can be contagious if people are late in treatment or refuse it, and that even then transmission takes time. Through the course of this research, I reflectively concluded that leprosy itself, the disease, is not the problem. The problem is the stigma attached to leprosy.

Stigma, as I learned from people affected by leprosy, is marked by 'worry, shame, fear, discrimination, rejection, isolation, and labelling or being labelled'. Because of these stigmas, they became passive, staying at home, waiting for someone, keeping silent, and eventually losing their rights to talk and participate at school, work and business, losing rights to interact with others, to have friends and to marry. I increasingly understood that what people affected by leprosy experienced was similar to my experience when I dealt with my blindness. My illness, retinitis pigmentosa, was not my problem at that time, my problem was the stigma that was attached to blindness. My direct questions were: What is stigma and how can I reduce it? And why do people affected by leprosy take so long to reduce their stigma?

It's only through knowledge and awareness of rights that people can positively deal with stigma. Moreover, learning from stigma is a way to have a better life. Last but not least, people affected by stigma related to leprosy or other chronic and neglected diseases need peers with whom to talk and share. They need peers for taking action, not only giving advice. Family and community involvement is more helpful in reducing stigma. I thank my parents, brothers and sister who have supported me with their deepest love.

Conducting research and the counselling interventions, and writing papers, were my main job in the SARI Project. Working with the research team was a unique experience. Sometimes I could not join the discussion. A colleague would discuss in the group using non-verbal communication such
as nodding or pointing, and I would have to educate them by asking to verbally communicate what they had been discussing. Over time they became more aware, more attuned to my presence, they used verbal communication to involve me in discussions.

I believe my colleagues in the team learned by having me in the SARI Project. I too learned people's characteristics and styles through social interaction. This project that transported me to obtaining a PhD meant traversing was very diverse. I am proud to be part of this project, to have been able to contribute to enlivening human diversity.
Summary

Chapter 1 introduces this thesis. For many people affected by them, leprosy and leprosy-related stigma are huge and complex problems. Despite the availability of medication to cure leprosy, which has led to major achievements in its control and management, new leprosy cases are found every day in countries such as Indonesia. Leprosy and leprosy-related stigma limit the opportunities available to people affected in terms of education, employment, marriage and family life, health care, housing and even religion. It negatively influences their quality of life and, worse, as a result their rights are often not respected and even violated.

The concept of stigma has changed over time. In the past, it was seen as a physical attribute (Goffman, 1963). The current emphasis lies much more on stigma as a social process and thus goes beyond the individual body. To differentiate between different types of stigma, Weiss (2008) extended the Hidden Distress Model developed by Scambler (1998). He identified six types of stigma. There are three types in the so-called ‘stigmatizers’: accepted, endorsed and enacted. There are also three types in those who are stigmatized: anticipated, internalized and/or enacted. This thesis focuses on the types of stigma facing the ‘stigmatized’ (Jacoby, 1994; Scambler, 1998), including discrimination (or experienced stigma), anticipated (or perceived stigma which is the fear of being discriminated against) and internalized (or self-stigma which is the stigma people apply to themselves).

Decades of stigma research have been helpful in analysing the causes and the relations between them. Many factors contribute to leprosy-related stigma, and there are similarities but also variations across continents and communities. In each community, there is a complex mix of reasons why leprosy is a feared, shameful and stigmatizing disease. Some of the more common reasons that cause stigma are beliefs about the cause of leprosy, ideas that leprosy is a death sentence, fear of contagion, and disability and deformities.

What is needed to change the status quo and improve the quality of life of the persons affected, their family and the community? What is needed to reduce shame and increase their participation in social and economic life? Several options for reducing stigma have been described, but one of the most promising interventions is counselling. The purpose of the counselling is both to reduce stigma and 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. Several examples of counselling for reducing stigma can be found in the field of HIV/AIDS and mental health. But many questions remain. How to reach people affected by leprosy? How to deal with their characteristics? And, most importantly, how to develop and implement an intervention that is effective in creating a fuller and more fulfilling life? The overall aim of this thesis is to understand the conditions under which counselling is an effective intervention to reduce leprosy-related stigma.
In order to deal with the complexity of leprosy-related stigma, the theoretical framework used combines several approaches. The counselling developed in this study uses cognitive behavioural therapy (CBT) and is also knowledge-based, rights-based and low cost. Three types of counselling are identified in the counselling guideline written by the International Federation of Anti-Leprosy Associations: individual, family and group counselling (ILEP, 2011). Individual counselling takes place in a safe and private setting and can help individuals to understand and express their own thoughts and feelings about living with the condition. In family counselling the focus lies on family relationships and dynamics. Group counselling facilitates peer support and the sharing of personal stigma-related issues, and members can support one another, for example, by discussing solutions to problems experienced.

This research is part of the Stigma Assessment and Reduction of Impact (SARI) project, which aimed to assess the effectiveness of three interventions to reduce stigma in people affected by leprosy. The project took place in Cirebon District in West Java Province of Indonesia. It was selected as the area of research and project implementation because it has a high number of new cases annually and according to local experts has a greater incidence of leprosy-related stigma than other districts. The transdisciplinary, Interactive Learning and Action (ILA) approach was applied to assess the effects of the counselling interventions on the social life of people affected by leprosy.

The main research question addressed in this thesis is: Under what conditions is counselling an effective approach to reduce leprosy-related stigma in Cirebon District, Indonesia?

Three study questions developed to answer this main research question are:

1. How is leprosy and leprosy-related stigma understood, experienced and dealt with by people affected by leprosy in Cirebon District, Indonesia?
   a. What meaning do people affected by leprosy give to their disease and the stigma attached to it?
   b. What aspects from the field of disability, personal knowledge and mind-sets of different actors involved might help in dealing with leprosy-related stigma through counselling?

The purpose of this first study question is to increase understanding of leprosy-related stigma in the study area by studying the perspectives of people affected by leprosy and other key persons including health service providers. These insights were to inform the counselling practice.

2. What are the characteristics of a counselling practice for clients affected by leprosy-related stigma in Cirebon District, Indonesia?

Although counselling is considered to be one of the most promising approaches to reducing stigma, it is not evident that it would be effective for people affected by leprosy-related stigma in
Cirebon District. The purpose of the second study question is to develop a counselling practice based on an understanding of the characteristics of the target group and their environment.

3. What is the impact of a rights-based counselling intervention on leprosy-related stigma in Cirebon District, Indonesia?

The purpose of the third study question is to assess as accurately as possible the varied impacts of counselling. Evidence is needed to inform policy-makers, scientists and society at large about the effects of the intervention and the possibilities for scaling up.

Chapter 2 presents how people – affected and not affected – give meaning to leprosy on a daily basis. This study involved people affected by leprosy and key informants such as health workers, community and religious leaders as well as families and teachers. Qualitative research was applied by drawing upon in-depth interviews with 53 participants and 20 focus group discussions (FGDs). The findings showed a variety of meanings and understandings. There is an overall lack of knowledge about the illness, its causes and how it is transmitted. The images and perceptions of leprosy give rise to fear. Several participants believed that leprosy is a highly infectious disease that can be transmitted by touching the same objects that have been touched by someone affected by leprosy. Hence, increasing knowledge about leprosy among people affected, community members and health workers remains an important goal for leprosy services, and although it is not the whole answer to stigma, it is an essential prerequisite.

Examples of anticipated, internalized and enacted stigma were found in the participants’ narratives. For example, in the reasons to discontinue school all three can be seen: i) embarrassed, ashamed and shy (internalized), ii) peers making fun of them and keeping their distance (enacted) and iii) fear of being insulted (anticipated). It was concluded that the experiences of persons affected by leprosy, those under treatment and those who have completed treatment and have been declared cured, are diverse and go well beyond leprosy as an infectious disease or medical issue. A majority of respondents related strongly to the prevailing stereotypes about the disease and the related social stigma and discrimination. This study showed that leprosy services, and in particular stigma-reduction interventions, should take into account the wide diversity of meanings and experiences of people affected by leprosy and key persons in the community.

Chapter 3 describes how people affected by leprosy and with disabilities deal with stigma. In this study I aimed to gain insight into the similarities and differences in experience between the two groups, highlighting the impact on emotions, thoughts, behaviour and relations. A qualitative approach was applied through in-depth interviews with seven persons affected by leprosy and seven with disabilities unrelated to leprosy, and three FGDs, one of which was with a mix of participants leprosy-affected persons and persons with disabilities.
The analysis shows that there are many similarities between the two groups in the impact of stigma in terms of emotions, thoughts, behaviour and relationships. The main difference is that those affected by leprosy tended to frame their situation in medical terms, while those living with disabilities described their situation from a more social perspective. In addition, most individuals responded by becoming passive and withdrawing from social relationships beyond the family, but some take a more active, positive stance that illustrated coping strategies. In conclusion, the similarities offer opportunities for interventions and the positive attitudes and behaviour can be modelled in the sense that both groups can learn and benefit. Research that tackles different aspects of stigma faced by people affected by leprosy and related impairments could lead to inclusive initiatives that help individuals to come to terms with the stigma and to advocate against exclusion and discrimination.

Chapter 4 charts the development of a counselling practice and module – the Rights-Based Counselling Model (RBCM) – in which stigmatized individuals are involved as lay and peer counsellors. An exploratory study including 53 interviews and five FGDs aimed to understand the characteristics of people affected by leprosy and the views of the community. Findings were used to develop a draft counselling practice, which was then piloted. Sixty-two clients and several family members received counselling during the pilot study. Notes of the counselling sessions were taken and evaluation meetings were held in order to make the module more appropriate, effective and sustainable.

The results of the exploratory and pilot study led to a counselling practice (see Box 1 below). The module integrated individual, family and group counselling. The provision of medical knowledge about leprosy played an important role in combatting stigma at different levels. Responding to views expressed during the pilot, the proposed module focuses less on feelings of stigmatization and more on taking action, including by raising awareness of rights. This showed that five counselling sessions can trigger clients to move from a seemingly hopeless situation to one where they could feel hopeful, take initiatives and experience less internalized stigma.
Box 1: Rights-Based Counselling Module

Key principles
1. Each client, whatever their condition, wants to change their life for the better and should decide what actions/solutions are needed to bring about this change.
2. Each client needs to be listened to, appreciated and acknowledged.
3. In a relaxed, though energetic, fun and joyful atmosphere, the client will be comfortable and more open and trust will come more easily and rapidly.
4. Medical knowledge about leprosy is a prerequisite for the rest of the counselling process.
5. Awareness of rights is the basis for developing confidence, making life changes and participating in society.

The 5C framework
The 5C framework describes five important counselling skills (confirmation, clarification, confrontation, compromise and commitment) and puts these skills in a certain order. In Bahasa Indonesia it is called the 5K framework -- Konfirmasi, Klarifikasi, Konfrontasi, Kompromi and Komitmen. These counselling skills are not new and have been discussed in the literature (Belkin, 1984; Egbochuku, 2010).

Confirmation: information and experiences shared by the client need to be confirmed and verified
Clarification: information from the client needs to be clarified to make it clear and understandable
Confrontation: a client should be challenged during a conversation to build knowledge, create rights awareness and to develop confidence; this helps create momentum for finding solutions and making change. The counsellor should confront clients during the counselling process with their own statements that have been confirmed and clarified earlier.
Compromise: clients should be encouraged to compromise, to see things from a different perspective and to acknowledge exceptions.
Commitment: clients should commit to an alternative solution and take action

Content of the five sessions

Session 1: Assessment of situation and trust building
Type of counselling: Individual counselling
Timing: 30-45 minutes
Content: Client and counsellor get to know each other (building trust); conversation about daily activities and happy things that occurred (repeated in sessions 2-3 and sometimes in 4); giving opportunity to the client to talk about any topic of interest (related to leprosy) and to confirm and clarify the information; dialogue about leprosy and sharing experience of stigma; discussing thoughts and feelings briefly.

Session 2: Knowledge, rights and dealing with stigma
Type of counselling: Individual counselling
Timing: 30-45 minutes
Content: Sharing medical knowledge on leprosy, the treatment and self-care; exploring the client’s expectations (of counselling), needs and demands; sharing about human rights, dialogue about dealing with stigma and ways to reduce stigma (using confrontation, compromise and commitment); discussion actions; preparing family counselling (expectation and planning).

Session 3: Knowledge and solutions in the family context
Type of counselling: family counselling
Timing: 30-45 minutes
Content: Discussions on daily activities; exploring and clarifying family worries and fears related to leprosy; reducing worries and fear with clarifying medical knowledge on leprosy, treatment and being cured; discussing the involvement of the client in the family roles and responsibilities; exploring how family members support each other’s; preparing group counselling (expectation and planning).

Session 4: Learning from each other and action
Type of counselling: group counselling
Group size: 4-6
Timing: 45-60 minutes
Content: Sharing personal experiences with leprosy and stigma, focusing on the challenges and success stories (counsellor focuses on raising awareness of rights); discuss group action (e.g. say hello to neighbours, go to the market, undertake household activities, talk about leprosy with family or community members); commitment to take action and support group members.

Session 5: Sharing and strengthening action
Type of counselling: group counselling
Group size: 4-6
Timing: 45-60 minutes
Content: Reflection on group action, discussion of both positive and negative aspects (using confrontation and compromise), strengthening action by enhancing self-confidence, stimulating taking initiative and commitment.

Chapter 5 describes the initial experiences based on the perspectives of the lay and peer counsellors and aims to provide lessons learnt for future initiatives. This study draws on the notes of seven monitoring and evaluation meetings and 21 group discussions the main researcher facilitated with the lay and peer counsellors and the notes written by both sets of counsellors.
The selection of lay and peer counsellors was based upon agreed criteria such as having completed junior high school and having a level of confidence. The peer counsellors have or previously had the same disease – leprosy – as the client. The lay counsellors are persons with or without disabilities and who do not have leprosy. In this study an effective lay or peer counsellor is characterized as a person who is confident to meet and communicate with clients and their families, is able to create a friendly atmosphere, has a positive attitude and has personal experience of the disease or has a connection with people affected by leprosy. The counsellors use active listening, showing empathy and trying to understand the client, and ask probing and reflective questions in their conversation. Effective counsellors also have knowledge about leprosy, disability and human rights, which they use to motivate and empower the clients to be self-confident. Before conducting counselling, the counsellors attended 56 hours of basic training on lay and peer counselling, followed by 12 hours of booster training to strengthen their capacity.

In total, 198 people affected by leprosy were offered counselling by the 11 lay and 12 peer counsellors, of which 145 accepted the offer. The other 53 either did not need counselling or did not want to participate, for example, due to worries about disclosure. Effective communication skills such as listening and asking effective questions were important, but also difficult to acquire. Sharing personal experiences was highly appreciated by clients and stimulated deeper reflection. The process of involving lay and peer counsellors in reducing leprosy-related stigma and its impact was challenging due to people’s wish to conceal their condition and the difficulty of developing effective counselling skills. Observing and analysing the different steps of the lay and peer counselling also showed the great potential of this approach, in particular the credibility generated by the knowledge and personal experiences that lay and even more so peer counsellors can share. We conclude that lay and peer counselling holds much promise as an effective and appropriate strategy for reducing leprosy-related stigma.

Chapter 6 aims to assess the impact of a counselling intervention (the RBCM) on reducing stigma in people affected by leprosy. The module involves lay and peer counsellors, combines three types of counselling and comprises five sessions as summarized above. Mixed methods (e.g. three scales, interviews, FGDs and reflection notes) were used to assess the impact of the intervention, which ran over two years. There was a control area with no interventions. The study participants were people affected by leprosy and other key persons (e.g. family members). The sample size differed by method. For example, data of 67 counselling clients and 57 controls from a cohort, and notes from 207 counselling clients were examined.

The notes showed that most clients faced internalized, anticipated and/or enacted stigma on a daily basis. A significant reduction was found between the before and after total scores of the SSS (p-value < 0.001), PSS (p-value < 0.001) and WHO-QOL BREF (p-value < 0.001) among the counselling clients. There is also an effect in the control group, but much less so than in the
intervention group. Qualitative data indicate that knowledge and rights are triggers for change. Clients took actions to change their life for the better such as reconnecting with neighbours, helping in household activities and applying for a job. Challenges include the wish to conceal their condition. The findings show that the counselling intervention is effective in reducing stigma, promoting the rights of people with leprosy and facilitating their participation in everyday life. More research is needed to create a more sustainable intervention, preferably embedded in the health or social services.

Chapter 7 reflects on the well-known phrase of M. Polanyi, ‘we can know more than we can tell’. This means that we all have and produce our own knowledge. This chapter describes the conscientization process among disabled and leprosy-affected research assistants (RAs) and lay counsellors in Cirebon District, Indonesia. Conscientization or critical consciousness refers here to the awakening of individuals regarding their personal and social situation, which stimulates individual and collective change. Qualitative methods comprised four written testimonies, 12 tape-recorded interviews and two FGDs.

The findings showed that disabled people and people affected by leprosy reflect the positions of many other social groups who occupy disadvantaged power positions. Their narratives recount how they are emboldened to say ‘we are here’ as holders and producers of knowledge. At that very moment, they are becoming aware of their personal knowledge. The main argument of this chapter is that although such people are not initially aware that they are holders of knowledge, interventions can create individual and collective awareness of the importance of their personal knowledge, involving a process of awakening. SARI provided a space for learning and teaching; intentionality was a key ingredient; various forms of knowledge interacted; personal experience was valued; and reflecting, creating new knowledge and sharing/interacting with others became possible.

Chapter 8 discusses the different mind-sets of the stakeholders of the SARI project, focusing on the key activities during its first three phases. The exploration and analysis of these activities are based on qualitative data. Data were collected using a variety of research methods between July 2010 and January 2012: notes were taken of informal interviews and discussions; there were numerous meetings of the SARI team; and there were also workshops with health workers. The RAs also wrote their personal reflections. Finally, interviews and FGDs of the in-depth phase were analysed, and facilitated a better understanding of constraints and new plans.

The project was able to identify differences in aspirations, attitudes to scientific validity and ethics of research, expectations in terms of interventions and timing, as well as conflicting intrinsic models of disability and diverse attitudes to people affected by leprosy. Although these differences represented a challenge to the project, making them explicit meant it could deal with them and that it did not reproduce attitudes and approaches to leprosy and disability that would have undermined its objectives. Indeed, these differences are not symptoms of failure but, rather,
should be actively sought out and investigated. This approach is radically different from the practice of seeking to ignore or suppress divergence.

**Chapter 9** Several scholars have highlighted the promising potential of counselling in reducing stigma. The thesis shows that counselling is indeed effective, and more importantly, under what conditions it is effective. In Chapter 1, I suggested that CBT-based, knowledge-based, rights-based and low-cost counselling could be effective, and included three types of counselling. These approaches turned out to be very effective and especially when they were integrated with each other. During the process, different dilemmas emerged relating to the number of sessions, location of the counselling and counselling style, and these needed to be addressed. This thesis demonstrates that the different approaches should not be dealt with separately but in an integrated fashion.

In Chapter 1 the shifts from a medical model towards a social model and from the charity approach to a human rights framework are described. This thesis shows the importance of these shifts and the thesis can be seen as an exercise to facilitate and embed them in people’s daily realities. Although this thesis makes an important contribution to advocating a more social model towards disability and for a human rights framework, the fight is far from over.
Acknowledgements

This thesis is part of the Stigma Assessment and Reduction of Impact (SARI) project conducted in Cirebon District, Indonesia from 2010 to 2014. The project was facilitated by the Athena Institute, Faculty of Earth and Life Sciences, VU Amsterdam in collaboration with the Center of Disability Studies, Universitas Indonesia. The study was made possible thanks to generous funding from Netherlands Leprosy Relief (NLR), Sasakawa Memorial Health Foundation (SMHF), the American Leprosy Missions (ALM) and effect: hope.

First I would like to thank all the participants of this study for sharing their personal stories.

I thank my promoter and co-promoters, Professor Joske Bunders, Assistant Professor Marjolein Zweekhorst and Professor Irwanto. I also thank my other supervisors: Dr Wim van Brakel, Dr Beatriz Miranda-Galarza, Dr Eri Seda and Dr Rita Damayanti. I am deeply grateful to Ruth Peters and Dadun for undertaking the research and implementing the SARI Project interventions together with me and particularly for working with me in writing papers and reporting on the project’s results.

I am grateful to and wish to thank the reading committee for assessing my thesis.

Sincere gratitude is owed to the Ministry of health, Provincial Health Office and District Health Office for supporting this study, especially thank to Cirebon District Health Office for facilitating it.

I am grateful to the research assistants and administrators of the SARI project: Mujib, Siti, Oni, Christine, Hassan, Hadi, Rohman, Ulum, Harry, Solihin, Yando and Yanty. I would also like to share my appreciation to all lay and peer counsellors who have been willing to implement the Rights Based Counselling Module (RBCM) and were successful in reducing stigma in people affected by leprosy.

My profound appreciation and gratitude to all SARI partners, in particular NLR Jakarta, who have successful placed leprosy and disability topics on the research and academic agendas.

I also would like to thank Visio for providing financial support for editorial services and all the editors – Sarah Cummings, Deborah Eade, Divya Nadkarni, Mike Powell and Liesbeth van Oostenbrugge – for helping me to write this thesis.

Also a word of appreciation to Renske Voorn and all the students from the VU University, Amsterdam who spend their time on the SARI project.

I also thank the staff of Mimi Institute.

Loving thanks to my parents, Kuswandi Lusli and Yuliawati Lusli; my brothers Sukianto Lusli, Budiyanto Lusli and Wat Fu Giap; my sisters, Lusiana Lusli, Angel Manembo and Septiana Iskandar; my nephews, Hendri, Aldo and Tigro; my nieces, Katrin and Zsazsa; son of Katrin and
Stanley, Louis; and last but not least my fond appreciation for my daughters, Ranti and Agnes. They never grew tired of supporting me whenever I needed assistance.

Finally, as a blind author, from the bottom of my heart I thank you all. I appreciate the opportunity that you have given to me and that you kept your trust in me. I am proud to be part of the SARI team that has really promoted the inclusiveness of people with disabilities, whether or not related to leprosy. Through the SARI project, I have lived my dream and made it come true by achieving a PhD as a blind person. I hope this thesis offers a light to enable people to get a better life in a better place without facing stigma, discrimination and barriers but with access to love and care.

Thank you and God bless you all.