Chapter 1
Introduction
"I am not shy... so I don’t have leprosy, right?"
In October 2011, my colleagues and I were interviewing persons affected by leprosy in Cirebon District. One day, a man who was waiting to be interviewed asked me a question. In one sentence, he illustrated one of the major problems leprosy poses. This makes it an exceptional quote and I decided to use it in the title of this thesis. He asked the following: “I am not shy and I don’t have a low self-confidence, so I don’t have leprosy, right?” At first, the question confused me, because as far as we had been told he was affected by leprosy. Then I realized that he perceived shyness and a low self-confidence as symptoms of the disease rather than its potential negative consequences. He rationalized or perhaps hoped that if he did not have these symptoms of leprosy, he might not have the disease. The fact that shyness and a low self-confidence can be perceived as symptoms exemplifies the strong ties between leprosy and some of its negative consequences. These ties have been shaped and reshaped throughout history, but are still relevant today. Releasing these ties is one of the challenges. It would have been great if this man had been fully aware of his infection with Mycobacterium leprae and at the same time felt outgoing and confident. There were examples like this in 2011, but more often we heard distressing stories in which stigma played a major role.

The central themes of this thesis are the design, implementation and assessment of leprosy-related stigma-reduction interventions. Ultimately, I seek to understand the reduction of leprosy-related stigma to inform recommendations for future strategies and to further the body of knowledge on this subject. This chapter starts with a section in which I describe the importance of health-related stigma as a subject of study and argue that stigma is a violation of the human rights. I then introduce the stigmatized condition of interest in this thesis: leprosy. Then I highlight the opportunities and challenges in the field of stigma-reduction and introduce the main aim of this thesis. This chapter ends with an outline of the thesis. The research described in this thesis is part of the Stigma Assessment and Reduction of Impact (SARI) project that ran from 2010 to 2015 in Cirebon District, Indonesia.

1.1 Why is health-related stigma an important subject of study?
Stigma plays a role in a diversity of diseases and conditions including tuberculosis, human immunodeficiency virus (HIV) / acquired immune deficiency syndrome (AIDS), mental illness, leprosy, cancer, disability, Buruli ulcer, lymphatic filariasis, onchocerciasis, leishmaniasis and Ebola (Stevelink et al. 2011; Rüsch et al. 2005; Christodoulou 2011; Somma et al. 2008; Corrigan et al. 2005; Person et al. 2009; Stienstra et al. 2002; Weiss 2008; Chapple et al. 2004; Fife & Wright 2000; Van Brakel & Miranda-Galarza 2013; Mak et al. 2006; Kinsman 2012). Some of these diseases and conditions are not very common. In 2014, 2,200 new Buruli ulcer cases were reported (WHO 2015) and due to a major outbreak in West Africa there were an estimated 26,864 Ebola cases
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(CDC 2015). Other diseases and conditions are widespread. Globally there are about one billion persons with a disability (WHO 2011b) and about 35 million infected by HIV/AIDS (UNAIDS 2013).

Many people with a stigmatized disease or condition are challenged in two ways. On the one hand, they experience the symptoms and impairments that result from the disease and – if any – the side-effects of treatment. On the other hand, they are challenged by the stereotypes and prejudices – from others and from themselves – that result from conceptions about the disease or condition. These stereotypes and prejudices are the underlying conditions for processes as discrimination, social exclusion and self-isolation. As a result, people affected by a stigmatized disease or condition have fewer opportunities to define their life in terms of education, employment, marriage, family life, religion, housing and health care than those who do not have a stigmatized condition living in similar conditions and with similar capabilities (Stevelink et al. 2011; Liefooghe et al. 1995; Rüsch et al. 2005; Livingston & Boyd 2010; Person et al. 2009; Van Brakel 2006).

Dishonouring someone’s dignity and inequality due to illness are violations of human rights. 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). The International Covenant on Economic, Social and Cultural Rights (ICESCR) is particularly relevant as it 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). As human beings we should promote and respect the rights and freedoms of the declaration and covenants and secure their universal and effective recognition and observance. This makes health-related stigma an imperative subject of study in particular if it is focused on finding ways to address it.

1.2 Leprosy

Leprosy is often seen as the archetype of a stigmatized health condition (Rafferty 2005; Van Brakel & Miranda-Galarza 2013). For centuries, leprosy has been a disease that evokes shame and disgust (Rafferty 2005; Jopling 1991). From the 17th to the 19th century, stigma against people affected by leprosy manifested itself in various forms, ranging from the use of artefacts such as a rattle to announce the arrival of a person affected, to the procession of those affected by leprosy to collect alms, to segregation in one of the thousands of leprosaria. Although manifestations, including social exclusion and discrimination, are now more subtle with less ostracism, stigma remains a reality for many people affected (Van Brakel et al. 2012). Before providing a detailed account of the current understanding of effects of stigma on people affected by leprosy, I will provide a global picture of the disease and introduce several medical aspects.
1.2.1 Global picture of leprosy

Despite major achievements in the control and management of leprosy, it remains an important public health issue. Over the last decades, efforts have focused on finding cases, curing the disease, controlling its spread, preventing impairments and rehabilitation. From a global perspective the results are impressive and commendable. In 1985, there were an estimated 12 million people with leprosy worldwide (Britton & Lockwood 2004). These numbers fell dramatically. An estimated 11 million people affected by leprosy were cured by Multidrug Therapy (MDT) and were removed from the registers (Britton & Lockwood 2004). In 2000, there were only 597,000 registered cases, but there were also 719,000 new cases (WHO 2002). Fortunately, the number of new cases detected also declined; there were 244,796 registered cases in 2009 and 215,656 in 2013 (WHO 2014). In 2013, India reported the highest number of new cases (126,913) followed by Brazil (31,044) and Indonesia (16,856). The World Health Organization (WHO) noted that 9.2% of the new cases were children, which, given the relatively long incubation period, indicates that the transmission of the disease is still active. In addition, WHO stated that of all new cases, 6.2% had grade-2 disabilities, meaning visible and often permanent impairments, at the time of diagnosis. This figure mirrors a late diagnosis. As a result, the disease continues to affect millions of people through the impairments and long-term consequences in large parts of Asia, Africa and Latin America.

1.2.2 Medical aspects

In this section, I address the main medical aspects of leprosy including the cause, diagnosis, classification and treatment. The disease leprosy is caused by *Mycobacterium leprae*. The leprosy bacillus was discovered in 1873 by the Norwegian physician Dr. Gerhard Armauer Hansen, at a when time leprosy was endemic in Norway and in Europe more widely. *Mycobacterium leprae* causes a chronic granulomatous infection of the skin and peripheral nerves. The mode of transmission of leprosy is not conclusively proven, but it is generally accepted that the principal route is from person-to-person via nasal droplets (Noordeen 1985). The period of incubation varies, but is on average believed to be between two and five years (Hastings 1994).

People affected by leprosy commonly go to a health centre with clinical features such as skin lesions, numbness, muscle weakness or an anaesthetic hand or foot (Walker & Lockwood 2006). Leprosy is diagnosed if a person has one or more of the following:

1. Care is needed with the interpretation of these numbers as they do not refer to prevalence or incidence. In addition, aspects as the completeness and reliability of the data play a role, as also described by Declercq (2009).
2. The WHO leprosy disability grading system grades leprosy patients according to disabilities of the eyes, hands and feet. Grade 0 indicates no anaesthesia, no visible deformity or damage in hands or feet, and no eye problem due to leprosy. Grade 1 indicates anaesthesia, but no visible deformity or damage in hands or feet and eye problems due to leprosy, but vision not severely affected as a result. Finally, grade 2 indicates visible deformity or damage and severe visual impairment (see also WHO 2009a).
definite loss of sensation in a pale (hypopigmented) or reddish skin patch; a thickened or enlarged peripheral nerve, with loss of sensation and/or weakness of the muscles supplied by that nerve; the presence of acid-fast bacilli in a slit-skin smear (WHO 2012a). There are two systems commonly used to classify leprosy patients. The Ridley-Jopling system (Ridley & Jopling 1966), which is based on histology, and a simple classification system described by WHO (2000). The latter classifies patients in one of two groups, paucibacillary and multibacillary leprosy. It distinguishes between the two by counting the number of skin lesions. If the person has five or fewer lesions, he or she is classified as paucibacillary, if there are more than five or if a positive skin smear is found, he or she is classified multibacillary.

Since the 1940s, leprosy has been treated with mono drug therapy. In the 1970s MDT was introduced. The WHO currently recommends 24 weeks of daily dapsone and four-weekly rifampicin for patients with the paucibacillary type of leprosy, and 48 weeks of daily dapsone and clofazimine and four-weekly rifampicin for patients with the multibacillary type (WHO 2000). Since 1995 MDT is provided free to persons affected in leprosy-endemic areas by WHO in conjunction with other organizations or companies such as Novartis (WHO 2005). Transmission of the disease to others is unlikely after MDT is started (WHO 2009b). A common side-effect of the medication is the temporary darkening of the skin due to the clofazimine component in 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. Besides MDT, other facets of the treatment are important including the treatment of complications, monitoring and treatment of nerve damage, management of reactions and neuritis, education of patients and prevention of disability (Britton & Lockwood 2004). Important complications of leprosy are immunological phenomena called leprosy reactions. Reversal leprosy reactions (also named Type 1) and erythema nodosum leprosum (ENL or Type 2 reactions) can occur during or after treatment and need to be treated with anti-inflammatory medication such as corticosteroids or thalidomide (Kahawita et al. 2008). A person affected by leprosy with an anaesthetic hand or foot needs to use special protective measures (e.g. footwear) and daily practice self-care (e.g. inspection) so that damage can be diminished (Britton & Lockwood 2004). Reconstructive surgery may be appropriate for contractures of hands and feet and to take care of a foot drop. The impact of the disease leprosy, however, goes beyond the medical implications.

1.2.3 The impact of leprosy-related stigma
Persons affected by leprosy are also challenged by the stereotypes and prejudices that result from conceptions about the disease or condition. The impact of leprosy-related stigma varies between individuals and ranges from minor implications to quite devastating consequences. The concept of stigma captures the processes at stake. A more theoretical account of this concept is given in the next chapter. Since I aim to clarify the
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impact of leprosy-related stigma here, it is important to underline that stigma is a social process that results from experience, perception or reasonable anticipation of adverse conceptions about leprosy and that it can take different forms. Processes within a person (e.g. internalization) and in relation to others (e.g. social exclusion, discrimination) are important.

Internal versus external processes
The processes of interest are quite complicated, but it is helpful to recognize that there are two aspects. On the one hand, people affected by leprosy might, for example, feel that they are worth less than others and exclude themselves from social life due to adverse conceptions about the disease. On the other hand, family members or community members might find people affected by leprosy are worth less than others and keep their distance due to adverse conceptions about the disease. The labels given to these experiences are the same. Feeling less worthy or being regarded as less worthy is also called devaluation (sometimes called status loss) and excluding oneself or being excluded is called exclusion (sometimes referred to as isolation). Obviously, there is an important interaction between these aspects. The dynamics of both sides have been studied in depth, for example, in a study of Heijnders in Nepal (2004b). This study found that some people affected by leprosy withdrew themselves from social life and, for instance, went to the fields in the early morning, worked outside the village or stayed near the house to avoid interaction with others. Some also withdrew from some aspects of family life and decided to sit, eat and sleep alone. In contrast, other persons affected in the same study were asked by family members to eat and sleep separately and were threatened by community members with expulsion from the village or had already been expelled. The study of Heijnders thus clearly illustrates the existence and dynamics of these two aspects.

Impact on key aspects of life
Feeling less worthy or regarded by others as less worthy, excluding oneself or being excluded by others are only two examples. There are also other processes such as rejection, blame and discrimination. All these processes together result in fewer opportunities to define life in terms of education, employment, marriage, family life, religion, housing and health care. Studies have shown that leprosy may jeopardize a person’s marriage prospects but can also affect existing marriages, for instance, through divorce (Van Brakel et al. 2012; Schuller & Brakel 2010; Try 2006; Vlassoff et al. 1996; Raju & Reddy 1995; Nicholls et al. 2003). Although evidence is scarce, children affected by leprosy have been reported to have been refused entry in schools (Nicholls et al. 2003). Work and employment are other areas that may be adversely affected (Calcraft 2006b; Stevelink et al. 2011; Rao et al. 2008). People affected by leprosy may be fired, not be employed in the first place or, if they are running their own business, lose their customers (Van Brakel & Miranda-Galarza 2013). Finally, Rao et al. found that some people affected by leprosy were not allowed to participate in religious activities (Rao et al. 2008). Not surprisingly, leprosy and leprosy-related stigma have been shown to result in a high
burden of emotional stress, anxiety and depression (Van Brakel 2006; Tsutsumi et al. 2004; Weiss et al. 1992; Tsutsumi et al. 2007; Leekassa et al. 2004). In addition, suicide, attempted suicide or suicidal thoughts are mentioned in studies (Nishida et al. 2006; Behere 1981; Leekassa et al. 2004). The study by Leekassa et al. in Ethiopia found that suicidal ideation was three times higher in leprosy patients compared to non-leprosy patients (Leekassa et al. 2004). Thus, leprosy-related stigma evidently affects in many aspects of life and has a major psychosocial impact.

Coping strategies: concealment
One important coping strategy is concealment. Studies have reported that people affected by leprosy often try to conceal their disease to prevent negative attitudes and behaviours from others (Heijnders 2004b; Kaur & Ramesh 1994; Vlassoff et al. 1996). Concealment is possible when the symptoms and possible impairments can be hidden. In Nepal, concealment strategies were avoiding attention, attending health centres far away from home to avoid being recognized, distraction by telling “stories” and moving temporarily to another village or city (Heijnders 2004b; Pearson 1988). Heijnders (2004a) had the impression that some not only concealed their disease, but also began believing that they had, for instance, a minor skin disease. Although, concealment might prevent negative responses from others, it frequently poses an additional burden on the person affected (Pachankis 2007). People’s desire to conceal the disease, the measures they take to achieve this and the burden they accept reflect in a way the importance of the negative social affects. Often, concealment is not possible or not achieved and feelings, attitudes and behaviours remain unchanged. Consequently, the negative impacts also endure.

Contributing factors
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. Impacts can also be temporal and are situation specific (Heijnders 2004b; Staples 2011a). Leprosy-related impairments have been shown to be associated with increased risk of being stigmatized (Van Brakel et al. 2012; Heijnders 2004a), participation restrictions (Boku et al. 2010) increased mental distress and depression (Leekassa et al. 2004; Tsutsumi et al. 2004) and poorer quality of life (Tsutsumi et al. 2007) compared to persons affected by leprosy without impairments. Several studies describe the experiences of women affected by leprosy in Brazil, Nigeria, India, Indonesia and Nepal and many indicate that women are worse off than men (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 & Reddy 1995). For instance, in Indonesia, women affected by leprosy disproportionately experience separation and divorce compared to men (Van

3. Described by Heijnders (2004b) who refers to Hyland (1993) as “saying something and not saying what (it is) wished to keep secret” (page 438).
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Brakel et al. 2012) and in Nepal, women have poorer chances than men of remarriage after divorce (Try 2006). In addition, the social status of the person affected also influences stigma. In Nepal, for some people who have a higher social status the impact of stigma was less than for those of a lower status (Heijnders 2004b). Likewise, in Sierra Leone persons in positions of authority who were affected by leprosy managed to retain these positions (Opala & Boillot 1996). Age was another influencing factor in the study of Nepal as persons aged over 50 years who were affected by leprosy were more often sent out their villages compared to those below 15 years of age, who received a great deal of support (Heijnders 2004b).

Impact goes beyond the person affected

The impact of leprosy-related stigma goes beyond the individuals directly affected by the disease. People associated with such a person, for instance, family members and friends, might also be stigmatized. This is called courtesy stigma (Goffman 1963). Studies have shown that family and friends risk social and economic loss (Barrett 2005). Others studies have found that the marriage prospects of a relative of a person affected by leprosy can decline (Van Brakel et al. 2012; Schuller & Brakel 2010; Try 2006). As a result, affected persons might decide to protect the family and isolate themselves or take an even more drastic measure and leave their family (Kaur & van Brakel 2002; Try 2006). Courtesy stigma can also be a reason for concealing leprosy (Try 2006). Thus, leprosy-related stigma does not only pose challenges for people affected, but also for people associated with the disease, which subsequently has a negative influence on the person affected.

Impact on diagnosis, treatment and management of the disease

Leprosy-related stigma can affect the diagnosis, treatment and management of the disease as summarized by Brown (2006). Some studies have shown that people affected by leprosy perceived medication as a way of preventing their disease becoming worse and more visible, thereby preventing further stigmatization (Heijnders 2004a). In contrast, others studies have shown that stigma can result in denial, delayed presentation of symptoms and in refusal or discontinuation of treatment (Nicholls et al. 2003; Heijnders 2004a; van de Weg et al. 1988; Barrett 2005). People affected may also go to health facilities far from their home (Pearson 1988), which increases out-of-pocket expenses and may influence adherence. The common misconceptions and sometimes poor attitudes towards leprosy among health professionals identified in China, Guyana, Nigeria and Paraguay (Nicholls et al. 2003; Awofeso 1992; Briden & Maguire 2003; Chen et al. 2004; Iyor 2005) contribute to this situation. A delayed diagnosis and non-compliance are important, firstly because it increases the risk of nerve damage and disability which in turn can increase negative social consequences as shown earlier. Secondly, a delayed diagnosis prolongs the risk of transmission, which negatively affects the control and management of the disease in general and might lead to an increase in new infections.
1.3 Opportunities and challenges in the field of stigma reduction

The above clearly shows that leprosy-related stigma is still a major problem. Not surprisingly, for many people affected by leprosy, stigma is the hardest part of the burden (Rafferty 2005; Barrett 2005). There is a growing awareness among health professionals and researchers of the importance of stigma-reduction interventions. Cross et al. wrote:

Where stigma is an effect of disease, the treatment of that disease is incomplete if stigma is not addressed. Interventions to address stigma should not be considered optional; they are essential. (Cross et al. 2011a:63)

Despite the fact that research has increased insight in the causes and impact of stigma, it has only recently begun to focus on stigma reduction (Heijnders & van der Meij 2006; Brown et al. 2003). Van Brakel and Miranda-Galarza noted:

With a few notable exceptions, stigma reduction has not been a focus of leprosy control programmes. It deserves much more strategic attention. (Van Brakel & Miranda-Galarza 2013:149)

Research has been undertaken on stigma reduction in the field of mental health and HIV/AIDS (Brown et al. 2003; Corrigan 2012; Thornicroft et al. 2008) and some studies have focused on leprosy. Most strategies are derived from or combined with education. As in other fields, the effect of education alone on stigma is subject to discussion (Heijnders & van der Meij 2006). Some studies show positive effects of education on reducing leprosy-related stigma (Croft & Croft 1999; van den Broek et al. 1998), but in general, the effects are seriously questioned (Cross et al. 2011a; Brown 2006). The failure of leprosy education in Sierra Leona aimed at achieving attitudinal and behavioural change at the community level is described in detail by Opala and Boillot (1996). Raju and Kopparty (1995) also concluded that a high level of knowledge does not necessary generate positive attitudes and state that knowledge is only one of the determinants – and not a very strong one – of positive attitudes. Besides education, several other strategies have been adopted to reduce leprosy-related stigma, for instance, group counselling in Nepal (Floyd-Richard & Gurung 2000), Community-Based Rehabilitation (CBR) in India (Gershon & Srinivasan 1992), a mix of community-based approaches in India (Raju et al. 2008), self-care groups in Ethiopia (Benbow & Tamiru 2001) and socio-economic development in Nigeria and Nepal (Cross & Choudhary 2005b; Ebenso et al. 2007).

1.3.1 Three promising stigma-reduction interventions

From all these stigma-reduction interventions, three are described as very promising (Heijnders & van der Meij 2006; Brown et al. 2003; Thornicroft et al. 2008). The first is counselling. 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). The second is contact. Contact refers to “all interaction between the public and persons affected, with the specific objective to reduce stigmatizing attitudes” (Heijnders & van der Meij 2006:359). The rationale – which originally comes from the field of social psychology – is that a more personal relationship through direct or indirect contact will demystify and discharge incorrect information, invalidate stereotypes and generate empathy, which in turn reduces stigma and prejudice (Brown et al. 2003; Allport 1954; Brewer & Miller 1984; Dalal 2006). Several studies in the field of mental health and HIV/AIDS showed promise regarding the contact intervention with approaches varying between video (indirect tool), presentations and training given by persons with a mental illness (direct tool) (Brown et al. 2010; Link & Cullen 1986; Corrigan & Penn 1999; Penn et al. 2003; Kerby et al. 2008; Brown et al. 2003). This intervention has to our knowledge not been tested in the field of leprosy. The third is Socio-Economic Development (SED). The value and challenges of socio-economic interventions such as micro-credit for poverty alleviation have been well documented (see among others Chowdhury 2005; Mahmud 2003). The potential of such an intervention for people affected by leprosy has been described in two studies. A pilot study in India indicated that socio-economic development may be an effective strategy to reduce leprosy-related stigma (Rensen et al. 2010). Likewise, Ebenso et al. (2007) argued that socio-economic rehabilitation interventions are needed to increase people’s dignity and to help them regain their social position as useful, self-supporting members of the community based on their findings in Nigeria. These three interventions are tested in the SARI project. In this thesis, I focus on the counselling and contact intervention and less so on the SED intervention.

1.3.2 Challenges in the design, implementation and assessment

The three interventions strategies that were to be assessed in the SARI project were clear from the start of the project. However, aspects related to the content of the interventions (what type of counselling? direct or indirect tools to establish contact?), the implementation (by whom? where? when? how often?) and the assessment (which instruments and methods?) were deliberately left open. During the SARI project the interventions needed to be designed, implemented and assessed. This process is not straightforward. 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. Target groups and communities should not only be involved in the design of interventions, but also in their implementation. Involving people affected by leprosy in the implementation of services is encouraged by WHO (2011a) and by the temporary expert group on this topic from the International Federation of Anti-Leprosy Associations (ILEP). Participation is not always easy to realize, in particular for people affected by leprosy issues of concealment and low self-esteem might hamper participation. Finally,
assessing the effectiveness of stigma-reduction interventions is challenging (Cross et al. 2011a). The evaluation depends on having a good set of measures that can effectively capture the complexities of stigma, assess a change in the level of stigma over time and generalize from a sample to a population. There are several instruments – and the number is increasing – that claim to assess aspects of stigma quantitatively (Van Brakel 2006). The cross-cultural validation of such instruments is a crucial process, because unreliable and invalid instruments can lead to imprecise or biased results and hence wrong conclusions. The number of qualitative methods to assess stigma mentioned in this review of Van Brakel is low. Nyblade (2006) in her review calls for measures that can capture the complexity of stigma.

In response to the analysis of the opportunities and challenges in the field of stigma reduction the overall aim of this thesis is to enhance the understanding of leprosy-related stigma and assess the effect of stigma-reduction interventions. This understanding will both inform recommendations for appropriate (addressing the needs and strengths of people), effective and sustainable stigma-reduction strategies, and also further the body of knowledge on stigma-reduction in general.

1.4 Outline of this thesis

In the previous section, I have described the importance of health-related stigma, in particular its relevance to leprosy and introduced the main opportunities and challenges related to stigma-reduction interventions. In Chapter 2, I elaborate on conceptualizations of stigma that are relevant for this thesis. In Chapter 3, I present the research questions and describe the research design.

Part 1 is concerned with the design of leprosy-related stigma-reduction interventions. Chapter 4 provides insights into the experiences of persons affected by leprosy and the meaning they and key persons give to leprosy, highlighting aspects of aetiology, spirituality, religion, darkening of the skin and sorcery. Chapter 5 the focuses on the experiences of women affected by leprosy, taking into consideration whether they concealed or disclosed their status, and by looking specifically at their agency. Chapter 6 reports the analyses the start of the SARI project and focuses on the different mindsets that emerged between or within scientific and social stakeholders on key concepts including disability, stigma and research. The importance of establishing meaningful relationships is highlighted.

Part 2 focuses on the implementation and assessment of the newly designed stigma-reduction interventions. Chapter 7 portrays the initial experiences with counselling as a stigma-reduction approach based on the perspectives of the lay and peer counsellors. Chapter 8 provides insights into another stigma-reduction strategy: participatory video. It centres on the impact of participatory video on the video makers and increases understanding on how to deal with foreseeable difficulties. Chapter 9 describes the cross-cultural validation of two instruments to assess aspects of social stigma.
Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CSS) and Social Distance Scale (SDS). In Chapter 10, the effectiveness of the contact intervention is assessed. In this intervention, testimonies were given and participatory videos and comics made by people affected by leprosy were used as methods to establish a dialogue with the audience.

Part 3 provides the discussion, conclusions and reflections. In Chapter 11, I will draw the final conclusions regarding the design, implementation and assessment of stigma-reduction interventions. The implications of the findings presented in this thesis are discussed and placed in a broader context. Two epilogues will conclude this thesis. In the first, I reflect on my own positionality in this transdisciplinary study. I share several realizations about the path I have travelled, which I believe could be relevant for others. In the second epilogue, I reflect on the following question: is it time to retire the concept of stigma?