Chapter 11
Discussion and conclusions
“I am not shy... so I don’t have leprosy, right?”
This chapter presents the conclusions of my research, which was guided by the following main research question: How can leprosy-related stigma be understood and addressed in an appropriate, effective and sustainable manner and the body of knowledge on stigma reduction be advanced? To answer this question, this thesis first focused on understanding leprosy and the experiences of people affected by the disease and on the beliefs and attitudes of people in the community where the live. Specific attention was paid to women affected by leprosy, their experiences of concealment and how they employ agency. In addition, the study explored the mindsets of scientific and social stakeholders who met from the start of the study and co-operated in addressing the complex and persistent problem of stigma. By making mindsets explicit this study sought to increase insights into how to deal with the differences that could potentially lead to problems. Part 2 was concerned with the implementation and assessment of stigma-reduction interventions. Insights were gained from the implementation of the counselling intervention in which lay and peer counsellors were involved. Next, the impact of making the participatory videos on the film makers affected by leprosy was analysed. To assess the effect of the contact intervention, two instruments to assess public stigma were validated. Finally, the impact of the contact intervention was described.

In this chapter I first summarize the findings and conclusions by sub-question and reflect on their contribution to the main research question. This is followed by the overall conclusion of this thesis. Next, I discuss the considerations regarding the methodological approach, validity and ethics. The chapter concludes with suggestions for future research.

11.1 Summary of findings and conclusions

How is leprosy understood and what are the experiences with leprosy of persons affected and not affected by the disease in Cirebon District, Indonesia?

Chapters 4 and 5 and sections from Chapter 8 and 10 set the scene by giving a broad perspective on how leprosy is understood by various actors and on their experiences of the disease in Cirebon District. Leprosy is understood in different and sometimes contradictory ways by the research participants. Not only do different groups vary in how they perceive leprosy, but there are also important intra-group differences. Research participants in these studies generally agreed on the following: leprosy is a skin disease, it is curable, and impairments play an important role. In other aspects perceptions varied. Health workers in general knew that leprosy is caused by a mycobacterium, but ideas about its aetiology of the remaining participants varied greatly. These ideas ranged from biological (e.g. bacteria) to environmental (e.g. hygiene) to supernatural (e.g. witchcraft). Ideas on the contagiousness of leprosy also diverged among participants, ranging from not at all to very contagious (Chapter 4). On several occasions, participants mentioned shaking hands and touching personal objects as routes of transmission. More value-laden associations with the disease also differed (Chapter 4). Some believed that leprosy is very frightening and disgusting, most believe it is
worrisome disease that evokes fear and which makes people feel uncomfortable, in contrast to some others who said it just like any other disease and not frightening. These understandings influence the experiences with leprosy. Those who believe that the disease is very contagious may distance themselves from a person affected, and someone affected who shares the same understanding might also take distance from his or her children to prevent transmission. Hence, understanding the spectrum of perceptions and associations with the disease is important for understanding experiences.

The experiences of persons affected with leprosy can be categorized as intrapersonal (in relation to oneself) or interpersonal (in relation to others), which corresponds to the two levels of Heijnders and van der Meij (2006). At the intrapersonal level, persons affected by leprosy can experience courage and acceptance but also sadness, shame and fears about what is happening and might happen. These conflicting feelings and emotions affect the relationship with others. Some spouses, parents, family members, community members and health professionals provided care and support to persons affected by leprosy (Chapter 5). In the same spirit, community members talked about the importance of inclusion, rights and dignity in the context of leprosy (Chapter 10). But there are also many stories of exclusion and discrimination. In particular, the accounts of children affected leaving school, adults losing their job or business and elderly persons who were abandoned illustrate the severe negative social impact that leprosy can have. The darkening of the skin (side effect of MDT) and even more so physical impairments can intensify these negative experiences. In turn, interpersonal experiences influence those at the intrapersonal level.

The experiences described may be experienced and relevant for some persons but not for others, but also different and opposing experiences can be present simultaneously. For instance, a young girl affected by leprosy might be loved and cared for by her grandfather, while her siblings might try to separate eating utensils, something the grandfather rejects and tries to discourage. For some, the negative impact of the disease declines over time, while others – also those without impairments or visible signs – may continue to suffer long after having been declared cured. In addition, the impact of the disease on the person affected and the attitudes of those not affected intersect with other aspects of a person’s identity (e.g. sex, age or socio-economic status). Taken as a whole, the understandings and experiences of leprosy are complex and sometimes contradictory and it is important to appreciate this complexity.

Existing theories of stigma have been helpful in understanding the negative social and psychological experiences and processes facing people affected by leprosy as a result of their disease. Various scholarly theories have helped, for example, to unravel and typify the experiences (Weiss et al. 2006; Bos et al. 2013), categorize the causes (Rafferty 2005; Sermrittirong & van Brakel 2014) and expose the process from labelling to discrimination (Link & Phelan 2001). While peoples’ experiences of stigma and its consequences might be remarkably similar for different health conditions and across
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cultures and countries (Van Brakel 2006), individual understandings and experiences – as also argued by Staples (2011a) and Yang et al. (2007) – differ vastly. Three themes in stigma theory lack sufficient attention: concealment, capacity to act and contradictory experiences. This thesis tries to address this gap.

The concept of concealment helped to deepen the level of enquiry in this thesis. Concealment is a direct effect of the anticipation of stigma. Disclosure may be involuntary, for instance, when health professionals share the information with others without consent. Interestingly, also concealment can be involuntary, for instance, when family members impose to conceal the illness. The extent to which the illness is concealed varied in this study. Findings indicated that most often significant others knew, but some women affected did not inform anybody or only one to three others (Chapter 5). Disclosure creates the opportunity for positive experiences such as care, but also might result in negative experiences such as rejection and discrimination. Concealment prevents both, but the concealment needs to be managed and the burden is then carried alone. Furthermore, how people act as a result of leprosy and stigma (what people do for and by themselves) was an important concept in the analysis of women (Chapter 5). Both openly acting against existing power structures and focusing on things to achieve were important for the women in this study. We identified three sources of agency: spirituality or religion, relationships and goal or hope of being cured. Finally, the findings in this study also encouraged me to study differing experiences to stigma such as care, inclusion and participation and their reassuring consequences. The current stigma theories focus on negative social and psychological processes. This can be a perfectly valid and helpful perspective, but the risk is that we look only through these lenses. If we fail to look through different lenses we miss out on a wealth of other social and psychological experiences of leprosy that are perhaps replicable and could provide a basis for reducing stigma.

I conclude this section by describing the contributions to the main research question. The exploratory study, from which most of these findings were drawn, proved a useful exercise as it enabled us to map out insights that are relevant for the design, implementation and assessment of stigma. The negative experiences illustrate the relevance and importance of stigma-reduction interventions. Given the vast diversity of experiences it may be safely assumed that no one intervention can address all needs and that multi-level and multi-faceted approaches are needed. In addition, the misconceptions about the disease can foster stigma, which means that knowledge needs to be an integral element of stigma-reduction interventions. Further, given that many people affected by leprosy wish to conceal their illness, interventions need to be tailored in such a way these people can also benefit from them. Finally, a strengths-based approach in which positive understandings and experiences (such as care, love and compassion) are at the basis of breaking down stereotypes seems to be an important yet relatively unexplored way forward.
How are different mindsets influencing the execution of a transdisciplinary stigma-reduction project?

The SARI project is an example of transdisciplinary research and thus from the start scientific and social stakeholders such as the SARI team, staff from a national DPO, health professionals from the CHC and persons affected by leprosy met and co-operated to address the complex and persistent problem of stigma. The study in Chapter 6 was concerned with the analyses of different stakeholders’ mindsets that would also be involved during the implementation of the interventions. The mindsets of these stakeholders differed on the nature of research, participation, leprosy, stigma, disability and sustainability. More specifically, the study was able to identify differences in 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. Differentiation was identified not only between groups of stakeholders (for example between the SARI team and the DPO), but also within groups of stakeholders (such as among SARI team members or among health professionals).

Mindsets of stakeholders were at times on opposite ends of the spectrum, which created resistance. Stakeholders’ stigmatizing behaviour towards leprosy was infrequent but had a major impact (e.g. health professionals who are not willing to shake hands with persons affected by leprosy) as it undermined the objectives of the SARI project.

Divergence is desired and intentionally sought in transdisciplinary research, but can also lead to serious challenges in, for example, decisions regarding the study design, timing and approaches. By making mindsets explicit this study tried to increase insights into how to deal with the differences that could potentially lead to problems. Occasionally, the way forward was the discontinuation of the stakeholder’s involvement or continuation in a different form. More often, it emerged that the acknowledgement of power dynamics was important and meaningful relationships needed to be established which took time, flexibility and inclination of the people involved.

A transdisciplinary approach is expected to be also beneficial in other settings and for other objectives in the future. Projects that adopt a transdisciplinary approach can through this analysis of mindsets become more aware from the outset of the anticipated nature and diversity of mindsets. The social and medical model of disability (Albert 2004; Oliver 2004; Barnes 1998) and diverging stigma theories such as described others (Link & Phelan 2001) proved helpful in understanding the reasons for the differences. This study encourages to perceive these differences not as symptoms of failure, but as opportunities for learning. It recommends actively seeking out and investigating mindsets. In addition, the experience of the SARI project shows that a new transdisciplinary stigma-reduction project needs to build in an awareness of power dynamics, the development of relationships within a team and with the stakeholders and establish appropriate structures for learning and reflection. If this is done, more appropriate stigma-reduction strategies can be developed, which can be implemented more efficiently. In addition, there is room for the co-creation of knowledge, which might further the body of knowledge on how to reduce stigma.
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What insights can be gained from the implementation of the leprosy-related stigma-reduction interventions in Cirebon District, Indonesia?

Chapters 7, 8 and 10 provided an analysis of the implementation of two stigma-reduction interventions: counselling and contact. The involvement of people affected by leprosy is one of the strengths of these interventions. As peer counsellors, people affected by leprosy felt a high level of responsibility towards their peers, were keen to share their newly acquired knowledge and were trusted by their clients. As video makers, some people affected by leprosy became aware of the issues leprosy poses in their communities and this increased their capacity to act. As those who testified about their lives, people affected by leprosy managed to touch the audience of the contact events by sharing their life stories. Although participation was overall a strength, it also generated some challenges. For instance, in the counselling intervention, peer counsellors were sometimes too keen to share their knowledge and experience, whereas listening is a more important counselling skill. In the participatory video workshops, some participants’ hand impairments posed challenges in operating the devices. The first insight is that the learning and action approach helped to promote the many strengths and deal with the challenges participation brings.

Findings from the exploratory study indicated the importance of concealment and accordingly the stigma-reduction interventions were designed taking this wish for concealment into consideration. During the implementation of the interventions the challenges brought by concealment became even clearer. For instance, women in the exploratory and baseline studies who concealed their illness mentioned sadness, shame and low self-esteem more frequently than women who disclosed their disease (Chapter 5). It was hypothesized that those who experience these negative emotions and feelings would particularly benefit from the counselling intervention. Lay and peer counsellors were trained in how to approach people affected with care and respect, on how to keep the illness secret from curious family members or neighbours, and were encouraged to choose a private and safe location for the counselling session. However, as described in Chapter 7, a worry about disclosure remained an important reason for people affected by leprosy to reject counselling. Hence, there was a discrepancy between some people’s needs and the intervention. Likewise, concealment raised challenges during the participatory video activity. It was anticipated that people affected by leprosy who wish to conceal their illness might not want to participate in making a video or that they would not want to appear on screen. In the end, many people affected by leprosy were keen to participate in the making of the video and also wanted their story to be told to the community, but screening in their own village was a step too far. The latter had major implications for distribution of the video, as described in detail in Chapter 9. The second insight is that concealment should receive more attention in the stigma-reduction field and leprosy services in general than it does currently.

Education was integrated in both the counselling and contact intervention. During the training of lay and peer counsellors, information about leprosy was provided. This was
important because sharing knowledge about leprosy with clients was an important task of the lay and peer counsellors in this study. Clients valued this information. In the participatory video workshop sharing knowledge was important. Participants shared information among each other and also the final videos have education elements. The latter means that people affected by leprosy believed it was important to share this knowledge with the community. Knowledge was well retained after the contact events where the videos were broadcasted and additional information about leprosy was provided. The third insight is that education is an important element and perhaps even a prerequisite of stigma-reduction.

Finally, the implementation of the interventions required well skilled facilitators. The SARI project RAs were the main implementers and were involved in all three interventions. Skills relevant for one intervention generated added value in the other interventions. If, for example, a participatory video participant dealt with internalized stigma and needed someone to talk to, the RAs who were also trained as lay counsellors could easily provide this. If a counselling client needed some advice on starting a business, the RAs who were also trained in providing micro-credit were able to offer this. Sometimes, though, the issue went beyond the implementation of the stigma-reduction intervention. For instance, a counselling client who had dropped out of school because of her disease decided she wanted to go back to school and requested assistance from her lay counsellor. Also, a community member was diagnosed with leprosy after attending a contact event and had to pay for the medical check-up and leprosy medication, although she was told in a contact event that these services are provided free of charge. Complaints about this payment were made to the RA who had to deal with this. The range of skills the RAs developed throughout the implementation of the intervention has been important for the successful implementation of the interventions. The fourth insight is that skilled facilitators are needed for the implementation of stigma-reduction interventions.

Analysing the implementation of the intervention in greater depth proved to be a useful exercise as it enabled us to gain insights both for future stigma-reduction strategies and for stigma-reduction theory. The insights highlighted here are of immediate value for national governments and others who determine the leprosy control strategies and decide on stigma-reduction interventions. As described in Chapter 2, stigma theories are useful only to a limited extent for the design of stigma-reduction interventions. Based on this thesis I conclude that participation, concealment, education and facilitation skills are important features of such a theory.

What is the cultural validity of the SDS and EMIC-CSS in Cirebon District, Indonesia? Stigma-reduction interventions also need to be evaluated, because in the end we want to know whether they are effective. For this we needed valid instruments. Chapter 9 described the study that was concerned with the cultural validation of two instruments to assess social stigma: the SDS and the EMIC-CSS. The findings demonstrated that,
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according to current international standards, the SDS and the EMIC-CSS have adequate validity to assess social stigma of leprosy in the Bahasa Indonesia-speaking population in Cirebon District. To determine more precisely the extent to which the instruments are valuable for this study it is important to consider the measurement aim. Three different aims can be identified: evaluative, discriminative and predictive (Terwee 2007). For the purposes of this study, the aim of the SDS and EMIC-CSS is to assess the effect of the stigma-reduction interventions. For this reason the instrument has to be sensitive to changes over time. Hence, the properties for evaluative purposes need to be adequate. This requires a small measurement error, in order to distinguish clinically important changes from measurement error (De Vet et al., 2006). The SDC at group level of the EMIC-CSS was 0.81 (on a score range of 30) and of the SDS it was 0.61 (on a score range of 21). This means that relatively small changes can be detected and distinguished from measurement error.

This is promising, but there were also two important reflections. First, despite the validity of the current instruments, several suggestions for improvements were given. This demonstrates that the scale development work does not stop once an instrument is declared to have adequate validity. Second, data collection can create discomfort or concerns among the interviewees and this needs to be prevented or addressed, for example, by a comprehensive training of the interviewers. Hence, continued effort needs to be put into the development of scales and their proper use. The advantage of scales with regard to generalizability is unique and essential in order to make recommendations for the replication and scaling up of stigma-reduction interventions.

The contribution of this study to the main research question is indirect. Tools such as the EMIC-CSS-CSS and SDS and reflections on their use have the potential to enhance understanding of how leprosy is socially constructed and experienced and whether interventions are effective in bringing about change. This is important for both stigma-reduction strategies and to further the body of knowledge on reducing stigma. In addition, the validation process can be an example for others who want to make use of the cultural equivalence framework and integrate quantitative and qualitative components.

What is the effect of a contact intervention on leprosy-related stigma in Cirebon District, Indonesia?

After designing the three stigma-reduction interventions and implementing them for two years in Cirebon District the impact of all interventions was assessed. For this thesis, I have focussed on one of the interventions – the contact intervention (Chapter 8 and 10). The primary aim of this intervention was to reduce stigma at the community level. A secondary aim was to empower people affected by leprosy through activities related to the intervention. These activities includes making videos and comics, providing testimonies and organising contact events. The contact intervention of the SARI project consisted of contact events in which an interactive presentation on leprosy was provided, a testimony was given, videos were broadcast and discussed and take-home comics
were distributed and discussed. The intervention was shown to be effective in increasing knowledge about leprosy and in changing negative attitudes towards leprosy to become more positive (Chapter 10). A large impact was seen in community members who attended the contact events. They were encouraged to share the messages of the event with others and about 80% indicated in the final survey that they had done this. Some did so quite profoundly, by disseminating the new acquired knowledge to 50 –100 community members. Some data on knowledge and attitudes was collected right after the contact events and some until 20 months after the event, indicating there is a longer term impact of the intervention. Although some findings suggested that the level of knowledge remained stable, while the change in attitudes reduced moderately over time. A few changes in behaviour due to the contact events were also reported. Overall, the contact intervention had a positive effect on several proxies of stigma, making it an effective and thus promising stigma-reduction intervention.

The intervention also had an effect on its secondary aim: the empowerment of people affected who were involved. Chapter 8 presents the analyses of the impact of the participatory video activity on the participants. It shows that participatory video provided different opportunities for the participants, who accordingly benefited in different ways. The diversity of impacts made it complex and difficult to pinpoint what exactly contributed to reducing stigma and for whom. This corresponds with the experience of Blazek and Hraňová (2012), who wrote “our experience shows that participatory video is an immensely complex activity because of the range of relationships and positionalities that various actors bring to the collaborative process” (page 164). In total, 11 factors were identified (e.g. having a good time, sense of togetherness, increased self-esteem) through which participatory video contributed to a reduction of stigma.

For this evaluation, the existing stigma and stigma-reduction theories were useful only to a certain extent. This study revealed important gaps in theory and sought to go some way to filling these gaps. The difficulty of assessing a concept such as stigma is one of these gaps mentioned by others (Cross et al. 2011a). Chapter 9 and also Chapter 10 illustrated how one can assess stigma and included reflections on the challenges. The assessment of the contact intervention is a very important exercise, because we need to know whether the carefully designed and implemented interventions are effective. Ultimately, we wish to estimate how effective they are, why they are effective and which elements can be replicated and scaled up elsewhere. This is aimed at providing clear and evidence-based recommendations to the different actors involved in the leprosy programme. The study described in this thesis has made some initial contributions by demonstrating that contact combined with education is effective and that the effect is large on the audience directly involved.

11.2 Overall conclusion
In the previous section, I have described how the answers of the sub-questions contribute to the answer of the main research question on how to understand and address stigma in an appropriate, effective and sustainable manner and advance the body of
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**knowledge on reducing stigma.** These sub-questions answered a substantial part of the main research question. Here I formulate my final conclusion. In addition, I complement the somewhat fragmented answers to the sub-questions with four insights that the study described in this thesis has contributed to answering the main research question. I close with describing why the complexity and persistency that makes stigma-reduction efforts difficult at the same time also creates opportunities.

I started this thesis by underlining the significance of health-related stigma in the field of public health and I concluded the discussion of the concept of stigma in Chapter 2 asserting that it is a complex and persistent problem. I then hypothesized that in order to reduce stigma it is important to understand stigma in the local context, to address its causes and to use multi-level and multi-faceted approaches to addressing it. As I come to the end of this thesis, I conclude that these four aspects are crucial for the design, implementation and assessment of leprosy-related stigma-reduction interventions, but also that the analysis of the context and the understanding of the complexity and persistency of stigma elucidate and specify the pathways that can be followed to reduce stigma. The process that facilitated this can be described as action research (as described in Chapter 3), which fosters reflexivity and creates room for adaptation. It can also be described as a trans-disciplinary research (see Chapter 3), which capitalizes on the knowledge, values and resources of different scientific and social stakeholders needed for this process of change. Interestingly, the complexity and persistency that are at the core of the stigma problem also provide the seeds and resources for dealing with it.

Now I will describe how to take into account the complexities and persistency of stigma – in particular the way the local context produces and reproduces leprosy-related stigma. I provide four insights or approaches. The first approach is that designing, implementing and assessing stigma-reduction interventions starts with **working with people who know the local context and have a thorough understanding of stigma**, including its causes and consequences. In SARI’s case, RAs, including people affected by leprosy and disabled people were hired. Some had an understanding of stigma from the outset, because of their personal experiences of living with a stigmatized condition. They had personally felt shame and had faced social exclusion and discrimination. They complemented their understanding – and others gained an understanding – through training sessions and the exploratory study in which people affected by leprosy and other key persons were interviewed. The recurrence of interviewees’ distressing stories and the subtle and brutal implications leprosy-related stigma had on them, enhanced the RAs’ implicit knowledge, understanding and dedication to the cause. Discussing and reflecting together on the issues people affected by leprosy face in Cirebon District helped in making this knowledge explicit and created the opportunity for mutual learning and the co-creation of knowledge. The RAs were essential for the project, for example in the way they solved the everyday challenges the design, implementation and assessment of interventions entailed. They knew how to manoeuvre in the local context – what to do and what not to do.
Hence, involving the right people and creating an environment in which they can learn and reflect is key to reducing stigma.

The second approach is the exploration of the local context by focusing on perceptions, needs and strengths of people affected by leprosy and other stakeholders. In the SARI project we incorporated the findings of the exploratory study in the design of the stigma-reduction interventions. An illustrative example is the contact events, in which SARI’s RAs and people affected by leprosy addressed the local beliefs and (mis)perceptions about leprosy that can foster stigma. It is noteworthy that the SARI team not only explored the context for the design of interventions but also continued this exploration during the implementation and assessment of the interventions. The interventions and instruments to assess stigma were adapted accordingly. For instance, during the implementation of the counselling intervention concealment appeared to be more challenging than anticipated and the interventions needed further adaptations. Hence, understanding the local context and not setting interventions in stone, but adopting a continued focus on learning and action, was important in the SARI project.

Third, counselling, contact and SED interventions as paired interventions were unmistakably multi-level and multi-faceted approaches. Interestingly, single elements of the SARI interventions have shown the potential to address multiple levels and multiple facets of stigma. In my view, the best example is participatory video. This activity, on its own, addressed stigma at different levels (e.g. intrapersonal, interpersonal, community). This is valuable for two reasons. If stigma-reduction interventions address only one mechanism it is likely that the effect erodes with time because other mechanisms remain in force. When different mechanisms are addressed simultaneously the effect is more profound and more likely to endure. But equally important, the participants can benefit, each according to their own personal needs. These needs differ substantially between participants, which renders a multi-level and multi-faceted approach even more important.

Fourth, the space that is created because of the reduction of stigma should be replaced with something new. Stigma-reduction interventions that aim to reduce exclusion should at the same time cultivate inclusion. Likewise, stigma-reduction interventions that aim to decrease feelings of shame in affected persons should simultaneously increase feelings of pride. In a way, the notion of stigma reduction is only one side of the coin, but there is no antonym of stigma that sufficiently describes the other side. There are notions, though, that describe important elements such as empowerment, restoring dignity, identity and social inclusion. Corrigan and Kosyluk describe the attitudes and behaviours that result from positive expectations and beliefs as “affirming attitudes” and “affirmative actions” (Corrigan & Kosyluk 2013:136). They argue that those “who seek to erase the stigma need to identify positive, affirming attitudes and affirmative actions that can replace the previous, unjust approach” (Corrigan & Kosyluk 2013:136).
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The finding that stigma-reduction interventions need to address complexities does not mean that the execution of these stigma-reduction interventions is automatically also complex. The interventions are relatively inexpensive and require no highly specialized or technical knowledge. These are essential prerequisites for the success of interventions in the resource-poor settings where leprosy is prevalent. The clearly written guidelines that currently exist are useful for implementation. Also the SARI project produced several video and written guidelines\(^{15}\) that might prove valuable. But equally important are approaches that appreciate and seek diversity, foster learning, reflection and action such as action research and transdisciplinary research do.

Finally, I conclude that the complexity and persistence of stigma that make stigma-reduction efforts difficult also create opportunities. Due to the complexity there are a wealth of issues that can be addressed and due to the persistence there are several feedback loops that can reinforce positive changes. In every context that is properly understood, the issues and feedback loops that need to be addressed illuminate. For instance, one could target the most destructive attitudes. I personally believe that positive attitudes of health professionals are key to prevent or address leprosy-related stigma. One could also enhance the care and support that is already provided by some family members and religious leaders. If it is difficult to reach one actor, another might be willing to work together to realise the changes needed in the field of leprosy. Thus, the complexity and persistence of stigma should be understood and can, through the opportunities this complexity creates, be used for the better.

11.3 Internal validity

The internal validity is concerned with the possibility that the researcher influences the study participants and introduces bias into data collection and analyses. In this section, I will reflect on the role of the researchers, the presence of the researcher, the research methods, data management and tasks of the RA during the implementation of the interventions.

The first issue in reflecting on the internal validity is the role of the researchers. My colleagues and I were involved in the design, implementation and evaluation of the stigma-reduction interventions, which makes researcher bias a pertinent issue. Several strategies were used to reduce researcher bias. One important strategy is investigator triangulation, as multiple researchers and RAs were involved in the design of the study, data collection, analyses and interpretation. Another strategy was paying special attention to discrepancies in evidence or negative cases that might provide new insights. For instance, the discrepancies presented in Chapter 4 led to a study with a focus on concealment and agency, the results of which were presented in Chapter 5. Also we organized three focus group discussions on preliminary findings with the participants of

\(^{15}\) See http://www.leprosy-information.org/keytopic/sari-project
this study and several workshops to discuss the findings with the RAs to deepen understanding and enhance interpretation. Discussions with researchers and practitioners not directly involved in the SARI project also helped to minimize researcher bias.

The presence of the researcher – a Dutch woman – during data collection is another threat to internal validity. This presence might, for instance, result in shyness, unrealistic expectations or socially desirable answers. Most of the data was collected by the RAs, who are all from Cirebon District or a neighbouring district. However I did join several data-collection activities in the community and a few contact events to observe and supervise the work. Some of the FGDs and interviews were co-facilitated by me. Also three FGDs were co-facilitated by a Dutch master’s student. To minimize any undesirable impact we spent considerable time before starting the FGD or interview to put all the participants at ease. Also my mastery of Bahasa Indonesia helped me to establish communication with the study participants.

Another important aspect of the internal validity is the methods used. For our qualitative data, we piloted our questions guide prior to commencing the study to ensure that the items were suitable for our population. Chapter 9 describes in detail the validity of the two scales used in this thesis: EMIC-CSS and SDS. RAs were trained extensively and frequent meetings were organized during the start of the data gathering to discuss difficulties. The triangulation of data obtained by different research methods worked well. For example, the data gathered to assess the effectiveness of the contact intervention included interviews, FGDs, a short questionnaire, informal interviews and two validated scales, which together provided a rich account.

The exploratory study had a broad focus and generated a wealth of data which created opportunities and challenges, hence reflecting on the data management is important. The SARI RAs visited 53 persons affected by leprosy at their homes on three occasions, and co-facilitated 20 FGDs. The collection, transcription, translation and the analyses of the data was a time-consuming process. Hence, in-depth analyses were not ready by the time the interventions started. Fortunately, the narratives transformed into tacit knowledge in the SARI team and after some preliminary analyses, a workshop to make this tacit knowledge explicit, and additional FGDs to check preliminary ideas with the stakeholders, enabled us to design and implement the interventions. If time and resources had allowed, it would have been valuable if at this initial stage we had been able to train the RA not only in collecting but also in analysing data. Major shifts in ideas about who can do research and the importance attached to exploratory studies by funding agencies are required to facilitate these changes. Finally, some thoughts on tasks of the RA during the implementation of the interventions. When the implementation of the interventions began, we decided to involve all (at that time nine) RAs in all interventions, rather than creating smaller teams that would be responsible for only one intervention. There were three main reasons for this. One of the sub-aims of the SARI project is to support the capacity building of a local DPO, where some RAs work. By
involving all RAs in all interventions they could learn and develop in the broadest sense. The second reason was that all SARI team members had gained tacit knowledge about leprosy and leprosy-related stigma through the preceding phases and by going together through the process of implementation we could build upon this comprehensive body of knowledge. The third reason is explained by the overlap between skills required for the different interventions. For instance, the participatory video activities and socio-economic development activities benefited from the fact that the implementers had counselling skills. At the same time, becoming familiar with the three new interventions of the SARI project and all the new skills required was at times overwhelming for the RAs. During one of the final meetings, the RAs said that while they were happy with our approach because of the skills they gained along the way, they noted that the quality of the interventions – especially in the beginning – might have been negatively influenced by this decision. In the end, I believe the benefits outweigh the disadvantages, but it is nevertheless a noteworthy consideration since the SARI project studies the effect of the interventions.

11.4 External validity
External validity is concerned with the applicability of the findings in this thesis to the broader context. In order to ensure external validity of the exploratory study, the research team conducted a large number of interviews (53 on three occasions) and FGDs (20). In total we involved more than 150 people, including people cured or in treatment for leprosy, health workers, teachers, religious leaders, community leaders and others. These participants came from 10 different sub-districts. To ensure external validity of the study that assessed the effect of the contact intervention again a large number of participants (>1250) and a large number of sub-districts (30) were involved (Chapter 10). In addition, several informal conversations were held with academic and non-academic stakeholders during Steering Committee meetings to help contextualize the findings of this thesis to a broader context. This study can be considered successful in including the perspectives of a variety of actors, achieving a large sample and working in a large number of sub-districts. Therefore, we can generalize the findings from our sample to Cirebon District.

However, it is more difficult to generalize to the broader Indonesian context given the substantial variations between districts and provinces in culture, socio economic status, health outcomes, geography and so on. The same is true for other countries elsewhere in the world. For instance, the findings related to the validation of the EMIC-CSS and the SDS are specific and cannot be generalized to districts and provinces that have a different culture and therefore would need to be re-validated. In spite of this, we argue that the broad themes elucidated in this thesis reflect issues faced by people affected by leprosy in Indonesia and elsewhere in the world. Thus, also many of the solutions outlined are expected to be applicable in other contexts. Comics and participatory videos have been developed in numerous places in the world including Barbados, Brazil, Uganda and Vietnam (Wheeler 2009; Braden & Huong 1998; Waite & Conn 2011; Richardson–Ngwenya 2012). Similarly, lay and peer counsellors
have been trained and used in other countries in particular in Sub-Saharan Africa (Baiden et al. 2007; Sanjana et al. 2009; Dewing et al. 2013). Also the contact intervention has been applied in many other places (Heijnders & van der Mei 2006; Brown et al. 2003; Corrigan 2012). For each of these interventions, the field of leprosy was new. Nevertheless, the fact that they have been applied in other places including countries where leprosy is endemic is promising for the applicability elsewhere.

One might also wonder whether findings related to scales and interventions can be generalized to other stigmatized diseases and conditions. Because leprosy is an archetype of a stigmatized condition in terms of its history and sometimes severe implications, the insights gained in this thesis can be also relevant to other stigmatized diseases and conditions, such as HIV/AIDS, disability, mental illness, Ebola and certain NTDs. For instance, with some adaptations the validity of the EMIC-CSS and the SDS can be tested for other stigmatized diseases and conditions. The SDS has already been applied in a study on mental health in Bali, Indonesia (Kurihara et al. 2000). But also outside Indonesia, the EMIC-CSS and the SDS have been used in other fields (Brieger et al. 1998; Stevelink et al. 2002; Angermeyer & Matschinger 2003; Atre et al. 2011; Somma et al. 2008; Raguram & Weiss 1996; Weiss et al. 2001; Raguram et al. 2004). Some of the approaches tested in this study were actually adapted from other fields. The contact intervention is widely used in the field of mental health (Corrigan 2012). Also, participatory video has been once applied in the field of mental health (Buchanan & Murray 2012). Although we cannot generalize our findings to other stigmatized conditions we have contributed to a body of evidence that supports the use of stigma measurements and a contact intervention using participatory videos across conditions provided that the local context and causes of stigma for these conditions are considered.

11.5 Ethical challenges

Stigma is a delicate subject. The interventions designed, implemented and assessed in this study aim to reduce stigma, but for several reasons there can be unexpected and unintended adverse experiences. First, distressing issues can arise that are unrelated to the study, but that nevertheless take place in the project context. Second, a focus on stigma might temporarily reinforce or amplify stigma. Third, de-stigmatization involves changing power relations, which frequently causes some disturbance.

Before the start of the project, ethical issues were described for the approval granted by the Ethics Committee of Atma Jaya University, Sub-Directorate for Leprosy and Yaws, Ministry of Health, PHO, West Java and DHO, Cirebon District. In addition, the SARI team looked closely into adverse experiences that had emerged during the course of the project. We wanted to learn from these experiences, but also wanted to share our own experiences so other researchers and practitioners working in similar fields could anticipate them. In total, 12 cases were identified in 2012. Three cases that related to activities and interventions described in this thesis are given in Box 11.1 The SARI team concluded that it is important to avert preventable adverse experiences, but underlined
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that not all issues are or will be preventable. Actively identifying and dealing with new and unexpected issues was thus equally important. The results of this endeavour were written up in a report and presented at the International Leprosy Congress in Brussels in 2013.

Box 11.1
Adverse experiences occurring in the project context

Case 1:
One young person affected by leprosy was one of the eight participants in the first participatory video project. The participants met on a regular basis and decided together when and where to meet. At some point, there was a time conflict between a participatory video session and a participant’s work obligations. The participant decided to be absent from work to be able to join the participatory video session. His boss fired him for not showing up. Response SARI team: Within a few days the RAs had found him a new job. For about six months he was a truck driver after which he moved to Kalimantan for a new job in construction.

Case 2:
One middle-aged man affected by leprosy had at some point during his treatment stopped taking his MDT. After a few months the treatment was continued, but as a result it had to be extended. He is now cured, but still suffers severe leprosy reactions. The relationship with his wife is not good. The leprosy officer told our RAs that his wife is angry because he had stopped taking the medicine. He joined the counselling intervention in November 2012. After two sessions he decided to stop because he believed counselling was not effective for him. It did not address his needs. According to him, he needed only medication to cure his leprosy reaction. Moreover, the focus on leprosy had reinforced his wife’s anger. Response SARI team: The right to opt out of the intervention was respected and the counselling sessions were suspended.

Case 3:
A middle-aged man affected by leprosy has been a client of the counselling intervention. His wife was not aware of her husband’s disease. While this client received counselling, his wife found the medicine card and asked a midwife to explain what it said. The midwife told her that her husband is affected by leprosy. As a result of this information, the client’s wife moved to her parents’ house. She had said that she was worried about infection. There has also been gossip in the community as neighbours talked about excluding the counselling client. The lay counsellors know this because one of the neighbours is a SARI participant and suspects that the neighbours have wrongly informed the client’s wife. Response SARI team: The lay counsellors provided correct information on how leprosy is spread and that it unlikely to do so after medication is started. One of the lay counsellors also gave an example from his own life. The lay counsellors have visited the client and also his wife a couple of times to tell them how things were going and whether SARI could be of any help. The wife told the lay counsellors that she was unhappy with the fact her husband never told her about the situation. After a couple of months the client and his wife were seen together and their relationship seemed okay again.

11.6 Future research priorities
This section presents recommendations for further research based on the findings of this thesis. The recommendations cover theory, methodology and application. In addition, aspects of sustainability and the changing leprosy landscape are considered. I conclude with a more personally motivated call for action.
Stigma research could benefit from a better theoretical understanding of stigma-reduction processes and models or frameworks to guide or assist them, as other scholars have also argued (Bos et al. 2013; Parker & Aggleton 2003). Stigma is complex and cannot be understood or addressed merely from one discipline or from one stakeholder perspective. The current understanding of stigma is dispersed. Hence, multidisciplinary but even better transdisciplinary research that aims at contributing to theoretical development is highly recommended. In particular, because a transdisciplinary approach would anticipate one of the main critiques of stigma theory, namely that those who develop such theories are uninformed by the lived experiences of stigmatized individuals (Link & Phelan 2001). It would be interesting to bring together a range of people involved in stigma-reduction efforts (stigmatized individuals, practitioners from NGOs and DPOs, health professionals and researchers including anthropologists, psychologists, sociologists, psychiatrists, and public health researchers) and ask them to co-create insights that are relevant for stigma-reduction theory. Interesting questions are: Which methods could facilitate such a dialogue? How to make knowledge from such an endeavour explicit so that others can benefit from it? And how to move beyond a theoretical discourse to the identification of frameworks and models that can actually help reduce stigma in practice? In my view this is a challenging, but also very interesting and relevant, avenue to explore.

Methodologically, the assessment of stigma is an area that needs attention. I strongly encourage more research on methods to assess stigma and specifically a change in stigma, which is fundamentally different from merely understanding its causes or consequences. I support and value how we approached the assessment of stigma in the SARI project but also see areas for improvement. I highlight three themes to explore further. The first is the compatibility of quantitative and qualitative methods. In contrast to the common practice of applying both types, we are aware of one method based on the EMIC framework developed by Weiss (1997) to assess stigma that integrates the two approaches in one method. A closer look at this tool for assessing a change in stigma would be helpful as it might allow us to understand changes and make generalizations more efficiently. Another theme is the assessment of different constructs, such as care, social closeness, participation and inclusion. And related to this, the development of more positively phrased questions, e.g. ‘Do people in your community support people affected by leprosy?’ Such methods would strengthen the assessment of experiences of people affected by leprosy. The third theme is the development of more participatory and visual ways to assess a change in stigma in co-operation with the target group. In the field of stigma, this area is to my knowledge underdeveloped, but we can learn from many others (see Mayoux & Chambers 2005; Wang & Burris 1997). These three undertakings would greatly advance research on stigma because they would allow us to make better connections between quantitative and qualitative data (first theme), could shed new lights on people’s diverse experiences (second theme) and take people’s realities more profoundly into account (third theme).
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Findings presented in this thesis provided insights into the application of different stigma-reduction interventions, in particular, lay and peer counselling, participatory video and contact. Avenues for further research were identified for each of them. Several aspects of the lay and peer counselling strategy are promising, but the approach could benefit from research to optimize the selection and training of lay and peer counsellors in order to improve the ‘success rate’ of becoming an effective counsellor. The findings related to the impact of participatory video are good and here I recommend careful scaling up. It would be interesting to see diversity in the makers of the videos and in the audience watching the video. Makers could be homogeneous groups such as children, adolescents or elderly persons affected by leprosy, family members of persons affected and those experiencing leprosy reactions. Target groups could include newly diagnosed persons, health workers, family members and policy-makers at a Ministry of Health. Specifically, I encourage a greater involvement of the video makers in the organization of activities for screening the video. In our case, there was involvement, but less than would have been desirable. The results of the contact intervention raised more technical questions for further research. For instance, we recommend studies that consider the effect of individual elements (testimony, video), the effect of contact events elsewhere in Indonesia, the effect of more than one event in one location (repetition) and the effect of reminder messages (through text messages or social media such as Facebook, Twitter). These results together will provide insights that will help to tailor the stigma-reduction interventions to make them more effective.

Studies that help to modify the interventions into more sustainable and integrated versions are also recommended. Sustainability was an important consideration during the design and implementation of the interventions in the SARI project. We need to acknowledge that since the end of the implementation phase (to our knowledge) no new comic workshop, participatory video activity or contact events have been organized in Cirebon District. The Ministry of Health, international NGOs and individuals outside Cirebon have shown an interest in the activities, which is great, but sustainability needs to be an even stronger aspect in future initiatives. In the Indonesian context, for instance, contact activities could be combined with activities of the routine health services such as contact surveys or rapid village surveys organized by the DHO. Contact activities could also be organized on an annual basis to celebrate World Leprosy Day. The latter is currently organized at the national level, but as part of the national leprosy programmes this could be stimulated at a much more local level such as the CHC. Finally, contact activities could be integrated into the leprosy training for health professionals. If direct contact is not feasible during such training indirect material, such as video testimonies, could be considered.

Despite decreasing incidence rates in some countries (not Indonesia), leprosy will remain an important public health issue for some time to come. There is still a lot of work to be done for leprosy organizations, but due to the decrease in numbers the landscape in which they work is changing. As a response, these organizations are
diversifying and initiatives for collaboration with those working with other diseases, such as diabetes, mental illnesses, NTDs that share similar characteristics are emerging. In this changing landscape with new collaborations, people are wondering whether there are valid generic research methods to assess stigma and generic interventions that address stigma. I understand the value of generic research methods and interventions and see the potential of, for instance, ‘contact events’ organized by people affected by different stigmatized conditions. At the same time, I foresee several challenges. It is, for instance, a question whether people with HIV/AIDS or a mental illness like to be associated with people affected by leprosy and vice versa. Also, how can the relevant (mis)understandings and causes of stigma of a set of stigmatized conditions be addressed when those of leprosy alone are already numerous, diverse and complex. Future research can perhaps try to increase our understanding and address these challenges.

Finally, though not connected to the findings in this thesis, I call for more research into leprosy-related mortality. It is extremely sad that after so many praiseworthy developments in the field of leprosy, people – possibly more than we know – still die of the disease. On 9 July 2013, Muhammad Nurhadiansyah – one of SARIs RAs – died of complications arising from the treatment of his leprosy reactions. In the course of the project, a few study participants died due to leprosy-related complications. Inadequate treatment of leprosy reactions, self-medication through over-the-counter drugs, drug dependency and barriers to referral to specialist hospitals are some of the challenges to be addressed. Also, here a multi-faceted approach seems to be the way forward. These deaths are preventable and with all my heart I call for appropriate action.
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