

## Chapter 4

# Development of a Rights-Based Counselling Practice and Module to Reduce Leprosy-Related Stigma and Empower People Affected by Leprosy in Cirebon District, Indonesia

### Abstract

*Background:* Leprosy-related stigma remains a major and difficult challenge to tackle. This study charts the development of a counselling practice and module in which stigmatized individuals are involved as lay and peer counsellors. The practice and module aims to reduce leprosy-related stigma in Cirebon District, Indonesia and is part of the SARI project.

*Methodology/ principal findings:* An exploratory study including 53 interviews and 5 FGDs aimed to understand the characteristics of people affected by leprosy and the views of the community. Findings were used to develop a draft counselling practice which was then piloted. Sixty-two clients and several family members received counselling during the pilot study. Notes of the counselling sessions and evaluatory meetings were made to make the module more appropriate, effective and sustainable. The results of the exploratory and pilot study led to a counselling practice, comprised of an integration of individual, family and group counselling. The provision of medical knowledge about leprosy played an important role in combatting stigma at different levels. Responding to views expressed during the pilot, the proposed module focuses less on feelings of stigmatisation and more on taking action among others by raising awareness of rights. This study showed that five counselling sessions can trigger clients to move from a seemingly hopeless situation into a place where one feels hope, takes initiatives and experiences less internalized stigma.

*Conclusion/ significance:* This new counselling module differs from other modules because it integrates three types of counselling and has a knowledge-based and rights-based approach. Despite the context-dependent nature of stigma, the counselling module has potential as a stigma-reduction intervention for Indonesia and other countries where leprosy-related stigma is widespread. The presented counselling module should be adjusted to a new context and tested before it can be scaled up.

## 4.1. Introduction

Diseases and conditions such as HIV, tuberculosis, but also several Neglected Tropical Diseases such as Buruli ulcer, lymphatic filariasis, onchocerciasis, leishmaniasis and Chagas disease and leprosy have long been stigmatised in society, and as a result have negative effects on an individual's quality of life (Christodoulou, 2011; Person, Bartholomew, Gyapong, Addiss, & Borne, 2009; Scambler, 2009; Stienstra, Van der Graaf, Asamoah, & Van der Werf, 2002; Weiss, 2008). Leprosy-related stigma has, for instance, been shown to hinder access to treatment and is associated with socio-economic problems, discrimination and the violation of rights (Heijnders, 2004; Nicholls, Wiens, & Smith, 2003; Tsutsumi et al., 2007; Varkevisser et al., 2009). People affected by leprosy might lose their jobs because they are fired or anticipate stigma by resigning themselves (see Chapter 2). They might be excluded by the community or family, or even exclude themselves (see Chapter 2). It is evident that people affected by leprosy not only experience stigma in relation to their community members, neighbours and family, but also internally. These different types of stigma places the quality of life of individuals and their families in a downward spiral. These dynamics reinforce each other, which makes the problem of stigma complex and persistent.

The negative impact that stigma has is widely recognized. Evidence-based information on how to reduce stigma and discrimination is, however, scarce (Cross, Heijnders, Dalal, Sermrittirong, & Mak, 2011; Heijnders & van der Meij, 2006). Although various interventions have been developed, which aim to reduce stigma at a certain level (such as the interpersonal, intrapersonal or community level) (Heijnders & van der Meij, 2006) most of these interventions are not specified to the local context of stigmatized individuals. New interventions are thus needed which are multi-faceted, involve low costs, build on people's own strengths, rights and resources and reinforce empowerment in which people take initiatives (on individual, family and community level) leading to more sustainable interventions (Cross et al., 2011; Heijnders & van der Meij, 2006).

Counselling is considered to be one of the most promising stigma-reduction approaches (Brown, Macintyre, & Trujillo, 2003; Heijnders & van der Meij, 2006). Counselling has been applied - as an intervention - to a range of diseases with a health-related stigma, often with the aim to prevent the spread of an infection and enhance medicine adherence and sometimes with the aim of empowering affected individuals or changing social attitudes (Dewing et al., 2013; ILEP, 2011; Richter, Rooyen, Solomon, Griesel, & Durrheim, 2001). The latter two are of great importance for stigma reduction. It is however not evident that counselling does work under the conditions clients affected by leprosy-related stigma experience. Can counselling which is affordable be realised effectively for these people who have dropped out of school, lost their job, are isolated by neighbours and friends, feel lonely and have a low self-esteem?

This study therefore aims to develop and analyse a counselling practice and module to address leprosy-related stigma in Cirebon District, Indonesia. Cirebon has a high prevalence of leprosy, a high number of new cases annually and, according to local experts, a relatively high level of leprosy-related stigma.

The study is part of the SARI project implemented during 2010-2014 by the Athena Institute of the VU University of Amsterdam, the Center for Disability Studies at the Universitas Indonesia and Disability Studies in Nederland. The aim of the SARI project is to assess the effectiveness of three different stigma reduction interventions: counselling, SED and contact.

## **4.2. Theoretical framework**

In order to deal with the complexity of leprosy-related stigma the theoretical framework of this study combines several approaches. The counselling developed in this study makes use of CBT and is also knowledge-based, rights-based and involves lay and peer counsellors. CBT (Dobson, 2010; Glickman, 2009; Kuyken, Padesky, & Dudley, 2009; Taylor, 2006) is a counselling approach with a variety of counselling practices and different aims, including empowering those affected. It is 'solution-focussed', 'action-oriented', relatively brief in nature and deals with problems clients face in their daily life (Dobson, 2010; Glickman, 2009; Kuyken et al., 2009; Taylor, 2006). A number of studies describe the contribution of CBT in empowering client to improve their self-awareness, self-image, self-confidence and capacity for taking initiatives and making change (Corrigan & Calabrese, 2005; Glickman, 2009; Hall & Tarrier, 2003). The framework is knowledge-based, because knowledge plays a very important role in dealing with misunderstandings with regard to causes and consequences of leprosy (Croft & Croft, 1999; van der Broek, O'Donoghue, Ishengoma, Masao, & Mbega, 1998). Next to the use of knowledge as medical information in counselling, knowledge is also important to tailor the CBT towards the characteristics and conditions of the clients and their environment. A rights-based approach is used to remind the client that even though they have an illness they retain their dignity and have the right to eat, drink, to friendship, love, to share their opinion, make decisions, have medical treatment and ask questions to health professionals about their disease as declared in the human rights formulated in 1948 (UN, 1948). Discussions about rights are used to facilitate the process of change in which stigma is reduced and to explore opportunities for a fulfilling life. Counselling is often provided by professionals, but counselling can also be given by peer and LCs which significantly lowers costs and therefore might be a more sustainable stigma-reduction intervention (Kagee, 2013; Sanjana et al., 2009).

## **4.3. Methods**

### **4.3.1. Exploratory study**

This study involved two phases. The first phase concerned an exploratory study executed between May - November 2011. This study aimed to understand the characteristics of people

affected by leprosy currently under treatment for leprosy and those cured and their perceptions, experiences and needs. It also aimed to understand the knowledge, perspectives and attitudes of the community regarding leprosy and stigma.

During the exploratory study, 53 IDIs were conducted with people affected by leprosy. RAs from the study area were hired and trained as interviewers. Due to the limited experience of these interviewers, the interviews were conducted by pairs with single participants. Sometimes a relative was present. The interviews started in an exploratory manner, progressing towards more in-depth inquiry. Topics addressed in the interviews were (i) socio-demographic information, (ii) medical history, (iii) current health situation, (iv) economic situation, (v) social situation and finally (vi) the impact of leprosy on their lives.

In addition, 5 FGDs were conducted with people affected by leprosy, family members and counselling experts. The aim of these FGDs was to validate the findings from the interviews and to deepen the understanding of their perspectives. The interviews and FGDs of the exploratory study were recorded, transcribed, and translated into English.

#### **4.3.2. Pilot study**

The author of this thesis is a trained counsellor with more than 20 years of experience. She was the main counsellor during the pilot study. She is visually disabled and worked using braille, a screen reader and with a personal assistant. The author of this thesis was assisted by 10 local RAs. In December 2011, the RAs received a 3-day basic counselling training from the author of this thesis which prepared them to assist, observe and make notes during the counselling pilot. In this training, they also learned about working together with health professionals at the health care centres among others to find and select the clients who could benefit from counselling.

In total, 62 clients and several family members (20 in total) received counselling during the pilot, which ran from January 2012 until April 2012. During the pilot counselling, personal counselling notes (PCNs) were written about each client. PCN are notes made by the counsellor (the author of this thesis) and included remarks of important things said and expressed by the client, remarks on the content of the counselling sessions, and aspects that related to the three different types of counselling provided (individual, group and family). The author of this thesis inserted observations of the RAs if, for some reason, she had not been able to provide the counselling herself.

To explore some aspects of the counselling in more depth, TRs were made of 12 counselling sessions. In addition, separate notes of group counselling sessions (GCNs) (5 in total) and family counselling sessions (FCNs) (17 in total) were taken. Evaluation meetings notes (EMNs) were taken at the monthly (4 in total) meetings that took place with the RAs. The notes on the pilot counselling are available in Bahasa Indonesia, but the most important ones were translated into English. Important notes were those that help create a diverse picture of clients and that helped

understanding the effect of the different types of counselling. All data was categorized under two categories: the content of the counselling (including themes such as knowledge, feelings, stigma, discrimination, rights) and practicalities of counselling sessions (themes such as type of counselling, duration). On the basis of the results of the pilot study, the counselling practice was adapted.

The study was approved by the Ethics Committee of Atma Jaya University, the Sub-Directorate for Leprosy and Yaws, MoH, the Provincial Public Health Office, West Java, and the District Health Office, Cirebon District. Written informed consent was obtained from participants in the exploratory and pilot study. If a participant was illiterate, the information was read out to him or her. Some participants did not want to sign because they did not have a signature or because they were unfamiliar with the practice of signing. Instead they gave their oral consent for the interviews (this was approved by the Ethics Committee). A few minors were involved in this study. A parent or a guardian provided oral or written informed consent on their behalf.

#### **4.4. Results**

First, the results of the exploratory study are presented. Based on the theoretical framework and the analyses of this study, a draft counselling practice was formulated. This is followed by an analyses of the pilot of this draft counselling practice. After which the resulting counselling module is presented.

##### **4.4.1. Key issues identified during the exploratory study**

###### *Participants*

In total, 53 IDIs were conducted during the exploratory study. This included 44 persons affected by leprosy and 9 caretakers of children affected by leprosy. Of the 53 interviewees, 34 (64%) were women. Different ages were included (8 were <20 years, 20 were 21 - 40 years, 12 were 41 - 60 years and 7 were > 61 years, 6 missing). In total, 5 FGDs with 38 participants, 26 women (68%) and 12 men (32%), were analysed. The number of participants per FGD ranged from 5 to 8. Below the most important findings of the exploratory study are presented. For a more comprehensive overview we recommend, Chapter 2, Chapter 3, Peters et al. (2014) and Dadun et al. (in progress).

###### *Health perceptions*

In the exploratory study it became evident that many people affected by leprosy had unhelpful and sometimes wrong perceptions about their health condition. Common misconceptions and a different health belief system were identified and discussed and confirmed during the FGDs. There were misunderstandings or different understandings related to the cause of the disease ('genetic', 'black magic', 'touching something dirty'). Perhaps even more problematic was the finding that many people affected by leprosy did not realise they were not longer infectious after

starting the MDT treatment. People also tended to perceive the effects of the disease worse than is often the case in reality. The disease was by some perceived as 'incurable' and as a death sentence ('the disease that kills people'). After finishing the treatment, many participants wondered whether they were cured and whether they would become 'normal' again. These doubts about being cured or not can be well understood because of impairments or leprosy reactions. From a medical point of view this is not justified. After 6 or 12 months of MDT people in general are cured.

### *Feelings and emotions*

A mixture of negative feelings and emotions were evoked when the respondents received their diagnosis. The interviews illustrate that people affected by leprosy often directly stigmatize themselves and feel strong emotions such as shame, disgust and fear. Some said during the interviews they denied their diagnosis and some decided to conceal their disease. This all resulted in a low self-esteem and feelings of loneliness.

*I was very embarrassed when I found out I had leprosy so I never tell others. Keeping silent is better. (IDI 8: woman, 50)*

Negative feelings and emotions were strong during the treatment. Also after being cured, negative feelings remained prominent for many. Some persons affected by leprosy said they wanted to bring about a change in their life but did not know how to realize this. Generally, people affected by leprosy were extremely passive, guilt ridden and under the impression that they are still ill. During the interviews people affected by leprosy described their often low socio-economic status and directly indicated the need for financial support. They requested money from the project, which links closely the first feature of passiveness.

*Sitting in the room, I know it is nothing [I know it is not good], I should go for work, maybe later if I am cured. (IDI: male, 23)*

*I am very sad and afraid, I feel alone, I feel a distance from my family, actually I like to help my family cooking but I am doubtful. (IDI, female, 28 years)*

Interestingly however, a few people affected by leprosy were doing quite well (e.g. run a successful business or could built on the support of the family) and found solutions to deal with stigma.

### *Rights and discrimination*

Very little reference was made to rights in the interviews and FDGs. The narratives, however, reveal that the rights of people affected by leprosy (right to access to medical care, work and education) are frequently disrespected and violated and that discrimination is common. There were, for instance, numerous examples of stigma from neighbours, friends, colleagues and sometimes family members.

*I used to run a small business, selling toys. Because of leprosy, I lost my customers and nobody buys my toys. Hence, my business is bankrupt. (IDI: male, 35)*

*I stopped going to school because of my leprosy. My friends are always making fun of me. I feel ashamed and uncomfortable going there. (IDI: child, 13)*

Not only does the 'outside world' denies people affected by leprosy rights, those affected also seem to accept and internalize the notion of being less worthy.

*Because of leprosy, my wife keeps away from me. She does not allow me to hold my granddaughter ... I am sad but I do nothing. (IDI 53: male, 60)*

Here we see the relationship between the mistaken health beliefs and violation of rights. The rationale 'you have leprosy, you are infectious and therefore you are not allowed and cannot go out into the public sphere' is sometimes shared by community members and people affected by leprosy.

#### *Role of family, friend and neighbours*

During the discussions in the FGDs it became clear that also the family of the person affected by leprosy is affected by the stigma associated with leprosy. Family members deal with the challenges of leprosy-related stigma in different ways. They can have a positive influence on the situation by giving care and support but they can also reinforce stigmatization, for instance by keeping distance or by stimulating the concealment of the disease. A similar pattern can be found among friends and neighbours.

#### **4.4.2. Evaluation and development of a counselling practice**

The exploratory study showed the interrelatedness and complexity of the issues at stake. In order to develop a counselling practice, this complexity needs to be addressed based on theoretical insights and the understanding of the local context. The counselling practice for clients needs to deal with the following elements the extreme passiveness, perception of oneself as ill and guilty, the feeling that life can be mainly improved by money, the violation of rights, and role of the families and the wider community.

The exploratory study influenced the development of the counselling practice in four ways. Firstly, many problems people affected by leprosy face are rooted in a lack of knowledge about their disease and the consequences of this disease. An effective counselling practice provides knowledge as soon as possible. Secondly, in order deal with the passiveness, guilt and low-esteem an optimistic and energetic counselling style seems appropriate. Such a style is described as motivational interviewing (Rollnick, Miller, & Butler, 2008; Rubak, Sandbaek, Lauritzen, & Christensen, 2005). With its empathic, supportive and yet directive style, motivation interviewing aims to provide conditions under which change can occur. It supports self-efficacy and generates confidence. Thirdly, the finding that human rights are violated justifies the rights-based approach.

People affected by leprosy might feel relieved by having an increased awareness of their rights. It also might create a sense of freedom, which enhances their options for changing their life. Finally, problems with stigma manifest themselves at many levels and in different ways. Instead of focussing on individual, family or group counselling alone, an approach with a combination of these three types seems needed.

The first version of the counselling practice with in total eight sessions was drafted. The eight sessions (4 individual, 2 with their family and 2 with a group of people affected by leprosy) were held on a bi-weekly basis. Each session was expected to last 60-75 minutes. This counselling practice was tested during the pilot.

#### 4.4.3. Key issues identified during the pilot

##### *Participants*

Sixty-two people affected by leprosy were offered counselling during the pilot (see Table 4.1. for demographic information). More than half of the participants showed a high level of interest in and enthusiasm for counselling, several had a moderate level of interest, while some did not like the idea and said that they did not need counselling. In total, 30 clients received 5 or more counselling sessions (see Table 4.1.). Clients considered that counselling at home was most comfortable: it could be kept confidential, they could talk more freely and privately, and there was greater flexibility in terms of time, which saved money. The number of sessions and the length of each session in the pilot did not seem to be appropriate for most clients because of the time demands from work, school, family matters and personal activities. A strong flow and focus during the sessions that lasted 60-75 minutes was not always realized.

**Table 4.1.** An overview of clients

| Participant characteristics |             | Counselling clients (n=62) |
|-----------------------------|-------------|----------------------------|
| Sex                         | Male        | 30 (48.4%)                 |
|                             | Female      | 32 (51.6%)                 |
| Age                         | 16-25       | 25 (40.3%)                 |
|                             | 26-35       | 14 (22.6%)                 |
|                             | 36 - 45     | 15 (24.2%)                 |
|                             | 46- 55      | 4 (6.5%)                   |
|                             | >56         | 4 (6.5%)                   |
|                             |             |                            |
| Marital status              | Not married | 27 (43.5%)                 |
|                             | Married     | 35 (56.5%)                 |

|   |                    |            |
|---|--------------------|------------|
| Education*                                  | Elementary school  | 35 (56.5%) |
|   | Junior high school | 21 (33.9%) |
|   | Senior high school | 6 (9.7%)   |
| Profession                                  | Paid job           | 16 (25.8%) |
|   | Own business       | 6 (9.7%)   |
|   | Student            | 9 (14.5%)  |
|   | Housewife          | 11 (17.7%) |
|   | No job             | 20 (32.3%) |
| Clients stopped during counselling sessions | 2                  | 5 (8.1%)   |
|   | 3                  | 15 (24.3%) |
|   | 4                  | 12 (19.6%) |
|   | 5                  | 15 (24.3%) |
|   | 6                  | 5 (8.1%)   |
|   | 7                  | 4 (6.6%)   |
|   | 8                  | 6 (9.3%)   |

\* including those not finished

### *Individual counselling*

Building trust and creating a relaxed, fun and joyful atmosphere during the counselling was key for the first sessions. The counsellor asked: 'How was your day?', 'Did any happy things happen today? Tell me?' It helped the clients to feel at ease and be more open. Clients, in general, showed a very positive reaction to the presentation of knowledge about leprosy. They were relieved once they had come to the understanding that leprosy is caused by a bacteria. Also the realisation that people affected by leprosy are no longer infectious once they have started taking medication and that they are cured when they have finished the treatment was key.

Talking about feelings and emotions too much was not appreciated by the clients because it forced them to concentrate on the negative aspects of their disease. Instead, they wanted to concentrate on the future, for instance, on their employment and education. Clarifying the discrepancy between the wishes for the future (a better life) and their current passiveness was a trigger for change.

Overall, clients responded positively to the discussion on rights. The understanding that they are human beings with human rights was powerful, created hope, energy and facilitated the discussion on solutions. The understanding that they could change, take action and address their

problems instead of waiting until the outside world had changed often generated joy. Most started with making small changes during the counselling period:

*Yes, you are right. I cannot just sit and wait for help. I should do something with my future like earning money. (PCN53)*

*I have talked to my teacher about giving me more time [to complete assignments] since I have to write with my left hand. (PCN20)*

The counsellor observed that with the help of new knowledge and initiatives the clients could re-evaluate their negative feelings and confront and reduce their internalized stigma.

#### *Family counselling*

Family members who participated in a family counselling session reacted positively to information about leprosy and its treatment. Family counselling also focused on solutions. The counsellor, together with the clients and their family members, tried to identify options for engaging the client in household activities, such as cleaning the house, cooking food, going to the market, and attending social gatherings. In general, and especially when there already was a clear support to start with, the family members responded positively:

*We take care of our child together. My husband now believes that I can do it and I share household tasks with him. He does not treat me as a patient anymore, even though he knows I am still taking medicine. (FCN1)*

Changing patterns of stigmatization in families where these patterns were deeply rooted was challenging. In about half of those families stigmatizing patterns were broken relatively easily and more supportive families developed naturally, but in the other half only small steps forward were made. It is also important to note that some clients or their families did not want to have family counselling sessions at all. A number of explanations were given: the family was busy; they did not want counselling to take up working hours; they did not want others to know about the presence of the disease; or they did not want to be disturbed by counselling. In some cases, the family counselling was replaced by an extra individual counselling session.

*My husband is very busy, he does not have the time. (PCN61)*

*You just meet me, it is enough! My family doesn't need to know about this visit. (PCN16)*

#### *Group counselling*

For most of the clients, group counselling represented the first time that they met other persons affected by leprosy. The counselling helped them realise that they were not alone and that there are others with the same disease. The group counselling had a different structure than individual and family counselling. The counsellor now facilitated interaction between the participants as they explained things to each other, talked about the variety of coping options available, stimulated each other to take a different perspective and have a more positive self-image.

*Let me be very open with you. Talking with you [another person affected by leprosy] motivated me. My perspective was wrong: affected persons still have the right to work. I learnt from you that I should not wait to be declared cured. (PCN14)*

Two main pathways to change were applied by the counsellor. The first involved joint activities and outings, such as going to the market, buying something and paying with the impaired hand, or going to park. The second was an imagination exercise: what happens if you do go to the market? What are you scared of? How do others feel about it? Why are they not scared?

#### **4.4.4. Evaluation of the pilot**

The pilot study showed that clients were comfortable talking about their feelings, thoughts and future with the counsellor. The CBT, knowledge-based, rights-based nature of the practice were appreciated by the clients – young and old, male and female – as it generated hope, helped them to take initiative and reduced internalized stigma. Group counselling was the favourite type of counselling by clients and family counselling was favoured least.

Three issues for improvement of the practice became evident. Dealing with a complex problem from different perspectives might jeopardize an effective and integrated approach. The integration of elements of the counselling sessions could be strengthened by a stronger integration of: i) the three types of counselling, for example, giving assignments in preparation for the next counselling session, ii) by connecting problems and solutions for example if a client talks about a problem, immediately the question is asked what can you do about it, and iii) by discussing human rights fully connected to daily activities and life in general. Secondly, although the counselling practice included from the beginning only 8 sessions of 60-75 minutes each, it was concluded that the number had to be further reduced. Five sessions of 30-60 minute each seemed to be a more appropriate scheme for the clients. The integration of elements, the energetic approach, attention to flow and focus and giving assignments made this reduction possible. Finally, this counselling practice was given by a professional counsellor during the pilot, but the final counselling module is meant to be given by lay and peer counsellors. The final counselling module needs to be simple, clear and suitable for lay and peer counsellors to apply. It was important, among others, to specify the process and the skills so that lay and peer counsellors can be taught to apply the practice themselves. This was done through the 5C framework. Also a set of principles and the content of each session was specified. The final counselling module is presented in the next section.

#### **4.4.5. The rights-based counselling module for lay and peer counsellors**

The results and analyses of the pilot led to the development of the so-called Rights-Based Counselling Module (RBCM). The final module includes a set of 5 principles, the 5C framework and 5 sessions featuring different types of counselling as described in Box 4.1.

#### **Box 4.1. Rights-Based Counselling Module**

##### **Key principles**

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

##### **The 5C framework**

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

**Confirmation:** information and experiences shared by the client need to be confirmed and verified

**Clarification:** information from the client needs to be clarified to make it clear and understandable

**Confrontation:** a client should be challenged during a conversation to build knowledge, create rights awareness and to develop confidence; this helps create momentum for finding solutions and making change. The counsellor should confront the client during the counselling process with his/her own statements that have been confirmed and clarified earlier.

**Compromise:** clients should be encouraged to compromise, to see things from a different perspective and to acknowledge exceptions.

**Commitment:** clients should commit to an alternative solution and take action

##### **Content of the five sessions**

###### **Session 1: Assessment of situation and trust building**

Type of counselling: Individual counselling

Timing: 30-45 minutes

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

###### **Session 2: Knowledge, rights and dealing with stigma**

Type of counselling: Individual counselling

Timing: 30-45 minutes

Content: Sharing medical knowledge on leprosy, the treatment and self care; exploring the client's expectations (of counselling), needs and demands; sharing about human rights, dialogue about dealing with stigma and ways to reduce stigma (using confrontation, compromise and commitment); discussion actions; preparing family counselling (expectation and planning).

###### **Session 3: Knowledge and solutions in the family context**

Type of counselling: family counselling

Timing: 30-45 minutes

Content: Discussions on daily activities; exploring and clarifying family worries and fears related to leprosy; reducing worries and fear with clarifying medical knowledge on leprosy, treatment and being cured; discussing the involvement of the client in the family roles and responsibilities; exploring how family members support each others; preparing group counselling (expectation and planning).

###### **Session 4: Learning from each other and action**

Type of counselling: group counselling

Group size: 4-6

Timing: 45-60 minutes

Content: Sharing personal experiences with leprosy and stigma, focussing on the challenges and success stories (counsellor focuses raising awareness of rights); discuss group action (e.g. say hello to neighbour, going to the market, doing household activities, talking about leprosy with family or community members); commitment to take action and support group members.

###### **Session 5: Sharing and strengthening action**

(Type of counselling: group counselling

Group size: 4-6

Timing: 45-60 minutes

Content: Reflection on group action, discussion of both positive and negative aspects (using confrontation and compromise), strengthening action by enhancing self-confidence, stimulating taking initiative and commitment.

## **4.5. Discussion**

This study describes the development of a counselling practice and module. In contrast to other forms of counselling given by lay and peer counsellors (Dewing et al., 2013; Richter et al., 2001), the counselling module developed as part of the SARI project focuses more strongly on empowerment and on creating a greater engagement in family and social life. The exploratory study and the counselling pilot resulted in a counselling practice and module appropriate to the diverse needs and strengths of people affected by leprosy in Cirebon District. The critical elements of the final module comprised of raising awareness through knowledge, the rights-based approach and an integration of three types of counselling. The provision of accurate medical knowledge of the disease and its treatment was incorporated in the practice. The integration of three types of counselling (individual, family, group) is important to the field of leprosy-related stigma where the problems are located at multiple levels and are deeply intertwined (Bos, Pryor, Reeder, & Stutterheim, 2013; Link & Phelan, 2001). The rights-based focus was in particular powerful and supported individual empowerment and agency. Therefore the module was named 'Rights-Based Counselling Module'.

This study showed that only a few counselling sessions can trigger clients affected by leprosy to move from a seemingly hopeless situation into a place where one feels hope, takes initiatives and experiences less internalized stigma. The practice and module can be implemented by lay and peer counsellors because the skills needed to generate this trigger can be trained. Detailed knowledge gained during exploratory study about the characteristics of the clients can be transferred to the lay and peer counsellors. With the help of the 5C framework and an energetic counselling style, lay and peer counsellors can structure the counselling process and help the clients to explore their own situation and find ways to solve problems or change their situation for the better.

Knowledge and awareness of the disease were – as anticipated – important elements of the counselling. We are aware that the effect of education on stigma-reduction is criticized (Brown, 2006; Cross et al., 2011; Opala & Boillot, 1996). This study shows that it is nevertheless a very important element of counselling in this particular setting. Medical information given by lay and peer counsellors to people affected by leprosy and their family members made it possible for clients to reclaim their rights and to participate in daily activities and social life. The relief generated by knowing that one is cured was immediately used by the counsellor as a driver for the change process. The dissemination of knowledge and the discussion of problems and solutions are deeply intertwined in the counselling practice and module.

The exploratory study highlighted the many differences and similarities that exist between people affected by leprosy. These similarities and differences have also been studied and described by scholars in India, Nigeria, Nepal and Brazil (Heijnders, 2004; Staples, 2011; Varkevisser et al., 2009). Group counselling offered the opportunity to use the differences between clients as an opportunity to discuss various options, points of views and strategies to deal with stigma and

other leprosy-related problems. This was also done in the study of Floyd-Richard & Gurung (2000). Thus instead of seeing the differences between affected people and complexity as a problem, in this a counselling approach they can be seen as advantages.

#### **4.5.1. Limitations**

First, although the approach taken was generally appropriate to the needs of the clients, this counselling practice and module are only effective when concealment was not the main priority of the client. The importance of concealment for people affected by leprosy was shown in the studies of Kaur & Ramesh (1994) and Vlassoff, Khot, & Rao (1996) in India, by Heijnders (2004) in Nepal and by Peters et al. (2014) in Indonesia. Those who were concealing their leprosy did not favour counselling as an approach to stigma-reduction. Second, sometimes it was schedule-wise not possible for the author of this thesis to be the counsellor during the pilot; these sessions were then taken over by trained but relatively inexperienced LCs.

#### **4.6. Conclusions**

There is a lack of insight in how to reduce stigma and realise empowerment in people affected by stigmatized conditions. This study shows that a counselling practice with a strong integration of three types of counselling can realise empowerment in people affected by leprosy and raise an awareness of rights. On different levels, initiatives and responsibilities were taken by the clients, which they believed earlier they did not have the capacity or right to undertake.

Although it is generally recognised in the literature that stigma is very much a local, context bound phenomenon, we consider that the counselling module presented here could be of use in other situations where leprosy is widespread and where stigma limits access to treatment and has socio-economic implications. The presented module should be adjusted to the new context and tested before it can be scaled up. The process followed with an extensive exploratory study and pilot might be relevant for those who like to develop a counselling practice for other stigmatized neglected tropical diseases or other stigmatized conditions.

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