Development of a rights-based counselling practice and module to reduce leprosy-related stigma and empower people affected by leprosy in Cirebon District, Indonesia

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

Results: An exploratory study including 53 interviews and 5 focus group discussions 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. 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 human 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 internalised stigma.
Conclusion: 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 counselling module presented here should be adjusted to a new context and tested before it can be scaled up.

Introduction

Diseases and conditions such as human immunodeficiency virus (HIV), tuberculosis, and also several Neglected Tropical Diseases such as Buruli ulcer, lymphatic filariasis, onchocerciasis, leishmaniasis, Chagas disease and leprosy have long been stigmatised in society, and as a result have negative effects on an affected person’s quality of life.1–5 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 human rights.6–9 People affected by leprosy might lose their jobs because they are fired or anticipate stigma by resigning.10 They might be excluded by the community or family, or exclude themselves.10 It is evident that people affected by leprosy not only experience stigma in relation to community members, neighbours and family, but also internally. These different types of stigma (so-called enacted, anticipated and internalised stigma as described by Weiss et al.5) place 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 of stigma is widely recognised. Evidence-based information on how to reduce stigma and discrimination is, however, scarce.11–12 Various interventions have been developed that aim to reduce different types of stigma often at a certain level (e.g. interpersonal, intrapersonal or community).11 However, most of these interventions are not specific to, or tailored to, the local context of stigmatised individuals. New interventions are thus needed which are multi-faceted, are inexpensive, build on people’s own strengths, rights and resources and reinforce empowerment in which people take initiatives leading to more sustainable interventions.11,12

Counselling is considered to be one of the most promising stigma-reduction approaches.11,13 There is an explicit interest in the individual who is counselled, but counselling can directly and indirectly address different types of stigma at different levels. For example, through individual counselling internalised stigma at the interpersonal level can be attended to and family counselling can focus on enacted stigma at the intrapersonal level. Counselling has been applied – as an intervention – to a range of diseases with a health-related stigma, often with the aim of preventing the spread of an infection and enhancing adherence to medication and sometimes with the aim of empowering affected individuals or changing social attitudes.14–16 The latter two are of great importance for the reduction of stigma.

Counselling is often provided by professionals but can also be given by leprosy-affected personnel – so-called peer counsellors – and lay counsellors. This significantly lowers costs and therefore might be a more sustainable stigma-reduction intervention.17,18 Peer counsellors are expected to connect and relate more easily to the clients as they have, or had, an illness and possibly related positive and negative experiences in common. At the same time, peer counsellors would have to overcome feelings of shame and disempowerment.
It was therefore until recently not evident if lay and peer counselling would work to address leprosy-related stigma.

The Stigma Assessment and Reduction of Impact (SARI) project recently assessed, among other aspects, the effectiveness of a rights-based counselling (RBC) intervention that involved lay and peer counsellors. The project was implemented between 2010 and 2014 in Cirebon District, Indonesia, by the Athena Institute of the VU University of Amsterdam, the Center for Disability Studies at the Universitas Indonesia and Disability Studies in Netherlands. The project concluded, as also described by Lusli et al. that the counselling intervention was effective in reducing stigma, promoting the human rights of people with leprosy and facilitating their social participation.19 Besides concluding that an intervention is effective it is also important to analyse how this intervention was developed. Understanding the rationale is especially important for others who would like to design and implement and perhaps even scale up a counselling intervention. This study therefore aims to analyse the development of the counselling practice and module that was effective in addressing leprosy-related stigma in Cirebon District, Indonesia.

First, we will introduce the theoretical framework that guided the development of the counselling module. In the section on methods we describe the two phases of this study. The first concerned a qualitative exploratory study that aimed to understand the characteristics (e.g. low self-esteem, feeling guilty), perceptions of leprosy, experiences with the disease and needs of people affected by it currently under treatment and those cured. It also aimed to understand the knowledge, perspectives and attitudes of the community regarding leprosy and stigma. Based on these findings a draft counselling module was developed. The second phase concerned a pilot study that aimed to test this draft counselling module (e.g. counselling styles, types of counselling) in practice, constantly taking into consideration that ultimately lay and peer counsellors would do this work. After the pilot study the Rights-Based Counselling Module was developed and is presented at the end of the results.

THEORETICAL FRAMEWORK

The main aim of the SARI project was reducing leprosy-related stigma. The aims of the counselling approach may have a positive effect on advancing this broad aim, but the idea of counselling implies explicit interests in the person who is counselled and who also lives in a social setting where stigma is a challenge. In order to deal with the complexity of leprosy-related stigma the theoretical framework that guided the development of the counselling module combines several approaches. The counselling approach makes use of cognitive behavioural theory and is also knowledge-based and rights-based. Cognitive Behavioural Therapy (CBT),20–23 which adopts a variety of counselling practices and aims, including empowering those affected. It is ‘solution-focused’, ‘action-oriented’, relatively brief in nature and deals with problems clients face in their daily life.20–23 A number of studies describe the contribution of CBT in empowering clients to improve their self-awareness, self-image, self-confidence and capacity for taking initiatives and making change.23–25 The framework is also knowledge-based, because knowledge plays a very important role in dealing with misunderstandings with regard to the causes and consequences of leprosy.26,27 Next to the use of knowledge as medical information in counselling, it is also important to tailor the CBT to the characteristics and conditions of the clients and their environment. A rights-based approach is used to remind the clients that even though they have or had 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 pose questions to health professionals about their disease as set out in the Universal Declaration of Human Rights adopted in 1948. It is emphasised that dishonouring someone’s dignity and inequality due to their illness are violations of human rights. Discussions about rights are thus used to facilitate the process of change in which stigma is reduced and to explore opportunities for a fulfilling life (see Lusli for a more detailed description of the underlying framework).

**Methods**

This qualitative study is part of the SARI project, the aim of which was to assess the effectiveness of three different stigma-reduction interventions: counselling, socio-economic development and contact. Cirebon District was selected because it has a high prevalence of leprosy, a high number of new cases annually and a relatively high level of leprosy-related stigma.

**EXPLORATORY STUDY**

The exploratory study was conducted between May and November 2011, during which 53 in-depth interviews (IDI) were conducted with people affected by leprosy or their caregivers. Health professionals from community health centres provided the contact details of people affected by leprosy in the selected areas. The participants were purposively selected based on characteristics such as age, sex and role in the community. After they were given information about the project, they were invited to participate in the study. Research assistants from the study area were hired and trained as interviewers. Due to the interviewers’ limited experience, 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 enquiry. Topics addressed in the interviews were (i) socio-demographic information, (ii) medical history (including perceptions of causes, infectiousness and prognosis), (iii) current health situation (including feelings and emotions), (iv) economic situation, (v) social situation (including role of family and others) and finally (vi) the impact of leprosy on their lives (including violations of human rights and experience of discrimination).

In addition, five focus group discussions (FGDs) were conducted with people affected by leprosy, family members and counselling experts. The aims of these FGDs were to validate the findings from the interviews and to deepen the understanding of their perspectives. The location of the FGDs varied from the SARI office to a local hotel. In addition, the design differed slightly for each group, but the common themes were: (i) understanding leprosy, (ii) stigma in the community, (iii) main issues in the community, (iv) current strategies, and (v) recommendations for strategies to reduce stigma.

The interviews and FGDs of the exploratory study were recorded, transcribed, and translated into English.

**PILOT STUDY**

The first author (ML) is a trained counsellor with more than 20 years’ experience and was the main counsellor during the pilot study. ML is visually disabled and worked using braille, a development of a rights-based counselling module.
screen reader and with a personal assistant. She was assisted by 10 local research assistants who were recruited for the SARI project and were involved in the data collection and implementation of the interventions. In order to create active participation of the beneficiaries of the project from the start, the project hired several people affected by leprosy or with a disability. In December 2011, the research assistants participated in a 3-day basic counselling training from ML 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 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 to April 2012. During the pilot counselling, personal counselling notes (PCNs) were written about each client. PCNs are notes made by the counsellor (ML) 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). ML inserted the research assistants’ observations if, for some reason, she had not been able to provide the counselling herself.

To explore some aspects of the counselling in more depth, tape recordings were made of 12 counselling sessions. In addition, separate notes of group counselling sessions (GCNs) (five in total) and family counselling sessions (FCNs) (17 in total) were taken. Evaluation meetings notes (EMNs) were taken at the monthly (four in total) meetings with the research assistants. 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 were divided into two categories: the content of the counselling (including themes such as knowledge, feelings, stigma, discrimination, human 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.

Ethical considerations

The study was approved by the Ethics Committee of Atma Jaya University, the Sub-Directorate for Leprosy and Yaws, Ministry of Health, 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 non-literate, 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 verbal 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 verbal or written informed consent on their behalf.

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. At the end of the results section
the Rights Based Counselling Module with its key principles, counselling skills and content per session is presented in summary form.

**KEY ISSUES IDENTIFIED DURING THE EXPLORATORY STUDY**

*Participants* – Of the 53 IDIs that were conducted during the exploratory study 44 were held with people affected by leprosy and nine with caretakers of children affected by leprosy. Of the 53 interviewees, 34 (64%) were women. Different ages were included (eight were <20 years, 20 were 21–40 years, 12 were 41–60 years and seven were > 61 years and in six cases age was not given). In total, five FGDs with 38 participants, 26 women (68%) and 12 men (32%), were analysed. The number of participants in the FGDs ranged from five to eight. The most important findings of the exploratory study are presented below. For a more comprehensive overview of the results of the exploratory study we recommend Lusli *et al.*,30 Peters *et al.*,10 Peters *et al.*,31 and Dadun *et al.*32

*Health perceptions* – In the exploratory study it became evident that many people affected by leprosy had incorrect perceptions about their health condition. Common misconceptions and different health belief systems were identified and confirmed during the FGDs. There were different understandings related to the cause of the disease (‘genetic’, ‘black magic’, ‘touching something dirty’). Many people affected by leprosy did not realise they were no longer infectious after starting multi-drug therapy (MDT) treatment. People also tended to perceive the effects of the disease to be worse than is often the case in reality. Some perceived the disease as ‘incurable’ and as a death sentence (‘the disease that kills people’).

After finishing treatment, many participants wondered whether they were cured and whether they would become ‘normal’ again. These doubts about whether they were cured can be well understood because of impairments or reactions to leprosy. From a medical perspective, they may still be at risk of complications of the disease. However, after 6 months to a year of MDT most people are cured of the leprosy infection, and definitely need not fear infecting others.

*Feelings and emotions* – Respondents felt a mixture of negative feelings and emotions when they received their diagnosis. The interviews illustrate that people affected by leprosy often directly stigmatise themselves and feel strong emotions such shame, disgust and fear. Some said during the interviews that they denied their diagnosis and some decided to conceal their disease. This all resulted in 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 years)

Negative feelings and emotions were strong during the treatment and many continued to experience negative feelings even after they had been cured. Some people affected by leprosy said they wanted to bring about a change in their life but did not know how to realise this. Generally, people affected by leprosy were extremely passive, guilt-ridden and under the impression that they were 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.

*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 years)
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. running a successful business or could build on the support of the family) and found solutions to deal with stigma.

Human rights and discrimination – Very little reference was made to human 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 (or enacted stigma) 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 years)

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 years)

Not only does the ‘outside world’ deny people affected by leprosy rights, those affected also seem to accept and internalise 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 years)

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 FGDs it became clear that also the family of the person affected by leprosy is affected by the stigma associated with it. 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 stigmatisation, for instance by keeping their distance or by encouraging the concealment of the disease. A similar pattern can be found among friends and neighbours.

HOW THE EXPLORATORY STUDY INFORMED THE COUNSELLING PRACTICE AND MODEL

The exploratory study showed the interrelativeness 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 understanding of the local context. The practice of counselling clients needs to deal with the following elements: the extreme passiveness, the perception of oneself as ill and guilty, the feeling that life can be mainly improved by money, the violation of rights, and the role of the families and the wider community.

The exploratory study influenced the development of the counselling practice in four ways. First, many problems facing people affected by leprosy are rooted in a lack of knowledge about their disease and its consequences. An effective counselling practice
provides reliable knowledge as soon as possible. Second, in order to deal with the passiveness, guilt and low self-esteem, an optimistic and energetic counselling style seems appropriate. Such a style is described as motivational interviewing. With its empathic, supportive and yet directive style, motivational interviewing aims to provide conditions in which change can occur. It supports self-efficacy and generates confidence. Third, 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 focusing on individual, family or group counselling alone, an approach with a combination of these three types seems needed. This also allows flexibility – some clients will probably not flourish in groups, others not in individual counselling sessions, whereas again others might reject family counselling because of the wish to conceal the illness. If different types of counselling are offered the client’s individual needs and wishes can be addressed.

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

KEY ISSUES IDENTIFIED DURING THE PILOT

Participants – Sixty-two people affected by leprosy were offered counselling during the pilot (see Table 1 for demographic information).

More than half of the participants who were approached 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. As shown in Table 1, 58 clients did receive three or more counselling sessions and 30 clients received five or more counselling sessions. 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 of work, school, family matters and personal activities. A strong flow and focus during the sessions was not always realised.

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?” This helped the clients to feel at ease and be more open. Clients, in general, showed a very positive reaction to the presentation of information about leprosy. They were relieved once they understood that it is caused by a bacteria. The realisation that people affected by leprosy are no longer infectious once they have started taking medication and that they are cured (which does not mean the end of risk of any leprosy-related problems) when they have finished the treatment was key.

Talking too much about feelings and emotions 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 their 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 internalised 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

### Table 1. An overview of clients

<table>
<thead>
<tr>
<th>Participant characteristics</th>
<th>Counselling clients (n = 62)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>30 (48.4%)</td>
</tr>
<tr>
<td>Female</td>
<td>32 (51.6%)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>16–25</td>
<td>25 (40.3%)</td>
</tr>
<tr>
<td>26–35</td>
<td>14 (22.6%)</td>
</tr>
<tr>
<td>36–45</td>
<td>15 (24.2%)</td>
</tr>
<tr>
<td>46–55</td>
<td>4 (6.5%)</td>
</tr>
<tr>
<td>&gt; 56</td>
<td>4 (6.5%)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Not married</td>
<td>27 (43.5%)</td>
</tr>
<tr>
<td>Married</td>
<td>35 (56.5%)</td>
</tr>
<tr>
<td>Education*</td>
<td></td>
</tr>
<tr>
<td>Elementary school</td>
<td>35 (56.5%)</td>
</tr>
<tr>
<td>Junior high school</td>
<td>21 (33.9%)</td>
</tr>
<tr>
<td>Senior high school</td>
<td>6 (9.7%)</td>
</tr>
<tr>
<td>Profession</td>
<td></td>
</tr>
<tr>
<td>Paid job</td>
<td>16 (25.8%)</td>
</tr>
<tr>
<td>Own business</td>
<td>6 (9.7%)</td>
</tr>
<tr>
<td>Student</td>
<td>9 (14.5%)</td>
</tr>
<tr>
<td>Housewife</td>
<td>11 (17.7%)</td>
</tr>
<tr>
<td>No job</td>
<td>20 (32.3%)</td>
</tr>
<tr>
<td>Clients stopped during counselling sessions</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>5 (8.1%)</td>
</tr>
<tr>
<td>3</td>
<td>15 (24.3%)</td>
</tr>
<tr>
<td>4</td>
<td>12 (19.6%)</td>
</tr>
<tr>
<td>5</td>
<td>15 (24.3%)</td>
</tr>
<tr>
<td>6</td>
<td>5 (8.1%)</td>
</tr>
<tr>
<td>7</td>
<td>4 (6.6%)</td>
</tr>
<tr>
<td>8</td>
<td>6 (9.3%)</td>
</tr>
</tbody>
</table>

* including those not finished
house, cooking, going to the market, and attending social gatherings. In general, and especially when there was already 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 any more, even though he knows I am still taking medicine.* (FCN1)

Changing patterns of stigmatisation in families where these patterns were deeply rooted was challenging. In about half of those families, stigmatising patterns were broken relatively easily and more supportive families developed naturally, but the other half made only small steps forward. 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 had met anyone else 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 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.* (PCN, 14)

Two main pathways to change were used 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 the 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?

**How the pilot informed the counselling practice and model**

The pilot study showed that clients were comfortable talking with the counsellor about their feelings, thoughts and future. The CBT, knowledge-based, rights-based nature of the practice was appreciated by the clients – young and old, male and female – as it generated hope, helped them to take initiative and reduced internalised stigma. Group counselling was the clients’ favourite type of counselling (though some did reject it as anticipated) and family counselling was the least favoured (though a few clients indicated they benefited most from this type of counselling).
Three issues for improving the practice became evident. Dealing with a complex problem from different perspectives might jeopardise an effective and integrated approach. The 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.

Second, although the counselling practice included from the beginning only eight sessions of 60–75 minutes each, it was concluded that the number had to be further reduced. Five sessions of 30 minutes to an hour seemed to be more appropriate for the clients. The integration of elements, the energetic approach, attention to flow and focus and giving assignments made it possible to reduce the time of each session.

Finally, and perhaps most importantly, 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 use. It was important, among other issues, 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, in addition to which a set of five principles and the content of each session was specified. Another crucial aspect is the feeling of ownership of the lay and peer counsellors. In order to achieve this, the module was not set in stone, leaving room for adaptations based on the wishes and needs of the future counsellors. A summary of the final counselling module is presented in Figure 1.

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 (33,34).

- 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

Fig. 1. continued


Content of the five sessions

Session 1: Assessment of situation and trustbuilding
Type of counselling: Individual counseling
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 counseling
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 counseling
Timing: 30–45 minutes
Content: Discussions on daily activities; exploring and clarifying family worries and fears related to leprosy; reducing worries and fear with clarifying medical knowledge on leprosy, treatment and being cured; discussing the involvement of the client in the family roles and responsibilities; exploring how family members support each other; preparing group counseling (expectation and planning).

Session 4: Learning from each other and action
Type of counselling: group counselling
Group size: 4–6
Timing: 45–60 minutes
Content: Sharing personal experiences with leprosy and stigma, focusing on the challenges and success stories (counsellor focuses 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.

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, 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 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. The rights-based focus was in particular powerful and supported individual empowerment and agency. Therefore the module was named ‘Rights-Based Counselling Module’.

Knowledge and awareness of the disease were – as anticipated – important elements of the counselling. We are aware that the effect of education on reducing stigma has been subject to criticism. 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.

This study indicated that only a few counselling sessions can trigger clients affected by leprosy to move from a seemingly hopeless situation into a place where they feel hope, take initiatives and experience less internalised stigma. All this is very promising, but more importantly it was also confirmed by the effectiveness study of the module. Different quantitative and qualitative methods (e.g. three scales, interviews, FGDs and reflection notes) were used in this study to assess the impact of the intervention. The study concluded that a significant reduction was found between the before and after total scores of the SARI Stigma Scale ($P$-value < 0.001), Participation Scale Short ($P$-value < 0.001) and WHO Quality of Life score ($P$-value < 0.001) among the counselling clients. For more detailed findings we refer to Lusli et al. and for comparisons of this intervention with other interventions (contact and socio-economic development) we refer to Dadun et al.

The practice and module can be implemented by lay and peer counsellors. Detailed knowledge gained during the exploratory study about the characteristics of the clients can be transferred to the lay and peer counsellors. Skills needed to generate the trigger can also be learnt. 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. In the counselling work it is both stigma that can be reduced (e.g. internalised stigma and perceived stigma in the individual affected and some enacted stigma in family members who participate in the family counselling) and resilience and ability to cope that is enhanced.

The exploratory study highlighted the many differences and similarities between people affected by leprosy. These similarities and differences have also been studied and described by scholars in India, Nigeria, Nepal and Brazil. Group counselling offered the opportunity to use the differences between clients as an opportunity to discuss various options, viewpoints and strategies to deal with stigma and other leprosy-related problems. This was also done in the study of Floyd-Richard and Gurung. Thus, instead of seeing the differences between affected people and complexity as problems, in this counselling approach they can be seen as an advantage.

**Limitations**

First, although the approach taken was generally appropriate to the needs of the clients, this counselling practice and module are effective only when concealment was not the client’s main priority. The importance of concealment for people affected by leprosy was shown in
the studies of Kaur and Ramesh\textsuperscript{42} and Vlassoff \textsuperscript{43} in India, by Heijnders in Nepal\textsuperscript{7} and by Peters \textit{et al.}\textsuperscript{31} in Indonesia. Those who were concealing their leprosy did not favour counselling as an approach to reducing stigma. Second, the pilot was conducted by the main counsellor, whereas it is actually meant to be done by lay and peer counsellors. This had advantages as she was able to test different counselling styles and types, but also had limitations as other ways to create ownership had to be found (e.g. not setting the module in stone). Third, sometimes it was schedule-wise not possible for the first author (ML) to be the counsellor during the pilot; these sessions were then taken over by trained but relatively inexperienced lay counsellors. Fourth, we did not systematically collect information about the duration of illness. This is an important variable and might have led to valuable information and insights.

**Conclusions**

There is a lack of insight in how to reduce stigma and realise empowerment in people affected by stigmatised 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, the clients took initiatives and responsibilities, which they believed earlier they did not have the capacity or right to undertake.

Although it is generally recognized 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 module presented here should be adjusted to the new context and tested before it can be scaled up. The process of an extensive exploratory study and pilot might be relevant for those who would like to develop a counselling practice for leprosy in other areas, other stigmatised NTDs or other stigmatised conditions.

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