

**THE WAY WOMEN EXPERIENCE DISABILITIES AND ESPECIALLY  
DISABILITIES RELATED TO LEPROSY IN RURAL AREAS IN SOUTH  
SULAWESI, INDONESIA**

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**ABSTRACT**

*Many leprosy affected persons who have been cured long ago, may have disability and have to cope with problems caused by stigmatization. Rehabilitation requires information about personal and environmental factors, the magnitude of the need and the types of disability in the area. To answer these questions, a rapid disability appraisal (RDA) method was developed. The RDA is a toolkit of (existing) questionnaires for planning, monitoring and evaluation of rehabilitation services. As part of a validation study of this toolkit, qualitative data were also collected. This paper reports on the latter and focuses primarily on how women in rural areas in South Sulawesi cope with disabilities and especially disabilities related to leprosy.*

*The results showed that most women with disabilities were not able to contribute to the family income, but did perform household activities. In general, the women were able to take care of themselves. The community treated people with disabilities not caused by leprosy well, respected them and did not avoid them. Women with leprosy encountered many more problems in daily life, mainly due to stigma. Not only did people avoid the person affected by leprosy, but also their family. Even leprosy-affected persons themselves avoided other people. A leprosy-affected person was not accepted as a marriage partner for a healthy person. All women with disabilities gave evidence of the existence of stigma, resulting in social participation restrictions. Especially women affected by leprosy were stigmatised by relatives and community members. They also suffered from self-stigma. Disabilities and stigma resulted in lower education, income and marriage prospects for all women. Action is needed to change beliefs*

*and attitudes regarding leprosy and disability and to improve access to appropriate rehabilitation services.*

## **INTRODUCTION**

Leprosy control is making good progress in Indonesia. But although affected persons are cured of their disease, many still have to cope with disability and problems caused by stigmatisation (1). They are not involved in social activities, have low marriage prospects, and are less likely to be employed. There is a need for rehabilitation which requires a locally relevant approach, and which cannot be duplicated necessarily between places or even from one person to another (2). The impact of a disability is determined by many physical, psychological, social and economic factors. So, before rehabilitation programmes are developed, planners need to be informed about these factors, the magnitude of the need and the types of assistance required. Questions to be asked include: Are stigma and social exclusion a problem? If so, what are the reasons? How many people are affected? Is there a need for an information campaign? These questions can only be answered by investigating the physical, psychological, social and economic aspects of disability related to individuals, families and communities.

To answer the questions related to the impact of disability, a rapid disability appraisal (RDA) method was developed. The RDA is a toolkit of (existing) questionnaires for rapid appraisal of disability in a particular geographic area, for the purpose of planning, monitoring and evaluation of rehabilitation services. The RDA toolkit was tested in a quantitative study in two rural areas around Makassar, South Sulawesi, Indonesia.

To complement and validate the results of this quantitative research, qualitative data were also collected. This included interviews with men and women with leprosy-related and other disabilities. In this article, information gathered from all female respondents will be discussed.

## **METHOD**

### **Research design**

The research was conducted in two rural districts around Makassar on South-Sulawesi, Gowa and Maros (3). The Hasanuddin University, located in Makassar, provided competent

staff for this research, both study supervisors and Research Assistants (RAs). RAs were post-graduate students at Hasanuddin University who followed English lessons. The Provincial Leprosy Programme carried out preparatory work for the field surveys, provided technical support and supervised part of the data collection. Netherlands Leprosy Relief (NLR) provided financial support and gave major inputs into the training of research assistants and field supervision of the data collection.

After training, a pilot study was conducted to establish whether any issues needed to be addressed related to the translation of the instruments and data collection methods. Some of the interviewers required further instruction to further improve their interview techniques, but, eventually, data were collected with adequate reliability (4) (van Brakel et al., in preparation).

The study consisted of a quantitative and qualitative part. The intention was to collect qualitative data to validate and support the quantitative data. The quantitative part of this research will be reported elsewhere.

### **Data collection**

Two methods were used to collect data for the qualitative part of this research: in-depth interviews and focus-group discussions. The in-depth interviews comprised both women with leprosy-related and other disabilities. The study was carried out in five different locations. At every location, focus-group discussions with about seven disabled women were carried out. Individual interviews were carried out with one disabled woman and with a woman suffering leprosy. In addition, two community leaders and one religious leader as key informants were interviewed. The in-depth interviews used an interview guide.

For the qualitative part of the study, local health workers (*kaders*) were requested to identify people suitable and capable of being interviewed. The main selection criteria were being capable of communicating understandably with the RAs (for example, deaf people were excluded), living accessibly enough for the survey team to visit and being willing to cooperate in the research.

## **Analysis**

From the qualitative data forms, a table grid was made listing the answers according to who had given them, the women with disabilities or the key informants. The results were screened for common themes discussed during the interviews. The results were then categorised according to these themes. The themes were 'work', 'social activities' and 'acceptance by the community', and for the key-informants, 'knowledge about disabilities and leprosy', 'acceptance of people who suffer from these conditions' and 'marriage prospects' of these persons. The representative answers are described in the results.

## **RESULTS**

### **Women with disabilities**

#### Work

None of the women interviewed had a paid job. The women said that they did not have a reasonable chance to get a paid job. They indicated that lack of proper education and of suitable vacancies were reasons for this. All women agreed that their disability was their biggest barrier to find a job. One respondent, who was a teacher in a high school before she got disabled, told us:

"If I was healthy I would get a job easily, especially with my educational background. But with my condition, of course it is different, because I am disabled."

Most women carry out household activities, which take a couple of hours a day, and are usually done in the morning. Working hours were limited between 1-6 hours a day and the women are unable to work quickly. The women experience the most problems with 'heavy' activities like collecting wood and carrying buckets of water. Most of the women get help from their families to perform these kinds of activities. One respondent said: "*My children usually warn me. They say: 'Come on mother, you don't need to do that.' For instance when I try to lift heavy things. When they say that, then I'll not continue that, I just leave it.*"

The women did not really feel bad that they do not contribute to the family income. But the women who could not do household activities at all felt guilty and ashamed about it. One

respondent said: *“I feel sad, because I feel like I have troubled my family. But my family doesn’t feel like that, they are very willing to help me.”*

Women with disabilities related to leprosy are suffering more severe problems related to their condition than women with other disabilities. They usually have severe disabilities making it impossible to work. One respondent said: *“My movement is limited and sometimes I do not feel well. Heavy things that I grab usually fall out of my hands.”*

They are dependent on their relatives to get enough money and food. One respondent said: *“I can’t earn money for a living. Only if I go to my nephew’s house he usually gives me money like 20 thousand, 30 thousand or 50 thousand Rupiah (about €2, €3 or €5).”*

#### Social activities

When social activities take place within the family, the women are involved in these activities. They take part in family celebrations like after-birth celebration (local term: *aqiqahan*), circumcision celebration and marriage. They also go to family gatherings, during which other family members were said to be interested in the opinion of the disabled women. The women experienced exclusion from social activities held at community-level. None of the women received invitations for community gatherings in the public affairs office. However, most of the women do attend important religious meetings:

*“When there is a community gathering in the public affair office, I’m not invited. I do go to the Maulid (Prophet Muhammed anniversary), which is celebrated in the mosque. Usually my niece picks me up.”*

Some women suffering leprosy-related disabilities did not live with their families any more. Neither did they visit family and relatives in the village. They only visit the closest related family living nearby. One respondent said: *“Right now, it is far different than when I was healthy. In former times, when there was a family having a celebration of an event, I always came if they invited me, although it was far away. Now not anymore, except for them who live very close. Then I still come, if they are close relatives and living nearby.”*

#### Acceptance by the community

All women told the interviewer that people in their communities were kind to them. They are not disgraced or insulted. The main problem they experienced was that sometimes they

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were treated differently from other healthy people. One respondent said: *“Healthy people seem to be very sorry for us. But sometimes their deep compassion creates a different treatment. What I mean is, of course their behaviour toward us and toward the healthy people is not similar. We have to understand that.”*

The women sometimes experienced problems meeting people they did not know. They feel shy and ashamed. This causes them to avoid meeting unknown people, because they are too embarrassed.

It became clear from the interview results that women suffering leprosy-related disabilities had the most psychological problems caused by their condition. They feel they are a disgrace to their families and have very little self-esteem. Respondents said: *“Actually, I feel embarrassed if people see my condition like this. If possible, I do not want to see them.”*

These women also indicated that getting married is not possible for them. One young leprosy patient said (while crying): *“I have no friends. No boy will ever want me.”*

#### Key-informants

In the interviews with the key-informants, special efforts were made to find out differences and similarities in behaviour of people towards people with disabilities caused by leprosy and people with other disabilities.

#### Knowledge about disabilities and leprosy

The key-informants indicated that disability is considered a gift from God. *“Disability comes from Allah’s will. We don’t have the power to reject it. But it is not a curse. It is like a test from Allah to someone’s faith.”*

Leprosy is considered to be a hereditary or transmitted disease, but also one that can be caused by a curse or a spell. A key-informant said: *“The cause is curse or spells. If it is a curse, there is no cure for the disease. The person who has it and his / her family will feel very humiliated. It is different if it is caused by spells. People do not feel that embarrassed because it is a spell and it is curable if you bring him / her to a ‘smart healer’ (kind of traditional healer who’s an expert in magical issues to cure)”*.

Various beliefs about people with other disabilities also exist. For example, a key-informant said: *“About other disabilities; usually people think that if a mother is half blind (local term: picco), her child will be half blind also. There is also another belief about picco: if someone who collects debts meets a person who is picco, it will usually bring bad luck that day. He would better return home.”*

#### Acceptance by the community

Before multi-drug therapy became available in 1981 (3), it was common for leprosy affected persons to leave their communities and live in separate leprosy settlements. Even now, some persons feel too embarrassed to live with their families. The key-informants said that, sometimes, families build separate houses for their relatives who have leprosy. Such persons sometimes received treatment, but sometimes not. The key-informants did not have information about whether they move back to their family-homes, when they are treated and cured. Nobody visits such persons, except close relatives who bring them food. Eating utensils are kept separate. This is also the case for the clothes they wear, and the bed they sleep in. This phenomenon, building a separate house for leprosy affected persons does not happen for other disabled persons.

The behaviour of healthy people from the community towards cured persons was also discussed. The feelings of disgust among healthy people are worse when someone has severe leprosy (with wounds) than towards people with ‘common leprosy’ (no wounds). People do not have these kinds of feelings towards the family of a leprosy affected person. The feelings of disgust are reduced if the persons receive treatment. Nevertheless, many people still feel disgust. A key-informant said: *“As a matter of fact, there’s no problem when they are cured. But even then, many people feel disgust even though they are cured. That’s because the signs they have, like mutilated fingers.”*

The local term for the behaviour of normal people toward persons affected by leprosy is: *nibamparekangji* (to ignore or treat them like they do not exist). This was also said to be the reason why persons affected by leprosy in general do not take part in community activities. Some of them do, but only after treatment. Behaviour towards people with other disabilities is different. The key-informants explained that people feel sorry for them and that they are treated like other normal persons. A key-informant said: *“It is Allah’s will, we just have to*

*accept and submit to it, we have to live with it. So, there is no reason to think less about these people. This community also does not disgrace people who have disabled children; we pay all the same respect.”*

#### Marriage prospects

It is difficult for people affected by leprosy to find a partner, except in cases where that partner is affected by leprosy also. The main reason is that people consider leprosy a hereditary disease, so healthy people are afraid to get a descendant with leprosy. This is not true regarding other disabled persons; for them it is therefore still possible to get a healthy partner. These lower marriage prospects also affect the family of a person affected by leprosy. A key-person said: *“It is also difficult for someone to get married, when people already know that he/she has a family member suffering from leprosy. Other people will be afraid of getting the disease, so they refuse to propose to a family member of that sick person.”*

This is not the case for siblings of persons with another disability. According to the key informants, another problem will be created if one partner gets leprosy in an ongoing marriage. In that case, it is accepted that the healthy partner divorces the affected one.

### **DISCUSSION**

In Indonesia, people with disabilities are stigmatised (5). Quantitative data from this study showed that, among people with disabilities, 21% reported to feel that people felt uncomfortable with them, treated them as inferior or avoided them because of their disability (4). Stigmatisation is the main cause of lower marriage prospects, a major cause of anxiety for women (6). Related to this, disabled women of younger age groups have higher depression rates. Elderly women with depression are more likely to be unmarried (6). Women who are more severely functionally disabled have higher depression rates and have more negative self-assessments of health (7).

Only a few young women were interviewed during this research. They all felt very ashamed about their condition and all were convinced no man would ever want to marry them. Apart from their disability, it is likely that women who do not marry because of their disability, are more vulnerable because they do not get the status of ‘married woman’ at all. This may be the reason why disabled women are twice as prone as able-bodied women to suffer violence,

separation and divorce (5). Also women who are divorced are more vulnerable than married women. They lose their status as 'married woman'. In addition, they also lose their income, because they were never expected to make their own.

All the disadvantages described, were more severe for women affected by leprosy. They were stigmatised much more than women with other disabilities. One reason for this stigma is lack of knowledge about the disease. Therefore, key-informants were asked what they knew about leprosy. Despite the fact that most of the key-informants had a proper education, they did not know that leprosy is a disease caused by bacteria, highlighting a need for more community education about leprosy.

Before multi-drug therapy came available, when leprosy was an incurable disease, separate houses and even settlements were built for leprosy patients. This also promoted the development of stigma, because of the separate treatment of the people affected. Since the late 1940s, leprosy is a curable disease. Despite the introduction of the multi-drug therapy (3), which makes leprosy a very well-treatable disease, people still feel very ashamed to have leprosy. Key-informants said that leprosy patients usually feel so embarrassed about their condition that they exile *themselves* from their communities. This is known as self-stigma (8). They often have feelings of guilt and shame, causing them to have a low self-esteem. If women with leprosy feel ashamed about their condition, they are likely to behave differently. This may in turn enforce the existence of stigma.

Better health care may improve the condition of all these women. However, disabled women also encounter problems accessing health care. First and foremost, this is caused by the circumstances the women live in. This study was done in a rural area. Access problems are more severe in rural areas. High rates of illiteracy, longer distances, bad roads and limited access to motorised transportation compound the difficulties experienced by women with disabilities (6). Even if they reach a health centre, disabled women frequently have problematic encounters with health care professionals, which they interpret as being due to their disability or female status, or the combination of both (9). This may be true in Indonesia also, but was not investigated in the current study.

It is evident from the results that something must be done about the beliefs and attitudes regarding disablement, especially the beliefs concerning leprosy. This is possible, as was

demonstrated in the community-based Stigma Elimination Project (STEP) in Nepal (10). Although this project was not about women as such, it showed that people with leprosy-related disability could play a major role as change agents in their own communities. The result was a complete change in attitudes towards them, resulting in their equal participation in the community. More easily accessible rehabilitation services must be set up. Such services can give health education, advocate for the rights of these women and improve their mobility. Efforts must be made to improve the social and economic status of both women and disabled people in the community. Eventually, this is likely to be one of the most effective ways to improve the quality of life of disabled people.

## **CONCLUSION**

All women with disabilities gave evidence of the existence of stigma, and, as a result, social participation restrictions. Especially women affected by leprosy, were stigmatised by relatives and community members. They also suffered from self-stigma. Women with other disabilities were more affected by the latter and by functional limitations. Disabilities and stigma resulted in lower education, income and marriage prospects for all women. Action is needed to change beliefs and attitudes regarding leprosy and disability and to improve access to appropriate rehabilitation services.

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