

ORIGINAL RESEARCH

Narratives Around Concealment and Agency for Stigma-reduction: A Study of Women Affected by Leprosy in Cirebon District, Indonesia

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ABSTRACT

Purpose: *This study analyses the experiences of women affected by leprosy, taking into consideration whether they concealed or disclosed their status, and looks specifically at their ‘agency’. The aim is to provide recommendations for stigma-reduction interventions.*

Methods: *The study population consisted of women affected by leprosy who live in Cirebon District, Indonesia. Study subjects were purposively selected on the basis of characteristics such as age and role in the community. After informed consent was obtained, they were interviewed in their homes. Data was collected through semi-structured in-depth interviews. Analysis was done with six points of focus: who knows, care, social stigma, feelings, self-isolation and agency.*

Results: *In total, 53 women were interviewed. Eight were omitted due to ambiguity over who knew about their leprosy status. Five different categories of ‘disclosure’ were identified, ranging from 1 woman who concealed completely to 19 (42%) who disclosed fully. Disclosure created possibilities for care and support, which 84% mentioned they received. In contrast, disclosure was also found to be linked to negative feelings, isolation and social stigma, which 18 women experienced. The women coped with this through acceptance, comforting themselves, trusting in God, focussing on recovery, friendship or finding inspiration in others.*

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Conclusions: *An analysis of these experiences helps to understand how women affected by leprosy are coping, and what they are already doing for and by themselves. This could be a starting point for more appropriate and effective stigma-reduction interventions. It is recommended to consider the following: i) assisting people with their choice, if any, of either concealment or disclosure, ii) the appropriateness of any intervention for people who (want to) conceal their illness, iii) the existing sources of care and support, and iv) the inner strength demonstrated and its three sources (spirituality, relationships and the desire to be cured).*

Keywords: *disclosure, stigma, support, relationships, interventions*

INTRODUCTION

The effects of stigma can be brutal; the discrimination it may engender can be a major affront to the dignity of affected people. The effects of stigma can also be subtle; the labelling, stereotyping and separation that characterise it can cause affected individuals to lose their identity, self-esteem and sense of purpose (Cross et al, 2011a).

Brutal and subtle; these are two distinct but prominent characteristics of the consequences of stigma. Unmistakably, stigma is something that should be addressed, for instance, with interventions such as self-care groups, counselling, education, contact, advocacy and protest (Brown et al, 2003; Heijnders and van der Meij, 2006). Reviews of studies on the effectiveness of these approaches have helped build an understanding of the factors that explain success and failure (Brown et al, 2003; Heijnders and van der Meij, 2006). This has led to some general principles: interventions should primarily aim at empowering affected persons, affect stigma at more than one level and require fine-tuning for greater specificity between conditions (Heijnders and van der Meij, 2006; Cross et al, 2011b).

In this paper, the focus is on how to adapt interventions to the specific experiences and needs of the target group. It is generally accepted that taking people's own social history, cultural meanings, understandings and concerns into account is essential for successful stigma-reduction interventions (Gussow and Tracy, 1970; Secker et al, 1999; Smith, 2002). The target group in this study are people affected by leprosy, the archetype of a stigmatised health condition (Frist, 2003; Rafferty, 2005; van Brakel and Miranda-Galarza, 2013). The authors argue that, even within this specific target group, interventions will benefit from being tailored to the

experiences and needs of sub-groups because social histories, cultural meanings, understandings and concerns differ between individuals, especially between men and women. It is the authors' belief that an in-depth look at the experiences and needs of these two sub-groups can provide new insights for stigma reduction. This study will focus on women only, though it is stressed that a focus on men is equally relevant.

Much research in the field of stigma reduction focuses on the negative effects of leprosy, justifying the need for interventions. This is important as such, but can also neglect what people affected by leprosy are doing for and by themselves, to bring about change in their own lives. The authors of this study set out to look for these 'hidden' actions and thoughts and their sources, or to put it differently, to look for the HUMAN CAPACITY TO ACT, also known as 'agency'.

Objective

The aim of this study was to analyse the experiences of women affected by leprosy in Cirebon District, Indonesia, in order to determine what needs to be taken into account when designing stigma-reduction interventions, and whether more effective use can be made of people's agency.

Theoretical Concepts

Concealment and Disclosure – The authors believe that concealment and, its antonym, disclosure are important and sometimes forgotten factors to consider while analysing the experiences of people affected by leprosy. The relevance is not only illustrated by Heijnders (2004b) while analysing the dynamics of stigma in Nepal, but also emphasised by Bos et al (2013). In this study, experiences with concealment and disclosure are connected with the potential positive and negative consequences of disclosure.

Stigma - Stigma is a complex social construct. Three interacting levels of stigma can be identified (Livingston & Boyd, 2010). The first level is the micro level which includes the three types of stigma exhibited by those who are stigmatised: 'anticipated' (or perceived), 'internalised' (or self-stigma) and 'enacted' (or experienced) stigma (Weiss, 2008, based on Scambler, 1998). The second level is the meso level, also known as social or public stigma. The third level is the macro level, also known as structural or institutional stigma.

Agency - Agency plays a role in both concealing and disclosing, as well as in the

potential positive and negative consequences of disclosure. There has been a long-standing debate by scholars on how to define the abstract concept of 'agency', beyond the **human capacity to act**. The work of Ortner (2006) was the basis for the analyses in the current study; she wrote that 'agency' in an abstract sense might seem a property of social subjects: "Some people get to 'have' it and others not; some people get to have more and others less". According to her, 'agency' is not a thing in itself, nor is it equivalent to the capacity of individuals to act **independently** or the exercise of free choices. On the contrary, Ortner underlines that 'agency' is part of a process, and social subjects are embedded "in the webs of relations that make up their social world" and in that sense, the acts of social subjects are never fully free or independent.

Ortner adds that it is useful to distinguish between 'agency of power' and 'agency of projects'. She wrote: "In one field of meaning 'agency' is about intentionality and the pursuit of (culturally defined) projects. In the other field of meaning, agency is about power, about acting within relations of social inequality, asymmetry, and force."

Introducing the SARI Project

This study is part of the Stigma and Assessment and Reduction of Impact (SARI) project that was initiated in 2010 in Cirebon District, Indonesia. The SARI project aims to assess the impact of three stigma-reduction strategies: counselling, contact and socio-economic development. In 2011, the SARI project executed an exploratory study to identify and analyse the problem perceptions, opinions and ideas of the different stakeholders, in order to design appropriate stigma-reduction interventions. The project also organised a large mixed-methods study to establish a baseline regarding the situation of persons affected by leprosy in Cirebon District.

METHODS

The analysis of the women's experiences is based on the qualitative semi-structured in-depth interviews that have been conducted during the exploratory and baseline studies. The *puskesmas* (community healthcare centres) provided the contact details of the persons affected by leprosy in their sub-district. The women were purposively selected based on characteristics such as age and role in the community. They were approached carefully - as some conceal their illness - and asked to participate in the study. Those who agreed were interviewed in their

homes. The interviews started in an exploratory manner and progressed towards more in-depth questions, and lasted for an average of one hour. During the interviews a guide was used. In the exploratory study the following topics were addressed: general information, life history, economic situation, social situation, health situation and leprosy. In the baseline study the topics were: leprosy history, feelings, family and friends, community, economic condition and future.

The interviews were recorded, transcribed and translated into English. Data management and analysis were performed using MAXQDA 2011 and NVivo. Analysis was done with six points of focus: who knows about the diagnosis, care, social stigma, feelings, self-isolation and agency. Occasionally there was ambiguity about who exactly knew about the leprosy status, and these interviews were left out of the analyses.

The study was approved by the relevant government offices and the Ethics Committee of Atma Jaya University. Written consent was obtained from individual study subjects. A small present (t-shirt, mug) was given to the participants as a token of appreciation.

RESULTS

Demographic Information about Participants

The 53 women who were interviewed were between 16 - 80 years old (average age 38 years). Of these, 33 (62%) were married, though some said that their current marriage was not their first, 9 were single, 1 was engaged, and 10 were widows. Most of the women were housewives and/or caregivers, 36 (68%) had children, and some were employed, for instance as shopkeepers, farmers, tailors, teachers or domestic workers. Most women had finished the 6 or 12 months of multi-drug therapy for leprosy. At the time of the interview, only 14 were still in treatment. Eight had a leprosy-related impairment to hands, feet and/or eyes.

Concealment versus Disclosure: *“This is my own problem and I can make it through”*

The women were asked who knew about their leprosy history or status. A clear picture emerged from the 45 interviews. The fact that others ‘know’ might be because the women intentionally informed them (disclosure), someone who knew informed others (disclosure of status by someone else), or because the

symptoms or side-effects of the medication were recognised as being leprosy. In the following instance, a doctor had informed others:

Interviewee: *"Yes, everyone [in the community] knows about it [her leprosy]."*

Interviewer: *"How can they know about your disease?"*

Interviewee: *"Because the doctor told them about my disease."*

(Interview 29: age 20years)

Five different categories of 'disclosure' were identified, as shown in Table 1. The category 'very few (1-3)' most often consisted of a husband and/or mother, and sometimes included the father or a sibling. Three women with a leprosy-related impairment managed to conceal their disease to some extent from others.

Table 1: Five categories of Disclosure of the Leprosy History or Status (N=45)

	Category: who knows?	Number (percentage)
1.	Nobody	1 (2%)
2.	Very few (1-3 people)	9 (20%)
3.	People in the household	3 (7%)
4.	Some extended family members, friends and neighbours, but not all	13 (29%)
5.	Everybody	19 (42%)

Table 1 also demonstrates that several women intentionally conceal their status from others. This is not perceived as an easy choice and has negative consequences, as illustrated by the following quote:

"It would be nice if someone could understand my feelings. It can also help me to talk freely with the person. However, many people who know that this person or that person is affected by the disease, might avoid us. I did not want that to happen to me. It troubled me."(Interview 9: age 35 years)

Apparently this woman conceals because she fears avoidance. This reason was mentioned most often by the women in this study, who feared avoidance by friends or customers. The women who intentionally concealed, managed to do so because the symptoms were not visible, appeared to belong to a different disease (e.g. rheumatism, measles, allergy), or because they deliberately covered spots and impairments (e.g. with veil, long sleeves, make-up) and asked people who

knew not to talk about the disease. This is demonstrated by the two quotes:

“The infection was not obviously seen in my case, so only few people asked me about it. On the other hand, my sister’s skin blackened. That was why everybody knew about her disease.”(Interview 13: age 30 years)

“I expect people around me, especially my family, not to talk about my disease to other people. This is my own problem and I can make it through.”(Interview 35: age 20 years)

Care and Support: “Stay strong”

When people around an affected woman knew about her condition, there was the possibility of what the women described as ‘care’, ‘support’, ‘love’, ‘compassion’, ‘closeness’ and ‘encouragement’. In total, 38 of the 45 women (84%) mentioned that they received some sort of care and support, frequently related to adherence to medication and getting cured. A total of 10 women specifically mentioned the care and support received from their husbands, and 6 mentioned their mothers. Some of the young women also mentioned the supportive role of their fathers. The responses of the husbands regarding the dark skin, and about not feeling ashamed, were important for the women:

“I suggested to my husband that he might want to leave me since I became black. ... Thanks to God that even though I suffered from leprosy and became black and dark, he [my husband] did not seem to have any evil-wish to leave his blackened wife. Not at all. He gave me his full support to get medication. He urged me to go and get the medicine when he saw me running out. ... He never felt ashamed of his wife who was suffering from such disease. He never tried to stay away from me. On the contrary, we became much closer to each other.”(Interview 18: age 35 years)

The same was relevant for people outside the household. One woman talked about the support she received from the head of the village, one about support from her extended family, and as illustrated by the following quote, one mentioned the motivation and support given by friends:

“Well, many of my friends who knew about it. They asked me about what happened with my feet and they told me to stay strong.”(Interview 15: age 50 years)

Social Stigma: “Well, let them be”

At the same time, disclosure can also create a mix of negative attitudes and behaviour. Words used by the participants that were categorised as social stigma included: avoiding, mocking, insulting, looking, gossiping, spreading rumours, feeling disgusted, separating utensils, asking them to stay away, and not buying their food or products. In total, 18 women mentioned that they had experienced some form of social stigma or still did; this is 62% of the women in categories 4 and 5 (see Table 1).

In one case this social stigma came from the husband, but more frequently the sources were friends, family, neighbours, vendors and children in the neighbourhood. For most of the 18 women, the social stigma was experienced during the time of treatment and faded away afterwards. However, for 7 (24% of categories 4 and 5) the social stigma persisted (sometimes for a long time) after being cured.

While coping with these negative attitudes and behaviour of others, some women showed strong inner, perhaps spiritual, strength and signs of inner acceptance. In other women, the “agency of projects” and the “agency of power” came to the front by respectively focussing firmly on getting cured and by standing strong against the ‘stigmatisers’.

“God meant this disease for me. Neighbour might not like me. Well, let them be. If they do not like me, then just continue not liking me.”(Interview 44: age 74 years)

“Well, I do not know. What I did was just taking the medicine. I resigned myself to God. That was all. Therefore, I did not feel shy or afraid. I did not feel such feelings at all. If people befriended me, I welcomed them, but if none wanted to do so, that was fine by me.”(Interview 18: age 35 years)

Interviewee: *“Often my friends and my neighbour made fun of me. They said that I looked like a scarecrow.”*

Interviewer: *“How did you feel?”*

Interviewee: *“I felt fine. I told them that I would restore my fair skin.”*

(Interview 32: age 18 years)

Internalised Stigma and Self-isolation: “She [my kid] inspires me to move on and live my life”

The mixture of negative feelings and emotions that may be evoked was also influenced by concealment and disclosure. These feelings could last for a long time – even after being cured – and were caused by a variety of factors. The main ones were: medical concerns (e.g. worry about contagiousness through breastfeeding or touching children), altered appearance (e.g. embarrassed by black skin), and the responses of other people (e.g. fear of being excluded). Mothers of young children were, in particular, afraid to infect others, as shown here:

“This disease is dangerous, contagious and pretty deadly. I felt pretty afraid that my children and other people that are close to me will be affected too.”

(Interview 8: age 31 years)

Other feelings related to perceived stigma (first quote) or were so intense that they could lead to self-mutilation (second quote) and suicidal thoughts:

“I act as a normal person who does not have any disease. Well, sometimes my colleagues did talk about one of our colleagues. ... His face is reddening and thickened, but it was not caused by leprosy. It is just a burn. ... People are avoiding him and avoid using the same gloves. ... I do wonder what if they know about my real condition. I started to worry after that. They must do the same to me or even worse [laugh].” (Interview 8: age 31 years)

Interviewer: “When you feel desperate, what do you do?”

Interviewee: “I have hurt my hand by myself, but my mother caught me.”

(Interview 10: age 20 years)

The women who had concealed their illness the most, reported feeling more emotions such as sadness, shame, low self-esteem and depression, compared to the other categories. Similar negative feelings were expressed more often by those who had experienced social stigma. These negative feelings, whether coming from within or being triggered by others, can result in self-isolation. It is important to note that a certain degree of self-isolation can exist, irrespective of having concealed or not.

“I sometimes felt a low self-esteem, meaning I know my position. So I kind of avoid gathering with them [neighbours] every so often. ... I used to be active in an organisation in Cirebon and now I pull myself away. ... It is because a voice comes to

my ear: Oh my, it might be contagious and I do not want that.”(Interview 44, age 74 years)

“After being affected by leprosy, I do not go anywhere. I do not go to the field either. I just stay at home like this. I just clean the house or wash the dishes.”(Interview 43: age 50 years)

An inner, sometimes spiritual, strength and the “agency of projects” could be found in at least 10 women who coped with these negative feelings and the self-isolation. The women who showed signs of acceptance tried to comfort themselves, trusted in God, focussed on recovering, reframed the meaning of a darker skin, and found inspiration in others:

Interviewer: *“You never felt like giving up?”*

Interviewee: *“No. Being affected by the disease was my destiny.”*

(Interview 4: age 30 years)

“Whether I feel comfortable or not with my life, I still need to live. So, what I should do is only enjoy what I can enjoy and be gracious about it.”(Interview 8: age 31 years)

“I cried a lot and kept thinking why God did not simply end my life. I once had an intention to hang myself, but then I remembered God and my religion, so I did not do it.”(Interview 20, age 34 years)

“I was sad, but I tried to comfort myself that I was being treated and will heal. I prayed to God to heal me soon. I did not want to think of my illness, I worried it will cause the other disease to attack me. So I tried to be indifferent.”(Interview 1: age 35 years)

“If I really had to suffer from the disease, then so be it. There is a cure for every illness. ... The most important thing was that I should not feel discouraged. ... I kept cool. What I needed to do was go to the Health Centre for a check-up every month.”(Interview 39: age 40 years)

“I remember when I had my first medicine. My skin turned so black, and that was when I knew the medication worked well.”(Interview 31: age 20 years)

“I used to be alone at home, while in the hospital, there were many people. ... I felt good. ... It is nice to have friends ... it feels rich. ... The doctor also advised: Mrs, you cannot be alone. There must be a friend for sharing things.” (Interview 44: age 74 years)

“I was going to end my life but then I knew that my kid was the reason I live. Sometimes I give up but then she inspires me to move on and live my life.” (Interview 37: age 27 years)

DISCUSSION

The analyses of the experiences of women affected by leprosy in Cirebon District, both those in treatment and those cured, with and without impairments, revealed dynamics around concealment and disclosure. In this paper, these were connected to potentially positive consequences (e.g. care, support) and negative consequences (e.g. social stigma, internalised stigma and self-isolation) and, most importantly to what women were doing for and by themselves, to bring about change in their own lives.

This study indicates that due to anticipated stigma, some women affected by leprosy in Cirebon tended to conceal their disease and hence reduced the risk of enacted stigma. However, at the same time, this coping strategy seemed to increase negative feelings and emotions (sadness, shame, fear) and internalised stigma. Concealment among affected persons has been described by others (Kaur and Ramesh, 1994; Vlassoff et al, 1996), as has the relationship with enacted stigma (Heijnders, 2004b). Considering concealment and disclosure in the analyses of stigmatised conditions, enabled the authors of this study to give a more precise picture of the consequences of leprosy. The value of considering concealment and disclosure is also shown in the work of Heijnders (2004a, 2004b).

This study confirmed that the consequences of stigma can be indeed brutal and subtle. They are brutal, in particular, when self-isolation, self-mutilation or suicidal thoughts are encountered; subtle, when things are less visible, as for instance responses like, “I act as a normal person”, or being given separate eating utensils. Social stigma, negative feelings and self-isolation are common themes in this, as well as in other studies (Oliveira, 1997; Shale, 2000; Zodpey et al, 2000; Varkevisser et al, 2009). Positive responses from others are mentioned a few times, but these are often not explored in depth (Kaur and Ramesh, 1994; Vlassoff et al, 1996; Heijnders, 2004b). Only Try (2006) explored this theme further in a study in Nepal, and showed that relatives provide support to women affected by leprosy more frequently than their husbands. This differs from the current study in which husbands often play a role in providing support.

Agency came to the front in this study, not only in the narratives around disclosure and concealment but also in the ways in which women coped with social stigma, negative feelings and isolation. Women who decided to conceal could show agency, for instance by going to work every day despite the attitudes of others that provoked the anticipation of stigma. Equally, women who decided to disclose could show agency by portraying a 'this is me' attitude. Openly acting against others who bully or make fun of people affected by leprosy (existing power relations) can be seen as Ortner's 'agency of power'. The focus on goals that the women want to achieve, such as getting cured, fits with Ortner's 'agency of projects'.

Three main sources for 'agency' related to coping with social stigma, negative feelings and isolation for women, were found in this study. First, religion or spirituality was seen, for example, among the women in this study who engaged in faith-based activities to get cured or among the women who found acceptance in their situation because it was created by God. Second, relationships with significant others for care, support and inspiration, for example the woman who considered suicide but found inspiration to live in her child. Third, the goal and hope of getting cured, for example the women who realised that feeling ashamed or discouraged would not help them get cured. The first source was also found in the study on leprosy of Oliveira (1997) who wrote that "religious beliefs appeared as a powerful panacea in helping individuals face physical and emotional afflictions". Similar results were found in a study of women with lymphatic filariasis by Person et al, 2009 who wrote "women, who positively reframed their situation, often drew upon their faith and engaged [in] faith-based activities to cope with their condition and manage stigma experiences". The third source is also addressed in the study of Heijnders (2004a), in which she describes the 'meaning of medication' and how this motivated people affected by leprosy.

Recommendation Arising from the Study

Several of the following recommendations seem to also be of value to men affected by leprosy. This raises the interesting question whether the gender of persons affected by leprosy in Cirebon or elsewhere really matters for stigma-reduction activities. Several studies have described the experiences of women affected by leprosy in India, Africa, Nepal, Nigeria, Indonesia and Brazil, and many indicate that women are worse off than men (Rao et al, 1996; Vlassoff et al, 1996; Oliveira, 1997; Morrison, 2000; Shale, 2000; Zodpey et al, 2000; Try, 2006; van Brakel et al, 2012). For instance, more women in India than men seem to

discuss the diagnosis more frequently with their family, and seem to get negative reactions rather than sympathy and support, more often than men (Vlassoff et al, 1996). Also, compared to men, women affected by leprosy in Indonesia are disproportionately affected by separation and divorce (van Brakel et al, 2012) and, in Nepal, women have poorer chances of remarriage after divorce than men (Try, 2006). Women are worse off than men, implying that they should be given priority for stigma-reduction interventions and interventions should ensure that women are not left out. More research using gendered analyses seems beneficial, and it is hoped that this study can contribute to a better understanding in the long term. In the recommendations that follow it has been decided to refer to people affected by leprosy.

Discuss the Implications of Concealment and Disclosure

The authors recommend that after sharing the diagnosis of 'leprosy' with a person, health professionals should discuss the positive and negative consequences of concealment and disclosure. If there is a choice, this might help them to make the choice more deliberately. They can then consider, by themselves or together with others, how to conceal or disclose and the coping strategies to deal with, for instance, increased sadness, shame (in case of concealment) or how to respond in an effective and appropriate way to negative community responses (in case of disclosure). The additional workload might be a concern for the health professional. If this is the case, lay or peer counsellors could take up this role as well.

Deal with Concealment while Designing and Executing Services or Interventions

The authors propose that those who design leprosy services and stigma-reduction interventions provide appropriate strategies or alternatives for affected people who have concealed their illness and do not want to disclose it. They could consider avoiding public announcements of their target group and instead focus on skin diseases, neglected tropical diseases, or take another inclusive approach. This is particularly challenging, but nevertheless very important, in the context of early case detection work and studies that focus on prevention of leprosy by giving contacts post-exposure prophylaxis. Also, the location for the activities should be considered carefully; family houses, health centres, government offices, public areas, all have advantages and disadvantages. Implementers should be careful when approaching people affected by leprosy as they might not have informed anybody, even their respective spouses, about their illness. Their consent should be taken before home visits are made.

Tap into the Support and Focus on Relationships

Another recommendation is to make effective use of the existing support. The majority of women in this study told the authors that they received care, support, love and compassion. For adult women, their husbands and mothers seemed to be the most important persons; for young girls, both parents played a key role. Hence, it is recommended that the sources of support be targeted with leprosy services and interventions, such as education and family counselling, as early as possible.

Strengths-based Approach

Several women in this study have shown great inner strength that lies in the sphere of personal self-esteem/confidence ("this is me") and in close relations with others, including their faith and relationship with God ("God intended me to have this disease"). Focussing on these strengths and considering strength-based approaches instead of, or as a strategy for, stigma reduction, seems promising.

Limitations and Reflections

This study was executed in Cirebon District, West Java, and the findings cannot necessarily be generalised to other areas. The in-depth interviews covered many topics (inductive approach) and did not focus on concealment and disclosure, its impact or on agency specifically. This might have provided an even richer picture. This study is based on the interviewees' perspectives. An interviewee might think that, for instance, neighbours are not aware of her leprosy status, but they might in fact know. The numbers presented are thus based on the perceptions of the women and not necessarily on the actual situation.

CONCLUSION

The main recommendation of this study is that anyone who designs or plans leprosy services and stigma-reduction interventions needs to understand what affected people are already doing for and by themselves, and should think about how they can support and engage with these processes. In the authors' opinion, this could have great potential for reducing stigma in the long run.

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