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TITLE

Health-related stigma related to leprosy– what can be learned from nurses in Ghana?

BACKGROUND

In a globalized world with increased migration different expectations and understandings of health and illness arise, including those surrounding health-related stigma. Health-related stigma exists worldwide and affects patients, relatives and caregivers. Leprosy, is one of the diseases that has long been associated with stigmatization and the mere word ‘leprosy’ is often met with disgust, shame and fear (1,2,3). The origin of the word ‘stigma’ was a tattoo mark, placed on criminals, slaves or traitors to facilitate for others to avoid the person. According to Goffman (4,5) stigma is defined as someone being different and less desirable than people in general, a weak, bad or dangerous person. Rejection, avoidance, prejudice and discrimination are further described in relation to stigma (6).

Leprosy, also known as Hansen’s disease, is a slowly progressive chronic disease caused by the parasite *Mycobacterium leprae*. (*M. Leprae*). The disease is transmitted via droplets from the nose and mouth during close contact with infected people who have not been treated (7). Those primarily at risk of being infected are people living under low socioeconomic conditions and those with weak immune status. However, factors such as gender, race and age have no effect on the occurrence of leprosy. If leprosy goes untreated it can lead to crippling, blindness and deformities (8,9).

Earlier studies show that stigma derives from several factors, including knowledge, attitudes and behaviours (2), and influences a person’s life and wellbeing (2, 7, 10, 11). Health-related stigma is often characterized as social disqualification of people and groups with certain health issues and can be considered as both a consequence and a cause of health issues (10) and is associated with low self-esteem, poor social adjustment and inferior quality of life (12).

Previous research shows that leprosy is often accompanied by mental distress. For example, a South African study showed that one third of those who had received a diagnosis of leprosy

contemplated suicide (2). Women with leprosy were found to be more severely rejected and isolated than men in the same situation, partly due to losing the emotional closeness to their children due to fear of transmission (13). Furthermore, the care encounter is affected for patients with leprosy, shown as being stigmatized by health care workers and refused treatment (14). Others raise to avoid seeking care or seeking care at a late stage when disabilities already being developed as consequences of health-related stigma (7,10,11). Efforts have been made in healthcare to tackle stigma and discrimination. However, the effectiveness of these efforts is not known, due to a lack of tools for evaluation, especially in developing countries (15, 3). There are some systematic reviews in the field of health related stigma and leprosy, eg. in relation to efficacy of interventions (16) consequences of stigma (17) and with comparison with other neglected tropical diseases (18). However, to the best of our knowledge there has only been limited research into nurses' experiences of health-related stigma in relation to patients affected by leprosy. At the same time healthcare workers, including nurses, generally hold a position of authority in society and thus have a significant role in preventing fear and stigma related to certain diseases (5,19). Therefore it was considered important to know more from the nurses perspectives, caring for patients with leprosy. The aim of the study was to describe nurses' experiences of how stigma affected the care and health of patients with leprosy.

METHODS

A qualitative descriptive study design was used. Data was collected during 2014 from interviews with nurses working with leprosy patients in the central region of Ghana.

Participants and setting

Information about the study was presented to the staff of a hospital in the central region of Ghana by a hospital employee. The hospital is a small primary hospital owned by the government. It began as a leprosarium in the 1950s but now works as a leprosy and general hospital. The hospital consists of two leprosy wards, one female and one male, a surgical ward, a delivery unit,

an emergency ward, a rehabilitation center, two theatres as well as a pharmacy. The hospital staff consist of registered nurses (RN), doctors, MD's, midwives, physiotherapist as well as administrative staff. The RN's rotate between each of the wards. The leprosy wards could hold 35 patients each and two RN's are in charge of each of those wards. From the nurses who were willing to participate in the study four were selected by the Deputy Head Nurse of the hospital based on the inclusion criteria; to be currently working as a nurse and to have experience of working with patients with leprosy.

Data collection

The initial interviews were performed by one of the authors using a semi – structured guide (Appendix 1) and were all performed at the hospital in a secluded office. The interviews lasted between 25 and 50 minutes and were tape recorded and transcribed by the two different authors (XX & YY). After reading the first interview transcriptions it was found that data gained was not sufficient to answer the aim of the study. Additional questions were therefore developed (Appendix 1) and follow-up interviews were conducted with three of the participants (the fourth participant was not available for a second interview). Two of the follow-up interviews were performed in the hospital and one in the home of the participants. These interviews were conducted with two of the authors present, one taking notes and handling the recording device, whilst the other acted as the interviewer (XX & YY). Later on the interviews were transcribed by the same two authors.

Data analysis

The analysis process inspired by Graneheim and Lundman (20) involved the steps “meaning units”, “condensed meaning units”, “abstracted meaning units”, “sub-themes” and a “theme”. Qualitative content analysis was considered appropriate, allowing different levels of abstraction based on the available text (20).

During the analysis process the interviews were read through several times, first separately by the

authors (XX & YY) and then together. Meaning units composed of words with a common content were extracted from the text (20), at first individually by two different authors (XX & YY) and then jointly in order to share an understanding of how to divide the text into relevant meaning units. As a next step ‘condensed meaning units’ were formulated, as a reduction of the original meaning units without changing the content of the text. The condensed meaning units were then abstracted into ‘abstracted meaning units’ and then related to each other into sub-themes and a theme, as a way of linking the core of the interpreted meaning of the text together (20). See Table I for an example of analysis procedure. The participants are referred to as ‘nurses’.

Table I (insert here) Example of the analysis procedure

Ethical considerations

The Research Ethics Committee at the Department of Health Care Sciences at Ersta University College, Stockholm, Sweden approved the study (1404/A) and the study was performed in line with the Council's scientific code of ethics (21), e.g. in relation to how to treat personal data. To protect the individuals and to guarantee anonymity, participants’ names were decoded. The data was saved on an USB memory and stored in a safety deposit box.

Participants in the study received both verbal and written information about the study stating that their participation was voluntary and that they could withdraw from the study at any time up until analysis of the data had been conducted. It was found out that one of the participants had not read the information letter prior to the interview, only received oral information by the head nurse. The participant therefore received oral information directly from the interviewer on the day of the first interview and after that gave her informed consent to participate. The participants were compensated for the time it took to perform the interviews with pay corresponding to their hourly

salary.

FINDINGS

The analysis resulted in one theme; ‘Increased knowledge and holistic intervention are important in the care of patients with leprosy’ and three sub-themes; ‘knowledge and beliefs are intimately interlaced with leprosy related stigma’, ‘information is important but not enough to change behaviors and attitudes’ and ‘long term intervention in a social context’.

The findings reveal the impact stigma has on daily life and health for patients with leprosy, together with the complexity of needs nurses have to consider for this group of patients.

Increased knowledge and holistic intervention are important in the care of patients with leprosy

According to the nurses in the study leprosy related stigma had a major negative impact on the patient’s wellbeing, and the care for those affected by the disease had to be different due to specific needs. The nurses stressed that knowledge and education were essential for reducing stigma. They described how a lack of knowledge among nursing colleagues and in society as a whole had negative consequences for patients and their relatives. To serve as educators and to provide holistic care with long-term goals, were described as essential for the nurses.

Knowledge and beliefs are intimately interlaced with leprosy related stigma

Negative attitudes due to the lack of knowledge were considered the main reason for stigmatization. Experience was expressed of a community where people believed leprosy to be

highly contagious, creating fear and discrimination. Patients with leprosy were excluded from social interaction by being denied physical contact and closeness. “For some of those people who are not educated they think it’s like a curse. They think that these people have done something for which they should be cursed”. The nurses explained that in Ghana leprosy is still commonly seen as a curse from God and incurs fear, which are reasons why patients do not want to be associated with the disease by being called lepers.

”If common people in the marketplace see that your hands are deformed due to leprosy no one will greet you, or touch you, or come near you, or even give you a bowl to share a meal with you.... So that is why they built the camp there for them”.

The camp referred to was a small community established especially for patients affected by leprosy. If nurses worked at a hospital known for treating patients with leprosy they were subject to negative remarks from their peers, due to the stigma surrounding the disease. At the same time the nurses also expressed a need to work in accordance with their own beliefs.

”I thought that if I ate well and exercised and all those things I wouldn’t get the disease, even though I have read that it is not eating well that will help prevent you getting it ... because it is a droplet infection”.

The nurses thought that the public notion of leprosy was for the most part negative and based on faulty information. However, they thought that there had been some improvement in the last few years. “Now it's better than it used to be. I used to go there, to the camp, when I was young, and

there was a lot of discrimination, the stigma was very marked, but now it's better, the patients are being accepted.” They described the diagnosis of leprosy as previously being seen as a death sentence and the process of dealing with the disease being met with aversion. In the past the leprosy ward was often described as the last stop in the journey of life.

“There is a church and a cemetery right next door, because before when you came here as a patient you would probably also die here”.

Information is important but not enough to change behaviors and attitudes

Stigmatization affects the health and care for those suffering. The nurses experienced an unwillingness to seek care, both among men and women, which they directly attributed to the stigma of a leprosy diagnosis. However, according to the nurses, women tend to seek care more often and at an earlier stage compared with men, resulting in women barely having any deformities, while deformities were common among the men. Patient education was considered important and to be one of their main duties as nurses. “Because they know me as a health professional and know that I am talking from experience and will accept it”. Patients were taught about the signs of leprosy and encouraged to seek care at an early stage if symptoms appeared. They were also taught about measures to prevent disability and injury. According to the nurses the staff tried to invite the relatives to the hospital so that they also could learn how leprosy is transmitted and treated.

“So we educate them on the condition, how to prevent it from getting worse, for instance what shoes to wear and the importance of not waiting to seek care”.

But education was not easy as both healthcare staff and relatives were unwilling to participate. Nurses described themselves as role models, showing how it is possible to interact with patients with leprosy without being infected. Nurses raised how important it was for patient to be touched in order for them to feel human.

“We touch them. We greet them. We are different, we are health personnel, we've been informed, but the information hasn't really got through to ordinary people”.

Information for patients as well as people in society was considered important by the nurses. However, as leprosy related stigma has a long tradition information alone was not considered enough to change attitudes. Relatives did not per se change their attitude or behavior towards the patient even if they attended education sessions. Even with information patients were regarded as lacking possibilities to follow recommendations.

“There is nothing there for them to do unless they beg, so some of them when they leave us don't take good care of themselves. Then they come back again. And when you want to discharge them, it's a problem”.

The nurses stated that despite being given information the patients did not care for themselves to prevent ulcers and other ailments. Being ashamed of their disease also interfered with patient's ability to take care of themselves. The problem with re-hospitalization was raised by the nurses.

“Some of them, after we have discharged them, can be here for as long as two months before they go, and when they go it won't be more than six months before they come back with even worse ulcers, and ulcers take time to heal, so they are here for a long period of time. They are in and out the whole time”.

Stigma was also manifested in patients asking the hospital staff to lie about the name of the hospital, and to exclude the fact that they had been admitted to a leprosy hospital when talking to their relatives. The nurses preferred to call the patients Hansen's disease patients instead of 'lepers' as people were not familiar with the term, as a way to protect the patient from stigmatization.

Long-term intervention in a social context

The nurses stressed the importance of not letting the general negative view of leprosy in society affect the care of their patients. Instead they looked to their Christian beliefs to guide the care. Even though more prestigious working positions were available the nurses talked about caring for patients with leprosy as a moral choice. One nurse said that she would not want to change her workplace because in the end she thought she would be rewarded for the work she was doing with the patients with leprosy in her current position.

“We Ghanaians, what we believe is that the clouds are the eyes of God. So God sees all that we do. And I have told them [the other nurses] that if you care for these people you will be rewarded”.

The importance of making all patients feel like human beings, regardless of diagnosis, was stressed by the nurses. However, patients with leprosy were thought to need extra care, as they usually had socio-economic problems due to disease-related stigma and often had no one, apart from hospital personnel, to take care of them. Examples of extra care included providing patients with more of the items such as soap and milk that the hospital received. Not discharging patients with leprosy too early from hospital was considered important. They would also be transferred to rehabilitation centers in the hope of helping them fit back into society after they were discharged. Some of them, because of the stigma, are not able to get work. Some keep making complaints so that we keep them here for as long as possible. Some of them keep coming back. They develop ulcers that they don't keep clean so that they can be admitted again, so that someone will care for them.

The financial situation for patients with leprosy was considered a major problem, having devastating consequences on their health and being a reason for them continuously being readmitted to hospital. According to the nurses many of the patients used to be farmers, but due to the nature of their disease they could no longer do any strenuous activity.

”I think if we can get something for them to do when they are discharged it would solve most of our problems. We wouldn't get the beggars, we wouldn't get those who are dependent on other

people (...) if there is something that could be done that could generate income, I think it would help”.

Nurses started workshops with the aim of helping the patients to learn a skill that would be useful when they were discharged. The nurses had to cater for the various needs of their patients in order to give them holistic care, address social, emotional and financial needs, and create long-term goals. Long term intervention focused on ensuring that the patient would be able to earn an income, as this would reduce the number of re-admissions to hospital. Continuous information and education for different groups in society were other examples of long-term intervention, with nurses hoping for changes in attitudes and beliefs in society as a whole.

DISCUSSION

In the present study caring for patients with leprosy meant facing and dealing with the general lack of knowledge of the disease, which affected the care and overall health of patients, as well as the role of nurses. Caring for this patient group involved supporting them to continue to contribute to society, giving them a meaningful existence in their community and improving their financial situation. Watson (22) describes the holistic approach encompassing establishing faith and hope in the caring process together and strengthening and humanizing patients. Holistic care with long-term intervention was a way of minimizing the risk of the patient returning to hospital just to get food and shelter. This is further described by Stevelink et al. (23), who found that unemployment and difficulty when seeking work were two of the major issues for patients with leprosy.

Physical impairment caused by the disease could hamper being able to continue with one's

previous work. However, it was mainly due to stigma that patients were devalued by society.

Similar findings related to mental illness in Ghana were described. Barke, Nyarko and Kleecha (24) found that being treated at a psychiatric clinic in Ghana was associated with being abandoned by one's family. Avoidance of healthcare and delayed treatment were seen by nurses as obstacles to successful treatment and a consequence of stigma, which is all in line with other studies focusing on leprosy (25, 26, 27).

Ghana is making considerable advances with regard to health outcomes and services even if health-related Millennium Development Goals (MDGs) set for 2015 have not yet been met (28).

Additionally, it is important to remember that health-related stigma is not only a problem in developing countries, it also exists in industrial societies, in regards to for example Alzheimers's disease (29), alcohol disorders (30) psychiatric illnesses (31) and HIV/AIDS (32,33,34,35) . The existence of leprosy camps, as a sign of the alienation of patients with leprosy in present study can be compared with alienation due to other disease and care settings e.g. mental institutions (27, 36,37,38). At the same time Premkumar (39) found that leprosy sanatorium, with time, significant contributed to new knowledge and treatments of the disease as research could be better coordinated. The lack of information and education for patients, relatives, and the community and healthcare providers was understood in this study to be the main reason for stigmatization. These results are consistent with Sobrinho et al. (37) and White's (38) claim that education and information are important if stigmatization is to be reduced. Further confirmed in a systematic review (16) described as information, education and communication programs, together with socio-economic rehabilitation as important for reducing stigma. Nurses in this study viewed education as one of their main duties, and through education nurses tried to improve the patients' understanding of their health as well as their overall life situation. In line with Watson (22) increasing teaching and learning in order to help patient to get a sense of self-control was

seen as a core element of care. Knifton (40) found that religious or supernatural explanations decreased stigma. In this study religious motivation and hopes of religious reward were incentives for nurses to care for this patient group, but were not described as acting to decrease stigma.

Even if stigma in this study is specific to leprosy the consequences show similarities to health-related stigma as a whole. Stevelink et al. (23) found that health-related stigma had the same negative consequences for the one affected, regardless of the type of disease. In this study providing education for society as a whole and at the same time being sensitive to patients' wishes and needs presented a dilemma for nurses. Others have shown that changing name of the disease and counselling have been successful strategies to reduce stigma (16). Being compliant to the wishes of the patient not to use the hospital's full name involving the word 'leprosy', was a way of showing sensitivity to patients, but can on the other hand be counterproductive to their efforts to educate the public and the patients' relatives in a process of demystify the diagnosis. This illuminates the complexity of caring for patients with a diagnosis associated with stigma.

Method discussion

The number of participants is not what is essential in a quality research, rather the variation of experience. However, more participants could have provided a broader foundation for findings (41,42). In order to illuminate the participants' experiences follow-up interviews were conducted with the aim of providing more extensive data. According to Bengtsson (43) cumulative data collections increase the possibility to deeper the understanding of the phenomena of interest. Even if it is considered a disadvantage that the participants were selected by the Deputy Head Nurse and not by the authors of the study, this was found to be the only possible way to proceed due to the hospital organization and expectations of staff. However, the selection of nurses was

based on the inclusion criteria and the nurses had various work assignments, which probably increased the likelihood of achieving a variation of experience of the studied phenomena (44). At the same time it has to be taken into account that there is a risk that the Deputy Head Nurse also has other criteria for selecting actually nurses. However, it has not been seen in the result of the study that there is a risk that of It would have been beneficial to organize the interviews outside of working hours without interference on their regular salary, or as a part of their ordinary workday. However, as this was not manageable it was considered the best way to compensate the participants with the salary they lose when participating in the interviews during regular working hours. As the amount payed was more or less equal to the regular salary it was considered as not to any greater extent affects their decision to participate in the study. Strategies to increase transferability as well as the validity of the study has been to describe the selection process for participants with examples of the analytical steps (c.f. 45,46) Furthermore, the analytical steps and findings were shared at seminars as a form of 'peer debriefing' (20), thus increasing the likelihood of being open to the phenomena of interest and for discussion of different analytical pathways (46, 47). It was considered to enhance the validity of the analysis process that two of the three different authors transcribed the interviews as the authors became familiar with data both in oral form and later on as text and then in a later phase shared their understanding of the text with each other. The present study was conducted in a limited geographical area and concerned a stigma related to a specific and rare disease. However, several similarities were found between the findings of this study with research concerning health-related stigma for other diseases. One way of understanding more about a certain phenomenon is to step away from one's ordinary or 'taken for granted' life, to go behind what one takes for granted in everyday life and to question everyday practice (45). Findings from this present study may therefore also be considered valuable in other contexts for other patient groups. The possibility of transferability is further raised by Hofstraat and van Brakel (18) finding in their systematic review that lessons from leprosy can be used in order to understand more of health related stigma in relation to other diseases.

CONCLUSIONS

Stigma has a negative impact on the physical as well as the psychological and financial wellbeing of the patient, with consequences for the care and the role of nurses. Education for patients, relatives in the community and for colleagues was a central nursing intervention. Caring for patients with leprosy involved addressing a range of different needs as well as focusing on long-term intervention and goals. The need for holistic care and massive educational support was thought necessary to enable the patient with leprosy to stay out of hospital and to live a more independent life. Nurses in present study raised the importance of nurses being role models for reducing stigma and showing a different way to treat this group of patients.

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Appendix 1

INTERVIEW GUIDE

Questions asked in the first interview section

Main question: Could you tell me about your experience in caring for patients suffering from leprosy?

Follow-up questions: Has working with leprosy patients affected you e.g. personally, socially or professionally and, if so, how?

Is caring for patients with leprosy different to caring for patients with other diseases and, if so, how?

In your view, how have leprosy patients traditionally been treated in Ghana? Have you noticed any changes over time?

What are the challenges in caring for leprosy patients?

Has your role as a nurse been affected by working with leprosy patients?

If you could change anything about leprosy patient care, what would you change?

Questions asked in the follow- up interviews

Could you please define the word stigmatization?

How would you define discrimination?

How do you associate to the word leper?

How has treating leprosy patients affected you?

Leprosy related stigma