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## **Nurse's experiences of leprosy related stigma in Ghana**

## **Abstract**

**Background:** Leprosy has long been associated with stigma and the disease causes a lot of suffering to those affected, not only physically but also emotionally and psychologically due to the effects of stigma.

**Aim:** To describe the nurse's experiences of leprosy related stigma in the Central Region of Ghana.

**Methods:** A qualitative interview study with semi-structured interviews. Seven individual interviews were conducted four with nurses working at a hospital, specializing in leprosy care, at in the Central Region of Ghana. The data was analyzed using a content analysis based on Graneheim and Lundmans concept.

**Results:** The nurses described an exclusion affecting leprosy patients because of their disease. Significant factors, such as lack of knowledge and social circumstances, could be linked to leprosy related stigma.

**Discussions:** The result was discussed using Watson's theory of human, referring to eight of her ten carative factors. Three main subjects were identified and discussed related to the result. These were educational factors, social factors and stigmatization.

**Keywords:** Stigma, leprosy, nursing, education, Ghana, healthcare

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## 1. Introduction

In the mandatory internships that are a part of the Swedish nursing program we have encountered what we perceive as being stigmatization of certain patient categories. This sparked a conversation between us authors about the mechanisms of stigma. We agreed that it would be beneficial for caregivers to get an insight in how their colleagues experience and handle the issue of stigma. To our surprise, as we searched for articles on the subject we could not find any studies that focused on the experience of the nurse in relation to treating traditionally stigmatized patients and conditions.

Leprosy has long been associated with stigmatization of those suffering from the disease (Krishnatray, Melkote & Krishnatray, 2006). Despite the great advancements that have been made in the treatment of the disease the occurrence of leprosy related stigma is still highly prevalent. Leprosy has one of the most negative connotations of any disease and the word leprosy or lepers itself has long been used synonymously to stigma (Rafferty, 2005).

In order to tackle the issue of stigma and its negative implications it is of importance to study the health care workers experiences of health related stigma. We have chosen to conduct our study in Ghana where leprosy still exists.

## Background

### 2.1 Health Care in Ghana

Of the 59.2 million that is the global health workforce, Africa is estimated to account for three percent, while dealing with 25 percent of the global disease burden. One estimates that the ratio between the health sector workforces in Africa is a tenth of that in the Americas. Ghana is among the sub-Saharan African countries that are making considerable advancements in regards to health outcome and services (Kaba Alhassan et al., 2013). Despite the many improvements in Ghanaian healthcare it is not enough to meet the health related Millennium Development Goals (MDGs) set for 2015. This is partly due to understaffing in health facilities, under-motivated health care staff, an unjust distribution of health sector human resources and an unsatisfactory healthcare infrastructure (Kaba Alhassan, et al., 2013).

In 2013 there were an estimated 52 258 people who were formally working in Ghana's health care sector, the majority of them worked in the public sector, which provides healthcare to more than 24 million people. The nurse-patient ratio has risen consistently under the 21 century (Kaba Alhassan, et al., 2013).

## 2.2 Leprosy

Today in the countries where leprosy was endemic in 1985 it is no longer seen as a public health problem and in 1997 the number of registered cases of leprosy in the world was under 1 million for the first time since registration began (Zodpey, Tiwari, Salodkar, 2000). Reports received from 115 countries and territories for the first quarter of 2013, showed that the registered prevalence of leprosy worldwide amounted to 189,018 cases (WHO, 2013).

According to studies, there is a prevalence of leprosy in the population in the Sene District in the Brong Ahafo region of Ghana and evidence suggests that there are still new infections in these communities since many of the infected are children (Ofosu & Bonso, 2010).

Factors such as gender, race and age have no effect on the occurrence of leprosy. Those who are primarily at risk of being infected are people living in low socioeconomic conditions and those with weak immune status (Guimarães et al., 2009). The disease is transmitted via droplets from the nose and mouth during close contact with infected people who are untreated (WHO, 2013).

Leprosy, also known as Hansen's disease, is a slowly progressive chronic granulomatous disease caused by the intracellular parasite *Mycobacterium leprae*. *M. Leprae* mainly affects peripheral nerves and skin cells and is viable for up to 36 hours in an optimal environment. The time of incubation is usually between two and seven years (Guimarães, Barros, Bassoli, Salotti & Oda, 2009). However, reports have been made of incubations of up to 20 years (Ofosu & Bonsu, 2010).

The early signs of leprosy include spots on the skin that may have a different color compared to surrounding skin. Usually these appear on the arms, legs and back. However, spots don't always appear and in some cases the only noticeable symptom is numbness in one or a few of the fingers and toes. If leprosy goes untreated small muscles become paralyzed and the entire hands become numb which causes the fingers to curl. When leprosy affects the legs it affects the communication of sensation in the feet. The ability to feel pain is lost and wounds may go unattended and cause infections leading to tissue loss. When the nerves in the face are affected the ability to blink is lost which eventually leads to dryness, ulceration and blindness. When bacteria enters the mucous lining of the nose it can lead to scarring and internal damage which in time causes the nose to collapse. Thus, if leprosy goes untreated it can lead to crippling, blindness and deformities (American Leprosy Mission, 2014).

Leprosy is one of the few chronic diseases that can be eliminated if the correct diagnosis is given and addressed at an early stage and opportunities to receive treatment with MDT is

available (Dogra, Narang & Kumar, 2012). A person who has suffered from leprosy can be medically treated and cured within a year and then return to normal life, provided the disease hasn't come to the stage where it is disabling (Rafferty, 2005) and there is today realistic hope that leprosy may be non-existent at the end of this century (de Stigter, de Gaus & Heynders, 2000).

### **2.3 Health related stigma**

Goffman (1963, p. 9) defines stigma as “the situation of the individual who is disqualified from full social acceptance”. Van Brakel (2006) suggests that the current conceptualization of the word stigma is largely associated with Coffman’s description of the word and differs from the dictionary definition of the word as referring to the occurrence of symbolic marking.

Health-related stigma is often characterized as social disqualification of people and groups with certain health issues. Individuals and groups who are marginalized because of various aspects of their identity suffer disadvantages, such as a limited access to services that subsequently affect their health. Therefore there is a substantial interest among health professionals to study and recognize the impact of stigma, as it is both a consequence and a cause of health issues. The study of the attitudes associated to stigma is of particular interest among health professionals because it is so prevalent among various chronic-diseases around the world and a hidden burden for many of those affected (Weiss, Ramakrishna & Somma, 2006).

There are few published studies in sub-Saharan Africa and Ghana regarding how the population perceives stigma and how the stigmatized persons themselves view their situation (Barke, Nyarko & Klecha, 2010). In the study by Barke et al. (2010) they show that stigmatization of mental illness affects both the patients and people surrounding them, such as their relatives. The study showed that 70 patients treated at a psychiatric clinic in Ankafu, Ghana, were abandoned by their families. Stigma contributed to low self-esteem, poor social adjustment, low quality of life and social exclusion for the patients. According to the study the worst perceived diagnoses in relation to stigma in sub-Saharan countries are leprosy, schizophrenia and TB.

There have only been a few strides to develop a tool to tackle the stigma and discrimination in public health programs, even though there is considerable knowledge about its consequences. Efforts have been made, but the efficiency is often not known, partly because the tools to measure the effects have not been available, especially in developing countries

(Van Brakel, 2006).

More research is needed to increase our understanding of stigma and develop programs to reduce the phenomenon. There are many factors that contribute to stigma and attitudes in society and healthcare are among the most important ones (Van Brakel, 2006).

## **2.4 Psychosocial aspects of stigma**

Despite the breakthroughs that have been made, leprosy related stigma is still a real phenomenon, affecting many people's lives both physically, psychologically, socially and economically. Ignoring the effects of stigma has negative consequences on overall health outcomes. In order for health care workers to be able to give holistic care to leprosy patients and other patients suffering from disease related stigma they need to take into account their psychological and social wellbeing. Second only to perhaps acquired immune deficiency syndrome (AIDS), leprosy holds one of the most negative images of any disease in the world. For years leprosy, or lepers, have been used synonymously to stigma. For several centuries the mere word leprosy has been met with disgust, shame and fear. Stigma is a complex matter and one that is hard to define as it is derived from different factors, beliefs, attitudes and behaviors. However, the fact still remains that for many it is the biggest burden of leprosy to bear (Rafferty, 2005).

Research has shown that leprosy has a negative effect on the sufferer's quality of life, affecting their marriage, social life, employment and personal relationships. In many of the communities where leprosy is an issue family life is highly valued, compared to the individualism, which is prevalent in the West. In these societies life is largely bound up in family and community life, so to lose that part of one's life due to stigmatization means to lose a significant part of oneself. One leprosy sufferer explained it as "We can endure losing fingers and toes, eyes and nose, but what we cannot endure is to be rejected by those nearest and dearest" (Rafferty, 2005, p. 120).

A study set in India showed that 16-44 percent of leprosy patients reported a decrease of their income because of their leprosy (Prabhakara-Rao, Rao, Palande, 2000). It is not uncommon either for people with leprosy to lose their jobs due to their employer's negative attitudes towards the disease and the disabilities that it entails. This is not only a great financial burden for many as the means to provide for one's family is lost, respect from the society can be lost and this could affect an already poor self-esteem. (Zodpey, Tiwari, Salodkar, 2000).



Women constitute a particularly vulnerable group of leprosy patients. They suffer the effects of stigma even more severely than men in the same situation. They not only have more restrictions placed on them, but they are also more severely rejected and isolated. If a mother suffers from leprosy the health of her whole family can be affected, for instance by fear of transmitting the disease preventing them from emotional closeness to their children (Zodpey, Tiwari, Salodkar, 2000).

Leprosy, while affecting the peripheral nerves, leaves the brain and the central nervous system undamaged. Despite this, many patients suffer mental effects of leprosy, not due to the disease itself but due to how they are treated because of their disease. The stigma associated with the disease is a barrier in getting people to seek care at an early stage (WHO, 2013). A study on black South Africans suffering from leprosy reported that one third of them had contemplated suicide when they learned about their diagnosis (Scott, 2000).

Stigmatization and peoples negative attitudes towards leprosy does not only lead to psychological ill-health it can also have physical effects. Because of the stigma associated with leprosy people suffering from it may be reluctant to seek treatment until the disease has caused severe disabilities (Meima, Saunderson, Gebre et al. 1999). This in turn worsens the stigma related to leprosy and continues the cycle of stigmatization (Rafferty, 2005). Also, many patients after beginning their treatment wont proceed with it due to fear of rejection and a lacking acceptance of their disease (de Stigter D, de Gaus L, Heynders M, 2000). At the same time those who might have received treatment are not holistically cured if they are not accepted back into their community afterwards. Even though patients may be cured from their micro-bacterial disease, the stigmatization that it caused can still be a great hindrance in resuming a normal life (Rafferty, 2005).

The causes of leprosy related stigma differ across continents and communities. Some of the most common factors however are beliefs regarding the cause of leprosy, the fact that leprosy has traditionally been seen as a death sentence, fear that it may be transmitted, fear of the disabilities that it can cause, odor as well as self-stigmatization (Rafferty, 2005).

## **2.5 The nurse's role**

When giving holistic care nurses view the patients as one unit, as a biological, psychological, social and spiritual being. To see the human as a unique individual and constantly considering the person as one unit is not always easy to put into practice. Practical and medical skills one learns by experience but learning to see patients in other dimensions, psychological, social

and spiritual, requires experience and a closer contact with the patient (Boswell, Cannon & Miller, 2013). The nurse has a role of health educator and deals with education regarding health promotion, prevention, treatment and rehabilitation (Pat & Ekpemiro, 2012). As Goffman (2011) states, because of the assumed knowledge that health care workers have about various diseases, they have become the “wise”. As Atsu Dodor and Kelly (2010) state, it is of particular significance when healthcare workers, who generally hold a position of authority in society, ascribe a label to any given entity since it can increase or decrease fear and stigma related to certain diseases in society.

### **3. Problem area**

Stigma is a phenomenon, which causes additional suffering to the diseased and has negative implications on the health efforts made among the people affected. Stigma can lead to psychological stress, depression and fear, all of which restrict the progress towards health. Although leprosy is curable in this day and age the social issue of stigma still remains, because even if the illness may disappear the social pathology of the illness may not.

There is a lacking amount of research conducted on the nurse’s perspective of patients affected by stigma. Since nurses have an influential and educational role in society and are among those who come in close contact with health related stigma, we believe that it would be valuable to learn more about their perspective on the issue, in order to tackle it.

### **4. Aim**

The aim of this bachelor thesis is to describe the nurse’s experience of leprosy related stigma in the Central Region of Ghana.

### **5. Theoretical context**

#### **Jean Watson's theory of caring**

The authors of this study have chosen Jean Watson's theory of caring as a theoretical context. Watson's theoretical nursing approach encompasses humanistic values and scientific methods as well as a holistic approach (Watson, 2007), which is relevant when working with stigmatized patients. Watson has identified ten factors that are at the core of caring for patients, which she believes should be active aspects of nursing care. The first is to establish a

humanistic altruistic value system, to see people as unique individuals and valuing their differences. The second is establishing faith and hope in the healing process and nurses being confident in themselves and their skills. The third factor involves having knowledge of self and understanding how to react in different situations, to develop sensitivity not only in regard to oneself but also towards others. This third factor is of particular importance when dealing with one's preconceived notions, because being secure in oneself helps the ability to meet other people in their life situations. The fourth is about developing a helpful and trusting relationship. As mentioned earlier stigma contributes to low self-esteem and social exclusion (Barke et al. 2010) and this may be a challenge when building trusting relationships between the nurse and the patient.

Fifthly Watson states helping the patient to express and accept both positive and negative feelings, by creating trust and thus getting the patient to open up. The nurse should have an open approach and speak the same language as the patient, while showing compassion and warmth. The sixth is the use of scientific methods when making decisions and making decisions based on work experience and scientific studying rather than taking chances. The seventh factor is about promoting interaction through learning and teaching. By helping patients to understand their situation, the nurse can strengthen the patient's sense of self-control. The eighth factor regards creating an environment that helps to improve the wellbeing of the patient both physically, psychologically, spiritually and socially. The ninth is about the satisfaction of human needs that also enable spiritual emergence. Lastly, the tenth factor is showing openness towards individual's existential-phenomenological, spiritual and cultural beliefs (Watson, 2007).

A large part of Watson's theory deals with strengthening and humanizing the patients. The core factors of nursing that Watson describes can be seen as central in a context where stigma figure.

## 6. Method

In this study a qualitative approach was used. The qualitative design has its roots in the holistic tradition and its purpose is to explore persons lived experiences (Henricson & Billhult, 2012). The design is suitable for the aim of the study that pertains to view the nurse's experience of leprosy related stigma. Interviews are an approach to collect data, what

is said in the interviews is the subject of analysis and it is important for the interviewer to be flexible (Henricson & Billhult, 2012).

### **6.1 Data Collection**

The data was collected through interviews. Interviews were the method of choice since it aligned with the purpose of this study; to view nurse's experience of leprosy related stigma. The contact person at the hospital was introduced to us through a personal contact. An informational letter was sent to the contact person at the hospital where the study was conducted who forwarded it to the proposed informants. One of the informants did not read the informational letter prior to the interview, however she was given verbal information with the same content as in the informational letter. Among the nurses who were willing to participate in the study, the deputy nurse of the hospital selected four nurses whom she saw best fit for participation. The requirement for participation was that they were currently working as nurses, had experience working with leprosy patients. The informants were interviewed one at a time. All of the interviews were done at the hospital except for one, which was done at one of the participant's homes.

The interviews were semi-structured, in other words, the informants were asked open ended questions from a beforehand-prepared questionnaire (appendix 1). Follow up interviews were done with three of the informants (the fourth informant was not available for another interview), after we developed additional questions after having read the first transcriptions. In total seven interviews were performed with four informants. A study with too few or too many informants can cause problems during the analyzing process; a study with semi-structured questions does not require as many informants as a study with structured questions (Danielsson, 2012). The initial interviews were each performed by one of the two authors separately, whereas the follow-up interviews were conducted with both authors present. During the follow-up interviews one of the authors was responsible for taking notes and handling the recording device, whilst the other acted as the interviewer asking the question. The interviews lasted between 25 and 50 minutes and were recorded with a tape recorder. The transcriptions were made as soon as possible after the interviews were completed. Both authors listened to the recorded interviews and went through each transcription.

## 6.2 Data analysis

The chosen method for the data analysis was a content analysis using Graneheim and Lundman's (2004) qualitative content analysis concept. Using a content analysis is a frequently used method in nursing research and is used to make implementations valid from data to context, in order to make the data applicable to nursing processes (Elo & Kyngäs, 2007). The analysis is based on a latent content, i.e. analyzing the underlying meaning of the text. According to Graneheim and Lundman, qualitative research based on interviews with semi-structured questions requires a consensus-based collaboration between the researcher and the informants.

Graneheim and Lundman (2004) describe a latent content and a manifest content. In the first stage of dissecting the text the manifest content is in focus, i.e. what is said in the text? The latent content can be seen as a deeper level of interpretation and refers to an underlying understanding of the meaning in the text. In the analysis of this study a latent content analysis was used.

During the analyzing process the authors read through the data several times, first separately and then together. One issue that Graneheim and Lundman (2004) emphasize is the fact that a text always contains multiple meanings and this is of fundamental importance in the discussion of trustworthiness of the findings. Meaning units consist of a number of words with a common message. Both authors constituted the meaning units, first individually and afterwards together to compare our findings and select the units to be used together. Another significant issue is the length of the meaning units; they should not be too short due to the problems this may cause in the analyzing process. The unit of analysis refers to the object of the study. Graneheim and Lundman's analysis concept (2003) uses codes when labeling the meaning units. We have chosen to skip this step and not use codes and instead proceed in the analysis process to condense the meaning units.

In this study the unit of analysis is nurses working with patients affected with leprosy. Condensed meaning units are a reduction, a condensation, of the original meaning units without changing their quality or content (Graneheim & Lundman, 2003). After the meaning units were condensed we interpreted the underlying meaning of the condensed meaning unit, we chose to call this abstraction after Graneheim and Lundman (2003) that refer this to an interpretation of the text at a higher level. According to Graneheim and Lundman's (2003) concept, the identifying of sub-themes and themes constitutes the next step in the analysis process. We have chosen to use sub-categories and categories instead of sub-themes and

themes, as the abstraction in our analysis replaces the themes. The abstractions were divided into categories and sub-categories. We could identify sub-categories within two of the three categories. An important part of the categorization process is making sure that a sub-category does not fit into more than one category (Graneheim & Lundman, 2004).

Three main categories were identified during the analysis; within the categories sub-categories were identified. The abstraction of the condensed meaning unit is described under each category and sub-category. This is something that both authors interpreted after discussing the meaning units. In the presentation of the result, under each category and sub-category, a quote was used to clarify how the categories were developed. A table was created to give an overview of the analysis process. All the categories and sub-categories are described in the results segment, along with singled out quotes from the interviews, meant to facilitate how the analysis has been conducted. All the data in the data analysis was decoded to minimize the risk of unauthorized persons getting access to the material. To aid in giving a comprehensive overview of the analysis process we have attached a table over the content analysis in appendix 2.

### **6.3 Ethical considerations**

Prior to the interviews, the proposed informants received information, both verbally and in writing that their participation is voluntary and that they could at any time terminate that participation, without having to give any reason and without fear of repercussions. The informed consent is used to protect the informant's freedom and self-determination (Kjellström, 2012). The respondents were informed of the fact that their participation and contribution in the study would be treated confidentially and that the information they provide would only be used in the present study. We followed CODEX (2014) international recommendations of how to treat personal data.

The informants were compensated for the time it took to perform the interviews with pay corresponding to their hourly salary. Our contact at the hospital where the study was conducted approved our chosen method. The Research Ethic Committee at the Department of Health Care Sciences at Ersta University College has also approved the study.

The authors have followed the Scientific Council's code of ethics, which has individual protection requirements that protect the studies informants from both harm and violation. The authors have also taken into account the research requirements, which involve creating a

qualitative study with an important purpose, while protecting those who participate in the study (Hermerén, 2011).

## 7. Results

In the results section below the nurse's experiences of patients with leprosy are presented. Each category and sub-category is presented separately. The categories are presented with the label of the main category, following are headings and descriptions of the sub-categories. Other than that the categories are not presented with any particular ranking.

### 7.1 Increased knowledge prevents stigma

#### *7.1.1 Negative attitudes; effects of lacking knowledge*

##### *- Lack of knowledge creates stigma and discrimination*

All the interviewed nurses were asked what they thought were the public's perception of leprosy. They had all experienced a community where knowledge about leprosy was lacking and where people believed leprosy to be highly contagious.

“The community, they have the stigma about the disease. They don't come close to the leprosy patients because they think they will get infected. So that is why they built the camp there for them.”

The camp referred to is a small community established especially for people affected by leprosy. Even though the informants thought the public's notions of leprosy was overall negative and based on faulty information, they agreed that there had been some improvements in the last few years in that regard. They described leprosy as previously being seen as a death sentence and facilities treating leprosy as being feared. Adding that in the past the leprosy ward could in fact often be a patient's last halt in life. “There is a church and a cemetery right next to here. It is because before when you came here as a patients you would probably also die here. “

The informants described their own beliefs and perception of leprosy prior to working with those infected. They described being fearful of the disease even though they had some knowledge about it from their nursing education, one of them saying “even though I knew the infection is spread through droplets, I thought handling them might be dangerous”. Upon being posted at the hospital known for treating leprosy cases some of them described receiving negative remarks by their peers, due to their notions about the disease.

### *7.1.2 Internal education among the nursing staff*

#### *- Knowledge reduces fear*

All of the informants said they had been informed about leprosy in their nursing education but despite their knowledge about the disease they were initially afraid of the leprosy patients. One of the informants mentioned how she, at first, thought that if she ate well and exercised she wouldn't get infected, even though she knew it was a droplet disease.

I thought if I eat well and if I exercise and all those things I wouldn't get it. But I have read that it is not eating well that wouldn't let you get it... because it is a droplet infection.

However, later she went on to say that one would not get the disease if one takes good care of the patient, but if you don't take good care of the patient, then you might get infected. She also added that she was protected from the disease because she has received the bacille calmette-guérin (BCG) vaccine.

Another informant talked about how his view of the condition had changed after receiving information about the disease from the chief physician at the hospital.

“Well, my thought about leprosy was that it was an airborne disease and very dangerous. And that is how ordinary people think. Initially that is how I also thought.”

There is a large personnel turnover at the hospital but new employees are gathered in groups to receive information from a doctor at the hospital, about leprosy and how it is transmitted. Also all of the nurses rotate so that they are able to work in all of the wards.

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

### *7.1.3 Educating patients and their relatives*

#### *- There is a desire to normalize the disease*

The informants said that they teach the patients how to take care of their ulcers and how to avoid getting new ones. They are informed about what shoes to wear and how they can avoid deformities by seeking care before their ulcers get infected. They went on to explain that despite the patients being informed most of the patients come back with even worse ulcers than before they were discharged. According to one of the informants one of the problems causing this is that many of the patients, who should wear special sandals due to their ulcers,



feel ashamed about their deformities and instead of wearing sandals, wear sneakers. Almost all of the informants stated this as one of the major problems with the leprosy patients, their inability to take care of themselves, which results in the readmission of many of the patients. One of the informants experienced that women tend to seek care more often and in an earlier stage compared to men and because of that most of the women barely had any deformities while deformities were common among the men. Her conclusion was that due to the men's unwillingness to seek care more complications emerged. They linked the unwillingness to seek care, both among men and women, directly to the stigma of a leprosy diagnosis.

According to the informants the hospital staff try to educate the patients about their condition and send them to the rehabilitation centre in the hospital. This is done in hopes of helping them fit into society after they are discharged and minimizing the risk of them being a burden on their community. The staff attempts to welcome the relatives to the hospital so that they can see that they are not being infected, in order for them to learn that leprosy is not as contagious as they may think.

Initially when they are diagnosed as leprosy patients we educate their families and most times they put the stigma aside. They think, "oh, he is my son or he is my daughter, no matter the condition he finds himself in I have to be close to him". The leprosy patient's relatives, we educate them. After that most of them they come around.

#### ***7.1.4 There is a need for community based education***

##### ***- A wish for increased knowledge in the community***

The informants expressed a lack of education regarding leprosy in the community and a wish for the media to get involved in the community based education, as they felt they never heard anything about the disease in the media. "We can do it community based, because stigma is all over. So if we could do it community based and maybe we could get the media involved. Because we never hear anything about it!"

The informants stated that the general public used to think that if you touch someone with leprosy, you became infected. Almost all of the informants stated that the stigma surrounding leprosy patients is lower now than it used to be, one of them giving the example that now even people who are not infected with the disease will live with their infected relatives in the leprosy camps. However, they add that fear is still very much existent among the general

public in the community. When asked who is responsible for educating the public the informants agreed that it is primarily health care professionals who have that responsibility.

It's health professionals! We have the responsibility! It is our responsibility to wherever we find ourselves, be it in a taxi, be it in a car, everywhere you find yourselves - educate people. If you do it then you are extending your education beyond.

## **7.2 Improvements**

### *7.2.1 Social improvements*

#### *- A need for long-term social improvements*

The informants expressed a wish to create workshops for the leprosy patients so that they could learn a skill that would be useful for them when they were discharged. They explained that many of the leprosy patients used to be farmers, but due to the nature of their disease they could no longer do any strenuous activity. The informants meant that if the patients had something to do that could generate an income it would diminish the revisits to the hospital. Their financial situation was considered a major problem. Some of the patient did not have any other opportunity than to go back to their former jobs, even if that had devastating consequences on their condition. As a result of the lack of jobs and activities, many of the leprosy patients have to resort to begging in the street, according to the informants.

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 depending on other people (...) If there is something that could be done that could generate income, I think it would help.

The interviewed nurses said that they prefer to call the patients Hansen's disease patients instead of the previously common term lepers, because of the negativity associated to the latter term. They said that the patients felt insulted when someone would refer to them as a leper; it made them feel rejected and stigmatized. The informants explained that in Ghana leprosy is commonly seen as a curse from the gods, so if someone has the disease they would rather not be further associated with it by being labelled "a leper". The staff attempts to call the patients by their name and refer to them as Hansen's instead of lepers, although the word

leper still figures among some of the health care workers. According to the informants people in the community are not familiar with the term Hansen's disease, while leper is a common word. That is why, the informants believe, using the word Hansen's has less negative associations than saying lepers.

I think it's the attitude out there. If you go out there and say 'this person is a leper' people's thought is that they have to be careful to not get infected. The term Hansen's disease, people don't understand it so much, while leper is a common word.

### **7.3 The core of nursing**

#### ***7.3.1 The nurse's moral views when caring for leprosy patients***

##### ***- Religious reward as an incentive***

The informants talked about how their beliefs and moral ground influenced the care they gave to their patients. On the one hand in a direct fashion, for instance through morning prayer which was performed with the patients each day. Statements were also made revealing values and beliefs as being an incentive to seeking and continuing to work with leprosy patients. The majority of the values described by the nurses were based on Christian beliefs. One of the informants described treating leprosy patients as a great deed that is seen by God, which one will be rewarded for.

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 informant went on to say that it is through their good deeds that they will get husbands and healthy children and eventually go to heaven. According to the informant this was the common belief among all the nurses in the hospital. She later added that she would not make an attempt to change her workplace, even though there are more prestigious positions that she could hold at other facilities, because in the end she will be rewarded for the work she is doing with the leprosy patients in her current position.

### ***7.3.2 Equal treatment; a central part in giving good care***

#### ***- Seeing each person's value***

All of the informants answered that there was no difference in how they treated any of their patients, regardless of their illness. There seemed to be a consensus regarding the importance of all the patients being treated equally.

When I first started working here I was afraid of them but as I got closer to them and got to know how the disease works I stopped being afraid. Now i treat them like any other. Because leprosy, it can affect anybody. It is like TB, malaria and other diseases, it can affect anybody, so we treat them fairly.

However one of the informants after having said that all patients were treated equally went on to say that the leprosy patients actually were treated even better than the rest. When asked why it was so she explained that it was because the leprosy patients usually are poor people and because of their disease have nobody to take care of them besides the hospital personnel, that is why she felt that they at times needed special treatment, for instance by giving them a larger portion of the donations that the hospital receives, such as soap and milk.

One of the informants stressed the importance of not differentiating between leprosy patients and other patients, in order to humanize them and avoid making them feel excluded. Another informant gave an example of how he treated all patients equally by giving them all what he called behavioural modification therapy (BMT) and stressed the importance of doing so in order to humanize the leprosy patients. "You have to make the patient feel that he is also part of the human being." He said that with BMT he would help patients to change, or forget, the bad feeling they had. According to the informant this was done by first getting to the bottom of what the bad feelings were caused by, as an example he said that depression for instance could be caused by divorce. After finding out what the feelings were caused by he supposedly helped them to forget about those feelings by giving them examples of other patients that were worse off and reminding them that their situation could be worse

### ***7.3.3 Exclusion; a main effect of stigma***

#### ***- A desire of be part of a context***

All the informants described the exclusion that people affected by leprosy go through as a major problem. They described leprosy patients as being excluded from social interaction by being denied physical contact and closeness.

Common people in the marketplace if they 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.

One of the informants said, “many of them when they are discharged and they go back to their house, their family won't accept them back again. Because the stigma attached to leprosy it is more even than HIV”, describing the occurrence of patients being denied by their family upon being diagnosed with leprosy. Many of the patients asked the hospital staff to lie about the name of the hospital, and exclude leprosy from its title when speaking to their relatives, in hopes of not disclosing their reason of admission. The informants explained that the relatives abandoning the leprosy patients was not only painful for the patients themselves, but it was also an issue for the hospital staff as the patients had no one to take care of them but the health personnel.

Some of them, because of the stigma, they are not able to get work. So some keep making complaints so that we can keep them here for as long as possible. Some of them keep coming back. They find ulcers that they don't keep neat so that they can be admitted again, so that someone will care for them.

## **8. Discussion**

### **8.1 Method**

Our first contact with the informants of the study went through the chief physician of the hospital where we later conducted the interviews. We gave written information to the chief physician with an introduction of ourselves, the aim of our study, our planned time-scale, as well as our proposed method. This letter was later forwarded to the deputy nurse of the hospital who helped us with the selection of the informants, although the trustworthiness of the study could have benefitted if the selection of the informants had been made in consultation with the authors, rather than letting a third person make the selection independently.

We chose to use four informants in our study. The number of informants in a qualitative content analysis can be restricting to the amount of information accumulated in the study (Danielsson, 2012). On the basis of our time constraints as well as the purpose of the study, the decision was made that a minimum of four interviews would be satisfactory. However, a

larger amount of informants could have given a more conclusive and applicable result.

Through interviews there is an opportunity to get an understanding of the participant experiences and views of different aspects of life, through them being able to express themselves in their own words (Danielsson, 2012). Ghana's official language is English (Ghana Embassy, 2014) and all of the informants spoke it fluently. However, other local languages are also spoken and the Ghanaian dialect of English may be hard to understand for the untrained ear, something we took into consideration when interpreting the interview transcriptions. Since one of the authors has English as her mother tongue and is familiar with the Ghanaian dialect we believe that we managed to avoid language misinterpretations.

Awareness about one's preconceptions increases the trustworthiness of a study. Through contemplation and discussion among the authors regarding the expectations prior to the interviews, as well as sharing earlier experiences that might be of importance, an effort was made to minimize the influence of preconceptions on the analyzing process. However it is difficult to exclude the possibility that the author's preconceptions may have had an affect on the analysis (Henricson, 2012).

The interviews were semi-structured with open-ended questions, in order to increase the flexibility of the interviews and encourage the informants to speak freely. In our opinion this was a good interview method to get the informants to describe their experiences freely.

As an interviewer it is of importance to have significant knowledge of the topic in focus, this will benefit the preparation of a fruitful questionnaire to be used in the interviews (Danielsson, 2012). We prepared a questionnaire that was written down and read through several times by both authors in order to see if the questions were adequate or needed any adjustments. Before the recording of the interviews begun the technical equipment was tested. Something we realized after the first sets of interviews were completed was that it would have been beneficial if we had first conducted a test interview to see if we could obtain what we wanted by using the questions in the questionnaire. This might have enabled us to avoid having to do the follow-up interviews.

To increase the trustworthiness of the study the authors had a prolonged engagement with the hospital where the study was conducted prior to the interviews being conducted. We spent time at the hospital, conversed with nurses and other hospital staff, visited all the wards and observed the nurses while they worked. This was done to get to know the environment, the disparity of the culture and different caring aspects.

It is recommended to use a table as help during the analyzing process. We used a modified

version of Graneheim and Lundman's (2003) qualitative content analysis concept to create a table with the meaning units, condensed meaning units, abstractions, categories and sub-categories. This is meant to clarify the analyzing process and give the reader a visual over the steps of the analysis. The exchange of themes and sub-themes to abstraction and focusing on categories and sub-categories modified the content analysis. The chosen qualitative content analysis was easy to use and the various steps helped in the organizations of the findings. Sub-categories were only identified in relation to two of the five categories. One might argue that having sub-categories in relation to all or none of the categories would have benefited the consistency of the results. However, in a study such as this one where the amount of data is relatively small we feel that it is not necessarily essential to go through all the four steps. In our opinion the process of coding in particular did not facilitate the analyzing process.

## 8.2 Result

The informant's answers confirmed what has been said about leprosy related stigma in previous studies, found in the background segment of this study. The results of this study are presented in relation to Watson's caring theory and relevant scientific articles.

### *8.2.1 Main findings in relation to Jane Watson's human caring theory*

The results are discussed in relation to Jean Watson's theory of caring (Watson, 2007). It aided the problematization of our findings to relate them to Watson's ten foundations of nursing. However, in the process we found that only eight of the ten points were relevant for our purpose and brought new insight to our finding. These were points one through eight.

In the interviews the importance of humanizing the patients was mentioned (Watson, 2007). This was said to be done by treating all patients equally. Very little was said about valuing the patient's individuality. The only thing mentioned that was interpreted as respecting the patient's individuality was presented in the results segment as a subcategory to improvements and is the effort to decrease negations, i.e. the fact that the nurses made an effort to call the patients by their names rather than referring to them as lepers as one had done in the past. This can be related to Watson's (2007) first point of what nursing entails, namely the importance of treating patients as unique individuals and respecting their differences, while developing a humanistic altruistic value system. Our interpretation of the lack of focus on the patient's individuality, along with other observations, is that the needs in Ghana in general and among leprosy patients in particular is of a much more basic nature compared to for instance

the needs in Sweden. The focus regarding the leprosy patients lies on fundamental needs such as them having enough food to eat, housing to go back to after discharge, work to sustain them financially etc. This could be a reason as to why less focus is put on other, perhaps less basic, needs such as actively valuing each person's lifeworld.

We saw examples of nurses at least wishing to do so by establishing workshops for the leprosy patients in order for them to be able to develop a skill that would be useful for them after discharge and prevent them from feeling the need to keep returning back to the hospital for care and shelter. We interpreted this wish as hope, a hope for change and development and a hope that leprosy patients can be re-established as a contributing part of society, this was presented as social improvement in the result, as it could be seen as a chance for the patient to fit in and get a meaningful subsistence in the community. Another concrete example of incorporating faith in the healing process was the daily morning prayer session with the patients. We compared this to Watson's second point of nursing regarding incorporating faith and hope in the care process (Watson, 2007).

In the interviews the informants confirmed that deformities and their consequences, such as stigmatisation, were one of the most difficult aspects of leprosy for the patients. The struggle they experienced when searching for employment and the stigmatization they suffered when their surroundings saw their deformities is also discussed in Bello, Dengzee and Iyos study (2013) about health related quality of life among people suffering from leprosy. Among the informants in their study several of them had been alienated by their community and felt devalued by their disease and the authors considered their physical incapacities to be their heaviest burden (Bello, Degzee & Iyors, 2013; Sobrinho, Mathias, Gomes & Lincoln, 2007). The mentioned finding correspond to the ones of the present study, for instance the informants explained that there still existed leprosy camps, which is a clear sign of alienation. Social stigma and discrimination is considered to contribute to disabilities and can lead to financial loss for those who suffer from it (Van Brakel et al. 2012). In a situation where the patient fears to be discharged due to the consequences of the disease one can presume that the matter of incorporating faith and hope is of major importance and the nurse has a key role when it comes to doing so.

The third point (Watson, 2007), involving the nurses sensitivity to his/her own needs as well as other peoples needs and the ability to react adequately in different situations, was discussed by the authors in light of many leprosy patients and relatives requesting that the hospital staff don't disclose the true nature of their condition. For instance patients did not want to use the



hospitals full name, which had the word leprosy in it. Others lied to their relatives and spouses about their disease and asked the nurses to do the same. Complying to the patients wishes is in one way an act of showing sensitivity to their needs, on the other hand it may be counterproductive in the efforts to educate the public and the patients relatives about leprosy in order to fight stigmatization.

The informants believed that leprosy patients generally didn't seek medical care until the disease had caused significant deformities and once they had been admitted they dreaded being discharged. Based on the informants narration one can make the interpretation that it was being diagnosed with leprosy that was the hardest thing for leprosy patients and a reason why they hesitated to contact the hospital. A leprosy diagnosis was associated with hearing the word leprosy associated with oneself, knowing that one may not be able to continue with ones previous profession and that one may experience devaluation by society. Just as Kazeem and Adegun state (2011), one of the consequences of stigma is that it leads to avoidance of healthcare.

The informants talked about a situation where the patients continued to return to the hospital multiple times and even created conditions that would get them admitted to the hospital. The patients doing so could be interpreted as them seeing the hospital as a safe haven. This could be related to Watson's (2007) fourth item of nursing, developing a trusting and helpful relationship with the patients. Even though such a view of the hospital and it's staff could be sought after in certain instances it is not desirable for the patients to keep coming back to the hospital or not wanting to leave. The nurses described a feeling of hopelessness when a patient returned time and time again to receive care. The interviewed nurses further described having close relationships with the patients even after they were discharged. They described having a continued relationship with their patients as a positive thing but one could imagine that it could possibly be emotionally draining as well.

Watson's fifth requirement of nursing entails helping the patient to express both positive and negative feelings and in a compassionate way encourage them to be open about their emotions (Watson, 2007). To our surprise we heard hardly any examples of this in the interviews, rather we heard examples of the opposite. One of the informants told us about a nursing strategy, which was termed BMT. The point was to help the patients forget about their own feelings rather than encouraging them to express them and deal with them. This goes directly against what Watson says and is also in our opinion not a beneficial way of dealing with emotional troubles in the long run. Asking patients to forget or disregard their feelings, we feel is a way

to diminish and belittle their emotions and not a helpful caring strategy in the long term.

As was mentioned earlier all new employees at the hospital had to go through a learning session about leprosy. Sobrinho, Mathias, Gomez and Lincoln (2007) state that qualification in health care is an on going process, but that the rotation of healthcare personnel makes the continuity of the care given to Hansen's disease patients difficult. Requiring all nurses to be knowledgeable of the disease they are treating can prevent such discontinuity. The nurses also gave examples of beliefs regarding their nursing that was not based on any scientific data. For instance one of the informants believed that if she treated the leprosy patients well the disease would not infect her, because all good things were seen by God. The same informant said that she also was protected against the disease because she had received a BCG vaccine. However, studies have only shown that the BCG vaccine only gives a certain, not a full, amount of protection against the disease (Moet, Pahan, Schuring, Oskam & Richardus, 2006). We could relate these findings to Watson's (2007) sixth item, which regards making nursing decisions on the basis of science and experience, rather than chance.

All the informants highlighted the importance of patient education. They viewed educating as their duty as nurses. For instance the patients were taught about the signs of leprosy and encouraged to seek care at an early stage. They were also taught about measures to prevent disabilities and injuries, such as choosing proper shoes. Many of the issues related to stigmatization of leprosy patients could be derived to education, or rather the lack of education, directed towards patients, relatives, the community and healthcare providers. Sobrinho et al. (2007) state the importance of education in order to prevent disabilities and to stimulate self-control. In the results of this study the informants explain that they teach the leprosy patients to take care of their ulcers and to seek care promptly when the ulcers emerge. They also described educating the patient's relatives about how to take care of them after they were discharged. Educating the relatives of leprosy patients is a first step in further educating the community; it is also of importance since many leprosy patients are abandoned by their relatives, which can have devastating consequences for them. The informants also explain that many of the patients did not know that leprosy is also termed Hansen's disease, something that they considered when using the latter term, since it did not have the stigmatizing aspect that the word leprosy has. Considering that the word leprosy is synonymous with grotesque deformities and since it is more than thirty years since the more unbiased term Hansen's disease was introduced (Nations, Lira & Catrib, 2009). The above findings can be viewed in light of Watson's (2007) seventh item, which is about the nurse helping the patient to get a

sense of self-control through teaching and learning.

Attempts to achieve a healthy and positive environment was shown in different ways, for instance they participated in morning prayer with the patients, something that was much appreciated. One of the informants also told us that the donations given to the hospital, after being distributed to all the wards, the leftovers were always given to the leprosy ward. This was done because the leprosy patients were often poor people without any relatives visiting them. The nurses thus took it upon themselves to try and make sure that the leprosy patients had enough of what they needed to better their environment. We related this behaviour from the nurses to Watson's (2007) eight factor, which mentions creating an environment that is positive physically, spiritually, psychologically and socially for the patients.

### ***8.2.2 Further research***

To our surprise, when searching for articles to be used in this study we did not come across a single one that touched upon the nurses relation to health related stigma. The studies regarding stigma that we came across most frequently concerned the issues of stigma from the perspective of those directly affected, i.e. the patients. Nurses, who work closely to stigmatized patients and have an authoritative voice in society in relation to health, should also be heard. We believe that the quest to minimize health related stigma would benefit greatly by researching what the nurse's role is in that quest. Our study showed that nurses were well aware of the issues of stigmatization and had great insight in how it could affect the patients. We suggest that further research be done to find out how nurses affect and are affected by health related stigma. It is also important to remember that health related stigma is not only a problem in developing countries, but also exists in industrial societies, which is why it is beneficial if research on the topic is also conducted in developed countries.

### ***8.2.3 Clinical implementations***

Cultural diversity in Sweden is growing due to an increasing amount of immigration from all around the world (SCB Befolkningsstatistik, 2013). This puts pressure on health care to take into consideration various patients different social and cultural contexts. It also means that health care workers themselves have more diverse cultural backgrounds, which might affect their view on disease and health care (Atkin, Bradby, & Harding, 2010). Therefore, in order to adapt to a changing climate it is valuable to study how other cultures, differing from Sweden, view and manage certain aspects of health care, such as the management of health

related stigma.

The importance of education was one of our main finding. The informants were agreed upon the fact that educating society, health care workers, relatives and patients was the surest way towards minimizing stigmatization. The importance of education related to health care is not specific to Ghana or leprosy related stigma; it can be applied to any part of the world and healthcare as a whole. For instance, by educating patients and relatives about the conditions that affects their lives one acts to empower them by giving them the knowledge to make independent decisions. Even though leprosy in Sweden is extinct, health related stigma is not. In Sweden stigma exists for instance in relation to psychiatric illnesses (Björkman, Angelman & Jönsson, 2008). White (2008) discusses the similarities between leprosy and mental illness in regards to stigma. She gives the example of isolating the diseased, in leprosy camps and in mental institutions, which subsequently increases fear and stigma. Just as with leprosy, by finding ways of educating and informing the public about psychiatric illness, in order for them to get a better understanding of it's true nature, it is our belief that stigmatization can be diminished.

## **9. Conclusion**

The aim of this study was to give a view of nurse's experience of leprosy related stigma. The results confirmed the finding of earlier research, which has shown that stigma, is a direct consequence of leprosy. Among our most significant findings was the importance of knowledge in order to prevent stigmatization. The informants expressed a need for education in the community, among nurses as well as for patients and their relatives. Another interesting find was the fact that the informants expressed a religious motivation for caring for leprosy patients and saw a religious reward as an incentive to continuing with their work despite the stigma surrounding it.

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**Interview guide****Appendix 1**

Could you tell us about your experience in caring for patients suffering from leprosy?

How has working with leprosy patients affected you personally, socially and professionally?

What is the biggest difference in caring for leprosy patients compared to patients suffering from other diseases?

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 how leprosy patients are cared for, what would you change?

**Follow up questions**

Could you please define the word stigmatization?

How would you define discrimination?

What associations do you have to the word leper?

How has treating leprosy patients affected you?

| Meaning unit  | Condensed Meaning unit                               | Abstraction   | Sub-category  | Category                            |
|---|--|---|---|-------------------------------------|
| The community, they have the stigma about the disease. They don't come close to the leprosy patients because they think if you get close to them you will get infected. So that is why they built the camp there for them.  | Isolation due to fear                                | Lack of knowledge creates stigma and discrimination | Negative attitudes; effects of lacking knowledge        | Increased knowledge prevents stigma |
| Well, my thought about leprosy was that it was an airborne disease and very dangerous. And that is how ordinary people think. Initially that is how I also thought.   | Health personnel is different due to their knowledge | Knowledge reduces fear                              | Internal education among the nursing staff              |                                     |
| Initially when they are diagnosed as leprosy patients we educate their families and most times they put the stigma aside. They think, "oh, he is my son or he is my daughter, no matter the condition he finds himself in I have to be close to him". The leprosy patient's relatives, we educate them. After that most of them they come around. | Education to the relatives                           | There is a desire to normalize the disease          | Educating patients and their relatives                  |                                     |
| It's health professionals! We have the responsibility! It is our responsibility to wherever we find ourselves, be it in a taxi, be it in a car, everywhere you find yourselves - educate people. If you do it then you are extending your education beyond.   | Health personnel have a responsibility to educate    | A wish for increased knowledge in the community     | There is a need for community based education           |                                     |
| 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 depending on other people (...) If there is something that could be done that could generate income, I think it would help.   | Establishing workshops for patients                  | A need for a long term social improvements          |   | Social Improvements                 |
| I think it's the attitude out there. If you go out there and say 'this person is a leper' people's thought is that they have to be careful to not get infected. The term Hansen's disease, people don't understand it so much, while leper is a common word.  | Negative associations                                | Attempts to avoid offending the patients            |   |                                     |
| 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.   | God sees your actions                                | Religious reward as an incentive                    | The nurses moral views when caring for leprosy patients | The core of nursing                 |
| You have to make the patient feel that he is also part of the human being.  | Humanize the patient                                 | Seeing each person's value                          | Equal treatment; a central part in giving good care     |                                     |
| Common people in the marketplace if they 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.   | Avoidance due to visible disabilities                |   | Exclusion; a main effect of stigma                      |                                     |

Content Analysis Table







