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The human being behind the disease: A qualitative study of nurses' view upon caring for patients with HIV in Colombia

Människan bakom sjukdomen: En kvalitativ studie om sjuksköterskors syn på att vårda patienter med HIV i Colombia

Abstract

Background: In 2014, 1.2 million people died from HIV related causes around the world. Colombia ranks second in HIV prevalence in Latin America and the number of people infected with HIV in Colombia increases. One of the reasons for the increase is the stigmatization and discrimination against patients infected with HIV that exists. Nurses are human beings, influenced by their surroundings, with personal beliefs and preconceptions and may, if not being aware of these preconceptions and personal beliefs, help supporting stigmatization and discrimination.

Aim: The aim with this study was to describe how Colombian nurses view upon caring for patients with HIV.

Method: A qualitative approach was being used in this empirical study. The data was collected through semi-structured interviews with six Colombian nurses at an infection unit in a university hospital. The interviews were transcribed and later analysed by using a qualitative content analysis.

Results: The findings resulted in three major themes: *Nurses' reflections on attitudes towards HIV, The role and responsibilities of a nurse and Nurses' thoughts regarding the patients, the disease and the profession.* The first theme illustrates how the nurses reflect upon the attitudes within the society, the patients' family and the patients' attitudes towards themselves. The second theme describes how the nurses worked with patients with HIV. In the third theme, the nurses reflect upon their previous experiences, the future and the profession.

Discussion: Based on the result from the interviews, the factors influencing ones' values and preconceptions were discussed. Some of these factors are religious and moral beliefs, lack of education and experience.

Keywords: HIV, Stigmatization, Intersectionality, Equality, Discrimination, Colombia

Sammanfattning

- Bakgrund:** 2014 avled 1,2 miljoner människor i världen av HIV-relaterade orsaker. Colombia återfinns på andra plats i Latinamerika vad gäller antal personer smittade med HIV och antal smittade i Colombia ökar. En orsak till ökningen är den stigmatisering och diskriminering av patienter smittade med HIV smittade som existerar. Sjuksköterskor är människor, influerade av sin omgivning, med personliga åsikter, värderingar och förförståelse. Om sjuksköterskan inte är medveten om sina värderingar och sin förförståelse, kan det bidra till stigmatisering och diskriminering.
- Syfte:** Syftet med denna studie var att beskriva sjuksköterskors syn på att vårda patienter med HIV.
- Metod:** En kvalitativ ansats användes i denna empiriska studie. Data samlades in genom semistrukturerade intervjuer med sex colombianska sjuksköterskor på en infektionsklinik på ett universitetssjukhus. Intervjuerna transkriberades och analyserades sedan med hjälp av kvalitativ innehållsanalys.
- Resultat:** I resultatet framkom tre huvudteman: *Sjuksköterskors reflektioner angående attityder till HIV, Sjuksköterskans roll och ansvarsområden* och *Sjuksköterskors tankar angående patienterna, sjukdomen och professionen*. Det första temat behandlar hur sjuksköterskorna ser på attityderna i samhället, i patients familj, samt patientens egna attityder. Det andra temat beskriver hur sjuksköterskorna arbetade med patienter med HIV. I det tredje temat reflekterar sjuksköterskorna kring tidigare erfarenheter, framtiden samt professionen.
- Diskussion:** Baserat på resultatet från intervjuerna, diskuterades de faktorer som påverkar ens värderingar och förförståelse. Några av dessa faktorer är religiösa och moraliska värderingar, brist på utbildning och erfarenhet.
- Nyckelord:** HIV, Stigmatisering, Intersektionalitet, Jämlikhet, Diskriminering, Colombia

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Introduction

The world we are living in is rapidly changing. People move around, which requires nurses to be able to work over cultural borders with an open mind in order to treat all the patients equally. Our experiences have made us aware, though, that health care is, by no means equal. The health care system is built on people, people that all have preconceptions, personal values and ideas about the world. We believe that these preconceptions, personal values and ideas could lead to discrimination. This may be particularly true when talking about sexually transmitted infections (STIs). As nurse students, we find it important to know more about how our personal values might affect the quality of nursing.

Background

The right to health

Health, in all respects, physical and mental, is a fundamental human right. Health has a wider meaning than just the absence of illness and has to be seen as something multi-dimensional (Willman, 2009). Health is considered a resource for a person to achieve his or her own goals. In other words, it is their own experience that states whether or not they have a good level of health - but health may be affected by illness, injury and suffering, as well as poverty, unemployment, lack of social relations and discrimination.

The right to health and care on equal terms for everyone, regardless of race, religion, political belief, economic or social condition, sexual orientation and gender, is stipulated in the Swedish Health and Medical Service Act (HSL, SFS, 1982:763), 2 §, the introduction to the constitution of the World Health Organization [WHO] (1946) and the Code of Ethics by the International Council of Nurses (2005).

Colombia

The republic of Colombia is located in the northern parts of South America, with neighbouring countries Venezuela, Panama and Ecuador (Central Intelligence Agency [CIA], 2015). The population is approximately 48 million inhabitants (June 2015) and the official language is Spanish. Catholicism is the main religion and 90 per cent of the people identify themselves as Catholic.

Colombia is categorized as an upper middle-income country (WHO, 2015) with a Gross Domestic Product (GDP) of \$377.7 billion in 2014. However, it is one of the most unequal countries in the world and two of every five Colombians live in poverty. There are big gaps between individuals, regions, and ethnical groups, and also between men and women.

United Nations Women established in a report (n.d.) that social and cultural beliefs are deeply rooted in the Colombian society and are generating rigid gender roles and patterns of sexist, patriarchal and discriminatory behaviours. This facilitates, allow, excuse and legitimize violence against women. Legally, homosexuals, bisexuals and transsexuals have gained rights in the Colombian society, however conservative and traditional views make it far from true in practice (www.landguiden.se/Lander/Sydamerika/Colombia/Sociala-Forhallanden).

The poverty is cemented by the nearly 50 year long on-going conflict between government forces and anti-government insurgent groups, armed paramilitary groups and guerrilla organizations (The Humanitarian Crisis in Colombia Caused by the Armed Conflict, 2011). The groups most affected by the conflict are women, children, adolescents and ethnic minority groups (Internal Displacement Monitoring Centre [IDMC], 2014).

Health Care in Colombia

In June 2013 the Congress of Colombia approved the Statutory Law, which establishes health as a fundamental right (WHO, 2014). About 98 per cent of the Colombian population has access to health care services, however the quality of the services varies enormously due to inequalities, especially in remote parts of Colombia and among minority populations. Ethnical minority groups have much higher prevalence rates in for example tuberculosis and trachoma than the national average (Pan American Health Organization [PAHO], 2012).

The health care system in Colombia is based on the System of Comprehensive Social Security in Health (SGSSS) (PAHO, 2012). The system is built on two regimes: the contributory and the subsidized regime. In theory, and by law, all Colombians have the right to adequate health care, but as previously mentioned, it is not the case in practice.

In Colombia there are 30,119 registered nurses and midwives (compared to Sweden with 9 million inhabitants and 107,000 registered nurses and midwives) giving a density of 6.16 nurses/midwives per a 10,000 population (The World Bank). To become a nurse, a minimum of four years of studies at the university is required.

HIV

The Human Immunodeficiency Virus (HIV) is a retrovirus that attacks the cells of the immune system to either destroy or impair their function (WHO, 2015). In 2014 there were 36.9 million people in the world living with HIV and 1.2 million people died from HIV related causes. As the infection progresses, the immune system gets weaker and the infected person becomes more vulnerable to a wide range of infections and diseases that a person with a healthy immune system easily can fight off. Without treatment, the infection will develop to the most advanced stage, Acquired Immunodeficiency Syndrome (AIDS), although it can take 10-15 years. There is no cure for HIV infections but the effective treatment with antiretroviral therapy (ART) control the virus. However, the treatment is very sensitive and it is important to adhere to the treatment in order for people with HIV to be able to live a long, healthy and productive life (Andreassen, Fjellet, Haegeland, Wilhelmsen & Stubberud, 2011).

HIV is transferred through certain body fluids such as blood, semen, vaginal or rectal fluid, breast milk and also between a mother and her infant during pregnancy and childbirth (WHO, 2015). A person cannot become infected through contact such as kissing, hugging, shaking hands, or sharing food or drinks.

One of the eight Millennium Development Goals (MDG) set by the United Nations [UN] is to *combat HIV/AIDS, malaria and other diseases* (UN, 2015). By 2030 the epidemic of AIDS should have come to an end according to this goal.

HIV in Colombia

HIV, in addition to the conflict and continuing violence, is a major problem in Colombia, which ranks second in HIV prevalence in Latin America (Zea et al., 2013). From 2007 to 2009 HIV infection was one of the leading causes of death among young Colombian adults and the infections affected highly vulnerable groups, such as sex workers and men who have sex with men (PAHO, 2012). Only 7.8 per cent of the women without any higher education have a comprehensive knowledge of HIV. Among women with higher education, the number is 41.8 per cent. The numbers of infected are rapidly increasing among married women and teenagers. UNAIDS (2014) estimates that 95,000-160,000 Colombian adults are living with HIV and the unreported cases are expected to be over a hundred thousand. The unreported cases are considered to be a result of the limited possibilities and/or will to get tested.

Despite the United Nations' Millennium Development Goal to combat the epidemic of HIV and AIDS, the numbers of newly infected persons in Colombia are increasing (Ministerio de Salud y Protección Social República de Colombia, 2014).

Stigmatization

In addition to the physical outcomes the disease causes, HIV is associated with a psychological and social burden and with an experience of stigma and discrimination (Foster & Byers, 2008). This has to do with negative reactions and social judgments towards people with these types of infections.

Raingruber, Uwaize and Bowie (2010) describes that 77 per cent of people in Ghana responded that they would not buy food from someone who was HIV-infected. Tyler-Viola (2007) revealed that nurses were unwilling to provide care to HIV-positive women if the women were infected by intravenous drug usage or prostitution, compared to those who were infected due to a blood transfusion. The nurses considered the women themselves to be responsible for their infection and treated the women accordingly.

In the study of Relf, Flores & Biederman (2015), it is shown that 16 per cent of the persons with HIV in North America are unaware of their status, largely due to stigmatization. Concerns over being stigmatized can lead people to not getting tested or hide their HIV infection, engage in risky behaviours and avoid taking their medication in the presence of others. This in turn might lead to devastating outcomes for both the person infected and others put at risk.

The nurses role and responsibility

Our values and attitudes affect how we view a person, (Willman, 2009), several studies (Hayter, 1996; Tyler-Viola, 2007; Cianelli et al., 2015) show that nurses' attitudes towards patients may have a negative impact on the nurse-patient relationship, especially within sexual health questions. The science of nursing includes a perspective where health is considered to be multi-dimensional and one of its purposes is to promote health and prevent illness (Willman, 2009). For that reason, it is important for nurses to be aware of the fact that their attitudes will have an impact on the quality of nursing (Dahlberg & Segesten, 2010). It is a part of the nurses' profession to address feelings of shame and isolation in order to decrease stigmatization (Relf et al., 2015; Svensk Sjuksköterskeförening [SSF], 2014).

Problem statement

Despite the fact that the right to health and care on equal terms is stipulated in the constitution by the WHO, differences in access, quality and approach in health care exist. Colombia is one of the most unequal countries in the world with big gaps between different groups.

Paradoxical to the goal set by the UN to reduce and ultimately eradicate the HIV virus, the numbers of HIV-infected people in Colombia still increases, especially in certain vulnerable groups. The unreported cases are expected to rise over a hundred thousand. One of the reasons for the increase could be the stigmatization and discrimination caused due to religious and cultural beliefs that affects patients living with HIV and causes them to not get tested even if they suspect they might carry the virus. Nurses have an important role in reducing stigmatization, discrimination and the pain it causes. The way one views a patient will have an impact on the quality of the care and the patients experience of health, therefore it is important for nurses to be aware of and reflect upon their preconceptions and personal values.

Aim

The aim with this study was to describe how Colombian nurses view upon caring for patients with HIV.

Theoretical framework

The theoretical framework chosen for this study is one of the four central concepts within the science of nursing as stated by Fawcett in 1984 (Basford & Slevin, 2003): *person or human being*. In order to get a wider perspective on the understanding of human being, the theories of gender and intersectionality are included as parts of the theoretical framework.

Human Being

Though health, as described in the background, is considered to be multi-dimensional and something experienced by the individual herself, it is important to understand the meaning of human being in the context of science of nursing (SSF, 2014). The science of nursing takes it starting point from the humanistic view with an idea that the human being is active and creative and has to be understood as a part of a context. She is also being seen in a holistic perspective as the sum of biological, psychological, social and spiritual parts (Willman, 2009). Fawcett, who stated the central concepts of the metaparadigm of nursing (1984),

describe human being as “(...) the individual who is being nursed, who must be recognized as a person in his/her totality” (Basford & Slevin, 2003, p. 158).

One perspective of human being within the humanistic view is the philosophical theory of *lifeworld* (Dahlberg & Segesten, 2010). One's lifeworld is based upon one's lived life, which means a human being's experiences throughout life. It is through one's lifeworld the understanding and beliefs towards oneself, the objective world and others, are present.

According to SSF (2014), our understanding of the meaning of human being is elementary for our ground values and will therefore reflect our perceptions towards one another, which is in line with the purpose of this study.

Gender is, by many, defined as one's social sex, constructed by the surroundings, culturally and socially (Määttä & Öresland, 2009). Simone de Beauvoir (1994), a French writer and feminist, stated: “One is not born, but rather becomes, a woman” (p. 162). The gender studies within the science of nursing are to a great extent based on the so-called *gender system* (Määttä & Öresland, 2009). The gender system is a perspective within the gender studies, where critics see the society in which women are subordinate to men (Hirdman, 1988).

Some state that to look at inequalities one must use a wider perspective than the theory of gender (Lykke, 2003; Määttä & Öresland, 2009). Intersectionality is a concept used to theorize how gender and other sociocultural power differentials such as ethnicity, race, sexual preference, age, profession and nationality are *interacting with each other* (strengthening or weakening) and affecting how a person might be viewed. With an intersectional perspective one is allowed to see a certain situation from different aspects, not only gender (Määttä & Öresland, 2009). To use intersectionality as part of the theoretical framework, the researchers of this study hope to widen the perspective and look at equality from several aspects, not only gender. Earlier, the focus was on gender-race-ethnicity, but the debate has started to move towards including sexual preference and class. According to Lykke (2003) we are all part of an intersectional web where structures and power systems will dictate our conditions, which is in line with how the researchers of this thesis understand the humanistic view upon which the science of nursing is resting.

Within the science of nursing, the nurse is considered to focus on the patients' lifeworld, and understand how health is experienced by that particular individual (Dahlberg & Segesten, 2009). It is therefore crucial to not see a certain patient group as homogeneous, assuming that the factors affecting health are the same for all individuals in that certain group. In order to

understand how discrimination and stigmatization is experienced by a particular patient, an intersectional approach will be useful.

Method

A qualitative approach was used as a method in this study. The qualitative framework is based on a holistic approach and seeks to understand the phenomenon in a specific context setting, together with researcher and informant (Henricson & Billhult, 2013). The data in a qualitative research is collected through interviews, focus groups, questionnaires or observations. In this study interviews were conducted where the participants own words and experiences are subject of analysis.

Setting

The location for the study was an infection unit at a university hospital in the capital of Colombia. During the initial work of this study, the researchers were in contact with the Swedish Church and got referred to the current clinic by them. Within the infection unit there was a programme for patients with HIV, where more than 1,500 patients were signed up at the time for this study. The programme was an interdisciplinary programme with different professions, such as nurses, medical doctors and social workers. The majority of the patients were men and so called contributors, belonging to the middle-class.

Participants

The participants in this study were selected through sample of convenience. Sample of convenience uses voluntary participants available at the time of the study and is, according to Kristensson (2014) an efficient way to find participants to a study.

After getting in contact with a team leader at the clinic, the project plan and information letter was sent to the team leader in order to be forwarded to possible participants at the clinic. The participants were six registered nurses connected to the clinic. The level of education and professional experience varied; while one of the nurses had a degree of nursing, the remaining five had different specializations and masters within the science of nursing. One of the participants had 34 years of experience as a nurse, working in many different specialties, but no experience from this specific programme. Another had been working as a nurse for four years, three of them within the programme. The age varied between 25 and 61. The only criteria for being able to participate in the study was being a nurse and working/have been

working with patients with HIV. Age, gender and background was not a criterion for participating in the study, however all participants were women. The participants were informed about the purpose of the study and they were assured complete confidentiality.

Data collection

Semi-structured interviews were conducted with six participants. The semi-structured interview method aims to let the participants speak narratively and free about experiences and views on situations using their own words (Danielson, 2013). Open-ended questions were prepared on beforehand in an interview guide (attached), which aimed to be used as support during the interview. The same questions were asked in all the interviews, but not necessarily asked in the same order. The researchers interviewed three participants each one-by-one at the clinic where the nurses work, in a separate room, separate from the patients, in order to achieve a calm trustful atmosphere. A professional interpreter was present during the interviews, translating from English to Spanish and then back from Spanish to English, simultaneously. The interviews were recorded, which allowed the researcher to be fully present in the conversation, and later transcribed, making the participants unidentifiable, and stored in the strictest confidence until no longer needed and then destroyed.

Data analysis

The transcribed interviews were analysed as a whole, only after all the data was collected, using a qualitative content analysis described by Kristensson (2014). According to Kristensson, a qualitative content analysis contains six phases. In the first phase the researchers read the interviews as a whole, several times, individually, in order to get an overall understanding of the texts (Kristensson, 2014). Both researchers for this study read all of the interviews independently and then met to discuss the impressions and understandings of the text.

In the second phase, parts of the text referring to the aim are being identified as meaning units (Kristensson, 2014). This was done together by the researchers by going through the interviews several times, back and forth.

In the third phase, the meaning units were coded with labels that described a part, or a whole, of the meaning unit as explained by Kristensson (2014).

In the fourth phase the codes are summarized into categories in line with Kristenssons', (2014) description.

In the fifth phase the researchers are getting closer to interpreting the meaning of the text, which is done by reading the categories, codes and texts again in order to see if any sub-categories can be identified (Kristensson, 2014). Sub-categories were identified by the researchers after discussing their interpretation and understanding of the underlying meaning of the texts.

Lastly, the categories and sub-categories were being read again, as well as the interviews and put in relation to the categories that emerged in order to identify main categories or themes as described by Kristensson (2014).

There were three themes identified: *Attitudes towards HIV, Nursing process, and Nurses' thoughts*. Each theme is presented in the result.

Ethical considerations

According to requirements of the Department of Health Care Sciences at Ersta University College, an application for ethical approval was submitted, which was approved by the Research Ethic Committee, diary number 1507/A.

As a researcher it is important to understand the ethical dimensions facing the study (Codex). It is every researcher's responsibility to reflect upon the ethics of research. Colombia was for a long time colonized by Spain and the same issues as for other ex-colonial countries have been present in Colombia. It is therefore important to be attentive to histories of colonialism and be mindful of the so-called western biases (Sultana, 2007).

The researchers made sure that the participants at all times were aware of the fact that the interviews were held on a voluntary basis, and that they could withdraw from the interview session at any chosen time without any further explanation provided. They were also informed that the information provided was to be held in the strictest of confidentiality, and anonymized, as advised by Kristensson (2014).

Results

Three main themes emerged when analysing the data: *Nurses' reflections on attitudes towards HIV, The role and responsibilities of a nurse and Nurses' thoughts regarding the patients, the disease and the profession*. Each theme is presented below followed by extracts from the interviews illustrating the themes. Many of the extracts could be considered taking place in more than one theme, however they are only described once and in relation to one of the themes.

Nurses' reflections on attitudes towards HIV

Nurses' reflections on attitudes towards HIV relates to *The nurses' reflections regarding the attitudes in the society*, *The nurses' reflections regarding the attitudes within the patients' family* and *The nurses' reflections regarding the patients' attitudes towards themselves*, which were identified as the categories within the theme.

The nurses' reflections regarding the attitudes in the society

The attitudes in the society have an impact on patients with HIV and all of the participants focused on the lack of education as a factor for how the attitudes are shaped. For example, one participant said: "It's useless to (...), to teach each patient and educate patients and protect patients from discrimination if you don't attack education deficit in society". This participant thought of it as pointless to educate the patient alone as long as the society is still prejudice and discriminating. The same participant suggested that the patients themselves should be an ambassador for the virus and thought that they should talk openly about how it is to live with the disease.

One major concern regarding the infection was identified by the participants – stigmatization. The society was not open or tolerant towards people with HIV, and the patients were worried about revealing their condition. By comparing patients with HIV and patients with cancer the participants illustrated the attitudes in the society: "I can say that I have cancer, not a problem. But if I say that I'm HIV-positive, it's a catastrophe". The patients would lie to their employer for example, and say that they had cancer, in order to be able to get time off from work to go to the doctor's appointments.

Another factor shaping the attitudes in the society is – apart from lack of education – according to several participants, religion. Religion influences the way the society looks upon homosexuality, which is illustrated by following statement: "But I think religion has a fundamental role, because religion tells you about men and women, men and women. Religion never opens the possibility to have men with men and women with women". The majority of the patients at the clinic were homosexual men and they were rarely open about their sexual preference. According to one participant, people thought that HIV would only affect homosexual men, and for her it was important to let people know that people with HIV are not necessarily homosexuals, that anyone could get infected.

According to the participants, the Colombian society is full of sexist attitudes. One participant clearly stated that: “Yes, it’s a sexist culture, a sexist society”. She thought that the sexism in the society affected the way women get infected. The one group of HIV-infected people that is growing most is the group of married women. According to the participants in this study, the husbands were unfaithful, got infected and passed the virus on to their unknowing wives.

The attitudes within the society exist on all levels in society and there were examples reflecting this where other hospitals have different doors for patients with HIV, stigmatizing the patients with the virus, separating them from other patients. An example about a nurse working in the same hospital as the participants was told as well:

We had an experience this year. We had a patient with HIV that went to the ER; he had an injury in his finger. The nurse isolated the patient immediately. She threw away all the utensils she had been using. She wore two sets of clothes.

The nurses’ reflections regarding the attitudes within the patients’ family

There were patients that did not want to tell anyone, not even their closest friends and family, about their diagnosis because of fear for the reactions, for example: “some patients ask us openly not to tell their relatives (...) especially their parents”.

Being homosexual and having the diagnosis HIV could mean double stigmatization. One participant said that the majority of her homosexual patients had not told their parents about neither their sexual identity, nor their disease: “But the vast majority, I mean their parents doesn’t even know they are gay”. It seemed as if the mothers were more accepting towards their homosexual sons, than the fathers were. According to one participant, the mothers would generally accept if their sons were gay and the family would split as the fathers would not tolerate their son being gay.

The nurses reflections regarding the patients’ attitudes towards themselves

According to the participants interviewed, the patients seemed to judge themselves and blame themselves for being infected with the virus. Some of the patients would not even seem surprised when they got their diagnosis. According to one of the participant, the patients would consider themselves having had a risky behaviour and it would almost seem as they expected getting the infection.

Furthermore, the participants considered the women to judge themselves harder than men: “women judge themselves quite harshly”. When getting the diagnosis the women would be shocked and unable to identify herself as someone that, according to themselves, would get infected with HIV. The women would see promiscuity as a risk factor and did not understand how they could have gotten infected, as they had only been with their husband.

One participant with over 30 years of experience considered the depressions among the HIV-infected patients to increase in response to the fact that the patients judge themselves so hard, she stated: “we increasingly find more depressed patients, we didn’t have and suicidal ideation or suicide attempts before”. This was because the patients did not look for any support, they would isolate themselves and live their lives with a poorly treated disease.

The role and responsibilities of a nurse

When working with patients, one of the responsibilities for nurses is to address the feelings of shame and isolation to help the patient cope with the situation. The participants worked with different strategies including; *educating and counselling*, *supporting and improving adherence* and *nursing and caring*, which are all described below.

Educating and counselling

As mentioned before, the lack of education is a main factor for how the attitudes in the society are shaped. Educating both patients and the patients families and surroundings was therefore a strategy within the programme and one of the participants said: “We like to incorporate the family into the programme, into the process (...) But you need to educate the family”.

Educating and counselling the patients was done by teaching and advising on their medication - when and how to take it and what side effects there are - how to take care of themselves, how to not spread the virus and also about the disease itself and how the patient should live with the disease. According to one of the participants, the counselling was a big part of their work, and she would advise the patient: “(...) why they should use a condom. They should avoid doing this and that” and “(...) we like them to be monogamous, to have one sexual partner. To avoid multiple sexual partners”. According to another participant, part of the initial consultation included questions about sexual habits and sexuality.

Supporting and improving adherence

The participants considered it as important to support the patients and to: "(...) help this person live a full life!", free from discrimination and stigmatization. To make this possible, the clinic offered them support on all levels and one participant expressed: "They need more psychological support, more spiritual support".

Furthermore, one of the main focus points in the programme was to encourage the patients to tell someone, a family member or a close friend. All of the participants used this as a strategy when working with patients with HIV, and they all emphasized it in the interviews. The purpose of this was for the patient to have support outside of the hospital. As one of the participant expressed it: "We advise those patients that they need to tell somebody (...) to take this weight off their shoulders, because this is a very heavy weight to lift, to be carrying around". One of the participant explained that colleagues of hers in other clinics actually addressed this by encouraging the patient to *not* tell anyone about their diagnosis as they expected the patients to be discriminated.

The participants thought that if the patient would have support from a family member or friend, it would increase the patients' adherence to the programme. The nurses worked genuinely and determined on getting the patients to adhere and wanted to guarantee that every single patient had counselling and medication. The importance of adherence becomes crucial when treating patients with HIV, as the treatment is so sensitive.

The participants would even call to check up on the patient who did not show up for an appointment and make sure the patients show up for a new appointment or make one of the patients kindred to pass by the clinic and at least make it possible to access their medications.

If there is a person, a relative, a friend that knows about his diagnosis or her diagnosis, please, let that person know so, tell that person to come instead of you, tell your relative to come and so he can take the prescription back with him so you can at least by the drugs.

Several participants considered it challenging to work with women, as they had to give more attention to adherence when it came to female patients. Many women did prioritize themselves lastly, taking care of family and work before her own health and "(...) if we have an HIV-positive couple the women end up asking about the medication, double-checking that he's taking the medication, forgetting about their own medication".

Nursing and caring

The participants found it essential to see the person rather than the disease and they consciously worked in an including way, making sure to not separate the patients with HIV from other patients: “I believe that the main thing here is to stop thinking about HIV; we need to think about the person that has HIV, and start regarding HIV-patients like a diabetic patient”. They would offer the same kind of consultation as for people that did not have the virus and including the patients in all of the wards at the clinic, not separating them from other patients.

Despite examples illustrating the participants seeing the patient rather than the disease, one participant explained that they would try to protect the patients by calling them the ‘special programme patients’, separating them from patients that were not in the programme.

Some participants expressed their caring towards their patients with love and feelings of empathy. They saw this as another important factor for nurses in the nursing process. As one participant expressed it: “I love them, I love them (...), I love my patients. I help them to fully extend with all my heart, with all my love (...), That’s how we as nurses can help those patients”. Another participant talked about the nurse-patient relationship and used that part in the nursing process in order to help the patient: “So as the patient involves, as we become more familiar with the patient and we understand the needs they have, so we steer him or her in the right direction”.

Nurses’ thoughts regarding the patients, the disease and the profession

Nurses’ thoughts refer to the participants’ reflections about the past, the future, themselves as nurses and as human beings. The ability to reflect upon themselves and their profession was very present and three categories emerged. *The nurses’ own view on the patients, the nurses’ view upon themselves and their profession and the nurses’ thoughts regarding the changes in attitudes in the society.*

The nurses’ own view on the patients

All of the participants had the idea that the patients are more than their diagnosis. One of the them explicitly said:

So what is the difference between you and other patients? Why are you different?
What is the big deal? This doesn’t make you different. This doesn’t send you apart from others. Cause we would be discriminating you if we treated you differently.

However, one thing stood out in regards to the nurses' own view upon the patients: the way the participants reflected upon the cause of infection. Their own moral standards and personal values affected the way they saw the patients. For example one participant expressed the following: "Not all of these patients are homosexuals", "You see them walking on the street and they look like normal men" and "on a personal level I don't accept homosexuality", making homosexual persons with the HIV infection stigmatized from two aspects. Not only homosexuals were pinpointed - another participant expressed it like this: "We have heterosexuals due to the fact that they are promiscuous, they have multiple sexual partners, they don't use the condom, they don't wear the condom, they are quite reckless (...)". Another group of patients that the participants expressed their opinion about was young mothers. The participants considered the young women as ignorant and uneducated.

Despite the fact that the participants acknowledged religion as an important factor to the way the society looks upon patients with HIV, some would still identify themselves as Catholics, admitting that it is difficult to separate your personal life from your professional. One participant considered the clinic to have a religious mandate, and that they should work with catholic approach.

There was one participant that could not see that they had been discriminating any of the patients during her time as a head of nurse at the intensive care unit, stating: "we didn't discriminate anybody".

The nurses' view upon themselves and their profession

A common feeling among the participants was the sense of pride. All of the participants took great pride in being part of the programme and they expressed deep care and affection towards their patients. When reflecting upon their profession, several participants spoke about different personality traits being important for the work, for example, to be empathetic, protective and loving. One participant even said she had learned how to love the virus and for her working at the clinic is a matter of being human.

When reflecting upon how things had changed over time, all participants stated that things had improved, especially their own way of working with the patients. They all expressed the idea that with experience they started seeing the patients differently and their understanding towards the patients had increased. One participant expressed the following:

It just happens when you get to know the patient, when you realize how the patient is, how the patient lives with his disease or her disease. This changes your mind if you, you learn to see the patient with different eyes, as a human, to respect the person, to respect his or her disease.

Several of the participants were honest when expressing that they had been afraid when they first started to work with patients with HIV. They expressed fear for the patients, but also a feeling of not knowing how to interact with the patients. They did not know how to touch the patients or how to talk to them. The participants felt it was a completely different thing to work at this clinic, from working with patients with other diseases.

The nurses' thoughts regarding the changes in attitudes in the society

The fact that there had been some changes in the way society looks upon patients with HIV was identified by all of the participants. One participant said that patients are more open today about their diagnosis than earlier and that family members will easier accept someone with HIV.

A drastic change was considered to have occurred in the way health staff looks upon patients, one participant stated that they had all been very ignorant only a decade ago, explaining that they would wear work clothes more similar to an astronaut than a nurse. Another participant: "So people were afraid of those patients, which is a very different picture from today".

Discussion

Methodological considerations

This study aims to describe how Colombian nurses view upon caring for patients with HIV. A qualitative method with semi-structured interviews was being used in order to describe and to get a deep and meaningful understanding about lived experiences of a certain phenomenon (Henricson & Billhult, 2013). Interviews are a result of the co-operation between the participant and the interviewer, and they will both influence the story told (Graneheim & Lundman, 2003). The method showed to be useful as the participants did, indeed, share their lived experiences from their professional lives.

Kristensson (2014) states that an interview situation can never be equal. As an interviewer one always has a higher position, which is important to be aware of. In addition to this, an interpreter was present during the interview, which adds to the inequality in the situation. This

could make the participants change their behaviour and adjust their answers in order to either satisfy the interviewer or to protect themselves and their field. In the awareness of this possible problem, the interviews were held in the participants' own environment and the questions asked were as open as possible in order to have the participant speak freely, without being led. This was also one of the arguments used when deciding to hire an interpreter for the interviews as the participants and the interviewers did not have the same mother tongue.

All researchers have some level of prior knowledge as well as preconceptions, and it is important that this is reflected upon (Henricsson, 2013). The authors of this study had during the education in nursing observed the inequalities in health care and one of the researchers had studied gender at university level. This has obviously altogether influenced the researchers' interpretation of the data. According to Graneheim and Lundman (2004), there is always some level of interpretation when analysing text.

According to Graneheim and Lundman (2004), choosing participants with various experiences "increases the possibility of shedding light on the research question" (p. 109). In this study the experience ranged from four to thirty-four years, including recently graduated nurses able to remember the fear they first had coming in to the ward, as well as nurses with significant experience able to see how things had changed during her time as a nurse. This allowed the researchers to understand that there is a difference in how one sees their work according to ones' experience. Using the convenience sampling method to select the participants meant that the variation in participants was less than if the purposive sampling had been used. It should be taken into consideration that all the participants were females and that the study might have gotten a wider perspective if the participants included males. Further on, the clinic of choice was specialized in treating patients with HIV, meaning the nurses had more experiences with this specific group than what might be expected from a nurse working in any other setting. The result might have been different if the study took place in a more general setting where the nurses did not have any special training regarding the diagnosis.

As this study took place in a clinic in Colombia, it has to be taken into consideration that religion has a big influence on the way society, including health staff, sees people with HIV. However, as literature referred to in the background showed that nurses do have preconceptions and prejudice also in countries where religion plays a smaller role, the researchers for this study would argue that, indeed, the aim of this study would work in any other setting where nurses meet patients with HIV.

Results discussion

The findings in this study, which aimed to describe how nurses view upon caring for patients with HIV in Colombia, resulted in three major themes: *Nurses' reflections on attitudes towards HIV, The role and responsibilities of a nurse and Nurses' thoughts regarding the patients, the disease and the profession*. In the following text, the findings will be discussed together with previous research and literature within the field, and with the theoretical framework chosen for this study - human being, seen from a gender and intersectional perspective.

The importance of adherence

Maintaining adherence was a main focus point when working with patients with HIV for the participants in this study. One of the strategies they worked with was to facilitate and make sure that their patients could adhere to the programme. To do so they would take rather unconventional actions by calling the patient that did not show up to an appointment, or offer them to send someone else to fetch the medications, or in other ways facilitate the adherence. According to WHO (2013) adherence is one of the most important ways to try to decrease the number of HIV infections. The importance of adherence becomes especially crucial when it comes to medical treatment, as it is the most important factor in preventing the disease to develop and to acquire a better quality of life for the people affected (Ohene et al., 2013).

Previous studies have shown that there is a higher adherence to the treatment among persons who belong to a higher socio-economic group (Arrivillaga et al., 2012; Kleeberger et al., 2004). According to Ohene et al. (2013) this might have to do with the cost of the treatment. Findings in the present study also show that working with women requires more focus on adherence. According to the participants, women have a tendency to prioritize themselves lastly, and this could be due to gender related differences and cultural beliefs where women are subordinate to men (Hirdman, 1988). Arrivillaga et al. (2012) claims that economic empowerment is a factor for improving the adherence for women living with HIV. Other studies have shown that it is not only the financial aspect that is of importance, but also that the level of social capital, access to quality education and a high level of democracy are directly correlated to the level of adherence (Campbell et al., 2013; Phillips et al., 2013). Socio-economic group, gender, social capital, education and level of democracy are through

an intersectional perspective, all factors interacting with each other, affecting a persons, in this case treatment adherence, which in turn will negatively effect the health (Lykke, 2003).

Another way to help the patients to adhere was to encourage them to tell a family member or a friend about their diagnosis. The participants in this study were convinced that if the patients told someone outside of the hospital, this would help the patient to adhere to their treatment. This has also been proven to be the case in previous studies of Ohene et al. (2013) and Li, Murray, Suwanteerangkul and Wiwatanadate (2014). To encourage the patient to disclose his or her situation was however one of the most challenging tasks when working with the patients, according to the participants in this study. Many patients with HIV do not want to reveal their diagnosis to anyone out of fear for the reactions (Rintamaki et al., 2007). According to the participants in this study, this was particularly true when the patients were young or homosexual. This is something to be considered when treating patients - from an intersectional perspective, a young, homosexual patient with HIV, might experience discrimination differently than for example a heterosexual married woman would.

Stigmatization as the main problem

The major reason for the fact that the patients did not adhere to the program and not wanting to disclose their diagnosis for someone was stigmatization. The fear over being stigmatized led the patients to isolation and depression, apart from living with a poorly treated disease. This was also the case in a similar study by Rintamaki et al. (2007) that says that concerns over being stigmatized can lead people to not getting tested, hide their HIV infection and avoid taking their medication, which can result in depression and suicide. Brown, Macintyre and Trujillo (2002) states that HIV related stigmatization affects preventive behaviours negatively, such as HIV testing and care seeking behaviour. The participants in this study claimed that they find more depressive and suicidal patients nowadays compare to earlier, and it could be explained by the fact that the patients seemed to judge themselves and blame themselves for being infected with the virus. This had to do with the patients' interpretations about themselves and about risky behaviour. According to the theory of lifeworld, described by Dahlberg and Segesten (2009), ones' world is shaped by our experiences throughout life and will form our understanding and beliefs towards ourselves.

Foster & Byers (2008) says that stigmatization and discrimination is highly associated with HIV and it has shown to be linked to the number of infected persons. HIV related stigmatization does usually not come alone, which was proved to be true for the homosexual patients treated by the nurses participating in this study. The homosexual patients had

difficulties revealing their sexual orientation for their parents and they also had to be treated by a nurse who was personally against homosexuality. The participants also expressed their moralising opinion about women, especially young mothers, as being promiscuous and ignorant. Brown et al. (2002) writes that HIV stigmatization is often layered on top of many other stigmas connected to groups such as homosexuals and prostitutes, and behaviours such as drug usage or promiscuity. This could be understood through the intersectional perspective described by Lykke (2003). The example brought up by one of the participants, where the families would split when the son would disclose their homosexuality and infection, is illustrating how intersectionality could be used to understand the patients' vulnerability. It is not only the virus that causes the discrimination, nor is it the homosexuality, but also the lack of social capital (for example, a shattered family) could have an impact on the patients wellbeing. Rogers & Kelly (2011) states that the multiple ways of discrimination influences a persons' health. People who experience multiple forms of discrimination related to race, gender, class, social capital and sexuality are marginalized in health care.

According to Gabriel Villalba Villalba (personal communication, 15 September 2015), human rights attorney at la Liga contra la SIDA, it is "not the virus itself that kills people, but rather the stigmatization and the discrimination of the people that are infected with virus". Thus from that perspective, and in line with SSF (2014), the researchers argue that one of the nurses' main responsibilities is indeed the one of decreasing stigmatization and in order to do so an intersectional perspective is considered to be useful.

Education – a solution to decrease stigmatization

All of the participants in this study emphasized the importance of education in order to decrease discrimination and stigmatization. The findings from several previous studies (Röndahl et al., 2004; Saunamäki et al., 2009) indicates that the relationship between education and positive attitudes is a fact. The participants had a minimum of four years of studies at the university and all showed a good level of knowledge about the virus. Some had specialized in the area. Specialization and further education should improve positive attitudes according to the study by Saunamäki et al. (2009). Education is essential for nurses in order to improve their ability to give the patient individualized, high quality care. (Saunamäki, Andersson & Engström, 2009).

The idea that experience will decrease the discriminatory and stigmatizing treatment towards patients was present with all of the participants. They explained that with time, their way of working with the patients improved and they started to see and understand the

patients. The study by Røndahl et al. (2004) claims that life experience may improve personal attitudes and another study by Saunamäki et al. (2009) showed a significant difference in positive attitude towards discussing sexuality for nurses with more work experience. This could be understood by the theory of lifeworld, described by Dahlberg and Segesten (2009), as it refers to the idea that our own concepts of understanding the world and the people in it, are being shaped by our experiences throughout life.

The need of education for as well patients, the patient's families and surrounding in order to reduce stigmatization and discrimination has been clearly demonstrated throughout this study. The lack of education and knowledge is one of the main factors shaping the attitudes in the society. Studies (Brown et al., 2002; Raingruber et al., 2010) show that attitudes are being based on lack of, or incorrect knowledge on, for example, how HIV is transmitted. The participants in this study considered it as a part of their profession to educate the society outside of the hospital, in order to decrease the stigmatization that HIV causes. They also considered the patients to be responsible, to be some sort of ambassador for the victims of the virus and that they should lecture about how they are living with the disease.

The findings in similar research claims that there is a particular need to educate young girls and women, due to the fact that women without any higher education lack a comprehensive knowledge about HIV and on how to protect themselves from getting infected (PAHO, 2012). WHO (2009) states that in cultures, where the women have limited knowledge about HIV, the death and disability from the infection increases. In fact, unsafe sex is the single leading risk factor for death and disability in women of reproductive age in low- and middle-income countries. To include a gender perspective and ensure this particularly need is an important part in the preventive work on HIV.

Beliefs and values influences ones' attitudes

Religion plays a fundamental role in shaping ones' personal values and beliefs, and also shaping the attitudes in the society. Religion influences the way society looks upon the role of men and women, sexuality and sexual behaviours. This was acknowledged and expressed by several nurses in this study. Some of the participants identified themselves as Catholics and one participant considered the clinic to have a religious mandate. Foster and Byers (2008) argue that conservative values and traditional views on the role of men and women are associated with discriminatory and stigmatizing behaviours. In a Chilean study by Cianelli et al. (2015) they found that traditional views on gender roles have a negative impact on attitudes, especially towards female patients as they are expected to be sexually naive and

passive. The human being is to be understood as a part of a context and ones' values and personal beliefs are being socially and culturally constructed through our surroundings (Sarvimäki & Stenbock-Hult, 2010)

Attitudes in the Colombian society were described as sexist and machist, where homosexuality is a big of an issue. One nurse clearly said that she did not support homosexuality. This was said from her personal point of view, but the researchers argue, in line with Willman (2009) and Rassins (2008) article, that our personal values and own lifeworld, indeed, influence our professional behaviour. It appeared that some of the nurses had a determined idea on how one should live their life, when for example recommending the participants to stay monogamous. Knowing that the vast majority of the patients at the clinic were homosexual men, this is of relevance when considering the nurses' attitudes towards homosexuality. The way the nurse looks upon caring for the patients, as well as the patient itself will have an influence on the nursing process. The way your social surrounding sees you will have an impact on the human being as whole.

Despite findings in earlier studies and the fact that the participants in this study emphasized the importance of education, they would still admit to being afraid of the patients, of the disease. This seemed however, to decrease with experience. It seems as if it is not only the level of education and knowledge that will help to diminish discrimination. The same way that patients are to be considered as the sum of biological, psychological, social and spiritual parts (Willman, 2009), nurses are as well. Nurses are also to be understood as part of a context, influenced by their surroundings, cultural and religious beliefs as well as their education and professional experience. According to Rassin (2008) several factors influences nurses' values: culture, professional education, training and experience. Nurses will have personal biases and preconceptions of their patients and may, if not being aware of them, help supporting stigmatization.

Clinical implications

To promote health and wellbeing for the patients, stigmatization and discrimination must be addressed, especially within sexual health issues. This study confirms the research already existing about how nurses' personal values might affect the quality of nursing, adding more precise information about how this is reflected by nurses in Colombia, a country where the number of HIV infected people are still increasing. The findings in this study could be particularly useful for nurses and other health care and social workers, as well as for

politicians and those in power, in the process of combating HIV and HIV related stigmatization in Colombia. Knowledge about how the personal values and beliefs might affect the quality of nursing, will improve nursing and the health experienced by the patient.

The Public Health Agency of Sweden (Folkhälsomyndigheten) launched a campaign in the autumn 2015 to promote the knowledge of HIV in order to decrease the stigmatization of HIV. At the same time, the magazine *Vårdfokus* published an article describing the stigmatization of patients with HIV in Sweden. Therefore, the researchers of this study states that the findings are also of relevance for nurses working in Sweden.

Further research

As a patients' first contact with the health care is usually with a general nurse, it would be of importance to get a better insight in how the general nurses view upon caring for patients with HIV. Therefore, the researchers propose to consider revising the selection of participants to include nurses less experienced working with patients with HIV.

Due to the fact that newly infected people in Colombia are increasing and the high amount of unreported cases, further research on HIV in Colombia should focus on the vulnerable groups, such as women and youths. As Folkhälsomyndigheten and *Vårdfokus* shows, further research in Sweden is needed as well.

Conclusion

The findings from this study illuminate how Colombian nurses view upon caring for patients with HIV. Adherence is considered to be the core to any HIV treatment and social support together with personalized care is important in order to maintain adherence. Education is crucial when it comes to reducing stigmatization and discrimination, however, not on its own. There are several factors influencing ones' values, such as culture and religion, education and experience. It is therefore of great importance for nurses to reflect upon their personal values and beliefs, to explore how their preconceptions and prejudices might influence their attitudes, in order to maintain high quality care on equal terms.

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Appendix 1. Enquiry for participating in study

You are being asked to participate in a research study conducted by Hanna Johansson and Maria Wallén from Ersta Sköndal University College in Stockholm, Sweden. The purpose of this study is to describe how nurses view upon female patients with sexually transmitted infections. The study will hopefully help to increase the knowledge among nurses on how ones' approach might influence the nursing process.

The study consists of a one-on-one interview in English which will be recorded and transcribed. The interview will require approximately 60 mins of your time. Individual responses are obtained and recorded anonymously and kept in the strictest confidence, however it will be presented using non-identifiable data in the shape of a thesis and will be available in paper copies, as well as electronical at the library of Ersta Sköndal University College.

With this information, you are being asked to participate in the study. Your participation in this study is strictly voluntary and you may interrupt your participation at any time without any further explanation.

Questions about the study

If you have any questions or concerns during the time of your participation in this study, or after its completion, or you would like to receive a copy of the final results of this study, please contact:

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The Research Ethic Committee at the Department of Health Care Science, Ersta Sköndal University College, has approved the study, 2015-08-27, Dnr 1507A.

Appendix 2. Interview guide

The participant whom we will perform the interview with, will have received an information letter regarding the study, but we will still initiate the interview by briefly explain about the purpose of the study. We will also inform the participant that the interview will be recorded and that all data will be kept completely confidential and that an interpreter will be present. We will also inform the participant that he or she can, at any chosen time, stop the interview without informing us why. We will ask the the participant if he or she has any questions before we begin.

Please, tell us about your work!

How is a typical day for you at work?

What patients do you meet?

How many of them are women?

To which socio-economic group do they belong?

For which reason do they come here?

Which is the most common way of infection?

What are your thoughts about that?

If the answer is prostitution -> Is it common with prostitution in Colombia? What are your thoughts on that?

If the answer is unprotected sex -> What is the general view on contraceptives in Colombia?

How would you say, the patients are feeling, psychologically and emotionally?

In what way does that show?

What are your thoughts on that?

Do you know if the patients told their family members about their diagnosis?

If no -> What are your thoughts on that?

If yes -> How was the information received?

If we feel that the situation allows it, we will mention the studies used in our background to see how the participants will respond and understand in which area we are moving.

Appendix 3. Examples of how data was analysed

Meaning unit	Code	Sub categories	Categories	Themes
So again – education! That’s a pillar.	Education is a pillar.	Strategies to help the patients	Education	The nurses’ reflections regarding the attitudes within the patients
Also it’s not that, the acceptance of treatment, treatment adherence. This is not necessarily direct related to education sometimes it is equally difficult for a patient, highly educated patients, to stick to the treatment.	Treatment adherence is not necessarily related to education level.	Nurses’ view upon patient	Adherence	The nurses’ reflections regarding the attitudes within the patients’
None the less there are still many myths, many stigmas around HIV-patients	There are still myths and stigmas around HIV	How nurses think that the society sees the patient	Stigma	The nurses’ reflections regarding the attitudes in the society
I can say that I have cancer, not a problem. But if I say that I’m HIV-positive, it’s a catastrophe.	It is a catastrophe to say I’m HIV-positive compared to say that I have cancer.	How the nurse thinks the society looks upon the patient	Attitudes in the society	The nurses’ reflections regarding the attitudes in the society
And we have kids, youths that have already been mothers	We have youth, that have already been mothers	Judgemental looks upon patients	Nurses thoughts about the patient	The nurses’ reflections regarding the patients’ attitudes towards themselves