



ERSTA
SKÖNDAL
HÖGSKOLA

Name: Doruntina Bekteshi and Shukri Sharif

Bachelor of Science in Nursing, 180 ECTS, Department of Health Care Sciences

Independent Degree Project, 15 ECTS, VKGT13, 2018

Level: First cycle degree programme not requiring previous university study

Supervisor: Anna Klarare

Examiner: FILL IN NAME

**Discrimination and stigma – an interview study with nurses
concerning persons living with HIV/AIDS in Nairobi**

Abstract

Background: There are approximately 1.5 million people living with HIV in Kenya. The prevalence is at a lower level than at the peak of the epidemic because of free antiretroviral treatment, education and new methods to HIV testing. The nurses' work situation is difficult trying to reach persons living with HIV in a society where stigma is common and therefore we were curious to learn more about nurses' personal experiences, to get a wider understanding of the situation.

Aim: The aim was to describe nurses' perspective of the complexity of caring for persons with HIV/AIDS in Nairobi, Kenya.

Method: The chosen design was a descriptive qualitative study consisting of semi-structured interviews with eight nurses in Nairobi, Kenya. The material was analyzed using qualitative content analysis.

Results: Two main categories were identified in this study: Nurses' strategies and approach to initiate care and Challenges in caring for people with HIV/AIDS. Four sub-categories were then formed out of the main categories: Approaching and building relationships with people that live with HIV/AIDS, strategies for reaching out to people that live with HIV/AIDS, structural barriers among people living with HIV/AIDS and practical obstacles within the healthcare system.

Discussion: The discussion addresses difficulties among nurses when it comes to persuading persons living with HIV/AIDS to receive treatment. The nursing role consists of caring for the patient, counseling and giving hope. Nurses are being affected emotionally when approaching persons living with HIV/AIDS since factors like stigma and fear of abandonment stand in the way for reaching out and giving treatment. Lack of resources in healthcare is another factor that causes frustration among nurses.

Keywords: HIV/AIDS, Kenya, nurse, approaching, caring

Sammanfattning

Bakgrund: Det finns cirka 1.5 miljoner människor som lever med HIV i Kenya. Prevalensen ligger på en lägre nivå än vid epidemins topp på grund av gratis antiretroviral behandling, utbildning och nya metoder för HIV-testning. Stigma kring sjukdomen är vanligt i Kenya, vilket gör det svårt för sjuksköterskor att nå personer som lever med HIV/AIDS och därför ville vi lära oss mer om sjuksköterskors egna upplevelser, för att få en bredare förståelse av situationen.

Syfte: Syftet med studien var att beskriva sjuksköterskors perspektiv av komplexiteten i vårdandet av personer med HIV/AIDS i Nairobi, Kenya.

Metod: I studien användes en kvalitativ metod bestående av semistrukturerade intervjuer med åtta sjuksköterskor i Nairobi, Kenya. Materialet analyserades med hjälp av kvalitativ innehållsanalys.

Resultat: Två huvudkategorier identifierades i denna studie: Sjuksköterskors strategier och tillvägagångssätt i initierande av vård samt utmaningar i vård av personer med HIV/AIDS. Fyra underkategorier bildades sedan ur huvudkategorierna: Tillvägagångssätt och att bygga relationer med personer som lever med HIV/AIDS, strategier för att nå ut till personer som lever med HIV/AIDS, strukturella hinder bland personer som lever med HIV/AIDS samt praktiska hinder inom hälso-och sjukvårdssystemet.

Diskussion: Diskussionen tar upp svårigheter som sjuksköterskor upplever när det gäller att övertyga personer som lever med HIV/AIDS att ta emot behandling. I sjuksköterskans roll ingår omsorg, konsultation och att inge hopp. Sjuksköterskor påverkas emotionellt när de möter och lär känna personer som lever med HIV/AIDS eftersom faktorer som stigma och rädsla för att bli övergiven kan hindra sjuksköterskor från att nå ut och ge behandling. Brist på resurser inom vården är en annan faktor som orsakar frustration bland sjuksköterskor.

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1. Introduction

In Kenya, approximately 1.5 million people live with human immunodeficiency virus (HIV) (www.nation.co.ke). HIV is a virus that destroys the immune system and makes it easier to get infections. It is recommended to start HIV treatment as soon as possible in order to slow the progression of the virus in the body as well as reducing the risk of comorbidities and complications (Andreassen, Fjellet, Hægeland, Wilhemsen & Stubberud, 2002). The topic inspired us since people who live with HIV/AIDS live longer than before because of access to drugs. However, there are still people living with HIV/AIDS that do not seek treatment. Attitudes of healthcare toward persons with HIV and AIDS differ in different parts of the world. With this study based on data gathered in Nairobi, Kenya, we wanted to get a deeper understanding of nurses' experience in approaching and caring for persons living with HIV/AIDS.

2. Background

2.1 HIV and AIDS in Kenya

Kenya has the fourth-largest HIV epidemic in the world alongside Uganda and Mozambique. 36,000 people died from AIDS in 2016. The number is high but it has decreased from 64,000 in 2010. New HIV infections are less than a third of what the numbers were at the peak of Kenya's epidemic in 1993. In 1984, the first case of HIV was detected in Kenya. In 1990, the epidemic had become one of the main reasons of illness. In 1996 the prevalence had reduced to half but still, 10.5% of the population in Kenya were living with the disease. The progress was due to the rapid scaling of treatment (www.avert.org).

The HIV epidemic in Kenya is generalized (established in general population) and sexual transmission is the most common factor. Although the epidemic is generalized, 30% of new HIV infections happen among key populations. A key population are groups who are at higher risk of HIV, such as: sex workers, homosexuals, transgender persons, prisoners and people who inject drugs (www.unaids.org).

Kenya has adopted innovative methods to identify persons with HIV that have led to a large rise in the number of people testing for the disease, including door-to-door testing campaigns, self-testing kits and targeted community-based testing. 86,000 people were tested

for HIV in 2008 and by 2015, the number had increased to 9.9 million people (www.avert.org).

The self-testing kits were introduced by the Kenyan government in 2017 and are available to buy at pharmacies. The demand has shown to be high among people in Kenya but the price (8 USD/kit) can be a barrier for some people. HIV awareness and education is increasing among young people in Kenya and is an important factor to HIV prevention in the country. In Kenya, education about HIV prevention has been part of the curriculum since 2003 (www.avert.org).

In Kenya, antiretroviral treatment (ART) is offered to all people living with HIV. In 2016, 64% of adults living with HIV and 65% of children living with HIV were accessing antiretroviral treatment. There are significantly more women accessing treatment than men, 68% women and 58% men. Among homosexual men, 6% access treatment and among female sex workers, 34% access treatment. Sex work and homosexuality is illegal in Kenya and key populations face stigma, discrimination and violence which adds to their vulnerability, although awareness about the disease is quite high and there have been anti-stigma-campaigns around the country. This deters many from seeking HIV treatment and care. Among key populations, antiretroviral treatment is therefore low. (www.avert.org).

In Kenya, there are approximately 8000 health facilities. The facilities are classified based on the owner of the facility and consist of public health institutions that are managed by the government, non governmental organizations, faith-based organisations and private investors (www.health.go.ke).

2.2 Pathophysiology of HIV/AIDS

Human immunodeficiency virus (HIV) is a virus that is part of the Lentivirus group and comes from the retrovirus family. The diseases caused by viruses belonging to the Lentivirus family are characterized by a so-called slow latent disease process. The process begins with HIV virus entering a host cell and gaining access to the copy function in order to produce new virus particles. The HIV virus attacks a type of white blood cells, “T helper cells” (also called CD4 cells), which are part of the body's immune system. When the body has a reduced number of T helper cells, the immune system ceases to function effectively. When T helper cells drop below 200/microliter or if the person gets other opportunistic infections, it may indicate that the disease has transitioned from HIV to acquired immunodeficiency syndrome (AIDS). Opportunistic infections then attack the body that no longer has an effective immune system (Andreassen, Fjellet, Hægeland, Wilhemsen & Stubberud, 2002).

Tuberculosis and pneumocystis carinii pneumonia are examples of opportunistic infections amongst HIV patients (Mitiku, Weldegebreal & Teklemariam, 2015). The HIV medications available today should be taken as soon as possible for the immune system to be able to recover and for the body to receive protection against infections and other diseases. Without antiretroviral treatment, the chance of living a long life with HIV/AIDS is small (Biswas et al., 2014).

2.3 Transmission of human immunodeficiency virus

HIV is a notifiable disease and is spread through sexual contacts, blood and blood products. A notifiable disease is considered to be a disease that is required by law to be reported to government authorities. The most common risk for infection is sexual intercourse. The infection is transmissible through vaginal, anal and oral intercourse, as the virus is contained in mucous membranes, sperm and blood. Adults who are infected with HIV can spread the disease to children during pregnancy, birth, as well as breastfeeding. The infection can also be transmitted through blood transfusion, as well as between people who share hypodermic needles, e.g. drug addicts (Wyzgowski, Rosiek, Grzela & Leksowski, 2016).

2.4 Symptoms and treatment of HIV/AIDS

HIV is divided in phases. The first period after a HIV infection is usually called primary HIV infection or acute HIV infection. Primary infection is the earliest stage and generally develops within two to four weeks after the person has been infected with HIV. During this time, some individuals have flu-like symptoms like headache, fever and fatigue (Hoenigl et al., 2016). Psychological symptoms such as anxiety and depression are also not uncommon symptoms during this period (Araya et al., 2013). The second phase, chronic HIV infection (also called asymptomatic HIV infection or clinical latency) is when the person does not usually experience HIV-related symptoms, but can still transmit the infection. Acquired immunodeficiency syndrome (AIDS) is the third and most severe phase of HIV infection. The person's immune system is damaged and can no longer fight off opportunistic infections. Most common AIDS symptoms are chronic fatigue, recurring fever, long-lasting diarrhea and severe weight loss (Hoenigl et al., 2016).

Although a cure for HIV does not yet exist, there are effective drugs that reduce the number of HIV viruses in the body. In order to inhibit virus production, the patient gets a combination of several antiviral drugs. Antiretroviral drugs help people with HIV live longer and reduces chances of passing the virus on to other people. Antiretroviral drugs cause certain side effects such as nausea and fatigue. However, it is important that the person does not stop taking the medicine because of side effects (www.hiv.gov). Replacement of medication is necessary if the person gets serious adverse side effects or if the combination of drugs does not work. Skipping medication increases the risk of drug resistance development (www.hiv.gov).

2.5 Living with HIV/AIDS

HIV is one of the most stigmatized diseases that still associates with negative beliefs and is considered by many as a consequence of immoral behavior. This can lead people that live with the disease to experience vulnerability and shame. There are people with HIV whose families and close relatives distance themselves after diagnosis. The fear of abandonment lead many people that live with HIV to carry a dark secret, develop a contempt for medicine and therefore choose to live without treatment. This raises major concerns since the disease is chronic and can cause death if not treated. People with the disease can feel relief when they open up about their diagnosis. Openness is necessary for the normalization of the disease and the control of the transmission (Larsson & Haanyama, 2007).

2.6 Caring and Nursing

Caring is defined in different ways and there are different theories that describe the concept. Watson for instance, defines caring as actions that involve pure devotion to care, the caregiver's values and knowledge. In caring, the dignity of the individual is meant to be protected. The nurse should be creative and open minded in a human-to-human interaction with the patient and the acts should be ethically and legally approved. Watson describes love and care as primal needs that often are overlooked. To evolve and live as humans side by side, it is important to love and care for humanity. To be able to express love and care for others, it is necessary to first treat ourselves with dignity and gentleness. The contribution of nursing lies in the devotion to human care (Watson, 1979).

Madeleine Leininger was the founder of transcultural nursing. She realized when working with children from different cultural backgrounds that there was a lack of understanding of how cultural backgrounds affect the behavior of humans, amongst the staff. According to

Leininger, human caring is a phenomenon that is universal but that patterns and expressions are different among cultures. To provide holistic care, the nurse should study different environmental dimensions (Leininger, 1991).

Both Watson and Leininger define nursing as humanistic science with caring as the central base. The difference is that Watson believes that the foundation of caring is "the ethical and moral ideal of nursing" whereas Leininger puts the concept in a cultural context. Watson believes in the interpersonal process where two people meet in a dimension that is transpersonal, a spiritual meeting where the two persons share life stories. Leininger separates professional caring from generic caring. She believes that professional caring can be taught cognitively to help individuals to live a healthy life (Leininger, 1991; Watson, 1979). In nursing, responsibilities are to prevent/treat diseases, promote health and relieve suffering. Nursing is about providing a genuine, respectful care to the patient on equal terms (Leksell & Lepp, 2013).

International Council of Nurses (ICN) is a federation that is operated by nurses internationally. ICN works to ensure nursing care for all individuals, advance nursing knowledge, the federation works for a respected and competent nursing profession worldwide and for sound health policies, internationally. ICN has four main areas that are the basis for ethical conduct that serve as guidance for nursing care. These are: nurses and people, nurses and practice, nurses and the profession and nurses and co-workers. The codes describe how the nurse should work to promote an environment in which human rights, individual values and the patient's relatives are respected. The fundamental responsibilities in nursing are to prevent illness, promote/restore health and ease suffering (www.icn.ch).

Ethical principles work as a template for the nurse, to maximize safe patient care. Nurses often find it difficult to handle ethical challenges in practice which can result in stress and burnout. The ethical principles work as a tool for nurses to use in difficult situations. Ethically difficult situations occur on a daily basis where the nurse has to balance routines with the patient's wishes. Ethic awareness helps the nurse to promote autonomy and well-being for the patient (Milliken, 2018).

3. Problem statement

HIV is an infectious disease that is chronic. It can develop quickly, destroy the immune system of the body and progress to the deadly disease AIDS. However, antiretroviral drugs are helpful as they slow down the course of the disease and keep levels of virus in the body low. Although the benefits of antiretroviral drugs are many, there are still people living with

HIV who are reluctant to seek treatment for various reasons. In Kenya, approximately 1.5 million people live with HIV and the most common factor of transmission is sexual intercourse. Through innovative methods to testing people for HIV, the number of people testing themselves has increased from 86, 000 in 2008 to 9.9 million people in 2015. Discrimination and stigma deter some people from seeking treatment even though ART is free to all people living with HIV/AIDS in Kenya. The disease requires lifelong treatment and patients need to be motivated to adhere to it. There is a great responsibility towards patients living with HIV/AIDS within nursing care. Nursing includes prevention of illness, promotion of life quality and encompasses support and autonomous care of the patients and their relatives.

The care of HIV and AIDS patients can be problematic and challenging. Previous studies on nurses' perceptions of caring for patients with HIV/AIDS in Kenya indicate that both fear, negative attitudes and lack of knowledge can create an obstacle in the care and thus prevent the nurses from pursuing optimal care. Nurses are seen as the primary link to the patient in any given health care facility and it is therefore important to see closer to nurses' perceptions of caring for HIV / AIDS patients. This study can contribute to new knowledge about the understanding of local context and issues regarding the care of people with HIV / AIDS in Kenya. This can be beneficial for healthcare professionals and hospitals both in and outside Kenya

4. Aim

The aim was to describe nurses' perspectives of the complexity of caring for persons with HIV/AIDS in Nairobi, Kenya.

5. Theoretical Framework

Joyce Travelbee's theory describes the human-to-human relationship and the importance of it in nursing. Travelbee defines the *human being* as "a unique irreplaceable individual – a one-time being in this world, like yet unlike any person who ever lived or ever will live" The creation of a human-to-human relationship is established between the nurse and the patient through a process of interaction with the purpose to help an individual, a family or a community to handle illness, cope with suffering and assist them to find meaning in the new situation. The nurse is there through the process and provides strategies and education to the

patient and the ones affected to assist them in avoiding distress during the journey. The nurse invests time in building the relationship through treating and seeing the patient as a unique individual. The human-to-human relationship helps the patient to feel safe and comfortable to opening up to the nurse. Travelbee believed that the relationship between an ill person as a human and the nurse as a human helps to reach the purpose of nursing and that the care relation can affect the patient's condition. Sympathy was explained as an attitude based on genuine concern for the other person and suffering as something common that all people experience. It is through communication and relationships that the patient and the nurse share thoughts and feelings and it is an important tool in coping with illness (Travelbee, 1971).

Travelbee's theory was suitable for our study since it focuses on the unique human being and his/her individual experiences and perspectives. Our study focused on nurses' personal experiences and the theory was used as an ideal of how to approach people in healthcare to cope with illness and suffering. The theory was compared to the results of the study to see if the nurses in Nairobi mentioned the human-to-human relationship as important when caring for persons living with HIV/AIDS.

6. Method

6.1 Design

The chosen design was a descriptive qualitative study. A qualitative study is a design that intends to describe the social reality of individuals that take place in a natural environment of the phenomenon. This design is used for understanding a phenomenon or situation by description and exploration, in this study through eight interviews. The primary aim in using qualitative design is to create knowledge of a phenomenon, as interpreted and experienced by others (Polit & Beck, 2012).

The authors chose to collect data by interviews, where the nurses' descriptions were in focus. They had experience in working with patients with HIV/AIDS. In order to understand the lived experiences, the authors tried to put aside their own opinions and ideas about the phenomenon (Henricson & Billhult, 2012).

6. 2 Recruitment and participants

The authors contacted a nursing supervisor at Médecins Sans Frontières (MSF) in Nairobi, Kenya, by email. MSF is a non-profit, member-based organisation that is self-governed. The organisation provide people affected by exclusion, epidemics, conflict and disasters with

medical assistance (www.msf.org.) It was decided that the nursing supervisor was going to help the authors find eight nurses to participate in the study through interviews. The authors sent the supervisor the consent letter which contained a description of the purpose.

The supervisor had found eight nurses that met the requirements to participate in the interview when the authors met with her in Nairobi. The inclusion criteria were that the nurses had to speak English, at least one year of experience in caring for patients with HIV/AIDS and the participation was voluntary.

Four of the nurses that were recruited worked in health centres (managed by the government of Kenya) and four of them worked for the non-governmental organisation Médecins Sans Frontières (MSF). The difference of the two, is that health centres are public and MSF is private. All nurses worked with infectious diseases like HIV/AIDS. The nurses consisted of seven women and one man. Four of the nurses had more than 14 years of work experience as nurses, one of them had worked as a nurse for nine years, another one for five years and two of them had three years of experience.

The supervisor handed the nurses the written consent letter (see appendix 1) before the authors met with the nurses. The authors met with the nurses for the first time on the day of the interview. The nurses then, gave oral consent and approved that the transcribed interviews could be used for the continued thesis. The interviews were audio recorded in two different recording devices. This in order to reduce the risk that the information would be lost if any of the recordings would stop working during the interview.

6.3 Data collection

A semi-structured interview form was used to allow participants to speak freely about the questions in the interview guide (see appendix 2) to get descriptions of their individual experiences. The Interview guide contained main questions and follow-up questions that were relevant to the objectives of the study. The questions were open and they did not follow a specific order as the control can destroy the interaction in the conversation (Polit & Beck, 2012).

The interview included questions like: How long have you worked as a nurse? How often do you meet patients with HIV/AIDS? Tell us about your view of a nurse's role in caring for patients with HIV/AIDS? Can you tell us about your approach towards patients with HIV/AIDS when you meet them for the first time? Follow-up questions were asked, for example: Could you tell us more about it? Can you describe that feeling? Can you give examples? How did it feel?

The questions and the technical equipment were tested before the interviews so that the authors could enter their roles as interviewers, to ensure that the equipment was working and to see that the timetable was reasonable (Danielson, 2016). This was done through a pilot interview between the authors. Each participant was interviewed one at a time and the interviews lasted 26-39 minutes. The authors were both present during all interviews, one of them interviewed while the other one took notes and asked supplementary questions.

All interviews were held in the authors' apartment for the environment to be as quiet as possible so that the participants could speak undisturbed. The authors tried to give the participants a warm welcome through smiling, offering something to drink and sitting on comfortable sofas in a spacious room with daylight. The authors were aware of their body language. They had no crossing arms to show that they were open to receiving what the participant had to say. To ease the participants into the interview and not put pressure, the authors started with lighter conversation before asking deeper questions.

6.4 Data analysis

The interviews were audio recorded. They were written down verbatim to bring in all shades of the conversation. The authors did not register facial expression and gestures since the material was based on a manifest content analysis that describes the visible, obvious and written words in the text. The analysis began with transcribing immediately after the interviews. Both authors listened to the same interview and discussed the content, to minimize the risk of misunderstandings.

The material was analyzed using qualitative content analysis. This method can be used to analyze stories and study content based on the participants' perspective. The authors chose to use an inductive approach. The inductive approach is based on collection to subsequently relate it to a theory. The authors did not know what answers the respondents would give to the questions. Based on the data collection, general conclusions were drawn. The analysis was done based on the content of the text and not by a specific theory. After the authors searched for patterns in data, a theory was developed that could explain those patterns (Polit & Beck, 2012).

Before starting the process of coding data, the authors read through the transcribed interviews several times to familiarize themselves with the data. The material was then divided into two content areas. The concept of content areas address a specific area that forms the base of the aim, in this case "challenges" and "strategies" in approaching persons living with HIV/AIDS. Subsequently, meaning units were identified. Meaning units are sentences or

phrases in the interviews that are considered relevant for the aim of the study. The meaning units were condensed to shorten the text while retaining the core of the content. The condensing sentences were encoded in terms of words and phrases that reflected the content of the sentences, this in form of codes. The various codes were then collected together according to their content. Based on a group of similar codes, a sub-category was formulated, and eventually a total of five subcategories were identified. The subcategories were sorted into two different categories which constitute the manifest content that deals with the obvious explicit content that is described in form of categories (Lundman & Graneheim, 2012).

Table 1. Example of the data analysis process

Meanings units	Condensed meaning units	Code
<p>I go around the community, look for people who may have HIV. When I meet them, i have to talk to them and tell them that HIV is not a disease for someone to hide for himself. It's just a normal disease. I tell them to go to hospital so they can test themselves and get treatment.</p>	<p>I go around the community and look for people who don't go for treatment. I tell them to go to the hospital so they can test themselves and get treatment.</p>	<p>Reaching out to the community</p>
<p>When a person is hard to encourage we go as a group. You know, a person with HIV, you can go there and he rejects you. But then maybe he is friendly to one in the group, so you can use that person to approach him. It depends on that person whom you are dealing with.</p>	<p>When a person is hard to encourage, we go as a group. Maybe he's friendly to one in the group, so you can use that person to approach him.</p>	<p>Creativity and adaptation in how to persuade the person with HIV/AIDS to get treatment</p>

<p>In the public system, patients have to pay, that is the reality. The only thing that is for free in the hiv-world is medicine, that is funded by global fund. You are guaranteed free medication for hiv. But I will maybe need to send you to the lab, then you will have to pay for it. So if you work there you have the knowledge to help someone but you are limited, because you can only help as much as their pocket allows you. So it's frustrating because you feel like you can't do enough and that makes me feel tired sometimes.</p>	<p>In the public system, patients have to pay, that is the reality. You are guaranteed free medication for hiv. But I will maybe need to send you to the lab, then you will have to pay for it. You have the knowledge to help someone but you are limited, because you can only help as much as their pocket allows you. It's frustrating.</p>	<p>Challenges nurses' face while caring for persons with HIV/AIDS</p>
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7. Ethical Considerations

Ethical considerations are important in all research methods that concern topics about people. The ethical challenge of a study involving individuals is to avoid exploitation and harm. One way of increasing well-being, rights and safety (defined both physically and mentally) is to follow research ethical principles. They are intended to guide the researcher in the planning of a project (Kjellström, 2012).

The study was conducted in accordance with established codes for research ethics, as: participants' voluntary participation, anonymity and safe data storage. In order to preserve the participants' autonomy and integrity, the participants received written information in form of a consent letter about the study and what a participation entails (see appendix 2) so that they could make a voluntary and rational decision about the participation. Collected material was used only for the purpose of the study. Participants' responses were handled confidentially and the content was unavailable to unauthorized. Except from the authors, only assigned supervisor had access to the material. Participants were also informed that they could choose to withdraw from the interview at any time without giving a reason. The recordings were

saved on a memory stick stored in a locked compartment and deleted when the thesis was completed (Kjellström, 2012).

Table 2. Overview of the results

Categories	Sub-categories
Nurses' strategies and approach to initiate care	Approaching and building relationships with people that live with HIV/AIDS
	Strategies for reaching out to people that live with HIV/AIDS
Challenges in caring for people with HIV/AIDS	Structural barriers among people living with HIV/AIDS
	Practical obstacles within the healthcare system

8. Result

The result is presented in two main categories: "Nurses' strategies and approach to initiate care" and "Challenges in caring for people with HIV/AIDS." Five subcategories were then formed out of the main categories.

8.1 Nurses' strategies and approach to initiate care

8.1.1 Approaching and building relationships with people that live with HIV/AIDS

Several nurses describe the importance of a good care relation. It is difficult to reach the patient and talk about HIV/AIDS if the patient does not feel safe enough to open up and talk about his/her situation. Nurses emphasize the importance to see the care relation as a process and to give it time to develop so that the patient opens up at his/her own pace. A nurse describes:

"First of all I say you should be friendly with him or her. So if you're friendly to a person, he or she can easily get what you are saying. The best thing is to show them love and to never

judge. If you love them, they will accept themselves and you. You explain to them, they will accept, they will listen to you, but it takes time."

The analysis shows that nurses establish the care relation with the patient based on the patient's individual needs. If the patient is a single mother and needs help with taking care of the children, cleaning the house or cooking, the nurse will help with that.

"It is hard, you need God to help you, it is hard to deal with these people, mostly those people that have kids are divorced. For me, I talk to them and give them something they need for their houses"

As described by the nurses, there is stigma around HIV/AIDS. They say it was worse before, when the epidemic reached Kenya. Back then, HIV/AIDS was seen as a consequence of an immoral behavior. Yet today the disease is stigmatized and it is difficult for many people living with HIV/AIDS to find work since the employers fear being infected. Nurses put a lot of effort into finding jobs for patients so that they can support themselves. A person who has no food on the table and a family to support, does not prioritize self care. Therefore, it is important to see the patient's situation as a whole and identify the patient's individual needs. A nurse describes:

"I put them to school where they can learn something to make on their own, like, they get these wedding cards that they can make and sell so they get food for the day because most people don't like employing them because they are scared of getting infected. You know in Kenya if somebody is HIV-positive, it's like she's not a good person, which is wrong. For me, I just want her to be able to provide for herself and her family, if not, she will not look after herself"

The importance of honesty in a care relation is highlighted by the nurses in the study. The patient must be included in his/her own care to feel that they can handle the situation. The patient will not be able to feel that he/she owns the situation if healthcare personnel "spares him/her" by not telling the truth about the patient's prognosis. Honesty makes the patient trust the nurse and it helps the patient become more susceptible to help. A nurse describes:

“My experience is that it is important to build trust. We started having meetings once a week where we would teach about diseases. We would sit together with the patient and the patient would see what exactly was happening”.

Several nurses mentioned the importance of the nurse's role. Giving drugs for the diseases is only part of the role as a nurse and much weight has been put on that part for many years. When the epidemic came to Kenya, there was no structure at the hospital and everyone did whatever work that needed to be done. The heaviest weight was laid on ensuring that patients received their drugs. The system has changed over the years and it has become clear that the nurse's role is necessary as it is difficult to reach out to the patients without first establishing a relationship and gaining a holistic view of the patient's individual situation. As described by a nurse, the nurse's role is based on establishing a relationship with the patient, educating the patient and sitting down with the patient, as well as counseling about lifestyle and healthy living:

“Patient came and the doctor treated them. But then you have HIV, where people say it is more than just medication. They need to go for counselling. They need to walk a journey to understand why they need to take their treatment and how they need to take it. Médecins Sans Frontières (MSF) said, we have nurses within the system so why don't we build their capacity so that they can sit and counsel. It is not happening everywhere yet but it's getting there”

8.1.2 Strategies for reaching out to people that live with HIV/AIDS

As highlighted by the nurses in this study, it can be hard to reach out to patients that live with HIV/AIDS. Several nurses mention that it takes time to build a relationship with a patient or to even get the patient to listen to what the nurse has to say, during the first meeting.

Depending on who the patient is, the nurse determines how to reach out to the patient. A nurse describes:

“See you can't tell somebody ”you are HIV positive, no no no, I'll just approach, I'll take some time, Ok I tell her ”ok come and sleep at my place today”, then I take the whole night to talk to this person. Because you can't talk to this person for like 30 minutes because she won't open her heart”

As described by the nurses, the care relation is important. Many patients find it difficult to accept that they have HIV/AIDS and therefore ignore the nurse when he/she brings up the topic. Some patients become defensive and do not want to talk about the disease since it sometimes is easier to suppress reality than to cope with the disease and do something about it, as they do not know that treatment can help them to a long life. Therefore, it is important that the nurse does not give up on the patient. The patient then sees that the nurse genuinely cares, which makes the patient trust the nurse and choose to listen:

”If the person do not want, you leave him. But don’t go forever. Just come another day. You come back. You have to keep on trying. That person will agree someday, when they see that you are not giving up on them”

Several nurses mentioned the necessity to give hope so that the patient will feel motivated to receive treatment and take the medications continuously. Many people believe there is no hope of a future when they have been diagnosed with HIV/AIDS and therefore do not want to engage or try. Nurses usually compare HIV/AIDS with other diseases, to give the patient perspective and hope. This to make them understand that they can live a long life if they follow the instructions they receive from the doctors and the nurses on how to live:

”You can help them by saying that there are so many other diseases, like cancer, that are much more dangerous than HIV so you can still live long when you follow the instructions from the doctor, when you eat well and they should avoid even this sex with too many people. If they are married, they should have trust between themselves”

Several nurses describe that many people with HIV/AIDS are worried and have anxiety about what their future will be like. It is difficult to reach the person when he/she is not feeling well. Nurses have a positive attitude about using music in nursing care. Listening to music is a tool for getting people in a better mood.

“I put music on to make them feel happy and when it makes them happy, it makes me happy because now we can talk”

8.2 Challenges in caring for people with HIV/AIDS

8.2.1 Structural barriers among people living with HIV/AIDS

Because of stigma and other factors, there are people that avoid testing themselves for HIV. Several nurses mention a number of obstacles that makes it hard to persuade the persons to test themselves for HIV.

Nurses emphasize that patients are expected to follow recommended drug prescriptions. However, this is difficult if the patient does not accept his/her illness. Many patients feel ashamed and wonder "*why me*" which results in lying about their diagnosis to keep it a secret. Circumstances where the patient use defence mechanisms such as denial makes it hard for the nurse to find the right strategy to approach and reach the patient.

"Somebody will just say it's malaria and that's why my body is weak"

Sometimes the patients mix medication with alcohol consumption. The effect of the medicine then changes, which can result in a patient not recovering well enough and, in addition, may cause serious side effects. Several nurses find it hard to motivate patients with addictions and make them see how serious and dangerous their actions can be. One way to approach this is to educate the patients about side effects and the importance of taking medication the right way.

"It is hard to motivate addictive persons to take medication and to not mix with alcohol. I try to educate them"

Nurses describe that multiple patients throw away antiviral treatment and instead choose to use naturopathic medicine which can be a stressful situation for the nurse as it contributes to even more suffering for the patient. It is sometimes impossible to convince a patient to take antiviral treatment when cultural values are involved.

"Sometimes there is conflict because the patient wants to go and get traditional medicine and you can't tell them OK do that and give me back my medicine."

The nurses experience that men are more difficult to reach than women. Some men do not want to receive treatment from female nurses. Those men sometimes become defensive and aggressive when female nurses try to talk to them about HIV/AIDS. There are different tribes in Kenya with different values that the nurse has to respect. Some tribes believe that women should not tell men what to do and how to behave. Therefore it is sensitive when a female

nurse approaches a man and tells him how to live his life. The approach has to be adapted to the individual and the nurse has to identify how to approach the person to be heard.

“ You know in kenya there are so many tribes, some tribes they got their own values. Maybe they say I can't stand with a woman to tell me what to do”

8.2.2 Practical obstacles within the healthcare system

Several nurses mention practical obstacles within the healthcare system. One challenge is lack of medicine, especially among patients with low socioeconomic status. The public healthcare supports all patients that have HIV/AIDS with free antiretroviral treatment alone. But if the patient, in addition to HIV, gets comorbidities like diabetes or pneumonia, the public healthcare will not provide medication for free, which makes it difficult for the nurse to handle the patient's health condition.

“As a nurse you have the knowledge to help someone but you are limited, because you can only help as much as the pocket allows the patient. So it's frustrating and you feel sad because you feel like you can't do enough and that makes me feel tired sometimes.”

There are also challenges regarding privacy and anonymity. Several nurses mention that there needs to be a change in the reception at the hospital where patients go to test themselves for HIV/AIDS. Patients also go there to collect antiretroviral treatment. The waiting room is an open area that is focused only on HIV/AIDS. Patients have no privacy there. The reception is open and waiting times are long. The stigma around the disease prevents patients from going to the hospital to test themselves and to receive treatment since they do not want to be seen there.

“you know where i I work, where people can take drugs is very open. That makes people to feel uncomfortable because everyone can see that they have HIV. The waiting area should be changed, it is very open”

Anonymity is mentioned in the study as important in managing patients with HIV/AIDS and that it can be crucial for the patient's care. Many patients suppress the diagnosis because of fear to become outcasts and judged. The nurses believe that the duty of confidentiality is necessary for the patient to dare to open up and report about his/her disease and to receive

treatment. An important factor to why many patients do not want to receive treatment is because they do not want others to know that they have HIV/AIDS. A motive for the patients to feel safe in the healthcare system is to treat them with confidentiality. A nurse describes:

“Nurses are shouting, these drugs, these drugs. That’s not good. That position has to change. I would take the patient in somewhere else. Then I would find out which drugs the patients needs this month. I take those drugs and hide them in a paper and take to patients. This way the patients would keep coming to the hospital”

8.2.3 Emotional difficulties in caring for patients with AIDS

Caring for patients with AIDS causes the nurse to face emotional challenges. Several nurses point out the importance of finding strategies to cope with the feelings that arise, but they do not always succeed. Talking to the colleagues makes it easier to process feelings when a patient’s condition becomes worse or when a patient passes away. When the patient has AIDS and the nurse knows that he/she does not have much time left to live, it is hard to stay positive and find strength to go to work. Some days the nurse works alone and does not have time to talk about emotions and thoughts with colleagues. In addition, the nurse experiences that he/she can not talk about work at home with the family because they are not allowed to discuss patients outside work. They also do not want to burden their families.

“I have a friend that I can talk to and I talk to my colleges, they will encourage me. And it helps, because maybe you feel fed up with the job but they will encourage you by saying that there are so many people that live because of the job we do.”

One important reason why the nurses find difficulties in leaving work behind when they go home is because of the relationship that they establish with the patients during the care period. As experienced by the nurses, it would be optimal to be able to achieve a balance between the emotional involvement in nursing and an emotional distance. Being a nurse means being a humanitarian and caring for people, which is impossible to turn off. A relationship comes with emotions and when someone is suffering that the nurse cares about, it is hard to not be affected.

“You know, I do not want to be a nurse with uniform only. I want to get close and establish a relationship with the patient so that he or she can open up and trust me. But at the same time, I do not want to get too attached, because that's when the problem comes.”

Several nurses mention fear as a constant feeling when treating persons with HIV/AIDS. Taking blood samples and being close to body fluids are parts of the nurses' daily work. Therefore the nurses are sometimes afraid of being infected. It is stressful to remain professional in all situations when fear is involved and the nurses suppress the feeling so that the patient does not notice and gets offended.

“I would only lie if I said that I am never afraid of being infected. I work with HIV-positive people everyday and in a stressful job as mine, it is easy to make mistakes. A small mistake can have big consequences”

9. Discussion

9.1 Methodological discussion

The participants were chosen by a nurse supervisor and it is unclear if the participants were chosen based on other factors than those that the authors required. The supervisor might have known that those persons would answer a certain way. The authors experienced that the participants were open about personal experiences and the fact that half of the participants worked in a public hospital and half of them worked for MSF gave wider perspectives.

In order to achieve credibility, it was important to interview nurses who had experiences of working with persons with HIV/AIDS. Only one male nurse participated in the study due to the difficulty of finding several male nurses. Every interview was done with one nurse at a time. This because of the aim that was based on nurses' individual experiences. It felt appropriate to interview one nurse at a time to give the nurse time and space to open up and share individual thoughts in privacy (Polit & Beck, 2012).

It is important that authors prepare participants by putting them at ease. The meeting started with “small talk” to overcome the nervousness that could occur on both sides. The authors were aware of that the participants would not share their experience if the situation felt uncomfortable. Therefore, the authors tried to listen without interrupting or sharing

opinions (Polit & Beck, 2012). It seemed like the participants eventually became more comfortable to talk and share their experiences.

Interview form is a widely used method of collecting data for a qualitative study. In the qualitative research interview, there is always a symmetrical power between the interviewer and the participant (Kvale & Brinkmann, 2009). The interviews were held at the authors' apartment so that participants could share their experiences and feelings in a silent and private atmosphere. However, this could be a risk since the participants might feel the pressure to answer all questions and answer so that the authors seem satisfied. In this case, it would be more suitable to interview in a neutral place to minimize the symmetrical power. However the participants seemed at ease during the interviews.

Confirmability means that the findings of the study should reflect the participants' answers in an objective way and not be influenced by the authors' thoughts (Polit & Beck, 2012). Both authors were present during the interviews. The authors transcribed different interviews that the other author then read whilst listening to the audio recording. Both authors then went through the transcriptions together while listening to the interviews. It felt important that both authors listened to the interviews to increase transparency in the process of analyzing. The credibility might have been stronger if all of the interviews had been transcribed by both authors individually, to make sure that all words were included.

Interviewing across cultures can be challenging. The authors need to be prepared and study the culture of the country where the interview will be held. The verbal and non-verbal communication differs in different cultures (Kvale & Brinkmann, 2009). The authors attended a preparation course held by Sida before going to Kenya which involved raising the differences that could occur in meetings with different cultures and during interviews. The course helped raising awareness about the differences, even though learning another culture takes a long time. Because of the differences, there could have been cultural misunderstandings during the interviews and in analyzing the interviews that the authors were not aware of.

Participation in the study required good knowledge of the English language. In Kenya, English is an official language which made it easier to understand the participants. The authors did not have much experience in interviewing and because of English being the authors' second language, the questions sometimes needed to be explained with different examples for the participant to understand the question. This factor could be a limitation since it could have led the participant to answer a certain way (Polit & Beck, 2012).

The meaning units were selected separately by the authors. The units were compared and similar ones were kept. The ones that were not similar, the authors discussed before either disregarding them or keeping them. The meaning units that were selected were representative for the findings and their category. The quotations were opinions of one participant but they were representative for the findings in general.

The final result was emailed to the participants in order for them to control what they had said during the interviews and give feedback. The participants agreed on the result and the quotations. This is a way to improve the validity and credibility of the study (Petersson & Lindskov, 2012).

This study has transferability since the results could be applicable in other African countries where HIV/AIDS is occurring and where the standards are similar to Kenya. Therefore we think that this study could be useful in those countries too. Understanding the consequences of living with HIV/AIDS and the consequences and difficulties nurses face caring for people living with HIV/AIDS might give other healthcare workers tools to cope with the situation in ways that are helpful and it might help against prejudice.

9.2 Discussion of the result

Discrimination and stigma are factors that prevent people living with HIV/AIDS to test themselves and seek treatment. The nurses in our study believed that knowledge about HIV/AIDS is an important aspect in order for people living with HIV/AIDS to adhere effectively to treatment. According to a study by Dubrocq and Rakhmanina (2018), there are factors that prevent people from following treatment correctly such as lack of trust in the healthcare system, limited face-to-face counseling with the patients and long distance to the clinics. Most people who live with the disease need more than an appointment and prescription to understand the importance to follow treatment. The authors believe that this shows the importance of the nurse's role based on ethical codes about promoting health and relieve suffering. The establishment of a good relationship is essential and a central part of nurses' strategies in general, to develop connection and mutual trust.

An interaction between the nurse and the patient based on trust has been shown to have a positive effect on the patient's well-being. The patient then feels supported and has someone to share the situation with (Haugan, 2014; Olshansky, 2011). This correlates to the purpose of nursing, which is to help a person cope with the experience of illness in one way or another. It can be reached by establishing a relationship with the person seeking care (Travelbee, 1971). The authors believe that a continuity in the care process is a way of

confirming and seeing the patient. This can be a strategy to create trust between the patient and the health care and motivate the patient to adhere to treatment. For a continuity to be established, a teamwork is required between healthcare, the patient and the support system of the patient. When putting together all factors of a person's life, it is possible to identify the needs and focus on the right strategies to help the person.

The results indicate that discrimination and stigma makes it difficult for people living with HIV/AIDS to find employment. Denial of employment is mainly based on fear of getting infected. This is in line with a study of Sprague, Simon and Sprague (2011) who also state the employment discrimination based on HIV status. Workplace discrimination against people living with HIV/AIDS leads to no employment which in turn makes it hard for people with the disease to be able to afford HIV-prevention. These persons also tend to be socially isolated which causes several psychological problems. People who have HIV/AIDS are internationally legally protected against discrimination at work and in recruitment under the Equality Act 2010. Employers are responsible to ensure that the person living with the disease is treated fairly and with dignity at work. Despite the chronic disease, people can live healthy lives and contribute to the society. The authors believe that education can result in a more positive attitude towards persons living with HIV. Employers should have a policy that includes a non-judgemental approach towards people living with a disease and discrimination should have consequences.

According to the results of the study, nurses strived to be non-judgemental when approaching persons with HIV/AIDS. The nurses acknowledged the importance of acceptance, patience and giving hope, in order to help the patient. In a study by Casale, Wild and Kuo (2013), social support like encouraging good health behaviors and promoting self-esteem has a positive impact on health. A patient that feels there is hope of a future, will realize the importance of adhering to treatment. Several nurses spoke about hope as a key factor to get the patient to listen and to take medicine frequently. Without hope of a future there is no motivation to go through treatment. Nurses sometimes even compare HIV/AIDS with more life threatening diseases to make the patient realize that there is a future if there is engagement in treatment.

The authors do not believe that comparing HIV with other life-threatening diseases to give the patient hope is a strategy that works on all patients. It is therefore necessary to get to know the patient well to be able to identify what gives that certain person hope. According to Travelbee (1971) a relationship between the nurse and the person living with the disease has

to be established for the nurse to understand the person's unique needs and to plan care accordingly.

In Kenya, the public healthcare provide free antiretroviral treatment to people living with HIV/AIDS. The paradox is that a consequence of HIV/AIDS are comorbidities as pneumonia and diabetes that require medicine that the public healthcare does not provide for free. Several nurses in our study discussed the frustration and stress knowing that lack of resources prevented them from giving the best care possible to patients. Lack of resources, such as medicines and staff is something that can lead to emotional stress for healthcare workers (Gysels, Pell, Straus & Pool, 2011). Several nurses mentioned the importance of having someone to talk to and the necessity to cope with the stress to be able to give full support to the patients. Evans et al. (2016) came to the conclusion that nurses find different coping methods to deal with their emotional challenges and with the stress that comes with treating people with HIV/AIDS. To be able to support the patients, it is important that the nurses get support and supervision. The nurses in our study explained that the emotional stress many times was also connected to treating persons with AIDS that are in the last stage of life. Being a nurse means being close to patients and creating a human-to-human relationship. This to be able to give the best treatment possible (Travelbee, 1971). Karlsson et al. (2010) highlight the importance of being present in existing feelings. That way, care workers also learn how to handle their perceptions and reactions of difficult situations which perhaps may allow nursing care free of prejudice and discrimination.

The teamwork and the emotional support colleagues give each other is an important and valuable part in working with patients that are in the last stage of life (Barnard, Hollingum & Hartfiel, 2006; Georges et al., 2002). The authors think that healthcare organizations should be able to provide healthcare workers with emotional support. The care workers' health should be something to focus on and prioritize since successful care depends on a healthy staff. If there are no resources to hire a professional therapist, the organisation should introduce scheduled reflection time where the care workers can gather to ventilate and reflect.

10. Clinical Implications

This study reveals that nurses are the healthcare workers who are mostly involved in approaching and encouraging people living with HIV/AIDS to test themselves and get treatment. Nurses in Kenya experience frustration and emotional exhaustion. Since the nurses are instrumental in upholding health promotion and adherence to treatment, efforts are needed in order to improve nurses' work conditions. Recognition and appreciation are factors that

may motivate nurses to keep working hard and making differences. Empowering nurses to manage independent health clinics, providing organized reflection and coaching of nurses as well as raising salaries are some suggestions to strengthen and support the ongoing work.

11. Proposals for continued research

Even though HIV/AIDS is a common disease in parts of the world, there is still stigma and fear connected to the perception of it. We found many articles about nurses' experiences related to working with patients living with HIV/AIDS but not many from Sweden, Scandinavia or even Europe. To reduce stigma it is important to educate healthcare workers and people in general about HIV/AIDS. Further studies on how nurses in other contexts approach people living with the disease may be valuable to understand how to improve care for people living with HIV/AIDS.

12. Conclusion

The results in this study show that nurses in Nairobi, Kenya, experience difficulties in approaching persons with HIV/AIDS. The disease is stigmatized which results in difficulties motivating individuals to test themselves and seek treatment. In order to handle difficulties, the nurses developed different strategies. The most prominent strategy was building relationships with people that live with HIV/AIDS. Nurses emphasized the importance of having a holistic approach and building trust. According to the nurses, lack of medicine and anonymity are examples of practical obstacles in the healthcare system that need to be changed for the patient to get the best care possible. Nurses can be involved in different situations that lead to emotional challenges while caring for people with HIV/AIDS. The results show that nurses' attitudes towards people living with HIV/AIDS is mostly positive but there is still certain fear of being infected.

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Appendix 1.

Consent to participate in a thesis project regarding nurses' approach in caring for persons with HIV/AIDS.

Our names are Doruntina Bekteshi and Shukri Sharif. We are nursing students at Ersta Sköndal Bräcke University College in Stockholm, Sweden. During our studies, we have the honor of participating in an exchange program in Nairobi, where will write our Bachelor thesis, with the aim to learn more about nurses' approach in caring for persons with HIV/AIDS. Human immunodeficiency virus (HIV) is one of the largest public health problems internationally. We would like to invite you to participate in our study to increase knowledge about the approach experienced from nurses' perspectives. If you want to participate, we would like to interview you for 45-60 minutes. The interview will be in the form of a conversation regarding nursing experiences. With your permission, we will audio record the conversation. The recording will be used by the two of us in writing our thesis and will be deleted when the thesis has been completed. Participation is voluntary and you can, at any time, choose to withdraw from the interview without providing a reason. Your identity will not be revealed in any texts and all information is treated confidentially. The audio recording will be saved on a memory stick stored in a locked compartment, until it is deleted. The completed thesis will be available on paper and published online through Ersta Sköndal Bräcke University College library. If you are interested in participating, please give notice to xxx, who in turn will provide us with your contact information. We will contact you within one week to schedule a time for the interview. The research ethics committee at the Department of Health Sciences, Ersta Sköndal Bräcke University College, has approved this thesis 20XX-XX-XX, Dw 20XX /x.

Kind regards,

Anna Klarare, lecturer, RN, PhD.

Phone: +4676- 636 5088

E-mail: Anna.klarare@esh.se

Doruntina Bekteshi and Shukri Sharif,

Nursing students at Ersta Sköndal Bräcke

University College

Tel: +4670- 448 2143, +4676- 078 5967

Email: Dorbekt@esbhstudent.se,

Shukri.Sharif@esbhstudent.se

Appendix 2. (Interview guide)

1. For how long have you been working as a nurse?
2. Can you describe what kind of work you do on your department?
3. How often do you meet patients with HIV/AIDS?
4. Can you tell us about your approach towards patients with HIV/AIDS when you meet them for the first time?
5. Can you describe your view on a nurse's role in caring for patients with HIV/AIDS?
6. What would you consider to be a good meeting with a patient?
7. Is there anything you would like to change in how to care for patients with HIV/AIDS? If yes, then what?
8. Can you describe the most challenging situations in caring for patients with HIV/AIDS?
9. How do these challenges affect you as a nurse?
10. How do you handle these challenges?