JÖNKÖPING UNIVERSITY
School of Health and Welfare

Nurses' role in educating and prevent HIV among young women, in Tanzania

-A qualitative study

MAJOR FIELD OF STUDY: *Nursing*
AUTHORS: *Märta Steinwall, Embla Borgh*
SUPERVISOR: *Pär Wennberg*
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Summary

Title: Nurses' role in education and prevent HIV among young women, in Tanzania – A qualitative study

Background: In 2021, 5.9 million people in Tanzania were living without the knowledge that they were infected with Human Immunodeficiency Virus (HIV). Lack of knowledge and stigma are two contributing factors to this. Young women live in an especially vulnerable situation. Nurses has a significant role in imparting knowledge and working against the stigmatization. The Health Belief Model describes how people need motivation and knowledge to choose a health-promoting behavior.

Aim: The aim with this study is to explore how nurses in Northern Tanzania work with patient education on HIV prevention and stigmatization in young women.

Method: A qualitative design with semi structured interviews has been used. The study contained interviews with eight nurses at a hospital in northern Tanzania.

Result: Built on three categories, 1. *Nurses' perceptions of their role and experience of patient health education regarding HIV, 2. Perceptions of how HIV related stigma effects young HIV positive women, 3. Necessary patient information regarding HIV prevention and treatment*. The three categories are clarified with eight subcategories.

Conclusion: The result of the study indicates that there is a lack of resources when it comes to time and education, both in the society and among the nurses. The nurses stated that they need tools on how to best educate and reach a larger number of people. Outreaches was mentioned as one of the most valuable parts in the work against HIV. They also experienced difficulties regarding the stigma and how to best council the young woman.

Keywords: HIV prevention, experiences, patient education, stigma, nursing, young women, Health Belief Model, qualitative study, Tanzania

Sammanfattning

Titel: Sjuksköterskans roll inom utbildning och prevention gällande HIV hos unga kvinnor i Tanzania – En kvalitativ studie

Bakgrund: År 2021 levde 5.9 miljoner människor i Tanzania utan vetskapen om att de var infekterade med Humant Immunbrist Virus (HIV). Bristande kunskap och stigma är två bidragande faktorer till detta. Unga kvinnor lever i en extra utsatt situation. Sjuksköterskan har en betydande roll i att förmedla kunskap och arbeta mot stigmatiseringen. Health Belief Model beskriver hur människor behöver motivation och kunskap för att välja ett hälsofrämjande beteende.

Syfte: Syftet med denna studie är att utforska hur sjuksköterskor i norra Tanzania arbetar med patientutbildning om hiv-prevention och stigmatisering hos unga kvinnor.

Metod: En kvalitativ design med semistrukturerade intervjuer har använts. Studien innehöll intervjuer med åtta sjuksköterskor på ett sjukhus i norra Tanzania.

Resultat: Byggd på tre kategorier, 1. Sjuksköterskors uppfattning av deras roll och erfarenhet av patienthälsoutbildning angående HIV, 2. Uppfattningar om hur HIV-relaterat stigma påverkar unga Hiv-positiva kvinnor, 3. Nödvändig patientinformation gällande HIV prevention och behandling. De tre kategorierna förtydligas med åtta underkategorier.

Slutsats: Resultatet av studien tyder på att det råder brist på resurser när det gäller tid och utbildning, både i samhället och bland sjuksköterskorna. Sjuksköterskorna uppgav att de behöver verktyg för att bäst kunna utbilda och nå ett större antal människor. Uppsökande verksamhet nämndes som en av de mest värdefulla delarna i arbetet mot HIV. De upplevde även svårigheter angående stigmatiseringen och hur man bäst kan rådgiva den unga kvinnan.

Nyckelord: HIV prevention, upplevelser, patientundervisning, stigma, sjuksköterska, unga kvinnor, Health Belief Model, kvalitativ studie, Tanzania

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Glossary of abbreviations

HIV	Human Immunodeficiency Virus
AIDS	Acquired Immune Deficiency Syndrome
LDC	Least Developed Countries
PrEP	Pre-Exposure Prophylaxis
HAART	Highly Active Antiretroviral Therapy
ART	Antiretroviral Therapy
HBM	Health Belief Model
SES	Socio-Economic Status
SRHR	Sexual and Reproductive Health service
WMA	World Medical Association

1. Introduction

Human Immunodeficiency Virus (HIV) is a transmittable virus found all over the world, more than 38 million people worldwide are infected. 19.7 million of 38 million are girls and women above the age of 15. HIV infection is classified as a generally dangerous disease (World Health Organization - WHO -, 2022). 25.6 million of the infected are living in African regions (WHO, 2022). United Nations program on HIV/AIDS (UNAIDS) (2020) states that in the year of 2020 the incidence of HIV in Tanzania was 1.26 infected persons per 1000. Globally the incidence of persons infected by HIV was 1.5 million (UNAIDS, 2020). In 2021 the prevalence of HIV in Tanzania was 1.7 million people, 1 million of the infected were women (UNAIDS, 2023).

Tanzania is listed as a Least Developed Country (LDC) which means countries with low social and economic development (United Nations, UN, n.d). In general, LDCs lack knowledge about HIV and how it is transmitted. Thus, the vulnerability is higher than in more developed countries (UNICEF, 2020).

Nurses' role in preventive work includes but is not limited to educating about the disease, providing support regarding treatment as well as to provide good care (American Nurses Association, ANA, Policy and Government Affairs, 2019; Mboineki & Chen, 2019). Rural Health Information (Hub) (2022) states that in addition to saving lives, well-functioning prevention work has also been shown to save large amounts of money. Savings amount to as much as $229 800 to $338 400 in medical costs per HIV infection that is prevented.

This interview study is focusing on nurses´ attitudes regarding HIV prevention work on young women in Tanzania. To meet the objective of this study semi-structured interviews will be conducted on a selected number of nurses in Tanzania. From a global perspective Tanzania is a priority country for HIV prevention work, treatment and education are in focus.

When an individual is notified that she/he is infected and receive education about the disease, research shows that she/he takes steps to protect their own health and prevent HIV transmission to others (Centers for Disease Control and Prevention, 2020). Therefore, further research on how nurses work with prevention and HIV education is valuable.

2. Background

2.1 Human Immunodeficiency Virus – HIV

2.1.1 HIV globally and in Tanzania

HIV is linked to inequality and is prevalent in sub-Saharan Africa, it is one of the leading causes of death in the area (Hajizadeh, et. al. 2014). United Nation (UN) have produced global goals that are included in agenda 2030. Goal 3, "Good health and well-being", includes targets that is relevant regarding the fight against communicable diseases and health education (United Nations, 2022). UNAIDS (2015) has developed targets regarding HIV and AIDS infection called 90-90-90. December 2020 (Frescura, et.al. 2022) UNAIDS released a new draft of the target, and it is now called 95-95-95. The target still has the same context, meaning that before 2030 the objective is that 95percent of all HIV infected people know their disease, 95percent of all known infections receive antiretroviral treatment and that 95percent of all with antiretroviral treatment achieve viral suppression. The final objective is that there should be zero tolerance for discrimination against HIV-infected people. Achieving these objectives require education and preventive measures (UNAIDS, 2015).

2.1.2 Pathophysiology

HIV belongs to the retrovirus family and is very prone to replication and mutation (Naif, 2013). HIV cells are constantly changing, and it is a virus that attacks the cells of our immune system, T-lymphocytes. HIV mainly damages the part of the T-lymphocytes that is called; helper T-cell. The purpose of the helper T-cell is to help other cells of the adaptive immune system to fight intruders (Tortora & Derrickson, 2019). The HIV anti-gen passes mucous membranes or comes into direct contact with blood vessels, the virus reaches the helper T-cells of the human immune system. HIV infects by binding to helper T-cell receptors, penetrate the cell membrane and post-transcriptionally integrate into the cell nucleus which allows new viral copies to be formed (Naif, 2013). The development is based on the virus cell capability to reside latent in the body and thus avoid the oppressive methods of the immune system. As the virus destroys and impairs the function of immune cells, infected individuals gradually become immunodeficient due to the decreased number of T-lymphocytes. This results in an increased susceptibility to infection for the individual (Naif, 2013).

2.1.3 Transmission

HIV is a transmittable viral disease. Sexual transmission is one of the primary routes of transmission (Center for disease control and prevention, 2022). The infection can also be transmitted from mother to child during pregnancy or breast feeding. HIV is a very fragile virus and cannot survive outside of the human body. The virus cannot be transmitted by insect bites or through casual physical contact with an infected person, such as hugging or sharing household items (Tortora & Derrickson, 2019).

2.1.4 Symptoms

Naif (2013) explains that HIV initially is asymptomatic. After about three months changes in the immune system have occurred, which leads to flu-like symptoms. HIV is an infection that is transient even though the disease always remains in the body (Naif, 2013). Antiretroviral therapy (ART) is needed to manage the disease, early treatment with ART is showed to give a more accessible good prognosis of the disease

(Mirahmadizadeh et.al., 2023). An untreated HIV slowly progresses to a developed Acquired Immune Deficiency Syndrome (AIDS) infection (CDC, 2022).

2.1.5 Treatment

HIV cannot be cured but there are three categories of drugs have proven to successfully extend lives of HIV infected persons. The recommended treatment is called; highly active antiretroviral therapy (HAART) which is a combination of three or more antiretroviral medications from at least two different acting inhibitor drug classes (Tortora & Derrickson, 2019).

The United Republic of Tanzania: Ministry of health, community, development, gender, elderly, and children (MOHCDGEC) (2019) states that in Tanzania services for HIV testing focus on screening patients in different occasions. For example, outreaches, doctors' appointments, school visits, all with the aim to find the infection early. In addition, promotion of regular rescreening is available to everyone, regardless of prospective suspicion of an infection.

Pre-Exposure Prophylaxis (PrEP) may be used by people who are at substantial risk for HIV acquisition with purpose to limit risks of HIV infection. Populations targeted for PrEP include sex workers, people who inject drugs, vulnerable adolescent girls (age 15-19) and young women (age 20-24) (The Ministry of Health., 2019). Another model used in Tanzania is called Differentiated Service Delivery Models (DSDMs) and explains antiretroviral therapy (ART) (Forsythe et al., 2019). DSDM categorize infected individuals as early presenters or late presenters; with or without advanced disease at initiation of ART and stable or unstable after being on ART for six months (The United Republic of Tanzania, (2019). ART is initiated within 7 days of a positive HIV test unless there is a medical or psychosocial contraindication. Instable clients will attend clinics monthly (The United Republic of Tanzania, 2019). At present, there is no vaccine against HIV, and in addition HIV infection is not curable. However, there are antiretroviral drugs that slow down and prevent the development of AIDS (Mirahmadizadeh et.al., 2023; WHO, 2022).

2.3 Knowledge about the disease

The lack of education as well as knowledge regarding HIV is a major problem in Tanzania. Tanzanian schools do educate in sexual health, in both primary and secondary school as well as training of teachers. Though, around 60 percent of the people aged 15-24 in Tanzania do not know how to correctly prevent sexual transmission of HIV and the knowledge level is low (Ndeki et.al., 1994; UNAIDS, 2020). If young people spread the information they have received regarding HIV and AIDS, they learn more about the disease and how to protect themselves in a better way than the young people who do not talk about the disease (Ndeki et. al., 1994). Consequences of acknowledge regarding ways of transmission is people becoming fearful and avoidant as the disease may be asymptomatic (Ndeki et. al., 1994). Ndeki et.al (1994) also mentions that people with good knowledge about the disease are more likely to report an HIV infection.

As many as 5.9 million people in Tanzania did not know that they were infected and living with HIV 2021 (UNAIDS, n.d.). Knowledge also plays a major role in stigma challenge regarding HIV (K. Bird & E. Picket, 2016).

2.4 Socio-economic deficiencies

Low education, limited access to media such as television, newspapers, and radio in LDCs result in the fact that parts of the population does not know that HIV exists and even less what it means (Jung et. al., 2013). Media consumption and socio-economic status (SES) have a strong connection to knowledge about HIV and prevention measures. Some people do not know that sexual prevention such as utilization of condoms during intercourse exist (Jung et. al., 2013). The availability of condoms is also a challenge as it is expensive and not available in a sufficient quantity (Unicef, 2020).

When HIV infection is detected in an individual, treatment in the form of antiretroviral drugs should be offered as soon as possible and status should be checked regularly (Fogel et. al., 2016).

LDCs are commonly strongly patriarchal and thus boys and men have influence and power over girls and women which for example makes it difficult for women to say no to sex (Unicef, 2020). In LDCs women and young girls are unfortunately still often forced to sell sexual services in exchange for food or other necessities in order to survive (Unicef, 2020). Sexual violence against women mean that females are more exposed to HIV infection than males (Unicef, 2020).

United Nations (2023) state that communicable diseases and the lack of medicine mainly affect LDCs, including Tanzania. They also state that research on medicines and vaccines should be supported to protect public health and ensure that everyone has equal access to medicines and vaccines (United Nations, 2023). This is relevant for reducing the spread and stigma of HIV. If the availability of education, condoms and antiretroviral drugs that slow down HIV are not available to everyone, the fight against the spread will be extremely challenging (United Nations, 2023).

2.5 Stigmatization

HIV-related stigma is deeply linked to lower health, depression, and general well-being (Ghosn et al., 2018). People living with stigmatization related to HIV transform from being a complete, forward-thinking, and self-confident person to a person that is more insecure, withdrawn, and fragile because of stigmatization from people around (Ghosn et.al. 2018).

Takada et.al (2019) mentions that stigmatization is based on hierarchy and positions of power. HIV-related stigma makes infected individuals experience discrimination and hostility, which in turn leads them to distance themselves from treatment and to disclose the illness to family and friends (Takada et.al., 2019). Consequently, their ability to achieve social support and adequate care is being jeopardized. In sum, the negative stigma leads to poorer health control (Takada et.al., 2019).

The stigma regarding HIV is a major obstacle to successful treatment, especially in LDCs (Tran et.al., 2019). The stigma surrounding HIV also affects the possibility of information about the care that is available (Tran et.al., 2019). Healthcare professionals should play a key role in informing patients about the benefits of

getting tested and the importance of early detection and treatment of HIV (Gesesev et al., 2017).

2.6 Cultural and religious aspects

Another obstacle in preventing spread of HIV in LDCs is related to the use of protective measures such as condoms. The fact that all forms of contraceptives are forbidden in many religions is an obstacle (Tigabu et.al., 2018). Several religions say that contraceptives, like condoms is against the Almighty (God/Allah) (Tigabu et.al., 2018).

In Tanzania, religious beliefs are related with the stigma. For example, people who are infected with HIV are perceived as people who do not follow the word of God or are punished from God these are things that effects disclosure of an HIV positive result (Zou et.al., 2009).

Other issues relate to predominant gender inequalities, access to comprehensive sexual and reproductive health service (SRHR) and various forms of violence against females. For example, Tanzania does not have any legalization against domestic violence. The culture regarding gender inequality is also accelerated by the sexual industry. Above 70 percent in the sexual industry states that they use condoms during sexual intercourse. Despite this, the dominant spread of HIV occurs in the sex industry (UNAIDS, 2020).

2.7 Nurses role in Tanzania

In Tanzania, nurses play a crucial role in the healthcare system, contributing to the delivery of essential healthcare services and improving the overall health of the population (Mboineki & Chen, 2019). They are at the forefront of patient care, health promotion, reduction of disease related stigma, disease prevention, and community outreach. Furthermore, nurses in Tanzania conduct health screenings, organize health camps, and provide healthcare services to underserved populations. Through these initiatives, nurses aim to reach those who may have limited access to healthcare and improve health outcomes in marginalized communities (Mboineki & Chen, 2019; TNMC, 2014).

2.8 Theoretical Framework

2.8.1 Health belief model

The Health Belief Model (HBM) is a research model of health behavior. The model was developed to understand people's failure to adopt disease prevention strategies or screening for early disease detection (Rosenstock, 1966). The HMB suppose that health related behaviors are based on a combination of different factors; perceived susceptibility, perceived seriousness, perceived benefits of taking action and barriers to taking action benefits, barriers and cues to action (Rosenstock, 1966).

HMB suggest that people are most likely to take preventive measures if they perceive the threat of a health risk as serious, if they are personally receptive and if the benefits are larger than the costs (Rosenstock, 1966). In more detail, HBM includes two variables. 1) the psychological state of readiness to take specific action and 2) the extent to which a particular course of action is believed, overall, to be beneficial in reducing the threat. Two main dimensions define whether a state of readiness to act

exists. They include the degree to which an individual feels vulnerable or susceptible to a particular health condition and the extent to which he/she feels that contracting that condition would have serious consequences in his/her case. Ultimately, an individual's performance often depends on how one perceives the benefits and barriers to health behaviors (Rosenstock, 1966).

2.9 Problem Description

The majority of the population in Tanzania do not have enough knowledge regarding HIV and how to protect themselves from it. This leads to patients waiting a long time before they contact health care when they become sick/infected. Ignorance and lack of knowledge about HIV lead to stigmatization and discrimination of the infected young women as well as to isolation. Isolation in turn often lead to the women not receiving treatment. Thus, isolation and exclusion have a negative impact on health and well-being. Nurses play an important role in the preventive work and stigmatization against HIV and as providers of education. One obstacle regarding this is that there is a limited amount of literature and knowledge about the preventive measures that can be taken. This study will explore how nurses in northern Tanzania work with HIV stigmatization, prevention, and education.

3. Aim

The aim with this study is to explore how nurses in northern Tanzania work with patient education on HIV prevention and stigmatization in young women.

4. Method

4.1 Design

In this study a qualitative design with semi structured interviews has been used. According to Polit and Beck (2017) data for a qualitative study is usually collected in the real world, in an authentical setting. In semi structured interviews the researcher has several topics with associated interview questions. The format utilized were open ended questions where there are opportunities to ask follow-up questions if necessary to answer the purpose of the study, depending on the participants answer (Polit & Beck, 2017). An inductive approach was used to analyze experiences and emotions of the interviewed nurses. The interviews were the main source of data in the study. No further theories were used.

4.2 Data Collection

The researcher's data collection was conducted between January 30 th, 2023 to February 8 th, 2023. A pilot interview was conducted with one nurse to test the interview guide. The researchers were satisfied with the information obtained from the pilot interview, and therefore the pilot interview was included in the study. No corrections were made to the interview guide between the pilot interview and further interviews.

4.2.1 Interview method

The interviews were conducted in a hospital in Northern Tanzania with 8 respondents about their perception, education, and preventive work regarding HIV and its stigmatization, in young woman (Table 1). A topic guide was prepared with a list of areas with associated questions that will be covered with each respondent (Polit & Beck, 2017). The topic guide for the study contains the main areas, HIV prevention, stigmatization, and nurse's role in patient education. The questions have been developed based on literature, research, and organizations' work regarding HIV as well as inductive studies. For the associated questions, see appendix (Appendix 1).

During each interview there were two interviewers, one of the interviewers was responsible for the recording, and one interviewer was responsible for conducting the interview. The hospital received information about the study in advance in addition to information before the interview took place, see information letter (Appendix 2). Each interview began with a presentation of the interviewers, the objective and directions for the study. Respondents were informed that their participation was voluntary and that they could terminate the interview at any time. Before the interviews started the respondents had to sign a consent form, see (Appendix 3). The respondents also received the information that their interview will be assigned a code, for example “Nurse 1”, to keep everything anonymous.

Respondents answered the questions and described what efforts, tasks they conduct as well as how they work with HIV prevention methods regarding young women, groups, and societal levels. The interviews were held in English. To prevent misunderstandings, the interviews were recorded after the respondent's consent. All collected data was kept safe and confidential on a computer with a password that only the two researchers could reach. The interviews took place in a calm and quiet environment at the hospital where the respondent worked. The recorded files were deleted after the work was approved and published in Diva.

The researcher is seen as a co-creator of the text, which means that the result cannot be seen as independent of the researcher (Johnson et.al., 2020).

4.2.2 Participant selection

Polit and Beck (2017) state that in a qualitative study it is desirable to have a smaller number of respondents. The inclusion criteria for the study were that all nurses had experience of working in the field of HIV prevention and care. For the best possible variation in the data collection, nurses of different ages and experience were selected. This study required eight respondents. After eight interviews the researchers felt that the participants provided data that answered the purpose of the study and therefore saturation was reached. The purpose is to select respondents who can provide as much information as possible (Polit & Beck, 2017) regarding the preventive HIV work.

The hospital was found after searching for hospitals in the area where the study was to be conducted. Contact was made thru e-mail with the director of the hospital and the criteria for the study were presented. After that the Matron of the hospital helped to find nurses at the hospital that could be interviewed. The respondents are not selected at random but through convenient selection. The Matron at the hospital were informed by the Director and received information in advance about the study and helped to pick out the participants. This to reach the best possible variation and to meet the purpose of the study. As far as the researchers knows, none of the nurses refused to participate in the study. Exclusion criteria were not a nurse, no experience of work in the field of HIV and/or insufficient English language.

4.3 Data Analysis

The interviews were recorded on a recording device and transcribed through a voice recognition program that converts audio into text. The transcription was done by both researchers to reduce the risk of misunderstandings. The transcript was written in a word document without the exposure of the respondent's identity. The interviews were listened to several times and the transcript includes all spoken words such as; yeah, ah, Ok. Only the material from the interviews that matches the purpose of the study was used.

The inductive analysis of this study is based on Elo and Kyngäs (2008). The process was broken down into three main stages, preparation, organization, and reporting (Elo & Kyngäs, 2008). The inductive approach means that the data collected for this purpose leads to new results, reflections on whose results are not based on any previous theory (Elo & Kyngäs, 2008).

4.3.1 Preparation

The preparation phase started with selecting the unit of analysis. A unit of meaning can consist of more than one sentence and contain several meanings (Elo & Kyngäs, 2008). Transcripts were read, the researchers made general notes, underlined meaning units and categories. Similarities, differences, or other important data were receiving a special color. Data that emerged through leading questions, interruptions or interpretation difficulties were excluded.

4.3.2 Organizing phase

The organizing phase includes coding of data, grouping codes to the categories formulating description of the categories and abstracting subcategories (Elo & Kyngäs, 2008). This phase started with both researchers reading the material several times. Quotes were then picked out and turned into condensed sentences. The condensed sentences were then turned into sub-categories (Table 1). Sub-categories were then grouped and turned into generic categories and main categories that would answer the aim of the study. The purpose of creating categories is to provide a means of explaining phenomena, increasing understanding, and generating knowledge (Elo & Kyngäs, 2008).

Table 1.

Examples of how quotes were analyzed into main categories.

Quote	Condensed sentence	Subcategory	Generic category	Main category
"The most challenging thing is counseling and giving the result, especially if someone is HIV positive, it is very difficult for them to understand." *-Nurse 5*	Difficulties regarding counseling, supporting, and giving the patient notice of an illness	Council and give emotional support	Health education	Nurses' perceptions of their role and experience of patient health education regarding HIV
"(...) Just giving the real information, the clear information, the importance of knowing, having the education on it, how to prevent yourself." *-Nurse 3*	The importance of having the correct information and being able to share that information	Sharing correct information		
" When we do outreaches, we will be the one who educate. We are also creating songs and videos about HIV to make people aware." *-Nurse 2*	Reaching the communities in different ways	Outreaches operation		

4.3.3 Reporting phase

This phase included processing, reporting and analysis of the result. Reporting and analysis of the result has been done with an explanation of the categories and subcategories (Elo & Kyngäs, 2008). Categories and subcategories have been used as headlines to create a structure for the researchers and to create clarity for the reader.

4.4 Ethical considerations

The researchers were given permission to implement the interview study by the Interim Country Director at a hospital in northern Tanzania. Potential ethical risks within this study are confidential data leaks, respondents fear of being criticized for their answers or how they perform their work. Misunderstandings were also a potential risk (World Medical Association [WMA], 2013). The fact that the Matron choose all the respondents for the study could also be seen as a risk due to the nurses feeling powerless in their choice to participate. In order to mitigate these possible risks, the following considerations were taken:
Before the participant left their written consent to be a part of the study, they were given both oral and written information about the study (Appendix 3). No interviews were conducted before written consent were given. The participants were able to withdraw at any time, before, during or after the interview. All private information and information that emerged during the interview were handled confidential to respect the individual's integrity. In addition, the respondents were given fictitious codenames. Furthermore, the recorded files will be deleted after this study has been approved and published in Diva.

The Helsinki Declaration developed by the World Medical Association (WMA) sets out clear ethical aspects that must be maintained in medical research. WMA (2013) states the importance of research maintaining confidentiality. They also highlight that research should protect the life, health, dignity, integrity and respect the self-determination of the participants. One requirement is that the participants must give written consent and be voluntary. The Helsinki Declaration (2013) state that the purpose and significance of research and studies should consider the possible burden that comes with it. After collected research material, the research participants should also be given access to the material and the results that have emerged from the research.
An ethical self-assessment paper from Jönköping University has also been used for ethical evaluation of the study (Appendix 5). There was a prior understanding of the phenomenon from the researchers due to previous education and work experience. This can be seen as a risk when it comes analyzing data because previous experience can affect interpretations of the result (Granheim et.al., 2017). To reduce the risk of affecting the analysis of the result, the researchers were aware and open to the preunderstanding of the phenomenon.

5. Result

The results were based on the analysis of eight 15-35 minutes long interviews, participants (Table 2).

Table 2.

The participants gender, age, and experience.

M*	W*	Age, 25-35	Experience of work with HIV <1 year	Experience of work with HIV > 1 year	Hospital 1
6	2	8	2	6	8

Comment, M*: Male, W*: Woman

After analyzing the data three categories were emerged. The three categories are: *Nurses' perception of their role and experience of patient health education regarding HIV, Perceptions of how HIV related stigma effects young HIV positive women, Necessary patient information to be able to prevent and treat the HIV infection.* The three categories are clarified with eight subcategories, (Table 3).

Table 3.

Main categories and subcategories for the result

Category	Subcategory	Subcategory	Subcategory
Nurses' perceptions of their role and experience of patient health education regarding HIV	Sharing correct information	Council the patient and give emotional support	Outreaches operation
Perceptions of how HIV related stigma effects young HIV positive women	HIV stigma	Lack of education and knowledge regarding HIV	
Patient information to be able to prevent and treat HIV infection.	Preventive measures	Compliance to receive treatment	Importance of disclosure

5.1 Nurses' perceptions of their role and experience of patient health education regarding HIV

This category describes how the nurse works with education around HIV. Different perspectives regarding methods, experiences, and challenges regarding subcategories; Sharing *correct information, counsel the patient and give emotional support and outreaches operation.*

5.1.1 Sharing correct information

All nurses mentioned the importance of sharing correct information and educate the women on how to prevent HIV. The majority also lifted the importance of having access to updated and correct information about the disease, preventive measures. Some of the nurses commented that there is a lack of education about HIV prevention in Tanzanian nursing schools. Thus, nurses sometimes lack knowledge on how to educate

and share correct information. Some nurses also expressed the challenges with reaching out to young women in the communities aiming to provide education and information about HIV in the best possible way.

Nurse 3

"(...) Just giving the real information, the clear information, the importance of knowing, having the education on it, how to prevent yourself."

Nurse 1

"One obstacle is that those women need more education about the disease and awareness of the disease and the prevention. Now they are not aware of the disease and prevention."

5.1.2 Council the patient and give emotional support

Counseling the patient was mentioned in several, but not in all, interviews as one of the most challenging parts of being a nurse. Especially when the nurses need to tell the patient that she tested positive for HIV. A positive HIV result can be very hard for the patient to receive and understand. A nurse's job is to provide education regarding the disease and the treatment in a proper way. Nurses have an important role in informing the patient that life will continue despite the disease and that HIV is not the end of her life. This is done through counseling and educating the patient. Of great importance is to educate and make sure that patients who receive a positive HIV result understands that HIV is a disease that one can live with, and that it is not a reason to isolate someone or oneself from the society.

Some respondents mentioned lack of time assigned for counseling. The nurses experience that pressure on the hospital is high and thus time for counseling is limited.

Nurse 5

" The most challenging thing is counseling and giving the result, especially if someone is HIV positive, it is very difficult for them to understand."

Nurse 2

" I do not see any obstacles because when I counsel the woman they understand, and it goes smoothly."

5.1.3 Outreaches operation

This subcategory describes how the nurses are trying to reach the young women in different communities. Most of the nurses perform outreaches to educate, inform and test for HIV. The objective with the outreaches is to reach as many women as possible in different communities. When performing outreaches, the nurses try to educate about HIV, how to protect infection, how HIV is treated and how it is transmitted. The nurses also bring brochures with information about HIV and devices for HIV testing. Sometimes they perform outreaches during events, they build up tents for testing, create songs and videos for education. The HIV testing is voluntarily and free of charge. Some nurses talked about the importance of outreaches and educating the whole society and not only the young women, but they also mentioned the lack of time and that they would like to have more resources directed towards outreaches. Several

nurses also described how they felt a responsibility to raise awareness and provide education towards the young women.

Nurse 1

"We are doing like outreaches. When we go out to treat with other services we include the HIV services, like testing, as well. It is positive we do counseling and then go back to the hospital for medications and to start treatment."

Nurse 2

" When we do outreaches, we will be the one who educate. We are also creating songs and videos about HIV to make people aware."

5.2 Perceptions of how HIV related stigma effects young HIV positive women

This category include various challenges that nurses face both at work and in society. Most of the interviewed nurses mentioned problems around HIV related stigma that HIV positive women face daily. Two subcategories were emerged: *HIV related stigma and lack of education and knowledge regarding HIV*.

5.2.1 HIV stigma

HIV related stigma is something that occur daily. Traditional beliefs and lack of proper knowledge regarding HIV were two of the reasons linked to stigma mentioned in several of the interviews. The community is not sufficiently educated in the HIV field leading to stigmatization, isolation, discrimination, and exclusion. In some traditional beliefs HIV does not exist and if someone has HIV the rural belief is that infected persons are bewitched. Worst case scenario is that HIV positive woman get kicked out from the families, villages or/and societies.

The nurses experienced that stigma can be reduced with education as people need to be aware of how the infection is spreading. You may get HIV, but with proper treatment you will survive. Some of the nurses in the interviews mention in order to reduce stigmatization protective equipment, such as gloves, only were used in cases of confirmed infection.

Nurse 7.

"Stigmatization can be prevented by giving education to the people about HIV. It is just a disease like every other disease. You may get it, but still survive."

Nurse 3

"Sometimes they the other people they do not believe in HIV. They just believe they like the witches. (…)"

5.2.2 Lack of education and knowledge regarding HIV

All nurses mentioned that there is a lack of education and knowledge regarding HIV. They talked about how young women get discriminated and isolated from their society. For example, how some people believe that HIV can be transmitted just through shaking hands or hugging. Nurses also mentioned that some people do not believe that HIV is a disease. Nurses expressed that the way HIV education is performed today needs to change. Education needs to be increased and everyone needs

to be aware of how HIV is transmitted, what preventive measures that are available and that HIV is treatable. According to the nurses the lack of education and knowledge is the main source for stigmatization in society. Several nurses brought up the subject of young women in Tanzania working in the sexual industry and how they lack knowledge of how to prevent infection. The nurses mention that many of the people who buy sex are intoxicated and thus do not care about protection. Nurses state that it is illegal in Tanzania to buy sex but that it is still prevalent and a route for the spread of HIV.

Nurse 7

"If someone is exposed to HIV they discriminate against him or her. Because they do not know that HIV is not transmitted from contact or from eating and playing together."

Nurse 2

"The government is already doing prevention of sexual working, if they cough you are doing that, you are going to prison. But it is still a problem."

5.3 Patient information to be able to prevent and treat HIV infection

This category describes preventive measures that patient needs to avoid HIV infection and spread. This category is also about the nurse's role in motivating young women to receive treatment and explaining the importance of disclosure. The subcategories are; *Preventive measures, compliance to receive treatment and the importance of disclosure.*

5.3.1 Preventive measures

There are many preventive measures that are performed by nurses. Several of the interviewed nurses mention that they always encourage young woman to protect themselves during sexual activity, to use condom to reduce the risk of getting infected. The nurses are educating the women in the field of HIV both at the hospital and during outreaches.

At the hospital where the interviews were conducted guidelines from WHO regarding HIV prevention are being followed. In addition, the hospital has protocols for testing both in hospital and on outreaches to optimize their preventive work. However, the nurses mentioned challenges in their preventive work for example counseling a young woman whose partner do not want to use condom for religious or other reasons. Another challenge is that many people do not know how to use a condom and where to find condoms. One nurse also mentions that educating the schoolteachers is often forgotten. Teachers are spending the most time with young people while health care staff only see them for a short period of time.

Nurse 6

"As you know we are going to outreach as medical personnel, but there is something you've forgotten. The schoolteacher, if you provide the teachers with information then more education starts. Student teachers spend time with students for a long period. And as medical personnel we go for maybe two hours two hours."

5.3.2 Compliance to receive treatment

Compliance to accept and receive treatment can be difficult for young woman. Some of the nurse's mention that sometimes they try to educate an HIV positive woman, but

the women in question do not believe in the disease and therefore do not even consider that they can infect someone else. How much compliance the woman has in healthcare also has a correlation on how well she trusts that medicines are important and that they are going to help her live with HIV infection.

Nurse 6

"(…) Because some are already given education but they didn´t take it as a big issue, they didn't even consider that they can infect someone else."

5.3.3 Importance of disclosure

One of the most challenging parts for young women, according to the interviewed nurses, is disclosure to family and partners. The nurses therefore encourage young woman to tell their family and partners. However, it is often difficult to convince a woman to tell due to stigma and discrimination. In response to this challenge the nurses inform the infected women that disclosing her HIV positive result is important in order for her to receive both medical and psychological support.

Nurse 4

" Most of them live in villages and are discriminated and stigmatized. That is why most Tanzanian do not disclose that they have HIV, because that means they have to live outside of the society and are very discriminated."

Nurse 1

"We are trying to encourage, but sometimes it is not possible because they do not want to be exposed to another person. (…) But we are trying to give the importance of disclosure."

6. Discussion

6.1 Method discussion

6.1.1 Design

The chosen design for the study was a qualitative design with an inductive approach that aims to examine attributes, relationships, and the meaning of a phenomenon (Polit & Beck, 2017). An inductive approach was therefore relevant and increased the trustworthiness of the study (Granheim & Lundman, 2017). A qualitative method is the best way to answer questions like "what is", "how does…work" and "what means" and when the purpose is to understand rather than explain (Polit & Beck, 2017). Qualitative methodology is also characterized by the researcher being flexible, adaptable, and having an open approach to the research field (Polit & Beck, 2017).

6.1.2 Data collection

The method utilized in this study was semi-structured interviews that were presented qualitatively. The researchers interviewed eight nurses. After eight interviews the data saturation was reached as the respondents had provided detailed, solid, and consistent descriptions of the preventive work and experiences conducted at the hospital. Less quantity of respondents is acceptable to focus on quality and desirable in this type of studies (Polit & Beck, 2017). To only have eight respondents and to have used convenience selection when choosing the respondents can be seen as a weakness due to the credibility decreasing (Polit & Beck, 2017).

The semi-structured interview is based on the topic guide that is presented to all respondents. The chosen method is suitable because it is a flexible method that gives the researchers the opportunity to compare all the answers from our respondents (Polit & Beck, 2017).

The Interim Country Director and the Matron of the hospital was well informed about the purpose and subject of the study. The Matron assisted to get in contact with nurses that were suitable for the study. This can be seen as a risk due to the nurses feeling powerless in their choice to participate, when being asked by a hinger-ranked person (Polit & Beck, 2017). Further it was important for the respondents to give written and verbal consent prior to the interviews (Polit & Beck, 2017). Most of the respondents had previous experience of working with HIV prevention in young women. Previous knowledge and experience of the phenomenon under research is crusial to increase the credibility of the study (Granheim & Lundman, 2017).

A pilot interview was conducted to test whether the setup questions answered the aim of the study. This to create an opportunity to correct if something other than the aim was detected. A pilot interview was conducted to test the appropriateness of the questions and the feasibility of the study (Polit & Beck, 2017). By doing a pilot interview the risk of being inefficient during the remaining interviews decreases and it made sure that the rest of the data was collected methodologically which increased the study's trustworthiness (Polit & Beck, 2017). No modifications of the questions had to be done and therefor the pilot interview was included in the result.

The interviews were transcribed in attendance of both researchers and were listened to several times to prevent risks of making mistakes and general misunderstandings. This increases the dependability of the study (Polit & Beck, 2017). That there were

two researchers conducting and analyzing data can be seen as a strength and increase the dependability (Granheim & Lundman, 2017).

6.1.3 Data analysis

A qualitative content analysis as described by Elo and Kygnäs (2008) have been utilized. Qualitative content analysis of the narrative data was used to efficiently identify prominent categories and patterns among the interview results (Elo & kygnäs, 2008). The dependability for the study was increased in that all interviews were conducted in the same way and that the same topic guide was used in all interviews (Granheim & Lundman, 2004).
The respondents´ data was vital in this study since the researchers had small prior clinical experience and theoretical knowledge about the phenomenon. Previous knowledge could distort the results (Polit & Beck, 2017). The researchers were aware that previous experience may influence the analysis, awareness minimizes the risk of distorted analysis.

The methodology utilized helped the researchers to condense a large volume of data into three content categories. This made data interpretation more structured and more interpretable for the researchers. The credibility was increased due to the categories covered all the collected data (Elo & kygnäs, 2008). The analysis of the material began with the transcription of the interviews. The data required detailed discussions and reviews by the researchers to understand what respondents disclaimed. Furthermore, the transcription was done the same day as the interview responses were fresh in memory of the researchers. By continuously analyzing and comparing different interviews the researchers had a greater chance to prevent mistakes and misunderstandings (Pilot & Beck, 2017). The analysis of the text in its entirety and over time identifies units of meaning that reflect the aim. Data was analyzed based on similarities and differences from the interviews and categories were created. Quotes were used to clearly show that the study is based on information from the respondents and not the interpretation of the researchers (Elo & Kygnäs 2008). This increases both transferability and trustworthiness (Graneheim & Lundman, 2017).

6.2 Result discussion

6.2.1 Nurses' role and experience of patient health education regarding HIV

Nurse's role in patient education shows that the nurses play an important role. Sharing up-to-date information and to counsel the patient with respect and care so that the individual woman understands the disease is of great importance to receive compliance from the patient. It is important to involve nurses and all health care staff in education towards the young women to reduce the spread of HIV (Bird & Picket., 2016). This can also be related to the HBM in such a way that the patient must feel that the information given is sufficient and credible to prevent illness (Rosenstock, 1966). The results from the interviews clearly indicate that the nurses face challenges regarding patient education and counseling. Especially when giving the young woman a positive HIV result. The nurses mention that a feeling of resignation and that life is over is common for the women when receiving a positive HIV test. It is of great importance for the nurse to provide information and education to the patient about effective antiretroviral treatment and that with ART the patient can live a valid life (Fauci., 2005). Frescura et., al. (2022) states that young women in

general are less likely to receive treatment with ART. According to HMB an individual´s beliefs of a particular disease combine with a individuals' beliefs in the effectiveness of a recommended health behavior or activity is a strong predictor to how that individual will respond to the suggested treatments (Rosenstock, 1966).

Another finding in the result of this study is that the nurses regularly do outreaches to different parts of the community to educate as many women as possible. Tanzania is a LDC with significant differences in socioeconomic standards between different ethnic groups. Jung and Viswanath (2013) mean that education and wealth are strongly associated with the ability to receive education, awareness and knowledge regarding transmission and prevention of HIV. A factor that makes the work in HIV education difficult towards young women is mentioned by all interviewed nurses who also felt that they do not have enough time to provide enough education and support.

6.2.2 Nurses' perceptions of how HIV related stigma effects young HIV positive women

The results from the study stated that there is a lack of knowledge in the society about how HIV is transmitted, treated and prevented which leads to stigmatization, discrimination, and isolation. Ghoson et., al (2018) states that this kind of stigmatization can transform a person from being a wholesome and friendly person to a person that is more insecure and fragile. According to HMB, ultimately, an individual's performance often depends on how one perceives the benefits and barriers to health behaviors (Rosenstock, 1966). Bird and Picket (2016) states that knowledge is a major factor in the stigma which matches what the nurses have said during the interviews. The stigma jeopardizes their ability to achieve social support and adequate care. In sum, the negative stigma leads to poorer health control (Takada et.al., 2019). The stigma also makes it harder for the nurses to provide the young women with the correct information and the importance of treatment of HIV (Gesesev et al., 2017). This reinforces what the nurses in the study mentioned about the difficulties in reaching and motivating the young women towards both treatment, knowledge, and education. Traditional beliefs were also mentioned by the interviewed nurses as a challenge because in some beliefs HIV doesn’t exist or that a person with HIV has been bewitched. Those beliefs and behaviors in combination with lack of knowledge about HIV make it hard to achieve good health and well-being according to the HMB (Rosenstock, 1966).

6.2.3 Patient information to be able to prevent and treat HIV infection

The interviewed nurses' states that they play an important part in sharing information about the preventive measures for HIV to the young women. Many of the interviewed nurses mention that they always encourage young women to protect themselves during sexual activity. They recommend the use of condoms to reduce the risk of getting infected. Jung and Viswanath (2013) states that awareness of HIV and knowledge of transmission and prevention of HIV and is significantly associated with condom use. Jung and Viswanath (2013) continues, likewise, socio-economic aspects play a role in the amount of knowledge and the frequency of condom use. The nurses mention that condom use is forbidden in some religions and traditional beliefs. Tigabu et.al., (2018) says that the use of contraceptives, like condoms is against the Almighty (God/Allah). The availability of condoms is also a challenge as it is expensive and not available in a sufficient quantity (Unicef, 2020). This is, according to the interviewed nurses, a major challenge, partly the limited availability but also

the attitudes towards condom use. One root cause of the problem is that a woman may be okay with using a condom while her partner does not want to use a condom.

The nurse has a duty to inform women about different available treatments. Bird and Pickett (2016) states that early initiation of HIV treatment slows the progression of the disease. Therefore, it is of great importance that the nurse recommends early treatment. The United Republic of Tanzania, [MOHCDGEC] (2019) states that in Tanzania there are services for HIV testing focus on screening patients with the aim to find the infection early and start the treatment. The young women's compliance to receive treatment was another challenge mentioned by the interviewed nurses. The nurses say that they can educate the HIV positive woman, but the woman does not take it as a big issue, and some do not believe in the disease and therefore do not even consider that they can infect someone else. According to HBM compliance is based on how well the woman trusts what the nurses say is true and how well the woman herself wants to receive treatment or use preventive measures regarding the disease (Rosenstock, 1966).

The last finding from the result of this study is that the nurse must promote the importance of disclosure. The nurses talked about the importance of disclosing to someone that they are HIV positive so that they can get both medical and psychological support. HIV-related stigma often makes the infected woman to distance herself from treatment and not to disclose the illness to family and friends. Consequently, their ability to achieve social support and adequate care is being jeopardized (Takada et.,al. 2019).

7. Conclusion

The results of the study strongly indicate that there is a lack of resources when it comes to education and time. Nurses find it challenging to council patients and to fight the stigma regarding HIV. To reach a patient and/or to educate about HIV the nurses need tools on how to individualize the information. The nurses also stated that there is a knowledge gap in the society and among nurses regarding HIV. Nurses are trying to minimize that gap by conducting outreaches and provide individual educating to infected patients. Further, the nurses stated that they need support and in terms of resources from the government to reach a larger amount of people.

Clinical implications

The compiled result in this qualitative study aims to contribute to greater insight into the important role nurses have in preventive care and targeted patient communication. In addition, the study clarifies the importance of active work that limit stigmatization linked to HIV. This study clarifies experiences, emotions, and the general understanding of HIV in northern Tanzania, which hopefully can lead to a better care and understanding for both nurses and patients. This study can also encourage further research within the subject, development of PM and teaching opportunities for nurses.

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Appendices

Appendix 1 – *Topic / Interview guide.*

JÖNKÖPING UNIVERSITY
School of Health and Welfare

Topic Guide

Information

· Welcome, presentation of the interviewers and an introduction from the interviewers and over all information about the approach and for how long the interview will take place.

-Letter of information.

· Consent/sign the consent form.

Socio-demographic questions:

Age, number of years working as a nurse, number of years working with prevention of HIV?

Questions for the interview:

· Ice-breaker: For how long have you been working at this hospital…..?

Theme – HIV Prevention

-How do you work with prevention of HIV in women aged 15-24 years?

-What strategies do you use? (EX: contraceptives? HIV testing?)

- Which are the guidelines in the prevention work?

- What kind of prevention is the most frequently used today?

- Are there any obstacles in the preventive work against HIV?

- Which priority does HIV prevention have in the society and healthcare?

- Where do you perform HIV prevention? In hospitals, or do you in the community, pls describe.

- What is the most challenging part of your prevention work?

- Please, describe how prevention work of HIV could be successful? Do you have time for it? If not? Pls, describe.

Theme - Stigmatization

- How do you work with stigmatization of HIV among young women, ….in the society?

- How do you encourage young women to test for HIV?

- Disclosure of HIV positive status to partners, families can be difficult. How do you encourage such disclosure?

- How do you think stigmatization can be prevented?

- Decrease of stigmatization? Suggestions…

- Partners' and families' role in stigmatization?

- How do religious factors and traditional believes influence stigmatization regarding HIV?

Theme – Nurses role in patient education

- What does HIV education for young women looks like today?

- How do you work with HIV education?

- Do you think that HIV prevention and education need to change, if so, in what way?

- What role do nurses have in HIV prevention and education among young women?

Ending

· Do you have anything that you want to add?

· (If needed a short summary of the interview to avoid misunderstandings)

· Thank the respondent.

· (Inform the respondent of what will happen next, transcription, analysis of the material, form a result. Inform the respondent that they will be able to take part off the finished result.

Appendix 2 – *Information about the study*

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Information to the participants of the interview study

This information is directed to general nurses working at the [redacted]. The study has been approved by the manager at [redacted].

We are two nursing students from Sweden who during the beginning of spring 2023 will be writing our examination papers by doing an interview study at Maternity Africa Hospital about HIV prevention among women under 15-25 years old.

HIV is a very large problem across the world and with this study we will receive knowledge that will help us as future nurses and hopefully you will find it valuable too.

We will be interviewing 8 general nurses to get more knowledge about what is done today in the HIV prevention work. The questions in the interview is going to be about HIV prevention, HIV related stigma and the nurse's role in educating young women about HIV.

Attendance is voluntary and you can at any time stop participation in the study. All the data will be handled confidentially, and your personal data will not be compromised as this interview comes under a fictious name.

When the study is finished you will be able to read our report. With this you are asked to be in the study.

If you have any questions, please contact:

Embla Borgh, embla.borgh@hotmail.com or Märta Steinwall, marta.steinwall@hotmail.com

King Regards, Embla & Märta

Jönköping Univerity

Sweden

Appendix 3 – *Concent form*

CONSENT FORM

I have read the information for this study and my questions have been fully answered by a member of the research team.

I agree to participate in the study.

Date……..

Name ……. **Signature……..**

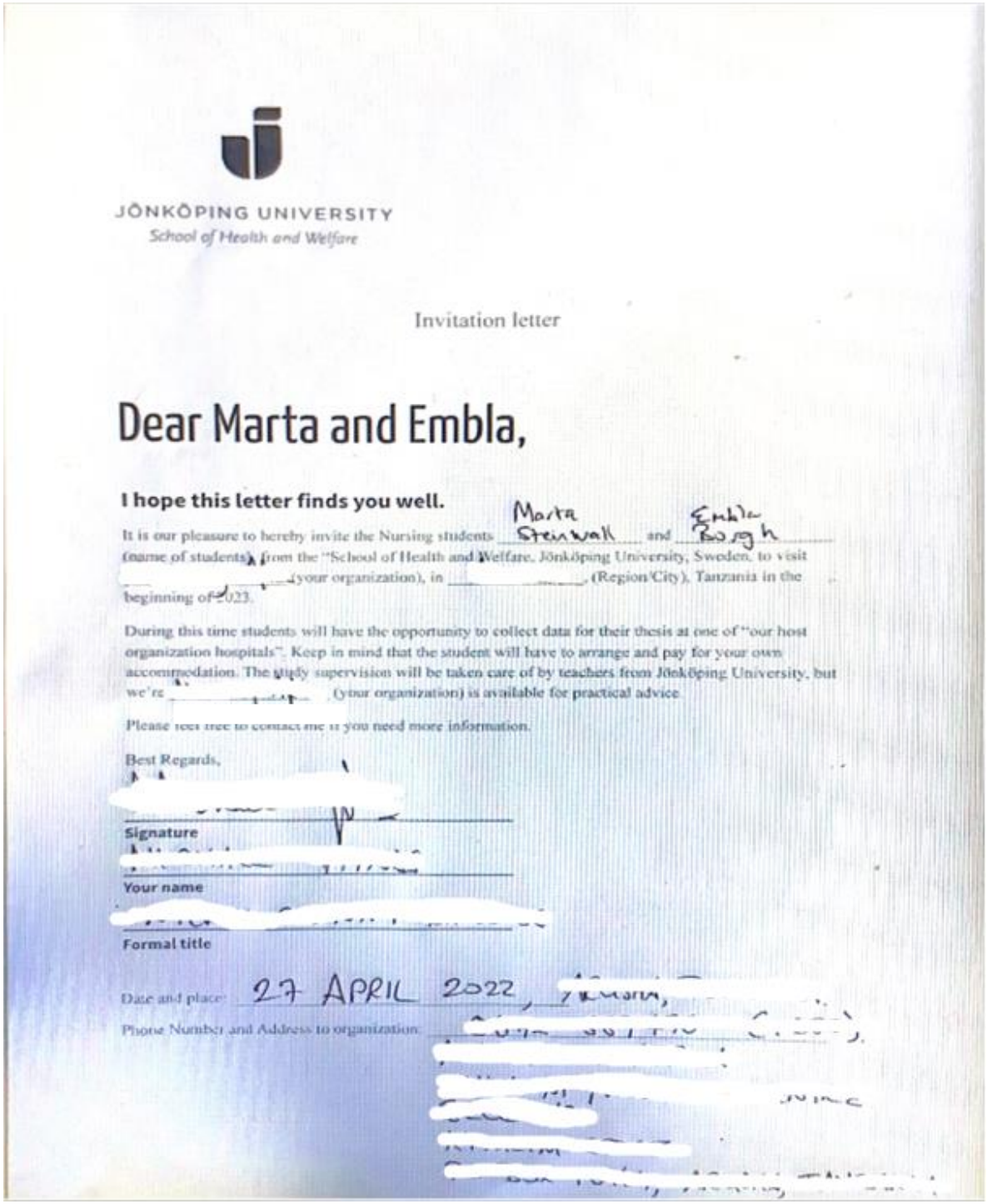
I have read and explained the study information to this person and have answered all question raised.

Date……..

Name ……. **Signature……..**

Further clarification in case of any doubt during the course of the study, I may contact the authors, Embla Borgh, embla.borgh@hotmail.com or Märta Steinwall, marta.steinwall@hotmail.com

Appendix 4 – *Invitation letter from the hospital*



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Invitation letter

Dear Marta and Embla,

I hope this letter finds you well.

It is our pleasure to hereby invite the Nursing students Marta Steinwall and Embla Borgh (name of students) from the "School of Health and Welfare, Jönköping University, Sweden, to visit [redacted] (your organization), in [redacted] (Region/City), Tanzania in the beginning of 2023.

During this time students will have the opportunity to collect data for their thesis at one of "our host organization hospitals". Keep in mind that the student will have to arrange and pay for your own accommodation. The study supervision will be taken care of by teachers from Jönköping University, but we're [redacted] (your organization) is available for practical advice.

Please feel free to contact me if you need more information.

Best Regards,

[redacted]

Signature

[redacted]

Your name

[redacted]

Formal title

Date and place: 27 APRIL 2022, [redacted]

Phone Number and Address to organization: [redacted]

Appendix 5 - *Ethical self-assessment paper from Jönköping University*

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Blankett för etisk egengranskning av examensarbeten[1] vid Hälsohögskolan

Datum:	2023-01-13
Examensarbetets titel:	Nurses' role in educating and prevent HIV among young women, in Tanzania – A qualitative study
Student/studenter[2]:	Emilia Borgh & Märta Steinwall
Student/studenter mejladress:	beem20pb@student.ju.se stma20ug@student.ju.se
Utbildningsprogram:	Sjuksköterska
Utbildningsnivå:	Högskola 180hp
Handledare:	Pär Wennberg
Handledare mejldress:	par.wennberg@ju.se

Examensarbeten vid Hälsohögskolan, Jönköping University, ska följa forskningsetiska principer så som de uttrycks i etikprövningslagen (EPL). Denna blankett är ett hjälpmedel för granskning av etiska frågeställningar knutna till examensarbetet.

Student och handledare går igenom blanketten tillsammans, identifierar etiska problem och enas om hur dessa ska hanteras. I de fall där tveksamheter kvarstår, tas dessa upp till diskussion med examinator.

Forskning som faller under EPL måste prövas av Etikprövningsmyndigheten[3].

Gränsdragningen mellan forskning och examensarbeten berörs inledningsvis i del A.

Del B hanterar vad som faller under EPL samt etiska principer som är viktiga att reflektera över inför genomförandet.

Den etiska egengranskningen ska alltid godkännas av examinator innan examensarbetet påbörjas.

[1] Blanketten gäller även verksamhetsförlagda förbättringsarbeten.
[2] Alternativt utförare av verksamhetsförlagt förbättringsarbete.
[3] www.etikprovning.se

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Del A: Är detta en forskningsstudie?

Del A syftar till att avgöra om studien avser vara forskning. Examensarbeten räknas normalt inte som forskning och kan då inte heller prövas av Etikprövningsmyndigheten. Under vissa omständigheter kan dock examensarbeten vara forskning. Examensarbetet:

1. Syftar till publicering i vetenskaplig tidskrift
2. Har en vetenskaplig frågeställning och en design som kan besvara densamma
3. Leds av forskare inom området, t.ex. som del av ett större forskningsprojekt

Är studien forskning i dessa tre avseenden?

☐ JA (Studien ska prövas av Etikprövningsmyndigheten.)
☒ NEJ (Fortsätt till del B)

Del B: Innehåller examensarbetet sådant som enligt etikprövnings-lagen kan identifieras som etiskt känsligt?

Frågorna i del B syftar till att undersöka;

1. om examensarbetet har sådana etiska problem så att det *om det vore forskning* skulle krävt prövning av Etikprövningsmyndigheten. Examensarbetet ska i dessa fall **inte genomföras**.
2. hur etiska principer hanteras i examensarbetet.

Om någon av frågorna besvaras med "tveksam" eller "ja" (fråga 1-13) respektive med "tveksam" eller "nej" (fråga 14-23) så bör en fördjupad etisk reflektion som involverar student och handledare genomföras kring hur dessa etiska risker och problem ska hanteras eller hur studien kan modifieras för att motverka identifierade risker. I dessa fall bör egengranskningen och den etiska reflektionen inkludera examinator för slutligt ställningstagande om examensarbetets genomförande. **Den etiska egengranskningen ska alltid godkännas av examinator innan examensarbetet påbörjas.**

		Ja	Tveksamt	Nej
1	Avser studien att behandla känsliga personuppgifter enligt GDPR[4], det vill säga vid något skede länka till en person och där uppgifterna avslöjar ras eller etniskt ursprung, politiska åsikter, religiös eller filosofisk övertygelse, medlemskap i fackförening, hälsa eller sexualliv?	☐	☐	☒
2	Avser studien att behandla personuppgifter som avser lagöverträdelser som innefattar brott, domar i brottmål, straffprocessuella tvångsmedel eller administrativa frihetsberövanden?	☐	☐	☒
3	Innefattar studien personer som kan identifieras som utsatta grupp och/eller personer som står i beroendeställning till den som rekryterar eller genomför datainsamlingen	☐	☐	☒

[4] GDPR är en förkortning av General Data Protection Regulation (EU:s dataskydds-förordning)

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		Ja	Tveksamt	Nej
4	Innefattar studien barn (personer under 18 år)	☐	☐	☒
5	Innebär studien ett fysiskt ingrepp på deltagarna, t.ex. någon typ av fysisk undersökning eller provtagning (även sådant som ingår i gängse rutiner, men också är del i studien)	☐	☐	☒
6	Är syftet med studien att fysiskt eller psykiskt påverka deltagarna?	☐	☐	☒
7	Innebär studien en uppenbar risk att skada deltagaren fysiskt eller psykiskt?	☐	☐	☒
8	Används biologiskt material som kan härledas till en identifierbar individ eller avliden människa (exempelvis blodprov eller vävnadsprov)?	☐	☐	☒
9	Kan frivilligheten för deltagaren ifrågasättas (exempelvis utsatta grupper såsom barn, personer med kognitiv nedsättning och psykisk funktionsnedsättning, eller personer i beroendeställning som patienter eller studenter i förhållande till försöksledaren)?	☐	☐	☒
10	Kommer personer med begränsad autonomi engageras (exempelvis personer med kognitiva svårigheter, underåriga) där förståelsen för innebörden av samtycket är begränsat?	☐	☐	☒
	Deltagarval och social utsatthet			
11	Tillhör deltagarna en extra sårbar och utsatt grupp i samhället (minoritetsgrupp)?	☐	☐	☒
12	Upprättas ett personregister där data kan kopplas til fysisk person?	☐	☐	☒
	Informerat samtycke			
13	Innehåller informationsbrevet övertalande formuleringar (som utgår från att personen ska eller bör ställa upp utan att fullt visa respekt för valet, exempelvis milt övertalande så som "tack på förhand")?	☐	☐	☒
14	Beskrivs studien så att deltagarna förstår dess syfte och upplägg och vad deltagande i projektet innebär (exempelvis antal besök, projekttlängd, med lätt svenska utan fackuttryck)?	☒	☐	☐
15	Framgår det i den skriftliga informationen til deltagarna att deltagandet i studien är frivilligt?	☒	☐	☐
16	Kommer informerat samtycke att inhämtas (det vill säga att deltagarna kommer att få information om undersökningen och/eller möjlighet att avsäga sig ett deltagande)?	☒	☐	☐
17	Framgår det tydligt att deltagaren kan avstå från medverkan utan att detta påverkar deltagarens omhändertagande eller behandling eller, om studenter, betyg?	☐	☒	☐
18	Framgår det tydligt att deltagaren när som helst och utan angivande av skäl kan avbryta deltagandet utan att detta påverkar deltagarens omhändertagande eller behandling eller, om studenter, betyg?	☒	☐	☐
	Konfidentialitet och deltagarnas säkerhet			
19	Finns det rutiner för att garantera konfidentialitet vid datainsamlingen?	☒	☐	☐
20	Beskrivs resultatet på ett sätt så att deltagarna är konfidentiella, det vill säga att de ej kan identifieras efteråt (inklusive små förutsättningar för så kallad baklänges-identifikation)?	☒	☐	☐

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		Ja	Tveksamt	Nej
21	Om anonymisering är utlovat, finns rutiner för att säkerställa detta?	☒	☐	☐
22	Finns det tydliga rutiner för att säkerställa hantering av insamlat datamaterial enligt GDPR?	☒	☐	☐
	Examensarbetets resultat			
23	Finns det skäl att erbjuda deltagarna att få ta del av examensarbetets resultat?	☐	☐	☒

Ovanstående frågor under del B är noga genomgångna, sanningsenligt besvarade och diskuterade med handledare.

Ort och datum: .....

Underskrift Student .....

Underskrift Handledare .....

Underskrift Examinator .....