Nurses’ experiences of working with Prevention of Mother-to-Child transmission of HIV
A minor field study in the Rufiji district of Tanzania

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Examensarbets

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Abstract

This study is a Minor Field Study and is funded by the Swedish International Development Cooperation Agency (SIDA). At the end of 2016 there were 1.4 million people living with HIV in Tanzania; That same year approximately 55,000 people were newly infected with the disease. The most frequent route of infection is through mother to child transmission (MTCT). The risk of transmission can be reduced with the help of medication and other strategies, called prevention of mother-to-child-transmission (PMTCT) of HIV. Tanzania is working actively with these prevention programs, however the rates of MTCT still remains high in the country. Due to their profession, nurses play a significant role in these prevention programs. They have an important role in educating the patients and encouraging a healthier lifestyle. Therefore, it is important to investigate nurses’ experiences of working with PMTCT of HIV to gain knowledge and valuable information of their experiences. The aim of the study is to investigate local nurses’ experiences of working with PMTCT of HIV in the Rufiji area in Tanzania. The data of the study have been collected through individual interviews with six nurses using a semi-structured guide with open questions. The nurses’ experiences of working with PMTCT of HIV covers three key areas. First, they work actively with motivating the mothers in several significant areas, such as motivating the mothers to take a voluntary HIV-test and bringing their partners to undertake the HIV-test. Second, the nurses described the importance of counseling the mothers and their partners. One part in counseling is to get the mother’s mind ready to receive the result of the HIV-test. Third, the nurses experienced stigma as something they all had to be aware of and meet in their everyday work life. Stigma from the community and relatives is one reason for poor adherence from the mothers to the PMTCT program.

Key words: PMTCT, MTCT, prevention of HIV, nursing, counseling, qualitative content analysis, Tanzania, minor field study.
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ABBREVIATIONS

AIDS – Acquired immune deficiency syndrome
ART – Antiretroviral therapy
ARV – Antiretroviral drugs
CTC – Care and Treatment clinic
HIV – Human immunodeficiency virus
ICN – International council of nurses
MTCT – Mother-to-child transmission
PMTCT – Prevention of mother-to-child transmission
RCH – Reproductive Child Health
SDG – Sustainable Development Goals
TACAIDS – The Tanzanian commission for AIDS
UNAIDS – Joint United Nations Programme on HIV/AIDS
UNFPA – United Nations Population Fund
UNICEF – United Nations Children’s Fund
WHO – World Health Organization
ACKNOWLEDGEMENTS

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We would also like to thank our contact in Mchukwi, Emanuel Kasekwa, for helping us out before and during our stay at Mchukwi mission hospital. To Hyacinta and Dina, for guidance and invaluable help in the field, and Priska who looked after us and made us feel at home. Finally, we want to thank the nurses who participated in this study, and the people in the Mchukwi community for their hospitality, their warm welcome and making the experience unforgettable.

Asante Sana (Thank you)
Kajsa Davidsson
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INTRODUCTION

Even though the worldwide number of Human Immunodeficiency Virus infections (HIV) is decreasing, there is still is a major issue with the HIV/AIDS burden in Tanzania today. Nearly a fifth of all new infections are through Mother-to-Child transmission (MTCT) of HIV and Tanzania is working actively with Prevention of Mother-to-Child transmission (PMTCT) of HIV. PMTCT are prevention programs set up where the goal is to virtually eliminate MTCT.

Due to their profession, nurses play a significant role in these prevention programs. They have an important role in educating their patients and encouraging to a healthier lifestyle. As nursing students we have a desire to improve health, not just locally but also globally and the interest in PMTCT arose when we came across an article on the topic, explaining the severity and the importance of these programs in Tanzania. After further research, we became curious and interested in the role that the nurses play. We travelled to Mchukwi mission hospital in the Rufiji district in Tanzania to carry out our study with an ambition to get further insight on the matter.

BACKGROUND

The United Republic of Tanzania

Tanzania is located on the east coast of Africa. The country’s topography includes the second deepest lake in the world (Tanganyika lake, 1435 m) and the highest mountain in Africa (Kilimanjaro, 5898 m) (NE 2017). The weather differs from the inland’s dry and hot weather to monsoon climate by the coast (Höglund 2016b). Tanzania is a low-income country (LIC), and despite years of loans and aid it still counts as one of the most poverty-stricken countries in the world (Höglund 2016a).

The total population in the country is 57,5 million (2017) and is characterised by vast ethnic diversity. The official languages are Swahili and English, but there are more than 130 different languages spoken in the country. Religious freedom is guaranteed in the country, and out of the population 60 percent are Christians, 30 percent are Muslims and an estimated 10 percent are adherent to native folk religion (NE 2017).

The health sector is mainly run by the government and the aim is to provide healthcare for everyone. Unfortunately, the economic situation in the country has made this impossible, and in 2009 only 5 percent of the total government expenditure was put into healthcare. Today there are 10 hospital beds per 10,000 inhabitants and one doctor per 100,000 patients (NE 2017).

Rufiji district

The Rufiji district is an area in the Pwani region and is located in the eastern region of Tanzania. The district of Rufiji is the 5th least populated area in Tanzania and is sporadically populated with 217,274 residents. Between 2002-2012 the district experienced a significant growth of the population with 7.6 percent. The region has a wide range of divergent indigenous ethnic groups; Wasaramo being the largest. The most
frequent occupation in the region is crop farming and the most desired and important skills are beekeeping, mining, hunting, fishing, wildlife tourism and forestry. Due to a deficient number of practitioners in the Pwani region, the provision of health services in the area is of low quality. The inadequate number of doctors has led to a constrained provision of health services particularly in curative and preventive areas including PMTCT (National Bureau of Statistics (NBS) (2013).

**Mchukwi mission hospital**

In the 1960’s Swedish missionaries from the free Pentecostal church (FPCT) founded Mchukwi mission hospital, but in 1997 the local church was given full authority for the hospital. Today the hospital has around 90 employees with a capacity of 100 beds, and the main source of funds are from donations and patient fees. The hospital also receives a minor contribution from the government to help with the cost of some hospital beds and a number of staff. The whole group of employees is natives of Tanzania, but there is still a close collaboration between the hospital and Swedish organisations regarding volunteers and students. The hospital has many different sections, such as, Reproductive and Child Health (RCH), a Care and Treatment clinic (CTC) and a maternity ward. There is also a division for outpatients, where patients can get their medication and simpler examinations. The hospital performs daily x-rays, deliveries, surgeries and other smaller procedures (Personal communication, Hyasinta Maneno, 2018-03-12).

**Health and social situation in Tanzania**

Tanzania struggles with financial hardship and over 20 percent of the population in the country are suffering from poverty (making less than $2/day). Clean water is a major problem, with fewer than half of the people in the country having access (NE 2017). The country also struggles with one of the highest rates of child and maternal mortality in the world (Ministry of Health and Social Welfare (MoHSW) 2010), and one in twenty children dies within their first year (NE 2017). HIV/AIDS, malaria and diarrhoea being the most common reasons. The number of childbirths per woman in the urban areas are roughly 3.7 and in the rural areas as high as 6.1 (Deutsche Stiftung Weltbevoelkerung (DSW) 2014).

**HIV/AIDS**

HIV is transmitted through sperm, blood, vaginal secretion and breastmilk and targets cells in the body with specific receptors, called the CD4-molecule. The virus attaches to this receptor and forces itself into the cell. Research shows that it is almost exclusively the T-helper cells that have CD4-molecules on their surface, and therefore HIV attacks these particular cells. The T-helper cells are lymphocytes that coordinate the immune system in the body (Andreassen, Fjellet, Hægeland, Wilhelmsen & Stubberud 2011, pp. 90-91). By making copies of itself inside these cells, HIV manages to destroy the T-helper cells and gradually breaks down the immune system (Avert 2017a). When the levels of T-helper cells are low in the body, the immune system cannot function, which leads to the body being unable to fight normal infections. This state is called Acquired Immunodeficiency Syndrome (AIDS) (Brändén & Andersson 2004, pp. 283-284).
AIDS is the final state of the HIV infection. AIDS is not a specific disease, but a combination of illnesses and symptoms developed from the infection (WHO 2017). This is a result of the immune system being destroyed; it is a very advanced stage and will lead to death if left untreated. Currently there is no actual cure for HIV, but with the right treatment and medication HIV infected people have the possibility to live a longer life (Avert 2017b). The medication used is called antiretroviral therapy (ART). ART was introduced in the mid-1990s, it is a lifelong treatment and the medicine should be taken every day. Before the introduction of ART the progression from HIV to AIDS could take only a few years. Today, a person diagnosed with HIV that gets treatment before the condition has progressed to an advanced stage, can live almost as long as a person who is not infected with the virus (HIV 2017). HIV Treatment leads to a decreased number of people developing AIDS, and an increased number of people staying well (Avert 2017a).

The impact of HIV globally

According to World Health Organization HIV is an infection that is one of the biggest health issues globally today. HIV has claimed more than 35 million lives so far, and in 2016 approximately 1 million people died due to HIV-related causes. By the end of 2016 there were an estimated 36.7 million people living with HIV, and roughly 1.8 million new infections that same year. The most affected area is Sub-Saharan Africa. In 2016 there were 25.6 million people living with HIV in Sub-Saharan Africa only, and the region accounts for almost two thirds of all new infections today (WHO 2017). Worldwide efforts to strengthen treatment programs and HIV prevention are decreasing the numbers of the transmission of HIV and between 2001 and 2012 the global scale-up of PMTCT programs credited for a 52 percent decline in new infections among children worldwide (UNAIDS 2013). Nevertheless, the pace of the decrease is far from enough to reach the Fast-Track Target negotiated by the United Nations General Assembly in 2016: Less than 500,000 new infections by 2020 (UNAIDS 2017).

The impact of HIV in Tanzania

At the end of 2016 there were 1.4 million people living with HIV in Tanzania; That same year approximately 55,000 people were newly infected with the disease. By scaling-up the access to ART, Tanzania has made significant progress in minimising the HIV epidemic over the last decade. Between 2010 and 2015 the number of people dying from AIDS-related illnesses was reduced by 50 percent and the number of new infections lowered with 20 percent. Although the HIV prevalence has declined over the past few years, it is still a major problem in the country (Avert 2018a). The Tanzanian commission for AIDS (TACAIDS) has determined some challenges concerning the ART scale-up, such as limited finances for HIV-testing and ART, poor drug management, non-efficient chain management systems and drug stock-outs (The united republic of Tanzania 2014).

The severity of the epidemic varies around the country and is generalised to key affected populations, such as sex workers and people who inject drugs. The majority of HIV infections are spread through heterosexual sex, where especially the women are affected (Avert 2018a). Women are particularly affected and tend to get infected earlier than men, due to both cultural and biological factors. For instance, biologically, the virus is more easily transmitted to a woman from a man than from a women to a man. Furthermore,
women tend to get married at an earlier age and having older partners, and older men are more likely to be infected with HIV than younger men (MoHSW 2012).

It is also known that women experience a difficulty in negotiating safe sex because of gender inequality between them and their partner. This leads to women being at a greater risk of getting infected, which then leads to a greater risk of HIV transmission to children during pregnancy, labour and breastfeeding (Avert 2018a).

**MTCT/PMTCT**

There are various ways for a child to get infected by HIV if the mother has contracted the virus. The transmission can occur during pregnancy, labour or breastfeeding. This is called Mother-to-child transmission of HIV (MTCT). These methods of transmission are the most common ways that children become infected with HIV today and without treatment the majority of infected children die within the first two years of their life (UNICEF u. å.). According to WHO, the percentage of transmission has a likelihood to range between 15-45 percent when any type of prevention intervention is inaccessible (WHO u. â.b). The risk of transmission can be reduced to as low as 2 percent or less with the help of ART and other strategies, called prevention of mother-to-child-transmission (PMTCT) (AIDSinfo 2017). Due to the implementation of PMTCT services, approximately 1.6 million children have been prevented from contracting HIV since 1995. Despite this improvement, in 2015 there were still 23 percent women living with HIV globally who did not have access to antiretroviral drugs (ARV) (Avert 2018b).

In the developed world the perinatal HIV transmission has been largely eliminated, where alternatives to safe breastfeeding exist and universal access to ARVs. Unfortunately, radical reductions like this have not been seen in Sub-Saharan Africa yet. There are three difficulties that stand out, amongst others, that contribute to higher rates of MTCT in this setting: Identification of HIV in pregnant women as early as possible, suitable initiation of effective antenatal prevention, and sufficient prevention throughout the breastfeeding period (Bositis, Gashongore & Patel 2010).

Successful PMTCT programs stand in need of mothers and their infants having access to a series of interventions: HIV testing and antenatal services during pregnancy, the chance for HIV infected pregnant women to use ART, appropriate recommendations on infant feeding and safe delivery practices as well as postnatal healthcare services and an uptake on HIV testing infants (Avert 2018b).

Due to the fact that MTCT can be prevented through ART, on May 2009 UNICEF, WHO, UNAIDS, and the United Nations Population Fund (UNFPA) launched a worldwide campaign for virtual elimination as one of their superior priorities (UNAIDS 2009). The strategy of eliminating new HIV infections amongst infants depends on reaching high rates of starting ART treatment for pregnant women living with HIV and to support and maintain them to comply to the treatment (Rollins et al. 2014).

In 2007 UNICEF and WHO set up guidelines to expand PMTCT, focusing on settings where resources are low aiming for global access for women, young children and infants. The ambition is to eliminate HIV and AIDS completely among children. The
comprehensive approach towards the PMTCT programs includes the four following components: (1) To prevent new HIV infections among women of childbearing age; (2) To prevent unintended pregnancies among HIV-positive women; (3) To prevent HIV transmission from HIV-positive women to their babies; and (4) To provide care, support and appropriate treatment to HIV-positive mothers and their families and children (WHO 2010; WHO & UNICEF 2012).

MTCT/PMTCT in Tanzania
The government in Tanzania has set a goal to reach 95 percent of the pregnant women with lifelong treatment and reduce maternal and child mortality by 90 percent by 2018 (Avert 2018b). However, the rates of MTCT still remains high in the country. Furthermore, there is still HIV-related stigma and discrimination ongoing in Tanzania, which is one of the main reasons for poor adherence to the prevention programs (MoHSW 2012). Avert (2018b) writes about how shortfall of medication, education and access to PMTCT clinics during pregnancy could be possible factors to why the MTCT rate still remains high in the country.

Gender inequality
Gender is a word that is used to describe the socially constructed view of men and women and their status in relation to each other (WHO u.â.a). Gender is mostly known as a base where privilege, power and status are granted, which creates inequalities between men and women. It is a common agreement that gender inequality is a major reason behind the HIV epidemic in eastern Africa, due to the women's inability to decide the outcome and circumstances of relationships and sexual encounters (Gupta, Ogden & Warner 2011). Due to gender inequality, the ability for women living with HIV continuing and accessing HIV treatment and PMTCT services are often impeded (Chinkonde, Sundby & Martinson 2009). In various settings the traditional gender roles empower the men to make decisions regarding the women's involvement in the PMTCT programs, such as whether or not the woman should take the HIV test, adhere to the ARVs or return for follow-up appointments (WHO 2009).

In 2016 the United Nations declared 17 Sustainable Development Goals (SDGs) as a part of the 2030 Agenda for Sustainable Development and applies to all countries universally (United Nations u.â.). Women and girls suffer from violence and discrimination all around the world today and Sustainable development goal 5 focuses on achieving gender equality and to empower girls and women. Gender equality is not only a human right, but is an important foundation for a sustainable, peaceful and successful world (United Nations u.â.).

Counseling
Nurses have an important role in counseling their patients. Providing good counseling means to rehabilitate the patient spiritually, physically and psychologically, and to help the patient regain his or hers previous social and personal roles in the best achievable way (Kotrotsiou et. al. 2008).
HIV testing and counseling is a crucial part of HIV/AIDS care and should be available to every woman of childbearing age including their partners. In the PMTCT programs, the mother should be able to make a personal decision whether or not to test for HIV in order to be aware of her status. The health care worker has a supporting role towards the patient and the patient’s decision-making. The health care worker is supposed to listen to the patient and help them to understand the choices they need to make. They also play an important role in helping the patients to explore different options and circumstances and to avoid any misconceptions. It is also of importance to help the patient develop the self-confidence that is needed to carry out the decisions (MoHSW 2012).

If the women are HIV negative, counseling gives the women an opportunity to receive information and encourage her to remain HIV negative in the future. If the women are HIV positive, the counseling can be valuable in many ways. If the women are pregnant, counseling gives an opportunity for timely and appropriate interventions to decrease not only MTCT but also to receive information about how to prevent the spread of the virus to others. The counseling also focuses on the woman disclosing her HIV status to her partner and to encourage her partner to test. If the tests are discordant, a risk reduction plan will be facilitated by the health care worker. Furthermore, follow-ups and ongoing health care along with ART and providence of support and care for the mother, her partner and the family is of importance. In the PMTCT programs counseling and HIV testing can occur in all following stages: Before and during pregnancy, during delivery and labour, postpartum care and follow-up for the child (MoHSW 2012).

**Stigma**

Stigma is defined as “a strong feeling of disapproval that most people in a society have about something, especially when this is unfair” (Cambridge Dictionary u.å.).

The main reason behind people choosing not to get HIV tested is stigma, violence within the relationship and the fear of knowing one’s HIV status that causes mental distress. HIV-related stigma involves several negative consequences, such as social and physical isolation and being a subject for rumors, name-calling and gossip. This can cause feelings of guilt, despair and self-blame related to the stigma. It can also lead to severe discrimination, where HIV positive people are refused basic human rights such as education, employment and housing (MoHSW 2012).

Furthermore, HIV-related stigma from one’s family, the community, health workers and even self-stigma are significant barriers in the PMTCT programs. At the period of HIV testing, there are many cases where women delay their enrollment in the program, expressing a need to deliberate with the husband first, and then, due to the prospect of the HIV related stigma, not returning to the health facility (Turan & Nyblade 2013). According to the Ministry of Health and Social Welfare (2012) the health care worker has a responsibility to respect and follow procedures and policies at the healthcare facilities to protect the patient from discrimination and stigma.
Nursing

The nurses’ role covers four fundamental principles: Prevention of illness, to promote health, to reduce suffering and to recover health (Svensk sjuksköterskeförening 2014).

Providing women living with HIV, support and care along with HIV treatment is crucial. This enables the woman to approach her health needs and supports the wellbeing of her child and family (MoHSW 2012). Dahlberg and Segesten (2010, pp. 126-128) describe the importance of understanding the patients’ lifeworld. The lifeworld can be explained as the world as each person perceives it. Meeting the patients’ lifeworld gives the nurse an opportunity to reach the patients’ health, illness, well-being or sufferings.

According to the ethical code of International Council of Nurses’ (ICN) the nurse has a responsibility to present professional qualities such as respect, responsiveness, compassion and integrity (Svensk sjuksköterskeförening 2014). In the caring meeting, it is important that the nurse uses these professional qualities to interact with the patient in a respectful and dignified way (Wiklund 2003, pp. 156-161).

RESEARCH PROBLEM

MTCT is a nationwide problem in Tanzania today and it’s the most common way children get infected with HIV. PMTCT are prevention programs developed where the aim is to eliminate these kinds of transmissions. The government in Tanzania has high ambitions to effectively eliminate MTCT. However, there is still a major problem in the country for various reasons, such as, stigma, lack of medication, education and access to healthcare.

Nurses play an important role in the prevention programs, and therefore this study focuses on gaining first-hand experience from the nurses with the ambition to gain valuable insight into key areas of PMTCT of HIV and an increased understanding of what benefits and/or difficulties there might be.

AIM

The aim of the study is to investigate local nurses’ experiences of working with PMTCT of HIV in the Rufiji area in Tanzania.

METHOD

Design

The data in the study have been collected through qualitative individual interviews with six nurses working at Mchukwi mission hospital. The interviews used a semi-structured guide with open questions, with the intention to fully understand each nurse’s own experience. According to Olsson & Sörensen (2011, p. 106) the fundamental goal by using a qualitative design is to explore descriptive data, such as a person’s own words. When using a qualitative design the persons lifeworld, the world as each individual perceive, has a chance to come forward (Olsson & Sörensen 2011, p.134). Therefore, this method was chosen as it is the best way to achieve the aim.
Participants

There were six nurses working at Mchukwi mission hospital who participated in the study, four women and two men, and the age ranged from 24 to 50 years. Two of the nurses had a certificate in nursing (two years of nursing studies) and four of them were registered nurses with a diploma (three years of nursing studies). Their work experience at the hospital ranged from one year to 29 years.

Data collection

To participate in the study the respondents had to have a Tanzanian nursing education, and have insight and work experience in the matter of PMTCT. The nurses were given the chance to read through the questions in advance of their interview, giving them the opportunity to ask questions of their own and raise any queries. Prior to the interviews all nurses were given information in English orally and were handed an information letter explaining the aim of the study, that all data gathered were handled confidentially, that the participation was voluntary and that they could end their involvement at any time. It was of great importance that this information was given comprehensively and all participants were asked to sign a consent form (Appendix 2). The participants were also given the opportunity to decide the location of the interviews to make them feel relaxed and to prevent any disruption throughout the meeting. Five of the interviews were held in a private setting outside of the hospital area and one of the interviews were held at the hospital. The interviews were conducted in English. All of the interviewees spoke good enough English to understand and respond to the questions and therefore the decision to not use an interpreter was made. The interviews were recorded using a Dictaphone.

The interviews were structured using a pre-prepared interview guide (Appendix 1). First, we performed a test interview, making sure the interview guide was useful and that the data collected was matching the aim. Dalen (2015, p. 35) illustrates the importance of using an interview guide while conducting semi-structured interviews and explains that the guide helps to cover key areas that the study wishes to explore. The questions were carefully selected to respond to the aim of the study, and the main questions were designed to make sure the nurses were able to talk about their knowledge and speak openly about their experience on PMTCT. With the intention of allowing the nurses to talk about their experiences more deeply, follow-up questions were constructed. All interviews were recorded and transcribed afterwards. To ensure there was regularity in the interviews the interviewers took turns in leading the interviews, whilst the other one took notes writing down main points throughout the interviews.

Data analysis

The method used to analyse the data collected was content analysis described by Lundman and Hällgren Graneheim (2012). According to Olsson and Sörensen (2011, p. 210) content analysis is a method used to help structure and analyse empirical data collected from interviews, and is the most suitable method for the study in terms of summarizing data and finding related themes or patterns.
To avoid any potential misunderstandings, and to make sure that no important information was left out, the transcriptions were read through several times. In doing so, the interviewers were able to analyse the content in great detail. Then the interviewers started the process of trying to identify meaning units, first separately and then through discussion, to make sure the units responded to the aim. To cut down the quantity of text the interviewers then condensed the meaning units, which were then abstracted and given a descriptive code. All codes were divided in to nine sub-categories and three categories. Throughout the process there were continuous reflection and discussions held, in order to make sure that each and every unit didn’t lose their core. In table one an example is shown.

Table 1: Table of analysis

<table>
<thead>
<tr>
<th>Unit of meaning</th>
<th>Condensed unit</th>
<th>Code</th>
<th>Sub-category</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevention of child means we must screen the pregnant woman. Screening is HIV-test. So, if we find the woman to be infected, we can prevent the child from getting infected. We must counsel the mother to take the HIV-test.</td>
<td>We must counsel the mother to take the HIV-test.</td>
<td>Counsel to take the HIV-test.</td>
<td>Voluntary HIV-test</td>
<td>Motivating the mothers</td>
</tr>
<tr>
<td>Every pregnant mother should come with her partner. They should bring the partner in order to test them as well, to find out if the partner is positive or negative. But not all pregnant women bring their husband.</td>
<td>They should bring the partner in order to test them as well, to find out if the partner is positive or negative.</td>
<td>They should bring the partner.</td>
<td>Involving the partner</td>
<td></td>
</tr>
<tr>
<td>No mixed feeding and other feedings. It’s not good, it’s dangerous for the baby, it can get diarrhea and infections, which is not good. So, we counsel them to do exclusive breastfeeding.</td>
<td>No mixed feeding and other feedings. We counsel them to do exclusive breastfeeding.</td>
<td>Counsel them to do exclusive breastfeeding.</td>
<td>Exclusive breastfeeding</td>
<td></td>
</tr>
</tbody>
</table>

Ethical considerations

The Declaration of Helsinki describes ethical principles concerning medical research with the involvement of human subjects. The declaration illustrates that it is the researchers’
responsibility to protect the participants integrity, to give information to the participants about the right to self-determination, their right to end their involvement at any time and that the personal data is handled confidentially. Medical research with the involvement of human subjects can only be carried out if the advantages of the study outweighs the burdens and risks to the people participating in the study, therefore the researcher needs to consider this before and during the research. Participation in the research must be voluntary, and the participants must be given information about the study and sign a written consent. All participants should be given the opportunity to see the results of the completed study (Världsläkarförbundet 2013).

The participants in this study received oral and written information in English about the purpose of the study, that participation was voluntary and that they could end their participation whenever they wanted throughout the study. The participants were informed that the interviews would be recorded, that the data would be treated confidentiality and be de-identified and that once the study is completed the conclusions and findings will be shared with both the nurses and the hospital. With these actions taken, and with the assurance that the risks of the study didn’t outweigh the importance of it, the study was completed.

RESULT

The nurses’ experiences of working with PMTCT covers three key areas. First, they work actively with motivating the mothers in several significant areas to gain a beneficial outcome in the prevention program. Second, the nurses described the importance of counseling the mothers and their partners. Third, the nurses experienced stigma as something they all had to be aware of and meet in their everyday work life. In the following table the categories and sub-categories found is shown.

Table 2: Categories and sub-categories

<table>
<thead>
<tr>
<th>Category</th>
<th>Sub-category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motivating the mothers</td>
<td>Voluntary HIV-test</td>
</tr>
<tr>
<td></td>
<td>Involving the partner</td>
</tr>
<tr>
<td></td>
<td>Exclusive breastfeeding</td>
</tr>
<tr>
<td>Counseling</td>
<td>Giving information on HIV-infection</td>
</tr>
<tr>
<td></td>
<td>Acceptance of HIV-infection</td>
</tr>
<tr>
<td></td>
<td>Strategies in counseling</td>
</tr>
<tr>
<td></td>
<td>Education</td>
</tr>
<tr>
<td>Stigma</td>
<td>Stigma from the community</td>
</tr>
<tr>
<td></td>
<td>Stigma from relatives</td>
</tr>
</tbody>
</table>

**Motivating the mothers**

This category shows that nurses play an important role in motivating and informing the mothers in various fundamental areas within the PMTCT program. This covers areas such
as, motivating the mothers to undergo a voluntary HIV-test and counseling, partner involvement and exclusive breastfeeding.

**Voluntary HIV-test**

The nurses found it important to get the mothers to understand the importance of counseling and taking an HIV-test. The HIV-test is voluntary, but the nurse has a responsibility to motivate the mothers to take the test. That is done by informing the mothers about the effectiveness of PMTCT and the advantages of taking the test. They provide information on how HIV can be transferred to their infants and explain that they can protect their babies by taking the HIV-test. Mothers who decide not to get HIV-tested are offered more counseling.

“In counseling it is important to talk about the advantages to the mother and the baby. When the mother understands the product of PMTCT, and when they understand the importance, the mother more easily follows instruction. She doesn't want her baby to be infected.”

(Interview no. 2)

The nurses found it important to make sure that the mothers understand the information, to be persistent but also give the mothers space if that is what is needed. If need be, they allow the mother to come back at a later date when they might be more receptive. This gives the mother time to reflect and digest the information given and hopefully it will cause her to come back and make good decisions. The nurses explained that when they experience difficulty in getting through to the mother, they would ask a follow nurse to meet with the patient in order to try and motivate the mothers to take the HIV-test.

**Involving the partner**

The nurses play an important role in motivating the mothers to disclose her HIV status and bring their partner for counseling and the voluntary HIV-test. It is important to determine the partners HIV-status in order to prevent potential transmission of HIV. There are occasions when the mother is found HIV-negative, that they automatically assume that the husband also is negative and therefore won’t bring their partner. The majority of the nurses experienced a great difficulty when giving different results to the mother and her partner, causing friction. The nurses spoke about the importance of preparing both parts on this outcome before testing.

“That is a big problem to the couples, ‘where have you got the HIV? I don’t have it? How do you get it?’ The mother say, ‘I don’t know’ But the husband gets angry. It is very challenging when you get cases like that. If someone is positive and someone is negative.” (Interview no. 2)

Mothers who bring their partner to the clinic, go first in line for testing and counseling, and mothers who come without their partner will receive assistance afterwards, this as a motivation for partner involvement. Bringing the partner for counseling is important since this comforts the mother to have an open dialogue with her partner about information
given at the hospital. This also gives the nurses the opportunity to counsel and provide important information directly to the partner.

“Men think, ‘It is the woman that is pregnant, why should we go to the clinic?’ But when the men are coming here, we are giving education about the importance of the program. About taking the HIV test for example, then they agree and they come.” (Interview no. 2)

“No, sometimes. We advise them, we counsel it is very important to come with your partner. Because there is some information that is very essential which is required to understand with your partner. So, it is better to come with your partner. And then they are responding.” (Interview no. 6)

Exclusive breastfeeding
The HIV-positive mothers are motivated and encouraged by the nurses to exclusively breastfeed their baby for six months. The nurses inform the mothers that mixed feeding should be avoided during this time, since this increases the risk of MTCT and for the babies to catch diarrhea and other infections. Mixed feeding means that the baby receives other food and water, as well as breast milk during their first six months. Both the mother and baby are given ARVs, and the baby is given the medication for the first six weeks to lower the risk of MTCT. The nurses emphasize the significance to the mothers of HIV-testing their babies after six weeks. If the child is HIV-positive the mother is encouraged to breastfeed the baby up to 24 months. The nurses found it important to motivate and remind the mothers on how to look after her and the baby and to continue exclusive breastfeeding.

“We advise them to continue with the exclusive breastfeeding so that we can prevent mother transmission for this baby. Feeding the baby with formula is difficult, the cost. They have no money, so this a problem. This is why we say exclusive breastfeeding.” (Interview no. 5)

Counseling
This category shows that the counseling is very significant in the PMTCT program. According to the nurses the key areas in good counseling is to show responsiveness, give comfort and being supportive.

Giving information on HIV-infection
The interviews showed the importance of comprehensive counseling, to take time and sit down with the mother in order to prepare and get her mind ready to receive the result of the HIV-test.

“And if anything happens, be ready to receive your result, negative or positive. There is a lot of things you are talk with her. So, there are
many things to talk with her in order to keep her mind to be ready for anything that will occur after testing.” (Interview no. 5)

Acceptance of HIV-infection

The nurses play a significant role in supporting the mother when she is found HIV-positive. Receiving this information is life changing and devastating for the mothers. Therefore, the nurse plays an important role in comforting and supporting the mothers to try and find acceptance in their condition. The nurses experienced that by talking to the mother about how to live a life with HIV, how to keep her baby safe and that being HIV-positive is not the end of life helped the mothers to facilitate acceptance.

“First we counsel the mother to keep in her mind that being HIV-positive is not the end of life. And it doesn’t mean that she have a HIV positive child. Keep counseling.” (Interview no. 1)

Strategies in counseling

The nurses expressed the importance of individual counseling. Individual counseling allows the nurse to meet each and every mother’s individual needs, and helps the nurse to provide the support that is needed. The nurses brought up the importance of listening to the mother and being able to pick up on different feelings and reactions she might have. By asking the mother how she’s feeling after the counseling, an opportunity to talk about her feelings is given. The nurses spoke about in-depth counseling, and that providing this created better adherence to the PMTCT program. However, there was a shared experience between the nurses that shortage of staff was a big challenge, which led to sometimes unsatisfying and shallow counseling.

“Challenges are shortage, we are few that are doing many things. Sometimes the counseling we give is not enough. You only go shallow. Then you test the mother without asking many things, when you counsel you must go deep.” (Interview no. 2)

A very beneficial strategy that the nurses talked about was group counseling, also called psychosocial groups. Group counseling gives the nurses the opportunity to provide further education to the mothers on different relevant topics. The interviews showed that the nurses also experienced a great value in these sessions, regarding mothers being able to share experiences, encouraging each other and realizing there are other mothers in the same situation. However not all mothers attended these sessions, due to what the nurses experienced was related to stigma and mothers not wanting to share their condition with other people.

“It is good, because it makes the mother know this problem is not only for me. Also it is good because they can share experiences. They have a fear of die, and sometimes they can encourage each other. Someone who used ARVs for maybe two or five years, and then someone for six months, they go, ‘ah, they used ARVs for long time, and are fine’.” (Interview no. 3)
Education

The nurses all spoke about the significance of providing education to the mother. All mothers should receive education about the importance of practicing safe sex. Nurses emphasize to HIV-negative mothers on how to stay HIV-negative and about retesting. HIV-positive mothers are educated in safe sex since there is a risk for the mother of being reinfected, which increases the risk of transmitting HIV to their baby. The mothers receive education in the significance of adhering to treatment and ARVs and the importance of delivering at the hospital, where they can provide good care. The interviews showed the importance of making an effort when educating in these areas in order to prevent the transmission of HIV.

“I think it’s the lack of knowledge and education. It is important to explain the importance of adherence to the care. If we educate them, and when they understand the importance, they continue it.” (Interview no. 1)

The nurses experienced that lack of education regarding HIV and the PMTCT program led to poor adherence from the mother's partner. There were shared opinions that the partners have thoughts of the clinic being for women and not for men. The nurses had mutual thoughts on that lack of education and knowledge in the community regarding HIV, MTCT and PMTCT is a problem. Interviews showed that people in the community had the belief that a woman diagnosed with HIV is either a prostitute or is believed to have several sexual partners. The nurses also spoke about people in the community having believes that HIV can be transmitted through only touching someone with HIV. Lack of education in the community is holding back the progress in the PMTCT program, and in order to get a better outcome the nurses expressed that more education on HIV in the society is required.

“I think if we give education to the community the segregation and discrimination is finishing. I think education is key.” (Interview no. 3)

Stigma

Stigma was mentioned in all interviews as an ongoing problem. The nurses expressed that stigma is something they have to acknowledge and deal with on a daily basis.

Stigma from the community

All nurses mentioned that stigmatisation and discrimination from the community occurs. The fear of being discriminated by the community results in some of the mothers going to a clinic in a different village further away. This enables them to receive care in the nearby health facilities. This fear also generates difficulties for mothers disclosing their HIV-status. It is important that the nurse supports and encourages the mothers to come to the nearby clinic and receive treatment. Most mothers don’t have the money for transport to other clinics, which leads to poor adherence to treatment.
“Others go to another clinic, in the health facilities nearby they are afraid for the neighbors to see “oh someone is using that medicine in that clinic.” (Interview no. 5)

**Stigma from relatives**

The nurses shared experiences that stigma from the family and within the relationship is common. The fear of divorce and being left alone results in difficulties for the mothers disclosing their HIV-status to their partner. It is important that the nurses encourages the mothers to disclose their HIV-status. Not disclosing their status and not being able to be open in their relationship might lead to the mothers not adhering to treatment.

“We counsel her to disclose her condition. If she will be quiet about her HIV-status, it results in lack of support from the family.” (Interview no. 1)

**DISCUSSION**

**Method discussion**

This study did not only lead to greater knowledge regarding the nurses’ experiences of working with the PMTCT program, but it also generated a deeper insight in empirical qualitative research with the use of a semi-structured interview guide. It has been a learning experience throughout the whole process.

Reflecting over the research made, we have come to the conclusion that there were things that could have affected the outcome of this study, such as gender roles and cultural differences. The majority of the participating nurses were female, and even though the interviews were anonymous, the question was raised if adequate data was collected or if some was left out due to gender roles and cultural differences. We found that men have more power than women and therefore believe that there is a possibility that the women we interviewed did not fully speak their mind. Another consideration we made was the language barrier. Although we found that the participants spoke good enough English to answer the questions, it might had been easier for the participants to express their feelings in their native language. One more thing we reflected over was our own pre-understanding. In qualitative research it can be difficult not to be affected by one’s own understanding, and one of our concerns was for this to influence the outcome of the study. However, by having a reflective attitude and carrying continuous discussions concerning these aspects the best possible result has been ensured.

**Data collection**

The data was collected through six individual interviews, the number of participants was realistic and achievable while at the same time provided enough adequate data to analyse. When conducting the interviews, we took turns in leading the interviews while the other one took notes. To minimise the risk of data loss the interviews were recorded with two separate devices and the transcriptions were made the same day as the interviews.
To collect the data we carried out a semi-structured interview guide. A test interview was made to make sure the interview guide was useful. We evaluated the data and some minor changes were made to the guide. Despite the changes made we were not fully satisfied with the answers. We found it difficult to get the interviewees to talk about their experiences of their work and found that they rather talked about how they work. Therefore, we made some ulterior changes in the question guide and we also reflected and discussed on how we were asking the questions with the intention to find the best possible way to reach the nurses thoughts and experiences. After these changes, we were satisfied with the interview guide and experienced less difficulty in getting answers matching the aim.

The participants English were good enough to answer our questions and the aim of the study, therefore we decided that there was no need for an interpreter. Since it was a small community, we also discussed the fact that there was a risk of not reaching the interviewees own experiences using an interpreter due to their potential relationship. There was also a risk of the interpreter not speaking good enough English which could then lead to a risk of data loss due to misunderstandings through the language barrier.

The use of a translator can affect the data collection, due to differences in interpretation and communicating through an additional person. This can create difficulties for the interviewer to get close to the participants and their own feelings and experiences. There is also a risk of verbal misunderstandings while using an interpreter (Dalen 2015, pp. 38-39). In retrospect, we can’t say if the use of an interpreter would have changed the outcome of the result, but with the study being completed and us being satisfied with the outcome, we feel like we carried out the right decision regarding the decision not to use an interpreter.

Analysis

Performing this study with the chosen analysing method has been an educational and a challenging process. During this process, we have had to constantly evaluate and amend the work we commenced before becoming satisfied with the result. We have gone back to subtract and add information in the units of meaning to get best result possible, there were also some units that were taken out completely when we found that they did not answer to the aim of the study. This was a time-consuming process and required careful and constant consideration before we were satisfied. This was also a necessary process due to the risk of loss of important and essential information. After finishing this analysing process, we felt satisfied with the result and with the method chosen.

Result discussion

The aim of this study was to explore nurses’ experiences of working with PMTCT. The result showed three key areas that responded to the aim. The first area concerns the importance of nurses motivating the mothers in several significant areas to prevent MTCT of HIV. The second area explains that the nurses experience providing counseling to the mothers and their partners being fundamental. The third area shows that the nurses experiences stigma as something being constantly present within their work.
One of the key findings was the importance of counseling. Nurses play an important role when counseling in various areas within the PMTCT program. They emphasized the significance of giving comfort and support to the mothers. The nurses spoke about individual and in-depth counseling and the importance of listening in order to provide support and to meet every mother’s individual needs. We did not predict that there were going to be such efforts put into counseling and we expected a more authoritarian care. This was due to our pre-understanding and believes that the nurses would not have either the time or knowledge it required. The nurses confirmed our anticipation regarding lack of time and staff, but it was still a priority in the care. We believe that this is a very essential priority, since it is important to help the mothers understand the significance of adhering to treatment but also to provide comfort throughout this process. By providing comfort and support we believe that mothers might feel more comfortable and confident which can create better adherence to treatment. Wiklund (2003, pp. 155-157) describes the importance of a caring meeting and caring relationship between the patient and the nurse. By giving the patient attention and support the patient is given the opportunity to express his or her needs, problems, and desires. Dahlberg and Segesten (2010 p. 193) explains that the patient can lose the feeling of comfort if the nurse is stressed or is perceived as unwelcoming and uncommitted.

Another finding was the significance of partner involvement. The nurses all mentioned it but did not speak frequently about it. However, we found this area highly important. We found that the nurses play an important role in emphasizing the importance of involving the partner to the mothers. Partner involvement can make it easier for the mother to disclose her HIV-status and get support. This is important, since mothers not disclosing their HIV-status are having an increased risk of not adhering to the program, due to the fear of their partner finding out. Partner involvement also gives the nurses a chance to motivate the partner to undergo the voluntary HIV-test and to provide them with further education and counseling. We believe these are crucial elements in order to prevent the transmission of HIV during pregnancy, breastfeeding, delivery and labour. However, the nurses found that there were many times that the partners were not involved. Dahlberg and Segesten (2010, pp. 119, 121) mention the value of involving a patients relatives. The support from relatives can help the patient to maintain or recover health and experience well-being.

We believe that the mothers experiences difficulties in involving their partner due to stigmatisation and gender inequality. It is the husband that makes the decisions in the family, and the mothers are afraid of divorce and rejection by disclosing their HIV-status. Kalembo, Zgambo, Mulaga, Yukai and Ahmed (2013) describes the importance of partner involvement, and that mothers involving their partner are more likely to complete and adhere to treatment, compared to mothers not involving their partners. The article shows that mothers involving their partner are also more likely to give birth to HIV-negative infants, in comparison to mothers not involving their partner. Kalembo, Yukai, Zgambo and Jun (2012) further shows that the countries that are doing better in the uptake of the PMTCT programs has already endorsed the partner involvement. However, the men are the decision makers and make the decisions affecting the family members health. Another recent study that substantiates previous findings is Naigino et. al. (2017) who has found that mothers disclosing their HIV-status increases the adherence in the PMTCT
programs. Furthermore, it was found that stigma was an extensive barrier not only to disclose the HIV-status but also to access PMTCT clinics.

The nurses can give the mothers important information about partner involvement and the importance of disclosing their HIV status, but critically, what good does it actually do if the mothers are afraid of sharing this information with their partner. We believe that providing more education about HIV and the transmission of HIV is the key when handling the ignorance from partners. We also believe that it is important that the nurses support the mothers throughout this process by being responsive and giving comfort. Dahlberg and Segesten (2010, p. 184) emphasizes the importance of the nurse using his/her professional skills as well as being comforting, open minded and caring in order to support and meet the individual's lifeworld.

The importance of education was another significant finding in the result, and that lack of education is holding back the progress in the PMTCT programs. The nurses can educate the mothers and partners, but they can not educate the community. We found that all nurses believed that more education to the community was necessary in order to get a better outcome in the programs. These findings compare well with our anticipations regarding this matter. Carrying out the research in a small community in a developing country, we knew they would not have the same prerequisite for education as people living in an industrialised country. Moghli, Al Habeesh and Shikha (2017) found that psychological barriers, education and knowledge has been mentioned less in recent studies, which can suggest that efforts made in counseling and education are beginning to have effect. However, we did not anticipate the level of knowledge being as low as some people believing that by touching someone they could contract the virus. In our opinion this clearly shows how important education is and that further efforts in this area are highly required.

Lack of education is what we believe one of the main sources to the third key area found, which is Stigma. The result revealed that stigma within the community and the relationship is a common occurrence and this creates a major drawback in the PMTCT programs. Stigma was one reason to why women decided not to go the nearest health facility. This correlates with Laher et. al. (2012) who has found that PMTCT decisions regarding treatment, testing and infant feeding are negatively affected due to mothers having a fear of community and family stigma. We believe that by the nurses being aware of stigma they can further support and encourage the mothers to adhere to treatment.

The national PMTCT program in Tanzania is acknowledging the importance of making efforts in reducing the stigma. Stating that it is of importance that healthcare workers are encouraged to work towards negative behaviour and attitudes, not only in their work but also in the community (MoHSW 2012).

CONCLUSIONS AND CLINICAL IMPLICATIONS

The result of this study states that nurses play an important role in the PMTCT programs. They have an important role in counseling in order to create better adherence to the programs. However, lack of time and staff is perceived as an obstacle. Partner involvement creates better adherence to treatment, yet the nurses experienced difficulties
in getting the mothers to bring their partner. Stigma is seen as a major barrier and is one reason for women not adhering to treatment. Lack of education concerning HIV is seen as a problem, and the nurses believed that more education regarding HIV to the community is vital. We believe that the government has a responsibility to provide further education perhaps through media and in early stages at school.

The nurses part in the PMTCT programs when educating and counseling can address problems that Tanzania is suffering from today such as, HIV-related stigma, maternal and child mortality, prevention of HIV transmission and the conservative view of women in the society. In aspects of a sustainable development we believe preventive care is essential, and by preventing the spread of HIV the costs for healthcare can be reduced. The ARVs are funded by the government and by reducing HIV the cost for the medication can be scaled down. People with HIV suffer a big risk of catching other infections which also increases pressure on healthcare. We believe that by preventing the transmission of HIV pressure on the hospitals can be reduced and staff and resources can be put into other areas where needed within healthcare.

We hope that the outcome of this study can be useful in finding difficulties and benefits in the current way of working with PMTCT. What we found especially important was that involving the partner created the best possible outcome for adherence to treatment. However, we believe the challenge lies in how to encourage the partners to be more positive to participate in the PMTCT programs. Therefore, we believe it is of great importance to further explore this area. We hope that this research will contribute and help the Mchukwi mission hospital to evaluate their work with PMTCT.
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APPENDIX 1

Interview guide

Questions for warming up
- Age and gender
- For how long have you been working as a nurse?
- For how long have you been working at the Mchukwi mission hospital?
- What kind of education do you have?

Main questions
- We have understood that Mother-to-child transmission of HIV is a problem in Tanzania today, and that prevention-of-Mother-To-Child-Transmission (PMTCT) of HIV are programmes set up to try and eliminate these kinds of transmissions. Do you want to tell us what you know about MTCT?
- How would you describe PMTCT at Mchukwi mission hospital?
- What is your experience, as a nurse, working with PMTCT?

Possible follow up questions
- What do you think are the benefits of PMTCT programmes?
- What do you think is the most difficult part of working with PMTCT?
- Out of your experience, what is the most effective way to work with PMTCT?
- What do you think are the obstacles in working with PMTCT?
- What are your thoughts on providing counseling/antiretroviral treatments/breastfeeding to HIV-positive mothers? Positive/negative

Corresponding words
- Why/why not…?
- How…?
- Can you describe…?
- Can you give an example…?
- Can you tell us more about…?

Final question
- Is there anything you wish to add?
Our names are Elisa Torstensson and Kajsa Davidsson. We are studying at the School of Health Sciences, at the university of Borås and are enrolled in the program of Bachelor of Science in Nursing. We are at the Mchukwi hospital to undertake a minor field study about “Nurses experiences of working with prevention of Mother-to-Child transmission (PMTCT) of HIV”. The Swedish International Development Cooperation Agency (SIDA) has granted us a scholarship which has enabled us to do this study.

The aim with our study is to gain valuable insight in nurses experiences of working with PMTCT of HIV at the Mchukwi hospital. If you decide to participate in this study, you will take part in an interview with questions regarding your experiences of working with PMTCT of HIV. The interviews will be conducted in English primary with the help of an interpreter if required. The interview will take about one hour and will be recorded and later analyzed.

Participation in this study is anonymous and all the information gathered will be handled confidentially. Taking part in this study is voluntary and participation can be ended at anytime throughout the study.

The study will later on be published and the hope is to increase our understanding in nurses experiences of working with PMTCT of HIV.

If you want to participate in this study, please sign below. If you have any questions or uncertainties, do not hesitate to contact us.

Thank you for taking your time!

University of Borås, Sweden
Elisa Torstensson
Kajsa Davidsson

Kajsa.Davidson_@hotmail.com

Name and place

Date