Assessment of Knowledge of Women about Prevention of Mother to Child Transmission of HIV in Gauteng, South Africa

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Abstract: While there are a number of health challenges that contribute to these deaths, it is argued that HIV related illnesses account for a large proportion and that the most common route of HIV infection for children under the age of 5 years is through Mother-To-Child Transmission (MTCT). This study was conducted in a level three (according to the South African levels of maternity care i.e. it is a referral hospital) academic hospital in South Africa**. Method:** This is a qualitative, explorative and descriptive study and contextual. **Aim:** The purpose of the study is to assess the knowledge of pregnant women on the prevention of mother to child transmission of HIV. Fourteen women consented to participate in the study; two were used in the pilot study. The remaining twelve women who consented to participate in the study were interviewed, until saturation was reached. After, ten women were interviewed. The age of the participants varied between 18 and 32 years, six had primary education, four had secondary education and eight were employed. **Results:** Four themes were identified, these are; mixed knowledge of mother-to-child transmission, knowledge of infant feeding, knowledge of Caesarean section and termination of pregnancy, and knowledge of adoption. **Discussions:** The participants expressed hunger for knowledge on how to live with the diagnosis and on how to continue with the prevention of mother-to-child transmission programme. Although, the participants reported that they were well counselled and that they were so overwhelmed by the diagnosis that they could not benefit from all the information they were given about the Prevention-of-Mother-To-Child-Transmission programme. The participants felt that they were given too much information on a short time, resulting in them being unable to internalise the results and information. The participants expressed a thirst for knowledge on how to live with the diagnosis and on how to continue with the PMTCT programme. Although, the participants reported that they were well counselled and that they were so overwhelmed by the diagnosis that they could not benefit from all the information they were given about the PMTCT Programme.

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1. Introduction

Human Immune Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) is a pandemic which has affected every part of the world. It is now the number one cause of death in Africa, and has moved up to fourth place among all causes of death worldwide. [1] With approximately 42 million people now living with HIV/AIDS, expanding access to worldwide anti-retroviral treatment for those who urgently need it is one of the most pressing challenges in international health.[2] The HIV/AIDS epidemic has resulted in more than 600,000 infants becoming infected each year, and in many countries HIV/AIDS has become the major cause of infant and young child mortality.[1] It was estimated that about 2.6 million children were living with HIV/AIDS in Sub-Saharan Africa at the end of 2001. [3]

While there are a number of health challenges that contribute to these deaths, it is argued that HIV related illnesses account for a large proportion and that the most common route of HIV infection for children under the age of 5 years is through Mother-To-Child Transmission (MTCT). MTCT of HIV can occur during pregnancy, labour, delivery, and breastfeeding, especially mixed methods of infant feeding. Well over 90% of new HIV infections among infants as well as young children may occur through MTCT. Without any interventions, between 20% and 45% of infants may become infected with HIV through MTCT, with an estimated risk of 5-10% of infections occurring during pregnancy, 10-20% during labour and delivery, and 5-20% through breastfeeding.

Preventing new HIV infections remains a significant public health challenge for South Africa. The high HIV-infection and mortality rates of under-five-year-olds due to mother-to-child transmission (MTCT) of HIV, together with the continuing need that pregnant HIV-positive women have for anti-retroviral drugs (ARD) and prevention-of-mother-to-child-transmission (PMTCT) interventions underscore the urgency for renewed efforts to offer quality PMTCT services in South Africa. Sub-Saharan Africa, with more than two-thirds of the world's total number

of HIV-infected people, remains the region most affected by the HIV/AIDS pandemic.

Problem statement

This study is prompted by lack of scientific information on knowledge of prevention of mother-to-child HIV transmission among HIV positive women in Gauteng province; South Africa. According to the researcher's knowledge; the knowledge of women as the major stakeholders in the process of implementing of PMTCT programme could not be found at the time when this research was initiated. The researcher identified this deficit and believes that it requires the attention of health care workers and, in particular, midwives.

Purpose

The purpose of the study is to assess the knowledge of pregnant women on the prevention of mother-to-child transmission of HIV and other reproductive and health related issues in Gauteng province, South Africa.

Objective

• To explore and describe the knowledge HIV positive pregnant women have about PMTCT and other alternatives.

2. Research design and methods

A qualitative study and data were collected between March 2007 and July 2008. This study was conducted in a level three (according to the South African levels of maternity care i.e. it is a referral hospital) academic hospital in South Africa. The hospital is situated in the large urban area in Gauteng Province. Participants were recruited from the antenatal clinic and the antenatal ward. The wards admit about 1000 women a month and the majority of these women attending this hospital have high-risk pregnancies and are referred from local clinics and private doctors due to complications in pregnancy (e.g. cardiac condition). In the antenatal clinic, there are eight midwives; three medical doctors and three trained lay HIV counsellors that work daily, where as in the antenatal ward, there are six midwives and four doctors. There is always a psychologist in the hospital in case there is a need to refer the women.

Two interviews were conducted as a pilot study, and adjustments were made including adding and removing some questions. These two interviews were not included in the final study because the preset questions were adjusted or changed. These interviews were useful because the women indicated how the questions can be improved for better understanding. Fourteen women consented to participate in the study; two were used in the pilot study. The remaining twelve women who consented to participate in the study were interviewed, until saturation was reached after ten women were interviewed. The age of the participants varied between 18 and 32 years, six had primary education, four had secondary education and eight were employed. Almost all of the participants had electricity and running water in their houses.

The following criteria were used to select participants; all women identified as HIV positive and were above 18 years of age between 09.00 and 12.00 hours on the study days were approached and verbally informed of the purpose of the study by the researcher. The women were asked if they were willing to participate, and written consent was signed. Most of them agreed to participate in the study because they wanted to know more about MTCT of HIV and options/components e.g. Caesarean section; that are available to them. In many cases they felt that they had not received adequate support and information from the antenatal ward and clinic.

Ethical considerations

Ethical approval from the Human Research Ethics Committee (HREC) of the local University was obtained. Writing permission was also obtained from the superintendent of the hospital where the study was conducted. The women were given written information regarding the study in order for them to have a chance to make their own decision whether to participate in the study or not (both verbal and written informed consent). The purpose of the study and the procedure of data collection were explained to the participants. The participants' names were replaced with pseudonyms to ensure confidentiality and anonymity, and the transcripts of the interviews were kept in a locked cabinet.

Data collection

Face-to-face semi structured interviews were conducted on ten HIV positive pregnant women and one broad question was asked: "Describe your knowledge on prevention of mother and child transmission of HIV/AIDS"? This was explored further, using an interview guide with semi structured questions such as; can HIV be transmitted from a mother to a baby? How is it transmitted? If a woman is HIV infected, is there any way to avoid HIV transmission from the mother to the baby? What can be done to avoid HIV transmission from mother to baby? What are the things that an HIV positive mother can do to reduce the risk of HIV transmission to her baby if she decides to breastfeed the baby? How did you come to know about PMTCT? Do you think an HIV positive woman should have a baby?

In the first section, socio-demographic characteristics were collected such as age, education, marital status, and the housing conditions. In the

second part, the same structured questions were based on knowledge about PMTCT and. other reproductive and health related issues. These interviews were taped and transcribed verbatim in the language preferred by the women, and the interviews were conducted by the researcher. The interviews were conducted in a quiet, comfortable and private venue with no distraction. The interviews lasted for 30-45 minutes. The participants gave both verbal and written consent to being interviewed. Permission was asked to use a tape recorder and participants gave their verbal consent to having the interviews recorded.

Trustworthiness

Validity in qualitative research refers to a continuous critical evaluation to describe different aspects of trustworthiness in qualitative research and to use the concepts of credibility, dependability (reliability), transferability and conformability.4 5 This was achieved as stated below.

Credibility

Credibility was achieved through prolonged engagement with these mothers in the clinic, by keeping reflexive field notes of sources added and most importantly, the type of information in the field journal is analogous to that found in a personal diary and reflects the researcher's thoughts, feelings, ideas, and hypotheses generated by contact with informants. After the interviews, the researcher summarised the relevant information and at the end, reflected it back to the participant. The participants were given a chance to clarify, add and withdraw anything. 6

Dependability

Dependability was achieved by providing a dense description of the research methodology and an audit trail. Data analysis was done according to Tesch's approach of descriptive analysis themes and sub-themes emerged. 5 An independent coder verified the findings of the analysis. Method of using a co-coder during data analysis was used to ensure dependability. 7 Peer checking was done by a colleague researcher, who played the devil's advocate and the supervisor from the Nursing department who has experience in qualitative research.

Transferability

This was achieved by extensive background description of the research methodology and verbatim quotes from the interviews. The sampling method was purposive, with no prior selection.

Conformability

In this study, this was attained by keeping of all the audio cassettes and field notes and supporting the findings with literature review.

Data Analysis

The co-coder was given unmarked copies of transcribed interviews for her analysis. Themes were identified from the verbatim transcriptions. Themes arose naturally from the data; they were fitted into the relevant categories.8 Thematic manifest content analysis was used to analyse the data. All useful material from the interview transcriptions was coded and put into a code list (open coding). The list of codes was then surveyed and grouped together under higher ordered headings to reduce the number of codes (collapsing). A new list from the 'collapsed' codes emerged.

The categories from the interviews were quite useful, and the headings were grouped into four categories as they emerged; knowledge about MTCT, infant feeding, Caesarean section and termination of pregnancy, and adoption. The new list of categories according to these interviews and subheadings was worked through again and a final list was produced. For validity of categorising, a master's student in the university used the same transcriptions, repeated the same coding process and she reached similar findings.

FINDINGS AND DISCUSSION

The results of the study showed that all pregnant women who were interviewed knew that there is prevention of mother-to-child transmission programmes, however, they lack detailed knowledge about MTCT, feeding of the baby, termination of pregnancy, and Caesarean section.

Mixed Knowledge of MTCT

Respondents who were not willing to take up PMTCT gave a reason that it is wastage of time since AIDS has no cure while the others were not sure that an HIV positive woman cannot have an HIV /AIDS free baby. However some respondents rose concerns 'why PMTCT should target the children only without considering the mother'. One of the respondents was quoted verbally as follows:

"My life is going on, you are not helping me but you are only concerned about my baby; who is going to look after the baby when I am dead? If you could also help me and prolong my life and I look after the child for some time then it would be better" (Participant 7).

One woman said: "*I do not have information on what is the meaning of mother to child transmission; I just know that I am pregnant and that I am HIV positive"* (Participant 6).

"We are told that the virus passes in the blood and my infant shares my blood. The contamination between me and my infant had already happened, so no hope of saving it. We have always been told that you can't cure AIDS, so the medication that I heard about is nothing but an illusion for me" (Participant 9).

Information also varied in quality and in quantity between and even within the different health centres. Information was mainly distributed in large classes, and rarely in one-to-one session. A lot of the information was found to be contradictory:

"We were told that it is good to know whether you are HIV positive or not; but some will tell you that knowing your status, because if you are HIV positive you are going to die early" (Participant 4).

Some mothers in this study were aware of HIV/AIDS, and the majority also demonstrated knowledge of mode of transmission and the course of the disease. This is commendable and may be attributed to many factors, including the level of education of the respondents. In spite of the levels of awareness and knowledge of HIV/AIDS reported in most parts of South Africa, the prevalence continues to rise among pregnant women, as shown by sentinel surveys. The main media of information on HIV/AIDS among mothers in this study were radio, television and public rallies. Radio programs and public campaigns have been quite successful in increasing the knowledge about HIV/AIDS in South Africa.

Poor-quality counselling often results in the transmission of incomplete knowledge, which can impede the effectiveness of PMTCT programmes. Research in South Africa found that while the communication skills of counsellors were good, the mother's knowledge remained low after counselling. Observations of counselling sessions found that inaccurate beliefs were corrected by counsellors in only 32% of the sessions.9

Knowledge of infant feeding

Most women knew that it is best to breastfeed but were unsure why, and only a few had been informed in the antenatal clinics about breast feeding, correct attachment and ways of avoiding breast infections. The definition of exclusive breast feeding (EBF) was not well understood among the mothers. Most women said that they would breast feed exclusively for six months, but many would also give water to their babies, this shows that, mothers were not well informed about infant feeding. This is supported by the following excerpts:

"I think for every human being, you cannot just live on milk, I think the baby will get thirsty. It will need water as well" (Participant 1).

"I thought that he would get the virus if I breastfeed him so I decided to bottle feed him." - Mother aged 19 years, infant aged 5 months, formula fed (Participant 3).

According to Chopra *et al*. 10; mothers who chose to formula feed cited protecting their child from HIV infection as the strongest influence on their infant-feeding decision. However, fears of HIV transmission through breast milk often resulted from information that over-estimated this risk. And in many instances, mothers face an internal struggle between prevention of infant HIV infection and the desire to breastfeed. Most mothers' knowledge about infant feeding remained poor at the end of the counselling session. Half of the mothers were planning to practice suboptimal methods of feeding, one-third were intending to discuss their infant feeding decision with somebody, and only eleven mothers were able to define EBF. However, two-thirds of the mothers correctly identified the dangers of mixed feeding for HIV transmission and other infections. In reply to the more open-ended questions, nearly all participants were positive about the counselling session.

Knowledge of Caesarean section

In the public hospitals in South Africa, HIV positive pregnant women can have an elective Caesarean section if their CD4 count is >200 cells/mol and they prefer it. However, it was identified that the only participants who knew about this option were those who found out about it through their own literature search. This is supported by Doull; 11 that a Cochrane systematic review found that Caesarean section deliveries are very effective in preventing MTCT. In many African settings, there is little choice in who provides care, *"What I read is that it is not necessary if you attended antenatal clinic and received the treatment"* (Participant 5).

In the study conducted by Suy et . 12, a key finding was that although nearly two-thirds of women still pregnant at 36 weeks were eligible for a vaginal delivery, a fifth of these declined this route of delivery, preferring to opt for an elective Caesarean Section and of the remainder, only 57% ultimately delivered vaginally. Regarding the 10 women who opted not to deliver vaginally despite fulfilling the criteria within the policy, it is possible that this was largely an historic phenomenon, although one must bear in mind the increasing trend for ''on request'' elective C/S in the general population in some European settings.

Knowledge on termination of pregnancy

Although in South Africa, termination of pregnancy has been legalised from 1996; HIV positive pregnant women do not know about this option. The

World Health Organization has said: ‘‘where termination of pregnancy is both legal and acceptable, the HIV-positive woman can be offered this option’’. However, many women learn of their HIV status during pregnancy, and will not be diagnosed in time to be offered termination. If termination is an option, the woman, or preferably the couple, should be provided with the information to make an informed decision without undue influence from health care workers and counsellors. *“I went to clinic for counselling and abortion. They said why not you sterilise because you will have an HIV-positive child and because of your condition. They said it is no use having another child. Your health will deteriorate* (Participant 7).

“If we do access the services we are treated poorly—no respect, healthcare workers are judgmental and often cruel….” One of the worst cases of abuse reported to the project team was of a woman living with HIV who said that she was given the foetus to take home after the procedure” (Participant 10).

There was no literature found to support knowledge of HIV pregnant women on knowledge of termination of pregnancy as an option.

Implications for clinical Practice

Midwives need to increase the knowledge of women attending antenatal clinic and provide the necessary information required for the strengthening of the PMTCT programme in the health facility. Women need empowerment regarding the availability of the programme as this would contribute to the uptake of voluntary counselling and testing in the antenatal clinics.

Implication for research

This research has shown that there is a need for more researches to assess the knowledge of pregnant HIV women so as to tailor sufficient information to empower theses women.

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