

## Study Protocol on HIV Positive Diagnosis During Pregnancy: Experiences and Coping Strategies Used by Women at Chilenje Level 1 Hospital, Lusaka, Zambia

Brenda Nambala Sianchapa<sup>1\*</sup> , Patricia Katowa-Mukwato<sup>2</sup> , Catherine Ngoma<sup>3</sup> 

<sup>1</sup>Department of Midwifery, Women's and Child Health, School of Nursing Sciences, University of Zambia, Lusaka, Zambia;

<sup>2</sup>Department of Basic and Clinical Nursing, School of Nursing Sciences, University of Zambia, Lusaka, Zambia, <sup>3</sup>Department of Midwifery and Women's, and Child Health, School of Nursing Sciences, University of Zambia, Lusaka, Zambia

\*Corresponding author: [brendamaabu@gmail.com](mailto:brendamaabu@gmail.com)

### Abstract

**To cite:** Sianchapa BN, Katowa-Mukwato P, Ngoma C., Study protocol on HIV positive diagnosis during pregnancy: Experiences and Coping strategies used by women at Chilenje level 1 Hospital, Lusaka, Zambia. JPRM 2021, 3(2):14-18. doi: 10.21617/jprm2021.324

**Background:** The HIV can be passed from an infected mother to her un-born child. Therefore, in an effort to eliminate mother-to-child transmission of the virus, pregnant women have to undergo HIV testing. A diagnosis of HIV during pregnancy is stressing to the woman because of its lack of cure, and it can add to the stress of pregnancy that she is already experiencing. We aim to determine the effects of an HIV positive diagnosis during pregnancy and the coping strategies used by women at Chilenje level 1 Hospital.

**Methodology:** We intend to use a concurrent mixed methods research design. The quantitative part will use longitudinal descriptive design, and the qualitative part will use interpretive phenomenological design. We intend to collect data from the same participants in three stages by using panel studies to yield better data for testing and understanding the effects of an HIV diagnosis during pregnancy and the coping strategies that women use. Sample size for the quantitative part (n=103) will be calculated using Cochran's formula while the qualitative part will have a sample size of 20, as guided by theories from Thomson et al 2011. Women will be assessed for stress levels using the Perceived Stress scale adapted from Cohen, 1983, and the coping strategies will be classified using the Coping Strategy Indicator adapted from Armikhan, 1990. In-depth interviews will be conducted to determine the experiences of women diagnosed HIV positive during pregnancy. Data will be analysed using Statistical Package for Social Sciences version 25.0, Chi-square will be used to test for associations between coping strategies and the independent variables (physiological health, psychosocial and spiritual support), and independent t-test will be used to test for association between stress levels and the independent variables. (Physiological health, psychosocial and spiritual support). Data will be merged at discussion

**Conclusion:** Findings from this study may be important in developing guidelines for caring for women diagnosed HIV positive during pregnancy in order that they and their babies can live healthy lives. This will be done by developing a tool that will be used to help them cope positively and reduce on stress and other problems that will come about due to the diagnosis of HIV.

**Keywords:** *HIV diagnosis, pregnancy, experiences, coping strategies*

## INTRODUCTION

A diagnosis of HIV usually causes stress in the affected individual due to its lack of cure [1, 2]. People who would like to know their HIV status usually undergo voluntary counselling and testing. However, in an effort to eliminate Mother-to-Child Transmission of HIV (eMTCT), pregnant women have to undergo HIV testing during antenatal care. Pregnancy is a stressful state as the body of the pregnant woman has to adjust throughout in order to maintain the pregnancy and prepare for labour and delivery; and the puerperium. As pregnant women undergo HIV testing, a diagnosis of HIV infection may be made during a routine antenatal care visit, when the woman may not have prepared adequately for the test and results. Receiving an HIV positive diagnosis can lead to stress [3] and other effects, and may add on to the stress that the woman is already experiencing due to pregnancy. An HIV diagnosis during pregnancy leads to high levels of psychological distress, including depression and anxiety [3]. When a mother diagnosed with HIV infection during pregnancy utilizes effective coping strategies, the outcome is usually good with decreased levels of internalized stigma and depression, and increased self-esteem [3].

With a diagnosis of HIV infection during pregnancy, the woman is faced with the constant fear of infecting her baby, and the dilemma of disclosing her diagnosis to the spouse or family members. Disclosure is cardinal for her social support, adhering to antiretroviral (ARVs) medication, and making a radical choice about infant feeding in an effort to eliminate mother to child transmission of the infection. However, disclosure sometimes leads to Intimate Partner Violence (IPV). The Zambia Demographic and Health survey reported that 85% of ever married women disclosed their diagnosis to their partner, and 10 % of ever married women aged 15 to 49 years have experienced physical violence during pregnancy from the husband in 63% of cases. [4, 5]. Some of this IPV could be resulting from disclosing an HIV positive diagnosis made during antenatal screening.

Mother-baby bonding, which sets the stage for the growing child to enter healthy relationships with other people throughout life and to appropriately experience and express a full range of emotions, can become unsuccessful due to the stress that the mother may be experiencing as a result of the HIV diagnosis [6,7]. Normally, a bond quickly occurs between mother and baby just hours after the birth of the baby. However, this

bonding process is disturbed when a mother is stressed, or incapacitated after delivery and does not feel like interacting with her newborn. Unsuccessful bonding leads to poor mental health in the mother and can have adverse and long-lasting effects on the child. It can lead to long-term mental health problems as well as to reduced overall potential and happiness in the child [8, 9].

Governments around the world have been working tirelessly to find solutions to the problem of HIV. However, even if there have been important medical advances in the treatment of HIV as well as the prevention of its spread, there are still emotional and social problems that can be as hard to deal with as the illness itself. For many people, it is a stigmatizing condition which makes the burden of illness more difficult to bear. Many studies have been conducted on HIV which have led to a lot of discoveries and successes in handling HIV infected individuals. As a result, new approaches have been introduced to manage HIV infections, and a number of studies have been made in antiretroviral medications which have improved the quality of life for HIV infected individuals. However, few studies have been conducted to determine the effects and coping strategies of women diagnosed during pregnancy. Further, in spite of having the 'test and treat' guidelines for management of the HIV infection, there are no guidelines for caring for women with an antenatal diagnosis of HIV infection and their families at Chilenje Level 1 hospital.

This study therefore will aim to identify the effects and classify the coping strategies among women diagnosed HIV positive during pregnancy, in order to develop guidelines for caring for them, including their families, in view of their stressful diagnosis in a stressful state (pregnancy).

### **General objective:**

To ascertain the effects of an HIV positive diagnosis made during pregnancy and how women cope at Chilenje level 1 Hospital in Lusaka, Zambia.

### **Specific objectives:**

The specific objectives of this study are to;

1. Measure the levels of stress in women diagnosed with HIV infection during pregnancy at Chilenje level 1 Hospital
2. To determine the experiences of women diagnosed HIV positive during pregnancy at Chilenje level 1 Hospital.
3. Classify the coping strategies used by women diagnosed HIV positive during pregnancy at Chilenje level 1 Hospital.

## METHODS AND MATERIALS

### Design and setting

The study will be mixed methods with the quantitative part using longitudinal descriptive, and the qualitative part using interpretive phenomenological design. It will be conducted on the same study participants in three stages. Stage 1 will be recruitment of study participants and measuring of their stress levels during their second antenatal revisit. Stage 2 will be conducted at 36 weeks' gestation to measure the stress levels and classify the coping strategies used. Stage 3 will be conducted at 6 weeks post-delivery to measure the stress levels, classify the coping strategies and conduct in-depth interviews to determine the experiences of women diagnosed HIV positive during pregnancy. The study will be conducted at Chilenje level 1 Hospital, an urban facility which offers In-patient and Out-patient services. It has a Maternal and Child Health Department that operates on a daily basis and offers antenatal, labour and delivery, postnatal, family planning and Child Health services. The antenatal clinic offers counselling and testing for HIV during pregnancy. The study will be conducted in a private and quiet venue which will be provided by the In-charge.

### Sample size:

The sample size has been calculated using the Cochran's 1977 formula

$$\text{Population size} = 1\ 500$$

$$n = Z^2 \times P(1-p),$$

$$N = 1.96 \times 1.96 \times 0.072 \times 0.928 / 0.05 \times 0.05 = 103 \text{ for stage 1 and 2 of the study.}$$

Sample size for stage 3 of the study will be 20 participants, arrived at based on the recommendation by Smythe of a sample size of 12 to 20 participants for a doctoral study [10] to ensure that each study participant will be honored by working intensively with their data.

### Sampling technique

Chilenje level 1 Hospital will be purposively selected, including the participants.

### Participants

All pregnant women who will be attending the clinic for antenatal revisits, and have been diagnosed HIV positive during their booking visit will be recruited in the study. Pregnant women who will be suffering from medical and other complications of pregnancy will be excluded from the study because they may be experiencing other effects related to their other complications of pregnancy.

### Procedures

All pregnant women diagnosed HIV

positive during pregnancy who will consent to take part in the study will have their levels of stress measured using the Perceived Stress Scale (PSS) by Cohen, 1983 and their coping strategies classified using the Coping Strategy Indicator (CSI) by Armikhan, 1990 during the second revisit and also at 36 weeks' gestation. The stress levels and coping strategies used will again be assessed at 6 weeks post-delivery, and in-depth interviews will be conducted to determine the experiences of women diagnosed HIV positive during pregnancy. The PSS is a 10-item scale ranging from 0-5, and the higher the scores, the higher the perceived stress. The CSI is a 32-item scale ranging from 1-3, and higher scores on problem solving and seeking social support, and lower scores on avoidance indicate more adjusted coping strategies. The interview schedule will have three sections; the first section will focus on the sociodemographic characteristics of the participants, the second on the effects and the third on the coping strategies used by women.

### Data analysis

#### Quantitative data

Data will be analyzed using the Statistical Package for Social Sciences (SPSS Version 25.0) for Windows. Chi-square test will be used to test for associations between coping strategies and the independent variables (physiological health, psychosocial and spiritual support) and independent t-test will be used to test for associations between stress levels and independent variables (physiological health, psychosocial and spiritual support)

#### Qualitative data

Data will be analyzed using Van Manen's (1997) 6 steps of analysis as follows;

1. Turning to the phenomenon of interest
2. Investigating experience as we live it
3. Reflecting on the essential themes which characterize the phenomenon
4. Describing the phenomenon (writing and re-writing)
5. Maintaining a strong and oriented relation to the phenomenon
6. Balancing the research context by considering the parts and the whole.

## DISCUSSION

The aim of the study is to ascertain the effects of an HIV positive diagnosis during pregnancy and the coping strategies that women at Chilenje level 1 hospital use. A diagnosis of HIV infection during pregnancy might add to the already stressful state that the pregnant woman has, because pregnancy is an emotionally fragile state as the woman is undergoing emotional and

physical adaptations to accommodate the pregnancy and prepare for childbirth and care of the newborn [3, 11, 12]. Coupled with a diagnosis of HIV infection during pregnancy, the woman may fail to cope positively as a diagnosis of HIV is stress inducing in any individual due to its lack of cure and the stigmatization that victims face [13, 14, 15]. A diagnosis of HIV during pregnancy may have a number of effects on the affected woman which can include increased stress levels, non-adherence to antiretroviral medication, Intimate Partner Violence and poor mother-baby bonding

In spite of availability of 'test and treat' guidelines for eMTCT, mental health factors could potentially undermine its effective delivery and affect the woman's quality of life and wellbeing. Pregnant women who are diagnosed positive during pregnancy might require deliberate effort to provide care that is appropriate for them. This study is timely as it will provide information on what women diagnosed HIV positive during pregnancy undergo, and the coping strategies that they use in order to develop guidelines for their care to enable them cope with their diagnosis.

There are some limitations in the proposed study. There may be a loss to follow up in this study due to the longitudinal nature of the study and it may span through a period of 6 -8 months. Participants may also be hesitant to provide information as HIV is a highly stigmatized condition, leading to an information bias in this study.

### Conclusion

There is dearth of data on effects of HIV diagnosis during pregnancy and coping strategies used by women at Chilenje level 1 hospital because the literature reviewed reveal inadequate studies done with a lack of consensus. There is need to assess the levels of stress due to an HIV positive diagnosis at different stages of a woman's pregnancy and puerperium, and the coping strategies that they use in order to develop care guidelines for the affected women.

### DECLARATION

**Contributors** BNS developed the idea and participated in literature review, CMN and PKM read through the documentary for accuracy.

**Funding** The study is partly funded by the University of Zambia, and the corresponding author will contribute towards the financial resources

**Acknowledgement** The authors would like to thank the Lusaka District Health Office and Chilenje level 1 Hospital management for providing anecdotal information on effects

and coping strategies used by women diagnosed HIV positive during pregnancy, my supervisors CMN and PPKM for their guidance and Professor Margaret Maimbolwa for providing mentorship.

**Competing interests** None declared.

**Patient consent** will be required.

**ethics approval** Ethical clearance will be obtained from the University of Zambia Biomedical and Research Ethics Committee. Permission to conduct the study will be sought from the National Health Research Authority. Participants will be informed that their participation is entirely voluntary and that they can withdraw from the study at any time without being victimised. They will be allowed to skip questions which they may not be willing to answer. Counselling services will be on hand for those who may break down during the data collection. They will be assured of anonymity and confidentiality of the information which they will provide and this will be upheld, especially because HIV is a stigmatized condition. No names or identifiers will be written on the data collection instruments. The findings will be disseminated through reports to the University of Zambia Medical library and Ministry of Health; and through seminars both locally and internationally. They will also be disseminated in the Midwifery journal.

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