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Being an HIV Positive Mother: Giving an Ear to HIV Positive Mothers at an Antenatal Clinic at Gwanda Provincial Hospital in Matabeleland South-Zimbabwe

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Abstract:

The HIV epidemic has posed a huge upset to the normal joys and elations of traditional motherhood. Life as an HIV positive mother is quite challenging, bearing the challenges of being both a patient and a caregiver. The study heard the lived experiences of HIV positive mothers. The study used the exploratory qualitative design and semi-structured interviews were used to collect data. Narratives were turned into thematic analysis to make sense of the findings. HIV diagnosis affects mothering in many forms such as fear of transmitting, dying, stigma and discrimination, and loss of intimate relationship. Participants also cited feelings of self-blame, regret, self-reproach, suicidal thoughts and low self-esteem. The research concludes that HIV positive mothers suffer from psychological factors as they battle with their positive status in their mothering process. The study recommends that HIV positive mothers should be empowered through counseling and education for them to understand life as HIV positive mothers.

Keywords: mothering, HIV positive mother, antenatal care, motherhood

1. Introduction and Background to the Study

The HIV/AIDS epidemic has a huge impact on traditional motherhood. Various social, psychological and emotional factors are associated with diagnosis. The field of health psychology has always been concerned with the way in which physical illness promotes psychological problems. The widespread of HIV/AIDS has posed vast challenges to the normal joys and elations of motherhood all over the world.

At the end of 2013 an estimated population of about 35 million people in the world were living with the HIV diagnosis while an estimated 19 million of that population were said not to know that they were living with the virus (UNAIDS report, 2014). According to the report, the highest number of people living with HIV was in sub-Saharan Africa a range of about 24.7 million precisely 23.5 to 26.1 million people. The UNAIDS Gap report shows that as people find out their HIV-positive status they resolve to seeking life-saving treatment. In sub-Saharan Africa, almost 90% of people who tested positive for HIV went on to access antiretroviral therapy (ART). Currently statistics suggest that close to half of the 35 million people living with HIV worldwide are women. As a result, growing numbers of children are living with an infected mother. Notably, an HIV diagnosis impacts not only mothers as individuals, but also affects how they care for their families (Schmidt & Goggin, 2002). HIV positive mothers must meet the demands of childbearing, care for their spouses and at the same time mediate the negative impact of their illness upon their family.

According to the Zimbabwe country report (2014), Zimbabwe has a total population of 13 million, with a population growth of 1.1%. She has a generalized heterosexually driven HIV epidemic with adult prevalence of 15% and an incidence of 0.98% (Zimbabwe country report, 2014). HIV prevalence in 15-24 age-group women is 1.5 times higher than in men. Motherhood is generally a demanding phenomenon. It is usually enveloped within a sector of challenges and frustrations associated with the child rearing process, dealing with the day to day demands of the family and also living up to societal expectations. On the other hand, the HIV diagnosis for any individual in general also brings with it a huge negativity and multiplicity of challenges such as psychological problems, social problems, and stigma and health problems. The study intended to explore the lived experiences of HIV positive mothers; difficulties and challenges associated with being both a patient and caregiver.

A look at the way in which mothering takes place among the black women in both Africa and beyond, makes it impossible to discuss motherhood as a separate entity from its context and culture (Daniels, 2004). Zimbabwe is largely a patriarchal society. Living in a society where men are in charge at home and the women simply have to oblige. A mother can simply be defined as a female person who gives birth to child, raises the child with maternal and tenderness. Motherhood generally defines the kinship relationship between an offspring and the mother. In motherhood, the woman in relation to a child or children she has given birth to bring up the children with love, care and affection. O'Barr, Pope and Wyer (1990) describe motherhood as a voyage that forever marks a woman's private

and cultural existence. Motherhood and mothering differ from family to family, from culture to culture, but these are socially constructed phenomenon meaning that most mothers behave in a way that is expected of them by the society (Wollet & Phoenix, 1991). According to Richardson (1993) the idealized view of the good mother is that of someone who willingly gives her time and energy to meet the child's needs for nurturance and stimulation. Intensive mothering means that the mother is largely responsible for the process of child rearing which are child-centered, expert guided, emotionally absorbing and financially demanding.

The characterization of HIV infection as a sexually transmitted disease, comprising concept such as indiscriminate "promiscuity", "pollution", and "uncleanliness" has worsen the situation of HIV positive mothers. Accordingly, women living with HIV have often been positioned as either a source or a potential source of infection and likened to prostitutes (Waldby, Kippax & Crawford, 1991; Batten, 1992; Goldin, 1994). Long (2006) describes an HIV positive mother as mother with a conflicting identity, viewed as the denigrated, hopeless and feared contrary to the idealized identity of motherhood with all its associations of purity and goodness. Both motherhood and HIV are created in a moment of intimate sexual contact, but both exist uneasily with sexuality. Motherhood, paradoxically, is associated with chastity rather with sexuality (Kristeva, 1983). Whether justified or not, HIV has, thus, become a metaphor for aberrant sexuality (Sontag, 1988). An HIV diagnosis when pregnant means entering into these two contradictory identities which, independently, encompass lots of psychological stress trying to cope with the diagnosis, fear of future illness or death, the stigma, fear for the children's lives if they are to die, fear of transmitting the virus to their children at birth or during the child rearing process.

Women with HIV are constructed as bad mothers for allowing themselves to fall pregnant and infect their innocent, unborn babies. Barolsky (2003) notes that women are often accused in cases of mother to child transmission. Eventually the focus shifted from the women to their unborn babies. Accordingly, the needs of the unborn baby were paramount and were placed ahead of the mother's. Much of the research on women living with HIV focuses on the issues of reproductive health, with the emphasis on either the foetus or the risk of mother to child transmission. Being an HIV positive woman and being pregnant with a child who may or may not also be affected is an extremely stressful process. Besides worrying about the future of the unborn child, the HIV positive woman also has to worry about her own health and also cope with the shock of the diagnosis, fear, guilty and anxiety (Steven & Gorey, 1997). Women with HIV often experience immense difficulty in telling others that they are infected and they may not disclose their status to anyone (Gebrekristos, Karim & Iree, 2003). Some due to fear of exposure are unable to take the ARV prophylaxis or to choose safe baby-feeding methods.

The discrimination which exists against women in various societies often means that attitudes towards those who become infected are often less accommodated as compared to the men in the similar situation. HIV positive women are often blamed for infecting their husbands and unborn child and are described in stigmatizing terms (UN/WHO, 2000). In Africa, various human rights violations have been reported as having perpetrated on HIV positive women. These include sexual abuse and coercion, discrimination in terms of access to health information, discrimination in property inheritance, rape and the government and society became preoccupied with mother-to-child-transmission, thus the focus shifted from the HIV positive women to their unborn babies. Much of the research on women living with HIV has focused on the issue of reproductive health, with much emphasis on the foetus (Human Rights Watch, 2003).

Many theorists in Psychology have shown significant interest in the way in which an HIV positive diagnosis may or may not compromise the ability to mother a child. Maternal role attainment is a psychological construct. Mercer (1995) maternal role attainment is the process in which a mother achieves competence in her role and also integrates mothering behavior into her customary role set so that she feels comfortable with her identity as a mother. The mother's sensitivity skill, empathetic response, and nurturing behavior that all promote the infant's health and development therefore becomes maternal role competence, (Mercer, 1995). Pakdeweng (2006) suggests that there are a number of factors that influence maternal role attainment. These factors include self-esteem, infant status and the environmental conditions such as social support and stigma. In the context of HIV infection, research suggests that women living with HIV work towards self-preservation on their own so as to protect their children from infection and stigma associated with HIV/AIDS. Past researches have shown that HIV positive mothers place value towards their children and their maternal roles despite the fact that HIV threatens their own health and psychosocial conditions, (Salayakhanon, 2007). Motherhood for HIV-positive women entails love, toil and trouble, (Brush, 1996).

Various mental health concerns are associated with the diagnosis of HIV/AIDS. The positive diagnosis can lead to psychological issues such as depression, loss of hope, grief, suicidal ideation, maternal ambivalence and anxiety among others. HIV positive women repeatedly feel isolated, experience shame, feelings of uneasiness, low self-esteem, and stigma to name but a few. HIV positive mothers are often challenged in their role as women, wives, mothers and caregivers, (Chung & Magraw, 2002). Roberston et al (2005) found that most women become suicidal soon after the diagnosis and these early thoughts clearly happen at a time when the individual feels severely threatened and is still in shock which in turn overwhelms the possible coping strategies. Aranda-Naranjo (2004) suggests that all these stressors represent potential threats to the individual's psychological wellbeing and quality of life. Past researchers have identified various factors that impact on disclosure to partners with barriers such as fear of accusations of infidelity, rejection, abandonment, and violence. Medley et al (2004) suggest that most women are scared of the economic loss; hence they might not disclose their HIV status to their husbands or families.

The HIV diagnosis may result in strained relationships for couples. Notably, HIV is viewed as a sexually transmitted disease and in cases where the risk of affection may have not be known, couples may face the psychological impact of the thought of one partner having infected the other. All this leads to high levels of blame games, regret and sense of guilt depending on the circumstances. The HIV diagnosis normally has a profound effect on one's social spheres. The social sector is a multifaceted concept with several

dimensions, inclusive of, emotional support, informational, and economic or instrumental support. Women living with HIV regularly turn to religion as a source of support and help in coping with difficulties (Doyal & Anderson, 2005). Individuals who report an increase in spirituality after the HIV diagnosis have also shown, after controlling for other factors to have significantly greater preservation of CD4 cells as well as a significantly better control of viral load, (Herson, Stuetzle & Fletcher, 2006).

2. Methodology

The research adopted the explorative qualitative research design because it was suitable for describing opinions, attitudes, feelings and perceptions of a well-defined group and population. Qualitative methods are helpful not only in giving rich explanations of complex phenomena (HIV positive mothers), but in creating or evolving theories or conceptual bases, and in proposing hypotheses to clarify the phenomena. Smith (2008) asserts that individuals are very active in their perceiving, they search, they pay attention selectively, they make choices, and their perception always has a meaning which relate to their life world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of meanings that people bring to themselves. Interviews were held in the offices provided for by the Hospital and participants were interviewed one by one so as to maintain confidentiality.

Purposive sampling was used to select participants. Purposive sampling relies on the judgment of the researcher, when it comes to selecting the units that are to be studied and the sample being investigated is quite small (10 participants). The sample size is determined by data saturation that is when the researcher is no longer getting any new information from the respondents. The main goal of purposive sampling is to focus on particular characteristics of a population (pregnant women) that are of interest, which will best enable you to answer your research questions. The target population was HIV positive pregnant women at an Antenatal Clinic in Matabeleland South Province, Zimbabwe. It is mandatory that pregnant women who are attending Hospital under antenatal care be test for HIV. There are lectures that are given to pregnant women by medical practitioners on a regular interval concerning pregnancy issues.

After going through all the ethical considerations through the Ministry of Health and Child Welfare, the researcher was cleared to carry out his research. The researcher was given the opportunity to address pregnant women who were attending their routine lectures. The details of the research were given to the pregnant women and the researcher asked those who met the criterion to volunteer. The researcher had pre-interviews one-on-one discussions with all the potential participants. In order to maintain the anonymity of the research participants, the participants were not identified by any reference.

Schostak (2006) views the in-depth semi-structured interview as a moment of listening for both the interviewer and the interviewee. Analysis was directed at determining the experiences of HIV positive mothers. Their reflections on the meanings of experiences and their survival with HIV were turned into themes. Hence, thematic analysis was used. The purpose of the in-depth semi-structured interview study is to understand the experience, not predict or control that experience. However, richly described data or sufficient contextual information can provide researchers with enough information to judge the fittingness of applying the findings to other settings. Validity, in qualitative research involves demonstrating that the interpretation (of data) is based on sound reasoning, systematically applied. Credibility infers that the research results are reasonable, possible and believable, not only to the researcher but to those researched.

3. Findings

3.1. Maternal Ambivalence

Maternal ambivalence emerged as one of the major themes in the lived experiences of HIV positive mothers. Maternal ambivalence occurs in all stages of mothering. It can simply be defined as the mixed feelings involved in having, caring for and shaping the necessary bonds with the child. On top of the usual frustrations and stress involved in raising a child, it became clear from the interviews that for most mothers, the diagnosis of HIV further heightens the challenges involved in mothering.

HIV positive motherhood is stationed within a conspiracy of inverse in terms of which the joy and excitement of being a mother is often overturned by an awareness of an uncertain and fearful future which somehow always seems inevitable. Mothers reported much conflict in caring for their children from the first minute they were diagnosed with HIV. The mothers noted that they were diagnosed with HIV when they were pregnant. One of the mothers said that, "When I found out that I was pregnant, I was so excited I thanked God for the blessing. Testing HIV positive felt like a blow in the face. All the excitement died out. I blamed God for giving me a baby and cursing me at the same time. I did not want the baby anymore. I just wished God could just take my life away." Evidently the HIV diagnosis brought with it mixed feelings towards mothering.

One mother narrated, "I get easily irritated when my baby keeps on coming to me asking me some silly questions such as 'mummy why is Sponge Bob yellow?' I know she is a child but at times I would be stressing with my own issues it becomes difficult for me to attend to her. I have my life to worry about yet she wants me to answer to such silly questions." Life is generally different from the initial thoughts of smiling at the baby, pleasure and amusement at each word he or she utters and helping him or her learns and understands the different aspects of life.

3.2. Conflict between Duty and the Self

After the HIV diagnosis, for most mothers a conflict between duty and the self could hardly be overlooked. Mothers further related that they had difficulties particularly in caring for their children with the necessary love and affection as expected from all mothers

under normal circumstances. One mother noted that, "With financial challenges it becomes even difficult for me to buy myself even the smallest things that I desire. When a few coins instead of buying me what I am craving say a banana, I end up buying my baby a sweet just to make her/him happy." This brings out the fact that the HIV diagnosis brings out a conflict between one's duty as a mother and one's own personal desires. A lot of emotions such as malice, anger, hatred or bitterness towards the child were expressed. One of the respondents noted that had it not been for the need for a child she would have remained HIV negative. She viewed her baby as a curse rather than a blessing from the gods hence it is difficult for her to love the baby whole heartedly. "All this time I had been having protected sex with my boyfriend and we thought trying for a baby my mother-in-law would love me. Maybe I should have walked away when I could, maybe I should have listened to the message God was sending through my mother-in-law. Now I am in this predicament and I feel that my baby is a curse from the gods."

3.3. The Psychological and Emotional Impact of having HIV

Mothers expressed various psychological challenges which they had to deal with as a result of the HIV diagnosis. Many of the mothers explained struggling with feelings of depression, regret, guilt, anxiety, suicidal thoughts, self-reproach and general failure to cope.

The mothers recalled a time in which they had felt depressed. Feelings of depression were noted mostly when they first discovered that they were HIV positive. It was also at this stage that some of the mothers even contemplated committing suicide. However, it is not clear whether these were appropriate feelings in the context of their lives at the time or whether they were true incidences of major depression. One mother indicated that her husband did not want to hear anything linked HIV testing instead he actually shouted at her and accused her of being unfaithful. "I was so sad. I didn't want to live anymore. I was giving up my life. I just couldn't see the reason for me to take the treatment and continue living. I did not care anymore about what was to happen to me and the baby. I would just have unprotected sex with him just to please him, but it was no longer enjoyable."

Further, some women narrated emotionally wrecking stories involving feelings of betrayal by their spouses. One woman said that the very day she found out about her status was the very day she discovered that her partner was on ART treatment. "Those days I cried rivers and I regretted ever sleeping with him before going for HIV testing. I just could not believe that the man I thought I knew could do something like that to me. I regretted ever trusting and believing that he would have been negative."

Some of the mothers also reported feelings of anxiety during pregnancy. Most reported that the whole PMTCT program was quite challenging, trying to adhere to all instructions in a bid to protect the baby, waiting for the very first test at birth and the subsequent tests every few months just to make sure. One of the mothers was quoted saying: "I would pray each day and at times force myself not to eat just to be closer to God and let him hear my prayers. Having my child test negative has been my happiest joy." Feelings of doubt and disbelief towards the child's HIV status after testing was also a problem as one woman was quoted: "When my baby was tested negative I just couldn't believe it. I was scared that maybe the nurses were just saying it to make me feel better. I would tremble each moment my baby would fall down at some sort of ailment."

Mothers noted that life becomes brighter when they look at their children grow up and look stronger each day. Some recorded that there are certain elements of relief joy and hope that at least their children will have a future after all. Mothers who had HIV positive children reported experiencing extreme feelings of guilt about the infection of their children. One of the mothers feared that one day her daughter would blame her for infecting her. She feared that her daughter might not be able to experience the normal youthful life expected of all ladies, have a boyfriend and eventually have a family. "You each day I watch her grow, playing and being joyful. I am scared she might not get her charming prince because of her status." She wished she had tested earlier and adhered to all the necessary PMTCT requirements.

3.4. Stigma and Discrimination

Stigma exists when elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them to happen. HIV/AIDS is a shunned disease believed to affected people with loose morals, hence it is highly stigmatized. HIV positive mothers lost friends, neighbors, and even family members who shunned them or treated them with suspicion. "My mother-in-law does not eat food that I cook for the family, no longer wants me to wash her clothes....." The loss of respect and acceptance on the part of friends and family was perceived as an extremely distressing experience. The isolation and loss of support had resulted in many mothers feeling extremely alone and hopeless. The participants had found it difficult to accept that those closest to them were often the ones who offered the least support and understanding.

3.5. The HIV Status as a Limiting Factor

The participants felt that being HIV positive was limiting in one way or the other. Different challenges were brought forward, namely, medication management and the need to constantly adhere. All this was described as quite stressful and frustrating. Stress associated with the response to treatment, concerns for future relationship, employment, sexuality and recovery from illnesses. All plans for the future should always involve the issue of being HIV positive, when you need children you should be reminded that you are HIV positive. When you are ill you should know that you are HIV positive and all of your endeavors HIV positivity should be incorporated in decision-making.

4. Discussion and Conclusions

4.1. *Impact of being an HIV Positive Mother to Parenting*

Most participants reported having a problem between the feelings of joy and sorrow emanating from fears of an uncertain future often overshadowing the normal zeal and excitement associated with motherhood. Brown (1996) described ambivalence in terms of identification with the child, forming of the maternal bond, and attaining a compromise between work and the family. Ill-health makes these frustrations more heightened and apparent for HIV positive mothers. Mothers cited experiencing ambivalent feelings towards motherhood and also noted difficulties in dealing with the usual struggles of raising young children citing HIV as an added burden in their lives. The findings demonstrate that conflict between duty and self for HIV positive mothers is a multidimensional phenomenon with distinct presentations and pathways associated with different social groups.

Ickovics and Rodin (1999) suggest that most of these mothers fall in the lowest socio-economic class and are faced with more barriers to health care and general survival tactics in a demanding world, failure to provide adequate meals and certain luxuries for their babies. Mothers were not sure of how to tell their children about their status and that the children would be able to keep the knowledge confidential. However, the burden of keeping the disclosure a secret may be stressful for the mother. Murphy et al (2001) observed that children know well in advance their parents' HIV status before they are told. Therefore, no matter how difficult it is at times telling the children who are old enough to understand the situation about their status helps HIV positive mothers cope well with the diagnosis as the children understand their mothers' predicament and try not to add on to the stressors.

HIV positive diagnosis brings with it a number of challenges for mothers. The mothers have to deal with the major challenge of being caregivers while at the time they are patients themselves. On top of the usual frustrations associated with raising children, other factors such as disclosing their positive status to their children at one point but suffer from the burden of keeping the disclosure from the child. Mothers are not certain about the future of their children, fear transmitting HIV virus to their unborn child.

4.2. *Life of being an HIV Positive Mother with Your Spouse*

Simbayi et al (2007) reported from their study that HIV positive women ill-treated and discriminated on by their husbands. Mothers blamed their husbands on their acquired status. Participants revealed a considerable amount of anger towards their husbands. The sadness of the possible future loss of intimate relationships that some women expressed in line with Kalichman et al (2000), who wrote about the benefits which intimate relationships offer to HIV positive women. It was suggested that intimate relationships provide a protective function at a psychological level by offering a defense against feelings of isolation and otherness. All these findings may indicate that a fairly chauvinistic attitude still exists in some men in society as they find it easy to abandon their wives after the diagnosis and move on with their lives with no calamitous consequences on their part, forming other social interactions with other women abandoning their spouses.

HIV positive diagnosis may pull a strain in intimate relationship or general relations among women and their spouses. Most of the participants revealed that they had a lot of cases involving constant fights, blaming of each other, regrets, self-reproach and many other negative attitude with their spouses. All these challenges enhance the psychological and emotional challenges for HIV positive women thus heightening the physical ill health.

4.3. *Life of being an HIV Positive Mother in the Society*

Findings revealed that the loss of respect and acceptance on the part of friends, family and societal members was extremely distressing to the HIV positive mothers. It was clear that HIV positive mothers felt that positive relations with societal members would help them feel a sense of ordinariness and also assist them to deal with the HIV diagnosis in a more effective manner. The sadness of the possible future loss of intimate relationships that some women expressed was disheartening to the HIV positive mothers. HIV positive status made women very uncomfortable, and this uncomfortable feeling usually occurred when they disclosed their HIV status to friends, family and societal members, and this led to their lowered self-esteem.

Most mothers reported stigma and discrimination. This had adverse repercussions not only to the individuals but also to their families. The mother's choice of a major pathway significantly impacts the type of challenge that the children experience. Children in the families in which the mother is very public about their statuses were more likely to experience stigma and discrimination than children whose HIV connection was unknown to the public. This is in line with the findings of Flannery and Borus (2006) which identified three pathways that organize the personal choices made by mothers living with HIV. The choices included the choice to tell no one, to tell some and not others, or tell everyone. According to Flannery and Borus (2006) the mother's choice of a major pathway significantly impacts the type of challenge that the children experience.

5. Recommendations

The study revealed and identified several psychological and emotional challenges confronting HIV positive mothers, therefore it recommends that more psychological services that go beyond the usual pre- and post-test counseling, be made available in the public health sector. It further recommends the implementation of educational programs that target both women and men focusing on the attitudinal change towards the perceptions of HIV/AIDS as a disease of people with loose morals

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