Original Research Article

Preventing mother-to-child transmission of HIV: The perception and experiences of HIV positive mothers in Benin City, Edo State, Nigeria

ABSTRACT

Introduction: Mother-to-child transmission of HIV remains a leading cause of morbidity and mortality among under-five children in Nigeria.

Aim: This study explored the perception and experience of HIV positive mothers who had accessed services for preventing mother-to-child transmission of HIV (PMTCT) in Benin City, Edo State, Nigeria.

Methodology: This was a qualitative study. HIV positive mothers accessing services for preventing mother-to-child transmission of HIV were recruited from seven health facilities across Benin City. Data collected through focus group discussions and in-depth interviews sessions.

Results: The mothers study were happy that antiretroviral medications were provided free of charge at the clinics. They commended the friendly attitude of most health workers and were particularly delighted that they could now breastfeed their babies following the availability of antiretroviral medications for mothers and babies. The mothers however complained about the discriminatory attitude of some health workers at the sites.

Conclusion: The mothers' were generally positive in their perceptions of the programme for preventing mother-to-child transmission of HIV. However, some mothers reported negative experiences during their interactions with health workers at some of the health facilities providing comprehensive services for preventing mother-to-child transmission of HIV.

Keywords: PMTCT, HIV, mothers, perception, experiences, Nigeria

1. INTRODUCTION

Mother-to-child transmission (MTCT) of HIV is the transmission of HIV from a pregnant woman infected with HIV to her infant during pregnancy, labour, delivery or through breastfeeding.[1] Risk factors for MTCT of HIV include high maternal HIV viral load, low CD4 count, advanced HIV disease, prolonged rupture of membranes, instrumental delivery and mixed feeding.[1,2] The rate of mother-to-child transmission of HIV is between 20% and 40% in the absence of interventions to prevent mother-to-child transmission of HIV.[1,2] However, this rate can be reduced to less than 2% with the use effective interventions such as antiretroviral prophylaxis for pregnant women infected with HIV, active management of labour and the use of elective caesarean section when indicated.[1,3] Prevention of mother-to-child transmission of HIV (PMTCT) is a term commonly used for programmes and interventions aimed at reducing the risk of mother-to-child transmission of HIV. The World Health Organisation (WHO) recommends the four-prong strategy for preventing mother-to-child transmission of HIV. This comprises: i) primary prevention of HIV infection in the women in the reproductive age-group and their partners; ii) prevention of unintended pregnancies among HIV positive women, iii) preventing transmission of HIV infection from HIV positive pregnant women to their children with the use of specific interventions; iv) treatment, care and support for HIV positive women, their children and their families.[4,5] Specific interventions for PMTCT include HIV counselling and testing, family planning, antiretroviral prophylaxis for HIV positive pregnant women and their babies, safer delivery practices among others.[4,5] The national PMTCT programme in Nigeria commenced in 2002 in eleven tertiary health facilities spread across the six geo-political zones of the country. [1] At present, the PMTCT programme is being implemented in over 684 sites across Nigeria. [6,7]

Nigeria remains a major contributor to the global burden of mother-to-child transmission of HIV with a total of 210,000 pregnant HIV positive women delivering and 380,000 children living with HIV in 2014.[8] The uptake of HIV testing among pregnant women in Nigeria remains less than satisfactory. The 2013 National Demographic and Health Survey reported that only 20% of pregnant women attending antenatal clinics in Nigeria were offered HIV counselling and testing services and received HIV test results.[9] Previous studies identified fear of a positive HIV test result and HIV-associated stigma as reasons for low uptake of HIV testing among pregnant women in Nigeria.[10,11] However, more recent studies identified low risk perception for HIV infection, fear of a positive HIV test result and the perception of being in good health as reasons for low uptake of HIV testing in the country.[12,13] In contrast, factors promoting uptake of HIV testing among pregnant women include knowledge of mother-to-child transmission of HIV and antenatal care provided by a trained provider. [13,14] In 2013, a national survey revealed that while 61% of pregnant women in Nigeria received antenatal care provided by a trained provider only 36% of pregnant women delivered at a health facility.[9] This observation may serious implications on efforts to reduce mother-to-child transmission of HIV in the country. In 2014, 29% of pregnant women living with HIV received antiretroviral drugs to prevent mother-to-child transmission of HIV while only 12% of children infected with HIV received antiretroviral therapy.[8] Similarly, the uptake for early infant diagnosis in Nigeria remains very low; in 2014 only 4% of HIV exposed infants in Nigeria received tests for early infant diagnosis of HIV.[8] These factors contribute to the high burden of mother-to-child transmission of HIV observed in the country.

Few studies in Nigeria have reported on the perception and experience of mothers receiving PMTCT services. Studies conducted in other countries reported discriminatory attitudes from health workers and unmet expectations from HIV positive women accessing PMTCT services. [15-17] Factors promoting participation in PMTCT programmes identified from previous studies include availability of friendly and supportive health workers, family support as well as spousal support.[15,16] Other factors that encourage participation in PMTCT programmes include provision of antiretroviral therapy and availability of free infant formula for children of mothers infected with HIV.[11] Similarly, barriers to accessing PMTCT services have been identified in the literature. These include disbelief of HIV test results, shame following the diagnosis of HIV infection and lack of funds to travel to the PMTCT programme site. [15,18,19] Other barriers identified include lack of spousal support and insufficient male involvement in the PMTCT programme.[15,19,20] The aim of this study was to explore patients' perception and their experience of the PMTCT programme in Benin City, Edo State, Nigeria as part of efforts to reduce the rate of mother-to-child transmission of HIV in the country.

2. METHODOLOGY:

This was a qualitative study conducted in Benin City, Edo State, Nigeria. Seven health facilities in Benin City provide comprehensive PMTCT services including HIV counselling and testing, antenatal care, delivery services, provision of antiretroviral medications for HIV positive mothers and early infant diagnosis (EID) of HIV.[21] In addition, some of these health facilities had support groups for HIV positive mothers (i.e.mother2mother support groups) and clinics for management of paediatric HIV/AIDS. The study population comprised HIV positive mothers accessing PMTCT services at health facilities that provided comprehensive PMTCT services in Benin City.

Inclusion criteria: Only HIV positive mothers who had participated in the PMTCT programme at the different health facilities were included in the study having had first-hand experience of programme at the sites.

Exclusion criteria: HIV positive mothers who declined to participate in the research were excluded from the study.

2.1 Procedure and participants:

The HIV positive mothers accessing PMTCT services were recruited from five health facilities in Benin City that provide comprehensive services for PMTCT of HIV and also had facilities for early infant diagnosis (EID) of HIV, support groups for HIV positive mothers (mother2mother support groups) or paediatric antiretroviral therapy clinics.

METHOD

A convenience sampling method was use to recruit the HIV positive mothers that participated in this study. The mothers were recruited from sites where HIV positive mothers normally gather to access care and support for themselves or for their children free from fear of discrimination and stigmatisation. These included support group meetings for HIV positive mothers, HIV early infant diagnosis clinics and paediatric antiretroviral therapy clinics. At these sites, the researcher approached the HIV positive mothers after obtaining permission from the health workers at the sites. The researcher explained the purpose of the study to the mothers. The mothers who agreed to participate in the study were then recruited into the study. The mothers were assured that not participating in the study would not affect their access to health services at the sites.

Focus group discussions and in-depth interview sessions were held with HIV positive mothers across five health facilities that provided comprehensive PMTCT services. At least one focus group discussion session was held at each of these sites. The focus group discussion and in-depth interview sessions were held in quiet rooms within the health facilities where the mothers could speak freely away from the health workers. Each focus group discussion session involved six to eight HIV positive mothers and lasted between sixty and ninety minutes. In-depth interview sessions were conducted at three PMTCT sites

where less than six HIV positive mothers were present at a time. Each in-depth interview session involved one to four HIV positive mothers and lasted between forty and sixty minutes. A focus group discussion guide was used to conduct the focus group discussion and the in-depth interview sessions. The questions in the focus group discussion guide were informed by the findings from similar studies conducted among HIV positive women. Attached is a copy of the focus group discussion guide.

Permission for audio recording of each session was obtained from the study participants prior to the commencement of each focus group discussion session and in-depth interview sessions. Similarly, ground rules were set before the commencement of each session. This included an agreement among the participants that there would be no side discussions during the sessions and that information divulged during the sessions would be kept confidential by each participant. Following agreement with these ground rules, the sessions started with the researcher introducing herself and stating the purpose of the research. Subsequently, each participant was encouraged to introduce herself to the members of the group stating her age, tribe and occupation. During each session, data was collected on the perception and experience of HIV positive mothers on the PMTCT programme at the sites. Recurrent themes on the perception and experience of HIV positive mothers about the PMTCT programmes were identified with the use of the focus group discussion guide. The focus group discussion and in-depth interview sessions were moderated by the researcher who had previous training and experience of moderating focus group discussion sessions. All participants were encouraged to participate fully in the discussion; no individual was allowed to dominate the sessions. At the conclusion of each focus group discussion and in-depth interview session, a summary of the key issues discussed during the sessions was presented to the study participants and any misunderstanding was clarified and resolved. Light refreshments were served at the end of each session and the study participants were thanked for their time.

The focus group discussion sessions and the in-depth interview sessions were conducted between July 2011 and October 2011. The recruitment of the HIV positive mothers for the study continued until the study reached saturation point i.e. the point at which no new themes or ideas were identified from subsequent focus group discussion sessions or in-depth interview sessions.

Data Analysis: The audio recordings of each focus group discussion and in-depth interview sessions were transcribed and analysed to identify recurrent themes on patients' perception and experience of the PMTCT programme at the sites. The same focus group discussion guide was used to conduct all the focus group discussion sessions and in-depth interview sessions. This made it fairly easy to identify the recurring themes from the transcripts of the different focus group discussion sessions and in-depth interview sessions. The transcripts of the audio recordings from the various sessions were read over repeatedly. Answers to the same questions in the focus group discussion guide were grouped together for analysis. The recurrent themes on patients' perception and experience of the PMTCT were identified in this manner were underlined and coded sequentially. Using inductive reasoning, the themes on patients' perception and experience of the PMTCT programme were identified. No software package was used in the analysis the transcript of the audio recordings.

3. RESULTS AND DISCUSSION

Nine focus group discussion sessions and five in-depth interview sessions were held across five health facilities. A total of fifty-five HIV positive mothers participated in the focus group discussion sessions during the course of the study while eighteen mothers participated in the in-depth interview sessions giving a total of 63 study participants.

3.1. Socio-demographic characteristics of study participants: The mean age of the mothers was 31.6 years (SD=4.6 years) with a range of 22.0 years to 44.0 years. Majority of the mothers were married (93.2%) with trading being the predominant occupation (69.5%).

3.2. Findings from the focus group discussion sessions and in-depth interview sessions: The themes that emerged from the focus group discussions (FGD) and in-depth interview (IDI) sessions held with the HIV positive mothers include:

1. Perception of HIV positive women on awareness of HIV/AIDS in the society:

The mothers unanimously agreed that discrimination and stigmatisation of persons living with HIV had reduced tremendously as a result the awareness that people living with HIV can live healthy lives and have children who are uninfected with the virus. The following excerpts from the focus group discussion (FGD) sessions and in-depth interview (IDI) sessions illustrate this point:

"Well, the way the people think about the illness now is not the way they were thinking about it before. That maybe when you know that somebody have it, the next thing you run away from that person. But in the society now, they now encourage people that even have it, that 'it is not the end of the world,' 'that there are other illnesses that HIV is better than'. That's why I believe that the awareness is increasing." (Participant 2, FGD 2)

2. **Perceptions of the PMTCT Programme**

a) Positive perception: The mothers were generally positive in their perceptions of the PMTCT programme. They unanimously agreed that the programme was beneficial to pregnant women, the family and the society as a whole. These excerpts from focus group discussions and the in-depth interviews highlight the mothers' perception about the benefits of the PMTCT programme.

i. Prevention of mother-to-child transmission of HIV: The HIV positive mothers were happy that the antiretroviral medications prevented their babies from becoming infected with HIV as the excerpts below illustrate:

"When you're taking these drugs, your baby will not be affected. You will be healthy; you will not be short of blood. There's no need to any medicine along side with it. Everything is inside it. There is no problem." (Participant 1, FGD 6)

ii. Availability of free antiretroviral medications:

The mothers were delighted that the antiretroviral medications and follow-up investigations were provided free of charge at the health facilities as these quotes illustrate:

"I am still thanking the people that are supplying these drugs for us, God will reward them. God will continue blessing them in abundance..." (Participant 1, FGD 7)

"I thank God, with these drugs they are giving us, we have hope, before o, no hope…" (Participant 4, FGD 7)

iii. Technical competence and supportive attitude of the healthcare providers:

The mothers were unanimous in their perception of the technical competence of their health care providers. They believed that their health care providers were well trained and had the technical competence to properly manage their illness. They also agreed that most of the health workers were friendly and supportive as the quotes below illustrate:

"They are perfect. The doctors and the nurses know their work very well. If they did not know their work, they won't know the actual drugs they will give us. So we are feeling fine." (Participant 1, FGD6)

"…I love all the nurses. They are encouraging us, both the doctor; how to take our drugs, how to feel free. They encourage us that we should not think about anything; that this thing would soon be over." (Participant 8, FGD 7)

b) Negative perception of the PMTCT programme: Although the mothers' perception of the PMTCT programme was largely positive, they also identified several limitations of the PMTCT programme. These include inadequate manpower, stock-outs of antiretroviral medications, laboratory reagents, etc. The lack of a permanent cure for HIV/AIDS was identified by the mothers as a major limitation of the PMTCT programme.

i. Stock-outs of Antiretroviral medications:

"Yes, for the pharmacy now, sometimes dem go say drugs no dey (not available)... and two make dem still try to bring the real drug out, the one wey go cure am… for myself, for the sake of the baby, for the sake of everybody." (Participant 4, FGD3)

ii. Lack of universal access to HIV Counselling and testing services:

Some mothers complained that HIV counselling and testing services were not available at all health facilities as illustrated by these quotes:

"In the village now, where my female friend gave birth, they did not do (HIV) test for her. They didn't ask her to do test on the first day she registered for antenatal (care)…" (Participant 6, FGD 2)

"Not all hospitals do tests for pregnant women even here in Benin." (Participant 2, FGD 2)

c) Perceived barriers to accessing PMTCT services: The mothers identified several factors that may constitute barriers to accessing the PMTCT programme. These include reluctance of HIV positive mothers to disclose their HIV status to their spouses and close relatives due to fear of rejection; long waiting time at health facilities and the discriminatory attitude of some health workers. The following excerpts from the focus group discussions and in-depth interviews illustrate some of these perceived barriers:

i. Reluctance to disclose HIV status to spouses and close relatives:

"When I hold my handset to call my husband, I will drop phone. I will say no, I will not tell him. Let me first keep quiet and monitor the environment… Up till today, as I'm talking to you, my Oga (husband) don't know anything concerning it…" (Participant 1, FGD 7)

"Up till today, my parents do not know. My mother said that if any of her child have HIV, that she will abandon that child. That child is not her child." *(Participant 5, FGD 2)*

ii. Discriminatory attitude of some health workers: Some mothers were concerned about the discriminatory attitude of some health workers at the sites as the quote below indicates:

"…Those people in the antenatal department, they don't even know if you're positive or negative… But there some nurses, they will use this kind eye if they know that the card is for someone that has this virus. They will use finger to pick the card like this but they do not know that there is nothing there." (Participant 1, FGD 6)

3. **Experiences of HIV positive women throughout the programme:** The mothers reported both positive and negative experiences while accessing PMTCT services at the health facilities. These experiences are illustrated below using excerpts from the focus group discussion sessions and in-depth interview sessions:

i. Experience on HIV testing & disclosure: Most of the mothers became aware of their HIV status through routine screening for HIV at the antenatal care clinics. Some of the mothers first received the diagnosis of HIV while in labour. A few mothers became aware of their HIV status after series of recurrent illness which prompted health workers to screen them for HIV. Some other mothers became aware of their illness following a diagnosis of HIV infection in their children or spouse which prompted health workers to screen the mothers for HIV.

> *"When I got pregnant, then I came here to register, then now tell me to go and do test. Then when I did the test, they now told me it is positive. I now went home to discuss with my husband. Then they sent me to call my husband. Then my husband came. He did the test, he was (HIV) negative…." (Participant 5, FGD 7)*

> *"That was in 2010 when I was pregnant. So, I was in labour, they rushed me down to this hospital. When they did the test, they found out that I was HIV positive." (Participant 3, FGD3)*

> *"It was my daughter that was sick. I now rushed her to this place. They now told me to do investigations. When I got the results they now told me this, this, this. I said how come, how about me that is carrying her… because as that time she was a baby. So I said okay, let me go for my own. I now went for my own. That's how I got to know." (Participant 4, FGD3)*

> *"My husband was very ill to the extent, people around us, were even suspecting. I have crossed my mind, if it's the sickness, we will carry it along…. Reaching there we did the test, even with my son. I have it, my husband has it but my son does not have." (Participant 7, FGD 7)*

The HIV positive mothers reported experiencing physical, social, emotional and psychological problems. The mothers reported a wide range of emotions following the initial diagnosis of HIV infection from anger, disbelief and denial of HIV test results to despair, suicidal ideation and depression. However, most mothers reported immediate psychological support provided by the health workers following the diagnosis of HIV. Some mothers reported breakdown of their families and being deserted by their husbands after being diagnosed with HIV. Others had difficulty disclosing their HIV status to their spouses or relations for fear of being stigmatised. The excerpts below illustrate patients' initial reaction to the diagnosis of HIV infection:

> *"When I found that I am HIV positive, I was thinking the whole world had gone. I had lost every hope for living. The doctors and the nurses, they calmed me down, they talked to us, and they made us to know that this thing is nothing. It's just like malaria." (Participant 5, FGD 6)*

> *"After the HIV test, I took a bike home while my husband returned to his work. I was now telling the bike man that it just looks as if the bike should have an accident so that I will just die and from there just go." (Participant 2, FGD 2)*

> *"I was afraid because I know that anybody that has the disease will surely die. Because of that, I was afraid." (Participant 3, FGD3)*

ii. Mood swings and psychological distress associated with diagnosis of HIV infection and attending routine clinic visits:

"Whenever I remember that I'm coming here, I do lean (lose weight) overnight, I do emaciate. I will feel that a week to my coming to this hospital, I will lean, I will think of it. As I'm talking to you, up till now, I haven't eaten. I will feel as if something move out from my body. But in all, when I'm about to go home or when I'm through with them, I will be feeling happy again and I will go home." (Participant 1, FGD 7)

"Though, I will not lie o, anytime that I'm coming to this place, in fact that day is not a happy day for me. I'm always moody, even people around me will be asking me 'what is wrong?' I will say I just had a bad dream, like that. Even since, anything around me, I'm always angry. Until this time, I now had my baby." (Participant 7, FGD 7)

iii. Challenges Experienced with Infant Feeding:

The mothers reported on their experiences with infant feeding. Many mothers complained of difficulties in sustaining replacement feeding due to the high cost of formula feeds. Others had to cope with pressure from their relations who urged them to practice mixed feeding (i.e. giving breast milk to babies who were on formula feeds). The excerpts below illustrate the experiences of the mothers with infant feeding:

a) Cost of buying infant formula: Several mothers complained about the high cost of buying infant formula feeds as the quotes below illustrate:

"Although it was not easy o, only God knows how many cartons of milk that I have bought." (Participant 1, FGD 7)

"This my baby now, ehn…, the food wey this my baby don eat, for that three months, I calculated it yesterday, almost forty something thousand (naira). E never reach three months." (Participant 4, IDI 2)

b) Coping with pressure from relatives to practice mixed feeding: Some of the mothers were under a lot of pressure to practice mixed feeding as they had not disclosed their HIV status to their close relatives. They thus had to proffer various reasons to justify their infant feeding options as the excerpts below illustrate:

"When I gave birth, I was sick. I was short of blood. We now use that as an excuse. If the brother or sister complains that 'can't you give your baby breast?'He (my husband) will tell them that 'don't you see that she is sick, that she cannot give baby breast? Is it someone that is sick that will breastfeed baby?" (Participant 2, FGD 2)

"My first child, my second child, this third one, I did not breastfeed. His family were asking, questioning us. He (my husband) now told them 'This is my child. I will tell my wife what to do. I don't know what you mean. Give my baby "baby food". I want the baby to look big.' The family now stayed away. Initially, they were like they want to know what is wrong. When he started talking to them, shunning them off, telling them to stop asking too many questions, they now stopped." (Participant 1, FGD 2)

"I thank God for everything, for person like me, that's exactly what would have happened if not my smartness and everything. I'm not using force to breastfeed my baby. I'm hiding and using the drugs. I'm applying my wisdom. Eight o'clock morning, eight o'clock night. I

will just drop the syringe (containing the nevirapine suspension) in her mouth." (Participant 2, IDI 2)

c) Concerns about the safety of breastfeeding:

The mothers expressed a strong desire to breastfeed their babies but were concerned about the risk of mother-to-child transmission of HIV through breastfeeding as the excerpts below indicate:

"So, I'm happy, if dem do the medicine so that we can breastfeed because I want to breastfeed. I'm not happy sometimes, if I look at this child without giving her breast, I don't I don't feel happy, I don't feel happy." (Participant 5, IDI 2)

"About this breastfeeding, I don't know, o. They will say 'don't breastfeed' that is my fear now. The first one, I no breastfeed; even this one, fear no let me breastfeed… I will like make my pikin suck my breast because that one na im be mother." (Participant 1, IDI 2)

iv. Experience of giving birth at the health facility:

The mothers reported mixed experiences of their interactions with health workers at the time of their delivery in the labour ward of the health facilities. The excerpts below illustrate some of these experiences:

"My children, this is the third one, they are all (HIV) negative… When I'm in labour, they will give me that pill that I will insert inside my private part. That's how I got the three of them. (Participant 1, FGD2)

In contrast, some other mothers made some very disturbing reports about their interactions with health workers at the time of they were giving birth to their babies at the health facility. These quotes illustrate the negative experiences of some the HIV positive mothers:

"I was shouting, crying, shouting, shouting, nobody answered me. That thing they're doing is not good o. It's not good at all…One lady told me about it, I thought she was lying until I experienced it myself." (Participant 4, FGD3)

Another mother agrees:

"Your own good, I pushed myself, the baby was on bed crying, even that placenta before they came and cut it." (Participant 3, FGD3)

v. Experiences with the use of antiretroviral drugs: The HIV positive mothers reported reduced morbidity and improved quality of lives with the use of antiretroviral medications as illustrated by the quotes below:

"Then secondly, with these drugs, when you're taking it, when your body system has already been already destroyed, it will restore everything. Everything will return to normal. In my own case, when I was rushed to the hospital when they noticed about this thing, so it was a wheel chair I used to walk there. But now, let me say eight months back that I know that this thing is in me, my body has changed. And for the past three years, I've not been able to get pregnant but now I'm carrying a baby." (Participant 1, FGD 6)

"…Today, sick, tomorrow sick, next tomorrow sick, nothing like that again." (Participant 2, IDI 6)

vi. **Successful pregnancy out comes, healthy babies:** The mothers were delighted to report that they successfully carried their pregnancies to term and gave birth to healthy babies while participating in the PMTCT programme. The excerpts below illustrate the success stories of the PMTCT programme:

"I thought that it's only me that will carry baby. I'm surprised that we're many. Not only me that has twins sef. We are almost two or three. One quality in it, God is blessing us with twins. Double blessings, to show you that 'madam don't cry, take this.' " (Participant 1, FGD7)

"Even my baby is very healthy. I thank God. We will do this test, the outcome will be fine." (Participant 7, FGD 7)

vii. Preventing mother-to-child transmission HIV: Most of the mothers who participated in the PMTCT programme reported that they delivered babies that were uninfected with HIV. Some of the excerpts below also illustrate the success stories of the PMTCT programme at the sites:

"I breastfed my baby for 6 months, after six months I stopped. Last month, I did my baby's test. It was negative." (Participant 5, FGD6)

"By the grace of God, there is nobody in our hospital that said when they take their drugs and they tested their baby, it (the HIV test) is positive. There is nothing like that, because by the time you take your drugs, regularly, your baby will not be infected by the virus." (Participant 1, FGD 6)

"My children, this is the third one, they are all (HIV) negative." (Participant 1, FGD2)

4. **Experience in the continuum of PMTCT services:** The mothers reported varied experiences following their interactions with staff at the pharmacy, the laboratory and the medical records departments. The mothers specifically complained about the delay in retrieving their case notes from the medical records department as well as the negative attitude of some of the staff therein. Some of the experiences were positive while others were negative as the excerpts below illustrate:

Experience in the medical records department:

"It's not easy like that, most especially coming to where you will drop your card here. For them to carry the thing go up (to the consulting room), they will just say you a word like if to say you are nobody…" (Participant 1, IDI 2)

Experience in the Pharmacy:
The mothers agreed that there were long queues at the pharmacy but that the staff there were friendly and polite.

"The experience (in the pharmacy), I will not say that it is bad. It is okay. It's just that they are trying…" (Participant 2, FGD 6)

"When I come to the pharmacy, if I come early, I will go early. If I don't come early, I will not go early. Sometimes, I spend two hours, three hours." (Participant 3, FGD3)

"…They attend to us well in the pharmacy…" (Participant 2, FGD3)

Experience in the laboratory: The mothers reported but positive and negative experiences following their interaction with the laboratory staff at the health facilities as illustrated in the excerpts below:

"When I went to the lab, I only went to the lab to do my CD4 count. But they attended to me well. There are many people there, children. But anytime I carry my baby there, they give respect, they pet her…" (Participant 4, FGD3)

"They attend to us very well in the lab…" (Participant 2, FGD3)

"I did my CD4 (count), they now said they misplaced it. They didn't put it inside my file. They looked for it, they didn't see it. Next coming Wednesday again, I will do it again so that I will know the normal number. I don't know the normal number." (Participant 2, FGD6)

Experience at the antenatal care clinic:

The mothers reported varied experiences while accessing antenatal care for PMTCT. Some of the mothers had to shuttle between hospitals as they booked for antenatal care at one hospital and obtained antiretroviral drugs from another hospital. Some other mothers had to register for antenatal care at more than one health facility in order to access antiretroviral drugs
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"They have too much population in the antenatal (clinic). It is too high. People will go there; three (p.m.), you will still be there, four (p.m.), you will still be there. To even attend to somebody is a war there. And there is discrimination there. If you have somebody there, they will attend to you first before other people you met there." (Participant 6, FGD 2)

"The population there is more than 300." *(Participant 2, FGD 2)*

In contrast, the mothers at another health facility were very pleased with the waiting time for antenatal care services as the quote below illustrates:

"The antenatal clinic here is very fast before 12 O'clock, everyone has gone." (Participant 2, FGD 2)

"They're trying. The nurse, she has been trying. Because even the first day they told me that I am positive, the way I feel. She is the one that encouraged me. I don't know how to tell my husband. She said that I should call him that she will discuss with him. She's the one that is encouraging us. There is no problem in the pharmacy, because I've collected drugs twice, there was no problem; no problem in the lab as well." (Participant 7, FGD 6)

5. **Lessons learned:** Having participated in the PMTCT programme, the mothers had learned that they could live healthy and productive lives with the use of antiretroviral therapy. The mothers were also confident that with proper adherence to antiretroviral therapy and regular attendance at the antenatal clinic, they could have healthy children that were uninfected with HIV. They also had several recommendations for other HIV positive mothers. These included encouraging adherence to antiretroviral therapy and involving close relatives in the care of persons living with HIV.

Importance of adhering to antiretroviral therapy and involvement of close relatives in the care of persons living with HIV:

"The only thing I will say, if you have the drugs as a woman, you don't suppose to use it to play because that is your life for now. To take it regularly, as instructed, you take it. You could even have somebody that is close to you, like your husband; somebody that will understand you. He is the next person that will say 'go and take your drugs, even if you forget. He will remind to 'go and take your drugs." (Participant 4, FGD 7)

"Mothers that know that they have the sickness; they should come and take their child to the hospital to do test, so that they will know. And so after the test, they should be attending clinic. And pregnant women should be attending clinic, not private o. Most of the private hospitals, they don't do the test. They should come to general hospital, central hospital or government hospital so that they will do the test and they will know." (Participant 4, FGD3)

Promotion of partner counseling and testing at the antenatal clinic:
"The only thing I will also say, if you're a woman, you have to drag your husband to this place (for HIV counseling and testing). It is very compulsory…." (Participant 4, FGD 7)

The mothers also had some recommendations for health workers, government agencies and the PMTCT programme sponsors. These include regular supply of antiretroviral medications, increased programme funding, training and re-training of health workers and the need to find a cure for HIV/AIDS. The excerpts below highlight some of the recommendations by the mothers to improve the PMTCT programme:

Desire for a cure for HIV/AIDS: The mothers in the programme desired that a permanent cure be found for HIV/AIDS as this would eliminate the requirement for daily intake of drugs. It would also provide a cure for children living with HIV/AIDS. They implored researchers and the Nigerian government to do more to find a drug that would completely cure the illness. The mothers were hopeful that the discovery of such a medication was near.

"We need the final drugs for this illness, the final solution." (Participant 3, FGD 7)

"Make dem still put effort to bring that rightful drug for cure because we cannot continue to be taking drugs, everyday, for life…" (Participant 3, FGD3)

Giving loans and stipends to HIV positive mothers to set up small business enterprises: This would empower the mothers and enable them to cater for their needs as the quote below illustrates:

"We women, we need money to start up a business. Like our sister that is a student, she has many things she needs money for. She cannot wait for only her husband. Since she's ready to work, we will still need to support her…. As she's a student now, she can be doing a trade, if she wants to pay school fees and other things, she can take from there. We need help." (Participant 5, FGD6)

DISCUSSION

This study examined the PMTCT programme in Benin City, Edo State from the perspective of HIV positive mothers accessing PMTCT services .The mothers highlighted the benefits of the PMTCT programme as well as the challenges inherent in accessing PMTCT services. Several factors promoted participation in the PMTCT programme in Benin City, Edo State. These included the availability of free antiretroviral drugs, free HIV counselling and testing services, supportive attitude of health workers and support groups for HIV positive mothers. Similar factors promoting participation in PMTCT programmes have been reported in the literature.[16,19,20] This study also identified several barriers to the PMTCT programme in Benin City, State. These include long waiting times at health facilities, delays in obtaining results of laboratory investigations. Others were the stigma associated with HIV infection, discriminatory attitude of health workers and the occasional stock-out of antiretroviral drugs. Similar barriers to participation in PMTCT programmes have been reported in several studies conducted in Nigeria and beyond. [17-20]

The discriminatory attitude of health workers reported by the mothers in this study remains a sore point in the PMTCT programme. This is because health workers are important stakeholders in the efforts to reduce mother-to-child transmission of HIV globally. The PMTCT programme brings health workers into close contact with patients living with HIV hence the negative attitudes from health workers potentially

could drive these patients from the health system thus negating the goal of the PMTCT programme. Similar findings have been reported in the literature.[15,17,18] The discriminatory attitude of some health workers may be borne out of a judgmental attitude towards persons living with HIV infection. It may also result from fear of becoming infected with HIV infection while providing care for persons living with HIV. Training and re-orientation of health workers is required to prevent discrimination and stigmatisation of persons living with HIV. In addition, the training of health workers on standard precautions and the use of personal protective equipment would help to reduce the spread of infections within the health care setting. The provision of antiretroviral prophylaxis for health workers exposed to blood and body fluids while providing care for patients living with HIV should form part of the infection control policy of every health facility. The implementation of these policies would greatly reduce the spread of infections within the health care setting and help to reduce the fear experienced by health workers while providing care for persons living with HIV.

Insufficient male involvement in the PMTCT programme makes it difficult for HIV positive mothers to adhere to antiretroviral therapy, routine clinic visits and adopt safer infant feeding options. Promotion of couple counselling or partner counselling at the antenatal care clinic would help to increase male involvement in the PMTCT programme and enhance the overall outcome for pregnant women living with HIV and their infants. The findings from previous studies are in line with these recommendations.[15,19,20] The fact that Nigeria remains a major contributor to the burden of preventing mother-to-child transmission globally requires that all hands must be on deck to address this problem. All concerned stakeholders comprising men and women in the reproductive age-group, people living with HIV, health workers, communities, government agencies and non-governmental organisation need to work closely together in order to achieve a global reduction in the rate of mother-to-child transmission of HIV.

Availability of services for care and support of persons living with HIV has increased tremendously over the years. This has resulted in an upsurge of patients accessing antiretroviral therapy at several health facilities across the country. However, the increased utilisation of these services has not been matched by expansion of the infrastructure or human capacity at such health facilities. This has resulted in long queues and lengthy waiting times for patients accessing these services. Long queues and lengthy waiting times may discourage mothers from accessing PMTCT services and thus hinder the goal of reducing mother-to-child transmission of HIV. Lengthy waiting times at health facilities for PMTCT services and laboratory investigations may discourage HIV positive mothers from returning to the health facilities on a regular basis for antiretroviral drugs, clinic visits, antenatal care and follow-up of infants born to HIV positive mothers. This may impact negatively on the efforts to reduce mother-to-child transmission of HIV in Benin City, Edo State. Similar findings have been reported in the literature.[15,17,20] Increased government funding of the PMTCT programme and the health system in general is required in order to expand the services and facilities for the care and support of persons living with HIV/AIDS following the increased utilisation of these services. In addition, the integration of the PMTCT programme into existing and maternal and child health programmes would help to ensure the sustainability of the PMTCT programme by providing essential manpower, funding and material resources.

Previous studies indicate that PMTCT programmes often adopt a biomedical medical model focusing mainly on the health status of HIV positive mothers and their children while neglecting other important aspects of life important to HIV positive mothers such as employment, access to finance and educational opportunities.[19,20] Financial empowerment of mothers living with HIV through the provision of stipends or soft loans to establish small businesses would help such mothers afford the cost of transportation to health facilities as well as the cost of feeding. Such financial aid would also promote access to health services for women and children such as antenatal care and immunisation services. Similar findings have been documented in the literature.[19,20]

Many mothers in this study experienced challenges with disclosing their HIV status to their spouses and close relatives. The mothers' non-disclosure of their HIV status to their spouses or close relatives deprived them of vital emotional and financial support from their closest relatives. It also made adherence to antiretroviral drugs, clinic visits and safe infant feeding options extremely difficult for these mothers due to fear of involuntary disclosure of their HIV status. Previous studies have documented similar findings.[15,19, 20]

Lastly, the mothers in this study desired a cure for HIV/AIDS. This is a challenge for health workers and researchers working in the field of HIV/AIDS to intensify efforts towards achieving a lasting cure for HIV/AIDS. In the meantime, all efforts should be made to ensure regular availability of antiretroviral treatment for all persons living with HIV in order to sustain the improved quality of life and reduce the morbidity and mortality due to HIV/AIDS.

Strengths of the study: This study provided a unique insight into the performance of the PMTCT programme in Benin City, Edo State from the perspective of HIV positive mothers who had first-hand experience of participating in the programme. It reflects the true perception and experience of HIV positive mothers who participated in the PMTCT programme in Benin City, Edo State. The study highlighted the strengths of the PMTCT programme in the state while identifying areas for further improvement. Such information is vital for strengthening the implementation of the PMTCT programme in Benin City, Edo State and Nigeria as a whole as part of the national efforts to prevent mother-to-child transmission of HIV.

Study limitation: This study was based on the perception and experiences of HIV positive mothers who had participated in the PMTCT programme in Benin City, Edo State. The findings from this study may not reflect the views and experiences of all HIV positive mothers participating in PMTCT programmes in different countries across the world. Further research is required to explore the perception and experience of HIV positive mothers participating in PMTCT programmes in different countries of the world.

CONCLUSION:

This study reported on the perception and experiences of HIV positive mothers accessing PMTCT services in Benin City, Edo State. The mothers generally had a positive perception of the PMTCT programme in Benin City. However, they identified several patient based factors and health system factors that constituted barriers to accessing PMTCT services in the state. Addressing the challenges is crucial to achieving the goal of reducing mother-to-child transmission of HIV in Benin City, Edo State and in Nigeria as a whole.

CONSENT

Informed consent was obtained from all the study participants. The mothers were informed that participation in the study was voluntary. They were assured of confidentiality and informed that their responses would only be used for the purpose of the research.

Consent Disclaimer:

As per international standard patient's written consent has been collected and preserved by the authors.

ETHICAL APPROVAL

Approval for the conduct of this study was obtained at various levels. These included the ethical committee of the University of Benin Teaching Hospital, the ethical clearance committee of the Edo State Ministry of Health in Benin City. In addition, institutional assent was obtained from the head of each health facility involved in the study. A summary of the research proposal was submitted to the head of each health facility for ethical consideration and to the ethical committees of the health facilities where applicable. The mothers who participated in the focus group discussions and the in-depth interview sessions received counselling on safer sex practices, infant feeding and treatment adherence. The researcher also conducted interactive health education sessions with HIV positive mothers attending support group meetings at the sites.

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