

# **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.<sup>[1]</sup> 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.<sup>[1,2]</sup> 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.<sup>[1,2]</sup> 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.<sup>[1,3]</sup> 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.<sup>[4,5]</sup> 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.<sup>4,5</sup> The national PMTCT programme in Nigeria commenced in 2002 in eleven tertiary health facilities spread across the six geo-political zones of the country.<sup>[1]</sup> At present, the PMTCT programme is being implemented in over 684 sites across Nigeria.<sup>[6,7]</sup>

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.<sup>[8]</sup> 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.<sup>[9]</sup> 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.<sup>[10,11]</sup> 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.<sup>[12,13]</sup> 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.<sup>[13,14]</sup> 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.<sup>[9]</sup> 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.<sup>[8]</sup> 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.<sup>[8]</sup> 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.<sup>[15-17]</sup> 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.<sup>[15,16]</sup> 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.<sup>[11]</sup> 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.<sup>[15,18,19]</sup> Other barriers identified include lack of spousal support and insufficient male involvement in the PMTCT programme.<sup>[15,19,20]</sup> 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.

## 2.0 METHODOLOGY:

**2.1 Research setting:** 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.<sup>[21]</sup> 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.

**2.2 Research participants:** The research participants comprised HIV positive mothers accessing PMTCT services at health facilities that provided comprehensive PMTCT services in Benin City. 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.

**2.21 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.

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

**2.3 Sampling strategy:** A purposive sampling method was used 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, one of the researchers 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.

**2.4 Data collection process:** Data was collected through focus group discussion sessions and in-depth interview sessions 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.

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.

**2.5 Study instrument:** 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.

**2.6 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. **Content analysis of the transcripts of the focus group discussion sessions and the in-depth interview sessions was conducted in this manner:** The transcripts from of the audio recordings of the different 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 to carry out the content analysis of the transcript of the audio recordings.

### **3.0 RESULTS**

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. Profile of research 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 following themes emerged from the focus group discussion (FGD) sessions and the in-depth interview sessions with the HIV positive mothers:

1. Perception of HIV positive women on awareness of HIV/AIDS in the society
2. Perceptions of HIV positive mothers about the PMTCT Programme
  - a) Positive perception of the PMTCT programme
  - b) Negative perception of the PMTCT programme
3. Perceived barriers to accessing PMTCT services
4. Experiences of HIV positive women throughout the programme
5. Experience in the continuum of PMTCT services:
6. Lessons learned and recommendations to improve the programme.

These themes are discussed in greater detail below:

**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)

206 **ii. Availability of free antiretroviral medications:**

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

209  
210 *"I am still thanking the people that are supplying these drugs for us, God will reward*  
211 *them. God will continue blessing them in abundance..." (Participant 1, FGD 7)*

212  
213 *"I thank God, with these drugs they are giving us, we have hope, before o, no hope..."*  
214 *(Participant 4, FGD 7)*

215  
216 **iii. Technical competence and supportive attitude of the healthcare providers:**

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

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

224  
225 *"...I love all the nurses. They are encouraging us, both the doctor; how to take our drugs,*  
226 *how to feel free. They encourage us that we should not think about anything; that this*  
227 *thing would soon be over." (Participant 8, FGD 7)*

228  
229  
230 **b) Negative perception of the PMTCT programme:** Although the mothers' perception of  
231 the PMTCT programme was largely positive, they also identified several limitations of  
232 the PMTCT programme. These include inadequate manpower, stock-outs of  
233 antiretroviral medications, laboratory reagents, etc. The lack of a permanent cure for  
234 HIV/AIDS was identified by the mothers as a major limitation of the PMTCT programme.

235  
236 **i. Stock-outs of Antiretroviral medications:**

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

240  
241 **ii. Lack of universal access to HIV Counselling and testing services:**

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

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

247  
248 *"Not all hospitals do tests for pregnant women even here in Benin." (Participant 2, FGD 2)*  
249  
250  
251  
252  
253

254 **3. Perceived barriers to accessing PMTCT services:**

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

261  
262 **i. Reluctance to disclose HIV status to spouses and close relatives:**

263  
264 *"When I hold my handset to call my husband, I will drop phone. I will say no, I will not tell him. Let*  
265 *me first keep quiet and monitor the environment... Up till today, as I'm talking to you, my Oga*  
266 *(husband) don't know anything concerning it..." (Participant 1, FGD 7)*

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

269  
270 **ii. Discriminatory attitude of some health workers:** Some mothers were concerned about the  
271 discriminatory attitude of some health workers at the sites as the quote below indicates:

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

276  
277  
278  
279 **4. Experiences of HIV positive women throughout the programme:**

280 The mothers reported both positive and negative experiences while accessing PMTCT services  
281 at the health facilities. These experiences are illustrated below using excerpts from the focus  
282 group discussion sessions and in-depth interview sessions:

283  
284 **I. Experience on HIV testing & disclosure:** Most of the mothers became aware of  
285 their HIV status through routine screening for HIV at the antenatal care clinics. Some  
286 of the mothers first received the diagnosis of HIV while in labour. A few mothers  
287 became aware of their HIV status after series of recurrent illness which prompted  
288 health workers to screen them for HIV. Some other mothers became aware of their  
289 illness following a diagnosis of HIV infection in their children or spouse which  
290 prompted health workers to screen the mothers for HIV.

291  
292 *"When I got pregnant, then I came here to register, then now tell me to go and do test.*  
293 *Then when I did the test, they now told me it is positive. I now went home to discuss with*  
294 *my husband. Then they sent me to call my husband. Then my husband came. He did the*  
295 *test, he was (HIV) negative...." (Participant 5, FGD 7)*

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

298 *FGD3)*

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

304  
305 *"My husband was very ill to the extent, people around us, were even suspecting. I have*  
306 *crossed my mind, if it's the sickness, we will carry it along.... Reaching there we did the*  
307 *test, even with my son. I have it, my husband has it but my son does not have."*  
308 *(Participant 7, FGD 7)*  
309

310 The HIV positive mothers reported experiencing physical, social, emotional and psychological  
311 problems. The mothers reported a wide range of emotions following the initial diagnosis of HIV  
312 infection from anger, disbelief and denial of HIV test results to despair, suicidal ideation and  
313 depression. However, most mothers reported immediate psychological support provided by the  
314 health workers following the diagnosis of HIV. Some mothers reported breakdown of their families  
315 and being deserted by their husbands after being diagnosed with HIV. Others had difficulty  
316 disclosing their HIV status to their spouses or relations for fear of being stigmatised. The excerpts  
317 below illustrate patients' initial reaction to the diagnosis of HIV infection:  
318

319 *"When I found that I am HIV positive, I was thinking the whole world had gone. I had lost*  
320 *every hope for living. The doctors and the nurses, they calmed me down, they talked to*  
321 *us, and they made us to know that this thing is nothing. It's just like malaria."*  
322 *(Participant 5, FGD 6)*  
323

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

327 *"I was afraid because I know that anybody that has the disease will surely die. Because*  
328 *of that, I was afraid."* (Participant 3, FGD3)  
329

## 330 **II. Mood swings and psychological distress associated with diagnosis of HIV** 331 **infection and attending routine clinic visits:**

332 *"Whenever I remember that I'm coming here, I do lean (lose weight) overnight, I do emaciate. I*  
333 *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,*  
334 *up till now, I haven't eaten. I will feel as if something move out from my body. But in all, when I'm*  
335 *about to go home or when I'm through with them, I will be feeling happy again and I will go*  
336 *home."* (Participant 1, FGD 7)  
337

338 *"Though, I will not lie o, anytime that I'm coming to this place, in fact that day is not a happy day*  
339 *for me. I'm always moody, even people around me will be asking me 'what is wrong?' I will say I*  
340 *just had a bad dream, like that. Even since, anything around me, I'm always angry. Until this time,*  
341 *I now had my baby."* (Participant 7, FGD7)  
342  
343

## 344 **III. Challenges Experienced with Infant Feeding:**

345 The mothers reported on their experiences with infant feeding. Many mothers complained of difficulties in  
346 sustaining replacement feeding due to the high cost of formula feeds. Others had to cope with pressure  
347 from their relations who urged them to practice mixed feeding (i.e. giving breast milk to babies who were  
348 on formula feeds). The excerpts below illustrate the experiences of the mothers with infant feeding:  
349



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:

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

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

400  
401 *"I was shouting, crying, shouting, shouting, nobody answered me. That thing they're doing is*  
402 *not good o. It's not good at all...One lady told me about it, I thought she was lying until I*  
403 *experienced it myself." (Participant 4, FGD3)*

404 Another mother agrees:

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

#### 407 **V. Experience with the use of antiretroviral drugs:**

408 The HIV positive mothers reported reduced morbidity and improved quality of lives  
409 with the use of antiretroviral medications as illustrated by the quotes below:

410  
411 *"Then secondly, with these drugs, when you're taking it, when your body system has*  
412 *already been already destroyed, it will restore everything. Everything will return to normal.*  
413 *In my own case, when I was rushed to the hospital when they noticed about this thing, so*  
414 *it was a wheel chair I used to walk there. But now, let me say eight months back that I*  
415 *know that this thing is in me, my body has changed. And for the past three years, I've not*  
416 *been able to get pregnant but now I'm carrying a baby." (Participant 1, FGD 6)*

417  
418 *"...Today, sick, tomorrow sick, next tomorrow sick, nothing like that again." (Participant 2,*  
419 *IDI 6)*

#### 420 **VI. Successful pregnancy outcomes, healthy babies:**

421 The mothers were delighted to report that they successfully carried their pregnancies  
422 to term and gave birth to healthy babies while participating in the PMTCT  
423 programme. The excerpts below illustrate the success stories of the PMTCT  
424 programme:

425  
426 *"I thought that it's only me that will carry baby. I'm surprised that we're many. Not only me that*  
427 *has twins sef. We are almost two or three. One quality in it, God is blessing us with twins. Double*  
428  *blessings, to show you that 'madam don't cry, take this.' " (Participant 1, FGD7)*

429  
430 *"Even my baby is very healthy. I thank God. We will do this test, the outcome will be fine."*  
431 *(Participant 7, FGD 7)*

432  
433 **VII. Preventing mother-to-child transmission HIV:** Most of the mothers who participated in the PMTCT  
434 programme reported that they delivered babies that were uninfected with HIV. Some of the excerpts  
435 below also illustrate the success stories of the PMTCT programme at the sites:

436  
437 *"I breastfed my baby for 6 months, after six months I stopped. Last month, I did my baby's test. It*  
438 *was negative." (Participant 5, FGD6)*

439

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

443  
444 *"My children, this is the third one, they are all (HIV) negative."* (Participant 1, FGD2)

- 445  
446 **5. Experience in the continuum of PMTCT services:** The mothers reported varied experiences  
447 following their interactions with staff at the pharmacy, the laboratory and the medical records  
448 departments. The mothers specifically complained about the delay in retrieving their case notes  
449 from the medical records department as well as the negative attitude of some of the staff therein.  
450 Some of the experiences were positive while others were negative as the excerpts below  
451 illustrate:

452  
453 **a) Experience in the medical records department:**

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

457  
458 **b) Experience in the Pharmacy:**

459 The mothers agreed that there were long queues at the pharmacy but that the staff were friendly and  
460 polite.

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

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

465 *"...They attend to us well in the pharmacy..."* (Participant 2, FGD3)

- 466 **c) Experience in the laboratory:** The mothers reported but positive and negative  
467 experiences following their interaction with the laboratory staff at the health facilities as  
468 illustrated in the excerpts below:

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

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

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

476 **d) Experience at the antenatal care clinic:**

477 The mothers reported varied experiences while accessing antenatal care for PMTCT. Some of the  
478 mothers had to shuttle between hospitals as they booked for antenatal care at one hospital and  
479 obtained antiretroviral drugs from another hospital. Some other mothers had to register for antenatal  
480 care at more than one health facility in order to access antiretroviral drugs.

482 *"They have too much population in the antenatal (clinic). It is too high. People will go there; three*  
483 *(p.m.), you will still be there, four (p.m.), you will still be there. To even attend to somebody is a*  
484 *war there. And there is discrimination there. If you have somebody there, they will attend to you*  
485 *first before other people you met there."* (Participant 6, FGD 2)

486  
487 "The population there is more than 300." (Participant 2, FGD 2)

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

490  
491 *"The antenatal clinic here is very fast before 12 O'clock, everyone has gone."*  
492 *(Participant 2, FGD 2)*

493  
494 *"They're trying. The nurse, she has been trying. Because even the first day they told me that I*  
495 *am positive, the way I feel. She is the one that encouraged me. I don't know how to tell my*  
496 *husband. She said that I should call him that she will discuss with him. She's the one that is*  
497 *encouraging us. There is no problem in the pharmacy, because I've collected drugs twice, there*  
498 *was no problem; no problem in the lab as well."* (Participant 7, FGD 6)

499  
500  
501 **5. Lessons learned and recommendations to improve the PMTCT programme:** Having  
502 participated in the PMTCT programme, the mothers had learned that they could live  
503 healthy and productive lives with the use of antiretroviral therapy. The mothers were also  
504 confident that with proper adherence to antiretroviral therapy and regular attendance at  
505 the antenatal clinic, they could have healthy children that were uninfected with HIV. They  
506 also had several recommendations for other HIV positive mothers. These included  
507 encouraging adherence to antiretroviral therapy and involving close relatives in the care  
508 of persons living with HIV.

509  
510 **a) Importance of adhering to antiretroviral therapy and involvement of close relatives in**  
511 **the care of persons living with HIV:**

512  
513 *"The only thing I will say, if you have the drugs as a woman, you don't suppose to use it to play*  
514 *because that is your life for now. To take it regularly, as instructed, you take it. You could even*  
515 *have somebody that is close to you, like your husband; somebody that will understand you. He is*  
516 *the next person that will say 'go and take your drugs, even if you forget. He will remind to 'go and*  
517 *take your drugs."* (Participant 4, FGD 7)

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

523 **b) Promotion of partner counseling and testing at the antenatal clinic:**

524  
525 *"The only thing I will also say, if you're a woman, you have to drag your husband to this place (for*  
526 *HIV counseling and testing). It is very compulsory...."* (Participant 4, FGD 7)

527  
528 The mothers also had some recommendations for health workers, government agencies and the PMTCT  
529 programme sponsors. These include regular supply of antiretroviral medications, increased programme  
530 funding, training and re-training of health workers and the need to find a cure for HIV/AIDS. The excerpts  
531 below highlight some of the recommendations by the mothers to improve the PMTCT programme:

**c) 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)*

**d) 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 who had participated in the PMTCT programme in the state. 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.

These findings are similar to those of a previous study conducted among HIV positive mothers in Gaborone, Botswana where it was reported that the availability of free antiretroviral medications and provision of free infant formula encouraged HIV positive mothers to participate in the PMTCT programme in the country.<sup>16</sup> In a similar study conducted among HIV positive women in Hanoi, Vietnam, the pleasant attitude of health workers and high quality counselling on preventing mother-to-child transmission of HIV motivated mothers living with HIV to participate in the PMTCT programme.<sup>17</sup> The findings from these previous studies are in conformity with the experiences of the HIV positive mothers reported in this study.

This study also explored the factors that hinder the participation of HIV positive mothers in the PMTCT programme in Benin City, Edo 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. These findings are very similar to the results of a previous study conducted among HIV positive women in Hanoi, Vietnam where the identified barriers to participating in the PMTCT programme included the discriminatory attitude of health workers, long waiting times at health facilities, poor quality of counselling on PMTCT of HIV and irregular supply of antiretroviral medications.<sup>17</sup>

In a similar vein, a study conducted among HIV positive women in Gaborone, Botswana identified several barriers to participation in PMTCT programmes.<sup>18</sup> These included negative attitude of health workers, the fear of knowing one's HIV status as well as the fear of stigmatisation.<sup>18</sup> These findings are in agreement with the barriers to the PMTCT programme identified by the HIV positive women accessing PMTCT services in Benin City, Edo State, Nigeria.

In a similar study conducted among HIV positive women in Abidjan, Ivory Coast who dropped out of a PMTCT programme, the mothers identified several factors that prevented them from participating in the

PMTCT programme.<sup>15</sup> These included the feeling of shame following the diagnosis of HIV, cost of transportation to the PMTCT programme sites, fear of involuntary disclosure of HIV status while accessing PMTCT services.<sup>15</sup> Others barriers identified by the mothers were fear of being reprimanded by health workers and disbelief of positive HIV test result.<sup>15</sup> Similar challenges were identified by the HIV positive mothers in Benin City that participated in this study.

The HIV positive mothers in Benin City, Edo State reported varying levels of psychological distress following the diagnosis of HIV. Some of the mothers felt suicidal and others felt deeply ashamed of being diagnosed with HIV infection. These findings are similar to those of the previous study conducted among HIV positive mothers in Abidjan, Ivory Coast where negative emotions such as shame and fear of stigmatisation discouraged HIV positive mothers from participating in PMTCT programmes.<sup>15</sup> In the study conducted among HIV positive mothers in Abidjan, Ivory Coast, some of the pregnant women wrongly believed that their unborn babies were already infected with HIV and so participating in the PMTCT programme would be of no benefit.<sup>15</sup> In contrast, the mothers in Benin City expressed strong faith in the ability of the antiretroviral medications to prevent mother-to-child transmission of HIV resulting in the birth of strong, healthy babies. Lack of spousal support significantly increased the level of psychological distress experienced by the mothers in Benin City. Similar findings have been reported in the literature.<sup>15,17,18,19</sup> 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. This observation among the mothers studied in Benin City is very similar to the results of a previous study conducted among HIV positive women in Lilongwe, Malawi, where the lack of spousal support contributed to women dropping out of the PMTCT programme.<sup>19</sup> Similar findings have been documented in studies conducted among HIV positive women in different countries of the world.<sup>15,19,20</sup>

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 hindering the achievement of the goal of the PMTCT programme. Similar findings have been reported in the literature whereby the discriminatory attitude of health workers discouraged HIV positive mothers from participating in PMTCT programmes.<sup>15,17,18</sup> Such negative attitudes may be the result of health workers being judgmental of persons living with HIV. It may also result from the health workers' fear of becoming infected with HIV while providing care for persons living with the disease.

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 physical 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.<sup>15,17,20</sup> In studies conducted among HIV positive mothers in Ivory Coast, Malawi and Vietnam, HIV positive mothers reported waiting for several hours at health facilities in order to access PMTCT services resulting in some mothers dropping out of the PMTCT programmes.<sup>15,17,19, 20</sup> 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.<sup>19, 20</sup> Studies conducted in Malawi and Ivory Coast among HIV positive women indicate that empowerment of mothers living with HIV through the provision of stipends or soft loans to establish small businesses would enable such mothers afford the cost of transportation to health facilities as well as the cost of feeding.<sup>19, 20</sup> Such financial aid would also promote access to health services for women and children such as antenatal care and immunisation services.<sup>19, 20</sup> These research findings documented in the literature are in tandem with experiences reported by HIV positive women accessing PMTCT services in Benin City, Edo State. In response to this challenge, the mothers in Benin City advocated for the provision of soft loans for patients living with HIV to enable them set up small business enterprise. The profit obtained from such business enterprise would enable the patients meet their basic needs of food, clothing, shelter in addition to the cost of transportation to the health facility for PMTCT services.

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. These findings are in agreement with the results of previous studies conducted among HIV positive mothers in other countries whereby the fear of being driven out of their homes discouraged the mothers from disclosing their HIV status to their spouses and close relatives.<sup>15,19, 20</sup>

Lastly, the mothers in this study desired a cure for HIV/AIDS. This finding has not been reported in previous studies conducted among HIV positive mothers.<sup>15-20</sup> It presents 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:** The conduct of this study raised several methodological and ethical challenges. However, all efforts were made to ensure confidentiality and protect the privacy of the study participants. The sampling strategy employed in this study ensured that the mothers recruited for the study did not feel singled out or stigmatised. 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 other parts of Nigeria and 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.

## 694 **CONSENT:**

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

## 698 **Consent Disclaimer:**

699 As per international standard patient's written consent has been collected and preserved by the authors.  
700

## 701 **ETHICAL APPROVAL:**

702  
703 This study was approved by the Ethics and Research Committee of the University of Benin Teaching  
704 Hospital, Benin City, Edo State, Nigeria with protocol number: ADM/E 22/A/VOL. VII/702. The study was  
705 also approved by the State Ethical Clearance Committee, Edo State Ministry of Health, Benin City, Edo  
706 State, Nigeria: reference number: HA.577/56. Institutional assent was obtained from the head of each  
707 health facility involved in the study. A summary of the research proposal was submitted to the head of  
708 each health facility for ethical consideration and to the ethical committees of the health facilities where  
709 applicable.

710  
711 **Benefits to study participants:** The mothers who participated in the focus group discussions and the in-  
712 depth interview sessions received counselling on safer sex practices, infant feeding and treatment  
713 adherence. The researcher also conducted interactive health education sessions with HIV positive  
714 mothers attending support group meetings at the sites.

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