Barriers and Facilitators to Care-Seeking among Pregnant and Postnatal HIV Positive Women in Rural North Western Nigeria

Rabi Yunusa

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Deepa Rao
Rachel Chapman

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Abstract

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Rabi Yunusa

Co-Chairs of the Supervisory Committee:
Deepa Rao and Rachel Chapman
Department of Global Health

In Nigeria, the scale-up of free antiretroviral treatment (ART), proactive anti-discrimination laws, and social awareness campaigns have contributed to bringing Nigeria closer to ending AIDS by achieving "Zero new infections, Zero AIDS related deaths and Zero discrimination by 2021." In the fight to end maternal and pediatric HIV/AIDS, however, multiple, intersecting stigmas have made stagnant any further gains in Prevention of Mother to Child Transmission of HIV (PMTCT) service delivery. As in the rest of Sub-Saharan Africa, Nigeria still carries a high overall burden of HIV. Maternal/pediatric HIV are troubling consequences of inadequate health services for HIV+ women in the region. We explored the interconnecting factors that perpetuate continued vertical transmission of HIV from mother to child in rural northwestern Nigeria. We conducted in-depth, semi-structured ethnographic interviews with 27 HIV+ pregnant women, aged 17 to 32 years, in four government-run rurally located secondary healthcare hospitals offering PMTCT services. Based on field notes and transcripts, we used grounded theory and thematic analysis and found that intersectional stigmas continue to create significant barriers to women living with HIV's ante- and post-natal ART adherence. Key strategies women employed to access needed care by keeping appointments, collecting medications and taking medications on time included peer support groups, spousal disclosure, child survival and economic autonomy. For optimal maternal/pediatric HIV services, providers should support established models these women already employ. If an AIDS-free generation is to be realized by 2030, Nigeria must also strengthen and enforce anti-HIV stigma and discrimination laws.

KEY WORDS: Nigeria, ART adherence, resilience, intersectional stigma, end of HIV/AIDS, PMTCT

INTRODUCTION

Worldwide, the HIV pandemic has been estimated to affect over 36 million people, of which over 2 million are children under the age of 15 years[1]. Over 90% of HIV in children is thought to be acquired via vertical transmission from mother to child mainly during pregnancy, childbirth and during breastfeeding[1,2]. It has been established that vertical transmission of HIV from mother to child can be prevented, with risk extremely minimized (to <2%) by giving the mother antiretroviral medications during pregnancy[3]. Transmission risk can be further diminished by ensuring adherence to anti-retroviral medication by the mother and baby (infant prophylaxis) combined with safe practices in health care delivery as outlined by the Prevention of Mother to Child Transmission (PMTCT) cascade[4]. The PMTCT cascade consists of a series of steps designed in the care of a woman living with HIV such that she and her baby receive the care they need from conception, throughout pregnancy to the birth and infancy of her child[4]. The cascade ensures that the survival of mother and child is maximized, while risk of MTCT of HIV is eliminated[4]. The steps are sequential, interdependent and are a continuum of care a mother is already receiving that she will continue to receive throughout her reproductive life. The care of the baby outside the womb begins with giving the baby anti-retroviral syrup as prophylaxis immediately after birth and continues up to 6 weeks[2]. At this time, the baby is tested for HIV infection (Early infant diagnosis or EID), the results of which will determine if the child will continue to receive ARV for life or not[2].

Challenges to Ending HIV in Nigeria

In Nigeria, with the most recent national prevalence rate being 0.2%, HIV rates are high among children 0-14 years, most of whom are thought to have acquired HIV via vertical transmission from their mothers or MTCT[5,13]. This rate is high despite robust PMTCT programs being scaled up across the country (from 6 centers in 2001 to 7,265 centers in 2016)[2]. Recent estimates have shown the national prevalence of HIV among women 15-49 years of age (childbearing age) to be 1.9%[19]. Overall, Nigeria has over 177,000 HIV positive pregnant women, of whom only about 30% received Anti-Retroviral Therapy (ART) in 2016 during pregnancy as part of PMTCT services[2,13]. As for early infant diagnosis (EID) within two months of birth, a vital part of the PMTCT cascade, nationally only an estimated 29.6% of babies had EID within two months of birth[2]. In Nigeria, the recorded maternal to child transmission (MTCT) rate is very high at 13% at 6 weeks, and 23% at the time of weaning from breastfeeding. These stark conditions both indicate poor maternal adherence to ART during the post-partum period[13].

In response to these challenges, in June of 2016, Nigeria adopted the World Health Organization guidelines to "Treat All" People living with HIV/AIDS (PLWHA) regardless of CD4 numbers or clinical staging[2]. To that effect, Nigeria has also adopted and implemented maternal "Early Test and Treat" ART – or Option B+ as it was initially called - into its PMTCT National policy to treat all women living with HIV presenting in pregnancy and to continue treatment even after childbirth for life[2]. Nigeria has also implemented an action plan to end AIDS by achieving "Zero new infections, Zero AIDS related deaths and Zero discrimination by 2021"[5]. HIV-related stigma is defined as "negative beliefs, feelings, and attitudes towards people living with HIV (PLHIV), groups associated with PLHIV and other key populations at higher risk of HIV infection"; while HIV-related discrimination is the "unfair and unjust treatment (act or omission) of an individual based on his or her real or perceived HIV status"[20,23]. The fight against stigma was added to the National HIV plan, because the government recognized the important role of both stigma and discrimination in the continued spread of HIV, and in causing major bottlenecks in HIV prevention and antiretroviral treatment adherence in the country[5,11,12].

INTERACTION WITH CARE

Poor adherence to PMTCT programs by pregnant women is not a new trend in Nigeria, where overall antenatal care attendance among all pregnant women is notoriously low (46% in 2015)[2] with even lower skilled birth attendance rates. In 2016, only 36% of all births in the country were delivered in a skilled facility with doctor, nurse or trained midwife in attendance, and only 14% of all newborns received post-natal care within two months of delivery[6]. It is no wonder that Nigeria accounts for 19% of all worldwide maternal deaths at 814 per 100,000 livebirths,[8] and infant mortality rate not significantly declining at 66.9 per 1000 livebirths[10].

It is important to note that these poor rates of engagement with care/ treatment have wide regional disparities in Nigeria, with Northern states faring much worse than Southern states in all indices[6]. As such, the Northern states contribute the most to the national burden of maternal, infant and under 5 morbidity and mortality[6,7].

The 2013 Nigeria Demographic and Health Survey (NDHS) captured further disparities between living in the Northern parts of the country versus in the South. Living in Southern Nigeria was associated with having higher levels of education for women and their male partners, being of the Christian faith, being a female head of household and being able to make autonomous decisions as a woman. These factors, in turn, are associated with increased likelihood to seek ANC care during pregnancy, utilization of hospitals for delivery and seeking post-natal care for infants within two months of delivery[7]. In contrast, women living in the North were found to be more likely to have little to no formal education, to not head households and to not able to make independent life decisions. The 2013 NDHS also found that living in rural areas was associated with poor health facility utilization than living in urban centers[7].

HIV in Rural Northern Nigeria

Demographically, the Northern region is predominately rural, and made up largely of Muslims of the Hausa/Fulani descent who are traditionally patriarchal and conservative and remain so even after the fall of the Fundamentalist Fulani Empire in 1903 by the British Colonialists[14,15]. Other Northern tribes include the Nupe, Kanuri and Gbagyi/Gwari tribes who have lived and interacted with each other for centuries and use Hausa language as lingua franca[17]. Traditional gender roles persist in the Northern states with men being polygamous subsistent farmers or traders and women staying at home to take care of the home and raise the children[7].

At the beginning of the Nigerian HIV epidemic, the prevalence of the disease in Kano, the largest city in Northwestern Nigeria (NW) with a population of over 15 million people, was 0.2%. At the peak of the HIV epidemic in 2007, prevalence was estimated to have increased to 3.4%[11,18]. Currently, Kano has an estimated 19,067 HIV+ pregnant women, of which 30% are expected to result in a new pediatric HIV infection[18] - that is 6,355 new pediatric infections by the end of the year. However, the recent Nigeria HIV/AIDS Impact and Indicator Survey (NAIIS) estimates the overall Northwestern regional prevalence to be at 0.6%[20]- much lower than previous estimates. Kano's closest southern border neighbor of Kaduna, a North Central state, has a regional estimate of 2.1%[19]. Several quantitative studies have blamed the increasing HIV burden of the state on the sociocultural factors highlighted above, the persistent MTCT, the general lack of access to information, and unprotected sex by heavily stigmatized PLWHA. This constellation of risk to PLWHA is attributed to the fact that they are forced to hide their identity and not disclose their status to anyone, including intimate partners, for fear of discrimination or other social persecution, which leads to infecting other people in the process[2,11,12].

No studies have documented the problem of poor uptake of PMTCT programs by northwestern Nigerian women and the role of stigma and discrimination in how they continue to be lost-to-follow-up (LTFU) during the postnatal period. For these reasons, rural Northwestern Nigeria presents a unique opportunity and ideal study location to listen to women from this region and to dig deeper to learn their perceptions of the problems they face, as well as possible solutions that could someday be used to solve the pediatric HIV epidemic in a way acceptable to this population.

The overall objective of this research is to explore the reasons behind the absences and LTFU from PMTCT clinics of women across North Western Nigeria living with HIV. This research also seeks to highlight factors that facilitate adherence to follow-up by the same women with the goal of using the lessons learned to make recommendations for improving PMTCT delivery. We were interested in addressing the following questions through qualitative inquiry: 1) why are some women and their babies lost to follow-up during PMTCT while others are not; 2) what are the key strategies to overcome barriers to seeking PMTCT treatment in North Western Nigeria, and 3) what are the key motivations that bring women back each time to seek care for themselves and their babies?

The experiences of a young generation of African mothers are woven below into unique stories tied together by a similar fate of living in rural northwestern Nigeria after a positive test result of early life infection with human immunodeficiency virus. The women described daily battles to keep their HIV status a secret, and their worry, anger, stigma, fear, breach of trust and grief over their health and the well-being of their family. They also told stories about the magnitude of their resilience, forgiveness of events past and hope for the future.

METHODOLOGY

We used an ethnomethodological participant-observation approach for this qualitative, exploratory study, and thus, we gathered data to better understand social norms[33,34]. In this case, the approach was informed by past clinical observations of the first author as a physician working with pregnant women living with HIV in Northwestern Nigeria. In this phase of the research, we sought to empirically study women living with HIV's engagement in PMTCT by eliciting retrospective and prospective narratives with the women themselves.

Procedures

We obtained written approval from the Kano State Ministry of Health Institutional Review Board to conduct the study and recruit from three rural publicly-run PMTCT clinics (in the districts of Bichi, Kura and Wudil) and one urban, publicly-run hospital (Murtala Hospital). At each site, the resident clinic nursing staff of each individual clinic obtained verbal informed consent. We conducted interviews in both English and the local Hausa dialect (whichever was preferred by the women).

The first author conducted individual in-depth interviews alongside a Health Care Worker (HCW), who served as a research assistant for the study. Each interview lasted approximately 30 to 60 minutes. The interview questions were directed towards women's experiences of being diagnosed with HIV, seeking and adhering to care in the form of testing, making appointments, taking medications for themselves and their children, the role of fear, stigma and discrimination in those experiences and strategies employed or perceived by the women to empower them to survive and live with HIV.

In-depth interviews (IDIs) were audio-recorded. IDIs were conducted each day over a period of 5 weeks. The audio-recorded IDIs were immediately transcribed verbatim into the local Hausa language, after which the original audio-recording permanently erased from the audio recording device. The transcriptions were later professionally back translated to English by another research assistant fluent in both English and Hausa to ensure linguistic and cultural equivalency.

Participants

The participants were included in the study if they were offered PMTCT services within antenatal and care clinics. We employed purposive sampling to select women to participate in the study based on our inclusion criteria by each resident's clinic nursing staff who were familiar with the potential study participants. They were considered eligible if they met the following inclusion criteria: living with a diagnosis of HIV, pregnant or recently pregnant (within the last 2 years), taking antiretroviral treatment for HIV in pregnancy, currently seeking treatment in the clinic/hospital described above within Kano state. We purposively sampled women to participate from rural demographic settings (publicly funded clinics/hospital), who had missed PMTCT appointments or medications according to health care worker reports, who were considered young (ages 17 to 32 years) and who were currently or previously married. Women who did not identify as Muslim were excluded as they did not represent the typical demographic of the area.

Data Analysis

After the audio-recorded interviews were transcribed and back translated into English, we set about to analyze the data using the principles of Conversational Analysis (CA) to develop codes which are strongly data driven but against making a priori assumptions and premature theory construction and idealization of research material prior to developing working codes[33]. Using CA, we developed a code book that contained codes organized into 89 separate categories. We then further systematically organized the coded categories to identify 7 desired themes relevant to our study (thematic analysis). Field notes were also used to capture non-verbal expressions and cues of the women participants and to provide context to their speech during the interview. Overall, the analysis helped identify core themes running through the narratives consistent with general perceptions of an HIV diagnosis; physical, sociocultural and ecological barriers and facilitators to seeking and adhering to care; the strategies and motivations developed and employed by the women to achieve adherence, maintain hope and develop resilience to living with the disease; and the overlapping role of stigma and discrimination in both preventing LTFU, and promoting adherence to care.

RESULTS

The individual interview participants were all women who all resided in rural areas of Kano state. A total of 30 women were recruited from four PMTCT clinics into the study but a total of 27 IDIs were used. Two participants withdrew their consent midway into the interview recording and one audio-recording was of poor quality that could not be transcribed. All the participants were between the ages of 17 to 32 years, all identified as heterosexual, all identified as Hausa-Fulani Muslims, all were currently or previously married (at least once). Most of the women were currently married (n=25). Many of the women (n=15) had been married multiple times following separation (n=1), divorce(n=4) or widowhood (n=10). About a third of the married women (n=8) were in polygamous relationships living with at least one co-wife in the same household. All the married women identified their husbands' primary occupations as primarily subsistence crop farmers, and secondary occupations during the post-harvest season which necessitated them leaving their families for months to supplement family income. The most common secondary occupations were petty trade, manual laboring and driving motorcycle taxis. These occupations were carried out in neighboring states (Jigawa, Bauchi, Gombe, Kaduna) or within the capital Kano city. Very few husbands ventured to places as far as Kogi (Obajana), Lagos and Ogun (Sagamu) states (n=4) which were located in far Central to South-Western Nigeria. Most of the women (n=25) had at least one child alive; one was in her first pregnancy and one had lost both of her children to a non-related HIV cause in the recent, rainy-season flood emergency.

Below, the narratives of the women are organized by themes that emerged from the data. The major themes identified include: reasons for diagnosis of HIV, words interchangeable with HIV, barriers and facilitators to seeking and adhering to care, the strategies and motivations employed by women to achieve adherence, maintain hope and resilience, and the wider social and ecological factors that pose the greatest barrier to these women- stigma, poverty, fear and culture. As expected, stigma was found to be salient and present in every social level of interaction, consistent with studies of the dynamics of the intersectionality of stigma and HIV. Stigma was also found to exist across various levels at the same time, a dynamic called "Intersectional Stigma"[29].

Mothers in Rural Northwestern Nigeria Surviving HIV

In observing and talking to the women, we identified major themes that played significant roles in the overall biological state of being HIV positive and state of overall health for the women. One major theme identified was that stigma coexisted within all levels of the psychosocial environment of the women (as identified and expected in the conceptual framework). Most impressive however was the ability of the women to display cross-cutting strategies for tackling stigma by developing various forms of resilience with some remarkable success that has somewhat translated into strategies to achieve adherence to PMTCT care for themselves and their children.

Receiving the diagnosis of HIV

When asked about how she found out that she was living with HIV, one woman angrily stated, "I got married and not up to a year later, he got really sick and passed away. I was taken to hospital to be tested and was found to be positive for this illness which also killed my husband." All the study participants reported being first married before the age of 16 years and being sexually naïve (never had engaged in penetrative coitus) at the time of their first marriage. All the women reported acquiring HIV from heterosexual intercourse with their husbands after marriage. All women report being faithful to their married husbands their entire lives. None of the women reported pre-marital testing as a feature of their lives- it was neither discussed nor considered as a feature of marriage culture/ rituals. One woman reported, “If I had known, I swear by God I would never have married him!” indicating perhaps the reason why, despite marriage being highly desired in the patriarchal culture, premarital testing remains unpopular among the men.

All the participants identified non-disclosure of HIV status as a common element in at least one level of the social structure of their lives. Not readily disclosing HIV status was practiced by both wives and husbands, some up to the point of diagnoses in the women. It was observed that the men usually knew of their HIV status when confronted by health workers at the point of the women getting diagnosed during pre-test partner counselling.

All the health facilities included in this research study employed pretest counselling prior to the Opt-out prenatal HIV test of pregnant women, and this counselling took place once during every first antenatal appointment if the woman was previously identified as being HIV negative. However, strict compliance by health workers to this policy was found to be sometimes lacking, as observed in one instance whereby one participant evaded testing. This participant explained that she evaded testing in order to keep her positive HIV status secret from her community, since her clinic was frequented by members of her social circle. Although less common, a woman’s family would take her to hospital and demand an HIV test if she was physically emaciated. Rapid weight loss is readily recognized as a symptom of AIDS by the Nigerian public.

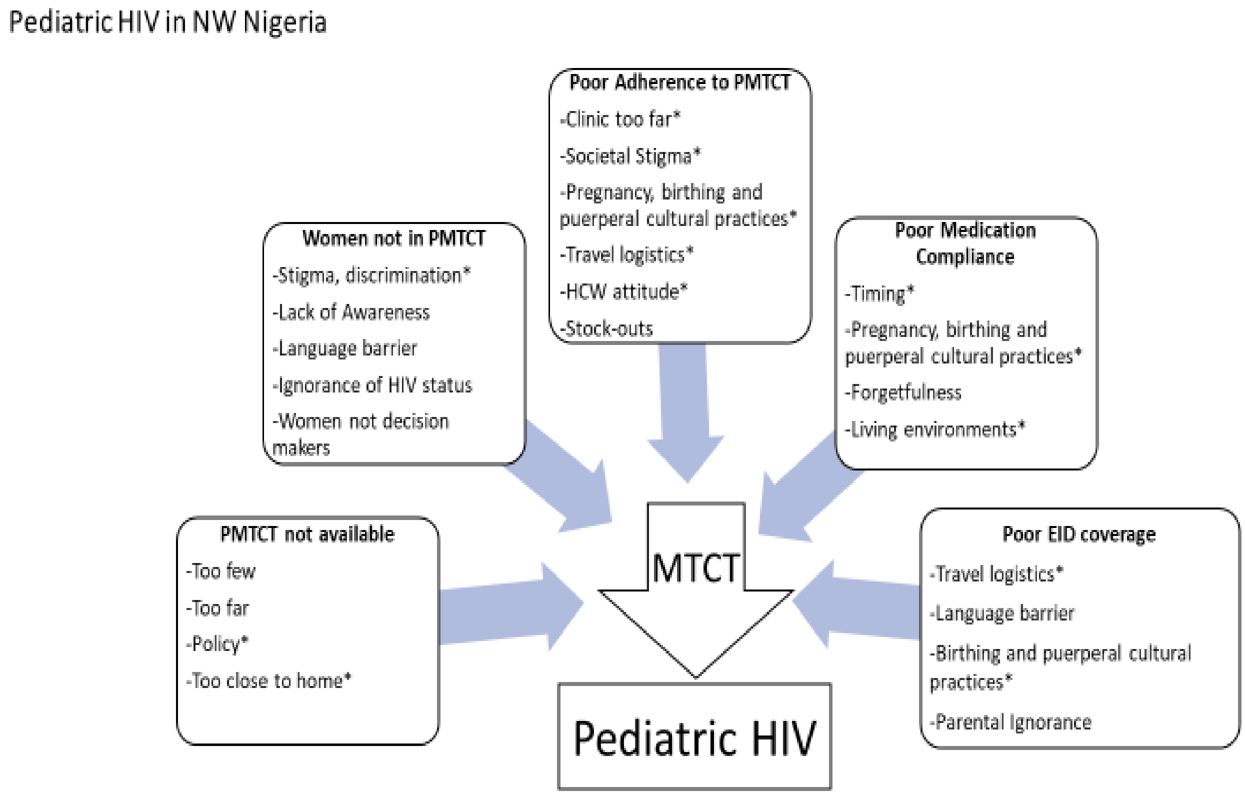
“This Big Problem”: Terminologies and Understandings of HIV

“This condition”, “this big problem”, “the condition”, “it”, “this disease”, “my situation”, “prostitutes’ disease”, “this illness”—all these terms were used by participants to refer to themselves living with HIV. Using the words commonly used in social marketing strategies by public health authorities to talk about HIV was unpopular with the women, while using subtle, non-specific words was a way to cope with “the condition” and build resilience for living with HIV. It provided a way to make living with the disease bearable. According to several participants, health worker at one health facility recognized this strategy, and as a rule they did not use the words HIV or AIDS when interacting with their patients.

Barriers to Care-Seeking and Adherence: Social, Economic and Ecological Level Factors

The barrier themes identified which contribute to LTFU and continued maternal and child HIV are represented in figure 1 below.

Figure 1: Summary of Barriers to PMTCT Care



* Represents the role of stigma and discrimination as confounders in each case

Healthcare Worker Attitude

"There was once I had an incident with a doctor that disturbs me. At a hospital where I had my Caesarian Section, the doctor was treating me badly with disgust (before the operation). In the end, he wasn't the one that performed the operation on me. It was another doctor. I was disappointed; I thought they [doctors] were not supposed to be like that." This woman traveled far from home to get higher level care than was available where she lived in a rural zone. Although great strides had been made in tackling institutional stigma in HIV care delivery in Nigeria, health care worker attitude was still a problem regarding the treatment of women living with HIV in antenatal, birthing and post-partum care.

Although most women participants expressed gratitude with the way they are served by their primary healthcare workers, clearly Health Care Worker (HCW) attitude continues to feature prominently in patient experiences and perceptions of care for HIV. Some patients were so satisfied with HCW attitude that their own personal biases against PLWHA were mentioned to express gratitude. One striking statement was one woman saying, "If it was me, I will not allow myself to touch people with this disease. But they [clinic staff] do". Many patients used words to state that they owed their lives to the care they received from the HCW, and they were ready to excuse other unpleasant behavior of the HCW such as coming late to work and truancy.

There were, however, certain situations in which participants seemed to draw a line in the sand when it came to HCW attitude. These situations included a concern for the care of children while in the hospital. Mothers were taken aback by hospital policies that were contrary to their long-held beliefs and customs. One woman reported, "I am worried about my child, I have a lot of questions about what they are doing— for example they told me that my baby will not take water at all, and that immediately after birth, the child will be taken away for a check-up. What will I tell my family that will be present when they ask me why [the baby] was taken away?" This anti-cultural practice, and the general lack of transparency in hospital birthing policies, seemed to be a major distress to our research participants.

Disclosure to Family

"My husband supports me, the clinic staff also encouraged us to take care of ourselves. But it has also been secretive because I have not told anyone of my condition, not even my parents. Only my husband knows." This is one woman's account which mirrors other women's accounts of how HIV has successfully severed the ties of kinship by permanently shrouding it with a heavy cover that dares not be lifted. Many of the women describe the pain they feel by not being able to disclose their HIV status for fear of being "treated as outcasts" by the people they loved and otherwise trusted their entire lives. As some women informed us during the interviews, they are certain of this outcome of being shunned because they also felt similarly towards people living with HIV before they knew their own HIV status.

"It rained heavily and there was flooding at my parents' house. So, my younger sister came to stay with me because our house was fine and dry. I didn't know how to avoid her without her following me to the hospital. So, I pretended to change my mind about coming. If she finds out, she will tell my whole family and ruin my marriage." While it may be a natural thing for sisters to support each other, or take a walk to the clinic together. This participant described a fear of disclosure to her sister, and as such, concern over disclosure to family was a real barrier to making her medical appointment, thus demonstrating the intersecting role of stigma with family norms, HIV, care seeking.

Stigma within the Community

All the women (n=27) cited recognition by someone they knew as a strong deterrent for keeping appointments. It was very common (n=20) for the women to deliberately travel to other towns for HIV care so no one from their community would recognize them. We had a sense of the community being so close knit that any aberration from the norm will be questioned and reacted to with social isolation. The women, however, did not report any history of actual physical violence whatsoever towards people who were discovered to be living with HIV. But social isolation such as ridiculing, gossip and outright unwelcoming behavior at family and social gatherings was routinely practiced in retaliation if a person was found to be living with HIV in the community. The women also admitted that these negative attitudes continue despite social marketing by the government using mass media which they recognize was to tackle stigma against persons living with HIV.

Religious and Cultural Rituals

Women often reported that religious and cultural rituals played a role in uptake of PMTCT services. One woman said, "…[M]y husband, had just died, and I had moved back home. I wasn't allowed to go outside the house because of *Takaba* and I went into labor. I did not get her meds and even I stopped taking mine for a while during the ritual baths (*Wankan Jego*). Ritual bath is a must here regardless of what happened to the baby— whether baby is alive or dead." The woman described *Wankan jego* as the ritual birth period of 40 days after the birth of the child when neither child nor mother are allowed outside the home except for medical life-threatening emergencies. During this time, mother and child move back with her natal parents where she is surrounded by family and support to care for the baby while she recuperates, away from her husband's intimate contact. *Wankan jego* was a prominent cultural ritual identified by all the women that must happen regardless of the outcome of the pregnancy- whether baby survives childbirth or not.

Takaba is the ritual woman only observed period of mourning that is observed by women who is widowed. Like *Wankan jego*, she is not allowed outside of the home. She is also not allowed to interact freely with anyone not considered a very close family member for a period of four months and 10 days, or until she delivers if pregnant - whichever comes first. For both *Wankan jego* and *Takaba*, the major barrier it presents is the creation of an environment that is both unpredictable and lacking in privacy for the women. This significantly affects adherence to hospital visits as well as life-saving medications for both mother and child.

Breaking with cultural norms - both traditional and acquired personal norms - were found to play a role in fulfilling the new roles required for comprehensive or ideal PMTCT care. One woman said, “I have been delivering on my own for 15 years, very short labor during childbirth, if I go to hospital now, what will people say?” Another reported, “I was so scared that I had to deliver here [at hospital]. I used to deliver at home before. People were surprised that I went to hospital for my number 4 as I didn’t use to even like going to hospital. [When I went home] I stayed in my room and my mother came. You know, so that no one will know what we were doing. It was the only way I could hide my medicines from everyone. She keeps them for me and hands them to me when it is time to take them”. This was contrary to her culture, which required her to go home for *Wankan jego*. Being able to bring medicines to her home to take in front of her mother seemed to help overcome this stigma.

Household Patriarchy

Familiar arrangements and dominance of the husband within traditional families played a role in women’s uptake of PMTCT services. One woman said, “My husband does not come to collect medications for himself. I think he is ashamed or scared. I don’t know. So, he sends me to collect mine along with his, and after a time, the clinic refused to give me his own [medications]. They insisted that he should come to collect it himself. He refused and began taking mine instead and when it finished, he did not allow me to come and get more." This is one woman's cry for help about a spouse who is so afraid to be seen in the community that he will take his wife's medications, forcing her to deal with the risk of community stigma if she is seen to be collecting the medications from the local HIV clinic. The lack of cooperation of the healthcare system to provide the husband's medications in an acceptable, more confidential way, is resulting in a situation whereby both woman and man are not adhering to medications, leading to breakdown of the care cascade for the woman and unborn child. However, it was surprising to see that the fear of community stigma was so strong in this woman that when presented with an option to have medications delivered by a postal worker or other agent, she vehemently declined and preferred coming by herself when she can. Other forms of patriarchy that were recognized included needing permission to go to the hospital for whatever reason, even the husband was out of town.

Intersectional Stigmas: Poverty, Fear and Culture

Most of the women reported not being gainfully employed and were mainly housewives. However, one widow in the study reported working as a maid in the city for income to sustain herself and her children. However, she reported being sent out of a job for developing some rashes on her legs which she said were seasonal rashes that she had all her life, even prior to her HIV diagnosis. Another time, she was discovered to be taking medications at the same time every day by her employer who promptly dismissed her.

For the married women, poverty is partly responsible for them acquiring HIV as the men travel for trade to supplement crop farming, during which they sometimes engaged in high risk casual sex in the towns where they travel for work. Fear of ending up in poverty has been reported by some women to be the reason why they continue to stay married even though they harbored unresolved anger towards their spouse for infecting them with HIV.

Facilitators to Seeking and Adhering to Care

Coping

Many women described ways that they coped with their diagnosis in order to move forward and engage in care to improve health. "I know he got it from his travels, too. I cried my heart out and asked him for a divorce. I left him to tell my mother, as I was afraid to tell my other family members in fear that they would stay away and run from me. My mother advised me to take things easy and have patience. She convinced me to go back to my marital home but to always take my medications no matter what and to free my mind that God was in control of my situation". Although all the participants identified as Muslims, religion was seldom mentioned as a prominent factor in the reason why the women continued to stay in the marriage. However, religion and references to God were powerful tools that other people in the lives of women living with HIV, including family and even healthcare workers, used to encourage and convince them to enroll and stay in care, and to remain in their marriages. North Western Nigeria is known for its strong Islamic influence, which is a prominent part of common speech, customs and practices of the people. The Hausa-Fulani culture is considered synonymous with being Muslim by other Nigerian tribes.

Strategies and Motivations Employed by Women to Achieve Resilience

Throughout the interviews, various strategies and motivations were identified as practices by the women to develop hope and resilience. Some were expected, some were surprising, but all were developed, tried and trusted by the women who depend on them for them and their children's very survival, literally.

Changing Travelling Routes to the Clinic

The most common strategy employed by participant women to avoid being recognized as a PLHIV in their community or home was taking a different route every time they had to go into the hospital for an appointment. They report that this strategy is made more effective by adding a stop on their way back from the hospital which provides them an alibi for where they were going so early in the morning. Another is by swaddling their child on their back such that if they were recognized and asked about the trip, they would say their child has a temperature and the hospital visit was to take the child to the hospital.

Cooperating with Close Family Members

Several women described finding an ally in at least one, sympathetic family member. One woman identified her mother as helping her take her medications. Her mother was able to visit her in her marital home, encourage her to take medications, and help her with safely hiding the medications, and even dispense medications to both her and her child while no one was looking.

In terms of finding allies in other family members, another participant reported disclosing her status to her brother who would come drive her on his motorbike every time she had a doctor's appointment. Lastly, another participant reported that disclosure to her mother enabled the mother to provide childcare to her children on days she has hospital appointments. This participant related that she forgot her hospital card once and she phoned her mother who dutifully went to her house, searched for it and delivered it to her at the hospital so she could keep her appointment.

Hiding Medications in Plain View (Camouflaging)

One woman reported simply hiding her child's syrup PMTCT medications in an unmarked syrup bottle among the other barrage of child vitamins such that no one would be able to recognize when she was giving vitamins or actual HIV preventive medications to her child. Brilliant.

PMTCT clinic as a Social gathering place

Women appreciated finding a social support space with other women and peers living with HIV. “I like coming here to meet people like me.” This is how Wudil clinic participants reported feeling about the fortnightly Saturday social gathering that is organized by their resident HIV officer. He developed a plan whereby he encourages his patients who are living with HIV to attend a support group that meets every two weeks to make friends and talk about their problems in the open. All support group attendees reported enjoying the group, and, in fact, in the past 18 months two women have met and married other men living with HIV. This model support group was not reported in any of the other sampled health facilities at the time of this research study.

Motivation to Care for “offending husband”

Many women found stability with continuing to be with their husbands. As one woman described, “Well, he takes care of me, but my whole family will attack him, as I was a virgin when we married. They will know he gave me the disease. They will tell everyone, then they will take me home and treat me very badly, thinking I will give them a deadly disease.” Marriage plays a very prominent role in these parts of Nigeria. Marriage is regarded as the natural transition of women from childhood to wifehood to motherhood in a cycle that repeats itself over successive generations for their daughters. There was also a sense that the women regarded marriage as a form of economic survival and regarded it as reason enough to stay in the marriage, even if they were angry with the husband for infecting them with HIV. For this economic role that marriage plays, the women will risk marriage without premarital testing for HIV, even though they are aware of it from mass media campaigns, and for it they will continue to live with unresolved anger at their husbands. And for fear of losing this economic stability that marriage provides, many women continue to guard their secret diagnoses of HIV from their immediate/close family including mothers, fathers, sisters and brothers.

Child’s Future as Motivation to Adhere to Treatment

Perhaps it is the future of their unborn and newly born infant, that is the greatest motivation cited by all women as the reason why they bother to seek care at all - the fear of raising a child living with HIV/AIDS. One woman describes how terrified she was of having a child that would grow up with HIV, and how her relationship with her child would be compromised. She reports “Well, I am terrified that I will give my child HIV (crying). Then what kind of life will that be for my child? Taking medicine all his /her life. Maybe get sick, then hate me and then die? Oh, I’m so afraid of that.” The hope of having a child growing up HIV-free was also observed to be central to the government’s HIV prevention social marketing strategy of an AIDS free generation, and also the hospital’s pre and post-test counselling strategy to enroll and keep women in care. Such is the intersectionality of hope for the child and the future, with building resilience to better survive HIV/ AIDS in the most challenging of situations.

DISCUSSION

Overall, we identified seven major themes: reasons for diagnosis of HIV, words interchangeable with HIV, barriers and facilitators to seeking and adhering to care which are affected by overlapping presence of explicit and implicit stigma/ discrimination, and strategies and motivations employed by women to achieve adherence and resilience in a wider context of patriarchy, poverty, fear and enduring culture. The most significant barriers identified by the women appeared to be stigma and discrimination by family members, the community and some healthcare workers, expensive transportation/ difficult travel logistics and patriarchy.

Intersectional Stigma

Stigma and discrimination remain major barriers to the successful outcome of the National HIV/AIDS strategic plan to eliminate HIV/AIDS by 2030. On the ground, both stigma and discrimination contribute to stress and erect physical and mental barriers to the wellbeing of PLWHA. In rural North Western Nigeria, the women we interviewed described patriarchy and limited economic independence for women –additional stigmas associated with womanhood—that may further complicate the lives of women living with HIV. These intersectional stigmas - the existence of multiple stigmatized identities in one person, may be an important consideration in understanding the challenges faced by the rural North Western Nigerian women who participated in our study[29]. These multiple competing negative attitudes that rural North Western Nigerian women navigate have been demonstrated in other studies across the country[22].

Although Nigeria has had a clear HIV anti-discrimination law outlining the rights and responsibilities of individuals living with HIV/AIDS since 2014, enforcement has been slow to non-existent in many spheres. National Aids Control Agency (NACA) and other stakeholders designed stigma reduction programs to be implemented across individual, community, structural and institutional levels[20]. In this study, participants were all aware of anti-discrimination social campaigns via mass media and agreed that they were widespread, but challenged the effectiveness of the campaigns considering that stigma remains a challenge for them.

The women cited poverty, not having enough money for transportation and not being gainfully employed as a major barrier to seeking care capable of preventing clinic visits or forcing the women choose between having food to eat or money for transportation. Since the women also avoid PMTCT clinics near them, they must have enough resources for travel to make it to another clinic. Poverty and its impact on HIV care is well-studied in Sub-Saharan Africa, and poverty carries additional stigmas that women in North Western Nigeria must navigate[25,26,30].

Resiliency Factors

During the study, we identified strategies that helped the participants develop some effective resiliencies, so they are better able to cope with living with HIV and maintain adherence to the ARV medications which should translate to better health outcomes for both the women and their children. These strategies were: 1) Social/ peer support group participation; 2) disclosure to spouse and or significant other/ close family members; 3) Putting the child's well-being first; 4) use of religion in counselling to encourage commencement of care and to improve adherence to the medications; and 5) financial independence of women or supplementing family income by women.

Innovative peer support groups like the one identified in the Wudil PMTCT clinic and those studied in the Enugu state of Nigeria have been associated with good medication adherence when compared with non-peer supported patients[19]. Similar results were found in South Africa where attendance in support groups improved HIV prophylaxis and ART medication by 1.6 times when compared to non-attenders[23]. Other studies, using peer education rather than peer support, have showed no improvement in medication adherence. Together, these studies confirm Corrigan's findings that education-only approaches to stigma reduction efforts are limited[31]. Thus, further study of replication and scale up of model programs like the one at Wudil PMTCT is warranted.

We found that the women disclosed to men in all cases whereas the husbands typically disclose only at the point of serious illness from the disease or post-diagnostic counselling of an incidental finding of HIV during pregnancy testing. This tallies with a rural North Central Nigeria study that disclosures typically following new diagnosis in pregnancy and disclosure were to male partners or family members[23]. Disclosure to a spouse or other close family member was agreed by all the participant women to be key to better emotional wellbeing. Interviewees also strongly agreed that premarital disclosure was important in dispelling resentment towards non-disclosing spouses. Similarly, the 2017 Lagos Nigeria study carried out to examine the experiences of seropositive women on the issues surrounding HIV status disclosure which showed that negative public opinion and fear of losing relationships was the most common reason for non-disclosure, while acceptance was the most common positive outcome of disclosure[22]. However, if disclosure is encouraged, health care workers and others encouraging women to disclose must analyze and identify any negative consequences of disclosure to ensure these women's safety[32].

All the women factored into their narratives the effectiveness of healthcare workers in 1 post-test counselling for initial ART uptake; and 2) helping come to terms with knowledge of being infected with HIV from their husbands. They explained how when health care workers brought up the future health of their child in discussions, this immediately motivated them to initiate and maintain care. They also emphasized how appealing to their sense of religion helped with acceptance of the initial diagnosis. These motivations are important and should be widespread in use when trying to initiate newly diagnosed pregnant and postnatal women into care. These strategies employed by the healthcare workers are well known and can be found resounding in other regional studies[24].

Limitations

Prior to this study, the first author worked as a doctor in this area of Nigeria and often observed that women inconsistently adhered to anti-retroviral medication regimens. During the period of bringing the study proposal together, the views and projections of the first author were from a woman and physician who identified as a citizen and resident of the same Northwestern Nigeria region where women were recruited into the research study. Then, at the time of data analysis, the first author became pregnant, gaining new insight into the unique additional barriers and that pregnancy presents in terms of the mental and physiologic challenges to the body. These experiences and positionality likely affected the manner and interpretation of results.

This research study is not intended to be representative of people who are outside of the inclusion criteria. Specifically, we could not include women in the study who were not engaged in PMTCT care, given our clinic-based recruitment. The viewpoints of women who were not engaged in treatment would have been valuable to fully understand barriers to service engagement. However, our clinic-recruited participants did provide well detailed perspectives on resiliency factors and how they overcame challenges to engage in care.

Conclusion

The scale-up of free PMTCT care outside of tertiary health centers into rural grassroot communities in Nigeria, combined with proactive policies such as anti-discrimination laws and social awareness campaigns/marketing, have contributed greatly to bringing care closer to women and children in the fight to end the pediatric HIV/AIDS epidemic in the country. However, multiple, intersecting stigmas have made stagnant any further gains in PMTCT care delivery. More should be done using the successful strategies employed by the women in this study to help improve their access to care (including tackling healthcare worker bias) in a culturally sensitive and acceptable way. More needs to be done to improve the financial status of women in rural communities if the dream of an AIDS free generation is to be realized soon.

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