Nigerian Medical Journal
NIGERIA MEDICAL ASSOCIATION
Print ISSN 0300-1652, E-ISSN 2229-774X

Original Research

Psychosocial Impact and Coping Strategies by Mentor Mothers Engaged in Prevention of Mother-to-Child Transmission of HIV Services in Taraba State, Nigeria: A Qualitative Study

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Abstract

Background: Mentor mothers (MMs) are women living with HIV who provide peer education, advice, support, and mentorship for HIV-positive women undergoing Prevention of Mother-to-Child Transmission of HIV (PMTCT) during pregnancy and after delivery. This study aimed to explore their experiences and the impact of the work on their psychosocial well-being, as well as the strategies they adopt to cope with the same.
Methodology: We conducted a qualitative study using in-depth interviews among 16 MMs in Taraba State, Nigeria, between September and November 2022.All interviews were recorded using a voice recorder. The collected data were transcribed and translated into English for analysis. Thematic analysis was applied to analyse the data.
Results: The key themes identified from MMs' account of their lived experiences as mothers living with HIV and providing support to other HIV positive (+) women were their fears and distress at diagnosis, disclosure challenges, stigma, and discrimination, the place of good counselling in helping newly diagnosed to accept and adhere to treatment, the ill-feelings evoked from repeated telling of their own stories to new clients, some negative impact on their psychosocial wellbeing, and various strategies to cope with the demands of the program.
Conclusion: The study concluded that there was no serious negative impact on the psychosocial well-being of the MMs from their work. They adopt various strategies, such as religious activities and relaxation with family and friends, to keep this intact**.** This program should therefore be scaled up with holistic support for the health and well-being of the MMs themselves**.**

Keywords: Mentor Mother; PMTCT; Psychosocial Impact; Nigeria.

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How to cite: Obadiah MAZ, Atinge S, Sonnen-Atinge GY, Kaleb AA. Psychosocial Impact and Coping Strategies by Mentor Mothers Engaged in Prevention of Mother-to-Child Transmission of HIV Services in Taraba State, Nigeria: A Qualitative Study. Niger Med J 2025; 66 (3):884-894.https://doi.org/10.71480/nmj.v66i3.529.

Quick Response Code:

Introduction

Generally, an HIV-positive diagnosis imposes a significant psychosocial burden on People Living with HIV/AIDS (PLWHA).[1,2] The diagnosis is often received with shock, anger, sadness, denial, and uncertainty.[3] As PLWHA adjust to the impacts of the diagnosis and the difficulties of living with HIV, including recurrent stressors like physical pain, side effects of anti-retroviral therapy(ARV), social stigma, and discrimination, they often suffer from fear, isolation, anxiety, depression, and other forms of emotional and psychological problems.[2,4].

Globally, more than half of the people living with HIV are women.[5] An HIV diagnosis is more complex and daunting for women.[6] Women often get diagnosed before their partners or husbands,[7]possibly because women tend to be more health-seeking than men.[7] This necessitates them sharing their positive status with their significant others.[8]HIV-positive women fear, and some have experienced adverse disclosure outcomes such as abandonment, judgment, labelling, stigma, intimate partner violence, etc.[4] Women are often first diagnosed during pregnancy,[4]meaning it is not about them alone, but also their unborn babies.[7]HIV-positive pregnant women specifically worry about whether their babies will be HIV-positive and whether they will be alive to care for those babies.[4] The difficulties of living with HIV and being pregnant are often intensified by poverty, poor housing, and relationship breakdown, among others.[4,7] The journey of coming to terms with the diagnosis, coping with the impacts of the virus, safe guarding their health, and then preventing the transmission of the virus to their unborn babies[7] creates a need for adequate information, support, and care, which cannot be met through biomedical treatment alone.[4]

In response to this need, the Mentor Mother (MM), also known as Mothers-to-Mothers (M2M) programme was created in South Africa in 2001.[9].The program provides peer education, advice, support and mentorship for HIV-positive women undergoing the Prevention of Mother-to-Child Transmission of HIV (PMTCT) during pregnancy and after delivery. The Mentor Mothers who undertake this task are HIV-positive mothers with lived experiences of HIV who have equally undergone PMTCT during their own pregnancy and postpartum periods.[10,11] The goal of the program is to help women accept their status, adhere to treatment, lead healthy lives, and prevent vertical transmission to their babies.[10,11]

Mentor Mothers are recruited and trained in basic medical knowledge of HIV, including prevention and care services, drug adherence, PMTCT; strategies to cope with stigma and disclose HIV-positive status; nutritious feeding, etc.[7,12] The mentor mothers then apply the knowledge and skills from these pieces of training together with their lived experiences of HIV and PMTCT to facilitate health talks, conduct support group meetings, carry out personal and group health education, follow up, encourage, support and mentor the HIV positive women through their pregnancy, birth, and postpartum journeys.[4] In addition, they carry out community outreaches to promote safer sex, family planning, and health-seeking behaviour.[4,12] Mentor mothers also support women to utilize effective strategies for disclosing their HIV status and coping with stigma.[4,7,13]

The work that mentor mothers do is critical in improving both maternal and infant outcomes.[14–16]. Since they are living with HIV themselves, mentor mothers understand the unique and complex needs of HIV-positive pregnant women and their families. Having experienced the health system, mentor mothers also guide the new HIV-positive pregnant and postpartum mothers to navigate it[7,13]. The Mentor Mother program has recorded significant positive outcomes.[17] It has improved the number of antenatal care (ANC) visits, ARV retention, early infant diagnosis, and early initiation of infant ARV.[4,13,18] Women participating in the program are more likely to take up PMTCT services and adhere to PMTCT recommendations.[4,8] Participants are also more likely to disclose their status, thereby improving treatment adherence, enhancing support, and reducing the incidence of new infections.[8,12,16]

Participants experience psychosocial well-being, can overcome hopelessness, and live positive lives.[4,12,16,19]

Despite the numerous gains brought about by the mentor mother program, including providing a task-shifting resource and improving maternal and infant outcomes, there have been some challenges associated with it.[13] A study conducted in North-Central Nigeria found challenging relationships between mentor mothers and healthcare professionals.[20] These include stigma and discrimination against mentor mothers based on their HIV status; questioning the legitimacy of mentor mothers' work; issues around workplace hierarchy, scope of work mentor mothers engage in apart from attending to the HIV pregnant and postpartum mothers, and lack of infrastructure such as an office and counselling rooms for mentor mothers to operate in.[20] Another study identified concerns about breach of confidentiality, inadvertent disclosure, as well as pervasive stigma and discrimination against both mentor mothers and their clients in the communities where mentor mothers work as challenges,[4] even though evidence shows that mentor mothers are acceptable to HIV positive women and other stakeholders[12]

The psychosocial impacts of the role of mentor mother on the experienced HIV-positive women who perform it are, however, not yet well known.[4,13] As noted above, the role requires mentor mothers to provide support, education, and mentorship for HIV-positive and postpartum mothers in health facilities and communities.[4,14,18] This requires the mentor mothers to disclose their HIV status and share their experiences of diagnosis, living with HIV, and PMTCT with their mentees.[4] Openness on the part of the mentor mother is a key mechanism in the success of the program.[4,13]On the positive side, mentor mothers report that sharing their stories serves as a medium of healing and makes them feel lighter and empowered.[4,13]They also report that the role gives them a sense of purpose and boosts their self-esteem and confidence.[4,13] On the negative side, apart from the stigma and discrimination that mentor mothers experience from healthcare workers and community members, some mentor mothers report that continuously recounting their HIV experiences in the course of mentoring HIV-positive women makes them feel traumatized. They also report physical and emotional symptoms consistent with posttraumatic stress and secondary trauma as they listen to their clients narrate their own experiences.[13] Mentor mothers have also reported distress as a result of their inability to do more for the mentees and difficulty maintaining boundaries in the relationship, making the role more cumbersome.[4,13]

The pivotal role that mentor mothers play as peer supporters to HIV mothers in the prevention of mother-to-child transmission of HIV requires that their health, including mental and social aspects, is equally sound to achieve the desired result. A breakdown in their own mental or social health will invariably defeat the purpose of the role they are expected to play. Yet studies focusing on this aspect of the PMTCT programme as scarce. In Taraba State, no such study, to the best of our knowledge, has been previously conducted since the commencement of the mentor mothers' programme in the state. The paucity of information on this topic in Taraba state and the significance of having the same for the optimisation of the PMTCT programme, therefore, justifies the conduct of this study. We therefore aim to investigate the psychosocial impacts of the role of mentor mothers in Taraba State and to identify the coping strategies they utilise to manage the negative impacts of this role. The findings will be beneficial in shaping future mentor mother programs as well as improving existing ones by considering the risks of these negative psychosocial impacts of the role and including components that prevent or minimise and respond to them adequately.

Methods

Study area

The study area was Taraba State, located in the northeastern part of Nigeria. The state has a projected population of3,213,744 and an annual growth rate of 2.9% (National Population Commission, 2006), with an estimated population of women of reproductive age (15-49 years) at 877,000.[21]Women in Taraba state are disproportionately affected by HIV, with a prevalence of 3.6% compared to 1.9% in men.[22]The state has a Federal Medical Centre, a State Specialist Hospital, 15 secondary health facilities, and several private and primary health centres. Health care services provided in these facilities include the PMTCT program, a major component of the HIV/AIDS response that is operated by all three levels of health care systems in the state: namely, primary, secondary, and tertiary care. According to information obtained from the State AIDS and STI control program, there are twenty-five [25] registered mentor mothers in Taraba State. The mentor mothers programme was formerly supported by the National Agency for the Control of AIDS (NACA) for tracking and adherence counselling, but currently the programme is under the support of the Johns Hopkins Programme for International Education in Gyneacology and Obstetrics (jhpiego)

Study design, sample size, and sampling methodology

This was a qualitative exploratory design using an in-depth interview approach. Sixteen (16) active mentor mothers, with at least 2 years' involvement in the PMTCT program, were selected using purposive sampling.

Data collection Instrument and procedure

An interview guide developed by the researchers from previous studies was used for data collection.[12,23,24]The researchers first met with the Taraba State PMTCT focal person to explain the research to her and ask for her permission to conduct the study among Mentor Mothers in the state. The focal person then informed the MMs and requested their permission for the researchers to contact them. Arrangement was made with each MM who agreed to participate at the place and time of their choice for the interviews. After obtaining written informed consent, participants took part in the semi-structured qualitative interview, which explored their experiences of giving support, education, and advice to women living with HIV. The interviews were audio-recorded and fully transcribed. Interviewees were encouraged to respond in their first language. Data collection continued until saturation was reached in the themes identified in the analysis. Two trained research assistants with university-level education in the social sciences were used for data collection.

Data analysis

Athematic content analysis was conducted. Post-interview transcription was carried out in English and manually coded per the themes. After field work, stakeholders' meetings were held to review the interview transcripts to begin to identify emergent themes. Another researcher reviewed and recorded the transcripts for the second time to see the level of concurrence or discrepancies for possible harmonisation. Finally, summaries of coded responses were produced according to type and frequency within each theme, which was used to examine the pattern in responses within and between respondent types.

Ethical issues

Ethical approval for the study was obtained from the Health Research Ethics Committee of the Moddibo Adama University Teaching Hospital, Yola, Adamawa State (MAUTHYOLA/SUB/S.128/206). Support was sought from the Taraba focal person, who oversees and supervises the MMs in the state. Written informed consent for both the interview and tape recording was obtained from the mentor mothers after explaining to them the purpose of the study. Their participation was voluntary, and the decision of those who declined consent was respected, without any consequence to them or withdrawal of any privileges or benefits due to them. Privacy was ensured, and interviews were held at venues chosen by each respondent as they deemed convenient. To protect anonymity, each participant was given a unique identifier beginning with 'MM' for Mentor Mother. Their names and personal identifiers, such as phone numbers, NIN, were not revealed in the data collection, analysis, and reporting of study findings. The information storage on a personal computer or laptop, hard disk, and memory stick was password-protected. Both written and electronic data from this study will be stored for five years. However, the interview recordings will be disposed of once they are no longer needed.

Results

Participants' characteristics

We conducted in-depth interviews with 16 mentor mothers in 4 LGAs of Taraba State. The mean age of the participants was 40.6 years ± 5.9 SD, and the mean years of practice as MMs was 6.3 years. All the MMs were educated up to secondary school level, with over half of them 9 (56.2%) having tertiary education. Most of the participants,10 (62.5%), were widowed, while one-quarter, 4 (25%.0), were married. They had all received training and retraining on the mentorship job through the support and coordination of some international partners, like FHI360, AHNNI, APIN, and RISE.

Table 1: Sociodemographic profile of MMs interviewed.

Characteristics	Frequency (%)
Age group (years)	
<40	6 (37.5)
≥40	10 (62.5)
Mean (SD)	40.6 (5.9)
Marital status	
Married	4 (25.0)
Separated	2 (12.5)
Widowed	10 (62.5)
Education	
Secondary	7 (43.8)
Tertiary	9 (56.2)
Years of HIV diagnosis	
<10	4 (25.0)
≥10	12 (75.0)
Trained in mentorship	
Yes	14 (87.5)
No	2 (12.5)
Years of mentorship	
≤5	7 (46.7)
>5	8 (53.3)

Personal experience upon HIV diagnosis

Many alluded to the fact that when they were diagnosed with the virus, they received the result with great shock, denial, nervousness, fear of disclosure, fear of death, stigmatisation, and thoughts of committing suicide. "*It was a moment I cannot forget… I was not myself again, and it took me a long time to accept the outcome and to live with it till now*" (MM1). "*It was a sad story because I was pregnant and the fear* *of disclosing the result to my husband further compounded my fear. My husband was negative*" (MM3). "*I was shocked with the fear of stigmatisation, how will people see me, and how will people say I got the virus from"* (MM5). On the other hand, 2 of the MMs expressed joy at knowing their status. "*I was so excited to just know about my status, I was so happy and felt like it was redemption that had come to me. Everyone in the hospital was surprised at my response to the result. But I had a feeling of joy that the problem that I have been suffering from that was unknown has been discovered, and the solution will not be difficult to find also*" (MM10). *"When the status was disclosed to me, it was like a burden lifted from my heart now that my status has been disclosed to me. I had a feeling of being healed and free"* (MM11).

The place of good counselling and follow-up.

Many respondents spoke glowingly about the quality of pre- and post-test counselling they received when they were diagnosed. This, they said, greatly assisted them in accepting their HIV results, overcoming the initial feelings, and enhancing their adherence to the medications. "*But with the best counselling I received in the facility it was very easy for me, that is why up to today I encourage us should have a very good counselor at the facility, because these are the entry paths for everyone that has HIV because the counseling you receive at the beginning is what will build you up. But if you did not receive very good counselling from the foundation, seriously, it will be very difficult for your subsequent years."* (MM2). Another 35-year-old respondent with 4 years' experience in mentorship had this to say: *"I was indeed worried and troubled, but the woman kept following me up and advising me on how to cope and live with the virus; I understood her, and we became good friends"* (MM13).

Client's ease of HIV status disclosure and sharing of their reactions to their HIV result.

While some women are usually open to disclosing their HIV status and sharing their own experiences with the mentors, others are slow and skeptical to open up to the MMs at first. *"Some of them would like to know yours before they dare to disclose their status. Once they know you are also HIV positive, then they open up to you*" (MM6). "*Our women have this issue of stigma. A lot of them don't open up to me until I disclose my status to them, and they were able to open up and tell me about their status too*" (MM9).

MM's sharing with clients of their personal experiences of living with the virus

All the respondents affirmed that they usually disclose their HIV status to mentees as a mark of responsibility to allay the fear of stigma, break down communication barriers, instill confidence, foster greater collaboration, improve drug uptake, encourage referrals, and enhance positive living with the virus. An MM puts it so elaborately, thus: "*It gives the client the confidence to believe that the program works. She would say seriously! If this woman passed through this, and she looks like this, at least I too, I will be able to look the same. Some even doubt the disclosure from the mentor mothers, believing that it is only a strategy to convince them of service uptake. So, if mentor mothers fail to disclose their status, it could be a barrier to both communicating freely and frankly. If mentor mothers fail to disclose their status, the clients will believe that the mentor mothers do not know how they feel being HIV positive*" (MM2). Another also corroborated this practice among the MMs. *"You know these women, if you don't tell them who you are and what you have passed through, they will feel shy in disclosing their status. So, I used to tell them about my experience and how I got infected. This gets them to come closer to me and speak more freely. And it offers me the opportunity to encourage them on regular drug uptake"* (MM5).

MMs' physical and emotional reactions to the stories of clients

Most of the MMs agreed that listening to the stories of their clients evokes different emotional and psychological feelings in them. *"I calm myself and reflect on my personal experience. (MM8) At times I cry, and sometimes I console myself" (MM14).*

Positive things that bring healing and empowerment and keep the MMs going on with their job.

Helping clients to accept the condition and bounce back to life, adherence to medications, and a negative HIV result of HIV-exposed babies are the dominant reasons that encourage the MMs to continue their work. "*By restoring hope in those who considered their situation to be hopeless"* (MM8). Another said: "*When clients who were distressed rebound in their medication pick-ups, through sharing of my personal experience, I feel elated"* (MM3). "*When clients follow the advice and give birth to negative babies"* (MM14). A particular MM said that her personal experience of having 4 negative babies after her diagnosis is her biggest encouragement to keep telling other women that they too can have the same result if they continue in the programme (MM2)

Impact of the MM's role on family and relationships

Most MMs said their role has not impacted their family and relationships negatively, but rather, they have strong family support in what they do. "*It has not affected my relationship with the immediate family members, nor my place of work and neighbours"* (MM5). "*My immediate family is aware and supportive, except for my neighbours. At the place of work, all of us are of the same status, so no discrimination"* (MM8). For one MM, the impact is both ways: "*I lost some friends because of my status, but on the positive side, I gained some friends who are kind to me and relate well with me because of the work I do"* (MM2). Another said: "*I became a source of encouragement to some family members, and it has enhanced our relationship"* (MM3).

Coping strategies adopted by MMs in managing the effect of their job on their lives and families.

MMs adopt different strategies to manage the effects of the job, such as secondary trauma, stress, discouragement, etc, on their personal and family life. The majority said they engage in religious activities and relax with family and friends to ease stress and tiredness. "*I interact with church members, participate in religious activities, listen to gospel messages, and have faith in God"* (MM1). *"I sleep, sing, play with children in my neighbourhood"* (MM4). *"I find time to interact with friends and families. And ask for support when necessary"* (MM6) *"Singing, dancing, joking and playing around with people"* (MM12)

Willingness of other women in the community to also serve as MMs.

While some women in the community also want to serve as MMs if given the opportunity, others resent the job for fear of having to disclose their status to other women. All the respondents agreed that they know some women who are interested in becoming MMs, too. The constraint for most of them is the lack of training and support on how to do the job. *"Some women like to be mentor mothers also but lack the opportunity to be enrolled and trained. Some are constrained by transport fares"* (MM5). An MM explained further what other women see as an attraction in the job, thus: "*Disclosure of status emboldens you to move freely in the society. It also removes the fear of people knowing your status and creates health consciousness in you to look after yourself as a good example to other women"* (MM8).

Discussion

In this study, we explored the experiences of MMs from the point of undertaking their own HIV counselling and testing, to how the work they do affects their relationship with friends and families; the positive and or negative sides of their involvement in the program and the strategies adopted to cope with the consequences of the negative impact on their health and wellbeing as well as on the program. We found that most women show varying emotional responses after receiving an HIV diagnosis, ranging from shock, weeping, fear of disclosure, fear of stigma and discrimination, to fear of death. This is, however, not peculiar or exclusive to MMs but all women and people generally who test positive at the initial time, as corroborated by other studies among non-MMs[4,25,26]. In a study in South Africa, 6 out of 10 pregnant and post-partum women affirmed that they were afraid of disclosing their status to someone after they received their test result.[27] This range of responses is considered expected to news of a chronic, potentially life-threatening, as well as stigmatising medical condition.[28]

However, very instructive during their initial experiences was the place of the counselling and testing they received. A good HIV post-testing counselling is vital in helping people manage the shocks and have a proper understanding of the meaning and implications of the result[29,30]. To this, the MMs in our study said the quality of counselling they received, and the compassion, empathy, and care shown by those who tested and counselled them, contributed significantly to their healing and eventual adherence to their medications.

The willingness of MMs to disclose their status and share their PMTCT and lived HIV experiences has been found as an essential quality that enhances the retention of women in the PMTCT program.[4,31] It is generally assumed that MMs have overcome self-stigma and are therefore not afraid to disclose their status.[12,24] This is, however, not always the case, as reported by a study in north-central Nigeria, where mentor mothers did not consistently disclose to their mentored clients, with community-level stigma and discrimination stated as major reasons for the non-disclosure.[32] This is unlike our findings, where all the MMs agreed that they always share their own lived experiences with the clients and that it helps build trust and confidence of the women in the effectiveness of the program.

Consistent with other studies, MMs in this study also stated that they were motivated by empowering other women to prevent mother-to-child transmission of HIV.[18,24,33] In addition, financial gains from the stipend provided by the program, as well as community recognition of their work, can also serve as motivators. Some respondents felt elated by their elevated status in society, as well as recognition and an increase in their cycle of influence, just for being MMs. Given the pivotal role they play and the costs associated with their job, it is important that adequate funding, at least to cover transportation costs for home visits, support group meetings, phone calls, and text messages to clients, is provided to serve as compensation and incentives to the MMs.[12,18] In a study, the MMs confirmed that their stipends were critically needed as part or all of their livelihood.[20] It is said that some MMs survive largely from the financial remuneration they get in the program, as some have lost their breadwinners and other means of livelihood.[20]

The role played by MMs has the potential to affect their emotional, psychosocial, and physical well-being; hence, the need for them to develop coping mechanisms to manage these effects. Most respondents admitted that repeated sharing of experiences with their clients oftentimes invokes traumatic and distressing experiences; due partly to some of the challenges they had faced, including discrimination and rejection from loved ones, as well as the aspect of poverty and lack of cooperation from their male partners. Previous studies have corroborated ours in reporting various strategies adopted by MMs to cope with such challenges as well as other demands of their work, including engagement in religious activities such as praying, singing, dancing, support group meetings, as well as relaxation and talking with family and friends.[13] Others added that they had to develop the courage to control their emotions and feelings to be good examples and models to their clients who look up to them. A study in South Africa also mentioned religion and social support as part of the coping strategies employed by HIV-pregnant women[34]. Elsewhere, MMs have also reported that the part of volunteering in providing support to other women has equally enabled them to experience personal growth in self-esteem and self-confidence.[4]

Conclusion

This qualitative study provides insight into the activities of MMs in Taraba State and the psychosocial impact of the job on their lives. MMs in Taraba have overcome fears, stigma, and discrimination; are living positively with the virus; and the role they play has no negative impact on their psychosocial well-being. To maintain this, the MMs engage in religious activities as well as spending time relaxing with family and friends. Recruitment, training, and retraining of MMs should therefore be considered by those who are designing programmes for the support of pregnant women with HIV and the prevention of mother-to-child transmission of HIV. This should include adequate provision for the holistic support of MM themselves to enable them to discharge their onerous responsibility successfully.

Conflicts of interest

The authors declare that they have no conflicts of interest.

Acknowledgment

The authors are grateful to Armstrong Finchur, a final-year student in the Department of Computer Science, Modibbo Adama University, Yola, Adamawa State, Nigeria. He assisted in doing voice recordings of the interviews and translations from Hausa to English. This study was supported in part by the Fogarty International Centre of the National Institutes of Health (NIH) under award number: D43TW010934. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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