ORIGINAL RESEARCH ARTICLE

Challenges encountered by human immunodeficiency virus positive pregnant women on taking antiretrovirals in a public health unit of the Manzini region, Swaziland

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*Trusty L. Mbatha and Debbie SK. Habedi**

Department of Health Studies, University of South Africa

***For Correspondence:** Email: *habeddsk@unisa.ac.za*; Phone: +27 72 520 1130

Abstract

In Swaziland, the Ministry of Health adopted the prevention of mother-to-transmission (PMTCT) Option A as a feasible and less costly way to expand the PMTCT services nationwide. Despite major success since the programme started, some barriers, such as the challenge of follow-up care for human immunodeficiency virus (HIV)-positive pregnant mothers still exist. The present study aimed to describe the challenges that HIV-positive pregnant mothers encountered on taking antiretrovirals (ARVs) in a health unit of the Manzini region, Swaziland. A qualitative, exploratory and descriptive research design was used, and data were collected through semi-structured individual interviews and field notes. Purposive sampling was used to select the study site and the population. Permission was requested from the participants to record the interviews. The study population were HIV-positive pregnant mothers, aged between 18 and 40 years, which were enrolled in the PMTCT B+ programme. The PMTCT B+ programme was perceived as preventing the transfer of HIV transmission from mother to child. It boosts the mother's immune system, prevents opportunistic infections and prolongs life. Challenges of taking ARVs emerged as a theme. The participants displayed knowledge and understanding of the programme, yet discrimination and no support from families and partners were mentioned. *(Afr J Reprod Health 2022; 26[5]: 41-49).*

Keywords: Challenges, HIV, positive pregnant mothers, antiretrovirals, health unit, Swaziland

Résumé

Au Swaziland, le ministère de la Santé a adopté l'option A de prévention de la transmission de la mère à la transmission (PTME) comme moyen faisable et moins coûteux d'étendre les services de PTME à l'échelle nationale. Malgré le succès majeur depuis le début du programme, certains obstacles, tels que le défi des soins de suivi pour les femmes enceintes séropositives pour le virus de l'immunodéficience humaine (VIH), existent toujours. La présente étude visait à décrire les difficultés rencontrées par les femmes enceintes séropositives lors de la prise d'antirétroviraux (ARV) dans une unité de santé de la région de Manzini, au Swaziland. Un devis de recherche qualitatif, exploratoire et descriptif a été utilisé, et les données ont été recueillies par le biais d'entretiens individuels semi-structurés et de notes de terrain. Un échantillonnage raisonné a été utilisé pour sélectionner le site d'étude et la population. La permission a été demandée aux participants d'enregistrer les entretiens. La population étudiée était constituée de femmes enceintes séropositives, âgées de 18 à 40 ans, inscrites au programme PMTCT B+. Le programme PMTCT B+ était perçu comme empêchant le transfert de la transmission du VIH de la mère à l'enfant. Il renforce le système immunitaire de la mère, prévient les infections opportunistes et prolonge la vie. Les défis liés à la prise d'ARV sont apparus comme un thème. Les participants ont fait preuve de connaissance et de compréhension du programme, mais la discrimination et l'absence de soutien de la part des familles et des partenaires ont été mentionnés. *(Afr J Reprod Health 2022; 26[5]: 41-49).*

Mots-clés: Défis, VIH, femmes enceintes séropositives, antirétroviraux, unité de santé, Swaziland

Introduction

Human immunodeficiency virus (HIV)-positive pregnant mothers who visit antenatal care (ANC) clinics, should be given information on HIV prevention, including prevention of mother-to-child transmission (PMTCT). Despite robust evidence that immediate antiretroviral therapy (ART) initiation reduces transmission of HIV from mother to child, some pregnant women living with HIV in sub-Saharan Africa (SSA), and Swaziland in particular continue to refuse ART[1].The global prevalence of HIV has expanded since its discovery and has spread across the globe despite advances in antiretroviral treatments. The mortality and morbidity rates related to HIV infections remain

high in developing countries largely due to food insecurity and malnutrition[2].

Effective management of HIV is possible through different combinations of available drugs. This method of treatment is collectively known as ART. Standard ART is a comprised a mixture of at least three medicines (termed as "highly active antiretroviral therapy" or HAART)[3]. One of the major challenges that patients and physicians face with ART, is the incidence of adverse drug reaction (ADR). ADR is defined as a "*response to a drug that is noxious and unintended and occurs at doses normally used in man for the prophylaxis, diagnosis, or therapy of disease, or for modification of physiological function"*[4]. ADR often discourages patients to continue treatment, resulting in suboptimal efficacy. A serious consequence of treatment discontinuation is the emergence of drug resistance, making future therapeutic interventions ineffective[5].

HIV and acquired immune-deficiency syndrome (AIDS) remain a serious health challenge, globally, particularly amongst pregnant women and their babies, through mother-to-child transmission (MTCT). MTCT of HIV remains one of the major causes of HIV infection amongst infants in resource-limited settings. In efforts to reduce MTCT, the World Health Organization (WHO) launched the Option B+ strategy in 2011, to reduce mortality in mothers with the goal of a 90% reduction of HIV incidents in children by 2015[6-8].

An estimated 1.7 million children are living with HIV worldwide. According to 2020 figures most of these children live in sub-Saharan Africa and were infected through transmission from their mothers during pregnancy, childbirth or breastfeeding. Around 150 000 children [100 000-240 000] became newly infected with HIV in 2020 globally[9]. Although the Government of Swaziland has demonstrated a high level of commitment to the virtual elimination of paediatric infection due to MTCT of HIV, there is still a significant increase in the number of HIV positive children born. eSwatini (formerly Swaziland), is a small population-sized sub-Saharan African country characterized by its highest HIV prevalence globally[10]. This prompted the researchers to describe the challenges that HIV-positive pregnant mothers encountered on taking ARVs in a health unit of the Manzini region, Swaziland.

The HIV prevalence in Swaziland is estimated at 31% among adults (between 18 to 49 years old) and the annual HIV incidences are 2.5%. HIV disproportionately affects women and peaks at 49% in the age group 25 to 29 years old and is overall 41.1% among pregnant women. Until 2014, the Swaziland National PMTCT progamme applied the WHO PMTCTA approach, whereby women with CD4<350 and/or who have stage 3 to 4 disease were eligible for lifelong ART. Women not fulfilling these criteria were offered AZT from 14 weeks of gestation, AZT/3TC at delivery for one week, followed by AZT until the end of the breastfeeding period. Because PMTCTA remained the standard of care nationally and per guidance from the Ministry of Health, women were still allowed to opt for AZT in the PMTCT B+ programme[11].

Therefore, the issue or gap addressed in this paper is about retention, adherence and follow-up to Option B+ programme by HIV positive pregnant mothers on taking ARVs in a health unit of Manzini region, Swaziland. So, commitment to lifelong enrollment of ARVs treatment is of importance because an ongoing practice of care would in one way or the other alleviate the challenges encountered by HIV positive pregnant women. It should also be noted that in 2014, eSwatini endorsed Option B+ for PMTCT, at which all health facilities in the country transitioned to the Option B+ approach.

Methods

Study design

Qualitative exploratory and descriptive research design was used for this study to describe the challenges encountered by HIV positive pregnant mothers on taking ARVs in a public health unit in the Manzini region, Swaziland.

Study setting and population

The study was conducted in a semi urban setting, in a public health Unit of the Manzini region, Swaziland. The facility provides services for out-patients and offers preventive care and a public health programme. Services provided include provider-initiated HIV testing and counseling (PIHTC), PMTCT, ART, antenatal care (ANC), child welfare (CWF), sexually transmission

infections (STIs) treatment, laboratory services and so forth. The choice of the setting was influenced by the fact that it was a pilot site where the PMTCT B+ programme was implemented. The identified and accessible population which could participate in the study consisted of HIV-positive pregnant mothers who had enrolled in the PMTCT B+ programme.

Selection of study participants

Purposive sampling was used to select the public health unit and the participants because it was a pilot site for the PMTCT B+ programme's implementation. The HIV-positive pregnant women who had enrolled in the PMTCT B+ programme were identified by the nurses at the antenatal department. Those who came to the facility for an antenatal check-up and agreed to participate were interviewed.

Data collection

Semi-structured interviews were conducted with HIV-positive pregnant women. The interview guide was developed in both English and siSwati, using research objectives and questions as guidelines. The interview guide consisted of open-ended questions that allowed the participants to freely describe the challenges they encountered when taking ARVs in a public health unit in the Manzini region, Swaziland. The pilot study was conducted with three HIV-positive pregnant women enrolled in the PMTCT B+ programme as they had similar characteristics to the actual participants to be studied. Data were collected over one month in the mornings on the stipulated ANC services dates. ANC unit nurses facilitated the process by introducing the researcher and informing all HIV positive pregnant women enrolled in the PMTCT B+ programme about the study. A room was prepared for the interviews to allow privacy and a tape recorder was used to record the interviews, after permission was obtained from the participants. Each interview recording was labelled with an assigned code according to the date the interview took place. The interview length ranged between 30 and 40 minutes per participant. A research assistant, who was experienced and knowledgeable about the ethical aspects of research, was recruited to assist with the research. The research assistant noted verbal and non-verbal responses during the interviews. Data were collected until the moment saturation was researched after the 17th participant.

Data management and analysis

Data were analysed using the Tesch steps format[12]. Computer software was used for analysis and data from the tape recorder were transcribed and transferred to it. The researcher read all the transcripts carefully and notes were made of some ideas as they came to mind. All underlying meanings were noted down, and all the same topics were put together and grouped into major topics. The entire data file was entered into the computer. The researchers read the data carefully to familiarise themselves with, after which all topics were assigned an abbreviated and identified code, written next to the data segments that corresponded with the codes. The next step was to find the most descriptive wording for the topics and turned them into themes and categories; related topics were grouped together to reduce the total list of themes and categories. The codes were then alphabetised after the final decision on the abbreviation for each theme/category. The data were cut and pasted to the different themes and categories before a preliminary analysis was done. This was followed by interpreting and reporting the research findings.

Measures to ensure trustworthiness

It is important to conduct high quality qualitative research that is informative, insightful and accurate while maintaining scientific excellence[13]. Credibility was adhered to by purposively sampling participants for the interviews. Semi-structured interviews were conducted and there was consistency in the questions asked, one interview tool was used throughout the interview process. To ensure transferability, participants were described. Data collection continued until saturation was reached. Dependability was ensured by consistency in the data collection (one data collection tool utilised). The steps of data collection were outlined and documented transparently. Confirmability was ensured by recording the field notes, themes and categories. A tape recorder was used to record the interviews, it was then transcribed. Regarding transferability, research findings would be forwarded to the research site to be used in improving the implemented PMTCT B+ programme. Authenticity was enhanced by the felt tone of the participants lives as they were lived, and the study being conducted within their natural environments.

Findings

Characteristics of study participants

The 17 participants were between the ages of 18 and 40 years and lived in the Manzini region in Swaziland, near the facility where the study was conducted. Regarding the level of education, four pregnant HIV- positive pregnant women enrolled in the PMTCT B+ programme completed primary school level, seven completed secondary school and six had completed a higher level of education. Four of the participants were working and 13 were unemployed. Ten participants were married and seven were unmarried. Six were pregnant for the first time, four were for the second time, two for the third time, two for the fourth time, one for the fifth time, one for the sixth time and one for the seventh time. Ten mentioned that they had tested their children for HIV (this question was excluded for those without children). Four women indicated that they did not test their children, hence this was worrisome. Most of the participants reported that they wanted to know their status and one reported that she was tested while in hospital.

Taking of antiretrovirals in a health unit by HIV positive pregnant mothers

The theme that emerged in the study was about challenges with taking ARVs. Four subthemes under this theme include disclosure and discrimination, partner testing, side effects of ART and challenges with failure of adherence. Table 1 indicates the theme and the sub-themes.

Challenges with taking ARVs

Regardless of the PMTCT B+ programme being good, there were challenges that HIV-positive pregnant women encountered. Knowledge and understanding of the programme were displayed by the participants even though challenges such as discrimination and no support by families and partners were mentioned. There was a great impact of starting the PMTCT B+ programme for the first time and also disclosing their HIV status to their partners.

Sub-theme 1.1: Disclosure and discrimination

Some participants reported that they we unsupported by their partners who discriminated against them, mostly after starting the medication. Others even left them, as they did not want anything to do with them. They did not only have the challenges to disclose their status to their partners, but also have challenges to disclose their status to their family members, as some said that they have a challenge to disclose their status to their parents or mothers. These responses indicated that most HIV-positive pregnant women have difficulty disclosing their status to their partners and family and this may have a huge effect on adherence to treatment since they need support from their partners and families. The following are some of the responses from the HIV-positive pregnant women (PW) enrolled in the PMTCT B+ programme about the challenges they encountered:

> *"I have known my status for five years now, but I have not disclosed my status to my husband because I am afraid, he may leave me and my children." (PW2).*
>
> *"I have difficulty with disclosing my status to my partner, also of telling him that I am now taking ARVs." (PW1).*
>
> *"It is really challenging when coming to disclosure, maybe I may disclose to my sister, but not to my parents and my partner." (PW5).*
>
> *"I am afraid of disclosing my status to my family and friends." (PW9).*
>
> *"I have a challenge of disclosing my status to my partner and family members because they may not be able to accept my status. I even hide my tablets from them." (PW11).*

HIV positive pregnant women needed to be encouraged to disclose their HIV status to their partners and family members. One benefit of disclosure is to assist HIV-positive individuals in taking their medication properly as they will be able to take the medication openly and acknowledge their HIV status[14].

Sub-theme 1.2: Partner testing

Even though the nurses at the facility emphasised partner testing, participants still had a challenge as some partners refused to do HIV testing. Some responded that:

> *"My boyfriend even refuses to have sexual intercourse with me after I disclosed my status. I do not even know his status because he refuses to test together even though I told him that the nurses requested that we must do HIV test together." (PW16).*

Table 1: Theme and sub-themes of HIV positive pregnant women

Theme	Sub-themes
1. Challenges with taking ARVs	1.1 Disclosure and Discrimination
	1.2 Partner testing
	1.3 Side effects of ART
	1.4 Challenges with failure of adherence

"I still had not disclosed my status to my partner even though I had known my status for five years. Every time when I visited the clinic the nurses encouraged me to disclose my status, but my husband refused to come with me for testing." (PW3).

The Swaziland Government has to come up with strategies to strengthen male involvement. The partners even refused to do HIV tests with them as a couple. For these programmes to be effective, HIV-positive pr/egnant mothers need to take their medication regularly and openly. One participant responded that once they disclosed their status to their partners, their partners left them. This indicates that there are a number of male partners who still have a fear of associating with HIV-positive partners. Even though the Swaziland Ministry of Health had been sensitising people through the media (television and radios), healthcare facilities, community gatherings, rural kraal, schools, health talks, pamphlets, drama, and advertisements about HIV; some people have not taken in the message fully, while others are illiterate[15].

Sub-theme 1.3: Side effects of ART

The other challenges reported were that some participants experienced side effects when starting to take the medication. This includes dizziness and swelling of the feet. Other participants reported that they have a challenge in taking their medication because they felt healthy and fit every day. Their responses were as follows:

"I have a challenge of taking medication every day even when I do not have any pains." (PW2).

"Knowing that I have to take drugs every day even when I am not sick is a huge challenge for me." (PW4).

"…Knowing that I will be taking medication for the rest of my life even when I am not ill is really stressing me sometimes." (PW6).

"The side effects of the drugs I am experiencing sometimes make me want to stop taking the medication. What make me continue taking them is that I want my child to be HIV negative." (PW8).

"When I started taking the tablets, I experienced swelling of feet, but now I am fine." (PW13).

"When I started the treatment, I had dizziness, maybe it was because my body was still adjusting to the medication." (PW14).

The study conducted on facilitators and barriers to lifelong use of ART among HIV-positive pregnant women in Uganda assert that all mothers reported side effects ranging from vomiting, headache, drowsiness, body weakness and nightmares. Some stopped taking the medication due to the side effects[16].

Sub-theme 1.4: Challenges with failure of adherence

These challenges may have a great impact on the effectiveness of the programme and may even result in some HIV-positive pregnant women to cease taking the medication. Some passed through the phases as their partners and family members supported them. Below are some of their views:

"I do not have any challenges because my family is supportive and my partner even went for HIV testing." (PW10).

"I had initially thought that I will fail to adhere to the time, but luckily I am reminded each time I had to take the medication." (PW12).

"None because I had disclosed to someone I trust; stigma is no longer an issue." (PW17).

The above responses indicated that with support from their partners and family members, the HIV-positive pregnant women overcame their challenges and took ART medication, which resulted in the success of the PMTCT B+ programme and the increased the number of children testing HIV negative. Support from family and friends, and good relationships between patients, health care workers,

and the community, had a positive influence on adherence to ART treatment[17].

Discussion

The study described the challenges encountered by HIV positive pregnant mothers while taking ARVs in a public health unit of the Manzini region, Swaziland. In 2015, in an effort to prevent MTCT of HIV and to improve maternal health, the WHO introduced the Option B+ programme, a treatment approach involving lifelong ART for all pregnant and breastfeeding HIV positive women, regardless of disease severity[18]. Compared to receiving no therapy, ART during pregnancy brings significant and undisputed benefits: as it reduces the risk of HIV MTCT, infant mortality and fetal demise[17]. ART use during pregnancy is an essential public health intervention that promotes maternal health and prevents HIV MTCT[19]. MTCT of HIV remains a major cause of HIV infection amongst infants in resource limited settings[6].

In 2014, Swaziland adopted the strategy of universal access to treatment, to ensure that all pregnant women living with HIV had unhindered access to ART services. Despite the noble strategy, some HIV positive pregnant women continue to refuse ART initiation in Swaziland[1].

Disclosure and discrimination

Mothers are the first port of call in the disclosure trail, in line with cultural practices. The study conducted on deterrents to immediate ART initiation by pregnant women living with HIV in the Hhohho region, Swaziland, showed that denial, emotional pain and shock were the main deterrents to ART initiation[1]. The shock and perceived stigma that manifested through fear of being discriminated against and rejected by partners, family and community members, is consistent across SSA[7,16].The findings on HIV positive pregnant women's fears of rejection and gossip by partners and the community, were congruent with the results from South Africa, Malawi and Tanzania, mostly in cases where women were financially dependent on male partners[20]. The study on reasons for delayed ART in Swaziland, the continued sensitivities around disclosure, even to close relatives, were reported[21]. Disclosure to family members was often complicated by the vulnerable economic circumstances in which women find themselves dependent on their partners and are concerned about the implications of stigma and maintaining the image of a good mother or wife.

Indeed, particularly for Swazi women, HIV-stigma is widely anticipated and experienced as disapproval from the wider community. Hence, anxieties about inadvertent disclosure to non-family members and its implications were evident among the patients who tested HIV positive and contributed to delayed HIV care. When ART was first made available, it was assumed that making HIV/AIDS treatable would lead to positive changes in denial, stigma and discrimination; unfortunately, this is not the case.

Partner testing

HIV positive pregnant women were concerned about the acceptance of their HIV status. Thus, the study found that they admitted that partners' and husbands' acceptance of their HIV status, was a factor that influenced their attitudes towards ART. With the participation of males in the antenatal clinics, they are more likely to accept partners HIV status to promote the PMTCT of HIV services. Further, the participation of partners or husbands in the PMTCT of HIV services for HIV- positive pregnant women, could help to encourage involvement in the PMTCT of HIV activities. This agrees with assertion that male participation in antenatal clinics and the PMTCT of HIV services helps to encourage adherence to health and safety protocols to protect pregnancies and prevent further transmissions among household members[22]. The participation of male partners in the PMTCT of HIV services enables midwives and health professionals to provide counselling services to couples and educate them about available treatments and support systems, which gives them the confidence to avail themselves for all the PMTCT of HIV activities[23].

Side effects of ART

The key reasons deterring women from immediate ART initiation, included shock, the perceived stigma, and fear of ART and its side effects[1]. Testing positive for pregnancy and then testing positive for HIV could be overwhelming, culminating in fear, pain, confusion, denial and disappointment, which in turn makes immediate ART uptake difficult. The findings are similar to those of the studies conducted in South Africa and Malawi, where women asked

health care workers for more time to assimilate their HIV results and confirm them in other health facilities. Like in other studies, HIV-positive pregnant women were not keen on being initiated on ART, fearing that side-effects would interfere with their physiological process, thereby affecting their psychological sense of self. Another barrier was skepticism about being subjected to lifelong ART, especially within the context of participants reporting that they did not feel sick.

Challenges with failure of adherence

Persons who test positive for HIV, delay care temporarily or indefinitely for a variety of social, cultural and health systems-related reasons. These include concerns about stigma, disclosure and toxicity of ART initiation that raise questions about the benefits of starting ART regardless of one's CD4 count[24].Qualitative research in southern Swaziland highlighted that patients need to come to terms with their diagnosis before initiating ART[25]. For a person who was not emotionally prepared, providers viewed hasty ART initiation as having negative implications on adherence. However, they were also aware that a patient who did not initiate ART and returned home, often with the intention of discussing their status with her or his partner, might not return to the health facility[26].

Factors such as, failure to disclose to spouses, the large size of the tablet and its side effects, the organisation of health services, and stigma, contributed to poor adherence[16]. Lack of disclosure was the most common reason for missing ARVs. Most women experiencing disclosure difficulties, consequently, struggle to adhere to their treatment.

Limitations

Like most qualitative studies, the findings cannot be generalised beyond the researched context. The study had narrow focus because only HIV-positive pregnant women between 18 and 40 years old participated. Even though Manzini is the largest region in Swaziland, only one public health unit was involved in the research. Future studies should include the whole of Swaziland and different age groups of HIV-positive pregnant women.

Ethical considerations

The researchers received ethical clearance from the University of South Africa Research Ethics Committee (REC-012714-039). Approval to conduct the study was obtained from the Ministry of Health, of the Kingdom of Swaziland (Ref: MH/599C/FWA 000 15267/IRB 000 9688). Participants were provided with detailed information about the study, and they voluntarily signed informed consent forms to participate. Participants were informed that they had the freedom to withdraw from the study at any time and that it would not affect the PMTCT Option B+ programme services offered to them. Furthermore, participants were informed that the study might be used for scientific purposes and may be published. Protection of the participants was ensured by adhering to the principles of beneficence, respect for human dignity and justice. Participants were protected from emotional harm by allowing them to volunteer to be interviewed. Confidentiality and anonymity were maintained by using codes instead of participants' names to protect their privacy. The procedures and expectations were explained to the participants in their own language and transparency was maintained. Interpretation of data was based on the collected data.

Conclusion

Understanding the benefits of taking antiretrovirals, adherence, and long-term retention, is crucial in increasing the benefits of lifelong ART. Therefore, adequate preparation of HIV-positive pregnant women before ART initiation and ongoing support through partners or husbands and families are important. Balancing between the need to urgently initiate treatment and comprehensively preparing HIV positive pregnant women to initiate and sustain treatment would require innovative counselling and support mechanisms to avoid compromising retention and adherence. Innovative interventions for assisted disclosure and the involvement of families and partners are critical in ensuring continuity of lifelong ART for HIV-positive pregnant women even after the ANC phase.

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Authors contributions

TL conducted the study. DSK provided overall scientific guidance in drafting the manuscript. All authors approved the submission of this manuscript.

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