

HIV Upsurge Among Children Aged Three to Eighteen Months. What are we missing? A Qualitative Study Conducted in Mangaung, South Africa

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Received Date: April 24, 2022 Accepted Date: May 24, 2022 Published Date: May 26, 2022

Citation: Phakis S (2022) HIV Upsurge Among Children Aged Three to Eighteen Months. What are we missing? A Qualitative Study Conducted in Mangaung, South Africa. J HIV AIDS Infect Dis 9: 1-9.

Abstract

Background: The Prevention-of-Mother-to-Child-Transmission (PMTCT) of the Human Immunodeficiency Virus (HIV) programme is showing significant embers of success globally, with some countries already achieving the goal of eliminating such transmission. South Africa has also shown significant reduction in this regard, as evidenced by data from the HIV Polymerase Chain Reaction (PCR) tests performed at ten weeks. Despite this success, the data from the National Health Laboratory Services (NHLS) shows more babies between the ages of three and eighteen months testing HIV positive in Free State Province and other parts of South Africa. It is in this context that the study sought primarily to identify the potential causal factors contributing to more children between the ages of three and eighteen months in Mangaung testing HIV-positive despite the low positivity rate at ten weeks.

Methods: A convergent mixed methods research design approach was adopted, with five purposefully sampled primary health facilities in Mangaung. The study population comprised mothers of children who tested HV-positive for the first time between the ages of three and eighteen months. Data was collected by means of unstructured individual interviews and saturation was reached with ten mothers already interviewed. The interviews themselves were transcribed verbatim and thematically analysed for incipient data preparation.

Results: The upsurge in children aged three to eighteen months testing positive was largely caused by their mothers' non-adherence to Prevention-of-Mother-to-Child-Transmission prescripts due to psychological, emotional, socio-economic and biological factors, post-natal HIV transmission through breastfeeding; as well as missed opportunities for the early infant diagnosis test and possible false negative results at ten weeks.

Conclusions: Failure of Prevention-of-Mother-to-Child-Transmission cannot be attributed to non-adherence to prescripts only, but also includes all qualitative factors entailed in the above-cited study results. These factors play a major role, but are sometimes overlooked.

Keywords: Upsurge, PMCTC, Non-adherence, Factors, EID, Prescripts

Introduction

The prevention of mother-to-child transmission (PMTCT) of HIV programme involves some strategies aimed at reducing vertical transmission of HIV, which is the main source of HIV infection in children [1]. Most countries have their own PMTCT guidelines, which are derived from the World Health Organization (WHO) and adjusted according to their specific contexts and unique demands [2]. These guidelines articulate helpful measures for the reduction of the mother to child transmission (MTCT) of HIV. To date, significant success has been manifested globally in reducing perinatal transmission as evidenced by PCR tests conducted at six/ten weeks; and the countries that have been validated to have eliminated MTCT of HIV according the WHO criteria [3,4]. In South Africa, babies undergo the HIV polymerase chain reaction (PCR) test at birth, ten weeks, six weeks post cessation of breastfeeding, and at sixteen weeks [5,6]. Furthermore, an antibody test is conducted for all babies at eighteen months, including those who are not HIV exposed. South Africa is also among the 23 UNAIDS priority countries for the elimination of mother-to-child transmission (EMTCT), and has demonstrated some remarkable progress in MTCT reduction [7]. This was also demonstrated by the 2012 South African Prevention of Mother to Child Transmission Evaluation survey (SAPMTCTE) conducted on babies aged four to eight weeks who visited primary healthcare (PHC) centres for the six-week immunisations [8,9].

Some studies have revealed some challenges regarding the positive results after the initial tests at ten weeks [7]. These mostly focus on post-natal transmission through breastfeeding, which is indeed a challenge [7]. However, little has been explored regarding whether breastfeeding is the only factor involved. Other factors regarding the sharp rise in positive tests after the six or ten-weeks test have not really been explored. Secondly, studies conducted to determine MTCT contributory factors have focused primarily on deviation from the PMTCT protocols, which includes identification and initiation of mothers who are HIV-infected on antiretroviral treatment (ART), adherence to treatment by these mothers, exclusive breastfeeding in the first six months, and early infant diagnosis [10]. In South Africa, few studies have been conducted to determine the reasons for such deviations. This is in spite of the gradual MTCT decline over the years, which was demonstrated by these tests conducted at ten weeks (six weeks prior to 2016). Data from the National Health Laboratory Services (NHLS) has shown that there are more babies who test HIV positive after the ten weeks'

routine tests in the Free State and other parts of the country [11]. It was also observed that the number of HIV positive children admitted in hospitals in Free State Province with positive HIV tests is still high compared to the low HIV negative tests around ten weeks and at birth. Accordingly, the primary aim of the study was to identify and describe the potential contributory factors which led to the non-adherence to PMTCT prescripts by mothers (why do mothers not adhere to PMTCT), and as well as the upsurge of HIV positive results in children aged three to eighteen months in Mangaung, South Africa.

Methods

The study employed a convergent parallel mixed methods approach, in terms of which both qualitative and quantitative data were collected and analysed separately, but compared for complementarity purposes [12]. However, the focus of this article will only be on the qualitative and descriptive aspects of the study.

Setting

The study was conducted at five primary healthcare facilities and one hospital in the Mangaung Metropolitan Municipality, Free State Province in South Africa

Study population and sampling strategy

The study population comprised mothers of HIV-positive children aged three to eighteen months. Cluster sampling was applied in the selection of the five primary healthcare facilities and one hospital in Mangaung. All mothers who met the eligibility criteria at the time of data collection were also included in the study.

Data collection

Data were collected by means of individual unstructured interviews in clinics where mothers attended their maternal and child health and HIV/AIDS services in 2018. Mothers whose babies were admitted they were conducted at the hospital. Information on when the HIV diagnosis was made was verified by the children's clinical records. The following 'grand tour' question was asked to the mothers: Please tell me about your journey (experiences) in the PMTCT programme. This was followed by probing questions. Saturation was reached after interviewing ten mothers. Overall,

Data analysis

The interviews were recorded and transcribed verbatim. Thematic data analysis was undertaken, in terms of which the interview scripts and field notes were read, coded and classified into categories and themes [13,12].

Ethical considerations

Ethical clearance was granted by the University of South Africa (UNISA) (HSHDC/599/2017). Permission to conduct the study at the Free State Department of Health public facilities was acquired from the Head of the Free State Health Department.

Results

Demographic characteristics

Some studies intimate that some demographic data aspects do impact on the challenges associated with PMTCT [14]. However, this was a qualitative study and the sample size was small as it was determined by saturation; therefore, the demographic findings may not necessarily have a significant bearing [15].

Table 1 below depicts the demographic information of the participants.

Table 1: Demographic characteristics of the participants

Demographic Information/ Variables	Number/ Frequency	
Age	18-25	2
	26-35	5
	36-45	3
Employment status	Employed	4
	Unemployed	6
Educational level	Primary school	2
	Did not complete high school	8
	Completed high school	3
	Tertiary education	0
Marital status	Single	6
	Married	3
	Cohabiting	1
Citizenship	South African	9
	Lesotho	1
Total	10	

Age

The majority of mothers (n=5) were aged 26-35 years, which is the average childbearing age in South Africa, as confirmed by South Africa's 2017 birth register information showing that the majority of live births were by women aged 25-34 [16].

Employment status

Four mothers were employed, while six were not, which is a general reflection of women's unemployment status due to childbirth related responsibilities [17]. Particularly for black African women, cultural factors do also limit employment opportunities [18].

Educational level

None of the mothers had tertiary education, while only 2 (two) completed high school education. Low level of education has been found to be one of the barriers to successful implementation of PMTCT strategies [17,19]. Contrarily, a systematic review of seven studies conducted in Sub-Saharan Africa showed there was an association between low education and non-adherence to ART, while nine studies found no association [20].

Citizenship

Nine mothers were South Africans, and one was a foreign national from the neighbouring Lesotho. Foreign nationals regarded the requirement of a South African identity document as a discriminatory measure against them, ignoring that it was mostly for identification purposes and that they could equally present their passports for the same purpose. Notwithstanding,

the Lesotho national did not attend antenatal care and HIV services for fear of deportation.

Emerging themes linked to PMCTC non-adherence

Table 2 below depicts some of the identified themes emerging from the data in relation to non-adherence to PMCTC prescripts.

Table 2: Themes and sub-themes

Themes	Sub-themes
1. Psychological factors	Overwhelming state
	Gullibility
	Unclosed life chapters
2. Socio economic factors	Migrant labour
3. Missed opportunities	Poor communication
	Inadequate accessibility to health services
4. Risky behaviour	Inconsistent or no condom use
	Non-adherence to ART

Theme 1: Psychological factors

Overwhelming state

One mother indicated that she was overwhelmed by the new diagnosis of HIV infection during pregnancy, and found it difficult to deal with it while also commencing ART and facing possible stigmatisation and discrimination. Consequently, she regularly received her ART from the clinic but threw the tablets away on the way home. She was classified as adhering to treatment because she adhered to the stipulated treatment intervals. To this effect, she stated:

“I got the medication each time I went to the clinic. But I did not drink them. I just fetched them because I did not want the nurses to scold me. This new diagnosis was too heavy on me, I suffered a lot of stress ... I did not have the strength to take the medications. I used to fetch them but threw them away on the way home from the clinic.... Whenever I came to the clinic I would lie about taking medication and they gave me more.”

Gullibility

Two mothers whose children tested HIV-positive before themselves, indicated that they did not consider themselves at risk of contracting HIV because they were gullible enough to believe in their partners' fidelity. One of these mothers corroborated thus:

“I was not scared of testing because I believed I was not at risk of contracting the disease I am married to a faithful husband..... There was absolutely nothing that could make me suspect that he could cheat on me..... It meant the three of us are all infected.”

The other mother indicated that she did not consider using condoms because her partner convinced her that he would not cheat. To that effect, she mentioned:

“We did not use condoms because I trusted my boyfriend, he had told me that I was his only girlfriend and he would not cheat on me. I do not know if he was already infected when we met, but I knew I was not positive.”

Unclosed life chapters

Two mothers experienced unclosed life chapters because they did not understand how, and when their children became infected. One of the mothers was HIV-positive and on ART prior to her pregnancy. She breastfed her child for six weeks and stopped for fear of infecting her child through breast milk. She also discontinued Nevirapine prophylaxis for the infant at six weeks. The child had tested HIV-negative at birth and at fourteen weeks. He was tested again at six months when he had an infection and was still negative. However, the child took ill at nine months, and was diagnosed pulmonary tuberculosis and HIV- positive. The mother was confounded by this development because the last exposure to the virus was at six weeks when she stopped breastfeeding and the child was negative at fourteen weeks and six months respectively. She related unclosed life chapter thus:

“Nobody is able to explain to me why my baby became infected I hope you will be able to tell me. I started giving the baby formula and stopped breastfeeding when he was six weeks ... the baby was tested at birth, at fourteen weeks and was negative. At six months my baby had some cough, I took him to the clinic where they gave him treatment for the cough and tested him for HIV and it was still negative. Why is it that my baby is now positive? It would make sense if the baby was positive at 14 weeks and now it's too late look at how sick he is? “

The other mother tested HIV-negative twice during pregnancy and twice during breastfeeding. She could not understand the reason for her baby becoming infected because she had never engaged in any sexual relationships since pregnancy when the father to the baby left her. However, the child tested positive at nine months, but was negative at ten and sixteen weeks. She related her experience thus:

“What I don't understand is why they could not detect it the four times that I tested and suddenly I hear it when the baby is sick, and I never had a boyfriend since I broke up with the father of this baby during pregnancy.”

Theme 2: Socio economic factors

Migrant labour

A twenty-six-year-old mother living in a farm left her baby with her mother while she went to work in Johannesburg. Her mother never took the child to the clinic after the three days check up until the child was admitted to hospital due to ill health at three months. The baby subsequently tested HIV-positive while admitted at the hospital. To this effect, the mother mentioned that:

“I breastfed for a month and left for Johannesburg where I got a job and left my baby with my mother. I came back home after 3 months because my baby was sick. My mother never took him to the clinic since I left, the only time was at that time when he was sick and had called me back home.”

Theme 3: Missed opportunities

Poor communication

Poor communication emerged as one of the reasons for late diagnosis of HIV in infants. One mother was diagnosed HIV-positive before her pregnancy and was already on ART. However, the ‘Road to Health’ booklet (child's clinic record) did not indicate any HIV exposure to her baby, and therefore was not tested for HIV at birth and at ten weeks, but was tested for the first time at ten months and was positive. In this regard, the actual moment of the child's infection was unclear. The mother had visited the clinic regularly for her own ART, but the baby's HIV exposure was missed because of fragmented services (separate rooms for provision of ART and child services). This mother testified as follows:

“The last time I took my baby to the clinic the nurse told me he was going to take blood for HIV test from my baby, he told me it should have been taken when the baby was ten weeks and now the baby was ten months old when the test was done.

Inadequate accessibility to health services

Some mothers reported that they lived very far from the clinics, and mobile clinic services were not provided regularly in their area. Consequently, they booked antenatal care late, missed their babies' clinic visits and HIV tests. One baby never had a

clinic visit until the age of six months because the mobile clinic had not visited their farm for months, as attested below:

“I went to the clinic late because I did not have money for transport, we mostly rely on the transport offered by the farmer when he comes to town. The mobile clinic had not been coming for some time..... the baby was also not tested at ten weeks because the mobile clinic did not come for a long time”.

Theme 4: Risky behaviour

Risky behaviour also emerged from the data, as demonstrated by inconsistent or no condom use, excessive alcohol consumption, PMTCT non-adherence despite the health education provided, and poor health-seeking habits. Five mothers reported the non-use of condoms, while another five reported inconsistent condom use. One mother reported drinking home brewed beer every day. Eight mothers did not adhere to PMTCT prescriptions (e.g., adherence to ART), exclusive breastfeeding, early antenatal booking, and early infant diagnosis (EID).

Inconsistent or no condom use

Some mothers reported inconsistent or no condom use because they trusted their partners. Some, because their partners did not like condoms, as indicated below:

“I did not use condoms. Men do not like condoms”.

“We did not use condoms because I trusted my boyfriend”

Discussion

The study findings demonstrate a variety of qualitative factors as narrated by mothers, that caused PMTCT non-adherence and the consequent upsurge in HIV positive tests in children aged three to eighteen months. Although the study focused on children who tested positive between the ages of three and eighteen months, some of these causal factors may also lead to transmission at an earlier age. The below-cited six factors linked to the non-adherence and upsurge were identified as specific to children aged three to eighteen months

The overwhelmed state of mothers following the new diagnosis during pregnancy and resulting in non-adherence to antiretroviral treatment, which is paramount to PMTCT. Accordingly, a false impression was created in terms of adhering to treatment with regular clinic visits to obtain ART, which was

thrown away on the way home. This highlights the importance of reviewing the strategies used to monitor adherence to treatment, since regular clinic visits do not guarantee this. Another common mistake would be to believe she is resistant to treatment if her viral load remained high despite obtaining her ART regularly. Some studies have also revealed the same action by mothers, but with the fear of stigma as the main cause [21-23]. However, lack of psychological support has also been cited as a reason for ART non-adherence [24].

Gullibility also emerged as a factor, where mothers trusted their partner's fidelity to a point that they did not believe they are capable of cheating on them and it has not really been documented much in literature. This is not only specific to PMTCT but to HIV prevention in general. This contradicts the popular HIV prevention mnemonic, namely: Abstain, Be faithful and Condomise (ABC). Accordingly, spousal or marital fidelity in this study being faithful has proven not to be feasible for all. The mothers were not overly bothered about abstinence or initiating condom use because they trusted their cheating partners, resulting in HIV infection acquisition during breastfeeding which is one of the high risk factors for post-natal transmission of HIV [25].

Failure of early infant diagnosis

The WHO recommends that all HIV-exposed infants should be tested at four to six weeks of age [26]. In South Africa the test is done at ten weeks [27,28]. This was a result of situations such as: poor accessibility to healthcare services (e.g., mothers from the farms with no reliable transport to healthcare facilities); migrant labour (as manifested by grandmother who never took the baby for required clinic visits since the mother was working in the city); and poor recording by health professionals (e.g., babies not properly classified as HIV-exposed). The latter issue could be averted with the provision of ART services in the same room as the child healthcare services. The fact that the mother received her ART regularly would alert the healthcare workers that the child was HIV-exposed, which in itself would prevent the late diagnosis of these infants. A meta-analysis conducted in Sub-Saharan Africa from 2002 to 2012 revealed that only two thirds of babies underwent the EID [28]. Those who missed the EAD could be erroneously classified as having acquired HIV through breastfeeding, when transmission during labour was not detected or ruled out through EID. Such a situation highlights the dangers of not classifying children who test positive or have clinical AIDS at a later stage as MTCT due to breast feeding [29].

Possibility of false negative results at ten weeks

This was manifested by babies who tested positive after an initial negative test without any subsequent exposure to HIV, which was established from the mothers' narratives and the clinical records. Some studies have suggested the possibility of false or indeterminate negative HIV PCR test due to maternal ART or infant prophylaxis [30]. Similarly, other studies have also questioned the ability of PCR tests to detect all sub-types due to HIV-I genetic diversity [30]. This was also demonstrated by a South African case-study conducted on a 15-month old boy who repeatedly had negative PCR test results despite the clinical picture suggesting HIV infection [31]. These babies could also increase the statistics of post-natal transmission through breastfeeding, whereas they could have been infected earlier during pregnancy or birth.

Late or no antenatal care

which was due to inaccessibility of health facilities and in turn resulted in late maternal diagnosis of HIV and delayed ART initiation [32]. A systematic review and meta-analysis also found that inaccessibility of health facilities also contributed to delayed maternal diagnosis of HIV [25]. Mothers went into labour only after a short period on ART, or only received prophylaxis during labour. Early ART initiation is paramount to PMTCT for purposes of ensuring that mothers go into labour without any detectable viral load [33].

Risky behaviour

This is manifested by lack of condom use and excessive alcohol consumption, which also caused PMTCT non-adherence. The study has shown that mothers' excessive drinking resulted in late antenatal booking, mixed feeding and poor adherence to ART, all of which are MTCT risk factors [25]. Lack of and inconsistent condom use could lead to primary infection or reinfection, which also poses an MTCT risk. The gullible (pliant) mothers form part of those who did not consider using condoms, whereas other mothers indicated their partners' refusal to use them. This accentuates the importance and benefit of partner involvement in PMTCT [34].

Limitations of the study

This study was qualitative, and characterised by limited generalisability to other areas of the Free State and the country. The study was conducted only among mothers who attended public healthcare facilities, and excluded those attending private facilities.

Conclusions

Mother to child transmission of HIV, or failure to prevent such transmission cannot be attributed only to non-adherence to PMTCT strategies. There are other causal factors, such as personal, social and biological influences. HIV-positive PCR or antibody tests after the age of six or ten weeks is not only due to post-natal transmission through breastfeeding. There are other influential factors, such as lack of EID and false negative results thereof. The strategy of service integration has to be strengthened to promote mother-child pair care and prevention of poor follow-up. The popular ABC mnemonic for HIV prevention is not feasible in all cases, and could be misleading in some instances [35]. Also, gullibility could negatively affect HIV prevention. To a greater extent, therefore, the study highlights the importance of considering all these relevant issues when providing and evaluating PMTCT services.

Acknowledgements

The author acknowledges Professor ON Makhubela-Nkhoto who was her supervisor during the undertaking of this study and the Health and welfare SETA – South Africa for funding this study.

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