

Initial reaction to HIV positive results during pregnancy and uptake of antiretroviral treatment among adolescents and young women; what are the implications for prevention of vertical transmission of HIV in Lesotho?

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Abstract

Introduction: In many settings in sub-Saharan Africa, most pregnant adolescent girls and young women (AGYW) are diagnosed with HIV during routine antenatal screening. Evidence points to low uptake of antiretroviral treatment (ART) in the immediate posttesting period, which put their infants at higher risk for HIV infection. Lesotho is one of the countries with high prevalence of HIV among this group, but limited studies have explored the experiences of pregnant AGYW with a positive diagnosis. This paper describes the initial reactions of AGYW after receiving the HIV positive results in pregnancy as well as their uptake of ART in the immediate post-testing period.

Methods: The study took place in prevention of mother to child transmission (PMTCT) sites located in urban areas of Maseru, Lesotho. Qualitative descriptive phenomenology was adopted and 15 AGYW were interviewed. Analysis used an inductive design with a thematic approach.

Results: Testing positive in pregnancy occurred in the context where most AGYW had not given thought to the routine antenatal HIV test. As such, they were emotionally unprepared for the positive test results. The AGYW reacted with intense shock, disbelief, fear, worry, sadness, and confusion. The intense emotions were compounded by the fear of vertical transmission of HIV and the urgency of initiating ART in the immediate post-testing period. In spite of all these emotions, most AGYW engaged in HIV care through the services offered in the PMTCT program.

Conclusion: The primary reason for initiating ART was to protect their unborn child. Hesitancy to initiate ART at the point of HIV diagnosis has implications for PMTCT interventions. Strengthening the programming for pregnant AGYW is essential to reaching global elimination of mother-to-child transmission goals.

KEY WORDS: Adolescents; antenatal care; antiretroviral treatment; HIV seropositive; elimination of HIV; Lesotho; pregnancy.

INTRODUCTION

Despite all the interventions to reduce the rates of new infections, the number of new HIV infections among adolescent and young women in sub-Saharan Africa (SSA) remains exceptionally high. Adolescents and young women (AGYW) account for sixty percent of all HIV new infections [1]. In Lesotho, the general prevalence of HIV is estimated to be 25.6% [2], and among young women (15–24) the prevalence of HIV is four times higher than that of their male counterparts [3]. Evidence points to increasing rate of acquiring HIV during pregnancy among AGYW, particularly in SSA. Almost one in five adolescents experience pregnancy between 10 and 19 years of age [4]. The rapid increase of new HIV infections among adolescents explains the rise to high prevalence of HIV positive pregnant adolescents [5].

Lesotho as one of the highly burdened countries in sub-Saharan, like other SSA countries, has adopted the World Health Organization's (WHO) recommendations on the prevention of mother-to-child interventions.

The prevention of mother-to-child transmission (PMTCT) program is an entry for HIV testing and for HIV-infected women. Research shows that AGYM are less likely to know their HIV status before their first antenatal care (ANC) [5–7]. Thus, in many settings in SSA, most AGYW are diagnosed during ANC services through PMTCT [5, 8, 9]. Lesotho has seen success in terms of uptake of PMTCT and early identification of HIV during the antenatal attendance [2, 10]. Those who uptake PMTCT in many settings regard it as a good program which protects their babies from acquiring HIV and provides a gateway to early treatment for the mothers [11–14].

Although HIV testing during routine pregnancy screening is generally accepted in many settings in SSA, women's experiences of receiving a positive HIV result in these settings have not been adequately explored in spite of the impact of a positive HIV result. HIV positive test result among pregnant women and adolescents induces feelings of

TAKE-HOME MESSAGE

A diagnosis of HIV received in pregnancy produces feelings of intense shock, disbelief, fear, worry, sadness, and confusion among adolescent girls and young women. The intense emotions that they experienced were heightened by the fear of infecting their unborn baby with HIV. Those that initiated ART in the immediate post-testing period did so to protect their unborn child from HIV infection.

Competing interests - none declared.

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intense shock, disbelief, anger, worry, and turmoil [15, 16]. Pregnant women experience these emotions because of the fear of infecting their unborn baby; having to start the lifelong treatment; fear of HIV related stigma and discrimination; and having to deal with disclosure of their HIV diagnosis to significant others [11, 13, 17]. Receiving positive test results during pregnancy is more psychologically devastating than learning about the HIV diagnosis prior to the pregnancy [18, 19]. Evidence points to low uptake of PMTCT services among pregnant AGYW in SSA, which puts their infants at higher risk for HIV infection [6, 8].

Many factors contribute to low uptake of ART in this population. AGYW presenting for ANC may be less emotionally prepared to accept the positive test result during pregnancy since they visited the clinic for non-HIV healthcare service and are most often asymptomatic. This might contribute to hesitancy or fear to initiate lifelong treatment immediately upon diagnosis [20]. The WHO recommends lifelong ART for HIV-infected pregnant and post-partum women initiated at the point of HIV diagnosis [21]. Further evidence points to reduced rate of uptake of PMTCT cascade [5], which begins with ANC, followed by HIV testing, and use of ART by the HIV-positive pregnant mother, and later her HIV-exposed infant [1]. The low uptake of ART in particular might also be linked to the fact that AGYW are less aware of their HIV status at the first ANC visit. Therefore, they perceive HIV testing on their first ANC visit as a mandatory entry requirement to access PMTCT services [11, 12, 18].

However, in Lesotho, as in many settings in SSA, little research has examined what pregnant AGYW experience after receiving the HIV positive result during pregnancy [15]. A small number of studies have explored the experiences of pregnant women [15, 22, 23] without focusing specifically on AGYW despite their vulnerability to HIV infection, unplanned pregnancy, and high probability of learning about their HIV diagnosis du-

ring pregnancy. Furthermore, there is dearth of data on AGYW in Lesotho to inform the efforts for targeted programming and HIV research to address the needs of this population [2, 9].

In this paper, we focused on exploring the initial reactions of AGYW after receiving the HIV positive results during pregnancy. We further examined their uptake of ART in the immediate post-testing period. Late or delayed uptake of ART results in increased vertical transmission of HIV and affects the achievement of eliminating new HIV infections in children [21]. Understanding AGYW experiences of receiving an HIV diagnosis in pregnancy is crucial to providing appropriate care and support to better engage them in the full continuum of HIV prevention, treatment, and care [1].

METHODS

Study design and setting

This paper presents data from a larger study that used descriptive phenomenology to understand how AGYW experience disclosure to their partners after testing HIV positive during their pregnancy [24]. The study settings were PMTCT sites located in urban areas of Maseru, the capital town of the Mountain Kingdom of Lesotho, a small landlocked country surrounded by South Africa. Women of childbearing age are estimated at 143,676 [25]. Maseru has about 60 public and private health facilities providing PMTCT services and other HIV-related services. The three PMTCT sites where the research was conducted see an average of 400 pregnant AGYW per month.

Descriptive phenomenology was appropriate to understand and describe the phenomenon of testing positive in pregnancy as experienced by AGYW without attempting to predict their behavior [26, 27]. We used purposive sampling to select AGYW who have experienced an HIV diagnosis in pregnancy [28]. The sample size consisted of 15 AGYW because the goal of phenomenological research is not to create results that can be ge-

neralized, but to understand a phenomenon. Phenomenology emphasizes rich qualitative accounts over the quantity of data, which is aligned with the principle of data saturation that guided the determination of the sample. We interviewed a small number of AGYW who received the HIV positive results in pregnancy to develop patterns and relationships of their experiences [29]. Whereas the sample in phenomenology is homogenous, we maintained variability and diversity in terms of the socio-demographics of the study participants to minimize information bias [30].

Data collection

The lead author (MP) used semi-structured in-depth interviews to collect data from the participants. The investigators developed an interview schedule of open-ended questions and, consistent with the tradition of phenomenology [27, 31, 32], the participants were asked broad, general questions. The researcher used the questions to gather data to come to a deeper understanding of participants' experiences of testing positive in pregnancy and uptake of ART in the immediate post-testing period. The researcher asked other questions and followed up on points raised in responses to the given questions, and used the interview schedule flexibly to allow the participants to speak freely about their experience of the phenomenon in their own words [27, 31]. To allow the participants to speak freely, the researcher conducted the interviews in Sesotho, the local language. The interviews were 30-45 minutes long and were recorded with consent. All participants were assigned a pseudonym to guarantee confidentiality.

Data analysis

The lead author and a trained research assistant transcribed verbatim the interviews in Sesotho, translated them into English, and checked the transcripts for accuracy against the audio recordings. We followed the thematic approach grounded in the tradition of descriptive phenomenology to analyse data as outlined in Sundler et al [33]. As the first step of data analysis, we listened to the re-

cordings and read the transcripts several times to get an overall sense of the data and to develop familiarity with the phenomenon described. Next, the authors searched and extracted statements for meanings to uncover emergent themes that described the lived experiences of the participants. Lastly, the emergent themes were integrated and synthesized into a meaningful whole that captured the phenomenon as experienced by the participants. The NVivo [34], a qualitative data analysis package, was utilized for the analysis process. In the presentation of the findings, we use quotes from the interviews to elucidate the AGYW's experiences.

In phenomenology, rigor is ensured through the thoroughness and completeness of the data collection and analysis [35]. The interviews were in the local language and were transcribed verbatim to ensure that meanings were not lost and that the data reflected the phenomenon as experienced by the participants. In addition, the authors adopted a reflective attitude throughout the data analysis to ensure that interpretation was free of bias [35], that credible conclusions were being drawn from the data and that procedures were being followed to ensure a quality study.

Ethical considerations

Ethical clearance for this study was obtained from the Research and Ethics Committee of Sefako Makgatho Health Sciences University (SMUREC/H/121/2017: PG) and Lesotho National Ethics Committee. The participants were informed that their participation was voluntary. All provided written informed consent before being interviewed. Pseudonyms are used to present the quotations to ensure privacy and anonymity.

RESULTS

Description of study participants

The 15 AGYW involved in this study were aged between 18-24 years with the mean age of 20 years. None was unemployed nor schooling, three had primary education, ten secon-

dary education, and two had tertiary education, while ten reported that they were married and five were single. Fourteen AGYW reported being pregnant with their first child.

Themes

Inductive analysis of the interviews yielded four themes; HIV testing in antenatal care,

initial response to HIV positive results, accepting lifelong treatment, and trust in ART medication. Five sub-themes emerged from the theme, initial response to HIV positive results (Table 1).

Table 1. Summary of themes.

Themes	Sub-themes
HIV testing in antenatal care	
The unexpected HIV positive result	
Initial response to HIV positive results	Shock and disbelief Denial of HIV test results Thoughts of death and dying Thoughts of terminating the pregnancy Worry about infecting the baby
Accepting lifelong treatment	
Trust in ART medication	

HIV testing in antenatal care

Most of the participants felt it was compulsory to test in pregnancy and accepted being tested to protect the unborn child from HIV should the mother test HIV positive.

“It was a matter of must to test because I was pregnant. We were told that we were supposed to get tested and know our statuses so that if ever we test positive we must take the treatment to save the babies’ lives and be born HIV free (Joyce, 18 years old). I was tested for HIV after realizing I am pregnant so that if I am HIV positive I do not infect the baby”.
 (Connie, 24 years old).

The unexpected HIV positive result

The HIV positive test result was unexpected for most of the participants, which made the experience about their diagnosis shocking. Prior to the HIV diagnosis, a number of the women did not perceive themselves to be at risk of HIV infection.

“I asked myself where I got it [HIV], it was my first time to engage in sex and I understood that I

got it from him, I am talking about my partner”
 (Kenny, 19 years old)

“I asked myself how I got HIV, how did it come about, I asked myself a lot of questions- a lot of questions came which I did not have answers for because they were just in my mind. I felt I did not know how and where I got HIV and I was asking myself many questions”
 (Lerato, 19 years old)

Initial response to HIV positive results

This paper explored the initial responses of women after testing HIV positive in pregnancy. On receiving the HIV diagnosis, participants expressed a wide variety of responses. They expressed devastating reactions such as feelings of deep pain, fear, hurt, deep shock, anger, and hopelessness upon receiving the diagnosis of HIV.

Shock and disbelief

For most of the participants, being informed about the HIV test results status was a very hard thing to believe. The initial reaction

upon receiving the HIV positive test result was shock. They found it hard to believe HIV diagnosis and described feelings of disbelief. The narratives of the participants conveyed their initial belief that they could not possibly be HIV positive because HIV happened to other people

“When I received my results, I was seriously shocked and pained..., I think it got me deeply thinking for two days I think”.

(Neo, 19 years old)

“It was hard for me to believe I now live with HIV..., I thought I was well behaved..., I thought people who have HIV are misbehaving...”

(Kenny, 19 years old)

Denial of HIV test results

A few participants reported being in denial after learning of their diagnosis. Denial was also common since the participants received the diagnosis during routine screening while they were symptom free. They explored reasons why a positive result could not be possible.

“I never thought I could be HIV positive. It is not something you can't imagine, I mean, come to think of it, waking up knowing you are HIV negative and the next thing you get tested for HIV and there are two lines showing you are HIV positive. It is not something you like and it is not as if you have been that mischievous to have it [HIV], that is what I mean”

(Neo, 19 years old)

“I think anyone would find it hard to accept, you are young, pregnant and positive. I mean it is three in one and I found out at the same time. I think if I knew before pregnancy, it would not be this hurting”

(Mary, 18 years old)

Thoughts of death and dying

The narratives of the participants showed that they were unaware that they could continue to be healthy because of the benefits of ART. Their initial experience of the HIV diagnosis generated feelings of the inevitability of death, and fear that they would not be alive to take care of their children. Some reported that they considered suicide immediately

after receiving the HIV diagnosis.

“After receiving the results, I felt there was no need for me to be alive because of the sickness [HIV], we got used to the idea that HIV infect those who were ill-behaved”.

(Lerato, 19 years old)

“I thought it was going to kill me, it was going to kill me emotionally first and it made me think about a lot of stuff including suicide”

(Neo, 19 years old)

The counselling that is provided in the PM-TCT and support received from families helped the participants to overcome the suicidal feelings.

“I just stopped having those thoughts [committing suicide]; I think it was due to some sort of counselling I got from my family though it was not professional”.

(Kenny, 19 years old)

Thoughts of terminating the pregnancy

Upon first hearing of the HIV diagnosis, many mothers experienced uncertainty about continuing the pregnancy. The temporarily desire to terminate the pregnancy was common for some of the participants after receiving their HIV diagnosis.

“I wanted to abort but I was afraid to do so. I just ignored the feeling and moved on with my life, I thought that because I was drinking alcohol maybe one day I would just have a miscarriage, but I realized the baby was growing and I ended up having that bond and could not continue with abortion. I am now 8 months”.

(Neo, 19 years old)

One participant verbalized that she did not contemplate termination but hated being HIV positive and pregnant.

“The truth is, for the first time when I thought of taking the treatment I felt I do not like pregnancy. I never felt like terminating but I just felt I hate pregnancy”.

(Mary, 18 years old)

Worry about infecting the baby

On diagnosis, most of the participants were concerned about the possibility of transmitting HIV to their unborn baby. However, they abandoned these thoughts after reassurance

that the availability of treatment would prevent HIV transmission to their unborn babies.

"I was hurting and felt frightened that HIV might be transmitted to my baby, which was worrying me a lot".

(Mary, 18 years old)

"Well at first some concerns were there, I was worried that my baby will have to live with HIV like I do but after I got a lesson from the nurses about steps to take in order for prevention of HIV transmission to the baby I felt relieved and free, yes"

(Thato, 22 years old)

Accepting lifelong treatment

Although the participants described feeling overwhelmed by the HIV positive results, some expressed that they made an effort to accept their diagnosis soon after receiving the HIV test results. Their narratives showed that their initial reaction was that of determination and readiness to take action to protect their unborn child from HIV infection.

"When I realized I am HIV positive truly, I was so frightened..., but after that, I accepted my positive test results".

(Tumi, 19 years old)

"I was a bit disturbed about taking treatment, but knowing this is my life I accepted to start on the treatment after I received the news that the treatment will protect my baby".

(Thato, 22 years old)

"The fact is that I am expecting a baby; I am protecting the baby. I will by all means to make sure the baby is safe so that it is born without this HIV".

(Kenny, 19 years old)

In contrast, some of the participants were not ready to start ART even after accepting their diagnosis of HIV. The knowledge that ART is a lifelong treatment led to hesitancy and delay in initiating ART.

"I had accepted my status but what was difficult for me was mainly to start on the ART treatment because I was told it is for life-time, I think that was the part I could not accept well".

(Mary, 18 years old)

"I thought I was going to die once I take the tre-

atment, I was thinking the ART was going to kill me, I was feeling healthy so I thought that ART was going to weaken me and kill me but I realized no such thing is going on".

(Mpuse, 20 years old)

Trust in ART medication

Those who initiated ART immediately did so because they had trust and confidence that the treatment would protect their unborn child. The participants further indicated that they were made aware that, with good adherence, the quality of their life would improve and they would live longer.

"I had accepted my status, the fact the baby is protected and I will be given the treatment to prevent HIV transmission, I accepted".

(Tumi, 19 years old)

"I could be able to live long with HIV only if I am faithful to my treatment".

(Thoriso, 23 years old)

"I learned that HIV can be transmitted to the baby from the mother to the baby through blood and during breast-feeding, but we could prevent HIV from being transmitted from the mother to the baby by taking treatment"

(Jane, 19 years old)

A few women were sceptical about the protection that the ART would provide for their unborn child.

"It is just me who is not getting satisfied..., I worry..., what if I could do what the nurses advised me to do yet at the end the baby gets born with HIV, I mean that's my concern at the moment".

(Mary, 18 years old)

"I wish mothers who are HIV positive did not have to breastfeed their babies at all. It is risky to breastfeed while living with HIV".

(Connie, 24 years)

DISCUSSION

The study explored the initial reactions of AGYW after receiving a positive HIV result in pregnancy to understand how their reaction influenced the uptake of ART in the immediate post-testing period. We found that testing positive in pregnancy occurred in the context where most of the AGYW had

not given thought to the routine antenatal HIV test. As noted in other studies, women who test positive in pregnancy are emotionally unprepared for an HIV diagnosis [15, 23] because, at the time of testing, they did not believe that they were at risk of HIV infection. The AGYW in the current study accepted the routine HIV testing to protect the unborn baby from being infected with HIV infection.

The study resonates with other researchers that women describe being devastated and highly distressed when they received the HIV diagnosis during pregnancy. After receiving a positive HIV results in pregnancy, AGYW experienced deep pain, fear, shock, disbelief, and denial at the diagnosis [15, 36]. Denial and disbelief were also attributed to the AGYW's belief that they were not at risk. Disbelief of the result was a common finding in other studies [15, 36, 37]. Understanding the experience of receiving a positive HIV result following routine antenatal screening is crucial to providing appropriate care to foster the wellbeing of the pregnant woman and her unborn child.

As noted in prior research, the participants found it difficult to deal with both pregnancy and HIV positive test results all at once [38]. Research suggests that the immediate shock experienced at the point of diagnosis may reduce the capacity of AGYW to understand or absorb the content of information they receive, particularly about ART [39]. A positive HIV result during pregnancy meant that the women had to immediately come to terms with their HIV status and initiate ART in one visit. Oshenon and colleagues [16] are of the view that women feel overwhelmed upon receiving an HIV diagnosis, making it difficult for them to absorb counselling content and commit to long-term treatment. It might also be argued that the urgency of starting ART immediately after the post-testing period without time to consider their feelings about ART might also be overwhelming to women who test positive in pregnancy [40]. This study's accounts resonated with other research [15, 23, 39] that women had extre-

me reactions to their positive HIV diagnosis. Most thought that death was inevitable shortly after diagnosis [41, 42]. Despite recent advances in the ART [43, 44], the participants equated HIV diagnosis with a fatal illness. Moreover, all of them were symptom free at the time they received their positive diagnosis [41]. However, as in other studies [15, 41], the concept of imminent death became less of a focus after they received assurance about the effectiveness of ART and had access to support networks. The initial diagnosis is often accompanied by suicidal thoughts for women who test positive in pregnancy [15, 16], these thoughts fade with the continuous counselling and knowledge that they acquired during the attendance of PMTCT.

Feeling overwhelmed at the initial stage of receiving the HIV diagnosis was manifested in thoughts of pregnancy termination. For some of the women, termination was seen as a solution to be able to cope with the diagnosis of HIV [38]. Other women consider termination out of fear for the baby being infected [15]. We found that the participants abandoned these thoughts after reassurance about the low risk of vertical transmission in the context of PMTCT interventions if medication is adhered to [40].

Despite the fact that the chances of vertical transmission occurring during pregnancy is minimal with ART [36], the immediate concern upon receiving HIV diagnosis was the fear of HIV transmission to the unborn baby. Findings from other studies showed that concerns for possible transmission of HIV to their baby take precedence over concerns about the woman's own HIV diagnosis [36, 37, 40]. As such, the focus for the participants was to prevent vertical transmission and have an HIV negative baby. Following assurance of the availability of ART and its effectiveness to prevent vertical transmission, AGYW developed good understanding of PMTCT interventions. The desire to protect their unborn babies from HIV infection was the key driver to initiate and adhere to ART and PMTCT schedules [11, 12, 45]. The intense fear related to possible transmission of HIV

to the baby requires that health professionals enhance the discussion on the effectiveness of ART vertical transmission.

Whereas most of the participants initiated ART to prevent vertical transmission, a few were hesitant to initiate ART in the immediate post-testing period. Research noted that the limited time to accept HIV diagnosis, urgent requirement to start lifelong ART before delivery, and being free of any symptoms at the time of testing might impact the uptake of ART among women who test positive in pregnancy [16, 20, 40, 46]. Focused interventions are required to address the psychosocial barriers to ART uptake and the linkages to care for pregnant women with HIV diagnosis [46]. It is crucial to prioritize swift initiation of ART to women who test positive in pregnancy to achieve elimination of mother-to-child transmission goals. PMTCT counselling should effectively communicate the importance of early initiation of ART to prevent HIV transmission and support the long-term health of mother and child [16].

This study is not without limitations. Consistent with qualitative research, the study sample consisted of a small number of participants; therefore, the findings cannot be generalised to other women who test positive in pregnancy in the whole country. The women who participated may have under reported or over reported their experience after receiving a positive result; this might have implications on the development of interventions to address the needs of pregnant AGYW. One other limitation is that we cannot report on the uptake of other PMTCT intervention because the sample consisted of pregnant

AGYW, research should investigate adherence to other interventions post-delivery.

CONCLUSION

The paper highlighted the psychological implications of receiving a positive HIV result in pregnancy and engagement with care in AGYW. The intense emotions that the AGYW experienced were heightened by the fear of infecting their unborn baby and the urgency of initiating ART. In spite of all these emotions, most AGYW engaged in HIV care through the services offered in PMTCT. For the AGYW in this study, the primary reason for initiating ART and adhering to PMTCT schedules was to protect their unborn child. Hesitancy to initiate ART at the point of HIV testing has implications for elimination of vertical transmission of HIV, a goal that all countries seek to attain. There is need for continuous counselling to reiterate and emphasise key information at subsequent attendance of PMTCT to prepare AGYW to understand the content of counselling messages. This strategy will foster early acceptance of HIV diagnosis and uptake of ART. Strengthening the targeted programing for pregnant AGYW and those living with HIV is essential for reaching global elimination of mother-to-child transmission goals to control the HIV epidemic.

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References

1. UNAIDS. HIV prevention among adolescent girls and young women. Putting HIV prevention among adolescent girls and young women on the Fast-Track and engaging men and boys. The Joint United Nations Programme on HIV/AIDS 2016. [cited 2021 November 04]. Available from: https://www.unaids.org/sites/default/files/media_asset/UNAIDS_HIV_prevention_among_adolescent_girls_and_young_women.pdf.
2. LePHIA. 2016-2017. Lesotho Population Based HIV Impact Assessment. Ministry of Health 2017 [cited 2021 August 20]. Available from: https://phia.icap.columbia.edu/wp-content/uploads/2018/02/Lesotho-Summary-Sheet_A4.2.7.18.HR_.pdf.
3. UNAIDS. Miles to go: closing gaps, breaking barriers, righting injustices. Geneva: The Joint United Nations Programme on HIV/AIDS 2018 [cited 2021 November 04]. Available from https://www.unaids.org/sites/default/files/media_asset/miles-to-go_en.pdf.
4. Kieling C, Baker-Henningham H, Belfer M, Conti G, Ertem I, Omigbodun O, et al. Child and adolescent mental health worldwide: evidence for action. *Lancet*. 2011;378(9801):1515–1525.
5. Fatti G, Shaikh N, Eley B, Jackson D, Grimwood A. Adolescent and young pregnant women at increased risk of mother-to-child transmission of HIV and poorer maternal and infant health outcomes: A cohort study at public facilities in the Nelson Mandela Bay Metropolitan district, Eastern Cape, South Africa. *S Afr Med J*. 2014;104(12):874–880.
6. Horwood C, Butler LM, Haskins L, Phakathi S, Rollins N. HIV-infected adolescent mothers and their infants: low coverage of HIV services and high risk of HIV transmission in KwaZulu-Natal, South Africa. *PLoS One*. 2013;8(9):e74568.
7. Woldesenbet S, Jackson D, Lombard C, Dinh T-H, Puren A, Sherman G, et al. Missed opportunities along the prevention of mother-to-child transmission services cascade in South Africa: uptake, determinants, and attributable risk (the SAPMTCTE). *PloS One*. 2015;10(7):e0132425.
8. Ronen K, McGrath CJ, Langat AC, Kinuthia J, Omolo D, Singa B, et al. Gaps in adolescent engagement in antenatal care and prevention of mother-to-child HIV transmission services in Kenya. *J Acquir Immune Defic Syndr*. 2017;74(1):30.
9. Sam-Agudu NA, Folayan MO, Ezeanolue EE. Seeking wider access to HIV testing for adolescents in sub-Saharan Africa. *Pediatr Res*. 2016;79(6):838–845.
10. Machekano R, Tiam A, Kassaye S, Tukei V, Gill M, Mohai F, et al. HIV incidence among pregnant and postpartum women in a high prevalence setting. *PloS One*. 2018;13(12):e0209782.
11. Dlamini N, Ntuli B, Madiba S. Perceptions of and Experiences of Participating in PMTCT Option B Plus: An Explorative Study of HIV-Positive Pregnant Women in Eswatini. *Open Public Health J*. 2021;14 EA-TOPHJ-2021-18.
12. Mitiku I, Addissie A, Molla M. Perceptions and experiences of pregnant women about routine HIV testing and counselling in Ghimbi town, Ethiopia: a qualitative study. *BMC Res Notes*. 2017;10(1):1–7.
13. Thomson KA, Hughes J, Baeten JM, John-Stewart G, Celum C, Cohen CR, et al. Increased risk of female HIV-1 acquisition throughout pregnancy and postpartum: a prospective per-coital act analysis among women with HIV-1 infected partners. *J Infect Dis*. 2018;218(1):16–25.
14. Buregyeya E, Naigino R, Mukose A, Makumbi F, Esiru G, Arinaitwe J, et al. Facilitators and barriers to uptake and adherence to lifelong antiretroviral therapy among HIV infected pregnant women in Uganda: a qualitative study. *BMC Pregnancy Childbirth*. 2017;17(1):1–9.
15. Lingen-Stallard A, Furber C, Lavender T. Testing HIV positive in pregnancy: A phenomenological study of women's experiences. *Midwifery*. 2016;35:31–38.
16. Oshosen M, Knettel BA, Knippler E, Relf M, Mmbaga BT, Watt MH. “She Just Told Me Not To Cry”: A Qualitative Study of Experiences of HIV Testing and Counseling (HTC) Among Pregnant Women Living with HIV in Tanzania. *AIDS Behav*. 2021;25(1):104–112.

17. Kotzé M, Visser M, Makin J, Sikkema K, Forsyth B. Psychosocial variables associated with coping of HIV-positive women diagnosed during pregnancy. *AIDS Behav.* 2013;17(2):498–507.
18. McLean E, Renju J, Wamoyi J, Bukonya D, Ddaaki W, Church K, et al. 'I wanted to safeguard the baby': a qualitative study to understand the experiences of Option B+ for pregnant women and the potential implications for 'test-and-treat' in four sub-Saharan African settings. *Sex Transm Infect.* 2017; 93(Suppl 3):e052972.
19. Katirayi L, Chouraya C, Kudiabor K, Mahdi MA, Kieffer MP, Moland KM, et al. Lessons learned from the PMTCT program in Swaziland: challenges with accepting lifelong ART for pregnant and lactating women—a qualitative study. *BMC Public Health.* 2016;16(1):1–11.
20. Myer L, Phillips TK. Beyond "Option B+": understanding antiretroviral therapy (ART) adherence, retention in care and engagement in ART services among pregnant and postpartum women initiating therapy in Sub-Saharan Africa. *J Acquir Immune Defic Syndr.* 2017;75:S115–S122.
21. WHO. Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection: Recommendations for a Public Health Approach 2016. World Health Organization, Geneva, Switzerland [cited 2021 November 04]. Available from: https://apps.who.int/iris/bitstream/handle/10665/208825/9789241549684_eng.pdf?sequence=1&isAllowed=y.
22. Contreras C, Rumaldo N, Lindeborg MM, Mendoza M, Chen DR, Saldaña O, et al. Emotional Experiences of Mothers Living With HIV and the Quest for Emotional Recovery: A Qualitative Study in Lima, Peru. *Assoc Nurses AIDS Care.* 2019;30(4):440–450.
23. Fords GM, Crowley T, Van der Merwe AS. The lived experiences of rural women diagnosed with the human immunodeficiency virus in the antenatal period. *SAHARA-J.* 2017;14(1):85–92.
24. Madiba S, Putsoane M. Testing positive and disclosing in pregnancy: a phenomenological study of the experiences of adolescents and young women in Maseru, Lesotho. *AIDS Res Treat.* 2020; 6126210, 8. doi.org/10.1155/2020/612621025.
25. LDHS. Lesotho Demographic Health Survey. Ministry of Health. Maseru, Lesotho. 2014 [cited 2021 June 30]. Available from: <https://dhsprogram.com/pubs/pdf/FR309/FR309.pdf>.
26. Dowling M, Cooney A. Research approaches related to phenomenology: Negotiating a complex landscape. *Nurse Res.* 2012;20(2):21–27.
27. Giorgi A. The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *J Phenomenol Psychol.* 1997;28(2):235–260.
28. Creswell JW, Poth CN. *Qualitative inquiry and research design: Choosing among five approaches*: Sage publications. Thousand Oaks, CA: Sage; 2016.
29. Converse M. Philosophy of phenomenology: How understanding aids research. *Nurse Res.* 2012;20(1):28–32.
30. Patton M. Purposeful sampling and case selections: Overview of strategies and options. *Qualitative research & evaluation methods: Integrating theory and practice*. Thousand Oaks, CA: Sage 2015:265.
31. Bevan MT. A method of phenomenological interviewing. *Qual Health Res.* 2014;24(1):136–144.
32. Moustakas C. *Phenomenological research methods*. Thousand Oaks CA: Sage; 1994.
33. Sundler AJ, Lindberg E, Nilsson C, Palmér L. Qualitative thematic analysis based on descriptive phenomenology. *Nurs Open.* 2019;6(3):733–739
34. NVivo. NVivo qualitative data analysis software; QSR International Pty Ltd Version 10 2016
35. Smith JA, Flowers P, Larkin M. *Interpretative phenomenological analysis: Theory, method and research*. London Sage; 2009.
36. Proudfoot D. Frozen in a Moment in Time: The Experiences of Mothers Being Diagnosed With HIV Infection. *Assoc Nurses AIDS Care.* 2018;29(2):323–329.
37. Kelly C, Alderdice F, Lohan M, Spence D. Creating continuity out of the disruption of a diagnosis of HIV during pregnancy. *J Clin Nurs.* 2012;21(11-12):1554–1562.

38. Watt MH, Knippler ET, Knettel BA, Sikkema KJ, Ciya N, Myer L, et al. HIV disclosure among pregnant women initiating ART in Cape Town, South Africa: qualitative perspectives during the pregnancy and postpartum periods. *AIDS Behav.* 2018;22(12):3945–3956.
39. Payán DD, Derose KP, Fulcar MA, Fariás H, Palar K. “It Was as Though My Spirit Left, Like They Killed Me”: The Disruptive Impact of an HIV-Positive Diagnosis among Women in the Dominican Republic. *J Int Assoc Provid AIDS Care.* 2019. doi:10.1177/2325958219849042.
40. Willcocks K, Evangeli M, Anderson J, Zetler S, Scourse R. “I Owe Her So Much; Without Her I Would Be Dead”: Developing a Model of Mother–Infant Bonding Following a Maternal Antenatal HIV Diagnosis. *Assoc Nurses AIDS Care.* 2016;27(1):17–29.
41. Barkish FG, Jalali R, Jalali A. Experiences of patients with primary HIV diagnosis in Kermanshah-Iran regarding the nature of HIV/AIDS: A qualitative study. *Heliyon.* 2019;5(8):e02278.
42. Ogueji IA. Experiences and predictors of psychological distress in pregnant women living with HIV. *Br J Health Psychol.* 2021;26(3):882–901.
43. Horter S, Thabede Z, Dlamini V, Bernays S, Stringer B, Mazibuko S, et al. “Life is so easy on ART, once you accept it”: Acceptance, denial and linkage to HIV care in Shiselweni, Swaziland. *Soc Sci Med.* 2017;176:52–59.
44. Madiba S. The Contextual Environmental Factors Shaping Disclosure of HIV Status across Populations Groups in Sub-Saharan Africa In: (Ed.) DND, editor. *HIV/AIDS - Contemporary Challenges: InTech;* 2017.
45. Madiba S, Letsoalo R. HIV disclosure to partners and family among women enrolled in prevention of mother to child transmission of HIV program: implications for infant feeding in poor resourced communities in South Africa. *Glob J Health Sci.* 2013; 5(4):1–13.
46. Stinson K, Myer L. Barriers to initiating antiretroviral therapy during pregnancy: a qualitative study of women attending services in Cape Town, South Africa. *Afr J AIDS Res.* 2012;11(1):65–73.