


# Parenting the child with HIV in limited resource communities in South Africa: mothers with HIV's emotional vulnerability and hope for the future

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## Abstract

**Introduction:** A diagnosis of HIV does not affect the well-being of mothers alone but also affects how they care for their children. The aim of this study was to explore how mothers who were diagnosed with HIV when pregnant or when their children became ill experience raising children living with HIV. The purpose was to understand how a diagnosis of HIV impacts mothering their children at different points on the mothering journey.

**Methods:** Using descriptive phenomenological enquiry, interviews were conducted with 28 mothers recruited via purposeful sampling from clinics in health district in South Africa. The interviews were audiotaped, transcribed verbatim, and analysed following the thematic approach.

**Results:** The mothers found mothering a child living with HIV stressful and associated with constant thoughts of death. The burden of mothering was increased for mothers who had to confront emotions of self-blame and guilt for unintentionally infecting the child. They used secrecy to protect their children from the social consequences of a diagnosis of HIV. The thought of living with HIV weighed on them every day and they expressed their experience of intense feelings of chronic worry, anxiety, and sadness. The findings identified high levels of stress, with the mothers expressing emotions suggestive of depression. With time, they accepted living with HIV and embraced motherhood, and became better mothers.

**Conclusion:** The negative coping strategies used to deal with the child's HIV diagnosis and high levels of stress and anxiety identified in the study underscore the need to address the psychosocial needs of mothers living with HIV. There is need to provide psychosocial support and continuous counselling for these mothers post diagnosis and upon a positive HIV diagnosis of the child to women enrolled in the prevention of mother to child transmission of HIV programme.

## Keywords

coping strategies, depressive symptoms, HIV-positive, motherhood, psychosocial well-being, secrecy, South Africa

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## Introduction

HIV and AIDS remain a global public health crisis that disproportionately affects women. As a consequence, a significant number of children in turn acquire HIV vertically.<sup>1</sup> In South Africa, women of childbearing age have the highest prevalence of HIV infection. The prevalence among young women aged 20–24 is 17.4%, which is three times higher

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than in men in the same group, at 5.1%. Women are also more likely to bear the double burden of being infected and having to care for children infected through vertical transmission of HIV.<sup>1</sup> It should be noted that the programmes of expanded access to antiretroviral therapy (ART) as well as the prevention of vertical HIV transmission have resulted in a substantial decline in paediatric HIV infections.<sup>2,3</sup>

With increased access to ART and advances in treatment, the quality of life for many women has improved, leading to their living healthy lives after the initial diagnosis of HIV. As such, these women are likely to continue raising their children while living with HIV for many years.<sup>4</sup> A diagnosis of HIV during pregnancy is life-changing and brings uncertainty, despite the fact that the chances of vertical transmission are reduced with ART.<sup>5</sup> A diagnosis of HIV not only affects the well-being of mothers as individuals but also affects how they care for their children.<sup>6-8</sup> The mothering of any child is naturally stressful, but mothering a child living with HIV is much more overwhelming.<sup>9,10</sup> Mothers living with HIV deal with the unique task of balancing their own physical needs and the needs of their children.<sup>10,11</sup>

Upon diagnosis, mothers and pregnant women have to deal with unique challenges, being a mother living with HIV is extremely hard and burdens mothering in a number of ways,<sup>9,10,12</sup> but finding out their children's diagnosis of HIV takes priority over their own personal concerns.<sup>13,14</sup> The literature indicates that the diagnosis of HIV is an emotionally charged experience, which results in feelings of shock, disbelief, guilt, and shame.<sup>15-17</sup> The feelings of guilt for unintentionally vertically transmitting HIV to the child result in most mothers putting the child's needs above their own. This places an increased burden on the mothers and may negatively influence their own health.<sup>11,18</sup> In addition, mothers living with HIV have to deal with the challenge of disclosing their own HIV status to their children as well as the HIV status of the infected child.<sup>7,9,10,18</sup>

There is limited research on the impact HIV and AIDS have on parent behaviour and how it affects parenting in low- and middle-income countries (LMICs)<sup>19</sup> with the exception of a few studies conducted in developed countries.<sup>20</sup> There is evidence that the emotional well-being of the mother is important for the emotional well-being of the HIV-infected child.<sup>20-22</sup> The limited data in South Africa show that maternal HIV diagnosis is associated with depression, stigma, financial difficulties, and increase parenting stress.<sup>19,23</sup> Estimates suggest a third of all children in sub-Saharan Africa, including South Africa, are most commonly cared for by a biological mother living with HIV.<sup>24</sup> Yet, in South Africa, studies have largely focused on caregivers of children living with vertically acquired HIV in general, and study samples have largely consisted of non-biological mothers because of the high prevalence of orphan hood.<sup>25</sup> In addition, a large body of research in South Africa has focused on disclosure of the diagnosis of HIV to children and adherence to medication.<sup>23</sup>

Mothers living with HIV in LMICs experience unique sets of challenges particularly in the context of the effects of poverty, gender inequities, and stigma.<sup>26,27</sup> Research conducted with women living with HIV before the advances of ART has largely focused on how HIV- and AIDS-related illness affect their mothering role.<sup>8</sup> However, due to the advances that have been made in ART, many women remain asymptomatic and live healthy lives after the initial diagnosis of HIV. The aim of this study was to explore how women who were diagnosed with HIV when pregnant or when their children became ill experience raising their children. The purpose was to understand how living with HIV impacts mothering their children at different points on the mothering journey in an era of improved access to ART. It is imperative that health professionals understand and respond to women's concerns at the point of HIV diagnosis, and how they fulfil their mothering responsibilities while enjoying improvement in maternal health due to access to ART.<sup>14,23</sup> Moreover, gaining an understanding of the HIV diagnosis experience at different points on the mothering trajectory will allow care provision to be more mother centred upon and beyond diagnosis.<sup>14</sup>

## Methods

### Study design and setting

This qualitative study used descriptive phenomenology to explore and understand how mothers living with HIV experience mothering a child who acquired HIV through vertical transmission. Descriptive phenomenology was a method of choice, since we intended to understand and describe mothering a child living with HIV without attempting to predict or explain how mothers experience the phenomenon.<sup>28,29</sup> Consistent with phenomenological enquiry, the participants were selected using purposeful sampling. We selected biological mothers living with HIV as information-rich cases for in-depth study of the mothering phenomenon.<sup>30,31</sup> In purposeful sampling, the researcher selects participants who can offer a meaningful understanding of the phenomenon of interest, from whom the researcher can gain insight into meanings attached to the experience of the phenomenon under inquiry.<sup>32</sup>

The setting of the study was 12 primary health care facilities in a sub-district in Tshwane, a Metropolitan Municipality with a population of about 3.3 million, in Gauteng Province, South Africa. Tshwane's estimated HIV prevalence among adults is 11.7%, while among pregnant women using antenatal services it is estimated at 23.4%.<sup>33</sup> All the health facilities provide prevention of mother to child transmission of HIV (PMTCT) programmes and offer counselling, HIV testing, and initiation of ART services to adults and children through the Nurse Initiation and Maintenance of Antiretroviral Therapy

(NIMART) initiative.<sup>34</sup> These services are provided for clients from urban, peri-urban, and informal settlements in the sub-district.

At the time of data collection, the PMTCT interventions in South Africa were implemented in line with the World Health Organization (WHO) guidelines. Under WHO Option A and Option B adopted in 2013, pregnant and breastfeeding women were entitled to ART for life if eligible by a CD4 count less than 350 cells/mm<sup>3</sup>. Under WHO Option B+ adopted in 2014, all pregnant women who test positive as well as breastfeeding women were entitled to ART for life regardless of clinical indicators. Provision of ART for all children under 5 years, regardless of their CD4 cell count or clinical staging, and ART initiation for children  $\geq 5$  years at CD4 count  $\leq 500$  cells/ $\mu$ L regardless of clinical staging.<sup>35</sup> The 2009–2010 WHO<sup>36</sup> protocols to prevent vertical transmission of HIV included dual therapy: highly active antiretroviral therapy (HAART) for pregnant women with CD4 cell count  $\leq 350$  cells/ $\mu$ L from 14 weeks gestation until 7 days postpartum and daily Nevirapine (NVP) prophylaxis for HIV-exposed uninfected infants. For children with a confirmed HIV diagnosis, all children less than 1 year should be started on ART. Children 1–5 years with WHO stage III or IV or CD4  $< 750$  cells/mm<sup>3</sup> and children  $\geq 5$  years with WHO stage III or IV or CD4  $< 350$  cells/mm<sup>3</sup> should be started on ART. The once daily fixed dose formulation tablet containing three drugs (Tenofovir (TDF), Emtricitabine (FTC), and Efavirenz (EFV)) was introduced in 2013–2014, but the priority at the time was ART-naive patients who were newly initiating ART.<sup>37</sup>

The participants in the study consisted of mothers living with HIV and raising children or a child living with HIV. They were accessing ART services in the health facilities in the sub-district. The mothers were eligible to participate in the study if they were mothering a child under 18 years old but older than 1 year. We recruited the mothers from ART clinics because they are referred to the mainstream ART clinic from the PMTCT programme when the baby is 18 months old. The recruitment was done with the assistance of the nurse clinicians who identified those who met the inclusion criteria and referred them to the researcher after they had completed their routine consultation for ART refill. The mothers were individually selected via purposeful sampling to participate in the study. The goal of a phenomenological enquiry is to select a homogeneous sample, and the sample consisted of 28 mothers living with HIV. Although the inclusion criterion when we conceptualized the study was mothers with children between 1 and 18 years, the oldest children were aged 13 years and none were between 1 and 3 years old. The sample size was influenced by data saturation and its ability to provide rich data to understand the mothering phenomenon.<sup>32</sup> While the sample was homogeneous, variability and diversity was achieved by selecting mothers with different

socio-demographics such as age, marital status, educational status, employment status, and child age.<sup>32</sup>

### Data collection

The lead author and trained research assistants conducted one-on-one interviews over a 3-month period, between November 2015 and January 2016, using interview schedule with open-ended questions and possible probes. The interview schedule was self-developed after extensive reading from the literature on the subject of mothering for women living with HIV and taking into considerations the objectives of the study.<sup>9,10,38</sup> It was developed in English and later translated from English into the local language (Setswana). All interviews were conducted in the local language to allow the participants to express themselves freely in their own language. Consistent with the tradition of phenomenology, the participants were asked broad, open-ended questions: (1) the experiences of their child being diagnosed with HIV, (2) being a mother living with HIV, (3) the experiences of raising a child with vertically acquired HIV, and (4) hopes for the future of the child.<sup>29</sup> To foster a dynamic exchange between the researcher and the participant, follow-up questions were asked to elicit meaning from the responses given. The participants were interviewed in consulting rooms in the health facilities, for the sake of privacy. Each interview was about 45 min long and was recorded with the permission of the participants. The participants were informed about the voluntary nature of their participation and their right to withdraw from the study at any stage prior to obtaining informed consent. Prior to the implementation of the study, the lead researcher and the research assistants attended a 1-day training session on the sensitive nature of the study, the objectives of the study, the interview schedule, and on conducting in-depth interviews. The training was done by the second author, who also supervised the project.

### Data analysis

The lead author and a research assistant who was involved in the data collection transcribed the interviews verbatim in Setswana, translated them into English, and checked the transcripts for accuracy against the audio recordings. Data analysis was inductive and followed the thematic approach in line with the tradition of descriptive phenomenology.<sup>39</sup> The recordings were listened to and a few transcripts were read repeatedly by the authors to get an overall sense of the data and to develop familiarity with the mothering phenomenon. Next, the authors searched and extracted statements for meanings to uncover emergent themes and develop a codebook. The authors met several times to develop the codebook, to reconcile emerging codes, and to finalize the codebook. NVivo version 12,<sup>40</sup> a qualitative data analysis package, was utilized for the analysis

process. Finally, the emergent themes were integrated and synthesized into a meaningful whole that captured the phenomenon as experienced by the participants. Quotes from the interviews were used to describe the lived experiences of the participants.

In phenomenology, rigour is ensured through the thoroughness and completeness of the collection and analysis of the data.<sup>41</sup> To establish rigour, the lead researcher adopted a reflective attitude throughout the research process to reduce researcher bias and enhance the credibility of results.<sup>42</sup> Both authors analysed the data to ensure that the interpretation was free of investigator bias.<sup>41</sup> In addition, the interviews were in the local language and were recorded using a good digital recorder to enhance verbatim transcription, which is a necessary step to take in ensuring that meanings are not lost and that the data reflect the phenomena as experienced by the participants. Finally, the lead author kept an audit trail throughout the research process as the key strategy to establish confirmability.<sup>43</sup>

### Ethical considerations

The study received ethical approval from Sefako Makgatho Health Sciences University Research and Ethics Committee (SMUREC/H/214/2015: PG). Permission to access health facilities was granted by relevant authorities from Tshwane Health District as well as the managers of the selected health facilities. All participants provided written informed consent, and participation was voluntary. The participants assumed pseudo-names, which were used during the analysis but deleted in this report. The services of a resident social worker were secured to provide counselling for participants who might break down during the interviews; however, none of the participants needed counselling as a result of the interview.

### Results

The sample consisted of 28 mothers living with HIV who were raising children living with vertically acquired HIV. Their ages ranged from 27 to 50 years. All the mothers and some of the children (7 out of 28) were on lifelong ART. The mothers initiated ART under different WHO protocols, 9 of 28 tested for HIV because the child was sick and was offered an HIV test through the provider initiated HIV testing and counselling initiative. Most 27/28 had one child who was living with HIV, their ages ranged from 6 to 13 years with a mean age of 9.5 years. Most (20/28) mothers had not revealed the child's HIV diagnosis to the infected child (Table 1).

### Themes

Five main themes emerged from the analysis of the interviews, namely the diagnosis and response,

**Table 1.** Characteristics of the mothers and children.

	Frequency	Percentage
Age		
Range	27–50	
Mean	35	
Marital status		
Married	4	14.3
Single	17	60.7
Living with partner	5	17.9
Divorced	2	7.1
Employment status		
Unemployed	19	68
Employed	9	32
Educational level		
Primary school	2	7.1
High school	24	85.8
Tertiary education	2	7.1
Child age		
Range	6–13	
Mean	9.5	
Children on lifelong ART		
Receiving ART	21	75
Not receiving ART	7	25
When was the HIV test done		
The child was sick	9	32.1
Tested HIV positive during pregnancy	19	67.9
Disclosed HIV status to child		
Disclosed	8	28.5
Not disclosed	20	71.5

ART: antiretroviral therapy.

mothering experiences, mothering practices, positive feelings about motherhood, and creating support networks. Under each theme, a number of sub-themes emerged (Table 2).

### The diagnosis and response

Most of the women had learned about their HIV diagnosis during pregnancy when they attended their antenatal care. They talked about receiving a HIV-positive diagnosis during pregnancy as extremely difficult. The diagnosis was unexpected for all the women and aroused a variety of emotions, including anger, disbelief, shock, sadness, pain, extreme distress, and thoughts of dying. They worried about infecting the baby with HIV. The data revealed that women who tested positive when their children became ill experienced similar intense emotional reactions to their HIV diagnosis.

*Immediate thoughts of dying.* I thought of death only. It was at the time when HIV made people to lose weight so I was thinking about all that. (Mother of an 11-year-old)

**Table 2.** Summary of themes.

The diagnosis and response	Immediate thoughts of dying Disbelief Concerns about the baby Pain Feelings of guilt and self-blame
Mothering experiences	Mothering is a difficult task Medication time a constant reminder Living with constant fear of death
Mothering practices	Ensuring adherence to ART Secrecy to prevent stigma Anxious about revealing the child's HIV status
Positive feelings about motherhood	Mothering a HIV-positive child changed my life Developing special bond with children Living for my children Hope for the future
Creating support networks	

ART: antiretroviral therapy.

The first thing that came to my mind was that I am going to die and leave my child. I thought HIV positive people die. (Mother of a 12-year-old)

**Disbelief.** This got the better of me . . . , and for a long time I could not believe that I was HIV-positive. (Mother of a 6-year-old)

I still do not believe that I am HIV-positive. Every time it comes to my mind that I am HIV-positive I feel confused. I ask myself how it happened because I was not promiscuous. Why me . . . , why did this illness choose me and not choose someone else? (Mother of a 7-year-old)

**Concerns about the baby.** At the time of their HIV diagnosis, the mothers were anxious about the fear of having transmitted HIV to their babies. Throughout pregnancy, the women lived with worry and uncertainty about the future of their babies:

The first thing that came to mind when I found out that I am pregnant and HIV-positive, was, what about the baby? (Mother of a 7-year-old)

Eish . . . I was stressed thinking that my child would die. (Mother of an 11-year-old)

Upon receiving a positive HIV diagnosis for the child, similar to the thoughts that the women had had about their HIV diagnosis, they thought the child would die:

I thought about death only. I thought my child would die. (Mother of an 11-year-old)

Yoh . . . , at first I thought I am going to lose my child. (Mother of a 9-year-old)

**Pain.** On receiving the diagnosis, the participants were overwhelmed by feelings of pain when they learned about the child's HIV diagnosis. They said that the pain was greater than what they felt when they learnt about their own status:

Yoh! I was feeling pain that my innocent child is punished because of me . . . , I just felt a deep pain; I had so much pain about my child's status. Hearing about my status was better because I have been around, but my child did nothing to get this disease, so I felt so much pain for him. (Mother of a 6-year-old)

The pain was so deep, it would have been better if it was just me and not the child infected. I was very much hurt. Even now when I look at her, I become emotional and heartbroken. (Mother of a 10-year-old)

The narratives of the women revealed chronic pain about the HIV diagnosis of their children:

The pain does not go away as you can see me now I am still in pain. (Mother of an 11-year-old)

Even when I look at her today, I can still feel pain. (Mother of a 12-year-old)

**Feelings of guilt and self-blame.** Following the HIV-positive diagnosis of the child, the initial feeling of pain was followed by intense feelings of guilt for having infected their children. The mothers felt guilty over their perceived failure as mothers and for infecting their children. They blamed themselves for not taking the HIV test during pregnancy:

I wish I had found out while I was pregnant. Maybe I would have been able to protect her. (Mother of an 11-year-old)

My heart was painful, knowing that I could not protect her as a parent. If I had tested, I would have been able to protect her. At the clinic, they would have told me how to make sure that I do not pass it to her. (Mother of a 12-year-old)

I did not listen to the clinic when they said I should come to them before pregnancy so they can help prevent passing the HIV to the baby. (Mother of a 7-year-old)

**Mothering experiences**

The mothers experienced caring for their HIV-infected children as difficult, they found administering the ART medication to be challenging, and they lived with the constant fear of death.

**Mothering is a difficult task.** The mothers described mothering a HIV-positive child as demanding and difficult with many challenges. They said that raising a HIV-positive child is different from raising a HIV-negative child:

Eish! It is demanding for me; it is a lot of work. The care is a lot, especially the food. You must make sure she eats properly. (Mother of an 8-year-old)

Raising an HIV-positive child is difficult because you are supposed to take her to the clinic every time and sometimes she is weak. You need the correct diet but you are unemployed and the only income is child grant, but it is not enough for my needs. (Mother of an 11-year-old)

**Medication time a constant reminder.** The mothers reported that medication time was unsettling. It is a constant reminder that the child is HIV-positive and that they infected the child. They said that this brought back their pain, guilt, and self-blame for having infected the child:

Sometimes you find that it is time for her to take her pills and she is playing with other children. I have to call her, and I feel . . . , I keep on blaming myself. It is worse because she does not know the real reason for drinking the pills. (Mother of a 6-year-old)

As for my child, it is still difficult. Immediately after I give him pills, my heart skips a beat . . . , I feel pain. (Mother of a 7-year-old)

**Living with constant fear of death.** The initial response to a positive HIV diagnosis was the thoughts of death, not only for themselves, but the fear that their babies would die too. Although the children were healthy during the interviews, the mothers had constant thoughts and fears of their children dying from common conditions. Whenever the child was sick, they thought that the end of life might be close:

I do not know the day he will die. I always think about such issues. It is not possible for a mother not to worry about dying. It crosses your mind when he gets sick and you wonder is it because he is HIV-positive? (Mother of a 6-year-old)

When he get sick, I ask myself 'Is it his time to die' because I do not know the day he will die. When he says he has a headache I become stressed because I think it is his time. I always think about such issues. (Mother of an 11-year-old)

### **Mothering practices**

The mothers shared several activities that make caring for their HIV-infected children overwhelming. They have to ensure adherence to ART, they have to keep the diagnosis of the child secret to prevent stigma and social rejection, and they have anxiety about revealing the child's HIV status. They prioritized the needs of the children above their own, were overprotective, and achieved special bond with the children.

**Ensuring adherence to ART.** The mothers reported that maintaining strict adherence to uninterrupted lifelong ART was challenging and requires discipline and care. They

believed that only the mother could ensure that the child adhered to ART and clinic appointments:

I am the one who gives him his medication. When he is at his father's place, I WhatsApp to remind them because sometimes they forget. (Mother of a 10-year-old)

I do not allow anyone to take her for her hospital checkups; I prefer to do it myself so that I see what is happening. As a mother, you are not satisfied with anything because you do not think other people can take care of her the way you do. (Mother of an 8-year-old)

Even though other family members know that she is HIV-positive, but they cannot take care of her the way that I do. (Mother of an 8-year-old)

In order to monitor adherence to the correct time and dosage of ART, sleeping over when the children visited friends or relatives was avoided at all cost. The mothers were concerned that the children might default on their treatment:

I never allow her to visit relatives because she will need to be taken care of. I am scared that they will not give him treatment properly, you know. When the child is not yours, you don't do that much care, because maybe you don't know the rules and conditions of treatment. (Mother of a 6-year-old)

I do not allow him to sleep over when he visits. I am afraid that he will not take his treatment properly. (Mother of a 9-year-old)

**Secrecy to prevent stigma.** Secrecy emerged as one of the strategies mothers practised to protect their children from discrimination. They delayed disclosing their own HIV status and that of their children, believing that secrecy was necessary to protect themselves and their children from social rejection:

I do not talk about my child's HIV status because I am scared that people will talk about her behind closed doors and their children might hear this and will stigmatize my child. (Mother of an 8-year-old)

Eish . . . I fear that she will go around telling others. (Mother of an 8-year-old)

Sleeping over when the children visited friends or relatives was also avoided to maintain secrecy:

People know these tablets [ARVs] and if they see that she is taking them . . . I do not want them to know that my child is taking tablets. (Mother of an 8-year-old)

It is difficult for her to visit with many bottles of tablets. If there was only one bottle, this could have been better. My challenge is people would see that my child is sick and taking tablets. (Mother of a 6-year-old)

**Anxiety about revealing the child's HIV status**

I feel bad, bad, and bad, that at the time when she is old enough and I decided to tell her the truth, she will not trust me anymore. (Mother of an 8-year-old)

She is about to start dating, so, I must discuss condom use with her. I fear that she will say she is ill because of me. (Mother of a 12-year-old)

**Positive feelings about motherhood**

With time, the mothers learned to accept themselves and live with HIV. This also changed the way they viewed motherhood. They said that mothering an HIV-positive child changed their lives. They were motivated to care for their children, hoped to live for their children, and had hope for the future.

**Mothering a HIV-positive child changed my life.** Having a HIV-positive child influenced the mothers' decisions to live a more responsible life:

Being a mother to a positive child has changed my life in many ways. I am now very conscious when it comes to my health, eating healthy food, and being hygienic. (Mother of a 9-year-old)

My mothering skills have changed and I have grown . . . I never used to go to church. Now I go to church regularly. (Mother of a 7-year-old)

**Developing a special bond.** Most mothers were overprotective of their children and described achieving a special bond with their children:

I am over protective of my HIV-positive child. (Mother of a 10-year-old)

I have bonded too much with her. I am attached too much to her more than I am attached to the others. (Mother of an 8-year-old)

The thing is, he is very much attached to my life . . ., but I love all my children. I am just concerned about him. I am wondering how he is going to survive if God takes me. (Mother of a 6-year-old)

**Living for my children.** In the midst of all the intense emotional experiences, the mothers wanted to be strong and live for their children and had hope that their children would live long and healthy lives, attain higher education, and continue to adhere to ART:

I want to live for all my children, and I pray that God does not take me before she matures, until she understands her status very well, so that even if I am gone she can look after herself. (Mother of a 9-year-old)

The thing that motivates me every day, is my child's life. I wish to live long. I am living for my child. The other children are fine. I so wish that God could keep me longer to see my child growing and finish his matric. (Mother of a 6-year-old)

**Hope for the future.** The mothers had positive expectations and hope for a cure for HIV. They wished for a cure for HIV and that their children would need to take fewer tablets and would live long healthy lives:

I believe one day they will find a cure, and I wish that they first find a cure for the children then us parents because the children are innocent. (Mother of a 10-year-old)

What gives me hope is that by the time she reaches 15 years, she will be taking fewer pills. (Mother of an 11-year-old)

**Creating support networks.** The mothers talked about the support resources that helped them accept their HIV status to live for their children. Some of them were able to disclose their diagnosis of HIV and reached out for support from family members, friends, and co-workers. The healthcare providers provided the support they need most, particularly at the time of the initial HIV-positive diagnosis:

To tell the truth, the thing that helped me a lot is counselling. (Mother of a 13-year-old)

We get support from the health facilities. They treat us well. (Mother of a 12-year-old)

My mother is there to take care of my child. (Mother of a 6-year-old)

When I meet with other women in the clinic, we share different stories about our children and about how we are coping. (Mother of a 10-year-old)

Some reported that they drew support from their faith to accept their HIV status and to cope with their child's diagnosis of HIV:

I am a born-again Christian. I rely on the Bible. It encourages me all the time. I believe and trust in my God. (Mother of a 7-year-old)

**Discussion**

This study aimed to gain an understanding of South African women's experiences of receiving a positive diagnosis of HIV in pregnancy or when their children became ill, and their experiences of raising a HIV-positive child in a resource-limited setting. The study found that mothering occurred in the context where most of the women had access to lifelong ART and reported living healthy lives.

The study corroborated other researchers' findings that women are emotionally unprepared for an HIV diagnosis during pregnancy,<sup>14,44-46</sup> or when their children become chronically ill.<sup>25</sup> For the women in our study, the feelings of shock, disbelief, distress, anguish, profound sadness, and hopelessness<sup>45</sup> were intensified by interpreting their HIV diagnosis as well as their children's as a death sentence. Upon learning about their HIV status, the women thought about dying a great deal and were worried that they would die and leave their children orphaned. It is crucial that healthcare providers recognize women's concerns on diagnosis and take account of how their diagnosis of HIV could impact on how they fulfil their mothering responsibilities.<sup>14</sup>

It is important to note that the immediate concern for the women upon receiving a HIV diagnosis during pregnancy was the possibility of having infected their children. Most of them were anxious to find out their children's HIV status throughout their pregnancy and lived in constant anxiety.<sup>10,12,14</sup> The mothers had concerns of infecting their babies with HIV, despite enrolment in the PMTCT programme during pregnancy and receiving ART.<sup>14</sup> In the initial stages of the child's HIV diagnosis, the mothers were weighed down by constant concerns over the child's health and worried about what the future might hold.<sup>9,47</sup> They experienced intense feelings of worry, constant anxiety, and chronic sadness, from the time of their child's diagnosis until the present.<sup>48</sup> They reported initial and constant concerns that their children will die prematurely even though the children had been receiving ART prophylaxis.

The mothers' narratives show that following the positive diagnosis of their children, they put their children's needs above theirs.<sup>10,14</sup> In this way, they neglected the importance of their physical health as well as their psychological needs.<sup>47</sup> The elevated levels of stress and anxiety reported by the mothers in the current study and in others<sup>8,13,20,47</sup> are an indication of the neglect of their needs in their desire to care for their children. Consistent with the literature, the mothers had felt emotions suggestive of depression, such as anguish, guilt, chronic sadness, hopelessness, and constant anxiety from the time of the first diagnosis to the present.<sup>7,13,22,26</sup>

The mothers found mothering an HIV-positive child a difficult and stressful task that is associated with the uncertainty of death, with the mother's declining physical health, with frequent medical appointments, and with financial challenges.<sup>9,12,13,49</sup> The burden was increased for those who had to confront emotions of self-blame and guilt for unintentionally infecting the child with HIV.<sup>9,13</sup> Studies conducted prior to the provision of improved access to ART reported that mothers feel guilty about not being able to adequately care for the child due to their own physical conditions.<sup>9,12,38,47</sup> This was not the case in this study, since most of the mothers reported good health due to effects of lifelong ART. In South Africa, HIV testing is not

mandatory for women in the PMTCT programme, but women are offered and encouraged to test for HIV in order to receive long-term ART.

Despite their saying that HIV made mothering hard and challenging, the mothers invested heavily in their mothering roles and took on the bulk of the caregiving responsibilities for their children. Like mothers in other studies, they believed that only the mother has the knowledge of the child to undertake the mothering task and conveyed a sense of a greater protectiveness towards their children.<sup>17,50,51</sup> In an earlier study, Hejoaka<sup>52</sup> had observed that the role of motherhood in raising a HIV-positive child is complex, as it includes ensuring that the child takes his or her medication as prescribed. Most mothers reported achieving a special bond with their children. The overprotectiveness and heightened sensitivity to their children that brought a closer connection between mother and child are key to children's behavioural development and emotional regulation.<sup>10,53,54</sup>

The mothers purposefully kept the HIV diagnosis of their children secret in an attempt to protect their children from the social consequences of a HIV-positive status. Many mothers practised secrecy as a coping strategy to protect themselves and their children from social rejection.<sup>10,13</sup> However, there were negative consequences to secrecy, as secrecy denied them access to social support networks that might have alleviated some of the intense feelings arising from mothering an HIV-positive child.<sup>13,16,47,52</sup> Lentoor<sup>13</sup> found that secrecy and fear of stigma is often accompanied by fear and anxiety, which entrap caregivers in social isolation and add to the already burdensome role of caring for an HIV-positive child. Social support can reinforce a positive attitude and thus enrich the experience of motherhood.<sup>55</sup> For women in the current study, counselling was provided at the time of the HIV diagnosis and there were no data to suggest the availability of continuous support post diagnosis and during the participation of women in the PMTCT programme.

When the women began to feel better due to the advances that have been made in ART, they begin to believe that they are not going to die immediately and grow to accept their HIV status.<sup>9,12</sup> They developed strategies to learn to cope with their diagnosis of HIV and created social support networks, including family, and support groups. They reorganized their lives, adopted self-care measures, were motivated to stay alive for their children, and embraced motherhood.<sup>10,12,45</sup>

It should be noted that with the passage of time the mothers began to have hope for the future of their children, when they realized that their children were healthy and responding well to the ART medication. At the time of the study, the ART regimen for their children consisted of many pills because they did not qualify for the once daily fixed dose formulation tablet containing Tenofovir (TDF), Emtricitabine (FTC), and Efavirenz (EFV). The fixed dose



tablet was introduced in 2013–2014 prioritizing ART-naive patients.<sup>37</sup> The mothers hoped for further advances in ART where their children would have to take the once daily pill. Some hoped for a cure for HIV and wanted to see their children grow up and attain educational qualifications.

## Limitations

A limitation of this study is that the discussion of the findings could not compare the mothers who have been on ART for a long time with those who were diagnosed less than 2 years ago. This would have made it possible to assess the impact of a recent diagnosis of HIV on mothering. However, this was not the purpose of the study; the findings of the study have bridged the gap in the literature, which is limited in South Africa and sub-Saharan Africa, particularly in the era of increased access to ART and quality of life of mothers after a diagnosis of HIV. We acknowledge that the time since diagnosis might have affected the recall for the mothers since the study sample consisted of mothers with vast differences in the children's age. For instance, recalling the time it took them to accept their status might be affected by the time since diagnosis. On the contrary, the sample did not include mothers of children 1–3 years old who might have had different experiences of motherhood and acceptance of the HIV diagnosis given the recent diagnosis. This provides an opportunity to conduct research with this population of mothers to understand how an HIV diagnosis affects their motherhood.

## Conclusion

The participants in the current study found mothering an HIV-positive child stressful and associated with constant thoughts of death despite enjoying a good quality of life as a result of improved access to ART. We found chronic pain that does not seem to dissipate with time but was experienced by mothers of children of varying ages. The findings corroborate those of studies conducted in developed countries among affluent mothers that their responses to living with HIV are child-centred and that their own needs are secondary and often neglected. The close connection between mother and child is an important cue for sensitive parenting.

The findings further suggest high levels of stress and anxiety among the mothers. The thought of living with HIV and the use of negative coping strategies to deal with the child's HIV diagnosis weighed on the mothers. The expressed emotions suggestive of depression and high levels of stress and anxiety identified in the study underscore the need to address the psychosocial needs of mothers living with HIV. Healthcare providers should provide psychosocial support and continuous counselling for these mothers post diagnosis and upon a positive HIV diagnosis of the child. This should be in addition to

the post-test counselling offered to women enrolled in the PMTCT. There is a need to integrate mental health and ART services to address mental health issues among people living with HIV, particularly HIV-positive mothers who have to raise both HIV-positive and HIV-negative children.

The enrolment of mothers in the PMTCT programme offers an opportunity to render comprehensive services catering for both the health and the psychosocial needs of mothers living with HIV. The healthcare professionals providing care to mothers of children infected with HIV have a crucial role to play to support them to deal with the burden of mothering HIV-positive children. However, this should not undermine the supportive role provided by extended family, friends, and the church.

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## Author contributions

M.M. contributed to conceptualization, investigation, data curation, formal analysis, and writing – original draft. S.M. contributed to conceptualization, supervision, formal analysis, validation, and review and editing.

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## References

1. UNAIDS. *Miles to go: closing gaps, breaking barriers, righting injustices*. Geneva: Joint United Nations Programme on HIV/AIDS (UNAIDS), 2018.
2. Le Roux SM, Abrams EJ, Nguyen KK, et al. HIV incidence during breastfeeding and mother-to-child transmission in Cape Town, South Africa. *AIDS* 2019; 33(8): 1399–1401.
3. UNAIDS. Global report: United Nations Programme on HIV and AIDS: report on the global AIDS epidemic 2016, [https://www.unaids.org/en/resources/campaigns/20160531\\_globalaidsupdate](https://www.unaids.org/en/resources/campaigns/20160531_globalaidsupdate)
4. Richter L and Naicker SS. *A review of published literature on supporting and strengthening child-caregiver relationships (parenting)*. Arlington, VA: USAID's AIDS Support

- and Technical Assistance Resources, AIDSTAR-One, Task Order 1, 2013.
5. National Department of Health (NDoH). South African Department of Health & South African National AIDS Council (SANAC), 2012, <https://health.gov.za/>
  6. Mellins CA, Brackis-Cott E, Dolezal C, et al. Mental health of early adolescents from high-risk neighborhoods: the role of maternal HIV and other contextual, self-regulation, and family factors. *J Pediatr Psychol* 2008; 33(10): 1065–1075.
  7. Rochat T, Netsi E, Redinger S, et al. Parenting and HIV. *Curr Opin Psychol* 2017; 15: 155–161.
  8. Sherr L, Cluver LD, Betancourt TS, et al. Evidence of impact: health, psychological and social effects of adult HIV on children. *AIDS* 2014; 28(Suppl. 3): S251–S259.
  9. Nelms TP. Burden: the phenomenon of mothering with HIV. *J Assoc Nurs AID Care* 2005; 16(4): 3–13.
  10. Walulu RN and Gill SL. ‘Living for my children’: mothers living with HIV disease. *South Onlin J Nurs Res* 2011; 11(1): 1–14.
  11. Murphy DA, Roberts KJ and Herbeck DM. HIV disease impact on mothers: what they miss during their children’s developmental years. *J Child Fam Stud* 2011; 20(3): 361–369.
  12. Liamputtong P and Haritavorn N. My life as Mae Tid Chua [mothers who contracted HIV disease]: motherhood and women living with HIV/AIDS in central Thailand. *Midwifery* 2014; 30(12): 1166–1172.
  13. Lento AG. Psychosocial challenges associated with caregiving in the context of pediatric HIV in rural Eastern Cape. *Front Public Health* 2017; 5: 127.
  14. Proudfoot D. Frozen in a moment in time: the experiences of mothers being diagnosed with HIV infection. *J Assoc Nurs AID Care* 2018; 29(2): 323–329.
  15. Cohen M, Hoffman RG, Cromwell C, et al. The prevalence of distress in persons with human immunodeficiency virus infection. *Psychosomatics* 2002; 43(1): 10–15.
  16. Miles MS, Isler MR, Banks BB, et al. Silent endurance and profound loneliness: socioemotional suffering in African Americans living with HIV in the rural south. *Qual Health Res* 2011; 21(4): 489–501.
  17. Fletcher F, Ingram LA, Kerr J, et al. ‘Out of all of this mess, I got a blessing’: perceptions and experiences of reproduction and motherhood in African American women living with HIV. *J Assoc Nurs AID Care* 2016; 27(4): 381–391.
  18. Murphy DA. The impact of maternal HIV/AIDS on mothers, their children, and the parent-child relationship. *Source* 2009; 19(2): 2–7.
  19. Allen AB, Finestone M, Eloff I, et al. The role of parenting in affecting the behavior and adaptive functioning of young children of HIV-infected mothers in South Africa. *AIDS Behav* 2014; 18(3): 605–616.
  20. Lachman JM, Cluver LD, Boyes ME, et al. Positive parenting for positive parents: HIV/AIDS, poverty, caregiver depression, child behavior, and parenting in South Africa. *AIDS Care* 2014; 26(3): 304–313.
  21. Brandt R. Maternal well-being, childcare and child adjustment in the context of HIV/AIDS: what does the psychological literature say?, 2005, [https://open.uct.ac.za/bitstream/handle/11427/19372/Brandt\\_Maternal\\_well\\_being\\_2005.pdf;sequence=1](https://open.uct.ac.za/bitstream/handle/11427/19372/Brandt_Maternal_well_being_2005.pdf;sequence=1)
  22. Chi P, Li X, Tam CC, et al. Parenting mediates the impact of caregivers’ distress on children’s well-being in families affected by HIV/AIDS. *AIDS Behav* 2015; 19(11): 2130–2139.
  23. Rochat TJ, Mitchell J, Stein A, et al. The Amagugu intervention: a conceptual framework for increasing HIV disclosure and parent-led communication about health among HIV-infected parents with HIV-uninfected primary school-aged children. *Front Public Health* 2016; 4: 183.
  24. Short SE and Goldberg RE. Children living with HIV-infected adults: estimates for 23 countries in sub-Saharan Africa. *PLoS ONE* 2015; 10(11): e0142580.
  25. Madiba S and Mokgatle M. Fear of stigma, beliefs, and knowledge about HIV are barriers to early access to HIV testing and disclosure for perinatally infected children and adolescents in rural communities in South Africa. *South Afr Fam Pract* 2017; 59(5): 175–181.
  26. Murphy DA, Marelich WD, Armistead L, et al. Anxiety/stress among mothers living with HIV: effects on parenting skills and child outcomes. *AIDS Care* 2010; 22(12): 1449–1458.
  27. Burgess R and Campbell C. Contextualising women’s mental distress and coping strategies in the time of AIDS: a rural South African case study. *Transcult Psychiatry* 2014; 51(6): 875–903.
  28. Dowling M and Cooney A. Research approaches related to phenomenology: negotiating a complex landscape. *Nurse Res* 2012; 20(2): 21–27.
  29. Giorgi A. The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *J Phenomenol Psychol* 1997; 28(2): 235–260.
  30. Creswell JW and Poth CN. *Qualitative inquiry and research design: choosing among five approaches*. Thousand Oaks, CA: SAGE, 2017.
  31. Patton MQ. Enhancing the quality and credibility of qualitative analysis. *Health Serv Res* 1999; 34(5 Pt. 2): 1189–1208.
  32. Patton MQ. *Qualitative research & evaluation methods: integrating theory and practice*. Thousand Oaks, CA: SAGE, 2015.
  33. Gutreuter S, Igumbor E, Wabiri N, et al. Improving estimates of district HIV prevalence and burden in South Africa using small area estimation techniques. *PLoS ONE* 2019; 14(2): e0212445.
  34. Cameron D, Gerber A, Mbatha M, et al. Nurse initiation and maintenance of patients on antiretroviral therapy: are nurses in primary care clinics initiating ART after attending NIMART training? *South Afr Med J* 2012; 102(2): 98–100.
  35. UNICEF. Option B+ countries and PMTCT regimen, IATT website, <http://emtct-iatt.org/b-countries-and-pmtct-regimen/>
  36. World Health Organization (WHO). Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants: towards universal access: recommendations for a public health approach, 2010, <https://www.who.int/hiv/pub/guidelines/pmtct/en/>
  37. Southern African HIV Clinicians Society. Fixed-dose combination for adults accessing antiretroviral therapy. *South Afr J HIV Med* 2013; 14(1): 41–43.
  38. Sanders LB. Women’s voices: the lived experience of pregnancy and motherhood after diagnosis with HIV. *J Assoc Nurs AID Care* 2008; 19(1): 47–57.

39. Sundler AJ, Lindberg E, Nilsson C, et al. Qualitative thematic analysis based on descriptive phenomenology. *Nurs Open* 2019; 6(3): 733–739.
40. QSR International. *NVivo qualitative data analysis software*, version 10. Doncaster, VIC, Australia: QSR International, 2016.
41. Smith JA, Flowers P and Larkin M. *Interpretative phenomenological analysis: theory, method and research*. London: SAGE, 2009.
42. Gearing RE. Bracketing in research: a typology. *Qual Health Res* 2004; 14(10): 1429–1452.
43. Lincoln YS and Guba EG. *Naturalistic inquiry*. Beverly Hills, CA: SAGE, 1985.
44. Kelly C, Alderdice F, Lohan M, et al. Creating continuity out of the disruption of a diagnosis of HIV during pregnancy. *J Clin Nurs* 2012; 21(11–12): 1554–1562.
45. Lingen-Stallard A, Furber C and Lavender T. Testing HIV positive in pregnancy: a phenomenological study of women's experiences. *Midwifery* 2016; 35: 31–38.
46. Fords GM, Crowley T and 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.
47. Potterton J, Stewart A and Cooper P. Parenting stress of caregivers of young children who are HIV Positive. *Afr J Psychiatry* 2007; 10(4): 210–214.
48. Antle BJ, Wells LM, Goldie RS, et al. Challenges of parenting for families living with HIV/AIDS. *Soc Work* 2001; 46(2): 159–169.
49. Contreras C, Rumaldo N, Lindeborg MM, et al. Emotional experiences of mothers living with HIV and the quest for emotional recovery: a qualitative study in Lima, Peru. *J Assoc Nurs AID Care* 2019; 30(4): 440–450.
50. Kennedy VL, Serghides L, Raboud JM, et al. The importance of motherhood in HIV-positive women of reproductive age in Ontario, Canada. *AIDS Care* 2014; 26(6): 777–784.
51. Vallido T, Wilkes L, Carter B, et al. Mothering disrupted by illness: a narrative synthesis of qualitative research. *J Adv Nurs* 2010; 66(7): 1435–1445.
52. Hejoaka F. Care and secrecy: being a mother of children living with HIV in Burkina Faso. *Soc Sci Med* 2009; 69(6): 869–876.
53. Willcocks K, Evangeli M, Anderson J, et al. 'I owe her so much; without her I would be dead': developing a model of mother–infant bonding following a maternal antenatal HIV diagnosis. *J Assoc Nurs AID Care* 2016; 27(1): 17–29.
54. Stein A, Desmond C, Garbarino J, et al. Predicting long-term outcomes for children affected by HIV and AIDS: perspectives from the scientific study of children's development. *AIDS* 2014; 28(Suppl. 3): S261–S268.
55. Etowa J, Babatunde S, Hannan J, et al. Motherhood among Black women living with HIV: a 'north-south' comparison of sociocultural and psychological factors. *Health Care Women Int* 2021; 42(3): 304–322.