



# Low Birthweight, Retention in HIV Care, and Adherence to ART Among Postpartum Women Living with HIV in Ghana

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## Abstract

Care for low birthweight (LBW) infants can contribute to psychological difficulties and stigma among mothers living with HIV, creating challenges for antiretroviral therapy (ART) adherence and retention in HIV care. We explored how caring for LBW infants affects maternal ART adherence and retention in care. We conducted 30 in-depth interviews with postpartum women living with HIV in Accra, Ghana: 15 with LBW infants and 15 with normal birthweight (NBW) infants. Compared to mothers with NBW infants, mothers with LBW infants described how caring for their newborns led to increased caregiver burden, prolonged hospital stays, and stigma—contributing to incomplete ART adherence and missed clinical appointments. For a few women, care for LBW infants created opportunities for re-engagement in HIV care and motivation to adhere to ART. Results suggest women living with HIV and LBW babies in Ghana face increased challenges that impact their adherence to care and ART.

**Keywords** Low birthweight · Retention in HIV care · ART adherence · Postpartum women · Qualitative

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## Introduction

Low retention in HIV care in the postpartum period has been shown across multiple studies in and outside of sub-Saharan Africa, with more than one in five recent mothers living with HIV not remaining in care 6 months after giving birth [1–6]. A systematic review also found that postpartum women living with HIV have lower ART adherence rates (57%) than pregnant women (75%) [7]. Both low rates of retention in HIV care and incomplete ART adherence (referred to as incomplete engagement in HIV care) are associated with increased risk of HIV transmission, mortality, and HIV-related morbidity [8].

Reasons for incomplete engagement in HIV care in the first postpartum year are insufficiently understood. Demands of caring for a newborn, prioritization of the infant's needs, and limited childcare help may be among the underlying factors [9–11]. Newborn health status may also influence postpartum engagement in HIV care; people caring for relatives with serious health conditions are less likely to use preventive health services compared to those without these responsibilities [12], as they often prioritize care for their sick family members (e.g. infants, spouses) over attending medical facilities for their own health [13].

Caregivers of children with significant health problems are also more likely to experience caregiver burden—a physical, emotional, and/or financial stress that results from caregiving [13]. Caregiver burden has been linked to low use of preventive health services and psychological difficulties [13, 14]. Among caregivers living with HIV, psychological difficulties are associated with ART non-adherence [15].

One population that faces significant caregiver burden and psychological difficulties is mothers with LBW infants—in particular, those with very LBW babies [16]. A recent meta-analysis of cohort studies showed that in sub-Saharan Africa, the odds of giving birth to a LBW baby are about two times higher among women living with HIV compared to those who are uninfected [17]. In some countries, the prevalence of LBW births among women living with HIV is as high as 15–20% [18–20].

The biological reasons why HIV is associated with adverse pregnancy outcomes are not completely understood [21]. One hypothesis is that HIV contributes to poor intestinal absorption of essential nutrients, reduced dietary intake, and metabolic abnormalities. These conditions lead to poor growth in utero, resulting in growth restriction [22]. Another hypothesis is that HIV triggers a severe inflammatory response in utero, which results in a strong, unscheduled immune response [22]. This response causes severe inflammation which can lead to premature birth [23], a leading cause of LBW [24]. Others have posited that a low CD4 cell count may increase transmission of HIV from mother to child [25]. Pediatric infection restricts infant growth in utero [26], leading to LBW.

Having a LBW baby may influence postpartum follow-up care for mothers living with HIV in Ghana. Among the *Akans* of Ghana, LBW is part of a traditional illness called *asram*. *Asram* is an umbrella term for 14 types of pediatric symptoms and conditions [27]. The term *asram kotre* refers to LBW, which literally means “as small as a lizard”. One cause of *asram* within the local etiology of diseases is the evil-eye. For this reason, *asram* is considered not to be fully curable at health facilities; thus, mothers seek care from traditional healers. Similar care-seeking behaviors have been observed among mothers with LBW infants in rural Nigeria [28] and have been noted to delay maternal interactions with the formal health sector [27]. This delay may contribute to missed visits for HIV care in the postpartum period among mothers with LBW infants.

Recent reports have advocated for a better understanding of the societal and interpersonal factors that influence women’s engagement in HIV care during the postpartum period [11, 29]. Such insights could facilitate the design of more effective, cross-cutting interventions to increase engagement and ultimately improve HIV control and treatment. To respond to these gaps, we conducted a qualitative study with the primary aim of exploring how caring for

LBW infants may affect mothers’ engagement in HIV care in the postpartum period.

## Methods

### Setting

The study was conducted in Ghana, where an estimated 2.0% of adults and 2.8% of pregnant women are living with HIV [30]. We recruited women from two large referral hospitals located in the capital, Accra: Korle Bu Teaching Hospital (Korle Bu) and Ridge Regional Hospital (Ridge). Accra is in the Greater Accra Region, which has an HIV prevalence of 3.8%, the third highest regional rate in the country [30].

About 23,000 births per year are delivered in the two hospitals. The hospitals provide care for all maternity patients, but disproportionately serve high risk patients. Based on hospital records, the prevalence of LBW among women living with HIV who gave birth at these hospitals in 2015 was 8%. Each hospital has a neonatal intensive care unit (NICU) where LBW babies who need intensive care are admitted. Reasons why babies are admitted to the NICU include, but are not limited to, difficulty breathing or LBW, jaundice, HIV-infection, and macrosomia. For LBW babies, those who weigh 1.6 kg or below are given preference for hospital admission.

Most mothers are not allowed to stay overnight with their babies at the NICU, particularly at Korle Bu Hospital. The majority of the mothers remain at home, visiting their babies during the day. Typically, mothers who are admitted have very preterm or sick babies. At Korle Bu, mothers who live far away from the hospital pay to stay at the Mothers Hostel or maternity ward. Very few services exist to meet the needs of caregivers at the NICU. Ridge Hospital offers mental health referrals and bereavement care. HIV-related services are not provided to caregivers living with HIV who stay with their babies at the NICU.

The two facilities follow the World Health Organization’s guidelines for Option B-plus for the prevention of mother-to-child HIV transmission: providing lifelong ART to women diagnosed with HIV, irrespective of CD4 cell count [31]. At both hospitals, mothers receive post-natal care and HIV treatment in separate units. Within the 12 months following delivery, mothers are typically expected to make 10 visits for themselves and their newborns: four visits to obtain ART, two visits to receive post-natal care for the mother-baby dyad, one visit for infant HIV testing, one visit to receive the infant test result, and two visits for immunization after the first 6 weeks of life.

## Participants, Recruitment and Sampling

Study participants included 30 postpartum women living with HIV who delivered at the study hospitals. The eligibility criteria were: having an infant 1 year of age or younger, being infected with HIV, giving birth at or receiving HIV treatment at one of the two hospitals, and being 18 years or older. We excluded women who gave birth at home. We did not exclude women who had infants with severe illness or disability.

Participants were purposively sampled based on hospital-recorded weight at birth and whether or not they were previously admitted to a NICU. We recruited mothers who were receiving care through (1) maternity clinics, (2) NICUs, and (3) adult and pediatric HIV treatment centers via health workers. Fifteen participants had LBW infants and 15 had NBW infants.

Semi-structured in-depth interviews were conducted from February to April 2016 by the first author and two research assistants (one male and one female). Interviews were conducted in either Twi or Ga and occurred at the recruiting hospitals (56%) or in participants' homes (44%). An initial guide, which was based on the study research questions, was pilot-tested with four individuals. The data collection team also role-played with the guide. They listened to audio recordings of interviews to further refine the content, structure, and wording of interview questions, such that the interview guides were modified iteratively during the time data were being collected (See Table 1 for a sample of questions and probes).

Key interview topics included experience as a mother living with HIV, HIV diagnosis and disclosure, caring for LBW and NBW infants, and ART treatment and clinical visits in the postpartum period. On average, the interviews lasted 46 min [ranging from 20 to 95 min]. Six of the thirty interviews lasted more than 1 h. Two participants were interviewed twice to get more in-depth descriptions of their experiences. Twenty-six of the thirty interviews were audio recorded and transcribed verbatim, while handwritten notes were taken during interviews with the four other women who declined audio-recording. Participants also completed a structured questionnaire that captured socio-demographic characteristics, HIV history, and birth outcomes. Information on birthweight was extracted from medical charts. We stopped collecting data after 30 interviews when data saturation was reached.

## Analysis

Data collection and preliminary analysis occurred concurrently, using methods adapted from grounded theory [32]. We chose this methodology for several reasons. First,

we wanted to move beyond description and interpretation of participants experiences to develop a mid-level theory about the processes we were studying. Second, because very little was known about how caring for a sick infant affects maternal engagement in HIV care, we did not want to impose an existing theory or framework on the data.

The field team, including the first and third authors, held regular audio-recorded debriefing sessions to identify salient themes in the data. After the first seven interviews, the team formulated a working theory about the linkages between LBW and ART adherence and retention. During subsequent debriefing sessions, emerging themes from new data were compared to the working theory to enhance, confirm, or discard aspects of the theory [32].

Following data collection, the first and third authors both read one transcript and performed line-by-line inductive coding to come up with initial codes. Discrepancies between the two coders were resolved through discussion. The first author subsequently coded the first four transcripts also line-by-line. The codes were refined to eliminate redundancies and grouped within categories, based on underlying themes. The codebook was then systematically applied to the rest of the interviews in Atlas.ti.7 by the first author, including the notes from the interviews that were not audio recorded. The interviews of mothers with LBW infants were coded first to identify the main salient categories. A more focused coding was done to identify linkages between the categories and engagement in HIV care. The same process was repeated for the data with women with NBW infants. For each group, a list of key themes was created and compared across the two groups. Themes that were similar were examined for their intensity, that is, how often each theme appeared in the interviews from that group. Through more focused coding, the context in which these themes came up was examined, i.e., whether in the home, hospital, or during caregiving or interactions with others. For themes that were dissimilar between the groups (for example, stigma toward small babies), the relevant text was read through several times to identify reasons for the differences. More extensive memos were written to describe how the two groups were different and why (focusing on the context and setting in which those themes emerged). Themes were grouped by positive and negative influences of LBW on engagement in HIV care. A conceptual model was created to show the underlying mechanisms that linked these influences to engagement in HIV care (See Fig. 1). Memos were kept to enhance this process. In this paper, we defined poor retention in HIV care broadly, ranging from any missed visits for a clinical appointment to obtain ART medications to prolonged disengagement from care.

**Table 1** In-depth interview guide with mothers living with HIV who have normal and low birth weight infants in Accra Ghana: sample questions and probe

## Part 1: birth experience and caregiver representations

1. Could you describe what happened on the day you gave birth to your baby?  
Probes  
How did your labor start?  
How did you get to the hospital?  
How was your experience at the hospital?
2. Could you describe your baby to me when he/she was born?  
Probes  
How did your baby look like compared to other babies?  
Tell me how you felt when your baby was born?  
How did you feel when you saw your baby?
3. Could you tell me about where the baby stayed after delivery?  
Probes  
Did the baby stay at the NICU? If yes, what was it like for you?  
Tell me about where your HIV drugs were at this time?  
How were you able or unable to take them?
4. Describe your experience caring for your baby at home  
Probes  
What was your family's reaction when they saw your baby?  
What about your friends and neighbors? What were their reactions to your baby?  
What has it been like caring for your baby at home?

## Part 2: living with HIV, child care, and engagement in hiv care

*Now, I want to ask you questions about living with HIV and caring for your child*

5. Could you help me understand how it has been like living with HIV?  
Probes  
Tell me the story of how you were diagnosed with HIV?  
Could you describe how people have related to you since your diagnosis?  
Tell me about any treatment you have received for HIV?  
Could you compare and contrast your experience with HIV care visits before, during, and after birth?
6. Tell me about how you combine caring for your baby and your own HIV needs?  
Probes  
How do you manage caring for your baby and your HIV care visits?  
What about adherence to your HIV treatment, how do you manage that?

## Part 3: perceptions of low birth weight babies

*Now, I want to ask about your thoughts concerning babies that are born small*

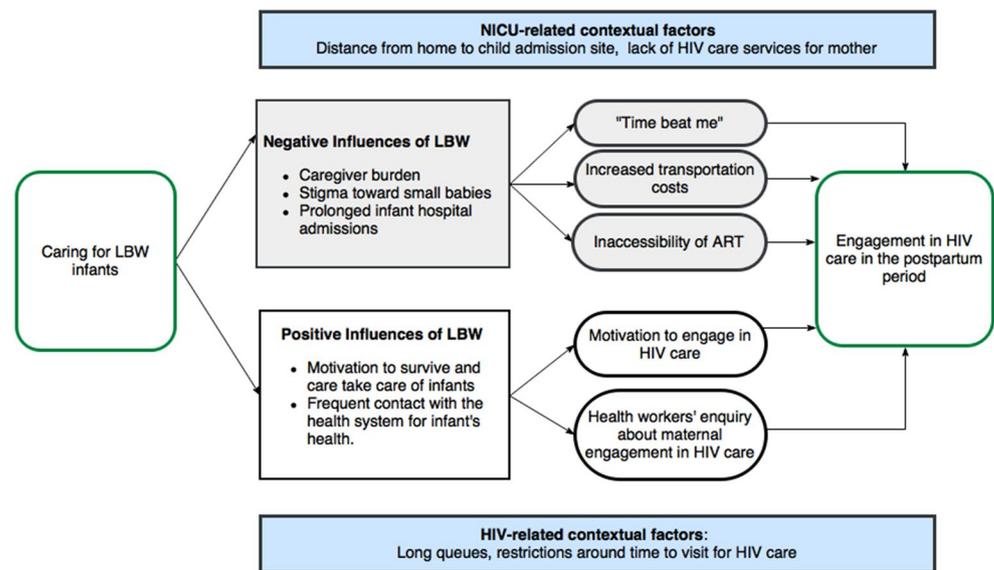
7. What do people in your community think about babies that are born small?  
Probes  
What names are such babies called locally?  
What are some of the reasons people think babies are born small?  
How do people interact with such babies?  
What have been your own thoughts about such babies?  
What has been your experience caring for a small baby (*for mothers with LBW babies only*)?

**Ethics**

Ethical approval was granted by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board (IRB No. 6651), the Ethical and Protocol Review Boards of the Ghana Health Services (ID: GHS-ERC 16/09/15) and the University of Ghana Medical School (ID: Ms-Et/M.2-P4.1/2015–2016) All interviews were conducted with participant informed consent. Participants were compensated with 20 Ghanaian cedis (~US \$5) and a pack of diapers. At the end of the interviews all

women who were no longer receiving treatment were encouraged to re-engage in care. The research assistants explained the benefits of staying in care and the risks of not receiving care to women who had disengaged from care.

**Fig. 1** Negative and positive influences of low birthweight on engagement in HIV care in the postpartum period among women living with HIV in Ghana



## Results

The majority of the 30 participants were recruited through maternity clinics (47%) and a pediatric HIV treatment center (30%), with the rest recruited in the NICU (16%) and adult HIV clinic (7%). Many of the mothers gave birth at the two hospitals because it was their regular site for maternity care; others were referred because of their risk for poor birth outcomes or cesarean section. The mean age of the mothers was 35 years old [range 24–44 years] and for infants, 5 months old [range 5 days–12 months]. About 68% of the mothers had beyond a primary school education, and 96% were either married or cohabiting. On average, participants had been living with HIV for 4 years and had two children. The mean birthweight in the LBW group was 1.96 kg and 3.01 kg in the NBW group (Table 2). Women with LBW infants had fewer children (1.24) than those with NBW infants (2.35).

Care for LBW infants had both negative and positive influences on maternal engagement in HIV care for a mother's own health. Negative influences included caregiver burden, stigma, and prolonged infant hospitalization. Positive influences included maternal motivation to survive and take care of the infant, as well as frequent contact with the health system for the infants' health, leading to greater engagement of mothers for their own health. (See Fig. 1 for a conceptual model of these influences on HIV care). All quotes used in this paper are from mothers with LBW infants, unless otherwise specified.

### Negative Influences of Caring for LBW Infants

#### Caregiver Burden

In contrast to mothers with NBW infants, many mothers with LBW infants repeatedly spoke about caring for their

newborns in terms of suffering. The concept of *suffering* resulted in a significant physical and emotional toll—dimensions that defined caregiver burden:

There was a lot of suffering... In feeding him, I suffered. At times, I had to pump the breast milk into a feeding bottle and give it to him on the bed. I did this until he turned 40 days old... [and even] after the 40 days, he still looked very tiny, like we just gave birth to him. [34 years, 1.8 kg baby]

He has made me suffer because even when you leave him temporarily to [go] do something, he would cry and wants you to carry him. I have to hold him in my arms always. This child, maybe because he is sick, that is why he is not able to put on weight. As for my first born, he stopped breastfeeding at four months old, yet he was able to put on some weight... He has made me suffer. [30 years, 1.3 kg baby]

Most participants' narratives suggested that caregiver burden contributed to mothers' incomplete ART adherence. Mothers used the phrase *'time beats me'* to capture a delay, distraction, or forgetting to take ART at scheduled times.

The nights that she disturbs me, even though my alarm rings for me to take my drugs at 8:30 PM, I do not wake up until 9:00 PM. That is when I wake up to take the medicine. [31 years, 2.1 kg baby]

I left home early in the morning [to come for my baby's well visit], and I did not put it [ART] in my bag directly, and so when I remembered, I could not go back for it (laughs). The last time I was beaten by time there was someone at home that I could reach to bring the medicine to me at the maternity, but today,

**Table 2** Background characteristics of study participants and their infants, N = 30

Characteristics	Total N (%)	Low birthweight, N (%)	Normal birthweight, N (%)
<b>Categorical variables</b>			
Education level			
No formal education	1 (4)	0 (0)	1 (7)
Primary school	8 (29)	6 (43)	2 (14)
> Primary school	19 (67)	8 (67)	11 (79)
Marital status			
Married	24 (80)	12 (80)	12 (80)
Cohabiting	5 (17)	2 (13)	3 (20)
Single/widowed	1 (3)	1 (7)	0 (0)
Ethnicity			
Akan	12 (40)	5 (20)	9 (60)
Ewe	7 (23)	5 (33)	2 (13)
Ga	3 (10)	2 (13)	1 (7)
Other	8 (27)	5 (34)	3 (20)
Occupation			
Trader	14 (46)	7 (46)	7 (46)
Seamstress	5 (17)	4 (27)	5 (33)
Other	11 (37)	4 (27)	3 (21)
Time of HIV diagnosis			
Before index pregnancy	21 (70)	13 (87)	8 (53)
During index pregnancy	8 (27)	2 (13)	6 (40)
During postpartum, index pregnancy	1 (3)	0 (0)	1 (7)
<b>Continuous variables</b>			
	Mean (range)		
Maternal age (years)	34.80 (24–44)	33.86 (24–42)	35.73 (26–44)
Number of children	2.09 (1–4)	1.24 (1–5)	2.35 (1–5)
Number of years living with HIV	4.14 (0.4–16)	4.31 (0.58–15)	4.25 (0.5–16)
Mean birth weight (kg)	2.49 (1–3.5)	1.96 (1–2.4)	3.01 (2.5–3.5)
Infant age (months)	4.80 (0.17–12)	5.98 (0.5–12)	3.4 (0.2–11)

there was no one to bring it; I also could not turn and go back. I will not be home until evening, so it's likely that it's only in the evening that I can take it today. [36 years, 1.5 kg baby]

Most of the mothers were on a triple combination pill twice a day, while a few were on a triple combination pill once a day. Several participants indicated that they put significant pressure on themselves to stick to their treatment schedules. When *time beat* the participants, most of them reported taking ART a few hours later, but a few missed a complete day: “Two mornings ago, time beat me, and I did not take the drugs. It has happened about twice now.”

While some mothers were aware that they could take their drugs when *time beats* them, others were not.

Sometimes, time beats me. I usually take my medicine at 8:00 PM, but when time beats me... I do not take it again since we were told at the hospital not to take it. Sometimes [I forget to take it] because I would not eat

early in the morning, and we were told to eat before taking it. I would be doing... housework and I would like to finish before I eat. This [work] includes getting the children bathed, washing the dishes, and clothes. It is nothing much; it is all about these house chores. Sometimes, I would be holding him, and then I forget that I have not taken my drugs. [30 years, 1.3 kg baby]

Both mothers with NBW and LBW infants reported being *beaten by time*; however, this experience was more commonly described in interviews with mothers of LBW infants than of those with NBW infants. The mothers' narratives suggested that LBW infants did not sleep well, cried often, and demanded to be often held, and as a result, taking care of them likely took more time than NBW babies. Many mothers emphasized that these occurrences made mothers more frequently *beaten by time*—that their focus on the infant made it hard to care for themselves and take their ART as prescribed. The act of taking care of the babies' needs had

negative impacts on the caregiver in terms of forgetting to take her medicine or not making it a priority.

He likes crying ... and always wants to be held and he does not like sleeping much. He delays me. Some children can even cry more than my child, and when this happens, it makes the mother distracted. She has to stop what she is doing to attend to the child. [36yrs, 1.5 kg baby]

As a nursing mother, you have to wake up, wash your baby's things, feed the baby and all that. You cannot leave your baby when she is crying to go and take your drugs. Every mother is first concerned with the child's well-being. Maybe too the mother has been disturbed by the baby all night and it is now time for her to sleep a bit since the baby is asleep, and then her medicine alarm goes off. She will definitely not be able to wake up to take her drugs except the one who was really determined to take the medicine. [31 years, 2.0 kg baby]

While caregiver burden was most saliently recognized as a challenge to full adherence to ART regimens, some women also noted that caregiving responsibilities could interfere with their ability to consistently attend their own HIV appointments. This difficulty, as mothers discussed, was related to a combination of *time beats me* and caregiver burden.

Participants' descriptions of *time beat me* and HIV clinical appointments related to two overlapping issues: (1) a 10:00 AM deadline for patients to report to at the HIV treatment centers, and (2) the hour of the day when participants felt they needed to be at the hospital to avoid long queues. One mother explained that when mothers are *beaten by time* they often would not attend their own HIV clinic appointments because arriving late would result in denial of services or a long wait with their babies.

It is very difficult... I have an older son, another one, and this child. When you wake up, you have to prepare and take those children to school or find someone to take care of them. Then you have to come to the clinic ... Sometimes you get here [HIV treatment center] late ... It is really hard. If you are not determined, you say 'forget it; I am not going to go this time' ... So sometimes the mothers feel that time has beaten them and they won't come. You get tired. [37 years, 2.3 kg baby]

The two recruitment hospitals had high patient volume. In particular, at Korle Bu, patients often reported waiting in long queues to collect their ART. Participants from Korle Bu said that in the past, hospital policy was to attend to women with infants first, regardless of the time they reported for care. However, the hospital then changed its

policy, requiring mothers with new babies to wait in line for their turn to be seen.

Most mothers expressed dislike for queues because they felt waiting in line with sick patients exposed their babies to diseases. They also disliked the long waits, often several hours. One mother described:

Yeah, I took the child with me to Korle Bu to the Fevers Clinic and spent a long time there. In the past, they used to attend to us first, and so we did not have to stay there too long. But now, they make us wait for a long time. I cannot take it anymore...I do not want my child to suffer like that... The children suffer when you are there ... [The last time,] I got there around 10:00 am because I went to Tema Hospital first to seek care for my child's health before I came to Korle Bu. When I left Korle Bu, it was around 2:00 PM. As for Korle Bu, you can wait there for a while, and no one would even consider that you are a mother with a child, and thus they should not make you wait so long. I do not want my child to get another disease while we are here—someone will be coughing, and another person will be sick with something else. All of these expose your child to diseases, and they will not do anything about it. [43yrs, 1.8 kg baby]

To avoid these queues, some mothers described that they needed to report to the hospital or leave home very early in the morning, as early as 2.00 AM for one participant. One mother suggested that when mothers thought of the stress of joining long queues, they get discouraged to seek care:

The health staff makes us join a queue and by 2:00 AM, when you get here, people would have already formed a line. If you decided to take care of your children at home before coming, by the time you get here, you would see hundreds of people queuing here. [34 years, 1.8 kg baby]

Let me tell you, this illness, when you have it and you do not have faith in God, as well as have support from people, you will soon give up because in your mind, you will have the thought that you will die [in this life] no matter what, so why don't you live your life [and forget treatment]. The going up and down too is too much... Three months ago, I even fought with these people [health workers], I got here in the morning at 5:00 AM, but I left here at 5:30 PM! When the person thinks of all the stress that she has to go through, she would just skip the clinic...The queue at the clinic too is another stress that we would have to go through. Today is the first time I have been able to leave earlier since I gave birth. Even when I am coming here, my husband complains that I should not come and that

whatever will happen to my health, it is okay. I would tell him not to give up. [31 years, 2.1 kg baby]

As illustrated by earlier quotes, for a few mothers, the delay in arriving at the hospital was partly because they had to take care of their children at home. In addition, delays were also caused by seeking care for their baby's health either at another hospital or a clinic within the same hospital. This added stressor, of seeking care in multiple locations within the same day, was compounded by the emotional stress of having to wait in long queues.

It is not easy ... When you go [to the postnatal clinic], by the time they find your [medical] folder and you get your vitals checked, it will be around 8:00-8:30 AM. After that, you have to take the baby to see the baby doctor [and join a queue there]. You have to finish with that before you can go and see your doctor and collect your drugs [ART at the HIV treatment facility]. When you get there, you have to queue, so it is still time-consuming...Stress! [31 years, 1.9 kg baby]

### Stigma Toward LBW Infants and Their Mothers

Another key theme that emerged from the interviews was stigma toward mothers with small babies and their infants. Participants' narratives suggested that the source of the stigma was often due to a perception that the babies did not look like human beings or looked "animal-like" because of their physical appearance.

I have given birth before. This is my second child. The first born was very big, but for this baby, when I noticed that I had acquired this illness [HIV], I cried and lost weight...When I gave birth to her, like a lizard's child, she was all white, her skin was very pale, and she was very tiny. I did not know her skin color could even turn black. You could see and count the ribs, like how the offspring of an animal looks like when it is born. Her eyes were very wide open; she did not look like a newly born baby when you looked at her eyes. [34 years, 1.8 kg baby]

Participant reports did not indicate that members of their families and communities associated their babies' LBW with HIV, but rather that the belief their babies were not normal led to negative social interactions.

Half of the participants with LBW infants discussed experiencing or fearing stigma relating to their baby's size, while none of the mothers of NBW infants discussed this. The majority of mothers with LBW infants who described experiencing stigma reported that their babies were small or very small at birth. As a result of this stigma, most mothers with very small babies described how they intentionally avoided going outside with their babies or how they

regulated visitors at their homes. One participant's comments illustrate this theme: "*So I could not even bring the baby out. I could not! If someone saw him, the person will think: "what kind of a 'thing' has this woman given birth to?"*" Another recollected: "*because the child was small, they used to whisper among themselves and when they saw me coming, they stopped.*"

Most participants who experienced stigma reported depressive symptoms, particularly prolonged sadness. When speaking about how her neighbors gossiped about her, one woman said: "It made life so hard for me. Whenever I looked at my child, I started crying. I stayed indoors and cried many times."

Mothers related that because of stigma against LBW babies, they generally avoided taking public transportation to prevent unwelcomed stares; they preferred to take private taxis instead. For most participants, taking taxis was costly and made attendance at clinical appointments more difficult. One mother spoke about her struggles: "*As for the medicine, I am able to take it, but it is going to the hospital that is the most difficult for me.*" She explained:

"It is not easy at all. You have to pay 30 Ghana cedis for a taxi (~US \$8), and on top of that, you have to think about what you will eat. You will see people selling food on the street, and you will want to buy something to eat. Before you realize it, the cost adds up to about 40 Ghana cedi. [43 years, 1.8 kg baby]

The cost of taking a taxi for this participant was about six times that of a regular public bus (5 Ghana cedi). This participant's report and others suggested that the experience of stigma relating to small babies created challenges for visiting HIV treatment centers, but not for taking ART.

It is important to note that mothers with NBW infants also preferred to take taxis with their newborns to seek HIV care, but not for reasons related to stigma. Many felt that crowded public transportation exposed their newborns to diseases, so they preferred taking taxis.

While experiences and fears of stigma led to sadness and isolation and often prevented women from leaving home, mothers of LBW infants did not generally discuss stigma or feeling sad as direct barriers to attending the HIV clinic or taking their ART.

### Prolonged Infant Hospital Admissions

Prolonged infant hospitalization contributed to incomplete ART adherence and missed HIV clinic visits. Ten of the 30 mothers reported that their infants had been admitted to the NICU; eight of these ten infants were LBW. Trouble breathing was the main reason why NBW infants were admitted, based on the mothers' accounts. Two of the LBW infants were readmitted to an emergency ward after their

first NICU admission. The duration of hospitalization ranged from 2 days to a full month. Among mothers whose infants experienced a prolonged hospitalization, about half reported not taking their ART because they forgot their medications at home or did not anticipate having a prolonged admission: “*Because my water had broken I thought I would not stay long there, and so I did not take my drugs with me,*” said one. Some mothers lived far away from the hospital and others were recovering from a cesarean section, so they could not access their ART. We also witnessed firsthand how two of the participants who reported they needed to get their ART could not leave their sick infants. One had been out of ART for 3 days.

Participants who reported having ART with them at the time of admission generally prepared in advance to have the drugs with them at the hospital. They often put the ART with the supplies they are required to bring to the hospital during labor. Even when they had their drugs, one of the mothers said that sometimes some women who were recovering from cesarean section further found it difficult to take their drugs.

I poured some of the ART into a rubber bag and placed them in the bag that contained things that I was going to take with me to the hospital to give birth. [31 years, 2.0 kg baby]

You have to take your medicine [ART] there. I was at the ward, and the baby was at the NICU. I brought the medicine with me to the hospital. I put it in a bottle and brought it with me. So my stay at the NICU did not affect me as much because I had my medicine. There is no need to play with taking the medicine. If you know your status... you can take your medicine. Take your medicine! It is what will make the baby strong and yourself too. There were many women who had cesarean section, and they were not able to take their drugs. [42 years, 2.3 kg baby]

## Positive Influences of Caring for LBW Infants

### Motivations to Survive, Prevent Mother-to-Child Transmission, and Take Care of Infants

While negative consequences of caring for LBW infants on ART adherence and retention in HIV care were more frequently mentioned, we also found that caring for LBW infants also had a positive impact for some women. A few mothers indicated that their motivation to live and care for their infants increased their ART adherence and retention in care.

When asked about reasons for taking ART and why other mothers struggled to take theirs, both mothers with NBW and LBW infants attributed their reasons to a desire

to prevent mother-to-child transmission of HIV, but this motivation was more strongly stated in interviews with mothers of LBW infants.

I always take my drugs... Ever since I tested positive for HIV, I have never missed taking my drugs. [What motivates me is that] I was told [at the hospital] that if I do not take my drugs, my child could get infected with HIV; but if I try to take them on time, it will help [26 years, 3.2 kg baby].

In addition, mothers with LBW infants more frequently stated that they wanted to live and care for their children. One mother with a LBW baby stated: “*The mother [who is not taking her ART] is not ready to fight for her life, in the sense that you have to live for your baby.*” Another commented:

It is my prayer that he should not suffer [acquire] this illness [HIV]. That is my only worry. Eh! This devilish illness, this little child does not even know from where it came. I do not want him to get it that is why I do not even breastfeed him but chose to give him baby formula. If the doctor had told me that there was a possibility of passing it to the baby, I would not have even had children... I cannot go and give birth and the child becomes a burden to others [if I died]. No one can look after your kids better than you can. My only prayer is that he will not get it [HIV]. That is my only worry. [40 years, 1.7 kg baby]

### Frequent Contact with the Health System for Infant's Health

The poor health of LBW infants brought many of the mothers into frequent contact with the health system. For a few mothers who were receptive and willing to engage in new behaviors for the sake of the baby, this created an opportunity to re-engage in HIV care following interactions with health workers. For example, some mothers with LBW infants had to visit the hospital multiple times to attend check-ups for their children's health. Two participants, who had stopped taking ART during pregnancy for more than five months because of side effects, described the benefits of these visits. In both situations, a health worker enquired about the mother's engagement in HIV care during a visit for the child. They were then referred to the HIV treatment center. One of these mothers explained her situation:

If it wasn't for the fact that I brought my child to complain about her scratching her eyes, and was questioned about my drugs [ART] ... I would still have been home. I would not have come to the hospital for my own care. [34yrs, 1.8 kg baby]

I told the nurses that I was having the problems [i.e., side-effects from ART]. They told me that is how it is at the beginning when you start taking the drugs, and then, they [side effects] go away. I still did not take them after that. Then after pregnancy, when I gave birth, the nurse told me to take them because of the baby. That is why I am taking them. [24 years, 2.4 kg baby]

Because pediatric services are provided separately from adult HIV care services, mothers had to make separate contact with the adult HIV treatment center. Both of the mothers described above visited the ART treatment center and resumed taking ART because they were responsive to advice given in the pediatric ward: *“I was glad that we were advised to continue with the drugs... what they tell us, that is what we will obey.”* None of the mothers with NBW infants indicated that they re-engaged in care as an indirect result of seeking services for their babies.

## Discussion

Our study suggests that caring for LBW infants has important implications for maternal ART adherence and retention in HIV care in Ghana. Due to caregiver burden and prolonged hospital stays, mothers with LBW infants reported facing more difficulties in adhering to ART and keeping clinical appointments for their own HIV care compared with mothers with NBW infants. We also found that on few occasions, caring for LBW infants facilitated re-engagement in HIV care.

To our knowledge, studies conducted in sub-Saharan Africa to date have only examined the relationship between poor maternal adherence to ART during pregnancy and the subsequent delivery of a LBW baby, while our study conversely explores how caring for a LBW baby may affect ART adherence in the postpartum period. In a clinical trial conducted in Zambia, pregnant women who were non-adherent to single-dose nevirapine were about five times more likely to give birth to a LBW baby compared to adherent women [33]. In addition, women who gave birth to LBW babies were also about twice as likely not to have taken the medication at the right time compared to those with NBW babies [33]. Moreover, across four sub-Saharan African countries, non-adherence to single-dose nevirapine during pregnancy was associated with a higher likelihood of having a LBW baby [34]. In our qualitative study, we found that caring for LBW infants after birth contributed to incomplete adherence to ART. Collectively, these two studies along with ours suggest compounded effects, i.e., that ART non-adherence during pregnancy may contribute to the birth of a LBW baby, and a higher demand of caregiving for a LBW baby may, in

turn, create challenges to ART adherence. While PMTCT programs have shifted from a nevirapine-based service to Option B-plus since the early research in this area, our study highlights that mothers continue to face many challenges with ART adherence.

Caregiver burden was one mechanism we found linking caring for LBW infants to incomplete ART adherence. Some researchers have speculated that the demands of caring for a newborn are likely to contribute to lower retention in HIV care in the postpartum period compared to during the antenatal period [3, 7, 11]. Our results suggest that this relation may be especially pertinent to mothers with sick or LBW infants. The newborn behaviors that made them forget or delay taking ART—poor sleeping habits, excessive crying, and needing to be held continuously—appeared to be less frequent among NBW infants.

Research has shown that caregivers of sick family members are less likely to use preventive services for their health [13]. One explanation often cited is that caregivers are more likely to prioritize the health of the person they are caring for over their own [13]. In our study, caregiver burden translated to missed visits more because of health system factors than individual factors. Mothers did not want to wait in long queues or be chastised by health workers for coming later than a hospital set appointment time. Thus, a delay at home because of caregiver burden led to a missed visit. A missed visit is important because, among adults living with HIV in sub-Saharan Africa, missed appointments can potentially result in a reluctance to return to care and contribute to long-term disengagement [35].

Studies have shown that the experience of stigma undermines utilization of health services, including HIV care itself [11, 36]. In a systematic review, high levels of stigma were strongly correlated with lower use of HIV care services [37]. Our study suggests that the stigma of having a small baby may be compounded with HIV stigma to have a stronger impact on the use of HIV care. For example, in response to stigma directed towards small babies, mothers relied on private modes of transportation to access HIV care—in this case, taxis—to prevent others from seeing their babies. This solution to avoid stigma, however, increased the financial cost of accessing ART and created challenges for keeping appointments. Our results thus extend knowledge of how stigma towards HIV and LBW affects health utilization among postpartum women living with HIV in Ghana.

To effectively support the HIV care needs of mothers with LBW infants, we recommend improved access to HIV drugs in pharmacies associated with NICUs. Relatedly, as part of routine care during prolonged admission of infants whose mothers are living with HIV, we suggest that clinical practitioners at pediatric care units ask about caregivers' access to ART and adherence. This family-centered approach will ensure that mothers without ART

are provided with treatment while they are taking care of their newborns in the hospital.

Given the caregiver burden and the prolonged suffering that our participants faced, health workers may consider delivering ART to the mothers at home. In addition to enhancing access, such a model will allow health workers to identify and refer LBW mothers with depressive symptoms to mental health services. Also, health workers may accommodate the needs of postpartum women by being more flexible with the schedule they require of mothers in the postpartum period. Other measures, such as reducing the wait time for postpartum women who report for HIV-related services, may also mitigate the contribution of caregiver burden to missed visits.

Moreover, counselors of pregnant women living with HIV at antenatal clinics should encourage women to have ART with them when they report for labor. Health workers can easily incorporate this advice into the birth preparedness education that already occurs in this setting [38]. Also, due to the influence of caregiver burden on missed doses of ART, interventions that promote cues to action, such as reminders, may be helpful to address failure to engage in HIV care when mothers are focused on their baby. Resources that provide tips on how to reduce caregiver burden may also be beneficial to mothers, including ways to enhance social support.

This study has some limitations. As participants were urban women recruited from tertiary hospitals, their experiences may not reflect the challenges facing rural women, or women in non-tertiary settings, limiting the transferability of our results. Participants were also asked to recall events that had happened in the past – for some women, up to one year postpartum. This time frame may have made it difficult for some women to recall how their children's birth and care impacted their ART adherence and retention in HIV care. However, in a few cases, we were able to interview mothers when their children were admitted to the NICU and children's emergency ward. These interviews allowed us to examine in real time how women experienced a prolonged hospital admission and how staying with their babies at the NICU impacted their engagement in HIV care. Moreover, four of the interviews were not audio-recorded; we had to rely on interviewer's notes, which may not have precisely or completely captured all that those participants said.

Study strengths include a focus on tertiary hospitals. Research shows that the problem of low retention among women is greater in tertiary than non-tertiary hospitals [36]. A further strength of this study is that we were able to document the experiences of a subpopulation of women whose experiences with ART adherence in the postpartum period have not yet been studied in Ghana.

## Conclusion

The postpartum period is a challenging time for women to engage in HIV care. Our results demonstrate how the demands of caring for a LBW baby can simultaneously create difficulties for mothers to care for their health and also lead to opportunities for engagement with the health system. The findings indicate that mothers with LBW infants may benefit from instrumental social support to reduce caregiver burden. This reduction may, in turn, increase ART adherence and follow-up with HIV-related clinical appointments. Interventions are also needed at the individual and health system levels to help mothers stay engaged in HIV care during prolonged hospital stays. Complementary future research may be able to quantitatively test the potential association between LBW and lower engagement in HIV care among postpartum women in Ghana.

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## Compliance with Ethical Standards

**Conflict of interest** The authors declare that they have no conflicts of interest.

**Ethical Approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed Consent** Informed consent was obtained from all individual participants included in the study.

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