Rates and Predictors of HIV-Exposed Infants Lost to Follow-Up During Early Infant Diagnosis Services in Kenya

Kathy Goggin, PhD,[1–3] Emily A. Hurley, MPH, PhD,[1] Vincent S. Staggs, PhD,[1,2,4] Catherine Wexler, MPH,[5] Niaman Nazir, MD, MPH,[6] Brad Gautney, MPH,[7] Samoel A. Khamadi, PhD,[8] May Maloba, MCH,[7] Raphael Lwembe, PhD,[8] and Sarah Finocchario-Kessler, PhD, MPH[5]

Abstract

Early infant diagnosis (EID) involves age-specific tracking and testing of HIV-exposed infants during the first 18 months of life and rapid initiation of life-saving treatment for those infected. In Kenya, pre-2013 data estimate EID lost to follow-up (LTFU) at 39–65%, yet no study has documented LTFU rates and predictors throughout the EID cascade since Option B+ fundamentally changed services by placing all HIV-positive expectant mothers on lifelong treatment. Using an explanatory mixed-method design, we assessed LTFU rates and predictors among 870 mother–infant dyads enrolled in EID in six urban/peri-urban Kenyan government hospitals. Mothers completed baseline surveys, and dyads were tracked through EID. We selected 12 baseline variables and modeled odds of LTFU at 9 and 18 months using mixed logistic regression. Qualitative interviews were conducted with 61 mothers to assess barriers and facilitators to completing EID. Thematically coded transcripts were used to interpret quantitative predictors of LTFU. By the 18-month test, 145 dyads (22%) were LTFU, with three-quarters of LTFU occurring between 9- and 18-month tests. Odds of LTFU at 18 months decreased by 10% for each additional year of maternal age and by 66% with HIV status disclosure. Qualitative data revealed how disclosure facilitated essential social support for EID completion and how older mothers attributed maturity and life experience to successful engagement in care. Findings suggest LTFU rates in Kenya have declined, but gaps remain in ensuring universal coverage. Efforts to improve retention should focus on increasing support for younger mothers and those who have not disclosed their HIV status.

Keywords: HIV, early infant diagnosis, PMTCT, vertical prevention, infants, global health

Introduction

WIDESPREAD DISSEMINATION OF prevention of mother-to-child HIV transmission (PMTCT) programs and policy changes to provide lifelong antiretroviral therapy (ART) treatment for all pregnant women have led to a dramatic decline in new pediatric HIV infections.[1,2] Nevertheless, in eastern and southern Africa, 10% of HIV-exposed infants still become infected through vertical transmission, resulting in ∼92,000 new infections in 2017.[2] Early infant diagnosis (EID) is a critical, yet understudied component of PMTCT that involves age-specific tracking and testing of HIV-exposed infants during the first 18 months of life and the

rapid initiation of ART for those found to be infected. Initiation of ART for HIV-positive infants before 12 weeks of age has been shown to significantly reduce mortality and disease progression in these vulnerable children.[3] Tracking and testing of HIV-exposed infants through 18 months, however, remains essential, as those who are not infected in the intrapartum period may still become infected through breastfeeding. Efforts of the Global Plan to scale up EID services in 21 priority countries, including Kenya, have led to significant gains,[4] yet only 63% of the nearly 1 million HIV-exposed infants born in 2017 received HIV testing within the first 8 weeks of life.[2] Recent data from Kenya indicate that 51% of HIV-exposed infants receive EID services at some

[1]Division of Health Services and Outcomes Research, Children's Mercy Kansas City, Kansas City, Missouri.
[2]School of Medicine and [3]School of Pharmacy, University of Missouri-Kansas City, Kansas City, Missouri.
[4]Biostatistics and Epidemiology Core, Children's Mercy Kansas City, Kansas City, Missouri.
Departments of [5]Family Medicine and [6]Preventive Medicine, University of Kansas Medical Center, Kansas City, Missouri.
[7]Global Health Innovations, Dallas, Texas.
[8]Kenya Medical Research Institute, Nairobi, Kenya.

point,[2] but a quarter still fail to receive their first test before 7 weeks of age, violating Kenyan guidelines.[5,6]

Once HIV-exposed infants are enrolled in EID services, retention throughout the entire 18-month cascade of care is critical,[6] but has proven to be poor. Timely data are lacking, but a 2013 systematic review of sub-Saharan African studies, published between 2001 and 2012 found that 33.9% (range, 4.9–75%) of HIV-exposed infants were LTFU within 3 months of delivery.[7] A 2018 meta-analysis of low- and middle-income countries estimated overall 18-month attrition at 39%, but recent data from sub-Saharan Africa (post-2014) were not available for inclusion.[8] Similarly high rates (39–65%) of LTFU by 18 months have been observed in Kenya, but there have been only four studies, and none have reported on data collected after 2013.[9–12]

Significant changes in PMTCT services in many sub-Saharan African countries occurred rapidly after the 2012 World Health Organization's ''Option B+'' recommendation for continued ART for HIV-positive women postpregnancy and breastfeeding regardless of CD4 cell count or WHO stage.[13] This change positioned HIV-positive women as lifelong rather than episodic clients of HIV services. These changes greatly improved the continuity of care and may have had an important impact on mothers' ability to engage and retain their HIV-exposed infants in EID, but more recent data to evaluate this notion are lacking. Data on retention in postpartum mothers' own care suggest there is still room for improvement, as rates of LTFU among women in Uganda did not significantly improve after transition to Option B+.[14] Understanding *when* along the cascade of EID care HIV-exposed infants are most susceptible to becoming LTFU and *predictors* of loss is critical to developing strategies to improve retention. Also lacking are data from mothers who have been successful in ensuring that their infants complete the entire EID cascade of care.

As part of a larger study testing the impact of the HIV Infant Tracking System (HITSystem), a novel web- and cell phone-based intervention to improve retention and efficient service provision for infants in EID,[15–17] we explored data on infants who were LTFU after enrollment in EID care. In this study, we (1) describe when infants were LTFU; (2) identify what, if anything, predicts infants being LTFU; and (3) present findings from qualitative interviews with mothers who were successful in bringing their child back for 18-month testing.

Methods

We used an explanatory mixed-methods design to identify quantitative predictors of LTFU and then explain these findings using qualitative analysis.[18] Data were collected from HIV-positive mothers and their infants (mother–infant pairs) who were enrolled in EID programs at six Kenyan government hospitals between February 2014 and June 2015. The hospitals ranged in size (provincial, county, and sub-county level), geographic regions (two western, two central, and two coastal), and population density (three urban and three peri-urban sites). Participants were enrolled in a larger RCT evaluating the impact of the HITSystem[16] (Clinical Trials Id: NCT02072603).

Participant eligibility and consent

HIV-positive mothers whose infants were <24 weeks of age at the time of initial EID enrollment, and who were

contacted through the maternal and child health department at each site, were eligible for inclusion. Mothers were informed about the study during EID enrollment by research or clinical staff, and those wanting to participate provided written informed consent. Less than 2% of mothers approached declined participation. The study protocol was approved by the Institutional Review Boards at the Kenya Medical Research Institute (protocol #2726), and the University of Kansas Medical Center (protocol #13793) and has been published.[16]

Procedures

At initial EID enrollment, a brief survey was conducted with each mother covering basic demographics and other variables: maternal age, number of biological children, travel time to hospital, education level, relationship status, worries about money, any disclosure of HIV status, how mother learned about EID services, and perceived stigma from medical staff. Infants were given a unique study ID number and their age at EID enrollment was abstracted from the HIV-exposed infant register (HEI register), the standard paper-based register used to record all EID services. Survey data were later entered into a protected Excel spreadsheet by study staff and merged with each infant's clinical data for final analyses.

We tracked enrolled mother–child dyads through each stage of the EID cascade including (1) PCR sample collection at 6 weeks of age, (2) mother notification of 6-week PCR test result, (3) return for antibody retest at 9 months of age, (4) mother notification of 9-month confirmatory PCR test result if applicable, and (5) return for antibody retest at 18 months of age. Depending on intervention arm within the parent RCT, these EID clinic data were captured either by an electronic record system (HITSystem) or standard-of-care paper records. Data from the HITSystem were securely stored on Linux Ubuntu LAMP servers and exported directly to an Excel spreadsheet. Providers at standard-of-care sites used the HEI register, and a study staff member populated an Excel spreadsheet with data points captured from the HEI register during biweekly visits.

A convenience subsample of the mothers who returned for 18-month tests were recruited to participate in qualitative interviews. Interview guides covered topics, including barriers and facilitators to completing EID, experiences with EID services, feedback on HITSystem, and programmatic ideas to improve infant tracking and retention. Interviews were conducted by study staff in the participants' preferred language in private interview rooms during their routine visits and were audio recorded.

Quantitative measures

The primary outcome variable was LTFU at any point before completing the 18-month retest. Infants known to have died or moved before they could be retested at 18 months were excluded from analysis, as were those who tested positive for HIV at the baseline visit or had PCR-confirmed HIV at their 9-month retest. We examined LTFU before 9-month retest as a secondary outcome. This included mother–infant dyads who were LTFU at any point before completing the 9-month test and did not subsequently return for the 18-month test. Infants who failed to complete a service but returned for

the 9- or 18-month retest were included as retained (not LTFU) in the analysis for that retest.

Based on findings from previous studies,[7,19–22] we considered 12 explanatory variables as potential predictors of LTFU (Table 1), including maternal age, infant age at EID enrollment, mother's number of biological children, and travel time to hospital. Worry about having enough money to get the infant to hospital was assessed using a 4-point Likert-type item. Perception of stigma from medical staff was assessed by averaging responses to two 4-point Likert-type items, one related to the infant's EID care and the other to the mother's own HIV care. The remaining explanatory variables, all dichotomous, were as follows: having some primary education, having some secondary education, relationship status, any disclosure of HIV status, having received maternal antenatal care, and being informed about EID by a health worker during PMTCT. We used additional survey variables for the purpose of multiple imputation (described as follows) but limited the number of explanatory variables to 12 to ensure an adequate number of LTFU cases per variable in the model for 18-month LTFU.

Quantitative data analyses

We modeled odds of LTFU before 18-month retest as a function of the 12 explanatory variables by fitting a mixed logistic regression model using the GLIMMIX Procedure in SAS 9.4 (SAS Institute, Cary, NC). A random site intercept was included to adjust for within-site clustering of dyads. Owing to the limited number of infants lost to follow-up before the 9-month retest, for this outcome we fit a single-predictor mixed logistic regression model for each explanatory variable except the two education variables, which were included together in a two-predictor model.

Before modeling, missing data for 10 explanatory variables were imputed using the *mice* package in R 3.5.1.[23] We generated five imputed data sets using multivariate imputation by chained equations, fit the mixed models separately to each set of imputed data, and then combined estimates across imputed data sets using the SAS MIANALYZE Procedure. To adjust for multiple testing we focused on only *p*-values <0.05 after adjustment using the Benjamini–Hochberg method, thus controlling the false discovery rate at 0.05.[24]

Qualitative data analyses

Audio-recorded interviews were transcribed, translated into English, and uploaded into Atlas.ti for analysis.[25] To create a codebook, two independent coders applied inductive coding to a subset of six transcripts. Through debriefing, the initial codebook was refined and codes were organized into a hierarchical, thematic structure. The original coders and an additional new coder then applied the codebook to three new transcripts, and reviewed and refined coding definitions until

TABLE 1. POTENTIAL PREDICTORS OF LOST TO FOLLOW-UP IN EARLY INFANT DIAGNOSIS AND SCALING METHOD

Independent variables	Definition/survey item	Scaling
Maternal age	Mother's current age	Continuous variable; years
Infant age at EID enrollment	Age of infant at the time of EID enrollment	Continuous variable; weeks
Number of biological children	Number of living biological children	Continuous variable; number
Travel time to hospital	Number of minutes	Continuous variable; converted to hours
Worries about money	"I worry that I won't have enough money to get to the hospital for my infant's scheduled HIV tests and re-tests"	1 (strongly disagree) to 4 (strongly agree)
Perceived stigma from medical staff	"Medical staff treat me badly because I am HIV positive"	1 (strongly disagree) to 4 (strongly agree)
	"Medical staff look down on me because I am HIV positive and had a baby"	Responses to the two items were averaged into a single variable
Education level	"What is the highest level of education you have completed?"	0 (no formal education), 1 (partial/completed primary), or 2 (partial secondary or beyond); coded using two dichotomous variables: some primary education, some secondary education
Relationship status	"Are you currently with a partner?"	0 (no) or 1 (yes)
Any disclosure of HIV status	"To whom have you disclosed your HIV status?"	0 (no one) or 1 (anyone)
Received maternal antenatal care	Regimen recorded in registry	0 (no) or 1 (yes)
How mother was informed about EID	"How did you learn about EID?"	0 (anyone else) or 1 (a health care worker while pregnant–PMTCT)

EID, early infant diagnosis; PMTCT, prevention of mother-to-child HIV transmission.

discrepancies were resolved. For this particular study, the goal of the qualitative analysis was to provide *explanation* and insight into how the quantitative predictors may have operated to influence LTFU. Thus, we identified codes related to the quantitative predictors and summarized results.

Results

Quantitative results

From the 870 dyads enrolled at the start of the study, 180 infants died or moved before 18 months, 27 tested positive for HIV at their baseline visit, and three had PCR-confirmed HIV infection at the 9-month visit, leaving 660 dyads for analysis at 18-month retest. As shown in Fig. 1, 145 (22%) of these dyads were lost to follow-up before their 18-month retest. Three-quarters of this LTFU (109 of 145 dyads) occurred between the 9-month and 18-month visits. Descriptive statistics are provided in Table 2. Rates of missing data for all 12 explanatory variables were <4.5%.

As given in Table 3, maternal age and disclosure were predictors of LTFU for both the 9- and 18-month retests. Estimated odds of LTFU decreased by 9–10% per additional year of maternal age, and mothers who had disclosed their HIV status to someone had 85% lower odds of 9-month LTFU and 66% lower odds of 18-month LTFU. In terms of observed rates, percentage LTFU was higher for mothers under age 30 than for those age 30+ at both 9 months (8% vs. 3%) and 18 months (28% vs. 15%), and two to five times as high for women who had not disclosed compared with those who had (24% vs. 5% at 9 months; 45% vs. 21% at 18 months). Odds of 9-month LTFU increased by 13% per week of infant's age at EID enrollment, but there was little evidence for this effect in the model for 18-month LTFU.

In a post hoc analysis, we explored what type of disclosure was most predictive of being LTFU. We created three dichotomous disclosure variables (i.e., disclosure to partner, disclosure to family, and disclosure to friends) and refit the model for 18-month LTFU with these variables included as predictors in place of the indicator variable for any disclosure used in the previous models. We also modeled 9-month LTFU as a function of each of these disclosure variables in three single-predictor models. Disclosure to partner [OR = 0.40 (95% CI = 0.19–0.84) $p = 0.016$] and disclosure to family [OR = 0.34 (95% CI = 0.12–0.94) $p = 0.038$] seem to drive the effect of any disclosure in reducing odds of LTFU at 18 months, whereas disclosure to partner was the strongest predictor of retention at 9 months [OR = 0.43 (95% CI = 0.21–0.86) $p = 0.017$].

Qualitative results

We had complete transcripts from 61 interviews with women who completed EID through 18-month retest [mean age 32.8 years (range, 20–45); 33 (54%) from urban sites; 28 (46%) from peri-urban sites]. Just more than half ($n = 31$) had revealed their status to both their male partner and at least one friend or family member. Sixteen (26%) had disclosed only to their partner, 10 (16%) only to family/friend(s), and four (7%) to no one.

Protective factors related to maternal age

Although participants did not directly credit their age as protecting against LTFU, some did express that after years of experience and maturity, they were able to overcome some of their fears associated with HIV and EID services:

> *With the first pregnancy when I was tested, I was still a young lady. I thought about how this was my first child and how I was still young, I was alone and I wondered how life would be. After becoming more mature and getting all the counselling here, even counselling with my husband, I saw that he did not abandon me […] I see that I'm fine* (age 34, urban site).
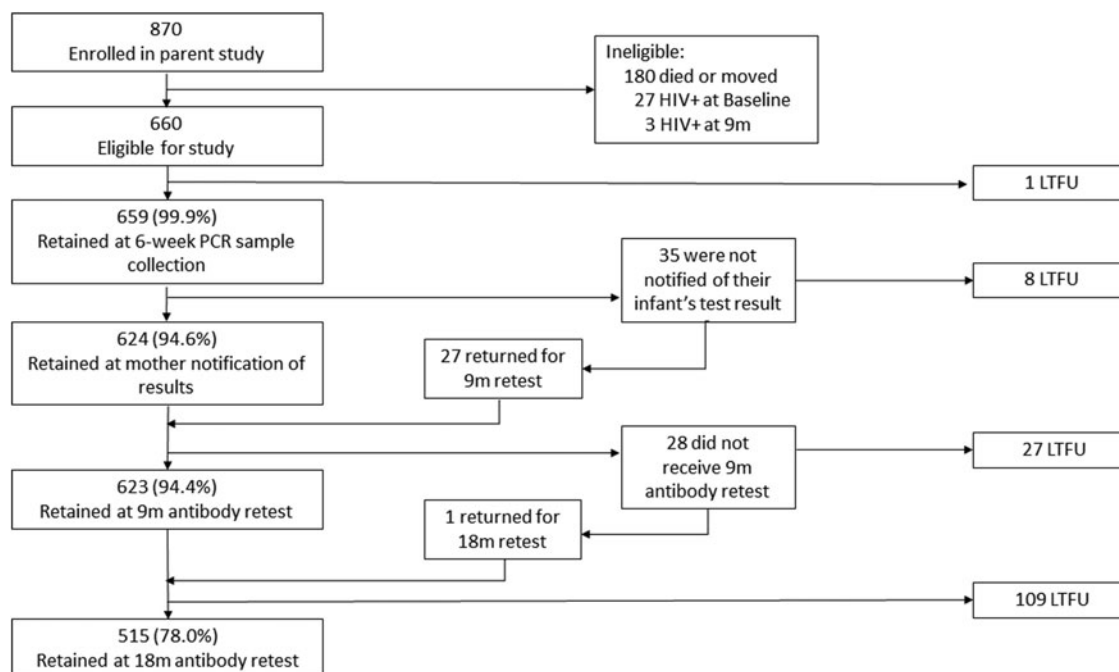

FIG. 1. Retention and lost to follow-up through 18 months. LTFU, lost to follow-up.

TABLE 2. SAMPLE CHARACTERISTICS AND DESCRIPTIVE STATISTICS

Variable	Missing (%)	Mean (SD)	Median (IQR)
Maternal age	0 (0.0)	29.8 (5.8)	29.0 (25, 34)
Infant age at EID enrollment (weeks)	2 (0.3)	7.3 (2.8)	6.3 (6.1, 7)
Biological children (no.)	16 (2.4)	2.7 (1.4)	2.0 (2, 4)
Travel time to hospital (h)	29 (4.4)	0.9 (0.6)	0.8 (0.5, 1.0)
Worries about money (1–4 scale)	10 (1.5)	2.2 (1.2)	2.0 (1, 3)
Perceived stigma from medical staff (1–4 scale)	9 (1.4)	1.2 (0.5)	1.0 (1, 1)

Variable	Missing (%)	Yes (%)	
Some primary education	11 (1.7)	609 (94)	
Some secondary education	11 (1.7)	278 (43)	
Currently with a partner	21 (3.2)	565 (88)	
Any disclosure of HIV status	28 (4.2)	590 (93)	
Disclosure to partner		449 (71)	
Disclosure to family		146 (23)	
Disclosure to friends		106 (17)	
Received antenatal care	0 (0.0)	600 (91)	
Informed about EID by a health worker	7 (1.1)	561 (86)	

Disclosure categories not mutually exclusive.
EID, early infant diagnosis; IQR, interquartile range.

Furthermore, some older mothers were living with HIV before EID had been implemented in their clinics, and had seen or personally experienced the tragedies associated with infant HIV infection. Those experiences may have contributed to their motivation to take full advantage of current EID services.

> I just thanked God for what he has done to me I saw like a miracle. Again I regretted that if back in the years they would have been educating like this, this other baby would not have been positive (age 38, peri-urban site).

Protective factors related to disclosure

The qualitative findings suggest that HIV status disclosure may be protective against LTFU because of the channels of support it may open up. Women offered numerous examples of support their male partners offered, including encourage-

ment, medication reminders for themselves and their infants, and finances for clinic transportation and other necessities. Although only one woman mentioned her husband accompanied her to EID visits, many others mentioned benefits of having a partner showing interest and involvement in tracking EID events: *"When I get home I'll tell him the next clinic date and he will remind me because he has seen the importance and also wants the children to be well"* (age 34, urban site). This ongoing support was especially salient when the male partner was also seropositive, as managing the disease became a family affair. *"So now the baby's medication is also 9:30 […] We have alarms on both phones. He set the alarm for 9:30. You will hear him say "drugs! Bring water for everyone to take their drugs"* (age 40, urban site)

Not all participants benefited from partner support after status disclosure, and for some, disclosure resulted in separation, abuse, or other hardships. Completing EID for these

TABLE 3. ESTIMATES FROM LOGISTIC REGRESSION MODELS FOR LOST TO FOLLOW-UP AT 9-MONTH AND 18-MONTH RETEST

Variable	9-Month LTFU Odds ratio (95% CI)	p	18-Month LTFU Odds ratio (95% CI)	p
Maternal age	0.91 (0.85–0.97)	0.005[a]	0.90 (0.85–0.94)	<0.001[a]
Infant age at EID enrollment (weeks)	1.13 (1.04–1.24)	0.004[a]	1.04 (0.97–1.12)	0.289
Biological children (no.)	0.80 (0.60–1.05)	0.109	1.23 (1.00–1.50)	0.048
Travel time to hospital (h)	0.88 (0.49–1.57)	0.666	0.80 (0.56–1.17)	0.250
Money worries	0.94 (0.69–1.29)	0.716	1.09 (0.90–1.34)	0.377
Perceived stigma from medical staff	1.02 (0.52–2.00)	0.946	0.72 (0.43–1.20)	0.204
Some primary education	1.58 (0.20–12.49)	0.666	0.55 (0.22–1.36)	0.194
Some secondary education	1.08 (0.54–2.17)	0.823	1.09 (0.67–1.75)	0.737
Currently with a partner	0.40 (0.17–0.93)	0.033	0.88 (0.47–1.66)	0.697
Any disclosure of HIV status	0.15 (0.07–0.35)	<0.001[a]	0.34 (0.16–0.72)	0.005[a]
Received antenatal care	0.64 (0.21–1.95)	0.437	0.83 (0.40–1.74)	0.625
Informed of EID health care worker	0.47 (0.20–1.12)	0.088	0.86 (0.45–1.64)	0.649

Estimates for 18-month LTF are from a single multiple-predictor model. Estimates for 9-month LTF are from 10 single-predictor models and 1 two-predictor model for the education variables.
[a]Denotes Benjamini–Hochberg q-value <0.05.
CI, confidence interval; EID, early infant diagnosis; LTFU, lost to follow-up.

women often meant developing resilience and self-reliance (*"It was a challenge, however, when I got work and got money, I was able to take care of myself"* [age 26, urban site]) as well as other networks of support (*"The partner I was living with already did not have any understanding. I had many worries. But when I joined the support group, I decided to focus on my life and my children's"* [age 26, urban site]).

Women who had disclosed to family and/or friends spoke of emotional, instrumental, informational, and appraisal support that helped them complete EID. Many women benefited from "encouragement," positivity, and optimism about their child's health that helped them to qualm fears and complete the EID cascade of care.

> *[My mother] was the one motivating me, telling me to not give up. And just the same way [the hospital] is staying in touch with me I should also do my best to keep up with them in terms of going to the hospital. She was my biggest motivator. If she sees me down, she would tell me to keep heart, and go to the hospital because these people who aren't even related to me care very much about my wellbeing* (age 34, peri-urban site).

Family/friends helped to make arrangements to facilitate EID appointments, such as watching older children or covering the woman's work responsibilities. Women who were part of support groups or who had disclosed to other mothers living with HIV spoke of the benefits of feeling like they were "not alone." Support group members provided mothers with emotional relief from the stresses surrounding EID (e.g., *"We would talk and laugh and the feelings would reduce because I'd find I'm with my peers"* [age 32, peri-urban site]), lessons from their own experiences, information about the EID process and infant care (e.g., *"…she said that I should not fear breastfeeding the child, but must always remember the six-month rule"* [age 40, urban site]), and on occasion, accompaniment to an EID appointment.

Support was not simply a consequence of disclosure, but a motivating reason behind many women's decision to disclose. *"My mother and I live together, so it was necessary for me to tell her especially if I need help"* (age 29, peri-urban site). Some mentioned the role health care providers played in encouraging disclosure as a gateway to support: *"I was advised at the clinic to also let someone else know about my status, so when I'm sick they can also come and help me out. That's when I told my brother"* (age 45, peri-urban site). The four women who had not disclosed did not directly mention nondisclosure as a barrier to successful completion of EID.

Discussion

This is the first study to report on rates and predictors of LTFU across the EID cascade of care since the rollout of Option B+ fundamentally changed service provision for HIV-positive Kenyan mothers and their HIV-exposed infants. At least in Kenya, there is evidence of reductions in LTFU, with just under a quarter of mother–infant pairs lost by 18 months as compared with 39–65% seen in prior Kenyan studies[9,10] and aggregate 39% LTFU estimate from a recent meta-analysis of the past three decades of data from low- and middle-income countries.[8] In contrast to the overall trend of prior studies suggesting greater LTFU by 6 months, we observed the greatest rates of LTFU between 9- and 18-month visits. This divergence from prior studies could be due to methodological differences between our study and prior in-quires[8–10] (e.g., varying definitions of LTFU, varying follow-up periods, varying use of patient tracing to determine if dyads transferred to care at another facility or were truly LTFU, and data from countries other than Kenya) or may represent a true shift over time to improved early retention of infants in Kenyan EID services. Our findings reveal the good news that Kenyan infants are being enrolled at younger ages (i.e., before 6 weeks in our study vs. 2–5 months in the prior Kenyan studies) and are demonstrating better early and overall retention. Improved retention is likely due to multiple factors, including increased government investment in HIV services,[26] increased efforts to improve engagement of women and male partners in PMTCT[12,27] where they can learn of the importance of EID services,[5] and effective interventions such as the HITSystem that leverage available technology to improve retention and efficient EID service provision.[17] Expanded coverage of ART through Option B+ has improved the health of many mothers,[28] and reinforced continuous engagement in HIV services for themselves and their infants. Nevertheless, this rate of loss still leaves 22% of HIV-exposed infants with an uncertain HIV status at 18 months, which is a major impediment to achieving 90-90-90 goals by 2021, documenting progress toward the elimination of MTCT, and meeting Kenya's national goal of reducing AIDS-related mortality by 25% by 2030.[29] Our results here indicate that service enhancements should focus on retention between the 9- and 18-month visits when most mother–infant pairs are lost.

More mature mothers and those who had disclosed to at least one other person were less likely to be LTFU. These were clinically meaningful differences, especially for disclosure where observed rates of LTFU were roughly two to five times as high for women who had not disclosed to anyone compared with women who had. These findings are consistent with other studies, in which more mature mothers are better able to stay engaged in PMTCT[30,31] and EID,[9,19] and enroll their infant in EID services earlier.[5] This is the first study to document the significant impact of disclosure on mothers' ability to stay engaged in EID services for the full 18 month cascade. Disclosure to partners and family members was most important to preventing LTFU. As born out in the qualitative findings discussed hereunder, disclosure's positive impact on engagement is likely attributable to the powerful social support it allowed mothers to access. EID program staff need to be aware of the increased probability of younger mothers becoming LTFU and should consider feasible ways to offer additional supportive services to younger mothers to increase the likelihood of long-term engagement in EID. At enrollment, EID programs should routinely screen all mothers to assess disclosure and determine sources of social support that mothers can access to ensure their adherence to PMTCT practices and EID services. Peer support groups and effective disclosure services should also be made available to all mothers who have not disclosed. Services at earlier points in the care continuum that increase initiation of antenatal care such as home-based postpartum couples' outreach[32] should also be provided. Strategies to implement these important recommendations in light of frequent staffing shortages and changes should be the focus of future research and policy efforts.

Findings from the qualitative interviews provide some explanation as to why and how maternal age and disclosure

may be so important in helping mothers to complete the entire 18 months of EID care. Mothers explained that with time, experience, and maturity, they increased knowledge and developed resilience that allowed them to overcome earlier fears of addressing their HIV disease and seeking EID services; such fears have been noted in prior studies.[9,12,33] Nearly all of the 61 mothers who remained engaged through 18 months had disclosed their status to someone. Supporting the quantitative findings, only four of the successful mothers interviewed had told no one beyond clinic staff about their HIV status. Mothers eloquently explained how disclosure had led to critically needed emotional, instrumental, informational, and appraisal social support from friends and family members they had shared their HIV-positive status with. Mothers described how family and/or friends had facilitated their ability to attend EID visits through planning, accompaniment to clinic, watching other children, covering work duties, and/or financial support, which have been noted as barriers to accessing EID in prior studies.[5,9] Disclosure also allowed family and friends to buoy mothers in downtimes and provide ongoing encouragement to adhere to life-saving medications.

This study makes a significant contribution to the literature, but nevertheless has limitations. The overall rate of LTFU may have been underestimated as half of the sample was provided access to the successful HITSystem intervention tested in the parent study.[17] Rates of LTFU at 18 months were indeed 17% higher in the control arm as compared with the HITSystem arm, but rates in both arms still represent an overall improvement from earlier studies where researchers documented loss of over half of all mother–infant pairs enrolled.[9,10] Furthermore, although retention interventions were scarce in the past, the HITSystem is now a National AIDS and STIs Control Programme (NASCOP)-recognized best practice currently available in 30 health facilities, and there are other text- or phone-based support systems at other Kenyan clinics as well.[15,34] This means that going forward, many Kenyan mothers will have access to the HITSystem or other strategies to increase retention making the data presented here highly generalizable and potentially setting the new benchmark for rates of LTFU in Kenyan EID programs. These data reflect retention of infants who were enrolled in clinic-based EID services and do not address HIV-exposed infants who never make it to care. The sample is also limited to mother–infant dyads attending urban and peri-urban facilities; thus, findings may not be generalizable to those served by facilities in rural areas. Additional potential predictor variables that were not available in the data set may have impacted the findings; however, this study still represents the most recent and thorough investigation to date of rates and predictors of LTFU in EID services in Kenya. The qualitative data are also limited in that it only include mothers who have successfully completed the 18 months of EID services. Future research on the experiences of mother–infant dyads who became LTFU is needed to more fully understand the risk factors identified in our quantitative findings.

This is the first study to report on rates and predictors of LTFU across the EID cascade of care since the rollout of Option B+ fundamentally changed service provision for HIV-positive mothers and their infants. Rates of LTFU have declined but are still far too high. Targeted efforts to improve retention should focus on increasing supportive services for younger mothers and those who have not disclosed their HIV-positive status to others. Investments in improving retention in EID services are critical to ensuring that HIV-positive infants are identified and started on life-saving medications as early as possible.

Author Disclosure Statement

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Address correspondence to:
Kathy Goggin, PhD
Division of Health Services and Outcomes Research
Children's Mercy Kansas City
2401 Gillham Road
Kansas City, MO 64108

E-mail: kgoggin@cmh.edu