

Maternal-related factors influencing retention of HIV-exposed infants in the early infant diagnosis (EID) care clinic at Nebbi General Hospital. A cross-sectional study.

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Page | 1 **ABSTRACT**

Background:

The study aimed to identify maternal-related characteristics influencing the retention of HIV-exposed infants in the EID Care Clinic of Nebbi General Hospital.

Methodology:

A descriptive cross-sectional study using quantitative methods was conducted at Nebbi General Hospital's EID clinic to assess factors influencing retention of HIV-exposed infants (HEIs). The study targeted 44 caregivers of HEIs, selected through convenience sampling. Data were collected via a semi-structured questionnaire on socio-demographic and maternal-related factors, after obtaining informed consent. Completed questionnaires were checked, stored securely, and analyzed using Excel for descriptive statistics. Validity and reliability were ensured through supervisor review and pre-testing. Ethical approval was obtained, maintaining confidentiality, anonymity, and voluntary participation throughout the study.

Results:

Most respondents were aged 20-29 years (17; 38.6%) and 30-39 years (15; 34.1%), while only 5 (11.3%) were 40 years or older. Over half had secondary education (26; 59.1%), 10 (22.7%) had tertiary, and 8 (18.2%) had primary education. Regarding maternal-related factors, 28 (63.6%) were aware of the importance of HIV testing for their babies. Fear of stigma (23; 52.2%) was the main reason for missed appointments. Most mothers (24; 54.5%) had not disclosed their HIV status, 25 (56.8%) sometimes adhered to medication, and 27 (61.4%) often felt too sad or worried to attend follow-ups, affecting retention of HIV-exposed infants in the EID clinic.

Conclusion:

Maternal issues such as fear of stigma, non-disclosure of HIV status, emotional distress, and irregular ART adherence greatly reduced clinic attendance.

Recommendation:

The Ministry of Health should strengthen maternal counseling programs to improve mothers' knowledge of HIV and Early Infant Diagnosis.

Keywords: Maternal-related factors, retention of HIV-exposed, HIV testing, HIV status.

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BACKGROUND OF THE STUDY

Retention of HIV-exposed infants (HEIs) is strongly influenced by maternal-related behaviors and circumstances. Non-attendance at follow-up visits, loss to follow-up, and home births without linkage to care are major contributors to attrition in the Early Infant Diagnosis (EID) care continuum (Hoosen, 2021). Stigma associated with HIV and fear of disclosure often prevent mothers from attending clinics or adhering to appointments. In Bangladesh, cultural beliefs labeling infants born to HIV-positive mothers as "cursed," combined with limited male partner involvement, resulted in only 55% of HEIs being retained in care, increasing missed diagnoses and delayed ART initiation (Kamble et al., 2023). Maternal ART non-adherence, mixed feeding practices, low maternal education,

and psychosocial challenges such as sadness, anxiety, or fear further reduce retention rates (Chapuma et al., 2024; Akunzirwe et al., 2025). In northern Uganda, factors including low antenatal care attendance, frequent maternal transfers between facilities, and delayed initiation of infant prophylaxis contributed to 78.7% retention at 18 months, with delays leading to late HIV diagnosis and increased infant morbidity and mortality (Apangu et al., 2019). Maternal adherence to antiretroviral therapy (ART) has been identified as a critical factor influencing the retention of HIV-exposed infants (HEIs) in Early Infant Diagnosis (EID) care. A study in Kenya reported that mothers who consistently adhered to ART were 82% more likely to retain their infants in EID programs, compared to only 39% among mothers with poor adherence (Gaitho et al., 2021).

Similarly, research in Malawi found that ART adherence not only improved maternal health but also reduced stigma and increased trust in health services, collectively enhancing infant retention (Hunt et al., 2024). These findings highlight that maternal engagement with ART reflects both commitment to care and active participation in the health system, directly affecting infant follow-up.

Maternal mental health and emotional well-being also play a significant role in retention. In Uganda, mothers experiencing postpartum depression or anxiety were 46% less likely to complete infant follow-up compared to those with stable mental health (Yeboa et al., 2023). Another Ugandan study indicated that emotional distress and lack of psychosocial support contributed to 28% loss to follow-up among HEIs (Ankunda et al., 2020). These results underscore the importance of integrating mental health counseling and psychosocial support into EID programs to improve retention outcomes.

The study aimed to identify maternal-related characteristics influencing the retention of HIV-exposed infants in the EID Care Clinic of Nebbi General Hospital.

METHODOLOGY

Study Design and Rationale

A descriptive cross-sectional study design employing quantitative methods was used to obtain data. The study was descriptive because it assessed characteristics influencing the retention of HIV-exposed infants (HEIs) in the Early Infant Diagnosis (EID) Care Clinic. It was cross-sectional because data were collected at one point in time without follow-up. Quantitative methods with structured questionnaires provided numerical data on retention rates and associated factors. This design was cost-effective, feasible within a limited timeframe, and suitable for analyzing retention characteristics in a large patient population.

Study Setting and Rationale

The study was conducted at Nebbi General Hospital, located in Nebbi Town, Northern Uganda, approximately 484 kilometers northwest of Kampala. Nebbi General Hospital is a government-owned referral facility providing outpatient, inpatient, maternal, Postnatal Care (PNC), Antenatal Care (ANC), ART services, child and HIV care services, including an Early Infant Diagnosis (EID) clinic for HEIs. The Early Infant Diagnosis (EID) clinic for HIV-Exposed Infants (HEIs) at Nebbi General Hospital is a specialized unit dedicated to the care, monitoring, and follow-up of infants born to HIV-positive mothers. The clinic provides a structured and child-centered environment designed to ensure timely HIV testing, initiation of prophylaxis or antiretroviral therapy when necessary, and regular follow-up visits to monitor growth, development, and overall health outcomes. The unit is staffed by trained healthcare providers, including pediatric nurses, clinical

officers, and counselors, who offer comprehensive services such as HIV DNA-PCR testing, cotrimoxazole prophylaxis, nutritional support, immunizations, and caregiver counseling on infant feeding and adherence to medications. The hospital serves a catchment population of approximately 25,000 people with over 1,000 HEIs registered for EID services annually. The site was chosen due to reported challenges in retention of HEIs in the EID care continuum, despite ongoing HIV testing, prophylaxis, and follow-up programs.

Study Population

The study targeted caregivers of HIV-exposed infants (HEIs) enrolled in the EID care clinic at Nebbi General Hospital. These caregivers are directly involved in ensuring follow-up and retention of HEIs in the clinic.

Sample Size Determination

According to the HMIS 002 EID Clinic Register, there were 50 HEIs actively enrolled in the clinic. Using Krejcie and Morgan's (1970) sample size table, a population of 50 corresponds to a sample size of 44 respondents. Therefore, the study targeted 44 caregivers to ensure representativeness.

Sampling Procedure

A convenience sampling method was employed, selecting caregivers who were readily available and willing to participate during the data collection period. Caregivers attending the EID clinic were approached, provided with information about the study, and invited to participate. Only those who met the inclusion criteria and provided informed consent were included.

Data collection was conducted over five clinic days, targeting approximately nine participants per day to achieve a total sample size of 44 respondents for the successful completion of the study.

Inclusion Criteria

Caregivers of HEIs registered at the EID clinic who were present at the clinic during data collection voluntarily consented, Ugandans, able to respond to questions in English/literates.

Exclusion Criteria

Caregivers whose HEIs are critically ill and unable to respond, and those with speech or hearing impairments.

Dependent Variable

Retention of HEIs in the EID care clinic.

Independent Variables

Socio-demographic factors, which included age, religion, marital status, and employment status

Maternal-related factors: Knowledge on HIV and EID, disclosure status, adherence to appointments, socio-economic status, attitudes towards HIV care.

Research Instrument and Rationale

A semi-structured questionnaire written in English was used for data collection. It was divided into three sections: Section A focused on the socio-demographic characteristics of caregivers and HEIs; Section B addressed maternal-related factors influencing retention; and Section C covered health facility-related factors influencing retention.

Data Collection Procedure

After approval from the Institutional Research Committee, an introductory letter was obtained from the Dean, School of Nursing, Mildmay, Uganda School of Nursing and Midwifery. This letter was used to seek permission from the Director of Nebbi General Hospital. An introduction was made to the EID clinic in charge, which facilitated contact with caregivers. The purpose of the study was clearly explained, along with a brief introduction, to seek participation and obtain the necessary clearances. Each respondent provided verbal and written informed consent, and interviews were conducted in a private corner of the clinic to ensure confidentiality.

Data Management

Completed questionnaires were checked daily for completeness and accuracy. Hard copies were stored in a locked cabinet accessible only to the researcher. Electronic data was saved on a password-protected computer.

Data Analysis

Data was entered into Microsoft Excel 2019 for analysis. Descriptive statistics (frequencies, percentages, means, and standard deviations) were generated and presented in tables, bar graphs, and pie charts for clarity.

Validity

The questionnaire was based on study objectives and reviewed by the supervisor to ensure accurate measurement of factors affecting retention of HEIs.

Reliability

The tool was pre-tested with 8 caregivers at Nebbi Hospital and refined with 3 additional respondents to ensure consistency.

Ethical Considerations

Ethical approval was obtained from the Institutional Research Committee of Mildmay Uganda School of Nursing and Midwifery. An introductory letter from the Dean, School of Nursing, was secured to seek permission from the Director of Nebbi General Hospital to conduct the study among caregivers of HIV-exposed infants at the EID clinic. Respondents were assured of confidentiality, anonymity, and their right to withdraw from the study at any time without penalty. Numeric codes were used instead of names to protect identity, and written informed consent was obtained prior to data collection.

RESULTS

Demographic information of respondents.

Table 1 shows the demographic data of the respondents, n=44

Variable	Response	Frequency(n)	Percentage (%)
Age	< 20 years	7	15.9
	20-29 years	17	38.6
	30-39 years	15	34.1
	40 years and above	5	11.3
Education level	Primary	8	18.2
	Secondary	26	59.1
	Tertiary	10	22.7
Marital status	Married	29	65.9
	Unmarried	9	20.5
	Divorced/widow	6	13.6
Employment status	Employed	11	25
	Not employed	33	75
Religion	Christian	30	68.2
	Muslim	14	31.8
	Others	-	-

Table 1 shows that nearly 17 (38.6%) of the respondents were aged 20–29 years, while at least 5 (11.3%) were aged 40 years and above. More than half 26 (59.1%) had attained

secondary education, whereas a minority 8 (18.2%) had primary education. Most respondents, 29 (65.9%), were married, while a smaller proportion, 6 (13.6%), were

divorced or widowed. Regarding employment status, three-quarters 33 (75%) of the respondents were not employed compared to only 11 (25%) who were employed. Most

respondents, 30 (68.2%), were Christians, while 14 (31.8%) were Muslims, and none belonged to other religions.

Maternal-related characteristics influencing the retention of HIV-exposed infants in the early infant diagnosis care clinic of Nebbi General Hospital

Figure 1 shows awareness of the importance of HIV testing for your baby n=44

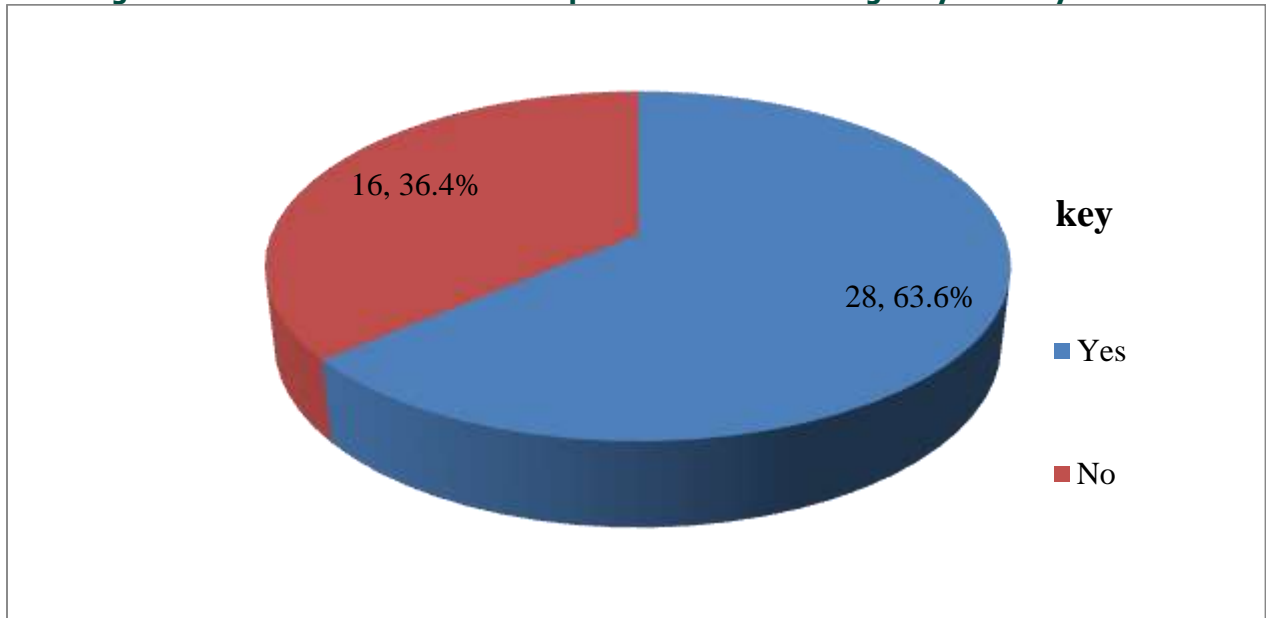


Figure 1 shows that 28(63.6%) of the respondents were aware of the importance of HIV testing for their baby, while the minority, 16(36.4%), were not.

Table 2 shows other maternal-related characteristics influencing the retention of HIV exposed infants in the early infant diagnosis care clinic of Nebbi General Hospital

Variable	Response	Frequency(n)	Percentage (%)
Why do mothers stop bringing their babies for HIV check-ups	Fear of stigma	23	52.2
	Lack of time or money	11	25
	They think it's not important	10	22.7
Telling your partner or family about your HIV status	Yes	15	34.9
	Told only a friend	5	11.4
	Not told anyone	24	54.5
Taking HIV medicine every day as advised	Always	12	27.3
	Sometimes	25	56.8
	Rarely	7	15.9
Feel too sad or worried to go back to their baby's clinic visit	Often	27	61.4
	Sometimes	13	29.5
	Rarely	4	9.1

Table 2 shows that the highest proportion of mothers, 23 (52.2%), stopped bringing their babies for HIV check-ups due to fear of stigma, while a minority, 10 (22.7%), believed the visits were not important. Regarding disclosure of HIV status, most mothers 24 (54.5%) had not told anyone about

their HIV status, while at least 5 (11.4%) disclosed only to a friend. In terms of adherence to HIV medication, the majority of mothers, 25 (56.8%), reported taking their medication sometimes, while a minimal number, 7 (15.9%), took it rarely. More than half of respondents, 27 (61.4%),

often felt too sad or worried to return for their baby's clinic appointments, while a smaller proportion, 4 (9.1%), rarely experienced such feelings.

DISCUSSION

The purpose of the study was to determine the awareness of the importance of HIV testing for your baby, which revealed that most (63.6%) of the respondents were aware of the importance of HIV testing for their baby, and this was in contrast to the problem statement. This might be due to ongoing PMTCT counseling given during antenatal and postnatal visits. This points out that continued health education remains essential in supporting infant follow-up. This is in line with a study done in India by Nikhare et al. (2024) on maternal knowledge and understanding of EID services, which revealed that mothers who received proper counseling on the importance of infant HIV testing were 71% more likely to complete EID follow-up compared to 38% among those who lacked information.

The purpose of the study was to determine why mothers stopped bringing their babies for HIV check-ups, where the highest proportion of mothers (52.2%) stopped bringing their babies for HIV check-ups due to fear of stigma. This was in line with the problem statement. This could be due to negative community attitudes and fear of being labelled HIV positive. This means that reducing stigma is crucial for improving retention in EID care. This is in contrast with a study conducted in Saudi Arabia, Alshehri et al. (2021), on maternal attitudes and beliefs toward EID care, which revealed that 68% of mothers with positive attitudes about HIV services completed their infants' follow-up, while 29% of those who perceived EID as unnecessary defaulted after the first visit.

The purpose of the study to determine whether mothers took their medication, where slightly above half of mothers, 25 (56.8%), reported taking their medication sometimes due to forgetfulness, side effects, or lack of psychosocial support demonstrating that poor adherence may negatively affect infant follow-up due to weakened maternal health and reduced motivation to attend clinics this was in contrast to the problem statement. This is in line with a study in Kenya. Gaitho et al. (2021) on maternal adherence to ART, which revealed that mothers who consistently took ART were 82% more likely to retain their infants in EID care compared to 39% among those with poor adherence.

The purpose of the study to determine whether respondents felt too sad or worried to go back for your baby's clinic visit which found out that 27 (61.4%) often felt too sad or worried to return for their baby's clinic appointments due to emotional distress related to HIV diagnosis or fear of infant test results thus implying that maternal mental health significantly influences EID retention and requires closer attention thus in line with the problem statement. This is in line with a study in Uganda on maternal mental health and emotional well-being, which found that mothers experiencing postpartum depression or anxiety were 46%

less likely to complete infant follow-up compared to those with stable mental health. (Yeboa et al., 2023).

CONCLUSION

Maternal issues such as fear of stigma, non-disclosure of HIV status, emotional distress, and irregular ART adherence greatly reduced clinic attendance and continuity of infant follow-up.

RECOMMENDATION

The Ministry of Health should strengthen maternal counseling programs to improve mothers' knowledge of HIV and Early Infant Diagnosis (EID).

Community leaders and local councils should lead community sensitization campaigns to reduce stigma associated with HIV and EID services.

Community leaders and local councils should encourage male partner involvement to provide social support and improve infant retention.

Hospital/facility management should provide mental health screening and counseling support for HIV-positive mothers. Healthcare providers should offer follow-up reminders, appointment tracking, and mother-friendly communication to support retention.

Healthcare providers should provide continuous health education to mothers on the importance of consistent infant HIV testing.

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LIST OF ABBREVIATIONS

AIDS:	Acquired Immune Deficiency Syndrome
ANC:	Antenatal Care
ART:	Antiretroviral Therapy
DBS:	Dried Blood Spot
DHO:	District Health Office
DNA:	Deoxyribonucleic Acid
EID:	Early Infant Diagnosis
EMTCT:	Elimination of Mother-to-Child Transmission
HEIs:	Exposed Infants
HEIs:	Retention of HIV-exposed infants
HIV:	Human Immunodeficiency Virus

HMIS: Health Management Information System
PCR: Polymerase Chain Reaction
PNC: Postnatal Care
UHPAB: Uganda Health Professions Assessment Board

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The study had no funding.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY

Data is available upon request from the author.

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AUTHOR CONTRIBUTIONS

JPA: collected the data.

HN: supervised the study.

IN: supervised the study.

JFN: supervised the study.

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