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Access to HIV/AIDS care for mothers and children in sub-Saharan Africa: adherence to the postnatal PMTCT program

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Despite scale up of perinatal prevention of mother-to-child transmission (PMTCT) of HIV interventions, postnatal continuity of comprehensive HIV/AIDS care, for both the mother and baby, remains a challenge in developing countries. We determined adherence to the postnatal PMTCT program (PN-PMTCT) and the associated factors among mothers at a public urban hospital in Uganda. We interviewed HIV-positive postnatal mothers on discharge and we determined adherence to PN-PMTCT by the proportion of mothers that honored their return appointments by the end of eight weeks postpartum. We had focus group discussions to assess factors that influence adherence to PN-PMTCT. Of 289 mothers, only 110 (38%) adhered to PN-PMTCT. Previous attendance of a routine postnatal review and having access to a phone were significantly associated with adherence to PMTCT among mothers older than 25 years (odds ratio (OR) 3.6 (95% confidence interval (CI); 1.2–10.4)) and (OR 3.1 (95% CI; 1.3–7.1)), respectively. On the other hand, Christianity (OR 3.2 (95% CI; 1.1–9.0)) was significantly associated with adherence to PN-PMTCT among mothers below 25 years of age. Mothers' perceived benefits of the PN-PMTCT program, easy access to the program, and presence of social support from a spouse were important motivators for mothers to adhere to PN-PMTCT. Even with improved antenatal and intra-partum PMTCT services, only a third of the HIV-infected mothers adhered to the PN-PMTCT program. Mothers who previously attended a routine postnatal care were 3.6 fold more likely to adhere to PN-PMTCT. We recommend strategies to increase mothers' adherence to PN-PMTCT interventions in order to increase access to HIV/AIDS care for mothers and children in sub-Saharan Africa.

Keywords: HIV/AIDS care; PMTCT; access; adherence; Africa

Introduction

Globally, about 33.2M people were living with HIV by end of 2007 (WHO/UNAIDS, 2007) with 70% of the HIV/AIDS burden in sub-Saharan Africa (SSA). HIV/AIDS remains a major cause of infant and maternal morbidity and mortality in resource limited settings (McIntyre, 2005a, 2005b; Newell et al., 2004). In Uganda, by the end of 2007, about 1M people were living with HIV. Women are infected more than men across the age spectrum from birth to age 45–49 years (60% for women versus 40% for men) and this poses a high risk of maternal-to-child transmission of HIV (MTCT). The annual incidence reached 132,500 new cases in 2005 including 25,000 mother-to-child transmissions that account for 95% of pediatric HIV disease (UAC, 2008).

The risk of MTCT HIV ranges from 25 to 48% in populations that practice prolonged breastfeeding (De Cock et al., 2000). Postpartum MTCT is reported at 14–20% in breastfeeding populations like Uganda

(Musoke, 2004) although, the greatest risk is intra-partum (60–75% of the cases) followed by in-utero (25–40% of cases). The integration of routine rapid HIV testing in antenatal and intra-partum care has facilitated both early diagnosis of HIV in pregnancy and peri-natal interventions for the prevention of mother-to-child transmission (PMTCT) of HIV (Manzi et al., 2005; Ministry of Health, 2005; Orne-Gliemann et al., 2008).

Despite the improved quality and access to PMTCT interventions in Africa (Gray, 2006; Guay, Musoke, Fleming, Bagenda, & Nakabiito, 1999; Nankinga, 2005; WHO, 2006), only 5% of HIV-positive mothers access PMTCT services (Musoke, 2004) with the rates at 4–12% in Uganda (Karamagi, Tumwine, Tylleskar, & Heggenhougen, 2006). Furthermore, health units still have limited postnatal PMTCT (PN-PMTCT) follow-up services for both the mother and child beyond intra-partum interventions (Nankinga, 2005). Failure of the postpartum

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link to continuing HIV/AIDS care for the mother and child beyond the peri-partum PMTCT interventions represents a missed opportunity for early determination of the babies' HIV sero-status and timely initiation of comprehensive HIV/AIDS care for both the affected mothers and children.

Although, return of mothers for PN-PMTCT has been reported between 30 and 63% in controlled MTCT trials (D'Adesky, 2001; Gray et al., 2005; Malonza, Richardson, Kreiss, Bwayo, & Stewart, 2003) there are limited data on the continuity of HIV/AIDS care, for both the mothers and the exposed babies, beyond the peri-partum period in PMTCT program settings in SSA (Perez et al., 2004). We determined the level of adherence of mothers to the PN-PMTCT program and the factors associated with adherence to PN-PMTCT among the HIV-positive mothers who deliver at a public urban hospital in Uganda. Identifying the gaps in continuity of care following the peri-partum PMTCT interventions will contribute to the development of practical strategies in policy and practice to improve utilization of the HIV/AIDS care programs. This study was approved by the Faculty of Medicine Review Board and the National Council for Science and Technology.

Methods

Study design

In a cross-sectional study, we investigated adherence to the PN-PMTCT program by mothers discharged from the Mulago hospital postnatal ward (PN-ward).

Study setting

Mulago Hospital Complex is the National Referral and Teaching hospital and the obstetric units deliver about 2240 mothers monthly; of whom about 16% are diagnosed with HIV infection. Mothers are discharged after one or four days after normal or cesarean births, respectively. On discharge, mothers are given appointments to return for: immunization, family planning, growth monitoring, and HIV/AIDS care for the HIV-positive mothers and the babies are linked to Pediatric Infectious Diseases Clinic (PIDC) for HIV testing and appropriate care.

Participants

From December 2006 to April 2007, we screened consecutive HIV-positive mothers discharged from the Mulago PN-wards over 24 hours during week days. Mothers were enrolled if they (1) provided written informed consent to participate in the study and (2) live within a 20 km radius from the hospital.

We excluded mothers who were not willing to be contacted at home. Using a postnatal follow-up rate of 31% (d'Adesky, 2001; Malonza et al., 2003), we calculated a minimum sample size of 261 participants plus 10% to cater for unforeseen data collection constraints and errors.

Procedures

We enrolled HIV-positive mothers with referrals to the PN-PMTCT clinic at discharge from the hospital. We obtained baseline demographic and clinical data using a pre-tested questionnaire. The questionnaire was developed in English, translated into the local language and back-translated to ensure consistency. At the same time, we developed a focus group discussion (FGD) guide to obtain supportive data on the possible motivators and hindrances to return for PN-PMTCT follow-up. The questionnaire was tested for face and internal validity during a pilot test on a test population and the eventual population after which it was re-designed. The data were collected by a trained-research assistant who was fluent in the local language. Using a patient's diary, we documented mothers who returned for PN-PMTCT (returnees) by the end of eight weeks postpartum. We conducted two FGDs to support the quantitative data on factors influencing return for PN-PMTCT; one for returnees and one for non-returnees. At the end of the follow-up period 15 returnees were systematically selected from the register by choosing every seventh returnee. They were invited by telephone or home visit (for those without telephone contacts) and the 10 mothers who confirmed attendance participated in the FGD. Similarly, 15 mothers who missed their appointments (non-returnees) were systematically selected from the register by choosing every 11th non-returnee. They were invited by telephone or home visits (for those without telephone contacts) and the first 10 mothers who confirmed attendance participated in the FGDs that were conducted by a trained interviewer who was conversant with both the topic and the local language in the presence of a note taker. A FGD guide, in the local language, was used to ensure consistency and an audio recorder was used. Views and opinions on the factors influencing the return for the PN-PMTCT program were recorded.

Measures

Adherence to the PN-PMTCT program was measured as the proportion of mothers who honored their appointment to the PN-PMTCT clinic by the end of eight weeks postpartum. We recorded the following socio-demographic and healthcare factors:

age, religion, physical address, telephone contact, marital status, education level, occupation of mother and spouse; obstetric history, antenatal care (ANC) attendance and previous PNC attendance. We evaluated PMTCT-program related factors that included previous attendance of PMTCT, knowledge of available services for mother and baby, registration into HIV/AIDS care, and disclosure of HIV-positive status. Other possible motivators and hindrances to return for PN-PMTCT were evaluated in the FGDs.

Statistical analysis

Data were entered into EpiData 2.1b and analyzed using SPSS version 12.0 statistical software. Descriptive statistics were used to summarize baseline characteristics of the study population. Multivariate logistic regression analysis was performed to assess factors that influence adherence to PN-PMTCT while adjusting for multiple potential confounders. Since age was found to interact with previous PNC attendance, the results are presented in two groups with final significant factors in the older mothers (over 25 years) and the younger mothers (below 25 years). Data from the FGDs were analyzed manually by the investigators and separated into the spheres of influence of adherence to PN-PMTCT. These data were triangulated with the quantitative data findings to substantiate the information obtained about the motivators and hindrances to mothers' return for PN-PMTCT.

Results

Study population characteristics

We screened 296 HIV-positive mothers on discharge from the Mulago hospital PN-wards between December 2006 and April 2007. Of these, 289 were enrolled and interviewed. Seven patients were not enrolled because two did not consent to participate in the study and five did not have time for the interview. The median age of the participants was 25.3 years (Inter-quartile range (IQR) 15–40) and Christians constituted 78% of the respondents which is representative of their distribution in the general population. Only 58% of the mothers were employed (see Table 1). The median age of the mothers who attended the FGDs was 21 (range; 18–35 years) for returnees and 21 (range; 18–34 years) for non-returnees.

HIV testing characteristics of study participants

Overall 93% of the patients had asymptomatic HIV disease (WHO Clinical Stage 1). Most (77%) of the

mothers had the HIV test during ANC. Only 41% of the mothers tested as partners and their HIV test results were delivered simultaneously. The returnee mothers reported in the FGDs that involvement of their sexual partners motivated them to return for PN-PMTCT (see Table 3). Several mothers said, "We want health workers to put a rule that all men should come with their wives to test for HIV on the first antenatal visit." However, only 42% of the mothers who tested individually disclosed their HIV sero-status to sexual partners. Fear to disclose HIV-positive sero-status to the sexual partners was reported as a hindrance for mothers to return for PN-PMTCT. "I could not return for the appointment because my husband might be inquisitive and find out that I am HIV-positive" said a non-returnee who had not yet disclosed results to her spouse. Similarly the non-returnees said that they neither disclosed their results nor returned for PN-PMTCT follow-up because they feared the negative consequences of disclosure (see Table 3). Most (92%) of the mothers had attended ANC but over half of them had not yet enrolled into HIV/AIDS care programs by the time of delivery (see Table 1).

Adherence to the postnatal PMTCT (PN-PMTCT) program

Only 110/289 (38%) adhered to the PN-PMTCT program by honoring their six week PNC appointments on the exact date or within the next 14 days.

Factors associated with adherence to the postnatal PMTCT (PN-PMTCT) program

At bivariate analysis, age above 25 years (OR 2.7 (95% CI; 1.7–4.4)), living with a partner 2.0 (95% CI; 1.1–3.8) and having one or no living child (OR 2.1 (95% CI; 1.2–3.5)) were associated with adherence to PN-PMTCT and so was ANC attendance (OR 7.2 (95% CI; 1.7–31.2)) and HIV testing before labor (OR 3.1 (95% CI; 1.2–7.7)) (see Table 2). However, there was significant interaction between mother's age and previous PNC attendance (Previous PNC stratum crude OR of 3.49 and 0.77, test of Homogeneity, $p=0.003$) and the data were stratified for age. Previous PNC attendance remained significantly associated with adherence to PMTCT among mothers older than 25 years. (OR 3.6 (95% CI; 1.2–10.4)) as well as having access to a phone (OR 3.1 (95% CI; 1.3–7.1)). The FGDs showed that previous attendance of successful PMTCT subsequently motivated mothers' return for PN-PMTCT (see Table 3). Christianity (OR 3.2 (95% CI; 1.1–9.0)) remained a significant predictor of adherence to PN-PMTCT among mothers below 25 years of age (see Table 2).

Table 1. Social and demographic factors of participants evaluated in the study for adherence to postnatal PMTCT in Mulago hospital, Uganda (2007).

Characteristic	Category	Adherent mothers <i>N</i> = 110, <i>n</i> (%)	Non-adherent <i>N</i> = 179, <i>n</i> (%)	OR (95% CI)	<i>p</i> -Value
Socio-demographics					
Age	>25 years	46 (42)	118 (66)	2.7 (1.7–4.4)	<0.001
	≤25 years	64 (58)	61 (33)		
Religion	Christian	95 (86)	132 (74)	2.3 (1.2–4.3)	0.011
	Not Christian	15 (14)	47 (26)		
Marital status	Living with partner	95 (86)	136 (76)	2.0 (1.1–3.8)	0.032
	Living alone	15 (14)	43 (24)		
Phone access	Has phone contact	70 (64)	80 (45)	2.2 (1.3–3.5)	0.002
	No phone contact	40 (36)	99 (55)		
Clinical characteristics					
Parity	Multipara	90 (82)	126 (70)	1.9 (1.1–3.4)	0.030
	Prime para	20 (18)	53 (30)		
Living children	One or none	26 (24)	70 (39)	2.1 (1.2–3.5)	0.007
	Two or more	84 (76)	109 (61)		
HIV-care program	Registered	58 (54)	61 (34)	2.2 (1.3–3.5)	0.020
	Not yet registered	52 (47)	118 (66)		
Antenatal care	Attended	108 (98)	158 (88)	7.2 (1.7–31.2)	0.020
	Never attended	2 (2)	21 (12)		
Timing of test	Before labor	104 (95)	152 (85)	3.1 (1.2–7.7)	0.012
	After labor	6 (5)	27 (15)		
Previous PNC	Has ever attended	63 (57)	70 (39)	2.1 (1.3–3.4)	0.030
	Never attended	47 (43)	109 (61)		
Return venue for review	Knows venue	91 (83)	121 (62)	2.3 (1.3–4.1)	0.005
	Don't know venue	19 (17)	58 (32)		
Patient/contact on ART	Yes	37 (34)	41 (23)	1.7 (1.0–2.9)	0.046
	No	73 (66)	138 (77)		
HIV testing history	Pre-conception	23 (21)	12 (7)	3.67 (1.74–7.75)	<0.001
	During pregnancy	87 (79)	167 (93)		
Testing facility	Mulago Hospital	85 (77)	134 (75)	1.14 (0.65–2.00)	0.674
	Others	25 (23)	45 (25)		
HIV testing by partner	Yes	31 (28)	41 (23)	1.23 (0.77–2.27)	0.314
	No	79 (72)	138 (77)		
Disclosure to partner	Mother disclosed	31 (39)	47 (29)	1.56 (0.91–2.67)	0.102
	None disclosure	57 (61)	113 (71)		
WHO stage of HIV	Stage 1	102 (93)	166 (93)	1.0 (0.40–2.50)	0.997
	Stage 2 and 3	8 (7)	11 (7)		

Discussion

We found that only 38% of the mothers adhered to the PN-PMTCT program by honoring their six week PNC appointments on the exact date or within the next 14 days. Our findings are similar to findings in Malawi where only 30% of the mothers returned for PN-PMTCT follow-up by end of six weeks (Malonza et al., 2003). Our results are close to the WHO estimates of utilization of routine PNC by 30% of the mothers (WHO, 1997) despite the fact that all mothers in our study were counseled about their HIV sero-status and physically shown the PN-PMTCT clinic where they were expected to return.

On the contrary, our level of adherence to PN-PMTCT was lower than previously reported at a private hospital in Uganda where 63% of the mothers returned for follow-up by six weeks (D'Adesky, 2001). The latter study is not directly comparable to our program setting since it was in a controlled research study of breast feeding practices and mothers were given infant formula milk on return.

Adherence to PN-PMTCT in our study was higher than Perez et al. (2004) reported in Zimbabwe (14.8% at six weeks) in a PMTCT implementation program (Perez et al., 2004) where mothers had challenges of transport to the hospital; moreover, they had to return and collect their HIV test results.

Table 2. Summary analysis for factors associated with adherence to PN-PMTCT (stratified for age) at Mulago hospital, Uganda.

Characteristic (n = 125)	≤25 years Category	Returned for PN-PMTCT N (%) (n = 64)	Never returned for PN-PMTCT N (%) (n = 61)	aOR ^a (95% CI)	p-Value
Religion	Christian	57 (89)	43 (71)	3.2 (1.1–9.0)	0.029*
	Others	7 (11)	18 (29)		
Phone access	Yes	40 (63)	31 (51)	1.7 (0.8–3.7)	0.194
	No	24 (27)	30 (49)		
Previous PNC review	Yes	38 (59)	40 (66)	1.1 (0.5–2.7)	0.796
	No	26 (41)	21 (34)		
>25 years (n = 164)		n = 46	n = 118		
Religion	Christian	38 (83)	89 (75)	1.9 (0.7–5.3)	0.215
	Others	8 (17)	29 (25)		
Phone access	Yes	30 (65)	49 (42)	3.1 (1.3–7.1)	0.009*
	No	16 (35)	69 (58)		
Previous PNC review	Yes	25 (54)	30 (25)	3.6 (1.2–10.4)	0.018*
	No	21 (46)	88 (75)		

^aaOR (Adjusted Mental-Hansel odds ratio).

*Significant p-Value.

Note: PNC, postnatal care.

We think that the higher rate of adherence to PN-PMTCT in our study was in part due to the same day results HIV testing protocol that is used in hospitals in Uganda. Similarly, in a study to assess the effect of rapid HIV testing on the uptake of peri-natal HIV testing in Kenya, only 15% of the mothers honored their referrals from a health center to Kenyatta hospital for prophylactic antiretroviral therapy (ART; Malonza et al., 2003). This interrupted the continuity of HIV/AIDS care to the mothers. Since the returnee mothers were motivated by the need to learn the baby's HIV sero-status, we would envisage a

higher adherence level at Mulago hospital, the only site in the country with facilities for DNA polymerase chain reaction (PCR) to ascertain the babies' HIV sero-status as early as six weeks.

Unique to our study is the fact that below the age of 25 years, mothers who had previously attended PNC were about four times more likely to adhere to PN-PMTCT follow-up than mothers who had never attended PNC. However, the FGDs showed that the benefits of PN-PMTCT follow-up such as previous involvement in PMTCT with an HIV-negative baby and enrollment into HIV/AIDS care were the greatest

Table 3. Influences for adherence to the PN-PMTCT program.

Sphere of influence	Motivators for adherence to PN-PMTCT (from the returnees)	Hindrances to adherence to PN-PMTCT (from the non-returnees)
Benefits of postnatal PMTCT program	Child's early HIV diagnosis	Fear to learn that child is infected with HIV
	Enrollment of mother into HIV/AIDS care	Lack of clinical symptoms of HIV disease
	Interaction with counselors and peer mothers for social support	
	Previous attendance of PMTCT program yielding an HIV negative child	
Access to PN-PMTCT services	Cancer screening and birth control interventions	Transport costs to health unit
	Awareness of the services offered for the mother and baby during PN-PMTCT	
	Receiving referral information at discharge	
Social support structure	Reminder calls from clinicians	Fear to disclose positive HIV sero-status to the partner Fear of divorce or separation from spouse after disclosure of HIV-positive results
	Close contact on HAART	
	Men involvement in couple HIV testing with their spouses	

motivators for mothers to return for PN-PMTCT. Our results imply that increasing the mothers' understanding of the benefits of PN-PMTCT program is likely to increase adherence to the PN-PMTCT program and subsequent linkage to comprehensive HIV/AIDS care including ART.

Younger mothers with access to a phone were three times more likely to adhere to the PN-PMTCT program than those without a phone. This indirectly implies that mothers who provided a phone contact demonstrated more openness and willingness to be contacted by health personnel. Mobile phones may also be an indicator of acceptance of technology and thus identify "innovators" in the society, individuals more likely to accept new things such as entry into the medical care system. Furthermore, a mobile phone is a surrogate marker for a relatively good socio-economic status that empowers women to make informed choices. Poor socio-economic status of mothers has previously been attributed to lack of disclosure of HIV sero-status and poor participation in PMTCT programs in Africa (McIntyre, 2005a; Onyango, 2008; Visser, Neufeld, de Villiers, Makin, & Forsyth, 2008). We recommend that PMTCT programs utilize the mothers' telephone contacts to remind them of their PN-PMTCT appointments in order to ensure continuity of comprehensive HIV/AIDS care.

Religion was a significant predictor of adherence to PN-PMTCT among the mothers older than 25 years as Christians were three times more likely to adhere to PN-PMTCT than non-Christians. This has not been reported in previous studies and we postulate that it is because many Christian leaders in Uganda directly address the HIV/AIDS challenge in churches and indeed many churches are linked to HIV care programs. We need more studies in this area since it implies a potential role of the faith-based organizations in promoting HIV prevention and treatment programs. Limited availability of HIV testing and ART (Nakanjako et al., 2007a), together with the lack of a perceived benefit for the mother and baby were previously major barriers to PMTCT implementation in Uganda (Karamagi et al., 2006). We are happy to report that these did not apply in our study because of the recent introduction of free routine HIV testing and ART in Uganda. Similarly, language barrier, stigma, and negative interactions with staff that hindered women's participation in PN-PMTCT (Nguyen, Oosterhoff, Ngoc, Wright, & Hardon, 2008; Painter et al., 2004) did not apply as 99% of mothers reported non-discriminatory care.

Only 42% of our mothers disclosed their HIV sero-status to partners and 14% of them received adverse outcomes such as divorce, withdrawal of support, and violence. Our data are comparable to previous reports of 30% disclosure of HIV-positive sero-status (Gaillard et al., 2002) and a 10% occurrence of adverse consequences of disclosure (Jones, Sherman, & Varga, 2005). Our data adds to the evidence that efforts to support the mothers' disclosure of their HIV sero-status to a spouse and/or other close family member will facilitate uptake of PMTCT interventions and continued HIV/AIDS care (Farquhar et al., 2004; Onyango, 2008; Visser et al., 2008).

Majority (77%) of the mothers were diagnosed with HIV through the newly introduced routine HIV testing program that is integrated into routine ANC. This is similar to previous findings that routine HIV testing at Mulago hospital significantly increased HIV diagnosis (Nakanjako, Kyabayinze, Mayanja-Kizza, Katabira, & Kanya, 2007). More important is the fact that over half of the HIV-positive mothers had not initiated HIV care during ANC. This calls for more practical integration of ANC, HIV testing, PMTCT, and ART. As a strategy to universal access to comprehensive HIV/AIDS care including ART in Africa, we need to strengthen postpartum linkage of HIV-positive mothers and their babies to care programs soon after the peri-natal PMTCT and optimize the benefits of routine HIV testing during pregnancy.

Our study was limited to the first eight weeks postpartum which is the period for routine PNC for all mothers irrespective of the HIV sero-status so we did not assess the rate of postpartum MTCT. However, mothers and their babies were linked to the HIV/AIDS care programs for follow-up and appropriate management. We conducted only two FGDs due to limited resources, however, these adequately supported the quantitative data to clarify the motivators and hindrances to PN-PMTCT that need further attention.

Conclusions

A third of the HIV-infected mothers adhered to the PN-PMTCT program and mothers who previously attended routine PNC were about fourfold more likely to adhere to PN-PMTCT. We recommend increased efforts to sensitize mothers and the general community about the role of PN-PMTCT interventions in complimenting the perinatal PMTCT interventions to reduce MTCT. In addition, we

recommend strategies to extend PMTCT interventions and comprehensive HIV/AIDS care beyond the intra-partum interventions in order to improve HIV/AIDS care delivery to mothers and children in SSA.

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