AIDS Care

Psychological and Socio-medical Aspects of AIDS/HIV

ISSN: 0954-0121 (Print) 1360-0451 (Online) Journal homepage: http://www.tandfonline.com/loi/caic20

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To cite this article: Julie N. Bergmann, Rhoda K. Wanyenze & Jamila K. Stockman (2017): The cost of accessing infant HIV medications and health services in Uganda, AIDS Care, DOI: 10.1080/09540121.2017.1330531

To link to this article: http://dx.doi.org/10.1080/09540121.2017.1330531

Published online: 18 May 2017.

AIDS CARE, 2017
https://doi.org/10.1080/09540121.2017.1330531

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The cost of accessing infant HIV medications and health services in Uganda

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ABSTRACT

Patient costs are a critical barrier to the elimination of mother to child HIV transmission. Despite the Ugandan government providing free public HIV services, infant antiretroviral (ARV) prophylaxis coverage remains low (25%). To understand costs mothers incur in accessing ARV prophylaxis for their infants, we conducted a mixed methods study to quantify and identify their direct costs. We used cross-sectional survey data and focus group discussions from 49 HIV-positive mothers in Uganda. Means and standard deviations were calculated for the direct costs (e.g., transportation, caretaker, services/medications) involved in accessing infant HIV services. The direct cost of attending HIV clinic visits averaged $3.71 (SD = $3.52). Focus group discussions identified two costs hindering access to infant HIV services: transportation costs and informal service charges. All participants reported significant costs associated with accessing infant HIV services – the equivalent of 2–3 days' income. To address transportation costs, community and home care models should be explored. Additionally, stricter policies and oversight should be implemented to prevent informal HIV service charges.

ARTICLE HISTORY
Received 18 May 2016
Accepted 9 May 2017

KEYWORDS
Patient costs; direct costs; HIV-exposed infants; mother to child transmission of HIV; sub-saharan Africa

Introduction

Uganda is classified as a high burden country in terms of HIV prevalence and incidence (Uganda AIDS Commission, 2015). Despite this classification, Uganda has made significant strides in curbing the HIV/AIDS epidemic. In 2014, while 1.5 million individuals in the country were HIV-infected, only 6% of cases were attributed to new infections acquired during that year (Uganda AIDS Commission, 2015). Further, in the same year, 51% of HIV-positive individuals in the country were on antiretroviral therapy (ART), up from 42% in 2013 (Uganda AIDS Commission, 2015). While much forward progress has been made in stopping the epidemic, less progress has been made in preventing vertical HIV transmission to infants. In 2014, only 25% of exposed infants received antiretroviral (ARV) prophylaxis (i.e., nevirapine) during their first 6 weeks of life; a substantial decrease from the 2013 coverage rate of 37% (Uganda AIDS Commission, 2015).

While 94% of HIV-positive pregnant women in Uganda received ART at some point during their pregnancy, the cascade of care and the resulting low rates of infant ARV prophylaxis uptake, demonstrate that access becomes problematic post-partum (Sibanda, Weller, Hakim, & Cowan, 2013; Stringer et al., 2010; Uganda AIDS Commission, 2015). Since Ugandan women are typically economically dependent on their partners and receive monetary support during pregnancy to access antenatal services, women frequently couple these visits with accessing HIV services as needed (Duff, Kipp, Wild, Rubaale, & Okech-Ojony, 2010). However, post-partum, women may find that monetary support ceases and thus, women may be unable to continue accessing HIV care (Bergmann et al., 2016). While the Ugandan government has committed to providing free HIV services to all infected individuals, (WHO, 2008) costs still exist that may prove insurmountable for post-partum women to fund independently (e.g., transportation costs). The few studies that have assessed patient costs associated with accessing HIV services in sub-Saharan Africa suggest that a clinic visit may cost nearly all of one's daily income and that yearly costs can be as high as $170 USD (Chimbindi et al., 2015; Pinto, van Lettow, Rachlis, Chan, & Sodhi, 2013). These continued expenses, and lack of partner monetary support, may be critical barriers women encounter when accessing HIV services for their infants post-partum.

This study sought to estimate financial costs among a sample of HIV-positive mothers encountered when accessing HIV treatment for their infants. To that end, we aimed to quantify the direct costs and then identify these costs through a secondary analysis of a focus

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group discussion (FGD) emergent theme with same sample population.

Methods

Study setting

Our study was based in Masaka, Luwero, and Mityana districts in the Central region of Uganda. This region of Uganda has the highest HIV prevalence in the country (12.5%) (Uganda Ministry of Health & ICF International, 2012). We used three health facilities for our study, one in each district: Masaka Regional Referral Hospital, Luwero Health Center Level IV (which functions as a hospital), and Mityana Hospital.

Standard of care for HIV-exposed infants in these districts is to provide post-partum women with a 6-week supply of infant nevirapine immediately after birth; women who do not deliver in a facility must go to a clinic post-delivery to collect nevirapine. After 6-weeks, most facilities then engage in integrated mother-baby care and ask for the pair to return monthly for the first 6-months after birth – thereafter policies vary, but typically advise follow-ups every 2 or 3 months until month 18. It is important to understand that integration requires a mother to bring her infant to receive her own medication.

In part, due to decentralization of health care throughout the country, coordination and standardization in care is minimal. Further, staffing levels are low and facilities experience high rates of staff turnover. Inadequate health sector funding has also led to a reliance on donor support for HIV-related laboratory tests, medications, and services. This results in frequent medication and supply stockouts, as well as duplicative services, with needed services still missing. Moreover, lack of financial leadership in reporting and management results in a lack of accountability for resources (Uganda AIDS Commission, 2015). These issues result in unreliable care, both in terms of having staff to treat patients and in having resources available every time patients seek care. Unreliable care leads to a lack of retention in care and inadequate HIV-medication adherence.

Study design

We conducted a mixed methods, cross-sectional study in three districts in Uganda (Masaka, Luwero, and Mityana). HIV-positive women participating in an ongoing longitudinal study (which was assessing the uptake of Option B+ in Uganda) were solicited for participation in this study. Women who participated in a quantitative face-to-face survey were then invited to participate in FGDs. FGDs were designed to understand ARV prophylaxis (nevirapine) administration in infants, not to elicit discussion on economic burdens. Written informed consent was obtained from all participants. Data were collected in November 2015. The study protocol was reviewed and approved by the Institutional Review Boards of Makerere University School of Public Health (Protocol #320), the University of California, San Diego (Project #151007), and the Uganda National Council of Science and Technology (Registration #SS3923).

Quantitative component

Sample selection

This cross-sectional analysis involved a sample of 49 women (13%) previously enrolled in the Option B+ longitudinal study. Pregnant women were originally recruited from antenatal care (ANC) visits, were HIV-positive, had initiated ART within 4 weeks of recruitment, and were aged 15–49 years. All post-partum participants from the longitudinal study were eligible for the cross-sectional study.

Procedures

We used contact information provided at baseline in the longitudinal study to contact participants for the cross-sectional study. Six lists were randomly generated of all participants, two lists for each district: one of women who had accessed infant nevirapine, and one of women who had not. We included this to differentiate women who accessed infant services from those who had not. From these lists, every 10th name was selected to participate. While all women we were able to reach agreed to be interviewed, only 60% actually participated. All data were gathered through face-to-face interviews, were paper-based, were conducted in the local language of Luganda, and lasted approximately 10 min. Interviews took place in private spaces at the health facilities. Participants received 1,000 Ugandan Shillings (~$0.30 USD).

Data analysis

Measures. All expenses reported were in reference to participants' typical HIV clinic visit for their infants. If they had not accessed services for their infant, participants referenced costs of their own care. All amounts were reported in Ugandan Shillings and later converted to USD (1USD = 3,475UGX). Cost measures were identified through consultation with local health economists to ensure cultural relevance.

Caretaker cost. Participants were asked how much they paid for a caretaker to watch or care for either a child or an elder while they attended a clinic visit.

Transportation cost. Participants were as asked how much they paid for round trip transportation to the health center.

Medication fee. Despite being free of charge, informal fees frequently require patients to pay for free medications. As such, we asked participants if they paid for any HIV-related medications (e.g., nevirapine, co-trimoxazole) and if so, how much.

Service fee. Similarly, patients may be charged informal fees to access otherwise free HIV services. As such, we asked participants if they had to pay for any HIV-related services (e.g., early infant diagnosis test) and if so, how much they paid.

Other fees/Refreshment cost. Participants were asked if they paid for anything else during their visits and if so how much they paid (e.g., food and refreshments for themselves or for anyone else such as a nurse or partner).

Statistical analysis. The distribution of each variable was determined prior to analyses. We used Wilcoxon Rank Sum test for non-parametric continuous variables and Chi-square tests for categorical variables. We also used Kruskal-Wallis equality-of-populations rank test to assess group differences among the three facilities. Means and standard deviations were calculated for direct costs and were also stratified by nevirapine access group and facility. All analyses were performed using STATA 14.1.

Qualitative component

Sample selection

Six FGDs were conducted; two in each district, one for mothers who had accessed infant nevirapine and another for those who had not. A total of 43 of the 49 women who completed the quantitative survey participated. Fourteen women were from Masaka District, 16 from Mityana District, and 13 from Luwero District.

Procedures

Upon agreeing to participate in the cross-sectional study, participants were solicited for participation in the FGDs, which occurred during the same visit as the survey. FGDs were conducted by trained study interviewers in the Luganda language, were held in private spaces at health facilities, and lasted 30–60 min. All FGDs were audio-recorded. Participants received 10,000 Ugandan Shillings (~$2.90 USD). This paper focuses on a FGD emergent theme, economic burdens.

Data analysis

FGD audio-recordings were transcribed and then translated into English. Transcripts were uploaded into MAXQDA for analysis. Our analysis was a four-step process. First, we reviewed all transcripts to develop a broad understanding of the content. During this process we developed short descriptive statements to document initial impressions of these topics/themes (Hancock, Ockleford, & Windridge, 1998). Second, we used these statements to identify emergent themes and to create open codes (Flick, 2009; Hancock et al., 1998). *A priori themes* (i.e., created from our theoretical framework/quantitative analysis) and *emergent themes* (i.e., identified in open coding), were used to create a codebook that included a description of each code's content, inclusion/exclusion criteria, and a text example (Hancock et al., 1998). Finally, we coded all responses in the transcripts using the codebook. Note, we exclude FGD number and location from quotes that may lead to the identification of either the participant or health care worker involved.

Results

Quantitative results

Participant characteristics

Among the 49 participants, women were on average 25 years of age (standard deviation (SD) = 5.7), 41% had attended either secondary school or higher, 84% were married, and 73% had at least one child prior to entering the study. Forty-three percent of participants self-identified as informal laborer, 31% sold goods, and 26% were farmers (Table 1).

Patient costs

On average, direct costs equaled $3.71 USD (SD = $3.52). While we did assess for group differences between participants who had accessed infant nevirapine and those who did not, no statistically significant differences were identified. However, we did find that direct costs varied significantly by facility ($p = 0.05$) (Table 2).

Qualitative results

Types of costs experienced when accessing infant HIV health services

Transportation. All participants incurred transportation costs. Women described that while they wanted to

Table 1. Characteristics of HIV-positive Ugandan women with HIV-exposed infants.

Variable		Total, $n = 49$ (%)
Mean age (SD)		25 (5.7)
Education	No School	3 (6)
	Primary	26 (53)
	Secondary+	20 (41)
Marital status	Married	41 (84)
	Not Married	8 (16)
Occupation	Informal Laborer	21 (43)
	Informal Merchant	15 (31)
	Farmer	13 (26)
Number of children	0	13 (27)
	1	12 (24)
	2	10 (20)
	3+	14 (29)
Accessed infant NVP	Yes	25 (51)
	No	24 (49)
Health facility	Masaka Hospital	15 (30)
	Luwero Health Center IV	15 (30)
	Mityana Hospital	19 (39)
Mean transportation time to and from clinic in minutes (SD)		79 (79)
Mean cost of transportation to clinic (SD)		$1.89 ($1.89)
Mean caregiver cost (SD)		$1.84 ($1.42)
Mean food cost (SD)		$0.64 ($0.51)
Mean informal fee among those asked for payment (SD)		$1.11 ($0.83)

Note: SD: standard deviation.

provide their infants with medications, follow medical instructions, and attend scheduled appointments, they frequently lacked the transportation funds necessary to get to the clinic for medication refills or needed appointments.

> *Personally, the journey is so long for me. Now a time may come when I have to return to the hospital, yet the maximum I can get in my wallet is 2,000UGX or 1,000UGX! So I feel a challenge because of that situation since I wanted to bring back the baby, but have no money.* ***FGD #1, Masaka***

Another woman discussed how keeping a clinic appointment is challenging when money is scarce. Women knew the necessity of attending scheduled appointments, but were unable to do so if they did not have the funds for transport.

> *The challenge I have gone through is when it is almost my appointment date to return, I fail to get money for transport.* ***FGD #6, Luwero***

Table 2. Mean costs associated with HIV-positive mothers accessing infant HIV services in Uganda by access group and facility.

Group	Total cost (SD)	*P*-value
All	$3.71 (3.52)	–
Accessed NVP Yes	$3.47 (2.57)	0.64
Accessed NVP No	$3.95 (4.34)	
Masaka Regional Hospital	$4.51 (2.47)	0.05
Luwero Health Center IV	$2.80 (2.17)	
Mityana Hospital	$3.79 (4.65)	

Note: SD: standard deviation, NVP: nevirapine.

Informal HIV service and medication charges. Most women reported experiencing informal HIV service fees. Many stated that since they attended health centers with only the exact amount of money they knew would be necessary for the clinic visit (costs for transportation, food, etc.), encountering demands for payment were critical in preventing access to services.

> *There is a gentleman who always works there, so there are times I usually go there when he is the only person who worked that day and he says, "If you do not have money for a soda [for me] I am not going to give you the baby's medicine." He has done that to me about thrice.*

Yet another woman discussed how access to and use of services was prevented by health care workers' demands for payment.

> *During registration the doctor asks you for a soda but when you tell her, "Doctor today I do not have any money" she then says, "I have been so busy and now I am concentrating on you, don't you see that I have worked so much" Then when you tell her, "I do not have money, but I will give you some another day when I come with money," she says, "No, I am tired."*

Discussion

This study quantified and identified direct costs associated with a sample of women accessing infant HIV health services. While there were no statistically significant differences between participants who accessed infant ARV prophylaxis and those who did not, we did find differences in direct costs between facilities. Our qualitative results revealed that women incurred costs for transportation and informal HIV service and medication charges.

Average daily income for a rural Ugandan is approximately $1.56 (Ugandan Bureau of Statistics, 2014). On average participants spent $3.71 for a clinic visit – the equivalent of 2–3 days' income – for care that may be unavailable/unreliable. We did detect significant differences in direct costs by site, which may suggest unique barriers by facility. This difference may concern the nature of the facility (regional hospital that attracts individuals from afar versus district facilities frequented by individuals located more closely). However, more research is needed to understand these differences. Regardless, our results provide trends that support previous studies demonstrating HIV-related financial hardships, including needing to forgo purchasing other essential goods (i.e., food, school fees) (Cleary, Birch, Chimbindi, Silal, & McIntyre, 2013; Kruk, Goldmann, & Galea, 2009).

FGDs highlighted the financial burden of transportation costs. Many women wanted to attend clinics for

medications, etc., but were unable to do so because they did not have the funds necessary for transport. On average, we found that round-trip transportation cost $1.89 for one clinic visit. Several studies in SSA have assessed transport costs and found this to be a critical barrier in accessing care and typically the largest contributor to the direct patient costs (Cleary et al., 2013; Goudge, Gilson, Russell, Gumede, & Mills, 2009; Kruk et al., 2009; Onwujekwe et al., 2010). Further, the cascade of care (Sibanda et al., 2013) suggests that different barriers exist for women during pregnancy compared to post-partum. A Ugandan study highlighted the lack of partner support, including financial support, that women experience after pregnancy, (Bergmann et al., 2016) which may prevent women from affording transportation to clinics during the post-partum period. Given this, we suggest transportation expenses be taken into consideration when developing programs to increase access to HIV services in Uganda.

While not all participants reported being forced to pay informal service fees, those who did stated that they were costly, unexpected, and frequently resulted in an inability to access services or medications. Many studies in SSA have looked at informal fees (i.e., bribes) when accessing care (Dovel & Thomson, 2015; Kankeu, Boyer, Fodjo Toukam, & Abu-Zaineh, 2014; Lindkvist, 2013; Macha et al., 2012; Mæstad & Mwisongo, 2011; Stringhini, Thomas, Bidwell, Mtui, & Mwisongo, 2009). While it can be argued that informal fees might make health care workers work harder as they feel they are being more adequately compensated for their time, (Mæstad & Mwisongo, 2011) most studies found that health care workers demonstrated no additional effort when receiving informal compensation and that in settings where informal compensation was demanded, quality of care diminished among the health care workers who did not ask for payments (Kankeu et al., 2014; Lindkvist, 2013; Mæstad & Mwisongo, 2011; Stringhini et al., 2009). Informal payments act to demotivate health care workers and discourage patients from accessing care. Unfortunately, in Uganda, there is a severe lack of financial oversight that contributes to this problem (Uganda AIDS Commission, 2015). Thus, while we think that increasing health care worker accountability is important, the larger problem of lack of governmental financial oversight must also be addressed.

Our study had three main limitations. First, we only recruited participants who attended at least one ANC visit. While ANC attendance is high in Uganda (95%), (Uganda Bureau of Statistics & ICF International, 2012) minimizing this limitation, we have no information on women who did not attend ANC at all during pregnancy. Given that women who do not access care probably experience the greatest barriers and perhaps the greatest costs, our study most likely underestimates the true cost incurred in accessing care among HIV-positive mothers. Secondly, a larger sample size may have allowed us to detect a statistically significant difference between the women who accessed infant ARV prophylaxis and those who did. However, our results have provided information on direct patient costs trends. Finally, our analysis would have been more complete if we had included indirect costs (e.g., opportunity costs) that women incur due to accessing infant HIV services. This would have allowed us to identify out-of-pocket expenses as well as income losses due to missed work. However, as indirect costs will always exist, we focused our assessment on costs that may be more actionable for intervention.

Despite these limitations, our study identified several trends in the cost of accessing infant HIV health services. To ensure universal coverage and free HIV services, it is important to address all costs at the policy level. As our study population was largely from rural areas, distance to health facilities and associated costs were long and high. However, transportation costs will always exist. Thus, we recommend exploring homecare models and community support groups for HIV-positive individuals in remote areas. Studies in Uganda have demonstrated that adherence improves when individuals do not have to overcome long transportation distances and expenses (Weidle et al., 2006; Woodd et al., 2014). These studies and others (Lubega et al., 2013; Tuller et al., 2010) have suggested homecare models may be a solution to transportation expenses. Community support groups are also effective in increasing HIV-adherence and retention rates and may be useful in this population (Bergmann et al., 2016; Decroo et al., 2014). We suggest additional research into the effectiveness of implementing these models. Finally, informal health service fees not only prevent access, but disillusion patients from attempting to access services at later dates. Long-term, changes to cultural perspectives and tolerance of corruption are need. In the short-term, policies to increase oversight and accountability of health care workers, eliminating their ability to require payments, may be useful.

The elimination of mother to child transmission is possible if barriers preventing mothers from accessing and utilizing HIV services for themselves and their infants are removed. While ART is free in Uganda, HIV services are not. We have quantified and identified several trends in direct costs that a sample of patients in Uganda experienced. Identifying these trends is the first step in their elimination. We suggest further research into the use of homecare and community support

models for HIV-positive individuals in remote areas. We also suggest creating policies targeting financial management and health worker oversight at public ART facilities. The elimination of some, if not all, unexpected fees will not only improve access and adherence to ART, but will also ultimately decrease vertical transmission rates.

Acknowledgement

We thank our participants for their time and willingness to participate in our study.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This work was supported by the Frontiers of Innovation Fellows Program (FISP) from the University of California, San Diego. Dr. Stockman is supported by the National Institute on Drug Abuse under [grant number K01DA031593] and the National Institute on Minority Health and Health Disparities[grant number L60MD003701].

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