

## African Journal of AIDS Research



ISSN: 1608-5906 (Print) 1727-9445 (Online) Journal homepage: https://www.tandfonline.com/loi/raar20

# 'Keeping healthy in the backseat': How motherhood interrupted HIV treatment in recently delivered women in Kenya

Opondo Awiti-Ujiji , Anna Mia Ekström , Festus Ilako , Dorcas Indalo , Abigael Lukhwaro , David Wamalwa & Birgitta Rubenson

To cite this article: Opondo Awiti-Ujiji , Anna Mia Ekström , Festus Ilako , Dorcas Indalo , Abigael Lukhwaro , David Wamalwa & Birgitta Rubenson (2011) 'Keeping healthy in the backseat': How motherhood interrupted HIV treatment in recently delivered women in Kenya, African Journal of AIDS Research, 10:2, 157-163, DOI: 10.2989/16085906.2011.593378

To link to this article: <a href="https://doi.org/10.2989/16085906.2011.593378">https://doi.org/10.2989/16085906.2011.593378</a>

	Published online: 22 Jun 2011.
	Submit your article to this journal 🗷
ılıl	Article views: 93
Q <sup>L</sup>	View related articles 🗗
4	Citing articles: 1 View citing articles 🗷

# 'Keeping healthy in the backseat': How motherhood interrupted HIV treatment in recently delivered women in Kenya

Opondo Awiti-Ujiji¹\*, Anna Mia Ekström¹,², Festus Ilako³, Dorcas Indalo⁴, Abigael Lukhwaro⁴, David Wamalwa⁵ and Birgitta Rubenson¹

<sup>1</sup>Karolinska Institutet, Department of Public Health Sciences, Division of Global Health, SE-171 77 Stockholm, Sweden

Although there is a large body of literature related to the experiences of motherhood and aspects of the change that it brings about, how the experience of motherhood affects the healthcare of women with chronic illness is less documented. This study explores how motherhood in newly delivered HIV-infected mothers in Kenya interrupted their antiretroviral treatment (ART). Qualitative interviews were performed with 26 mothers on ART in a rural or urban area. The data were organised and interpreted using content analysis. The study found that adherence to ART was influenced by contextual differences in socio-cultural expectations and family relationships. Urban life enabled women to make decisions on their own and to negotiate challenges that were often unpredictable. Women in rural areas knew what was expected of them and decisions were normally not for them to make alone. The women in Busia and Kibera had difficulties combining adherence with attaining the socio-cultural definition of good mothering. Lack of support from health providers and weak healthcare systems contributed to inadequate stocks of HIV drugs and inaccessibility of HIV-related care. From the data, we developed the main theme 'keeping healthy in the backseat' and the two sub-themes 'regaining self-worth through motherhood' and 'mother first — patient later.' We suggest that motherhood is context-specific and follows socio-cultural practises, which made it difficult for the women in Kenya to follow ART instructions. There is a need to reassess HIV-related services for mothers on ART in order to give them a better chance to stay on treatment and satisfy their aspiration to be 'good mothers.' Contextspecific HIV-treatment policies are necessary for ensuring adherence and successful treatment outcomes.

**Keywords:** adherence, antiretroviral therapy, HIV prevention, Kenya, mothers, qualitative research, socio-cultural aspects, sub-Saharan Africa

#### **Background**

Increased access to antiretroviral therapy (ART) has enabled HIV-infected people to live longer and healthier and to pursue childbearing. As ART has to be taken for life, adherence is crucial for treatment success. In the past two decades human rights and equity considerations have played a key role in the formulation and implementation of HIV-treatment policies. Recently there has been increased concern about the little attention given to the local socio-cultural realities that determine treatment success in sub-Saharan Africa (Hardon, 2005). ART gives hope to resume normal life courses, including sexual relationships, marriage and childbearing, as well as hope to attain sociocultural aspirations. Surrounding pregnancy and motherhood, women follow cultural practices and perceptions that at times complicate their adherence to ART and to general HIV-related treatment and care.

Motherhood takes place within a cultural context and is shaped by the perceptions and practices that give meaning to the social construction of motherhood in that culture. Beliefs and practices take shape around the cultural traits that are passed on from one generation to the next. These practices are deeply rooted and embedded in society and thus become part of people's lifestyles. They are innate and difficult to change as people have adhered to them throughout their entire lives (Ngomane & Mulaudzi, 2010). Bhopal (1998, cited in Pescosolido & Rubin, 2000, p. 492) stated that "the woman is judged as a good or a bad mother [within her social context]." HIV-prevention campaigns have advocated many changes in the lives of women in the last decade, such as the appropriate age at which to start sexual relationships, to marry and even to have children. Although there is a large body of literature related to the context-specific experiences of motherhood and the aspects of change that it brings about (e.g. Sethi, 1995; Weaver & Ussher, 1997; Liam, 1999; Liamputtong, 2002; Liamputtong & Naksook, 2003), how the experience of motherhood affects the care of women with chronic illness like AIDS and HIV infection is less studied. Obviously, illness disrupts

<sup>&</sup>lt;sup>2</sup>Karolinska University Hospital, Department of Infectious Diseases, SE-141 86 Stockholm, Sweden

<sup>&</sup>lt;sup>3</sup>African Medical Research Foundation (AMREF) in Kenya, PO Box 125-00100, Nairobi, Kenya

<sup>&</sup>lt;sup>4</sup>AMREF Kibera Community Health Project, PO Box 30125-00100, Nairobi, Kenya

<sup>&</sup>lt;sup>5</sup>AMREF Busia Child Survival Project (BCSP), PO Box 30125-00100, Nairobi, Kenya

<sup>\*</sup>Corresponding author, e-mail: patricia.awiti@ki.se

mothering ability as has been shown in nursing studies (Vallido, Wilkes, Carter & Jackson, 2010). However, how the association between the management of chronic illness and the socio-cultural expectations of reproduction is less understood. In a recent study in Kenya on women's sexual behaviour accompanied by the hope of becoming pregnant we found that the ability to perform household chores was a sign of resumed strength and meant good health, which was a motivation for pursuing motherhood against the advice of ART providers (Awiti-Ujiji, Ekström, Ilako, Indalo & Rubenson, 2010). In another qualitative study in the same setting, we found that women reasoned and behaved differently about adhering to prevention-of-mother-to-childtransmission (PMTCT) practices depending on the social structural variations in a slum as compared to those in a rural area (unpublished data). We argue that the patterns of social relationships in urban and rural areas influenced the pregnant women's identity formation and decisionmaking on PMTCT adherence differently depending on the social environment. Referring to previous work on 'group affiliations' and social relationships (see Simmel, 1955; Pescosolido, 1992), we suggest that the complete overlap of 'group affiliations' in rural areas ensured strong ties between the pregnant women and their family and community. This inclusive closeness entailed a level of control and enhanced social security, but gave little room for deviating personal development, and people's levels of tolerance for the new and unexpected were low. This made following PMTCT difficult as decisions were not for the pregnant women alone to make but were often taken over by elderly women in the extended family who assumed responsibility for the pregnant woman and her unborn child. That study further showed that pregnant women receiving ART accepted traditional medicine and participated in cleansing ceremonies to fulfil community expectations (unpublished data).

When describing social relationships in urban areas, Simmel (1955) found that 'group affiliations' to a larger extent only overlap partly and that they can be joined and left at will, without affecting other affiliations. In our previous qualitative study (unpublished data), we observed that the pregnant women in the slum were able to join different groups who provided them with choices and the freedom to make personal decisions. Hence, they maintained ties with different groups: having loose and weak connections with some circles, while stronger ones existed with others. Overall the affiliations were more flexible and short-lived and thus also provided less interference. This made the pregnant women in urban areas more vulnerable to the challenges of daily survival which was normally unpredictable but they were also more decisive about finding solutions to overcome their immediate problems. At times, this unfortunately led to not following PMTCT instructions. Those findings implied that the behaviours and experiences of residents in rural and urban areas are bound to differ following contextual variations.

Adherence to ART is crucial for treatment success. The socio-cultural expectations in the contexts where women live determine mothering. Therefore, this study explores how motherhood led to interrupting HIV treatment among newly delivered mothers in Kenya.

#### Methods

#### Study areas

The study was designed to represent both urban and rural areas in Kenya with a slightly higher HIV prevalence than the national average. The Kibera slum is composed of multiple villages, with a population of 0.5 to 1 million (Erulkar & Matheka, 2007). It has been estimated that one in four Nairobi residents live here (Central Bureau of Statistics, Ministry of Health & ORC Macro, 2004). Most of the residents are tenants, with the land being governmentowned, and the dwellings are generally small and of poor quality. High levels of poverty characterise Kibera, with over half the population living in poverty (Kenya National Bureau of Statistics & ICF Macro, 2010). People in the slum tend to earn their living through small-scale business or as casual labourers on building sites; jobs for women are scarce and many perform domestic work that is often not regularly paid. There are no government hospitals in Kibera and health services are generally provided by non-governmental organisations (NGOs). The many entertainment spots providing alcohol and drugs as well as the large networks of sex workers make Kibera a high-risk environment for HIV transmission (Gulis, Mulumba, Juma & Kakosova, 2004).

Busia is a rural and resource-poor area in western Kenya and has a high level of HIV prevalence (Central Bureau of Statistics *et al.*, 2004). The study catchment area had a population of approximately 202 350 living in 312 villages, with about 50 000 women of reproductive age and 38 000 children under age five years. There were 22 health facilities, either private, church or government owned. Agriculture, fishing and commercial undertakings on a small scale have been the main economic activities in the district. The average household in the district generated approximately US\$84 per month (Central Bureau of Statistics *et al.*, 2004).

#### Study design

The study had a qualitative design and aimed to explore how motherhood mitigates HIV treatment in newly delivered mothers on ART. The data were collected in a dialogue between the participants and the researcher. The findings could be used to develop an understanding of the personal relationships, decision-making and behaviour of new mothers on ART or those being managed for chronic illnesses like HIV.

#### **Participants**

Female ART recipients with infants aged less than six months were purposively selected from the registers in the Kibera and Busia PMTCT programmes. To get a wide representation, the women were selected not only by residence (the urban slum of Kibera or rural Busia) but also to represent different marital status (married or unmarried), duration on ART before pregnancy (newly initiated and >1 years experience), and number of children (women with older children and first-time mothers). A community health worker at each site introduced the study and its objectives to women clients. Those who were willing to share their experiences and agreed to participate in the study gave

verbal informed consent and were asked to suggest the time and place for the interview. Twenty-six women (16 in Kibera and 10 in Busia) were interviewed; no one declined to participate.

Of the 16 women residing in Kibera, three were single, three were married and 10 were cohabiting. Ten had been on HIV treatment for less than one year before their pregnancy; the longest and shortest times on ART were six years and one year, respectively. All were unemployed and relied on their partner or spouse for food, rent and general upkeep. Almost all had immediate family members living in rural areas. Five had disclosed their HIV infection to their partner or spouse and 14 had disclosed to a female relative. Thirteen of the women chose to exclusively breastfeed their infants at birth.

All 10 women in Busia were married and lived in a hut with their husband in a shared homestead with the extended family. Even though the women had decision-making power within their respective households, there was an elder woman in the family (usually the mother-in-law) who oversaw that the larger family lived in harmony. All the women participants in Busia had disclosed to their husbands. The longest and shortest times on ART were four years and one year, respectively, with one woman becoming pregnant during her first year on ART. All the women were aware of their HIV infection before pregnancy and were exclusively breastfeeding their infants.

#### Data collection

The main author performed all the interviews in Kibera and a midwife trained in qualitative research conducted the interviews in Busia. A semi-structured question guide was used during the interviews, which were tape-recorded with the participants' permission. The interviews were done in Kiswahili in Kibera and in Luhyia in Busia. We asked the women to reflect on adherence to HIV treatment after childbirth and to tell about their experiences. Probing was used during the interviews to explore views about adherence when being a mother, including motivations for adherence and challenges in adhering. Each interview lasted between two and three hours, depending on the participant's willingness to talk. The interviews were sometimes interrupted by the demands of childcare and other tasks the woman had to perform. When needed, the interviewers stayed on to assist the mother with childcare, and sometimes cooking and cleaning. The interview guide was piloted to provide insights and a chance to improve the flow and clarity of the questions. The women were not given any incentives or rewards for participation. A counsellor was available for referral for participants who needed support, but no woman was referred.

#### Data analysis

The data were analysed qualitatively using content analysis, guided by Graneheim & Lundman (2004). Initially, the transcribed material was read a number of times to get a general sense of the interviews. Meaning units were identified, condensed and coded. The codes were compared and grouped into subcategories and categories. In the process of consistently moving between the fragmented texts and

the whole, the subcategories and categories were reorganised and the overall theme developed (cf. Graneheim & Lundman, 2004). The first author initially performed the coding and analysis independently and then together with the research team. The categories and the main theme were arrived at by consensus between the authors to describe why mothers interrupt HIV treatment during the postnatal period.

#### Trustworthiness

Trustworthiness relates to how well a study captures the reality of those being studied. The interviewer's prolonged engagement in the study area, her subsequent support group sessions and participation in the data collection were crucial for understanding the situation and the stories of the participants. Using face-to-face interviews enabled the interviewers and participants to build rapport and discuss issues freely. Peer debriefing sessions and joint analysis by the research team, which represented different disciplines and experiences, were important to increase the credibility of the study's results.

#### Ethical considerations

Ethical approval was obtained from the ethical review committee of the Kenya Medical Research Institute (KEMRI) and the regional ethical board at Karolinska Institutet (Sweden). All study participants were assured that their anonymity would be strictly upheld throughout. It was stressed that participation in the study was voluntary, and that individuals could withdraw at any time without any effect on them, their family or the care and treatment given. Due to the high level of illiteracy and the reluctance among the women to have a written record of their signatures, only verbal consent was asked for.

#### **Findings**

The main theme 'keeping healthy in the backseat' and the two sub-themes: i) 'regaining self-worth through motherhood' and ii) 'mother first — patient later' were developed from the data (Box 1). The theme 'keeping healthy in the backseat' illustrates how the experiences of motherhood when one is infected with HIV vary in different contexts. leading to different expectations, dilemmas and contextual realities that influence adherence to ART/PMTCT, hence the need for context-adapted HIV-treatment programmes. The sub-theme 'regaining self-worth through motherhood' points to how becoming a mother gave hope for a normal life, which initially seemed challenged by the HIV infection, by way of the possibilities for improving social relationships and achieving cultural aspirations. The sub-theme 'mother first patient later' highlights contextual difficulties in following ART/PMTCT guidelines, leading to poor adherence.

### 'Regaining self-worth through motherhood'

Finding self in motherhood

The women explained how having their child had changed their socio-cultural context, making it possible not only to achieve womanhood but also to regain normal life even if infected with HIV. For the women in Kibera, becoming a

Box 1: The main theme and two sub-themes derived from the interview data

Theme: 'Keeping healthy in the backseat'				
'Regaining self-we	orth through motherhood'	'Mother first — patient later'		
Finding self in motherhood.	Reduced support for woman after childbirth.	Not pregnant, not sick.	Healthcare not supportive after childbirth.	

mother made it possible to regain dignity while negotiating the challenges of being HIV-infected, which included loneliness, poverty and stigma. A child was perceived to make a relationship stronger and to keep the male partner close. Single women in Kibera told about how a child indicated a male presence and a possible entry into marriage, which gave the woman purpose in life and a feeling of being seen as useful in the community. However, the women explained that disclosing their HIV infection had made it difficult to start relationships and they were worried that as single women they would be belittled and loose people's respect:

'I feel like am contributing something with my life now that I am a mother. I can show that there is a man in my life...it is hard to get a man when having HIV. I am not afraid of being despised anymore because of not staying with a man.... I worried about not having a man...now I am respected and treated well...my child links me to a man' (age 22; two years on ART, Kibera).

Motherhood guaranteed some security and the women in Kibera told about actively planning a pregnancy in order to have a man provide for food that is crucial to taking HIV medicine. Women whose HIV infection was known in the community described negative reactions from the community when their pregnancy became visible. Yet, they believed that a child would convince the community that they still cared about human life despite being HIV-infected and that it was not their intention to transmit HIV to partners or anyone. They explained that being a mother provided the opportunity to show they were humane, good and responsible.

The women in Busia expressed that motherhood would ensure that they fulfilled the many expectations of childbearing which they felt were otherwise threatened as a result of being HIV-infected. They told of their worries not only about having children, but also about having children infected with HIV. Motherhood was a role they had been socialised to attain, and childlessness meant failing in a wife's duties and not conforming to cultural values. Children were thought of as a natural result of marriage and having a son was important for clan continuity. For first-time mothers, having a child justified marriage and would show her determination to abide by the role of wife. For the mothers with more children, motherhood secured the woman's position while the constant praises given to her after childbirth gave her self-worth. Thus, the women expressed that they were happy to 'overcome' the HIV infection and ensure continuity of kinship by attaining motherhood:

'I have proved to myself that I can still be a real woman even when sick. Having my child reminds me that I have not allowed this disease to hold me down. Becoming a mother has saved my face and brought pride to my husband and his family. I am the same [as] the one without it [i.e. an uninfected woman]' (age 25; two years on ART, Busia).

Despite the different experiences of the women in Busia and Kibera, motherhood was an opportunity for them as recipients of ART to fit in, be real women, and to not be seen as failures.

#### Reduced support for woman after childbirth

After the delivery of a child, the women overall felt constant pressure to prove that they were good mothers by performing childcare and domestic chores. It also meant not being allowed to be sick, and especially to not have any visible signs of illness (a consequence of ART). But a lack of social support was mentioned as hindering their HIV treatment.

Generally, the women in Kibera did not live close to their family members, but during their pregnancy they had received some support from relatives in the form of food and even help with chores. This social support was mentioned as crucial for them when on ART. After childbirth, however, the women typically continued to live as before their pregnancy, often facing loneliness and a lack of food and money.

Instead of being alone with their responsibility, the women in Busia mostly lived with the constant presence of some older woman who advised them on how to take care of their children and house duties. They felt obliged to do things right according to those requirements and they strived to be 'good mothers' to attract the family's pride and respect. However, their own health needs were often placed in the background as everyone seemed more concerned about the new child.

#### 'Mother first — patient later'

Not pregnant, not sick

The participants were all women on ART and needed regular contact with a health facility. They knew about the relationship between good health and ART adherence, and between adherence and a low viral load. Good nutrition was also mentioned as contributing to good health — a prerequisite for good mothering. However, as a mother, a woman was expected not to be sick and the participants in both locations felt it became difficult to seek timely health services. The women in Kibera were restricted this way when visiting their families in rural areas, for instance, and also said they sometimes delayed seeking healthcare, as they were unsure about the nature of their health problems:

'I do have headaches and feel unwell... it could be because of too little sleep or worry about the future of my children. Motherhood is stressful and can make someone feel sick. In my condition it is hard to know [whether] my HIV is the cause or [whether] it is because of mothering these children of mine' (age 26; three years on ART, Kibera).

To the women in Busia a successful delivery meant that the perceived health risks of pregnancy were over. While it was common knowledge to the elder women in the community that some mothers had health problems after delivery, these were not always considered serious enough to warrant a visit to a health facility:

'I have delivered and all went well. How can I convince my mother-in-law that I need to see a doctor without any severe diarrhoea, pain and constant vomiting or physical signs? She says headache, stomach pains and body weakness are health changes caused by childbirth and can be managed at home. She will just give me herbs and keep me at home' (age 21; three years on ART, Busia).

For a woman who had not disclosed their HIV status, it could be difficult to explain the need to maintain clinic appointments, for example, when she did not have any visible symptoms of HIV infection. Thus, it was hard to convince elder women to accept a young mother's visits to a health facility, especially when the baby was not involved.

#### Healthcare not supportive after childbirth

Staff at the clinics who had been very supportive during a woman's pregnancy had enabled the woman to adhere to the guidelines of ART/PMTCT. But after childbirth, the women explained they had difficulties combining the care of their newborn child plus the expectations of being 'good mothers and housewives' with the ART services, especially the acquisition of HIV medicines. Although the services were the same as during their pregnancy, others had readily helped them then with the care of older children and housework. But with a newborn child, the women felt that there was less consideration for their reality and the possibility of following their HIV treatment regime. In addition, the typically long waiting time at a clinic was a main reason for non-adherence to HIV treatment. The women in Kibera also complained about nepotism among the clinic staff. A persistent lack of food and income in a woman's household, together with the tasks of motherhood were mentioned as reasons for forgetting to take medicines. Women in formal relationships had partners who could remind them about the medicines, however. The participants knew the importance of eating well while on ART and they feared the negative side effects from taking medicine without food. Nearly all the women in Kibera said they had interrupted breastfeeding and opted to feed their babies with formula milk after realising that they did not have enough to eat. Then they had to skip meals for the sake of the child as formula milk was too expensive:

'During the pregnancy I had decided to breast-feed my child. I did so when she was born but stopped when she was two months because of food shortage. I had little breast milk and was worried that it was not good enough for the child. I started on formula milk, which is very expensive. I only eat once a day and save the money for my baby's food' (age 30; four years on ART, Kibera).

NGOs providing PMTCT services made it possible for the women to occasionally get free formula milk for their infants.

In Busia the women worried that the long waiting times spent at clinics could make them seem incapable and irresponsible as mothers and possibly distort the aspired-to image of being 'a good mother.' The women complained that the local clinic was not flexible or willing to accommodate their needs now that they were mothers of newborns, with all expectations that meant in the family environment:

'There are only two doctors here at a time to see us [ART patients]...it is slow...if only there could be more doctors, it would take less time.... The clinic should consider that I am now a mother.... I should not have to stay here long...my duties are not complete at home...what kind of mother am I? ...sometimes I choose not to come, and stay home without my medicine' (age 25; four years on ART, Busia).

The women in Busia were also concerned that that the ART clinic was separate from other buildings offering routine healthcare and that their attendance could lead to the disclosure of their HIV infection to the community and their extended family.

#### Discussion

Our study illuminates how motherhood impinges on following HIV treatment, with a focus on: a) the influence of social context on the experiences of motherhood when infected with HIV, and b) how changes that come with becoming a mother affect adhering to HIV treatment. The findings illustrate how Kenyan women living with HIV engaged in maternal practices that included love for their children and the wish to protect them from the virus, toiled to be good mothers and to meet others' expectations, and found difficulty with adhering to ART/PMTCT guidelines, thus risking good treatment outcomes. Kitzinger (1993) observed that becoming a mother is not only a biological process but also a social transformation involving the whole life situation of the woman and her relationships. We show that motherhood among this sample of rural and urban Kenyan women living with HIV involved managing the illness itself as well as the social consequences when trying to protect the child from HIV infection and preserving a positive mother identity. In addition, we found that adherence behaviour was different in urban and rural areas because of the variation in socio-cultural expectations and family relationships.

The participants knew that adhering to HIV treatment was a prerequisite for staying healthy. Both in Kibera and Busia, a woman's pregnancy had attracted attention from relatives who became involved in maintaining the health of the woman.

In the context of Kibera, survival was tough and the women faced extreme poverty. The environment was unpredictable and it was not unusual for them to miss meals. The women told about having immediate family members living in rural areas; some had distant relatives staying within Kibera, but usually not close to them. Thus, for the mothers on ART in Kibera, life was largely about surviving on their own while being vulnerable to poverty

and facing challenges to treatment adherence. Even though relatives did not live close to a woman, they often showed concern, brought food and helped with household chores. After the birth this involvement generally decreased and the women described how they had to move on with their lives, living much as they had before their pregnancy. The women had to toil to satisfy basic needs like food, which was important for medication adherence. Taking ART on an empty stomach produced negative side effects and the women feared taking their prescribed HIV medicine when hungry. In Kibera the reality of poverty and high levels of unemployment made it hard to obtain the essentials for survival. Apart from worrving about food for herself and her children, the women also needed money to cater to other needs, such as clothes and bedding. They frequently decided to skip their own meals so as to save money. Although aware of the importance of adhering to HIV medicine and eating regularly, they chose to prioritise their children's wellbeing over tending to their own illness to prove that they could meet the demands of motherhood and were capable mothers — hence 'finding self through motherhood.' Other studies have similarly shown that a lack of food contributes to patients not adhering to HIV treatment (Unge, Johansson, Zachariah, Some, Van Engelgem & Ekström, 2008). Our study demonstrates how the responsibility for a child adds additional reason for poor adherence especially when resources are scarce and have to be shared.

For the women in Kibera, sustaining exclusive breastfeeding during ART without sufficient food was difficult. The women knew that their health would deteriorate if they were non-adherent to ART. Adherence is important for suppressing the HIV infection and keeping the viral load in the breast milk low. The women worried about transmitting HIV to their infants and thus all had stopped exclusive breastfeeding. Instead they alternated between breast milk and formula milk, while knowing it was wrong and despite initially deciding to breastfeed their infants at birth. The women were also concerned about being undernourished and that the breast milk would not be enough. According to PMTCT guidelines, infants exposed to HIV should be either exclusively breastfed for six months and rapidly weaned or they should be provided with alternative feeding exclusively. Instead of exclusively breastfeeding, the women in Kibera began to alternate between formula and breast milk, depending on the availability of formula, which was distributed free of charge as part of some PMTCT programmes (but not where the study was done). This had implications for the sustainability of exclusive breastfeeding. The NGOs providing PMTCT services operated independently from each other but shared patients within Kibera: women could thus obtain free formula milk for their infants from other NGOs. Some poor women even sold some of the formula to get money for food and instead breastfed their child intermittently (pers. comm., Dorcas Indalo, social worker and community mobiliser at the AMREF clinic in Kibera). It is important for PMTCT programmes to counsel women about the benefits of sustaining infant feeding methods and prepare mothers in relation to their individual concerns.

We observed that too many demands as a result of motherhood and the women's striving to be 'good mothers' interfered with adherence to ART. In the context of Busia, the mothers on ART mostly had the continuous involvement and presence of female family members. But this also meant that the new mothers could not always make decisions on their own. Older women were often responsible for the health of both the mother and child, during the pregnancy and in the period after childbirth. It was common knowledge that health problems can be experienced after childbirth but that hospital visits are normally unnecessary. Traditional medicine was used to manage health problems at home. Recently, the World Health Organization acknowledged the importance of integrating indigenous medicine with national healthcare systems (Homsy, King, Balaba & Kabatesi, 2004). Despite the fact that traditional medicine is the primary source of healthcare in sub-Saharan Africa, little is known about the interaction between traditional medicines and ART (Mills, Nachega, Bangsberg, Singh, Rachlis, Wu et al., 2006). For women who had not disclosed their HIV infection to the elder women in their households, it became hard to explain the need for visiting the clinic to pick up medicines. This is consistent with findings that non-disclosure and the lack of social support encourage dropping out of ART (Dahab, Charalambous, Hamilton, Fielding, Kielmann, Churchyard & Grant, 2008). To that, we add that the extent of social support from a partner during mothering is context-specific. While it could benefit mothers on ART who do not live close to family members, such as in Kibera, partner support was found to be limited among those living in a traditional rural homestead. While the husbands of the women in Busia knew about the HIV infection, they did not play a significant role during mothering and did not make any decisions regarding the woman's or child's visits to the clinic. This points to the need for HIV-related service providers to find better ways of reaching rural women enrolled in ART after childbirth.

Because the women participants looked healthy, there was little understanding for their need for regular follow-up at a clinic. However, the women themselves understood the importance of keeping appointments and taking medicines. In Kibera the women generally made their own decisions about visiting the clinic. However, they often had to wait a long while and instead would choose to go home to perform duties so as to maintain their role as good mothers. For the women in Busia the decision to visit the clinic for their own sake was normally not for them to decide on. If they managed to visit the ART clinic at the same time as their child's clinic visit, the long waiting hours often made them give up and return home. They did not want to be perceived as irresponsible mothers and rather missed picking up their HIV medicines. Long waiting times, work and family responsibilities, and being away from home have been shown to be barriers to ART adherence (Mills et al., 2006; Hardon, Akurut, Comoro, Ekezie, Irunde, Gerrits et al., 2007; Dahab et al., 2008). Spending a long time at the clinic could also make family members follow them there to see why they were delayed, which could possibly reveal their HIV infection.

#### **Conclusions**

Motherhood is context-specific and follows socio-cultural practises that make it difficult to follow ART instructions. There is a need to reassess HIV-related services for mothers on ART in Kenya to give them a better chance to stay on treatment and to be 'good mothers.' Context-specific HIV-treatment policies are necessary to ensure adherence and successful treatment outcomes. An option could be to combine the clinic appointments for mother and infant and to provide HIV-related care for mothers at the postnatal clinic. There is also a need to reduce waiting times when women come to pick up their ARV medicines.

Acknowledgements — The authors would like to thank the women participants and the staff of the Kibera Community Health Centre and the Busia Child Survival Project who made this project possible. Special thanks to the Funyula and Samia district health management teams for providing unlimited support during the data collection. This study was funded by the Swedish International Development Cooperation Agency (SIDA).

The authors — Opondo Awiti-Ujiji is a social scientist doing doctoral studies in global health. Anna Mia Ekström (PhD in epidemiology) is an infectious disease specialist and an associate professor. Festus llako (MSc in epidemiology) is the Deputy Country Director of the African Medical Research Foundation (AMREF) in Kenya. Dorcas Indalo (MSc in public health) is a community coordinator at the Kibera Community Health Project. Abigael Lukhwaro (BA in anthropology) is a research assistant at the Kibera Community Health Project. David Wamalwa (MSc in community health and development) is the programme manager of the Busia Child Survival Project. Birgitta Rubenson (PhD in international health) is a senior lecturer and specialises in child rights.

#### References

- Awiti-Ujiji, O., Ekström, A.M., Ilako, F., Indalo, D. & Rubenson, B. (2010) 'I will not let my HIV status stand in the way': Decisions on motherhood among women on ART in a slum in Kenya a qualitative study. BMC Women's Health 10(13) [doi: 10.1186/1472-6874-10-13].
- Central Bureau of Statistics (CBS) [Kenya], Ministry of Health (MOH) [Kenya] & ORC Macro (2004) Kenya Demographic and Health Survey 2003. July 2004. Calverton, Maryland, CBS, MOH and ORC Macro.
- Dahab, M., Charalambous, S., Hamilton, R., Fielding, K., Kielmann, K., Churchyard, G.J. & Grant, A.D. (2008) 'That is why I stopped the ART': Patients' and providers' perspectives on barriers to and enablers of HIV-treatment adherence in a South African workplace programme. *BMC Public Health* 8(63) [doi: 10.1186/1471-2458-8-63].
- Erulkar, A.S. & Matheka, J.K. (2007) *Adolescents in the Kibera Slums of Nairobi Kenya*. Nairobi, Kenya, The Population Council.
- Graneheim, U.H. & Lundman, B. (2004) Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today* 24(2), pp. 105–112.
- Gulis, G., Mulumba, J.A., Juma, O. & Kakosova, B. (2004) Health status of people of slums in Nairobi, Kenya. *Environmental Research* 96(2), pp. 219–227.

- Hardon, A. (2005) Confronting the HIV/AIDS epidemic in sub-Saharan Africa: policy versus practice. *International Social Science Journal* 57(186), pp. 601–608.
- Hardon, A.P., Akurut, D., Comoro, C., Ekezie, C., Irunde, H.F., Gerrits, T., Kglatwane, J., Kinsman, J., Kwasa, R., Maridadi, J., Moroka, T.M., Moyo, S., Nakiyemba, A., Nsimba, S., Ogenyi, R., Oyabba, T., Temu, F. & Laing, R. (2007) Hunger, waiting time and transport costs: time to confront challenges to ART adherence in Africa. AIDS Care 19(5), pp. 658–665.
- Homsy, J., King, R., Balaba, D. & Kabatesi, D. (2004) Traditional health practitioners are key to scaling up comprehensive care for HIV/AIDS in sub-Saharan Africa. *AIDS* 18(12), pp. 1723–1725.
- Kenya National Bureau of Statistics (KNBS) & ICF Macro (2010) Kenya Demographic and Health Survey 2008–09. June 2010. Calverton, Maryland, KNBS and ICF Macro.
- Kitzinger, S. (1993) Ourselves as Mothers. London, Bantam Books.
  Liam, I.I.L. (1999) The challenge of migrant motherhood: the childrearing practises of Chinese first-time mothers in Australia.
  In: Liamputtong Rice, P. (ed.) Asian Mothers, Western Birth: Pregnancy, Childbirth and Childrearing The Asian Experience in an English-speaking Country (2nd edition). Melbourne, Australia. Ausmed Publications.
- Liamputtong, P. (2002) Childrearing practices and child health among the Hmong in Australia: implications for health services. *International Journal of Health Services* 32(4), pp. 817–836.
- Liamputtong, P. & Naksook, C. (2003) Perceptions and experiences of motherhood, health and the husband's role among Thai women in Australia. *Midwifery* 19(1), pp. 27–36.
- Mills, E.J., Nachega, J.B., Bangsberg, D.R., Singh, S., Rachlis, B., Wu, P., Wilson, K., Buchan, I., Gill, C.J. & Cooper, C. (2006) Adherence to HAART: a systematic review of developed and developing nation patient-reported barriers and facilitators. *PLoS Medicine* 3(11), p. e438.
- Ngomane, S. & Mulaudzi, F.M. (2010) Indigenous beliefs and practices that influence the delayed attendance of antenatal clinics by women in the Bohlabelo district in Limpopo, South Africa. *Midwifery* (2010) [doi: 10.1016/j.midw.2010.11.002].
- Pescosolido, B.A. (1992) Beyond rational choice: the social dynamics of how people seek help. American Journal of Sociology 97(4), pp. 1096–1138.
- Pescosolido, B.A. & Rubin, B.A. (2000) The web of group affiliations revisited: social life, postmodernism, and sociology. *American Sociological Review* 65(1), pp. 52–76.
- Sethi, S. (1995) The dialectic in becoming a mother: experiencing a postpartum phenomenon. *Scandinavia Journal of Caring Sciences* 9(4), pp. 235–244.
- Simmel, G. (1955) Conflict and the Web of Group-Affiliations (Translated by K.H. Wolff and R. Bendix). New York, The Free Press
- Unge, C., Johansson, A., Zachariah, R., Some, D., Van Engelgem, I. & Ekstrom, A.M. (2008) Reasons for unsatisfactory acceptance of antiretroviral treatment in the urban Kibera slum, Kenya. *AIDS Care* 20(2), pp. 146–149.
- Vallido, T., Wilkes, L., Carter, B. & Jackson, D. (2010) Mothering disrupted by illness: a narrative synthesis of qualitative research. *Journal of Advanced Nursing* 66(7), pp. 1435–1445.
- Weaver, J.J. & Ussher, J.M. (1997) How motherhood changes life
   a discourse analytic study with mothers of young children.
   Journal of Reproductive and Infant Psychology 15(1), pp. 51–68.