

“Now I’m alright, I can raise my children”: Motherhood reimagined for Kenyan women in an HIV-Livelihood-Empowerment Program

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Abstract: HIV/AIDS remains a global public health crisis that disproportionately affects women, particularly in low- and middle-income countries where women face substantial social and economic inequalities. Integrated HIV and livelihood programs (IHLPs) that simultaneously target HIV-related health behaviors and economic security are increasingly being employed as public health best practice with women in low resource contexts. Yet, evidence on IHLPs remains limited, and little is known about the experiences of women participants or the impact on family stability and mother-child relationships. Using qualitative interviews, this study explored the experiences of single mothers in extreme poverty living with HIV/AIDS (n=27) who participated in an IHLP in Kenya. Analysis yielded four themes: (1) Meeting children’s basic needs, (2) Disclosing their HIV status to children, (3) Parent-child role reversal, and (4) Re-imagining the future. Overall, narratives illustrated participants’ evolution from an experience primarily defined by poverty and ill-health to a position of empowerment, capability, and hope. Findings suggest that treatment and care plans emphasizing mothers’ improved health as a vehicle for improving the wellbeing of her children may be most successful in this context.

Key Word: HIV/AIDS; poverty; intervention; livelihoods; women’s health; participatory research.

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I. INTRODUCTION

Despite nearly four decades of prevention efforts, HIV/AIDS remains a global public health crisis (UNAIDS, 2018). More than 1.7 million new infections still occur annually—which is more than triple the 2020 global target (UNAIDS, 2020b). Sub-Saharan African remains one of the regions hardest hit by the epidemic, home to over 20 million people living with HIV and accounting for nearly half new infections globally (UNAIDS, 2019). Among the countries in this region, Kenya’s HIV infection rates rank among the highest (UNAIDS, 2018) with roughly 1.5 million citizens currently living with HIV (Kenya Ministry of Health, 2018).

As elsewhere in Sub-Saharan Africa, women in Kenya continue to bear the brunt of the HIV/AIDS epidemic, accounting for over 60% of new HIV infections (Kenya Ministry of Health, 2018). In addition to the disproportionate likelihood of living with HIV/AIDS themselves, women are also more likely to bear the burden of caring for HIV-infected children compared to men (UNAIDS, 2018).

Poverty is inextricably linked to HIV/AIDS in Sub-Saharan Africa and in low- and middle-income countries (LMIC) around the globe. Individuals living in poverty are at heightened risk for contracting HIV, and poverty exacerbates disease impact and serves as a barrier to treatment and adherence (Kakuhikire, Suquillo, Atuhumuza et al., 2016; Nadkarni, Genberg & Galárraga, 2019). Therefore, integrated HIV and livelihood programs (IHLPs; Yager, Kadiyala & Weiser, 2011) that simultaneously target HIV-related health behaviors and economic security are increasingly being employed as public health best practice with women in LMIC. Yet, evidence on IHLP is still limited, and little is known about the experiences of women who participate in such programs or their impact on family stability and mother-child relationships.

While valuable insights can be gleaned from the substantial literature on parenting and HIV/AIDS generally, studies have largely focused on mother-to-child transmission of HIV or have been conducted with women in high-income countries (Lachman, Cluver, Boyes, Kuo & Casale, 2014). Yet, mothers living with HIV/AIDS in low- and middle-income countries (LMIC) experience a unique set of challenges—particularly in the context of the additive effects of poverty, gender inequities, and chronic disease (e.g., Burgess & Campbell, 2014). Given the cultural significance of motherhood in Sub-Saharan Africa, the need remains for women’s voices to illuminate the ways in which participation in HIV interventions may (or may not) transform their lives as women, mothers, and caregivers.

II. LITERATURE REVIEW

Mothers living with HIV/AIDS in low- and middle-income countries (LMIC) encounter a range of challenges, particularly those mothers who are diagnosed while already raising children. Two key challenges are explored below.

Impact of HIV Stigma

Decades into the epidemic, the stigma of HIV/AIDS remains “a ubiquitous and pervasive barrier to every point along the HIV continuum of care” (Sullivan, Rosen, Allen et al., 2020, p. 357). Like other women living with HIV/AIDS, mothers must endure the persistent effects of stigma, but her children may be subjected to stigma by association, as well.

The stigma of HIV/AIDS manifests in overt ways through discriminatory treatment of the infected mother and/or her children. In professional service settings such as healthcare, women living with HIV/AIDS can be denied care, mistreated, or experience breaches of confidentiality (Okoror et al., 2014; UNAIDS, 2020). In their study of women living in urban informal settlements in Nairobi, Amuyunzu-Nyamongo and colleagues (2007) found that discrimination was widely reported, and these negative experiences further reinforced the reluctance to disclose their HIV status to others. Similarly, in a study of pregnant Kenyan women, researchers found that work discrimination, verbal abuse, neglect, and social isolation were common among those who had disclosed their HIV status (Cuca, Onono, Bukusi & Turan, 2012).

Stigma can also lead to social exclusion, isolation, and loss of social support. It is not uncommon for women in Sub-Saharan Africa diagnosed with HIV/AIDS to experience loss of kinship ties and/or abandonment by a husband or partner (Amuyunzu-Nyamongo et al., 2007; Burgess & Campbell, 2014; Rankin et al., 2005). Rejection by family members or neighbors forces some women living with HIV/AIDS to migrate from rural to urban areas or move to informal settlements where living conditions are extremely poor (Amuyunzu-Nyamongo et al 2007). This loss of community social support also manifests as refusal to engage in business or trade with the stigmatized mother, further compounding the negative economic effects of HIV/AIDS on the household (Rankin et al., 2005). Given the importance of social connectedness and its impact on access to resources and opportunities needed for survival (Kagotho & Kyriakakis, 2015), exclusion from social and economic networks has a detrimental deleterious effect on household wellbeing.

The emotional toll of these and other stigma-related experiences is highlighted in research linking stigma to poorer mental health outcomes for both HIV-infected mothers and their children. Experiences of HIV stigma may result in depression, anxiety, anger, post-traumatic stress, or suicidal ideation (Amuyunzu-Nyamongo et al., 2007; Brandt, 2009; Cuca, Onono, Bukusi & Turan, 2012). Given that mental health services to help individuals living with the challenges of HIV/AIDS are not often readily available in Sub-Saharan Africa (Brandt, 2009; Kulisewa et al., 2019), informal strategies women have traditionally used to mobilize social support (Burgess & Campbell, 2014) are even more critically needed for HIV-infected mothers.

Disclosure of HIV Status to Children

Although disclosure to children is generally considered an integral part of a parent’s coping with HIV/AIDS, pervasive barriers to disclosure remain in LMICs. For example, parents report avoiding disclosure out of fear that children will not keep the diagnosis a secret (Gachanja, Burkholder & Ferraro, 2014; Madiba, 2013), fear of losing children’s respect (Kyaddondo, Wanyenze, Kinsman & Hardon, 2013; Tiendrebeogo et al., 2013), fear that children will assume the parent is dying (Madiba, 2013), and a desire to protect their children from HIV-related stigma or discrimination (Kyaddondo, Wanyenze, Kinsman & Hardon, 2013; Tiendrebeogo et al., 2013).

Even parents who have already decided to disclose to their children may struggle to determine how, when and how much to disclose (Gachanja, Burkholder & Ferraro, 2014; Iwelunmor, Zungu & Airhienbuwa, 2010). A study by Kyaddondo and colleagues (2013) found that HIV-positive parents in Uganda wrestled with disclosure timing, often delaying disclosure until children reached adolescence or were otherwise perceived as mature enough to handle the news.

Other factors may promote parental disclosure. Tiendrebeogo and colleagues’ (2013) study of parents living with HIV in Burkina Faso found that mothers were significantly more likely than fathers to disclose, as were parents who were widowed or divorced. Extreme poverty may also have the inadvertent effect of facilitating disclosure in the sense that congested living situations can leave HIV-infected individuals without privacy to maintain their treatment regimens without children taking notice (Amuyunzu-Nyamongo et al., 2007).

Despite these myriad challenges, research suggests that disclosure can enhance mental health outcomes for both mother and child as well as reduce parental stress (Rochat, Arteché, Stein, Mitchell & Bland, 2015). Moreover, in their study of low-income HIV-positive parents in Kenya, Kagotho and Kyriakakis (2015) found

that disclosure not only functioned as a coping mechanism for parents but was also essential to obtaining the information, mental health, and economic resources necessary for securing household wellbeing.

There is a clear need for interventions to effectively address HIV-specific health outcomes alongside these and other socio-economic impacts of HIV/AIDS. As integrated health and livelihood programs represent a promising approach, this study explored the programmatic impact and experiences of participants in one such IHL in Kenya to help address this gap.

III. Material and Methods

Qualitative data were collected as the first phase of a larger mixed method study evaluating the impact of an IHL for single mothers living with HIV/AIDS in extreme poverty. This initial project phase employed individual interviews and follow-up focus group interviews to explore participants' lived experiences before and during the program, particularly those experiences related to their roles as mothers, and to inform development of evaluation instruments to be used in the second study phase. A participatory research approach was used, involving program participants and staff as collaborators throughout the study (Springett & Wallerstein 2008).

Program and Participants

The Women Equality Empowerment Project (WEEP) is a faith-based initiative to empower HIV-positive mothers who have been widowed or abandoned by their husbands or partners and are economically vulnerable. Women are eligible to participate if they are (1) single mothers diagnosed with HIV or AIDS, (2) caring for biological children under age 18 in their home, and (3) living in extreme poverty (<\$1.90 USD equivalent/day). The program operates through seven community centers located in both urban informal settlements and rural villages throughout Kenya. Approximately 110 women were enrolled across all sites at the time of data collection.

The program aims to improve mothers' health, reduce household economic vulnerability, and improve family wellbeing. After enrollment, mothers progress in small cohorts through three consecutive program phases, each lasting approximately six months. The Stabilization Phase involves direct service provision to address basic household needs such as food and shelter while helping mothers, who are often in advanced stages of AIDS at enrollment, to regain physical health necessary for them to participate in daily program activities. The Skills Development phase provides trainings to enhance literacy and numeracy, develop income-generating skills, and increase health literacy. Finally, the Sustainability Phase supports mothers to develop entrepreneurial skills, launch a microbusiness, accrue assets, and begin saving to build the family's future economic security.

Sampling and Recruitment

A purposive sample was drawn from current program participants and recent graduates from three of the seven centers. Respondents were selected through a collective decision-making process: center coordinators explained the purpose of the interviews, and women collectively determined which current participants and recent graduates would be interviewed. Coordinators verified that each nominated woman was interested in being interviewed then created an interview day schedule which was shared with the PI (first author). This process resulted in 7-12 respondents interviewed from each site.

Procedures

Informed consent was obtained using consent forms in English and Kiswahili. Interviews were conducted at each program site by the first author with assistance from local interpreters, depending on respondents' primary language. Semi-structured interview questions focused on women's experiences both prior to and during program participation. Interviews were digitally recorded and transcribed verbatim. Women received a handheld dry-erase board and set of dry-erase markers for their participation. Protocols were approved by the first author's university Institutional Review Board and the Kenyan community partner's Board of Directors.

Data Analysis

Exploratory analysis was conducted to examine emerging themes beginning with open coding to identify relevant segments and open up the inquiry (Strauss, 1987) and followed by a second round of coding to group and collapse initial codes into categories. Overarching themes and sub-themes were identified based on these codes. Data were collaboratively coded by both authors with the second author taking on role of primary coder for this analysis. The first author coded a subsample of the data with these codes compared and reconciled with those of the second author. An inductive approach was applied using the overarching objectives drawn from the participatory evaluation study as the initial guiding principles (Thomas, 2006). The following iterations yielded 23 open codes collapsed into six trees which represented major emergent themes. This paper

presents findings related to the topic of motherhood with participant names and locations changed to protect anonymity.

Several strategies were used to address the trustworthiness of findings including prolonged engagement, reflexivity, member checking, peer debriefing, and parallel coding (Barbour, 2001; Lincoln & Guba, 1985). The first author spent an extended amount of time in the field interacting with both program participants and staff at several sites prior to and following the interview process, and these interactions informed the interpretation of the data. To further enhance the credibility of the interpretations, stakeholders (i.e., program staff and select participants) were given the opportunity offer comments on the main findings through focus group sessions and one-on-one communication with program staff. Finally, both authors were cognizant that their interaction with these data—including construction of codes, selection of quotes presented, and framing of the discussions—were shaped by their respective life experiences. Constant communication, especially in the initial stages of the analysis process, created an environment where both authors were able to engage in critical reflection of how their experiences, preconceptions, and worldviews influenced their perspectives on the data.

IV. Results

Participants (n=27) were single mothers ages 20-48 caring for between 1-6 children each. The sample was geographically diverse with women from two urban informal settlements and five rural villages. Pseudonyms are used in the quotations below.

Women's narratives traced their motherhood experiences from the moment they were first diagnosed with HIV or AIDS. Collective descriptions of the initial months and years of dealing with their illness largely emphasized their feelings of powerlessness in their role as 'mother'—particularly as single mothers with sole responsibility for their children's physical and emotional needs. Many recounted how participation in the IHLP enabled them to regain firm footing as a parent and provided a secure foundation from which to care for their children. Narratives illustrated how women's connection to the program not only gave them brief respite from the pressing struggles created by poverty and ill health but empowered them to develop unanticipated knowledge and skills. Narrative analysis revealed four themes: (1) Meeting children's basic needs, (2) Disclosing their HIV status to children, (3) Parent-child role reversal, and (4) Re-imagining the future. Each theme is described in detail in the sections below.

Struggle to Meet Basic Needs

All 27 mothers had faced tremendous challenges in meeting their children's basic needs, giving detailed accounts of their inability to provide prior to entering the program. Lydia, mother of four, recounted: *"I didn't have food, I didn't have money to pay my house rent, and I had stayed for one year without paying house rent."* Lucy, mother of seven, shared: *"When I was really sick, I had a hard time and was really struggling, and my children were not even getting food and at that time."* Despite these struggles to obtain food and other basic needs, narratives captured a selflessness of motherhood as mothers chose to put their children first even if this jeopardized her own health. For example, women experiencing food insecurity shared how it was sometimes impossible to maintain the dietary requirements of their antiretroviral medication regimens because they opted to feed their children in lieu of themselves.

In addition to HIV-related physical health complications, several other factors prevented mothers from meeting basic household needs, including loss of financial support from a previous spouse/partner, women's lack of income and employable skills, and rejection by family members due to stigma and conflict related to her HIV status. The economic strain women experienced as a result of becoming single parents was especially prominent in these narratives, as illustrated by Naleke, mother of three: *"My life wasn't good, it was bad because my husband chased me away, ran away when I got sick. He left me with the children, and I was bed-ridden, I couldn't do anything."* The loss of a spouse put a subsequent strain on relationships with others, as well:

That was when life became very difficult because when he was around, he was helping with the children he used to bring food now when he ran away, I had a problem getting food my neighbors were the ones who used to help me. I was so sick until my neighbors got tired, some were even just laughing that I have HIV...at times I just used to cover myself in the blankets and cry, I even contemplated "do I hang myself...or what do I do?" but I was thinking of my children. I just tried as hard as I could I continued to take the medication even when there was no food, I was just swallowing it with water. (Jackie, mother of 2)

For most participants, disclosing their HIV/AIDS status resulted in the deterioration of previously strong family ties. Women attributed this to family members' fear and stigma of HIV, anticipated added burden of providing care both to the mother and her children, and competition for family resources. Jackline, mother of three, shared how her feeling helpless to provide for her children was exacerbated by isolation from her

immediate family: "I just thought 'I will die' so my worry was now 'How will I leave my children?' Because now I am still alive but even my sisters cannot take care of them, we are just in the house alone sleeping hungry and they are just around. So that was my worry [...] I thought everything was just at the end."

Aware of the costs of HIV/AIDS treatment and expecting that they may be called to care for orphaned children, some families tried to protect themselves by distancing from these women. Benter, mother of five, recounted how her birth family drove her out of her home in an effort to keep her health expenses from draining the family's resources:

I had children, and one, the last born was on medication. I got sick when I was still at home, the place where I was born. I got very sick. I was kicked out of home; even one day I was beaten so bad I was admitted at Kenyatta [hospital]... I was beaten by my brothers and my father because I had an illness and had medication, I was using up the family wealth and finishing it up for the rest.

This abusive treatment women endured reflects another layer in their struggle to provide for their children in the face of social networks weakened by the stigma and impact of HIV/AIDS.

Decisions about Disclosing Mother's HIV Status to her Children

The emotional repercussions of raising children in a household where she and sometimes others were living with HIV/AIDS made careful consideration of disclosure of HIV status an integral part of strengthening family functioning. In all cases, mothers opted to first disclose to other adults who were in a position to help them cope with their diagnosis. Mothers disclosed to their children only after they themselves had gotten a good grasp of their disease; the more information mothers had about HIV/AIDS, the more confident they felt in disclosing.

Timing and method of disclosure was considered very carefully, and all mothers wanted to retain control about *how* their children learned of their serostatus. With the exception of two mothers whose children accidentally learned of their HIV through other adults, each instance of disclosure was a conscious and deliberate encounter between the mother and an individual child in the household. The need to fully accept their own status before disclosing to their children was expressed by most mothers, including Joyce, mother of two: "My children, they know because when I accepted myself, I was able to tell them." Another noted, "if you accept yourself you can take it like any other disease like malaria. Because I had accepted myself, I sat down and spoke to my two children. I told them of my status" (Joan, mother of 4).

Mothers were especially concerned about how their children would perceive them following disclosure and the possible harm to their mother-child relationship. Rachel, mother of three, articulated the worry about how children would cope with the emotional consequences and fears of having a parent with HIV/AIDS:

At the time I told them the one [child] said, "So you are soon following our dad [in death]." I told them, "Drugs...I've introduced myself to drugs, so we pray hard that I don't follow your dad. I don't die soon as your dad. I be there to care for you." So even they used to be so much close to me. They come cook for me prepare for me and tend to when I fall sick [...] they prepare for me. They came to be useful, and now they know that mom is positively living life.

Mothers remarked that a number of factors were taken into account when deciding whether and how to disclose, including age, gender, and the child's own HIV status. Women shared how they designed the disclosure process accounting for each child's mental health status and maturity level, often disclosing to one child at a time so she could help each child individually process the information. Purity, mother of three, described how she staggered disclosure discussions over the course of several months to help emotionally prepare her son before fully disclosing her status:

I just prepared [his] mind because [he] was too small by that time, now he's in class where they're started at least learning about HIV. I disclosed my status to him. I tried like December so it's still difficult because I ask [him], what will you do if you know somebody's HIV and you know him or her? [He] said [...] "if I knew like my mom is HIV positive, I will just kill myself." And I said, this is not the right time. So, I talked with [him] that December but no disclosing, no telling him anything, and...right he came in April I still continued like talking like those stories to him and I told him—I, I just ask him, "[Son], what are you going to do if you don't have anybody else to take care of you? And have your sister here she's small, what are you going to do?" [He] said, "I will take care of them and I will accept, and I will take care of my mom." And I just prepare his, prepare his mind like two weeks before we went back to school, I just told him and he is alright, that is not really a problem.

Parent-Child Role Reversal

For many mothers, daily efforts to manage HIV/AIDS resulted in a blurring of parent-child roles, and they expressed both gratitude and concern about the ways in which their children had taken on household responsibilities when their mothers were incapable of doing so. This role reversal was described as taxing on

both the child and parent, yet several mothers were able to reconstruct household responsibilities in a way that made children feel more in control of the instability brought on by their mother's illness.

Minimally, a mother's illness required children to take over household chores such as cooking and laundry. Lydia, mother of four, described how children followed her guidance with these new responsibilities:

I think they had God help them to have wisdom because every time I'm like "I'm giving up" my daughter would tell me "No, mommy you're not going to die because we need you more than ever and you know we are just okay seeing you here and joking with you here." And one day we didn't have charcoal in the house, and we were using firewood, so she wanted to boil water and we don't have anything, so she is using firewood and we are just in a squeezed house and she put on everything she wanted, and the fire went OH! Like we would have been burned, now we were scared because we wanted to use this firewood to boil water so that we can drink water because we had nothing to eat and I'm like "Even if we boil water and we drink warm water it will give us strength." So, children are just following what I'm telling them to do.

Some children took on even greater responsibility for the household. One mother recounted how, after learning of her illness from a third party, her 10-year-old son decided to drop out of school to scavenge in the local trash mounds in order to provide for the family while his mother was becoming more bedridden by AIDS:

He disappeared from home and went to the dump site. And after I went all around searching for the boy, he told me that he want to stay here to start the hard life because I— he knew I will die, and he want to take care of the younger ones. [...] He told me, he told me, "mom I wasn't expecting that you stay for this long." Now this is when I know that you—how they were being taught at school that he, that they—he took that thing very serious [...] he told me "even if my mom died today, I'll be able to go to the dustbin and get food for the kids. And I know how to be paying the house rent" (Purity, mother of 3).

In the context of these reversing parent-child roles and the anxiety their ill health was exerting on their children, some women assigned HIV-specific caregiving tasks to children as a way to help them cope with mother's compromised health and gain some control of the resulting unstable environment. One mother described how her children's assistance also gave her hope:

I'm telling you my daughter gave me encourage...So I get so much encouraged so I told her that, "You will be my drug assistant. I'm taking my drugs at 6 am in the morning, 6 pm in the evening. So, you will be reminding me. So, but not tell your brother." She was my drug assistant when I'm late, when I'm even when I was somewhere she must be worried "Where is my mom? Where is my mom? Mom, it is this time. It is time to take your medication." So, I get encouraged with my children. (Deborah, mother of 2)

Thus, whereas some mothers were cautious about these blurring lines of responsibility, others actively incorporated these new demands in ways that strengthened family functioning.

Re-imagining the Future

Acceptance into the IHLP was described as a major turning point as women received initial assistance to address the urgent basic needs of their families including food and rent. Agnes, mother of three, explained, "Now when I came here [program] I saw that my problems had greatly reduced because I was getting food, I was getting money to pay rent and my children would go to school...that is what I'm most grateful for. Now I became strong and started coming to the center." Once able to join center activities, women benefitted from social support from the center coordinator and a cohort of other mothers living with HIV/AIDS—for many women, this was the first time they had met others "like them." As women grew more accepting of their HIV/AIDS status and subsequently gained support from their children, they developed coping mechanisms that informed their approach to mothering.

After completing the initial stabilization phase of the program, mothers learned income-generating skills and received livelihood supports including access to microfinance and trainings in budgeting and business management. Women described the program as critical in strengthening their roles as mothers and minimizing—in some cases, ending—the struggles they had experienced, as illustrated by Violet, mother of two:

[The program] used to give me porridge flour, flour for cooking, because at that time I wasn't able to cook or even go for casual work. And that's when I started lifting my life slowly. I rented my own house, I moved out of our home. Because at home we...you just used to take tea, my mother didn't want to know whether you were taking any medication, once you take tea that's it. I decided that if I rented my own place at least I would be able to cook food for myself to eat with the child I had and then I would be able to take my medication.

As women continued to participate in the program, their perception of what was possible for their futures changed. Three mothers in particular described a drastic change in future orientation, from considering

suicide as a viable option to developing a positive future outlook both for themselves and their children. Benter, mother of five, explained:

I was so stigmatized that even when my children went to school no one wanted to get close to them. I felt like was a dead person, and even if I was sick, I became really worried and felt like I had completely lost direction in life. Now one day I told the children “we should buy poison and take it!” one of my children told me “we’ll take it because we don’t want to be left and continue suffering.” [...] I joined [the program], I became strong I even teach. Everywhere we go, we teach people, and they go for testing. If they find that they have a problem like mine I speak to them until they start taking their medication well. Now we have friends [...] I have three people working for me as casual workers.

Eventually mothers felt empowered enough to start a small business and envision new and innovative ways of providing for their family. Encapsulating the path she traveled to finally having the ability to exhibit her entrepreneurial skills, Silvia, mother of two, shared:

We were taught how to sew, and we learnt. We learnt, and we were really helped because at that time it was difficult because one couldn’t even afford your own food at that time. [...] Since the day I entered class, to the time I left, I never looked back. We stayed for a year and eight months and left [to make space] for another group of seven women. We started our own businesses. Now I sell panties, I sell viko.

In addition to small business ventures, women described future goals of homeownership, helping others in the community, and participation in community education and policy advocacy. Several women described how they were planning or in the process of acquiring fixed assets such as land and houses to secure their children’s future, including Lucy, mother of seven: “Right now I’m praying that I will buy my own land too so I don’t live in a place that’s built for me, though I’m very thankful because that house that was built for me is where I’ll move from by the time I buy my land, to go and build my own house on my property.” Underscoring the primacy of their children’s wellbeing, mothers consistently expressed a strong desire to own their own home so income could be used to consistently pay children’s school fees and lay the groundwork for a better future for them. As Deborah, mother of two, explained:

Yea, then I rent another house, so I came here, I join again, I started sewing. Now I know how to sew so I started sewing very hard. When I get 15,000 [shillings] I can pay the rent, I buy food, the rest I keep to the bank I save. Like that, like that, like that. Then I bought another house where I was staying now where I’m staying now, yes. I bought money I was getting from the uniforms, yea. Then my daughter ask me, “Mom, you will you have bought another house?” “Yea, that it what I was my desire. I don’t because I know where going it is still far but if I can just keep on paying house rent every day you will not go to school.” So, you see she has done class eight, she has passed, she has to go to high school, and I have to pay school fees. I told I told my daughter, “You will learn.”

V. DISCUSSION

Four emergent motherhood themes illustrated the evolution of women’s experiences while in the IHLP, from their initial inability to provide basic needs and difficult disclosure decisions to coping through parent-child role reversals, and finally, a hopeful re-imagining of the family’s future. As illuminated by narratives from this study, mothers living with HIV/AIDS are often left to provide for the household’s economic needs after being widowed or abandoned by spouses or partners (Nyblade & Field-Nguer, 2001; Roby et al., 2009). Consistent with findings from Burgess and Campbell’s (2014) study of South African women living with HIV/AIDS, respondents expressed the “agony of not being able to feed their children” (p. 892) due to their compromised state. When any resources were available mothers gave them to their children rather than themselves, even at the risk of compromising their own fragile health, echoing the sentiment of “mother first—patient later” described by Awiti-Ujiji and colleagues (2014).

The single mothers in this study detailed how initial admission into the IHLP provided them with respite from the immediate crisis they faced enduring both extreme poverty and HIV/AIDS. With housing, food, and children’s basic needs met, the women were able to focus on vocational skill development and training, in addition to maintaining their own health through adherence to HIV medications and attention to nutrition. They perceived the livelihoods component of the program as critical to their ability to move beyond the provision of consumption needs and begin working toward long-term economic security and family stability.

Disclosure in the context of the broader mother-child relationship was extensively discussed by respondents, including the goal of many mothers to protect their children from the consequences of HIV/AIDS (Tiendrebeogo et al., 2013). Mothers generally delayed considering disclosure to children until they had come to terms with their own diagnosis and understood the physiology of the disease. Disclosure decisions were then made based on each child’s perceived readiness and weighing potential consequences for the child and the mother-child relationship.

Increased HIV/AIDS knowledge acquired from the IHLP played an important role in disclosure, and participants discussed ways that they were able to reassure their worried children by sharing this knowledge of their disease. However, disclosure remained inconsistent across the sample, with many mothers discussing the numerous challenges that had kept them from disclosing to their remaining children (even if they had disclosed to a sibling already). Given the holistic focus of IHLPs, counseling services for both mothers and their children as recommended by Tiendrebeogo and colleagues (2013) could be incorporated to mitigate barriers to disclosure and strengthen the family unit in ways that would further support wellbeing for the mother.

Because becoming a mother is so central to the conceptualization of womanhood in Sub-Saharan Africa, the limitations or barriers HIV/AIDS presents for childbearing represents a critical struggle for many HIV-positive women (e.g., Awiti-Ujiji, Ekström, Ilako et al., 2011; Schaan, Taylor, Gungqisa & Marlink, 2016). Although the mothers in this study all had children prior to becoming aware of their HIV status, the interconnection of being woman/mother was nevertheless interwoven throughout most of the narratives.

Consistent with previous research, mothers in this study reported that their children—especially those to whom they had disclosed their status—made positive contributions to their care and wellbeing. Children took the initiative to remind mothers about their medication regimens and dosing schedules (Kyaddondo, Wanyenze, Kinsman & Hardon, 2013; Tiendrebeogo et al., 2013), addressing the forgetfulness that is a primary determinant of medication adherence among people living with HIV/AIDS (Tiendrebeogo et al., 2013). Children also took on new roles related to household maintenance, including doing chores that the mother had previously done and, in some cases, even making efforts to generate income (Tiendrebeogo et al., 2013). Research suggests that mothers living with HIV/AIDS feel pressure to still complete household chores in order to prove themselves a “good mother” which consequently keeps them from ever feeling as though they are “allowed to be sick” (Awiti-Ujiji et al., 2011, p. 160). It’s possible that the mothers in this study felt conflicted at times about their children stepping up to take on new roles within the household and the corresponding reflecting on the mothers themselves. However, these narratives suggest that, in addition to the overt emotional support that their children provided (Kyaddondo et al., 2013; Tiendrebeogo et al., 2013), mothers felt relief from these expectations through their children’s actions, and perhaps more freedom to acknowledge and tend to their illness, as well.

Although many respondents expressed fear about their mortality and their children’s futures (Amuyunzu-Nyamongo, et al. 2007) prior to entering the program, other mothers were able to remain optimistic as they sought out resources to secure their family’s wellbeing (Kagotho, 2012). Overall, women’s narratives traced their journeys from housing instability to plans for homeownership, from social exclusion to strong relationships, and from isolation to active community members and HIV educators—ultimately emerging into a space of hope.

The IHLP strengthened long-term economic capabilities alongside initial supports of food, shelter, and social support increased women’s personal agency enabling them to thrive. Participants reported rejuvenated health, strengthened parenting skills, and the ability to envision for the first time a future in which they, as single mothers, were free to exercise agency in their roles as parent, income-earner, and community member. The goal expressed by South African HIV-positive women in Burgess and Campbell’s study (2014) to “be a good mother who provides for her children” seemed to provide a guidepost for these Kenyan women, as well, and IHLP participants appeared to be well on their way to attaining it.

Taken together, these themes illustrate an overarching story of ‘struggle’—and its evolution throughout women’s participation in the IHLP. This is not to suggest that all elements of struggle were absent at the conclusion of women’s narratives, but for most mothers the stressors they described had transcended the initial urgency of a family in crisis to represent a future orientation characterized by asset building and hopefulness.

Certainly, these findings should be viewed in light of study limitations. Because some interviews utilized a translator, misinterpretation of some words or phrases was possible. To minimize this likelihood, program staff selected local translators who had both experience with the program and strong language skills in Kiswahili and local language(s). Further, although the goal of qualitative research is not to produce generalizable findings, we note that findings are based on experiences of participants from one social development program in Kenya which may not reflect experiences of HIV-positive mothers in poverty elsewhere.

Despite these limitations, findings offer valuable insight into the ways in which motherhood profoundly shapes—and is shaped by—women’s experiences of poverty and HIV/AIDS, presenting both unique challenges and important context for increased personal agency and longevity. The extraordinary efforts women made to engage in caregiving despite their physically compromised states suggests that mothering roles must be a central component of HIV prevention and treatment efforts in Kenya and elsewhere in Sub-Saharan Africa. In alignment with arguments for reconceptualizing HIV/AIDS as a “family illness” (e.g., Rotheram-Borus, Flannery, Rice & Lester, 2005), qualitative findings about the prominence of motherhood in women’s lives suggests that treatment and care plans emphasizing mothers’ improved health as a vehicle for improving the wellbeing of her children may be most successful in this context.

VI. CONCLUSION

Although the purpose of this analysis was not to explicate program outcomes specifically, these narratives nevertheless tell an important story of transformation for single mothers in Kenya participating in an IHLIP. Mothers described the evolution of their struggle from the urgent need for basic resources created by poverty and deteriorating health to navigating motherhood and community participation once their health had improved. Ultimately, the struggle these mothers had endured evolved into a state of self-described empowerment where they had re-imagined a future in which they—single mothers living with HIV/AIDS—were fully capable of providing for their household's wellbeing. As Janet, mother of three, expressed: "Probably I wouldn't be alive if I hadn't come here [program], and now I'm alright, I can raise my children."

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