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Antiretroviral therapy maintenance among HIV-positive women in Ghana: the influence of poverty

Rebecca A. Poku [a], Adobea Yaa Owusu[b], Patricia Dolan Mullen[a], Christine Markham[a] and Sheryl A. McCurdy [a]

[a]School of Public Health, The University of Texas Health Science Center at Houston, Houston, TX, USA; [b]Institute of Statistical, Social, and Economic Research, University of Ghana, Legon, Ghana

ABSTRACT

This study examines the role of poverty in the acquisition of and the adherence to antiretroviral therapy (ART) and prescribed clinical follow-up regimens among HIV-positive women. We conducted in-depth interviews with 40 women living with HIV (WLHIV) in Ghana and 15 stakeholders with a history of work in HIV-focused programs. Our findings indicate that financial difficulty contributed to limited ability to maintain treatment, the recommended nutrient-rich diet, and clinical follow-up schedules. However, enacted stigma and concurrent illness of family members also influenced the ability of the WLHIV to generate income; therefore, HIV infection itself contributed to poverty. To further examine the relation between finances, ART adherence, and the maintenance of recommended clinical follow-up, we present the perspectives of several HIV-positive peer counselor volunteers in Ghana's Models of Hope program. We recommend that programs to combat stigma continue to be implemented, as decreased stigma may reduce the financial difficulties of HIV-positive individuals. We also recommend enhancing current support programs to better assist peer counselor volunteers, as their role directly supports Ghana's national strategic HIV/AIDS plan. Finally, additional investment in poverty-reduction across Ghana, such as broadening meal assistance beyond the currently limited food programs, would lighten the load of those struggling to combat HIV and meet basic needs.

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Introduction

Poverty has been discussed as both a result of and contributor to health outcomes for HIV-positive individuals within sub-Saharan Africa (Steinert, Cluver, Melendez-Torres, & Romero, 2017). Food insecurity, often found in situations of poverty, is linked to adverse health outcomes and non-adherence to antiretroviral therapy (ART) (Young, Wheeler, McCoy, & Weiser, 2014), the combination of antiretroviral medications (ARVs) prescribed to combat HIV infection. A review of seven studies by Chop et al. (2017) concluded that food insecurity negatively affects ART adherence and sexual risk behavior. The Chop et al. (2017) review included Fielding-Miller, Mnisi, Adams, Baral, and Kennedy (2014), Miller et al. (2011), Murray et al. (2009), Musumari et al. (2013), Peretti-Watel et al. (2006), Shannon et al. (2011), and Whittle et al. (2015).

Currently available programs to address food insecurity and nutrition in Ghana include the Livelihood Empowerment Against Poverty (LEAP) program and the World Food Programme (WFP) (Ghana AIDS Commission [GAC], 2016). WFP provides rations for patients on ART; through LEAP, community-identified indigents, including PLHIV, are given small financial assistance monthly by the Ghanaian government (GAC, 2016). However, those who do not meet the body mass index requirement for WFP (World Food Programme, 2011) or inclusion criteria for LEAP may continue to struggle.

Ghana currently provides ARVs free-of-charge (Yarney, Amankwah, Mba, Asamoah, & Bawole, 2016), but separate out-of-pocket payment or insurance coverage is required for clinical testing and follow-up, and other prescribed medications. Structural problems related to ART acquisition in Ghana have been identified previously, including insufficient funding, stock-outs of ARVs, and privacy issues related to treatment at healthcare facilities (Poku, Owusu, Mullen, Markham, & McCurdy, 2017b; Yarney et al., 2016). Additionally, transportation to healthcare facilities and other indirect costs impact patients' ability to acquire medications (Ankomah et al., 2016). Particularly for women, low-wage occupations or low-profit businesses limit their ability to pay for medication, testing, recommended

CONTACT Rebecca A. Poku rap723@hotmail.com School of Public Health, The University of Texas Health Science Center at Houston, P.O. Box 20036, Houston, TX 77225-0036, USA

nutrition, and follow-up care (Asante, Poku, Owusu, & Zekeng, 2014).

In light of these issues, Ghana has employed some efforts to increase adherence, including the peer counselor Models of Hope program. Through this program, HIV-positive volunteers ("Models of Hope") provide words of encouragement and support to newly-diagnosed individuals, assist with healthcare facility navigation, provide treatment tips, and conduct home visits (GAC, 2015). The health of the Models of Hope is meant to provide a hopeful example of the tangible result of adherence to ART and recommended clinical follow-up visits. Currently a subset of the Models of Hope receives a monthly stipend to offset transportation costs, but no other benefits (Lee, Naik, & Kenu, 2017).

Other research examining HIV-positive peer counselors' experiences highlight the positive role of peer counselors in linking others to care and fostering hope (Genberg et al., 2016; Hilfinger Messias, Moneyham, Vyavaharkar, Murdaugh, & Phillips, 2009), though the impact on clinical outcomes varies (Genberg et al., 2016). Ghana's Models of Hope program has not been formally evaluated (Lee et al., 2017); however, research in Ethiopia and Uganda indicates that the high patient load and voluntary nature of the work strains the peer counselors (Gusdal et al., 2011).

Few studies have explored poverty and resulting constructs as they pertain to Ghanaian women living with HIV (WLHIV). In our research with Ghanaian women taking ART, finance-related themes associated with ART adherence emerged. This paper reports on these themes and examines the experience of HIV-positive peer counselor volunteers in Ghana's Models of Hope program.

Methods

Design and participants

Our research was conducted from January 2014 to March 2014 in Ghana's Greater Accra region. We interviewed 40 WLHIV receiving ART, and 15 stakeholders from five non-governmental organizations (NGOs), two healthcare facilities, and one government agency serving WLHIV. We conducted interviews with our WLHIV participants within the offices of an HIV advocacy organization and an office at a healthcare facility that cares for HIV-positive persons. We interviewed the stakeholders in their office or a private room at their affiliated organization. Additional details regarding methods have been published elsewhere (Poku, Owusu, Mullen, Markham, & McCurdy, 2017a, 2017b). The University of Ghana's Noguchi Memorial Institute for Medical Research's Institutional Review Board and the University of Texas Health Science Center at Houston's Committee for the Protection of Human Subjects approved our research.

Analysis

Using ATLAS.ti version 7 for transcript organization, we conducted our analysis by repeated review of the transcripts and notetaking. We employed thematic content analysis (Saldana, 2009) to code the interview transcripts and identify themes. For the stakeholders' interviews, we based our codes in part on an *a priori* deductive list and in part on inductive codes that emerged from the data. We triangulated the sources, WLHIV and stakeholder interviews, to examine points of convergence and difference.

Results

Our sample of WLHIV was similar to many other women in Ghana's urban areas (Ghana Statistical Service, 2014): they were petty traders (sellers of small commodities by the roadside or in markets), hairdressers, seamstresses, food and laundry services workers, or unemployed. The majority of the sample were married currently ($n = 16$) or previously ($n = 15$). Reported time from diagnosis was less than 5 years ($n = 11$), 6–10 years ($n = 12$) and more than 10 years ($n = 13$) prior to our study. Age was not reported by approximately half ($n = 21$). Reported ages ranged from 30 to 60 years. Thirteen of our WLHIV participants were Models of Hope. Our thematic content analysis identified sharp contrasts between the benefits of ART and a major hindrance of its acquisition: poverty. The themes we explore are: Financial struggles restrict personal care; widowhood, stigma, and destitution; poverty-related food deficiencies; and the case of the Models of Hope.

Financial struggles restrict personal care

The women knew and praised the benefits of adherence; yet, some struggled to take their ART regularly. At the time of our study, Ghana was beginning to provide free ARVs to patients; our participants mentioned continuing to pay the previously-established fee of five Ghana cedis (about US$2.18 during our study) for a one-month supply. Participants noted that in addition to their ART regimen, they shared the financial struggles of non-HIV-positive Ghanaians: trying to manage the increasing prices of commodities, school fees, and transportation.

One woman described the difficulty obtaining enough money for hospital visits in this manner:

> It's only that, when I came at first I was selling rubber bowls. But it was not selling. Sometimes when I need to go to the hospital then I don't have anything, so it was the capital I was taking money from. (GW02SA)

Another woman noted "I have strength. I can do any work. But, there is no money so, I was managing myself small small [*sic*]". (GW09RP). Poverty restricted access to healthcare and therefore ART; using limited funds for ART and HIV-related care threatened household sustainability. Thus, difficulties obtaining basic needs exasperated and were influenced by limitations in ART acquisition.

Widowhood, stigma, and destitution

For some, poverty occurred due to the HIV-related illness or death of a spouse, as described by a widow who was diagnosed four years prior to our study: " … he didn't know that he have [*sic*] HIV and died … left me nothing … I don't have anything. Only God". (GW17RP). Additionally, poverty was suddenly induced or worsened due to stigma. Several women mentioned being evicted from their homes due to a sickly appearance or suspicion of HIV infection:

> So the house that I used to stay also, when they also saw that I often get sick, they approached me and sacked me out of the house. At that time I was not renting the place, it was … my auntie's husband's house. (GW10SA)

> Because already, there was a rumor, in my area, that I have HIV. And due [to] that, my family started rejecting me … Although, I have not come out to tell them this is my problem. But because of the rumor, still, I'm not finding things easy. And due [to] that they throw me out of my house, so as of now … I don't even have a place that I am staying, [where] I could take you to my home to tell you "this is my house". I jump from one tree, to the other. (GW19RP)

Enacted stigma based on suspicion or knowledge of HIV infection also caused several women to lose their businesses: "As for my neighborhood, they are aware. So, first, I sold provisions but nobody came to buy them … Nobody came to my shop for more than one year. And the business collapsed". (GW27RP). The effects of stigma-related housing and financial loss persisted for years beyond the initial event. Looking solely at the financial aspect of these actions, the suspicion of HIV infection can render a WLHIV homeless and abandoned, pushing some into poverty and others deeper into the poverty that they were trying to overcome.

Poverty-related food deficiencies

Once ART commences, it is recommended that people living with HIV (PLHIV) eat a full, vitamin-rich diet. However, some WLHIV mentioned their inability to obtain the food necessary to follow these recommendations: "At times I am unable to eat from morning up 'til evening but I take my medication. I know that all of these things do harm me … " (GW10SA). Due to the lack of food, some skipped ART doses to avoid taking them on an empty stomach. As one woman noted:

> I do my best to [take ART as recommended]. I take my drugs. I eat well when I get … And if I don't get, I eat whatever I get. Yes, I know what I'm supposed to eat. But if I don't get … (her voice trails off). (GW25RP)

Healthcare providers and other stakeholders were very aware that poverty fostered inadequate nutrition and ART administration. One stakeholder explained a particular hospital's efforts to address this problem: "So we probe down to your nearness to the clinic, whether you have some source of food– where you can get food and manage to come". (S03). The influence of financial problems on ART response was particularly troubling to the stakeholders because they observed the negative effects but had limited ability to change the situation. Concerns about sub-optimal adherence related to poverty were echoed by a nurse:

> … if you are not eating well, and you are taking the medicine … you are not going to achieve the objective you want, like total wellbeing and stuff … the main challenge … is the poverty. People not being able to afford, you know, food and transportation. And because of that, they will default. (S04)

The case of the models of hope

Most Models of Hope whom we interviewed were frustrated and tired. While they enjoyed assisting others, they no longer received benefits for participation, including ART, after funding and policy changes post 2011. They worked long hours, even being called on the weekends, and were often burdened with bringing food, clothing, and other necessities to the homes of PLHIV whom they assisted in healthcare facilities. One participant described the work this way:

> Challenges, it's very plenty because … the family members used to bring [HIV-positive individuals], then they will leave them. *We* have to cater for them. Some people we have to cook food from our houses and bring it to them … You see? So we have to use our own money, to cook for them … Because we don't get anything from the hospital, and we don't get *anything* from Ghana AIDS service. We used to go work from Monday to Friday. You see. So five days a week. We are there. Sometimes when you are in the house, Saturday, they will call you for you to attend to your clients. And we are moving, we are taking car, [paying for transportation], up and down, without *anything*. So it's very challenging. (GW04RP)

These activities exceeded their volunteer role. The socioeconomic profile of the Models of Hope in our study was similar to that of our other participants. Thus, they were subject to the same financial struggles previously described, in addition to using their own resources to supplement the needs of others. While working, the Models of Hope lost time they needed to address their own financial needs. Some found it difficult to access their own clinical care and basic needs:

> You see sometime [*sic*] in the morning what to eat is a problem … That is why I don't want to tell people my situation. Because people rather come to me for help, so if I go to them that I want this and this- you see, so it is God that I'm rather praying to that I will get money. (GW04SA)

Another woman expressed her frustration: " … the Model work we are doing, is voluntary! And this voluntary [work], I have a child in school, and I'm not doing anything [else to make money]- how am I going to take care of my child?" (GW19RP). In the process of struggling to assist PLHIV to obtain basic needs and regular access to treatment, the group filling a critical gap in care and service provisions in turn has little to no support- hoping only in God, as several women said, as their source of vitality.

Discussion

Our research indicates that poverty hinders the benefits of ART in several ways. It is influenced by family and community mindsets, as shown through the stigma-driven actions described by our participants. Simultaneously, it negatively influences the conditions necessary for WLHIV to manage their well-being and benefit from ART, as indicated in cases of widowhood and financial struggles restricting healthcare access. Therefore, initiatives to reduce poverty in Ghana will not only help the general population, but may also reduce barriers to optimal HIV treatment, including irregular ART administration.

Stigma reduction interventions could help reduce evictions and the power of rumors that severely interfere with people's livelihoods. Likewise, initiatives promoting existing policies to prevent discriminatory actions against PLHIV, recognized as a necessity in Ghana's National HIV & AIDS Anti-stigma and Discrimination Strategy 2016–2018 (GAC, n.d.), need to be devised. Such actions can place HIV-positive individuals in a better position to obtain necessary healthcare and experience the benefits of consistent ART. Current plans to reduce stigma in Ghana highlight the participation of PLHIV in seven areas, from campaigns and public speaking to program development and implementation (GAC, n.d.). Though the contribution of PLHIV is imperative, the case of the Models of Hope indicates that overreliance on peer counselors can have adverse consequences.

As others have noted, food insecurity and inadequate nutrition greatly hinder the benefits of ART (Chop et al., 2017; Young et al., 2014). As stated by our stakeholder participants, adequate nutrition may support physical recovery and response to ART (Olsen et al., 2014; WHO, 2003); thus, it is recommended with treatment regimens. Against medical advice, our respondents described eating based on food availability rather than nutrition, skipping medication doses due to lack of food, or taking medication without food. Laar et al. (2015) report on strategies used by families to manage food supplies after a family member is diagnosed with HIV. Similar to our findings, families most often described skipping meals and reducing portion sizes, all of which can impact ART administration and therapy outcomes (Laar et al., 2015). Thus, food insecurity must be tackled before individuals can make recommended dietary choices and regularly take medications as prescribed.

Programs such as LEAP and WFP are beneficial, but limited in addressing food insecurity for many. Stakeholders noted food insecurity created problems for their patients, but were not in a position to respond to patients' food needs. Change must occur at the policy level for concrete transformation to occur. Offering free ARVs is a positive step. However, policymakers need to address factors beyond direct ART costs, including transportation and clinical follow-up. In situations of poverty, the initial steps necessary to access medication are often out-of-reach and the steps needed to adhere to treatment make taking medications regularly untenable.

With dwindling funds and reductions in Global Fund and The United States President's Emergency Plan for AIDS Relief (PEPFAR) activities, the substantial need for support services is only partially addressed by the current programs. The experiences described by our Models of Hope participants demonstrate that thoughtful consideration is imperative in constructing and maintaining programs to increase ART adherence and linkage to care. Due to financial difficulties, the Models of Hope themselves had difficulty accessing the very care that they were assisting others to obtain. Provisions need to be made for peer counselors who bear the burden of others while managing their own condition.

Dissatisfaction with government action to secure the needs of citizens living with HIV rang loudly in statements from both the WLHIV and the stakeholders. Although people knew funding losses were related to reduced contributions from international organizations,

they blamed these circumstances on weak government policies or poor spending and management practices. WLHIV and stakeholders want more concrete support from the government. Without multi-level efforts to address stigma and people's financial challenges, the goals outlined in Ghana's National HIV & AIDS Strategic Plan 2016–2020 (GAC, 2016) will remain elusive.

Our study has some limitations. Our research was conducted in a predominantly urban region; therefore, the experiences of those residing in rural areas may not be fully represented. As our project intended to focus on the experiences of women, additional research would be necessary to identify differences in the experiences of HIV-positive men. Because our research focused solely on a Ghanaian population, our findings may not be fully generalizable; however, our study contributes to research outside of our study population when considered in conjunction with findings from other social contexts.

Conclusion

Our research highlights how poverty limits the benefits of ART by hindering the regular administration of ART, consumption of high nutrient diets, and adherence to recommended clinical follow-up. Poverty and HIV infection had a synergistic relationship noted by our participants. HIV-related illness, such as the HIV-related death of a spouse, and enacted stigma, such as eviction or loss of business due to one's HIV status, instigated the persistence or worsening of poverty by drastically reducing one's income and ability to meet basic needs. Being impoverished made it more difficult to access and stay on ART. People's inability to consistently meet their food and ART needs may result in an increase in HIV-related morbidity in Ghana, leading to a failure to meet proposed health goals and improve population health.

We recommend anti-stigma interventions and policies that respond to discrimination experienced by PLHIV. We strongly endorse policy-based and programming changes that will provide poverty alleviation interventions. Improving the economic condition of a community is key to helping them improve their health and well-being.

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ORCID

Rebecca A. Poku http://orcid.org/0000-0002-7314-895X
Sheryl A. McCurdy http://orcid.org/0000-0003-0526-1608

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