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# Managing HIV-positive sero-status in Ghana's most HIV concentrated district: self-perceived explanations and theoretical discourse

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As of December 2015 there were 37 million persons living with HIV/AIDS (PLWHAs), 70% of whom are in sub-Saharan Africa. Ghana, which contributes a relatively small number to Africa's HIV burden, has a generalised HIV epidemic. The current national prevalence is 1.47%. Agormanya, one of the HIV sentinel sites in the county and where this study was conducted, has current prevalence of 11.6%. This makes it critical to explore how persons infected with HIV manage their lives, especially in the midst of entrenched stigma and discrimination. However, available information on how PLWHAs in sub-Saharan Africa handle their day-to-day lives mostly dwell on food and nutrition. Thus, there is dearth of information on how PLWHAs in Ghana particularly handle the circumstances of their daily lives which are mostly coloured by their HIV-positive statuses, given their stigmatised identity. We explore how PLWHAs respond to the experiences and challenges of living with HIV/AIDS in Lower Manya Krobo, consistently most HIV-infected district in Ghana. Data were collected from 38 combined purposive and randomly selected HIV-positive persons in two leading hospitals (St Martins Depores Agormanya and Atua Government hospitals which provide specialised HIV care in the district. Using in-depth interviews, we studied how PLWHAs managed their routine livelihoods in the midst of extreme stigma. We combined the social capital and resilience theoretical frameworks to show that our respondents were mostly resilient and strategically mostly drew upon extended family social support to cope with their livelihood challenges. We recommend that community opinion leaders and other stakeholders sensitise community members in Lower Manya Krobo to better understand the mode of HIV infection and encourage/strengthen family and community cohesion and social support.

**Keywords:** livelihood management, Lower Manya Krobo district, persons living with HIV/AIDS, resilience, social capital, social support, stigma and discrimination

## Introduction

The HIV/AIDS pandemic has left an infamous imprint on the world map with an estimated 37 million people worldwide infected as of the end of 2015 (UNAIDS, 2016a). Sub-Saharan Africa bears a disproportionate portion of the affliction from the pandemic, with roughly 70% of its inhabitants infected (UNAIDS, 2016b). For most persons living with HIV/AIDS (PLWHAs), the disease largely influences and defines their livelihood. This is particularly so for PLWHAs who live in sub-Saharan Africa, due to the entrenched poverty, and where several daily challenges such as difficulty accessing health care which makes most people vulnerable. Managing the livelihood of PLWHAs is thus of extreme importance. However, very little research exists on how PLWHAs manage their day-to-day lives and livelihoods in Ghana and in sub-Saharan Africa. The output of our search of the literature on managing the lives of PLWHAs in sub-Saharan Africa was dominated by information on managing their livelihoods mainly through food and nutrition and, to a lesser extent, medications.

This paper is part of a bigger research project. Given the compelling evidence on the critical connectivity between housing and health (Bond et al., 2012; Dunn, 2004; WHO,

2010), the project aimed principally at exploring the linkages between housing conditions, HIV and the reported health status of PLWHAs in the Lower Manya Krobo district (LMKD). Furthermore, the project purposed to fill the gap in the paucity of research and literature on the housing and health needs of PLWHAs and other vulnerable populations in sub-Saharan Africa (Tenkorang, Owusu, & Laar, 2017), and to also fill the related policy gap in Ghana. This paper is linked to the project by using additional information from the qualitative data to contribute to the literature in several critical areas where HIV is known to produce difficulties in the African setting particularly, and to further worsen the vulnerability of PLWHAs: 1) stigma, discrimination and abuse; 2) housing/accommodation; 3) (un)employment; and 4) poverty (Asiedu & Myers-Bowman, 2014; Fobil & Soyiri, 2006; Parker & Aggleton, 2003; Tenkorang et al., 2017; Wright & Mwinituo, 2010 ). Furthermore, the paper provides more in-depth information from the project data to fill the contextual gap the project's survey is mostly unable to fill (Babbie, 2013). Most importantly, the paper has the primary objective of providing information on the day-to-day management of PLWHAs in Ghana. This critical area lacks adequate local scientific literature. Thus, the paper is particularly cogent in the instance of our study area which

is Ghana's most endemic HIV/AIDS district. Previous researchers have literally opined that dealing with the implications of HIV/AIDS is a daily routine in the LMKD (see Langmagne, 2016; Lund & Agyei-Mensah, 2008).

This paper explores how the 38 PLWHAs we studied in a mostly rural district in Ghana, which has always had the highest rates of HIV infection nationally (NACP, 2003; NACP, 2013), live, respond to their daily challenges, and manage their livelihoods in the context of their HIV-positive infection. To highlight the background, the paper provides findings on the challenges they face, and concentrates on how they manage these to sustain their livelihoods. We use the two related theoretical frameworks of social capital and resilience for the study. Our paper contributes to the scant literature on how PLWHAs manage their routine livelihoods, particularly in the context of Ghana's most HIV endemic district. Moreover, we are unaware of a prior application of these two social science frameworks to the livelihood management of PLWHAs. Furthermore, we contribute to policy on PLWHAs in Ghana.

### **Background, history and context of HIV/AIDS in Lower Manya Krobo district**

The first case of confirmed HIV/AIDS in Ghana in 1986, was from LMKD. Since then, the district has consistently had the highest prevalence of HIV in the country. The 2014 estimated prevalence at Agormanya, one of the HIV tracking sites in Ghana, which is located in LMKD, was 11.6% (GAC, 2015), compared to a national 2016 prevalence of 1.37% (GAC, 2016). In 1999 the national prevalence was 3%, making Agormanya's prevalence rate of 13% at the time higher than four times the national HIV prevalence (Ghanaweb, 2013; NACP, 2003).

LMKD is a predominantly farming and fishing community located in the Eastern region of Ghana. Previous researchers have used the material and non-material deprivation of LMKD to explain the high prevalence of HIV in the catchment area (Collins & Rau, 2000; Fobil & Soyiri, 2006; Langmagne, 2016; Tenkorang et al., Laar, 2017). The relationship between the entrenched poverty in LMKD and HIV infection has been given further attention by some researchers. They mention that this relationship is bidirectional, rather than unidirectional (Collins & Rau, 2000; Langmagne, 2016).

### **Managing HIV/AIDS**

In Ghana, and internationally, particularly in Africa, previous researchers have indicated that PLWHAs manage their HIV infection by either disclosing their sero-status or hiding it (Asiedu & Myers-Bowman, 2014; Holzemer et al. 2007; Poku, Owusu, Mullenn, Markham, & McCurdy, 2016). If they disclose it, it is for several reasons but principally for getting support from the confidant (Asiedu & Myers-Bowman, 2014; Earnshaw et al., 2014; Poku et al., 2016). Asiedu and Myers-Bowman (2014) and Poku et al. (2016) indicate that in Ghana, healthcare workers require PLWHAs to disclose their status to at least one confidant who can support them to comply with their adherence to antiretroviral therapy (ART). In the context of this paper this refers to support for the whole HIV therapy given by the PLWHA's physician (antiretrovirals, other supportive care medications and treatment plan).

A recent nationwide study on HIV/AIDS stigma index in Ghana by the National Association of Persons with HIV/AIDS (NAP+), the Ghana AIDS Commission (GAC) and UNAIDS (2014) clarified PLWHAs in Ghana's disclosure strategies and demystified why PLWHAs focus on disclosing to healthcare providers. The study documented high levels of "strategic disclosure" of HIV-positive status by the PLWHAs to healthcare workers and "a few trusted persons" (p. xiv), which was said to be effective in getting collaboration from healthcare workers. The study found that the respondents were most likely to have disclosed their HIV-positive status to health professionals (76.8%), followed by other PLWHAs (74.9%), and then to counsellors and/or social workers (61.5%). It was explained that healthcare workers were the most important persons for PLWHAs in the study to disclose their HIV-positive status to because the former were most likely to refer them for testing, upon finding suspicious signs and symptoms of HIV, but also, PLWHAs perceived that they could have access to specialised medical care if they disclosed to healthcare providers. In addition, the study concluded that such disclosure to healthcare providers and other social workers lead to more positive support rather than discrimination.

Asiedu and Myers-Bowman (2014) also documented another reason for which PLWHAs manage their HIV status through disclosure: to get financial and emotional support, particularly the female PLWHAs. Another approach to managing HIV is the use of ART to help PLWHAs improve their health status and looks (Asiedu & Myers-Bowman, 2014; Holzemer et al., 2007). Alternatively, they keep their HIV sero-status secret as a way of avoiding stigma and discrimination (Asiedu & Myers-Bowman, 2014; NAP+ et al., 2014; Poku et al., 2016) or as a way of keeping their jobs (Asiedu & Myers-Bowman, 2014; Holzemer et al., 2007; NAP+ et al., 2014).

We encode one of three types of stigma described by Holzemer et al. (2007, p. 547) and conceptualise it as a way of managing stigma by PLWHAs. They state as follows, and cite Weiss et al. (1992) in part:

Internal stigma is thoughts and behaviours stemming from the person's own negative perceptions about themselves based on their HIV status. It is similar to the concept of the emic view of stigma, or the person's perceived or self-interpreted view of stigma. Sub-categories of internal stigma include perception of self, social withdrawal, self-exclusion and fear of disclosure.

This is because, as described later, our data lend support to these examples of "internal stigma" as approaches some PLWHAs use to navigate around their stigmatised statuses stemming from being HIV-positive.

Holzemer et al. (2007, p. 548) highlighted further on their concept of internal stigma ("emic view") which covers: 1) "thoughts and behaviours stemming from the person's own negative perceptions about him or herself based on their HIV status" which would lead to having a "self-negative evaluation" of themselves "based on HIV-positive status", and includes "fear and self-stigmatisation"; 2) "social withdrawal", including "self-withdrawal of PLWHAs... from sexual and or loving relationships to protect self from discrimination"; 3) "self exclusion", defined by these

authors as “the process by which the person decides not to use [the] services due to being HIV-positive and fear of discrimination”; and 4) fear of disclosure, which they explain as “all behaviours related to revealing HIV status”, and includes keeping one’s HIV status secret, and avoiding seeking health care for HIV due to unwillingness to disclose to healthcare workers or be identified with the disease within the healthcare settings. Based on the aforementioned, we conclude that PLWHAs manage HIV status essentially by managing the stigma related to being HIV-positive.

### Theoretical framework

We used the theoretical approach of Grounded Theory (Corbin & Strauss, 2008). Specifically, we used the social capital framework by Bourdieu (1986) and in relation to it, the resilience framework as well. These two are interrelated (Opoku-Mensah, 2016). According to Bourdieu (1986, p. 51), social capital denotes “the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalised relationships of mutual acquaintance and recognition...” He asserts further that the amount of social capital an individual commands “...depends on the size of the network of connections he can effectively mobilise and on the volume of the capital (economic, cultural or symbolic) possessed in his own right by each of those to whom he is connected.” The World Health Organization (WHO, 2007, p. 3) also defines social capital as “a range of interpersonal relationships or connections that have an impact on the individual’s functioning, and generally includes support provided by individuals and social institutions.”

Bourdieu (1986, p. 47) distinguished between three forms of capital: economic, cultural and social. He defined economic capital as forms of capital that can be “immediately and directly” converted into money and can also be institutionalised as property rights. He explained cultural capital as capital that can be converted, based on “certain conditions, into economic capital” and may be applicable to educational qualifications. Finally, by social capital, he implied social obligations (“connections”) which can be converted, under certain conditions, “into economic capital and may be institutionalised in the form of a title of nobility.” Social support is a by-product of social capital. It promotes a sense of comfort and enhances an individual’s ability to adapt to environmental stressors. Having and using social support is generally protective and moderates health and development (Opoku-Mensah, 2016; WHO, 2007).

The concept of resilience has also been used widely to apply to contexts whereby an individual or a group of people are exposed to stress. Obrist, Pfeiffer and Henley (2010) conceptualise social resilience as being multi-layered. They defined social resilience as the actors’ capacity to access capital so as to not only cope with and adjust to adverse conditions, but to also search for and create options that should lead to the development of increased competence in handling a threat. Like Bourdieu’s (1986) division of capital into three, Masten and Obradovic (2008, p. 10) also categorised resilience into three but limited these to the level of the individual: 1) when high-risk groups overcome the odds against their healthy development; 2) the ability

to sustain competence or maintain effective functioning under severely adverse conditions, which they referred to as “stress resistance”; and 3) regaining/attaining effectiveness or normalcy in functioning after “a period of exposure to traumatic experiences or conditions of overwhelming adversity...” which they described as “...recovery, bouncing back, normalizing, or self-righting”.

In our view, the two concepts of social capital and social resilience are intertwined in that the individual is the subject; he/she is at the core of it all, and his/her self-efforts are important. Yet, the issues go beyond him/her to involve others. It also involves the bigger environment in which there are additional actors and institutions. The expected end is that these exogenous factors should be supportive to the individual, and interactively, he/she should be able to nurture and also tap into them to ensure his/her normalising and effective continuing. Beyond being individually multi-layered (Obrist et al., 2010), we also conceptualise resilience and social capital as being interlinked and interdependent, with a view of resilience being more of an inner individual trait although influenced by the exterior characteristics, while social capital is more of an environmental and external trait although it starts with individuals.

In this context, both the individual and the environment become interdependent as well and the poor amalgamation of either of these becomes dysfunctional and affects the chances of the individual bouncing back/self-righting. Applied to HIV/AIDS, we do not imply the infection would vanish as an outcome. We imply that the individual would be able to use the resources at his/her disposal to circumvent the odds, seek health care, cure opportunistic infections, look “normal”, find a job if possible, and mostly live his/her other aspects of life without HIV/AIDS being a huge impediment to survival and livelihood adjustment.

### Methods

As stated above, this paper uses part of the data from a larger research project on the relationship between housing conditions and the health status of PLWHAs in LMKD. The LMKD is a mostly rural district in the Eastern region of Ghana. The sample size for this qualitative study was 38. Initially, the district, towns, hospitals used, and respondents were selected purposively, based on anecdotal information and extensive review of the literature and statistics on HIV/AIDS in Ghana. The district is the worst affected in the country by the HIV/AIDS pandemic (Langmagne, 2016; Lund & Agyei-Mensah, 2008). The two hospitals in the district provide specialised care for PLWHAs: the St Martin Porres hospital in Agormanya, and the Atua government hospital in Atua, a town close to Agormanya. Before the study started, we made recognisance visits to the hospitals and their authorities. Some of the methods reported here emanated from the discussions with the key staff of the HIV clinics used.

We obtained ethical clearance and permissions from several institutions. First, we went through both the Ethical Review Board of the Memorial University at St Johns, Newfoundland, Canada, where the co-principal investigator has employment affiliation, as well as the Ethical Committee for Humanities at the University of Ghana, Legon, where the remaining co-investigators work (ECH 017/14-15). We

obtained written clearance from the Ghana Health Service's Ethical Review Committee (GHS ERC) to comply with its requirement that studies involving its facilities or staff receive approval from their ERC (GHS-ERC: 02/11/14). We also sent written permissions to the Eastern Regional Directorate of the Ghana Health Service, as well as the District Health Management Directorate of the LMKD, and the administrators of both hospitals used. These last three institutions gave us verbal permissions although we had written to them formally to seek consent.

The primary data were collected in June and July 2015. The respondents had reported to these hospitals for care for HIV-related co-morbidities. We accessed respondents from the voluntary counselling and testing (VCT) centres of the hospitals with permission from the staff. The respondents attested to their HIV-positive status through verbal self-confirmation. HIV care is provided by both hospitals on weekdays only. We made a list of all the PLWHAs who reported on weekdays for each hospital. If more than 40 respondents reported in a day in a particular hospital, we randomly selected one-third, with a random start. If fewer than 40 PLWHAs reported at a hospital in a day, we selected half in a similar procedure. We made conscious attempts to include male respondents if an initial selection in a day had fewer than a quarter being males. We did this by randomly selecting every fourth male from the list of males who were not selected initially. This was important because in Ghana, as in most parts of sub-Saharan Africa, more females are infected by HIV than males (Asiedu & Myers-Bowman, 2014). In fact in 2015, of all PLWHAs in Ghana 57% were females and 43% were male (GAC, 2016). In addition, more than 70% of 618 new clients who were receiving HIV clinical care in LMKD from January to June 2010 were females (Antwi, 2010).

We used an in-depth interview guide to collect the data: 21 from Atua government hospital and 17 from St Martin de Porres hospital. Our initial target was to have 15 respondents from each hospital interviewed qualitatively. One person turned down an interview. This sampling for the qualitative study was concurrent with the sampling for the bigger project which also used a survey. Respondents for both data collection approaches were selected using an initial random start from the group of pre-selected respondents each time an interview ended. Our finalised qualitative sample was guided by 2 things: first, the literature indicates that for qualitative studies a sample size of 30 is adequate most of the time (Guest, Bunce, & Johnson, 2006; Mason, 2010). Second, and more importantly, we reached saturation after interviewing about 10 respondents from each hospital. Thematic saturation is the repetitive occurrence of themes in qualitative data (Baxter & Eyles, 1997; Sedziafa, Tenkorang, & Owusu, 2016). This was because our sample was fairly homogenous. Both Guest et al. (2006) and Mason (2010) attest to the importance of saturation as a key factor in determining a sample size for qualitative studies.

The quality of our data was further strengthened through a three-day interviewer training, pretesting, and field supervision by the principal researchers. We used both male and female interviewers. The purpose of the study was first explained to them verbally. The explanation included that they were not obliged to participate in it, and

if they did, they could opt out without any penalty. They were also verbally assured of confidentiality and informed that the outcome of the study would be used for academic and possible policy purposes to the appropriate institutions. The respondents gave verbal (if they could not read or write) or written consent in the presence of a witness they selected on their own. Alternatively, provision was made for them to use one of two retired nurses from the specialised HIV clinics whom we trained to help manage our study, if they did not self-select a witness. Most of the respondents already knew the retired nurses since they worked in the respective hospitals they were assigned to collect data. We also avoided using identifiable markers for the respondents (see Tenkorang et al., 2017). An interview lasted between 35 and 50 minutes. We gave the respondents no tangible rewards, except to have the two nurses involved in the study collect medications for them, to make up for their time during the interview. Based on the preference of the respondents, the interviews were conducted in Krobo, the indigenous language in LMKD, or in Twi, one of the main local languages spoken in Ghana. Few opted for English, Ghana's official language. The interviews were audio-recorded.

### **Analysis of data**

Data processing started with verbatim transcription, which was reviewed to ensure accuracy. The data analysis followed the norms of Grounded Theory (Corbin & Strauss, 2008). Through coding, we identified subthemes and themes from the key issues in the data. Two experts did an initial line by line independent open coding for each interview. To ensure accuracy, 40% of the interviews were selected randomly and recoded. Thematic content analysis facilitates exploring each narrative to determine how it contributes to an overall result from a sample (Lieblich, Tuval-Mashiach, & Zilber, 1998). After this, each coder independently generated sub-themes and themes relevant for the study. The final details used for the write-up were reached through an intercoder agreement which involved a series of conversations on the meanings and interpretations of the themes and subthemes, guided by one of the research assistants who was a Krobo indigene and spoke all the three languages used in interviewing.

### **Results**

With the exception of one respondent who could not specify her age, their average age was 47.64 years (range = 25 years to 68 years). Most were females (32). They were mostly of low socio-economic status, especially the females. Most respondents were basic school dropouts, and a few had no formal education. Two males had tertiary level education; one was lower than bachelors ("diploma"). All respondents professed the Christian faith, and heterosexuality. Thirty-one had younger dependants, who were mostly their biological children, but also grandchildren and other extended family members. Fifteen were unemployed, and the rest were mostly petty traders. They were mostly unmarried, particularly the females, who were mostly separated, divorced or never married. Six were currently married, and four were co-habiting. Most (27) belonged to the indigenous Ga-Dangme ethnic group.

Our findings indicated that the respondents managed their livelihoods in several ways, primarily in response to their HIV/AIDS status, and also within the extended family context. For purposes of volume of information, we focused on four out of seven main things we found them actively managing as part of their daily livelihood: 1) stigma, discrimination and abuse; 2) housing/accommodation; 3) (un)employment; and 4) poverty. The focus on these was also limited to what we think are their daily essential engagements, that is, seemingly the most prominent/dominant issues they dealt with, based on the data.

### ***Managing stigma, abuse, discrimination, and “flight from” an HIV-positive status***

Most of the respondents reported being stigmatised and discriminated against. Almost all of these were women. Stigma and discrimination took several forms including insults, physical abuse, insinuations, gossiping, nagging, and name-calling. Some had been evicted from their homes, or a room they shared with other family members. They had also been restricted from parts of the home or items in the home. In addition, contrary to what pertains in most Ghanaian homes, family meals were not shared with some of them, or they were isolated from eating from the same bowl with other family members. The rest included refusing to interact with, deny knowing, refusing to employ or buy from, refusing to rent a room to them, and restrictions from having sex. Extended family members, usually, parents and siblings, followed by their older children were more likely to be the perpetrators of these abusive acts.

The respondents dealt with these acts of abuse, stigma and discrimination in several ways. First, most, usually the females, hide their HIV status from most of their relations, particularly extended family members and their children. Yet, almost all respondents had revealed their HIV-positive status to one or two people. These were usually a female adult sibling, and for the males, usually, a wife. These confidants were usually the persons who were primarily providing the needed social support for the respondents, and usually were also keeping the issue a secret:

*People in the house that I am staying relate to me normal because they don't know I am HIV-positive. My daughter relates to me very well. She supports me financially and emotionally. She has been of great assistance to me. My son also brings me foodstuffs occasionally.... (R1).*

*Actually they are five [his children] and only my wife knows but the children don't know. Even the nurse doesn't know. [Why?] I don't want them to know my status but we are careful they don't use anything of mine (R18).*

Often, other family members, co-tenants and persons in their compound homes or even persons they shared room with did not know of their HIV-positive status. They typically did not reveal their HIV status to their children either, especially, the young ones, whom they thought would mostly not understand, or leak the information to others which would lead to further stigmatisation, or would be disturbed by that information. A few planned to inform the children when they were older.

Consequently, seven of the respondents said they hide their antiretroviral (ARV) medications or take it on the blind side of others they lived with by, for example, going outside the room to take it, slipping it into their mouths when nobody is watching, or waiting to take it when other occupants of the room are away. Some also lied about the type of medicine they were taking, especially if they lived with children, or when on a few occasions others accidentally saw respondents take the medication. One respondent said she takes the ARVs with her wherever she goes. Another said the last thing he does before leaving home is to ensure that he has hidden the ARVs, otherwise he is disturbed the whole day if he forgets to do that before leaving home.

One other critical way in which they minimise and manage the stigma is that some (six) of the respondents bypass a competent hospital close to where they live and seek healthcare from more distant places. These respondents mostly lived in Accra-Tema (the capital city and its twin-city which are in another administrative region) and travel by car for at least 2 hours or more to Atua or St Martin De Porres hospitals. Others would say they were going somewhere else when they were going to hospital for HIV care, and if people found out they were going to hospital, the respondents would say they were going for treatment for ailments other than HIV. A few of the respondents also moved away from their hometown to hide their HIV status. More respondents moved from elsewhere to their hometowns for a similar reason, in addition to others.

*Yes, yes, there are hospitals around my place. I live at Spintex; there is LEKMA Hospital, there is Tema General Hospital, but you know the implications when people get to know. I am a professional teacher and I work at [name of a second work place], I am well known over there. But the Krobos they don't know me so when I come here scarcely, I don't know anybody here so it's secluded. Actually, it's far from my place so when I come here nobody knows me (R18).*

The respondents took being stigmatised in good faith and did not fight back. For example, one respondent, who had been asked by her extended family members to stay away from the single room she shared with more than 10 of them, said she had agreed to live and sleep on a veranda outside the home but had to keep her belongings and ARV in the room, and “know[s] how to go about that.” She rationalised that she gets fresher air sleeping outside on the veranda than in the room under such conditions. Yet another who was living under similar conditions said she took it in good faith. Another who said her brother slapped her in the face several times and threw away her belongings and those of her daughter and grandchildren from the room they shared with him said she had no choice but to eventually rent a place for herself with the help of her daughter. The respondents also reported ignoring the gossips, name calling, nagging and insults.

Furthermore, most of the respondents self-stigmatised. They usually kept to themselves, staying away from other occupants of their homes, and also limiting their mingling with the public to keep their HIV-positive status secret and/or avoid stigma, discrimination and abuse. This was particularly so for those who were renting homes.

### **Managing accommodation/housing**

Moreover, most respondents (about three-fifths) changed their housing, that is, moved from the original house they lived in before they were diagnosed with HIV to another residence. They often did this immediately after the diagnosis. They gave two main reasons for this — to conceal their HIV-positive status to avoid the stigma, discrimination and related abuse, and to find rent-free accommodation mostly in homes belonging to extended family due to inability to afford their own housing. Often, a romantic partner had died from AIDS and they sought to move to another place to avoid the related stigma. Some respondents rented homes instead, although they could barely afford it. A few quickly found their own accommodation away from renting or extended family resources. One such respondent said he quickly put up a building as soon as he was diagnosed with HIV, which he has yet to complete, so he would be away from others. Such respondents often ended up with more insecure accommodation. For most of such cases, their previous housing was better in terms of location, construction material and spatial dimensions. For example, one respondent had put together an enclosed but infirm wooden structure for herself and her two young children. Yet, another had moved into a kiosk on a piece of land that was liable to flooding, etc. Some of the respondents moved back to their hometowns and few moved away from their hometowns primarily to the capital city, Accra, and surrounding areas. To a large extent, financial ability to move and be on their own was an important underlying factor.

They usually also dealt with overcrowding in their extended family homes particularly, and with lack of essential amenities, in diverse ways. For example, one respondent said he decided to use a public toilet instead of one in the home that usually overflows (a pan/bucket latrine) and stinks. Two females said they were coping with extended family homes with parts of the buildings broken off and causing threats to their lives; the rain comes into such rooms and all other extended family members have moved from these two homes. Some managed by collecting water from the rooms that flood when it rains because the roofs were old and leaking. One said she and her children routinely collect water and trash that come into their room because the external periphery of their house is liable to flooding. All other tenants had moved out of the house due to this problem. Another said she moves from an uncemented floor on which she sleeps into a chair when it rains at night and rain water seeps into her room.

*I was afraid I was going to die after I was informed, so I quickly started building. I started in 2004 and completed it in 2008 [but some essential amenities had still not been provided]. I built it at Atua... (R36). When it rains it carries the rubbish along and the whole place is in a mess. Today I suffered before removing all those rubbish from the house. Yes I don't have the money to rent a better place so if we push the water away with the help of the broom then we sleep. That is why I am living on the water way. That's the only reason. There are other rooms in the house but because of the water the other tenants have left the place (R26).*

### **Managing (un)employment**

Fifteen of the respondents were unemployed, including one who took early retirement. The rest were mostly underemployed as petty traders. One of the unemployed said he did not have the strength to work due to his HIV-positive status, and another said prospective employers told her she was too sick to work, as her looks make people suspicious of her HIV-positive infection. For most respondents, fear of being stigmatised due to their HIV-positive status when people in the community knew, or suspicion of being HIV-positive kept them from seeking and holding jobs. Some also just discontinued their job or apprenticeship when they were diagnosed with the disease and had not resumed for reasons similar to those already reported. Few respondents, mostly males, responded in the exact opposite way: they worked harder so they could afford their needs which some said had increased due to their HIV status. For example, additional money was needed for transportation to the hospitals, eating healthier foods, to help improve their health status, and take care of their dependents.

*I was selling [uncooked plantain/foodstuff] and the person told me 'Is it you who have HIV who is coming to sell for us to buy so we can also contract HIV?' So am I selling so as to share the virus? (R3).*

*I couldn't enrol the children in school so they are not able to take care of me. Sometimes I force myself to sell some things in order to feed myself and buy water...My feet hurt even whiles sitting now (R34).*

### **Managing poverty**

Most of the respondents, especially the females, complained of extreme poverty, and hunger. As already explained, it is either because they were not working, had additional needs, were turned away by prospective employers, or their HIV status usually meant additional financial requirements. Also, most respondents still had dependents who were both children and young adults, both biological and non-biological. They mostly managed these with the help of extended family members and their adult children.

Adult children were most helpful when they knew of and accepted their parent's HIV-positive status. This help usually took the form of providing money, and cooked or uncooked food. As already stated, most respondents managed the otherwise potential destitution by moving into extended family homes to cope with whatever situations they were faced with because they could not afford to rent places for themselves. Others mentioned sometimes taking ARV without food or waiting to take it later than recommended, when they get food. Others also said they simply cope without food sometimes. One mentioned asking the healthcare providers at the hospital for money for transport and food, and walking a long distance from another town to go to the special HIV hospital. Another mentioned seeking help from colleagues in the market without revealing her HIV-positive status, and one mentioned moving to a non-relative's home where she is not paying rent. One said she was receiving a small amount of money from the government, and another said her church was assisting her. A few, however, said they skipped hospital appointments and taking medicine on a few occasions due to poverty.

*I live in a family house. At first, I rented a room but due to financial difficulties I returned to the family house (R31).*

*I normally don't take my medicine because I don't get food to eat, so on days I want to take the medicine, I will feel like vomiting, I then drink water and wait for a while before taking my medicines... It's far [her house] and even now the fare has been increased — in and out is 2 cedis [the equivalent of 50 US cents] and others charge 2.40 cedis. Initially when they were charging 0.80 pesewas, for in, I sometimes walk from Kpong to this place but when I come I tax [sic] the doctors and nurses for my transportation back and also money for food. The doctor in room 4 — I don't even know whether he came to work today. Because of food/what to eat... If not for the fact that I am talking with you I would have gone to tax [sic] the doctor for money (R23).*

## Discussion

The main problem/issue respondents faced was fear of stigma and would do everything to prevent it. As such, it was clear from our findings that the respondents were typically managing their livelihoods in response to managing the real or perceived stigma, discrimination and abuse they faced as PLWHAs (Holzemer et al., 2007). Our findings corroborate those of several others in Ghana and elsewhere. They confirm the generally low disclosure of HIV-positive status by PLWHAs in Ghana, and also, explain the “strategic” low levels of disclosure of HIV status to family members found earlier by NAP+ et al. (2014). Asiedu and Myers-Bowman (2014) and Poku et al. (2016) found that the PLWHAs they studied in Ghana hardly disclosed their HIV-positive status and had concerns about the stigma which would follow such disclosures. Data from a national study on the economic impact of HIV on households also indicate that when disclosure occurs, only a few confidants are chosen (Asante, Poku, & Owusu, 2011). Both Asiedu and Myers-Bowman (2014) and Poku et al. (2016) explain why nearly all our respondents had told one or two people: although not documented, PLWHAs they studied in Ghana are required to inform at least one person who would be surety for them to be given ARVs; the surety would ensure that PLWHAs take their ARVs. All these authors also mentioned that the PLWHAs they studied disclosed very cautiously and mostly for purposes of seeking compassion and support. As already illustrated, the study by NAP+ et al. (2014) affirmed this. The negative effect of disclosure on employment was also found by previous researchers (Dunn, 2004; Holzemer et al., 2007; NAP+ et al., 2014; Owusu, Tenkorang, & Laar, 2016). We also confirmed that PLWHAs in Ghana face high levels of stigma, discrimination and abuse (Asiedu & Myers-Bowman, 2014; GAC, 2015; NAP+ et al. 2014; Owusu et al., 2016), which is also the case internationally (Holzemer et al., 2007; Kalichman & Simbayi, 2003; Lieber, Li, Wu, Rotheram-Borus, & Guan, 2006). Also, our findings support those of others (Collins & Rau, 2000; Langmagne, 2016) that HIV has a dual and bidirectional relationship with poverty in LMKD: it contributes to poverty for the affected. Furthermore, we confirmed several ways in which previous authors found

PLWHAs managed their HIV-positive status. These include internal stigmatisation, social withdrawal, self-exclusion, and fear of disclosure (Earnshaw et al., 2014; Holzemer et al., 2007; NAP+ et al. 2014). In fact, NAP+ et al. (2014) elucidated the self-inflicted stigma among the PLWHAs they studied; it primarily emanates from their great fear of being targets of gossips particularly, but also harassment or verbal abuse/assault from the public.

In relation to the conceptual frameworks we drew upon in this study, we found that mostly, the PLWHAs we studied largely made use of their economic, cultural and social capital, and mostly garnered social support to help them move beyond their personal capabilities. For example, most respondents had moved into their extended family homes. Most of those made reference to those homes at their fathers' houses. The Krobos are patrilineal and inherit through male descent. Thus, they made use of their cultural capital. Also, they primarily depended on extended family members for their survival, although most of these had negative twists. Generally, all respondents made self-efforts at managing their situation and were resilient in diverse ways such as managing the stigma and poor housing they faced, realising that they had to rise above these to survive.

More importantly, our results demonstrate the interdependence of resilience and social capital (Opoku-Mensah, 2016) in facilitating the livelihood and survival of our PLWHA respondents in LMKD. Our findings also demonstrate the multiple-layered attributes of both resilience and social capital (Masten & Obradovic, 2008; Obrist et al., 2010); economic, cultural and social capital. With regard to resilience, our PLWHAs who are highly vulnerable, were found to be mostly stress resistant, and attained quite effective functioning after their exposure to extremely traumatic circumstances. Nevertheless, given their difficult socio-economic context, we cannot talk about the respondents having “recovered”, “bounced back”, “normalised”, or “self-righted” which are additional attributes of the third layer of resilience as discussed by Masten and Obradovic (2008). Arguably, they have some self-motivation at least, since they had all made efforts to come to the hospital for HIV-related care. Others may not.

Our study had some limitations. Among these, our respondents were a hospital-based sample. In relation, the findings do not have external validity as the sample is not representative. Finally, the data were self-reported, and retrospective, making room for possible recall and other biases.

## Conclusions

Our data indicated that the respondents managed their HIV sero-status and general livelihood in several ways. Basically, managing their livelihoods is determined by or is a reflection of the context of their circumstances. Primary among these were poverty, stigma, discrimination and abuse, and poor housing. They made use of extended family resources. Our respondents were essentially managing their livelihoods in response to perceived or real HIV-related stigma and discrimination. Thus, for example, although most of the respondents felt housing-insecure; it was both directly and sometimes, indirectly from their

HIV-positive status because most found it expedient to make alternative housing arrangements right after their diagnosis with HIV. They seemed mostly resilient and were found to be consciously contextualising and managing their high risk and odds in several other ways by managing their poverty, employment, and abuse, stigma and discrimination to ensure their survival. To a large extent, the respondents depended upon and used their social capital, and showed a good level of stress resistance although they may never bounce back due to their mostly harsh socio-economic circumstances as individuals and also as persons within a rather vulnerable community. Our paper has also confirmed the interrelationship between the social capital and resilience theoretical frameworks and furthermore, the multi-layered nature of each of these.

We recommend that the Department of Social Welfare in league with community opinion leaders in LMKD organise community events such as *durbars* (general meetings) and smaller group sessions to help residents better understand the modes of infection of HIV, to help reduce the infection rate and address stigma, abuse and discrimination against PLWHAs, and to encourage family and community cohesion and social support in the light of the more than generalised HIV infection rates in their communities. The more cultural/traditional nuances of such approaches are likely to be more appealing and have greater impact, as Lund and Agyei-Mensah (2008) found in our study communities (LMKD).

Our extensive search of the literature for such community interventions have revealed two such interesting and related community interventions which has been successful in helping community members learn about HIV/AIDS, reduce related stigma and make community and family members more supportive of PLWHAs. Lund and Agyei-Mensah (2008) report the efforts by some queens and other opinion leaders in the study district who used community and cultural-based interventions through adoption and formal education of some vulnerable children orphaned by AIDS in the LMKD, amid limited success. Aggleton, Wood, Malcolm and Parker (2005) cite the example of the Sangha Metta (“Compassionate Brethren”) project<sup>1</sup>, in Thailand which seems to have been more successful. The project mobilised and used Buddhist religious leaders to aim at prevention of HIV, foster respect, solidarity, care, support, and compassion for PLWHAs, using community seminars and other strategies. These project objectives were achieved. Reported outcomes include a greater involvement of PLWHAs in community and social group activities, and their acceptance by such group members, as well as acceptance of previously dismissed HIV-positive children back to schools. Also, families received their HIV-positive members whom they had dismissed back and supported them. In addition, a child whom grandparents had withdrawn from an HIV-positive mother was returned to the care and nurture of the mother.

In terms of how our theoretical frameworks helped to embellish the issues of stigma and discrimination, or peoples’ perceptions of these, we conclude that the PLWHAs we studied make tactical use of their social capital to best protect themselves. They also augment their resilience by minimising their risk of abuse through

intentional and calculated very low levels of selective self-disclosure of their HIV/AIDS status. Furthermore, they prudently direct such disclosures towards enhancing their general chances of survival and continuous wellbeing. Their general resilience is demonstrated by how they weather the storm in their livelihoods, as outlined in this paper, including finding shrewd ways to hide and take their ARVs, seek health care, and handle their accommodation.

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## Note

- <sup>1</sup> Approach: Mobilising religious leaders to foster respect and compassion for people living with HIV and AIDS, and participate in prevention activities. Retrieved from: <http://www.buddhanet.net/sangha-metta/project.htm>

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