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A qualitative analysis of factors influencing antiretroviral adherence among persons living with HIV in Ghana

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Abstract

Adherence to antiretroviral therapy (ART) remains an important factor in HIV prevention and treatment efforts. We explored the individual and environmental factors influencing antiretroviral adherence among PLWH in Ghana. This study used 20 semi-structured in-depth interviews and three focus group discussions (FGD) involving 29 PLWH attending one of three antiretroviral clinics. Thematic analysis covered experiences of PLWH clinic visits, knowledge, attitudes, self-efficacy related to ART adherence, psychological wellbeing and stigma. The findings suggest that both individual and environmental factors including treatment outcome, coping skills, disclosure, self-regulation, healthcare-provider interaction, family and partner support, organization of ART clinics, stigma, and transportation cost influenced treatment adherence. Interventions that empower PLWH and reduce HIV-related stigma in the community will most likely support antiretroviral adherence. Please refer to the Supplementary Material section to find this article's Community and Social Impact Statement.

KEYWORDS

adherence, antiretroviral, determinants, Ghana, HIV, stigma

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1 | INTRODUCTION

The availability of antiretroviral therapy (ART) for persons living with HIV (PLWH) has changed the dynamics of living with HIV (human immunodeficiency virus) and its treatment. The “Treat All Policy” further enhances current HIV prevention, treatment, and care. This policy requires that, unlike previously where CD4 (white blood cells that fights infection and an indicator of immune function) was used as an indicator for starting antiretroviral treatment, immediately a person is tested HIV positive, this person should receive ART irrespective of the CD4 count (UNAIDS, 2019). In Ghana, an estimated 342,307 people were living with HIV in 2019 out of a population of about 31,072,940 with an HIV prevalence of 1.7 and 46% were on ART (Ghana AIDS Commission, 2020). The National Strategic Framework (2016–2021) seeks to ensure that by the year 2020; 90% of all PLWH know their HIV status; 90% of all people diagnosed with HIV infection receive sustained ART; and 90% of all receiving ART will have viral suppression. Ghana is currently using triple therapy for HIV treatment. The recommended triple-therapy regimens are two nucleoside/tide reverse transcriptase inhibitors (NRTIs) and one non-nucleoside reverse transcriptase inhibitor or 2 NRTIs and 1 boosted Protease Inhibitor (Ghana AIDS Commission, 2020).

Adherence to ART reduces disease progression and drug resistance (Lucas, Chaisson, & Moore, 1999), increases life expectancy, reduces HIV transmissibility, as well as well-being among PLWH (Teeraananchai, Kerr, Amin, Ruxrungtham, & Law, 2017). Adherence is the “extent to which patients take medications as prescribed by their health care providers” (Osterberg & Blaschke, 2005). The primary elements of adherence are starting a recommended regimen, completing the prescribed regimen, and staying on the medication for the length of time allotted before discontinuation.

A meta-analysis of ART adherence studies conducted in sub-Saharan Africa estimated an adherence rate of 77%, which is below the optimal adherence of 95–100% (Mills et al., 2006). Studies in Tanzania and Eastern Ethiopia estimated adherence of 63.7 and 85.6%, respectively (Achappa et al., 2013; Jima & Tatiparthi, 2018), while some studies in Ghana reported an ART adherence of 60 to 80% (Obirikorang, Selleh, Abledu, & Fofie, 2013; Ohene & Forson, 2009). A comparative analysis of adherence in some African and Asian countries reported adherence of 92.7 to 95.2%, respectively (Bijker et al., 2017). Sub-optimal adherence (i.e., adherence below 95%) is associated with a change from the standard treatment to more expensive treatment options and an increased likelihood of treatment failures (Ickovics et al., 2002).

To intervene on sub-optimal adherence, it is necessary to understand what factors influence correct and consistent adherence to ART among PLWH. The socio-ecological model recognizes that the factors influencing health behaviour span through individual, interpersonal, community, and societal levels (Williams, Renju, Ghilardi, & Wringe, 2017).

Individual factors including socio-demographic (Croome, Ahluwalia, Hughes, & Abas, 2017) as well as psychosocial factors are shown to influence ART adherence (Shubber et al., 2016). Religion is a facilitator when the belief in a deity serves as a coping strategy for medication uptake; nevertheless, it becomes a barrier when the belief informs PLWH decision to reject medication, for example, PLWH who turn to believe in deity's power to cure infection may refuse to take ART (Kretchy, Owusu-Daaku, & Danquah, 2013). Self-efficacy influences the adherence behaviour of PLWH in that when a patient has low self-efficacy, (s) he may doubt her/his confidence to adhere to medication towards viral suppression. Those with low self-efficacy are also more likely to hide their HIV status (Dima, Schweitzer, Diaconit, Remor, & Wanless, 2013).

In addition, PLWH who is not satisfied with his/her treatment are likely to make individual decisions not to adhere to medication without consulting their health care provider. The fear of stigmatization, mistreatment at work, and social circles reinforces concealment of HIV status and affects medication adherence. This is because PLWH will have to ensure secrecy when taking medication, which is not always possible (Azia, Mukumbang, & Van Wyk, 2016). When PLWH are under the constant fear of being identified as HIV patients, they are likely to be depressed and anxious (Shubber et al., 2016). Psychological distress can have a toll on their quality of life and medication adherence (Bijker et al., 2017). Additionally, when PLWH has insufficient access to safe and nutritionally adequate food, which is essential for the body to respond to ART, medication intake, and adherence may be compromised. Health-behavioural theories (Ajzen, 1991; Bandura, 1977; Rosenstock, 1977) support these individual factors in explaining treatment non-adherence. *Interpersonal factors* were also reported as barriers to ART adherence (Heestermans, Browne, Aitken, Vervoort, & Klipstein-Grobusch, 2016). Often PLWH decides not to disclose their HIV status to their partners or family members for fear of their negative reactions such as verbal abuse and abandonment. The decision not to disclose their HIV status undermines the support they could get from their family members or

partners (Adeniyi et al., 2018). Social support, which refers to the psychological and tangible resources PLWH receives from their social network (Cohen & Wills, 1985), is relevant to the overall well-being of PLWH. This support reduces depression (Tsai et al., 2012), improves medication adherence, coping, and quality of life of PLWH (Katz et al., 2013).

Globally, *community factors* related to ART adherence are mostly ART facility-related factors (Shubber et al., 2016). The healthcare provider may be the only one who knows the HIV status of PLWH. As such, the relationship between the healthcare provider and the patient is crucial to the patient antiretroviral adherence. A patient who enjoys a good relationship with health care providers has better adherence and vice versa (Mwamba et al., 2018). PLWH who keep their clinic appointments are likely to adhere to medication. In resource-constrained settings, this comes at a cost to the patient: cost of transport, cost of foregoing daily income-generating activities, and some unexpected cost at the clinic. When PLWH is not in the position to manage these costs, they will miss their appointments for a refill.

Within all the levels of the ecological model, HIV-related stigma plays a role, thus affecting medication adherence (Dovidio, Major, & Crocker, 2000). PLWH, especially those in developing countries, often live in communities where negative norms related to being PLWH exist. These norms could be internalized by PLWH. Community members' perceptions of how they were infected will inform their decision to be either empathetic or aggressive towards PLWH. These stigmatizing responses in turn influence adherence (Bos, Pryor, Reeder, & Stutterheim, 2013).

Societal factors that influence adherence are evident in laws and policies in many countries (Ferguson et al., 2018; Health Policy Plus, 2017). Even though these factors are beyond the scope of this paper, it is worth mentioning that the Ghana AIDS Commission Act 938 has anti-discriminatory laws for persons living with and affected by HIV (Health Policy Plus, 2017); however, there are punitive laws for key populations which may serve as a barrier to ART adherence (Laar & Debruin, 2017). Anecdotal evidence suggests that these restrictive laws are barriers to accessing HIV care and treatment.

PLWH antiretroviral adherence is influenced by factors that may overlap but can also vary across different regions of the world (Croome et al., 2017; Mills et al., 2006). Although the literature review shows several scientific publications on this topic, there is limited research on the context-specific factors influencing ART adherence among PLWH in Ghana. The available publications on treatment adherence among PLWH in Ghana so far focus on adolescents (Ankrah et al., 2016; Nichols et al., 2019) and used a quantitative approach (Obirikorang et al., 2013; Ohene & Forson, 2009) with emphasis on individual-level factors. To fill this gap, our study sought to explore the individual and environmental factors influencing ART adherence of PLWH in the Bono East Region located in the middle belt of Ghana using qualitative interviews and focus group discussions (FGD). A clear understanding of the perspectives of PLWH on factors influencing medication adherence in Ghana will contribute to the literature and the development of targeted evidence-informed interventions for optimal treatment and health outcomes.

2 | MATERIALS AND METHODS

2.1 | Study design

A qualitative semi-structured interview protocol was used to guide both in-depth individual interviews (IDI) and Focus Group Discussions (FGD) to explore the factors influencing antiretroviral treatment adherence of PLWH. The use of a semi-structured interview guide allowed us to adapt to the course of the conversation, respond to social cues and permit the participants to express their opinions while maintaining consistency across the different interviews.

2.2 | Study setting and site selection

The Bono East Region is one of 16 administrative regions in Ghana. The region has 11 districts and over 40 health facilities that provide health services to its inhabitants. HIV prevalence in this region is 1.43% (Quaicoe Rebecca &

Maafo, 2018). Interviews were conducted in Kintampo South District, Kintampo North, and Techiman South Municipality.

We purposively selected three ART clinics that attend to a PLWH- registered population of 4,237. Their strategic locations within the region, the set-up similarities for ART clinics in Ghana, the size of the clinic, and its organization (stand-alone vs. integrated) informed the selection of these facilities. The ART clinics are located within the Kintampo North Municipal hospital, Kintampo South District hospital, and Holy Family Hospital, Techiman.

2.3 | Participants

In total, 49 PLWH participated in the study, 20 in IDIs and 29 in FGDs. The mean age of participants was 38.3 years ($SD = 10.3$, range 23–58). The participants were mostly females (81.6%). Most participants (59.1%) had some form of education. Near 45% of PLWH were married and 55% were unmarried. Most of the participants were Christians (90%); the remaining 10% either were Muslims or had no religion. Of the participants 39% were farmers, 37% were traders (yam sellers, cosmetic sellers), and 22% were unemployed. The participants in this study had been living with HIV for 2 to 12 years.

2.4 | Study procedures

We asked adult PLWH who were queuing at the ART clinic to participate in a 30–60 min interview. If they were willing, we confirmed the eligibility criteria (age 18+) and gave information about the study. The average number of PLWH visiting these ART clinics in a week for either refills or general consultation was 20. We explained individually to participants that the study was exploring PLWH perspectives and experiences with antiretroviral uptake and hospital visits. We assured potential participants of confidentiality, the voluntariness of participation, and the right to withdraw from the study at any point in the study.

Those who agreed consented right after their consultation and refill. Before starting the IDI/FGD, written informed consent was obtained from each participant in advance of the IDIs and FGDs after the aim, objectives, and procedures of the study were once more explained. A signature or thumbprint from each participant was printed on each written informed consent with a copy on file and another copy provided to the participant who was willing to keep a copy. In total, 23 PLWH were approached for the IDI of which 20 agreed to participate (75% female). Two PLWH refused to participate in the IDI due to other engagements. We achieved saturation by the 18th interview; two additional interviews were conducted after which we ended recruitment. After finishing all 20 IDIs, models of hope (HIV+ peer models) invited PLWH to participate in FGD according to the same procedure as described above. Models of Hope are trained PLWH who provide adherence counselling and track defaulters. They are mostly people with lived experiences. Models have gone through the process of starting ART and understand the challenges newly diagnosed clients face with issues related to stigma and discrimination. They are more effective in reintegrating defaulters. Three participants from the Kintampo site were recruited via phone: because their medication was mostly home-delivered by the models of hope. All twenty-nine approached agreed to participate in one of the three FGDs.

All IDI's were conducted within the hospital premises in an unused room that ensured the privacy of the participants. The FGDs were conducted at an unused children's clinic, a vacant reproductive health room, and a vacant adherence counselling room. Some nuances that emerged from IDI were further explored in the FGD. The three FGDs had six (one male, five females), six (one male, five females), and seventeen (three males, fourteen females) PLWH, respectively. Although we recognize 17 to be a large group, we could not divide the group due to practical issues. Nonetheless, we organized the discussion such that each participant was able to talk during the discussion.

The lead author, together with a social scientist from the Kintampo Health Research Centre, moderated the interviews and discussions. We conducted all interviews in Twi (the local language spoken by all of the

participants). All the participants received a bar of key soap as a thank you package for their time and voluntary willingness to participate in the study. Focus Group discussants in addition to the key soap received a soft drink and a pastry after the interviews.

2.5 | Study materials

The interview protocol was semi-structured and guided by literature review and theoretical concepts explaining factors influencing ART adherence including experiences with ART adherence and clinic visits. The protocol was discussed with relevant stakeholders in the field of HIV prevention, care, and treatment. The interview protocol was structured according to themes including experiences with treatment and adherence and experiences at the ART centers. Each theme included follow-up questions for further exploration of factors such as knowledge, attitudes, self-efficacy related to ART, psychological well-being, and stigma.

2.6 | Data management and analysis

All digital audio recordings were transcribed verbatim and translated from the local language into English. Twenty-five percent of the transcripts were double-checked by the lead author to confirm the translation. We checked for the validity of the data by triangulation using IDI, FGD, and different interviewers. The transcripts were entered into the software program Atlas Ti version 8 for analysis.

The first and the second author coded three interviews together. Any different opinions on the coding were discussed until we reached an agreement. The first author coded the remaining interviews. The first and the second author did all summaries together and discussed any nuances. We used inductive thematic analysis that allows for the identification, analysis, and reporting of common themes within the qualitative data. The use of this method allowed us to develop codes and themes based on the content of the data (Boyatzis, 1998).

We analysed the data by carrying out open, selective, and theoretical coding at three levels: at the initial coding level all transcripts were read to identify general themes emerging, these themes were grouped into smaller themes at the second level. Levels one and two codes were reviewed at the third level to develop the major thematic categories. Reports were generated for each thematic category and reviewed. All quotes that did not fit the selected code were recoded from that category into its appropriate category. Other emerging themes that were peculiar to some transcripts were then added. The summaries for all categorized themes have been presented as results for exploring the factors (individual and environmental) influencing antiretroviral treatment adherence of PLWH in the Bono East Region of Ghana.

Ethical approval for the conduct of the study was obtained from the Institutional Ethics Committee (IEC) of the Kintampo Health Research Centre (FWA00011103) and the Ethical Review Committee Psychology and Neuroscience at Maastricht University (ECP_04_09_2012_S22). Permissions were received from the Medical Superintendents of the selected hospitals to carry out interviews in their facilities.

3 | RESULTS

First, we report on the adherence behaviour of the participants. This is followed by the determinants that influence ART adherence grouped into two categories: individual and environmental (including interpersonal and community factors).

3.1 | Adherence behaviour

Most of the participants had been on ART for the past 5 years at the time of data collection. Irrespective of age, PLWH revealed that they take ART because their life depends on it. While most indicated they never skipped their medication, a few others said they sometimes forgot to do so because they were preoccupied with their jobs.

3.2 | Individual factors

3.2.1 | Self-regulation for ART adherence

All participants in the IDIs and FGDs indicated that they could take their medication without any difficulty. They were able to take the medication with ease as prescribed by the health care provider. They used self-regulation strategies like using a different pill bottle when travelling (to avoid stigma), or memory cues such as putting the medication in clear vision (e.g., table), incorporating it as part of their daily schedule by using wake-up and bedtimes or breakfast and dinner times.

“No sister [it is not difficult], once we eat every day taking the medication is as easy as that”. (30-year-old IDI participant)

3.2.2 | Outcome efficacy of ART treatment

All PLWH indicated that their condition has improved since they started taking the antiretroviral. They are optimistic that if they continue to take antiretroviral, they will no longer die from HIV; it makes them look very healthy, stronger, and able to work and therefore reduces potential HIV-related stigma. For most PLWH, the improved health status has helped to conceal their HIV status. Altogether, IDI and FGD participants corroborate that, the fast and visible improvement in health is one of the major drives for treatment adherence:

“Oh, the medication is very good. If I say it is not good, I would be lying. Apart from God who gives me life, it is my God. I was not like this. I was wasted. However, upon taking the medication, I am fit...”. (28-year-old female IDI participant)

Interestingly, one participant said even though ill health reduced she noticed that the antiretroviral made her chronically weak and has affected her daily activities.

“Ever since I started the medication (ARV), I have never been able to go to the farm. I am chronically weak” (32-year-old female FGD participants)

Another participant indicated that the efficacy of the antiretroviral helped him to abort any plans of committing suicide.

“My recovery from frequent ailments after taking the antiretroviral motivated me to discard the idea of poisoning myself. Before I started the antiretroviral, I went to the hospital severally without recovery until my brother came from Britain and took me to the hospital” (45-year-old male IDI participant)

3.2.3 | Side effects of ART medication

Most participants said they had experienced side effects especially at the start of taking the antiretroviral. Some participants mentioned side effects such as dizziness, weakness, diarrhoea, skin rashes, nightmares, palpitation, confusion, and vomiting.

“I started the ARV for two weeks, when I began, my legs were swollen and oedematous, and I was bedridden for 6 months. I was admitted at the hospital for 3 months to take the fluid from my thigh. It took the intervention of both local and foreign doctors to survive...Since then I have never experienced any side effects. For that particular antiretroviral that gave me this side effects, no matter what I will not take it” (33-year-old female IDI participant)

Some participants said health care providers warned them about the side effects. The side effects diminished after a while or upon complaining to the healthcare provider, they changed the medication. In general, it seems that the side effects did not stop them from taking the medication.

3.2.4 | Knowledge about HIV and ART

Most PLWH who were knowledgeable about the causes, treatment, and management of HIV, (learned it either through counselling, training from health facilities, or various courses related to HIV) were inclined to understanding HIV transmission and antiretroviral intake. This seemed to help them with ART uptake.

“What helped me most was that in the same year that I was diagnosed, there was an opportunity to do a course in HIV at the University of Ghana... This exposed me to a lot of information on HIV and I learned many things”. (56-year-old male FGD participant)

3.2.5 | Anticipated stigma

The majority of participants in both IDI and FGD said that they believe that when their community members or family knows their HIV status they will devalue them. A few participants felt family members may even laugh at them if they came to know. For the majority of the PLWH, the fear of stigma makes them travel to other ART centres far away, from where they stay to get antiretroviral medication.

“Stigma is still high; it is the main reason why PLWH will rather pick their medication from an ART far away... Some even go as far as Kumasi because of the stigma” (33-year-old female IDI participant).

Although quite a few participants mentioned real stigma experiences, it appears that the majority of PLWH have not experienced public stigma but have a strong fear it could happen.

3.2.6 | Disclosure vs. non-disclosure

The majority of the participants in IDI and FGD had informed only one person about their HIV-positive diagnosis. Most PLWH said that people who they disclosed to did not judge them but empathized. PLWH mostly disclosed to their spouses, parents, or siblings. Reasons for disclosure included trustworthiness of the person, the need for

financial, or emotional support to regularly come for antiretroviral refills or feeling obliged to disclose because of the visibility of the infection.

Some reasons ascribed to non-disclosure were a strong fear for the other persons' response (gossip, maltreatment, and abandonment), not needing help and the fact that their health is a personal matter.

“When I was diagnosed with HIV, I was not worried about my diagnosis; I was rather worried about how my wife will maltreat me and how unhappy she will make me if she came to know”. (34-year-old male FGD participant)

To avoid stigma or disclosure, some PLWH resorted to disguising the medication bottles, hiding the antiretroviral, or denying or lying about their HIV status.

3.2.7 | Fear of recognition at ART clinic

PLWH in both IDI and FGD were afraid to be identified as HIV patients when visiting the clinic for fear of gossip. This fear influences clinic attendance, hence pill refill and antiretroviral adherence.

“As for the location, hmm it is difficult especially when you start off from the hospital entrance. The moment you start coming towards the facility everyone knows what is wrong with you”. (24-year-old female IDI participant)

3.2.8 | Role of religion

Both IDI and FGD participants positively reappraised their purposes in life post-HIV-positive diagnosis because they believe in God and ART. While others believe that they are still alive by the Grace of God, others depend on their relationship with God to ignore stigmatizing attitudes of other people. Some PLWH also believed that HIV is from a deity as such they are predestined to have HIV. PLWH believes that ART is efficacious because God allowed it.

“...I think everything is by God. All you need is to cast all your burdens on God. If I look at the medication, without God it will never work. I look up to God alone. God is my only hope. No man can help me but only God”. (30-year-old female IDI participant)

3.2.9 | Coping with HIV

Most PLWH in IDI who accepted their HIV-positive status focused on how to deal with it. Some PLWH compared HIV to other chronic conditions like hypertension and diabetes and took solace in the fact that living with HIV is more manageable than hypertension and diabetes.

“....Any illness can kill someone. If you have HIV and you take your medication, it is better than having diabetes. I think diabetes is more dangerous than HIV” (36-year-old female IDI participant)

They mentioned that with antiretroviral, PLWH could live their lives to the fullest without any problems; they can have children who are HIV negative and very healthy despite their HIV positive status. For others, knowing that they are not the only ones living with HIV makes them accept their condition.

3.3 | Environmental factors

3.3.1 | Response and support from family and friends

Although most participants indicated that the person to whom they disclosed was sympathetic, some family members who knew their HIV status were unwilling to accept that PLWH tested positive. Some PLWH were not allowed to cook or share their food with any other person. While the relationship of some family members of PLWH remains unchanged, FGD participants mostly recounted unpleasant experiences such as insults, abandonment, and divorce.

“Honestly, when I came to know I was infected (HIV) I went through a lot, my marriage was broken, and I was disgraced” (33-year-old female IDI participant)

The support that participants receive from partners, family, or friends varied from financial support, help with collecting medication and receiving food to receiving reminders for medication intake and advice and real emotional support, care, and encouragements. Support seemed mostly financial. Some participants described the support they received from partners and family members as empathic, loving, trusting, and caring.

“Ooh because he [husband] knows [I am HIV positive] he does not disturb me. He takes very good care of us and supports me with my medication intake”. (30-year-old IDI participant)

However, quite a few also seemed to be just satisfied when family or partner is accepting them and when receiving money or food, while emotional care seemed to be completely lacking.

“[...] he [husband] was accepting and when I need to come for medication, he gives me money for transportation if he has it [...] but my husband was not angry or anything because he tested negative, he believed that it was a spiritual illness. [...] The only thing is that, recently, there was a funeral in my village and an aunt of mine got a girlfriend for him who stays in Kintampo. That has caused some problems for us. When we sleep, he does not even want my body to touch his”.

M: Does it mean his support has dwindled?

R: Well, I will say no. He still provides food for us and takes care of the house' (30-year-old female IDI participant)

Most PLWH stated that financial support (mostly used for transportation to hospital) was not constant as partner or family regularly stated not having money. Some participants stated not receiving any support at all.

3.3.2 | Community responses

Participants in both FGD and IDI indicated that community members respond negatively towards PLWH even if it is a mere suspicion that they are HIV positive. The suspicion leads to gossiping or insults. However, when PLWH are looking healthy (because of ART) these responses tend to stop.

“.....I hoped that, when I took the medication, it was going to help me live long. Therefore, I do not joke about the medication. Some people are now confused, they are not sure whether I am indeed infected or not...”. (35-year-old female FGD participant).

PLWH with real stigma experiences indicated that people around them who know their HIV-positive status tend to avoid them. They described avoidance to include dissociation and exclusion, not touching PLWH or anything that belongs to them (food, drinks, etc).

3.3.3 | Organization of ART clinics

Despite the integration of the ART clinic with other chronic conditions like diabetes, the location of ART clinics within the hospital premises poses a chance of recognition and therefore for stigmatization.

Even though most of the younger participants were afraid of being seen, a few older PLWH were not bothered about recognition, they said this is because people have different reasons for visiting the hospital.

“Even if it is a bother, we are all sick that is why we are at the hospital. You do not know what is wrong with me. For all you know your reason for coming to the hospital is bigger than mine” (51-year-old female IDI participant)

Some PLWH opined that holding a clinic for only one day in a week as was practiced in some ART centres did not only increase the waiting hours but it also coincides with market days which increases the likelihood for meeting familiar people. Sometimes they travel all the way to the clinic but do not receive a refill because the medication is out of stock.

3.3.4 | The attitude of health care providers (HCP)

In general, most PLWH were satisfied with the services they received at the ART clinics. They appreciated the service and counselling. They stated that the staff was friendly and respectful.

“Ooh, when we come they do not frown. They are very friendly and take good care of us [...]”. (36-year-old female IDI participant)

However, some participants said HCP rudely treated them because of their HIV status. They described stigmatizing experiences such as HCP frowning, unwillingness to help, taking extra precautionary measures especially with PLWH, rude, unfriendly, and impatient.

“Some nurses are unfriendly and intolerant. When they know you are infected the way they sometimes respond to you is not the best” (26-year-old female FGD participants)

3.3.5 | Treatment adherence counselling

The majority of the participants received counselling from two weeks up to several months by either an HCP (nurse, midwife, pharmacist, doctor) or a model of hope. It was, however, not always clear whether the participants received both the pre-test counselling and the post-counselling. The counselling that most participants remembered was centred on information on the efficacy of medication, adherence, medication side effects, transmission routes (including mother to child), and having a healthy diet/lifestyle (including safe sex and positive future perspective). *“Yes, initially I used to worry a lot... However, whenever we come for medication we are counselled that, if we consistently take our medication HIV will not kill us. We can live our lives to the fullest” (50-year-old female FGD participant).*

The information received also seemed to help in counselling family members. Few participants received the advice not to disclose, choose a PLWH as a partner in order not to further spread the virus, or to report stigmatization. Treatment options that suited the lifestyles of the participants and self-regulation were rarely mentioned.

3.3.6 | Transportation costs

The majority of the participants indicated that unlike previously when an NGO used to support them, the cost of transportation to the ART clinic was now a challenge for their regular visit to the clinic and they often lack (financial) support.

“We have challenges with the cost of transportation. That is why we are requesting that we be supported to be able to do some work so that we can cater for our medication” (40-year old female FGD participant).

4 | DISCUSSION

In this study, the individual and environmental factors that may influence adherence to ART among people living with HIV (PLWH) in Ghana were explored using IDI and FGD. The findings suggest that self-regulation, outcome efficacy, medication side effects, knowledge on HIV, stigma, disclosure, coping, partner, family and community support, the attitude of health care providers, organization of the ART clinics, and transportation cost may influence ART adherence. Among these factors, the outcome efficacy of ART, anticipated stigma, the attitude of healthcare providers, and transportation costs to the ART clinic seem to have the strongest influence.

A very interesting finding was that participants showed a strong intrinsic motivation to continue their ART medication because of visible improvements in their overall health. Despite reporting some side effects, mostly during antiretroviral initiation, the positive outcome of taking ART strongly supported intake. To our knowledge, this strong impact of visible treatment outcome on ART adherence has not yet been reported in the literature. However, evidence suggests that outcome expectations do indeed influence treatment adherence in patients with various other medical conditions (Laferton, Kube, Salzmann, Auer, & Shedden-Mora, 2017). We argue that the fast and visible improvement in our sample influenced their motivation to take their medication. This underscores the need to develop adherence-counselling models that reiterate PLWH expectation of an efficacious outcome by assessing and understanding these expectations to optimize treatment outcomes.

Another striking finding was the positive relationship between PLWH and the ART Health Care Provider (HCP). Most PLWH described HCP as being friendly, supportive, respectful and helpful. They felt healthcare providers listened to them and did not report any experiences with insults. This finding is in contrast with the majority of the literature that reports strong stigmatizing responses from HCP to PLWH (Madeleine, Chan, & Thayala, 2011). Our study adds to the limited data on the positive attitude of HCP towards PLWH (Dapaah, 2016). An explanation for the positive relationship that we found among HCP as compared to other studies may be that we focused specifically on HCP working in ART centres while most publications focus on HCP in a broader, general health care sector. The contact hypothesis may be an explanation that HCP in ART clinics are more empathetic towards PLWH as compared to HCP in the general health care setting (Chan & Tsai, 2017). The difference between HCP in ART centres versus those in the general health care sector and the role of contact would be worth exploring further as a stigma reduction strategy.

This notwithstanding, few participants' experienced negative attitudes from the health care providers. In an attempt to protect themselves from infection, HCP awkwardly interacts with PLWH or treat them differently as supported by (among others) (Stutterheim et al., 2014). On the other hand, PLWH may have an expectation of

stereotypic behaviours from HCP and interpretation of HCP behaviour, which may not be necessarily entrenched in actual prejudice or undesirable attitudes towards PLWH. In their discussion of HIV-related avoidance attitudes among health care providers in China, Li et al. (2007) assert that HCP's negative attitudes towards PLWH may be due to fatigue, emotional distresses or work-related stress rather than stigma. We are not suggesting that stigmatization is not happening in health care facilities, but we argue that the expectation of stereotypic behaviours may also influence PLWH clinic visits, hence their medication adherence.

Narratives from PLWH show that they used emotion-focused coping (e.g., religious coping) and problem-focused coping (e.g., selective disclosure) to deal with stigma and improve medication adherence. A very interesting finding was that PLWH in this study downplays their seropositive status by comparing it with hypertension and diabetes as a way of coping. For example, PLWH tells themselves that hypertension or diabetes is more dangerous than HIV, and missing a dose in the case of the former will lead to a medical emergency.

Literature suggests that people who find positive meaning to their illness can mentally adjust to the disease (Farber, Mirsalimi, Williams, & McDaniel, 2003). Attaching a positive meaning to HIV may be beneficial on the psychological adjustment of PLWH. We would contend that the fact that participants mentally adjusted to their HIV status by comparing HIV to other chronic conditions shows the resilience of PLWH to live positively with HIV. This may be beneficial on the psychological well-being of PLWH and may elicit protective health behaviour like adherence to medication.

Interestingly, the accounts of most participants conveyed that only a few of them had experienced enacted stigma. The majority of the participants merely seem to anticipate stigma, which is one of the main reasons they fear to visit a nearby ART clinic and were prepared to travel long distances at extra cost for antiretroviral refills. This finding is corroborated by some studies that reported that anticipation of stigma influenced PLWH adherence to ART (Camacho, Kalichman, & Katner, 2020). Indeed, PLWH is aware of being discriminated against in their social interactions because of which PLWH anticipates stigma (Bos et al., 2013). This anticipation influences adherence to medication in that PLWH may have to access and take the medication in secrecy with its consequent challenges. Multi-component interventions that support PLWH to deal with anticipated stigma and engage community agents who are sources of stigma will be useful for PLWH medication adherence.

Even though ART in Ghana is free of cost to PLWH, results indicate that transportation costs were a barrier for a clinic visit for an antiretroviral refill and hence adherence. Tuller et al. (2010) reported similar findings that even though patients had a high level of commitment to adhering to their medication, the high cost of transportation compromised adherence to ART and access to care. Supporting PLWH with jobs will enhance the affordability of services.

PLWH in our study showed that religion is an important form of coping. The importance of religion in HIV stems from the fact that PLWH receives comfort, care and relief by praying, depending on God to heal or help them to cope with HIV. When PLWH believes that God grants knowledge to humans to provide medicines for their relief, it motivates them in adhering to antiretroviral. Religious organizations are important social networks that have the potential to support or stigmatize PLWH, encourage or hamper HIV education, make PLWH accept or refuse antiretroviral treatments. As such in Ghana and elsewhere, religious leaders are important stakeholders in HIV management support (Nyblade et al., 2003).

However, religion can also negatively influence PLWH by motivating them to stop medication intake and depend solely on their belief in a cure from HIV (Kretchy et al., 2013). Wanyama and colleagues in their discussions of ARV adherence in Uganda indicated that about 1% of patients discontinued medication because they believe in spiritual healing. This treatment interruption not only resulted in treatment failure but also a transition to second line more expensive options (Wanyama et al., 2007). Few participants perceived HIV was either a spiritual condition, airborne, foodborne, or a gift from God. Religious leaders who are engaged as stakeholders in HIV care and support would benefit from tailored training on how to contribute to PLWH treatment adherence and well-being. The superstitious beliefs and myths about HIV and antiretroviral will need to be addressed to improve adherence to medication.

PLWH disclosed their HIV status only to people they trust to support them when they need help. The findings suggest that any form of support is useful in living with HIV and medication intake. However, PLWH who enjoys a partner's or close family members' support may receive emotional care, which is especially important for patient medication adherence and well-being (Cohen & Wills, 1985). This is, however, lacking because most of our participants were not in stable relationships. The lack of support may be influenced by cognitive representations among the patients' relatives such as perceived responsibility, perceived severity, perceived dangerousness, and perceived norm-violating behaviour (Bos et al., 2013). Family interventions to reduce these representations may help in increasing emotional care.

The current study has some limitations. Mostly adherent PLWH may have been included in our sample; we envisage that their responses could be different from PLWH who do not often come for refills. Also, the majority of our participants were females, this, however, is reflected in the total number of persons in HIV care in Ghana (Ghana AIDS Commission, 2020). This could in part be due to the prevention from mother to child transmission (PMCT) program and in part due to non-disclosure by females to male partners. Our study recognizes that policies and punitive laws may be a barrier to ART clinic visits and medication adherence (Laar & Debruin, 2017). This is, however, beyond the scope of this study. Future research should explore how policy influences PLWH antiretroviral adherence.

This study looked at both individual and environmental factors using qualitative interviews. This allowed for in-depth knowledge on the context-specific factors that influencing ART adherence. Although PLWH appreciates the need to adhere to antiretroviral, they face practical challenges. This study identified factors influencing ART adherence that could be used to develop interventions. We suggest the intervention-mapping approach (Bartholomew, Parcel, & Kok, 1998) to be used to develop, implement and evaluate interventions. These interventions may target PLWH, partners, families, and health care providers as change agents within the community to improve PLWH adherence behaviour.

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CONFLICT OF INTEREST

The authors report no potential conflict of interest.

DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available from the corresponding author (MAA), upon reasonable request.

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