

# Models of Hope

## Qualitative Case Study Evaluation

Conducted by West Africa AIDS Foundation, Ghana



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## EXECUTIVE SUMMARY

HIV and AIDS continue to be considered an epidemic in Ghana. One of the initiatives across the country includes utilising volunteer healthcare co-providers known as 'Models of Hope' to facilitate better client outcomes through the provision of hope and services. Models provide basic education and counselling while embedded at facilities, and provide some home-based nursing care to clients. During 2016 and 2017, across 4 regions (Greater Accra, Eastern, Western and Ashanti regions) the Models of Hope (MoH) program has been funded by The Global Fund through the Community Systems Strengthening project (CSS).

This case study evaluation interviewed 120 participants (Models, clients and facility staff) across 30 sites within the 4 CSS regions. It investigated client enrolment and services received from Models; the current support and potential improvements to the MoH program; opinions on existing funding, support and governance structures, as well as the state of the facilities where Models are embedded. The case study also explores the current challenges and barriers for Persons Living with HIV and AIDS (PLHIV), including their quality of life and experiences of stigma or discrimination.

With regards to newly diagnosed clients, the two most common barriers to treatment are client attitudes and desire to seek alternatives such as spiritual or herbal treatment. Education is also a significant barrier. Overall, the services provided by Models vary between facilities, although a large portion of their time is dedicated to administrative tasks, often due to shortage of paid staff and other constraints. Counselling and education are provided to almost all clients in contact with a MoH. Home-based care and home visits are conducted by Models alongside follow-ups of defaulting clients; such services would potentially not be offered by facilities without the MoH assistance. Clients consider education and adherence support to be the most important services received from Models. Areas for future improvement were identified as: HBC kits & training; financial aid for Models; increasing the Model presence at sites, through either more clinic days or including more Models in the program; and more education/counselling training. Models exhibited concern regarding the current governance of the program and how funds had been managed, and expressed doubts about the sustainability and future of the program.

In terms of challenges for PLHIV more generally, the barriers to adherence included distances travelled to a clinic or to collect medications, and other illnesses. Stigma and discrimination were over-reported by Models in comparison to clients. However, stigma still represents a significant issue for PLHIV in Ghana. Clients were also most concerned with their ability to attend to family responsibilities. Gaps exist in current data collection, as there is limited focus on qualitative data. Clients who default do so multiple times and often need home-based care due to severe illness. The lives of both Models and clients had improved through the MoH concept, due to the education and adherence support and improvements to health. Past experiences of stigma were high for Models, occurring more often at home, while experiences were low for clients but occurred more often in healthcare facilities. Avoidance of perceived or anticipated stigma was high and greatly affects healthcare-seeking behaviour and health choices made by PLHIV.

Recommendations for future research are included, as well as recommendations for improvements to current practice.

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# INTRODUCTION

## *Project Background:*

Almost 37 million people globally live with HIV; 70% of these are located in Sub-Saharan Africa (Fenny, Crentsil & Asuman 2017). It is estimated that there are over 220,000 Persons living with HIV and AIDS (PLHIV) in Ghana (Ghana AIDS Commission 2014), and these individuals face many challenges when seeking healthcare. HIV continues to be considered an epidemic in Ghana (Fenny, Crentsil & Asuman 2017). Models Of Hope (MoH) is a community-based HIV and AIDS concept operating across the ten regions of Ghana. In the Greater Accra, Western, Eastern and Ashanti regions it is officially supported with financial assistance from The Global Fund, through the Community Systems Strengthening project (CSS) for 2016 and 2017. While the project has been active for over a decade, it has been situated under governance of multiple different organisations during this time. At present, MoH within the four supported regions falls under the care of the National Association of Persons Living with HIV and AIDS (NAP+), assisted by West Africa AIDS Foundation (WAAF) for capacity building. PLHIV are selected as role models, acting as volunteer peer educators and counsellors within specific anti-retroviral therapy (ART) sites in hospitals and clinics. For the past 2 years, quantitative data has been collected on the project in the four regions by the CSS project under funding from The Global Fund. There had been no known qualitative project evaluation carried out for MoH at the time this study was conducted.

To the best of the researchers' knowledge, the current CSS monitoring lacks in-depth analysis of MoH activities; it has limited links to project outcomes and lacks clear indicators. Existing indicators were entirely healthcare-based, focusing on quantitative data pertaining to services at facility level, and numbers enrolled in or exiting the home-based care (HBC) service. It appears that no detailed data has been collected as to the reasons clients require HBC, and no data as to the quality of care provided at facility level or ongoing outcomes for clients. A qualitative study was conducted on the MoH project in 2013 to explore the motivations for PLHIV to become Models, which revealed a desire to provide hope to newly diagnosed PLHIV needing support (Avornyo 2013). However, little is known about the challenges that Models or their clients face at facilities, especially in regards to education, psychosocial challenges and barriers with adherence to medications.

## *The Model Role:*

Models provide basic psychosocial counselling, nutrition, anti-retroviral medication (ARV) advice, and home-based nursing care. Models in this setting act as volunteer healthcare workers, simultaneously taking on the role of additional facility and administration support, peer educator and counsellor. In healthcare, such a volunteer role has become known as 'healthcare co-provider' through task-shifting, a common mechanism to handle constraints within healthcare systems (Tulloch et al 2015), particularly in resource-poor settings. Such co-providers are considered to be 'expert patients' within their context because of their personal experiences living with HIV (Kielmann & Cataldo 2010; Tulloch et al 2015). This is thought to make them more effective communicators with the wider PLHIV population as they are able to build trust and relationships with clients (Medley et al 2009; Go et al 2013; Tulloch et al 2015). A facility staff respondent from this case study explained that Models function as *"a good bridge between the facility and clients"*

through the peer support they offer. In HIV and AIDS care provision, there is evidence that co-providers “can be important in supporting monitoring, HIV status disclosure, adherence, quality of life indicators, greater equity in access to services, increased paediatric testing, shortened waiting times, reduced stigma and better overall ART outcomes” (Tulloch et al 2015, p. 185; see also Orne-Gliemann et al 2008; Wouters et al 2009; and Kabore et al 2010). HIV infection impacts not only one’s physical health, but also affects mental health through the experience of stress, stigma and discrimination (De Santis & Barroso 2011), resulting in particular vulnerability of PLHIV.

The MoH project also assists clients who cannot access healthcare facilities or need assistance in a home environment can receive basic care. These clients may be unable to access medication or services, generally because they are bedridden or suffering severely ill health. Currently, the only indicator for MoH HBC is level of health: unwell clients are enrolled into HBC, then exit once they become healthy. MoH also assist facilities in tracing and finding clients who have stopped regularly taking their medications - known as defaulting - to attempt to maintain their adherence to ARVs. The tracing of defaulters has been reported as a major problem, with lack of a coordinated system or process through which to follow-up. There is little data available to provide insight into the reasons that clients default.

One of the key features of the MoH role is to inspire others and set an example. The goal of this is to inspire other PLHIV to maintain their health, for their own quality of life, and in particular through adherence to medications. Understanding how prevention, treatment and support works for clients at ART sites - and the barriers to care - is a key aspect of ensuring the program continues successfully.

This case study investigated processes and services offered by the ART sites that utilise Models. Current governance of, support and potential improvements to the program are considered. Finally, this report explores specific challenges regarding adherence to medications, and the wellbeing of PLHIV (both Models and clients), including stigma and discrimination.

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# METHODOLOGY

## *Research Questions:*

Our aim was to explore and understand the broad range of activities related to the MoH concept across the 4 CSS regions. Respondents included clients, Models and facility staff. This investigation was qualitative in nature to capture broad and detailed data relating to known and expected activities and new or unexpected. Therefore, this was part qualitative case study and part evaluation of the current state of activities. The results will inform future evaluations, and recommendations have been included at the end.

Research questions were designed to explore the factors influencing client participation in the MoH activities, from initial enrolment to ongoing participation. This relates to the potential for psychosocial, economic and socio-cultural factors to influence healthcare-seeking behaviour, quality of care, overall wellbeing and adherence to medications. The findings can also be viewed as revealing the state of existing ART sites, as well as the experiences of PLHIV more generally. Although this was not an explicit review of ART sites, data have been included on the state of facilities and how this affects outcomes for PLHIV and Models. The experiences of both clients and Models contributed to better understanding the benefits and consequences of participating in the MoH concept and on disclosure, stigma and discrimination.

Research questions included:

- How do the Models impact PLHIV?
- What is the correlation between PLHIV quality of life and the MoH program?
- What is the current situation for PLHIV working as Models?
- How could the MoH activities be better supported?

Other considerations:

- Client experiences of care: services received; ability of the Models to influence outcomes (education/training and advice/counselling provision, ability to offer 1-1 support, facility conditions);
- Model ability to provide quality of care (within their ART site; with their level of training; with the support currently received);
- Experiences of stigma and/or discrimination;
- Socio-economic, psychosocial or other factors affecting PLHIV (nutrition, finances, education and understanding, stigma and support).

## *Ethics:*

Due to the sensitive nature of the topic, it was ensured that: participants were over 18 years of age; and were verbally informed of their rights to participate, and ability to refuse or withdraw at any time. Respondents were provided a brief verbal summary of the purpose of the interviews, including potential resulting publications and reports. Respondents were also informed that the data would remain confidential and any resulting reports or publications would be anonymous. Consent was then obtained verbally from each respondent before beginning.

Only two potential respondents refused to provide an interview. No issues regarding ability to consent or withdrawal of consent arose. Some respondents expressed concern regarding the

volunteer researcher Stephanie Houghton being a foreigner, and the potential for identification outside of Ghana. These respondents were reassured regarding the use of information, anonymity and consent, and provided an opportunity to withdraw.

Respondents had the opportunity to ask questions, and were reassured that only the two researchers would have access to their personal data and identifiable responses. When possible, the researchers ensured that no one else was present for an interview, especially those in positions of power. However, at times this was unable to be avoided because of practicalities, and during these interviews, sensitive questions were omitted.

Volunteer researcher Alice Asante, a MoH herself, often disclosed to clients before beginning an interview session to ensure they were comfortable and encourage them to be honest in their answers. This also helped to alleviate their fears of stigmatisation.

### ***Data collection methods:***

This study took a qualitative approach, because an exploratory study of all project activities was required but also to uncover detailed experiences of participants. Some data was able to be used quantitatively, such as number of responses to closed questions and responses to multiple choice questions. The data were coded to conceal the identities of respondents and was stored in a secure location, where only the two researchers had access to identifiable data. The two researchers deliberated until consensus was reached on coding of themes and analysis. Emerging themes and categories were used to address the research questions and objectives.

Respondents included Models and clients from available facilities in the 4 official CSS Project implementing regions, and ART facility staff, usually the in-charge nurse, administrator or matron. The implementing regions include: Greater Accra region (GAR), Ashanti region (AR), Eastern Region (ER), and Western region (WR). Observations were made at each of the ART sites visited, with an average of 2 hours spent at each site. The total number of Models interviewed was 49, with 40 clients and 31 facility staff across 30 unique ART sites (4 sites in WR, 5 in ER, 7 in AR, and 14 in GAR) for a total of 120 respondents.

Triangulation was completed between the three categories of respondents (clients, Models and staff), and also within categories between certain related questions, to determine reliability of responses. The qualitative nature of questions and lack of existing relationship with researchers could have impacted responses. For Models, the researchers had prior knowledge as to the potential respondent bias towards over-reporting of economic matters, which was accounted for and is believed to have occurred. The researchers discussed such potential biases while designing the surveys and maintained awareness throughout the data collection process. Clients were encouraged to answer honestly, and while it is possible they under- or over-reported on certain aspects of their experiences, again the possibilities for this were taken into account.

### ***Limitations:***

Budget was a restriction, especially in terms of distances travelled and cost of travelling and accommodation. Having only two volunteer researchers resulted in ability to utilise public transport when a vehicle could not be organised. The restrictive timeframe in which to complete this case study exercise meant the researchers did not wait for coordination of a vehicle. Many MoH ART sites are located in rural areas not serviced by reliable transport routes and affected by inadequate

infrastructure. Many of the sampled ART sites are located in urban centres or nearby urban centres, and effort was made to sample equal numbers from rural and urban areas when possible.

The researchers attempted to visit every ART site on a designated clinic day to ensure client availability, however, due to the voluntary nature of participation, we focused upon convenience sampling. Therefore, gender, age, ethnicity or membership within a key population (KP) group (such as female sex workers (FSW) or men who have sex with men (MSM)) could not be targeted. As a result, our participant group may not be representative of the entire PLHIV population.

As external researchers and not directly related to the facilities visited, participants seemed to understand the need to review the state of the project in order to make improvements. There was no conflict of interest or reason to suspect dishonesty in any responses.

At times, privacy was an issue, as some sites do not have private areas for counselling and therefore nowhere to discretely conduct the interview. This didn't affect willingness to participate. The researchers attempted to ensure privacy and discretion with each participant. All clients we interviewed while attending clinic, therefore were assumed to be in a healthy state and able to consent. Only one client we visited was a HBC client suffering an opportunistic infection.

The expectation was that each respondent understood the question and context in either English or Twi. All responses were reliant on the respondent explaining their own experience, belief or opinion. The survey questions were designed by a non-Ghanaian researcher, and while advice was sought on the phrasing of survey questions, initial feedback was minimal. Some adjustments to phrasing of question were made in the field.

One of the limitations was the lack of specificity in the ways that questions were answered. This may be typical of the cultural context or lack of experience in qualitative inquiry, and this has been included as a known limitation and responses analysed with this in mind. It could also be attributed to poor record keeping on behalf of ART sites. The capacity of individuals to generalise and draw conclusions from past experiences may have been limited due to our method of data collection being a new concept to many participants.

Recall bias was a potential limitation, as participants were asked to recall or provide their own generalisations regarding activities. However, due to the general lack of record-keeping on many topics, actual data is unavailable. This is also discussed in the recommendations section. Some record-keeping was available (at 2 ART facilities), however, it existed in the form of a notebook completed over the course of years, by multiple people, and due to limited time and resources, the researchers were unable to utilise this data.

The lack of available qualitative data from the CSS project is also considered a limitation, as there could be no comparison to previous existing data. Without external qualitative data collection, Models and clients could have over- or under-reported, without a verifiable comparison.

### ***Timeframe:***

Some questions were not asked of respondents if privacy presented an issue. Other questions were removed altogether because of limited time to interview or lack of relevancy or because questions elicited similar responses to other questions.

# MODEL OF HOPE PROGRAM

**Table 1:  
Client Respondent Demographics**

	<b>GAR</b> (22 respondents)	<b>AR</b> (8 respondents)	<b>ER</b> (6 respondents)	<b>WR</b> (4 respondents)	<b>TOTAL</b> (40 respondents)
<b>AGE: AVERAGE</b>	36.86 years old	44.75 years old	49.16 years old	37.25 years old	41.25 years old
<b>GENDER: WOMEN</b>	18	5	4	4	31
<b>GENDER: MEN</b>	4	3	2	0	9
<b>EDUCATION LEVEL</b>	<ul style="list-style-type: none"> <li>• Tertiary 1</li> <li>• Secondary 5</li> <li>• JHS 15</li> <li>• No education 4</li> </ul>	<ul style="list-style-type: none"> <li>• Tertiary 1</li> <li>• Secondary 2</li> <li>• JHS 4</li> <li>• No education 1</li> </ul>	<ul style="list-style-type: none"> <li>• Tertiary 1</li> <li>• Secondary 0</li> <li>• JHS 3</li> <li>• No education 1</li> </ul>	<ul style="list-style-type: none"> <li>• Tertiary 0</li> <li>• Secondary 0</li> <li>• JHS 2</li> <li>• No education 0</li> </ul>	<ul style="list-style-type: none"> <li>• Tertiary 3</li> <li>• Secondary 7</li> <li>• JHS 24</li> <li>• No education 6</li> </ul>
<b>CURRENT EMPLOYMENT</b>	<ul style="list-style-type: none"> <li>• Informal/Casual 1</li> <li>• Part-time 0</li> <li>• Full-time 15</li> <li>• Unemployed 6</li> </ul>	<ul style="list-style-type: none"> <li>• Informal/Casual 0</li> <li>• Part-time 0</li> <li>• Full-time 6</li> <li>• Unemployed 2</li> </ul>	<ul style="list-style-type: none"> <li>• Informal/Casual 0</li> <li>• Part-time 0</li> <li>• Full-time 5</li> <li>• Unemployed 1</li> </ul>	<ul style="list-style-type: none"> <li>• Informal/Casual 0</li> <li>• Part-time 0</li> <li>• Full-time 2</li> <li>• Unemployed 1</li> <li>• N/A 1</li> </ul>	<ul style="list-style-type: none"> <li>• Informal/Casual 1</li> <li>• Part-time 0</li> <li>• Full-time 28</li> <li>• Unemployed 10</li> <li>• N/A 1</li> </ul>
<b>RELIGION</b>	Christian 22	Christian 8	Christian 5 Muslim 1	Christian 4	Christian 39 Muslim 1
<b>MARITAL STATUS</b>	<ul style="list-style-type: none"> <li>• Married 8</li> <li>• Not Married 14</li> </ul>	<ul style="list-style-type: none"> <li>• Married 4</li> <li>• Not Married 4</li> </ul>	<ul style="list-style-type: none"> <li>• Married 3</li> <li>• Not Married 3</li> </ul>	<ul style="list-style-type: none"> <li>• Married 2</li> <li>• Not Married 2</li> </ul>	<ul style="list-style-type: none"> <li>• Married 19</li> <li>• Not Married 23</li> </ul>
<b>NUMBER OF CHILDREN: AVERAGE</b>	2.15	3.14	3.33	2.5	2.37
<b>DISTANCE TRAVELLED TO ART SITE: AVERAGE</b>	1 hour 30 minutes	2 hours 30 minutes	1 hour 10 minutes	45 minutes	1 hour 30 minutes

**Table 2:  
Model of Hope Respondent Demographics**

	<b>GAR</b> (23 respondents)	<b>AR</b> (13 respondents)	<b>ER</b> (6 respondents)	<b>WR</b> (7 respondents)	<b>TOTAL</b> (49 respondents)
<b>AGE: AVERAGE</b>	47.34 years	43.84 years	52.5 years	46.71 years	46.95 years
<b>GENDER: WOMEN</b>	20	10	3	4	37
<b>GENDER: MEN</b>	3	3	3	3	12
<b>EDUCATION LEVEL</b>	<ul style="list-style-type: none"> <li>• Tertiary 5</li> <li>• Secondary 9</li> <li>• JHS 7</li> <li>• No education 1</li> </ul>	<ul style="list-style-type: none"> <li>• Tertiary 1</li> <li>• Secondary 1</li> <li>• JHS 11</li> <li>• No education 0</li> </ul>	<ul style="list-style-type: none"> <li>• Tertiary 0</li> <li>• Secondary 1</li> <li>• JHS 5</li> <li>• No education 1</li> </ul>	<ul style="list-style-type: none"> <li>• Tertiary 0</li> <li>• Secondary 1</li> <li>• JHS 6</li> <li>• No education 0</li> </ul>	<ul style="list-style-type: none"> <li>• Tertiary 6</li> <li>• Secondary 12</li> <li>• JHS 29</li> <li>• No education 2</li> </ul>

	<b>GAR</b> (23 respondents)	<b>AR</b> (13 respondents)	<b>ER</b> (6 respondents)	<b>WR</b> (7 respondents)	<b>TOTAL</b> (49 respondents)
<b>CURRENT EMPLOYMENT</b>	<ul style="list-style-type: none"> <li>• Informal/Casual 4</li> <li>• Part-time 5</li> <li>• Full-time 3</li> <li>• Unemployed 9</li> <li>• N/A 2</li> <li>• Total 23</li> </ul>	<ul style="list-style-type: none"> <li>• Informal/Casual 1</li> <li>• Part-time 4</li> <li>• Full-time 1</li> <li>• Unemployed 6</li> <li>• N/A 1</li> <li>• Total 13</li> </ul>	<ul style="list-style-type: none"> <li>• Part-time 4</li> <li>• Unemployed 2</li> <li>• Total 6</li> </ul>	<ul style="list-style-type: none"> <li>• Informal/Casual 1</li> <li>• Part-time 4</li> <li>• Unemployed 1</li> <li>• Retired 1</li> <li>• Total 7</li> </ul>	<ul style="list-style-type: none"> <li>• Informal/Casual 6</li> <li>• Part-time 17</li> <li>• Full-time 4</li> <li>• Unemployed 18</li> <li>• N/A 3</li> <li>• Retired 1</li> <li>• TOTAL 49</li> </ul>
<b>RELIGION</b>	<ul style="list-style-type: none"> <li>• Christian 22</li> <li>• Muslim 1</li> </ul>	<ul style="list-style-type: none"> <li>• Christian 10</li> <li>• Muslim 2</li> <li>• N/A 1</li> </ul>	<ul style="list-style-type: none"> <li>• Christian 6</li> </ul>	<ul style="list-style-type: none"> <li>• Christian 7</li> </ul>	<ul style="list-style-type: none"> <li>• Christian 45</li> <li>• Muslim 3</li> <li>• N/A 1</li> <li>• TOTAL 49</li> </ul>
<b>MARITAL STATUS</b>	<ul style="list-style-type: none"> <li>• Married 10</li> <li>• Not Married 13</li> </ul>	<ul style="list-style-type: none"> <li>• Married 5</li> <li>• Not Married 8</li> </ul>	<ul style="list-style-type: none"> <li>• Married 4</li> <li>• Not Married 2</li> </ul>	<ul style="list-style-type: none"> <li>• Married 5</li> <li>• Not Married 2</li> </ul>	<ul style="list-style-type: none"> <li>• Married 24</li> <li>• Not Married 25</li> </ul>
<b>NUMBER OF CHILDREN: AVERAGE</b>	2.5	2.5	3.1	3.7	2.7
<b>DISTANCE TRAVELLED TO ART SITE: AVERAGE</b>	1 hour 30 minutes	40 minutes	37 minutes	26 minutes	54 minutes

### ***New Client Enrolment:***

For initial enrolment of newly diagnosed clients, walk-ins were most common with 14 clients being first tested this way; 8 clients came to their current ART site because of a referral; 7 came through Prevention of Mother-to-Child Transmission (PMTCT) programs; and 6 clients were tested because of a partner. A total of only 4 respondents sought HIV testing because they experienced HIV-related symptoms, and a further 3 sought testing because of a recommendation on behalf of family or friends. Clients were asked for details on their reasons for enrolling, and explanations for walk-ins included that they went to a facility for another illness, which subsequently resulted in HIV testing and disclosure of their HIV-positive status.

Client reasons for first being tested and enrolled included: Walk-ins (11 respondents); referrals (10); PMTCT (9); because of a partner (4); recommendation (4); and experience of HIV symptoms (1). The responses between Models and clients match, indicating a high level of reliability that these are the most common reasons for testing and enrolment of new clients.

Walk-ins for client testing were highest, suggesting that clients enter a hospital voluntarily for HIV testing. However, clients also reported entering hospital for a different illness and undergoing an HIV test, with limited or no consideration that their visit will result in a positive HIV test. This could be a contributory factor for some clients in denial, due to the unexpected nature of an HIV diagnosis.

Referrals from another facility were second most common. Reasons for referrals are difficult to determine, and could be a result of limited resources or capacity at the initial clinic, or related to suspected HIV or an HIV diagnosis that requires referral to an ART site. PMTCT cases were not a focus so no further comments are able to be made. Receiving HIV testing because of a partner or recommendation were not common, and seeking HIV testing because of suspected HIV symptoms was lowest.

## ***Attitudes to Diagnosis & Enrolment:***

Models were asked if newly diagnosed clients ever declined enrolment, with 27 'yes' responses and 21 'no' responses. Findings revealed that there can be a low level of immediate acceptance or high denial of status for new clients. Respondents who responded 'yes' clarified multiple reasons behind why clients refuse assistance, while respondents who answered 'no' also outlined their major challenges. This question was open to personal interpretation and experience; for example, a Model may have a client who repeatedly refuses help but eventually accepts after several months, but the Model may not consider this a refusal; while answering 'no' to this question, they still provided an explanation as to the struggles they have experienced. Therefore, 'yes' and 'no' detailed explanations have been grouped together to expose the major barriers Models face when disclosing to a new client and enrolling them onto ARV treatment.

According to Models, the most common barrier to the acceptance of disclosure is attitude, relating to denial and refusal, ignorance, or 'stubbornness'. Models described different client attitudes under stubbornness - understood as a strong and continued refusal to accept and seek treatment; denial is understood to mean a deeply personal inability to accept the disclosure of the HIV status. One Model was told by a 'stubborn' client who refused to take any medications that "taking medications is the acceptance of the disease into the body". Such attitudes can relate to cultural, personal and spiritual beliefs, presenting a particular challenge to the medical setting where HIV treatment occurs.

The second most common barrier relates to client refusal to adhere to or seek treatment due to alternative options. Such options are often believed to be both available and effective, such as visiting a prayer camp or pastor for spiritual advice, or visiting a herbalist for a herbal concoction. This again can be related to personal and spiritual beliefs, but become problematic when clients utilise these alternatives as their main treatment. Findings from a study by Fenny, Crentsil & Asuman (2017) indicated that 53% of their respondents believed that the supernatural caused HIV and AIDS. Ghanaian society has a variety of medical practices including those of herbalists, Muslim healers, Christian pastors, and traditional healers (Kwansa 2010). Frequently, these alternatives are promoted and sold to PLHIV as 'cures' for HIV.

Models believe that lack of education is the third most significant barrier, especially in relation to client understanding of their ARV medications, and the reality of the disease in terms of its lifelong timeframe for infection. Newly diagnosed clients exhibiting low levels of knowledge is indicative of the state of knowledge in the wider population of Ghana. Client struggle with HIV being a lifelong illness continuously came up throughout the data collection, as many PLHIV find it difficult to either understand or come to terms with the length of time they will require daily medication. Stigma, other illnesses and financial problems were also reported, however insignificantly.

## ***Services:***

ART sites are expected to offer specific services and care to clients, through administrative staff, data officers, counsellors, nurses and others. Models are embedded within ART sites to facilitate HIV services, with a focus on providing an example of hope to newly diagnosed and existing clients. This provision of hope is meant to assist during initial disclosure and provide ongoing peer support. Beyond this, the Models are to assist in other areas to support the facility, however as unskilled, volunteer co-providers, should only be enlisted to provide a basic level of assistance.

On average, clients had been in contact with their Model of Hope for 3.5 years. Clients reported visiting their ART site and Model on average every 2.3 months to collect their ARVs, with few clients coming more regularly for counselling or other services. Low frequency of visits to a clinic is to be expected, as a common barrier to seeking healthcare is financial constraints for transportation to and from clinics.

At some sites, Model's are a key part of the entire enrolment process for a newly diagnosed client, while for others, it was clear that site staff only call upon the Models for difficult cases. Responses revealed that a large part of the Models' time is being spent on administrative tasks such as the collection of folders for clinic days, filing of folders, and general administration. Some facility staff respondents explained that there has been little communication from stakeholders governing the MoH as to the specific definition of the role. Without communicating a specific and clear Model role, it is the responsibility of facility staff to set tasks according to the needs of the facility. Models at multiple facilities were identified as carrying out numerous tasks beyond MoH project tasks, including administrative filing and nursing tasks such as checking vitals of clients. A staff respondent in GAR explained: *"Shortage of nurses means Models of Hope do testing, defaulter tracing, home visits, escort patients to consulting or doctor, and assist with outreach, screening, education, adherence counselling. They accompany nurses to do some of these"*. This could have a detrimental effect on the MoH activities and client outcomes, as Models are not embedded at ART sites to perform some of these tasks, and are not qualified as nurses. The Model role as co-provider can be diminished if there is limited opportunity for interaction with clients to provide education, disclosure, peer support and counselling.

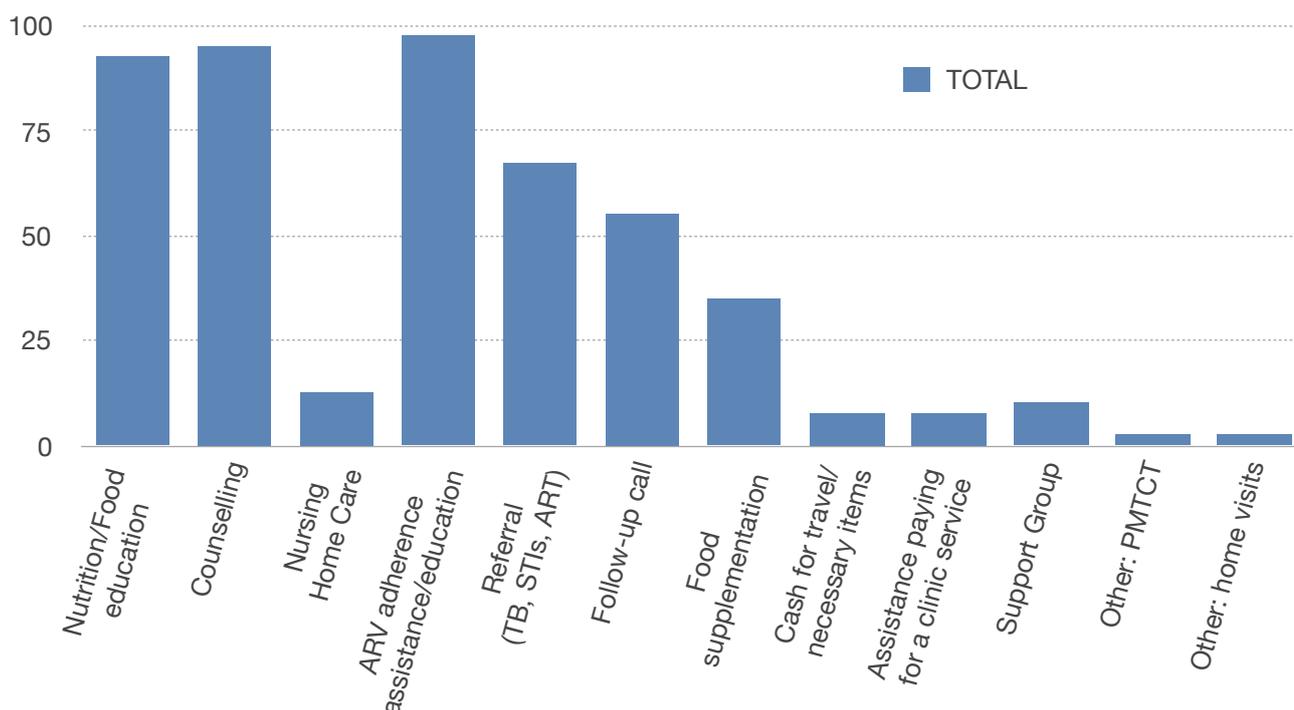
Home visitation by volunteer co-providers in other settings is seen as a helpful way to provide health support and advice, to not only the client but their family (Tulloch et al 2015). When asked about home-based activities, respondents did not differentiate between HBC and HV for follow-up. As both require finances and time, this analysis does not distinguish between the two. 35% of clients interviewed had received HBC/HV. Facility staff ranked HBC/HV as the third most provided service by the Models (16 responses). Facilities should be further examined to determine whether without Models they have been or would be providing home-based services at all to PLHIV clients. No accurate or coordinated record-keeping is known to exist at facilities for HBC/HV follow-up activities. As a task that requires leaving the ART site, HBC/HV may be a difficult task to perform for nursing or administrative staff at facilities. It is also possible that because of the extra finances required to complete HBC/HV, facilities place responsibility for this task on Models who will utilise their monthly allowance to undertake the task. As one Model explained, *"HBC clients, [they are] adhering or trying to adhere but there is expectation for money for foods [or] Models to bring foods when visiting them. There is lack of family support, so they want food and money, even those who come to the site, [I] sometimes pay for labs too"*.

Comprehensive HIV and AIDS knowledge has been found to be above 50% in Ghana, however there was a decrease from 72% in 2008 to 59% in 2013 (Fenny, Crentsil & Asuman 2017), a considerable drop in the level of comprehensive knowledge across the country. Knowledge of HIV and AIDS is critical to behavioural change for prevention of HIV transmission (Fenny, Crentsil & Asuman 2017); education needs to be expanded, improved and maintained for effective prevention. The decrease in comprehensive knowledge can be attributed to inadequate dissemination of information during media campaigns, but also because campaigns by government and civil society organisations have lost momentum (Fenny, Crentsil & Asuman 2017). Models

confirmed these issues exist within the broader media landscape, stating that current maintenance of public education is low and government initiatives are sporadic. General information on all topics (general HIV advice, condom-use and safe sex, psychosocial advice and counselling on personal problems) is considered to be provided through the counselling category (group or one-on-one), but in other sections of this report it is also referred to as 'education'. Nutrition and Adherence education were included as separate categories.

### Model Effectiveness:

**Figure 1:  
Clients: Services Received from MoH (%)**



97.5% of client respondents reported receiving ARV adherence assistance/education; 95% reported counselling; and 92.5% reported receiving nutrition/food education, indicating that the Models of Hope overall are providing these three key areas of information to their clients consistently (Figure 1). 67.5% of respondents had been referred for tuberculosis, an STI or to another ART site before. This indicates a high prevalence of other illness alongside HIV infection, while referrals between ART sites can contribute to lost-to-follow-up (LTFU: lost during initial enrolment process). A follow-up call had been received by 55% of respondents. Food supplementation (not from an official program, rather from a staff member or Model) was received by 35%, and this is considered high due to the financial constraints of both Models as individuals and the ART sites. Only 1 ART site visited during data collection had an existing and operational food supplementation program, funded by an external donor, and applied for and governed by the facility's nutritionist.

Models potentially emphasise and over-report instances of providing their clients with cash or paying for necessary items of services. Far fewer clients than expected had received cash for travel or necessary items such as vitamins or supplements, or received assistance paying for a service at the hospital. The figure for Support Group responses seems low, considering that when

directly asked another question on support groups, responses were high. Nursing Home Care inquired about HBC, with 10% of respondents previously receiving this service. Further research and improved data collection is required to understand how and why home-based services are used, in order to assist clients better and prevent serious illness that requires such care. Within this case study, this was explored more thoroughly and discussed in the section: *Challenges to Adherence & Links to Defaulting*.

Both clients and Models were asked what they believe the main goal of the MoH program is: *'In your opinion, what is the main goal of the program?'* 'Goal' was not a term understood by the majority of respondents. This question revealed the lack of clarity for staff and clients alike regarding the position of the Model of Hope and their relation to the facility, details of their role, and that they are a part of a wider network of Models and PLHIV under an NGO-supported program. In English and Twi, this was rephrased to be 'the most important part', and sometimes 'of what the Models do' was added for clarity.

For clients, education was cited as the most important by respondents; adherence (including adherence education, defaulter tracing and follow-ups) was considered second most important, while disclosure, hope and peer support was minimally important. For Models, education was considered most important, while adherence (including defaulter tracing and follow-up) was the second top priority. Disclosure, hope and peer support was considered to be almost equally as important as adherence by Models, while they considered HBC/HV and ending stigma to be minimally important. There is confirmation between clients and Models that education is the main goal of the project, and therefore the most important aspect of what the Models offer. Adherence, relating to specific adherence education, counselling and advice, and not limited to defaulter tracing and follow-ups, is considered the second most important aspect. Disclosure, hope and peer support is considered third most important.

For reliability of responses, clients were also asked *'What part of the program has been most beneficial to you? Why?'* Clients explained that they personally valued the education, adherence support, and disclosure, hope and peer support. These responses confirm what both clients and Models reported as the most important services from Models.

Clients revealed the type of education and counselling advice that Models provide, when asked about their relationship with their Model. The translation from English to Twi may have resulted in a focus on what had been gained from the Model-client relationship in terms of knowledge rather than their personal connection. Clients potentially view Models as healthcare workers rather than as peers, because of the role and hospital environment where the majority of Model-client contact takes place. Some clients stated they only know their Model as a healthcare worker, suggesting that public knowledge of the MoH concept is not high.

All clients responded that they had a good relationship with their Model of Hope. They emphasised the education they had received, by stating: *"They educate on how to eat healthily, how not to transfer sickness to other people, are very kind in the counselling"*; *"Models always do counselling for nutrition and adherence"*; *"She wants to help me and my son with a better life"*; *"the Model visits twice a month at home, educates mother too"*; and *"They encourage us, positive thinking that HIV is not the end of life"*.

The overall response from facility staff members was positive, with no staff responses explicitly identifying any negative experience. Facility staff identified the Models as being able to provide a personal approach. A facility staff member clarified that *"They help with language barriers. I have confidence that they're telling the clients the right things"*. This finding is in line with the expectation

that Models, as PLHIV themselves, are able to provide unique peer support within facilities. This peer support includes acting as a role model and providing hope to clients. One staff member in GAR said:

*“They help remove folders for the clients, and counsel them with health education. Patients will often deny their positive status, so we then refer to the Model of Hope who can explain on a more personal level. The Models say “I am one of you”. Staff assist with some follow-up calls, health education talks (nutrition and personal hygiene), counselling and adherence assistance”.*

### **Current Support & Future Improvements:**

47 out of the 49 Models interviewed receive 250 cedis per month allowance through the CSS project funded by The Global Fund. One is not currently being compensated through the CSS project due to illness, and another receives 200 cedis per month due to not undertaking any home-based activities. 2 Models in GAR each receive extra site support of 250 cedis per month; 2 Models in ER receive 50 cedis per month from their sites; and 1 Model in WR receives 200 cedis extra per month from the facility, while another receives 50 cedis per month. No Model in AR receives any extra payments from their facility, including other forms of compensation such as bonuses. Only 1 Model reported receiving a bonus in December from their facility.

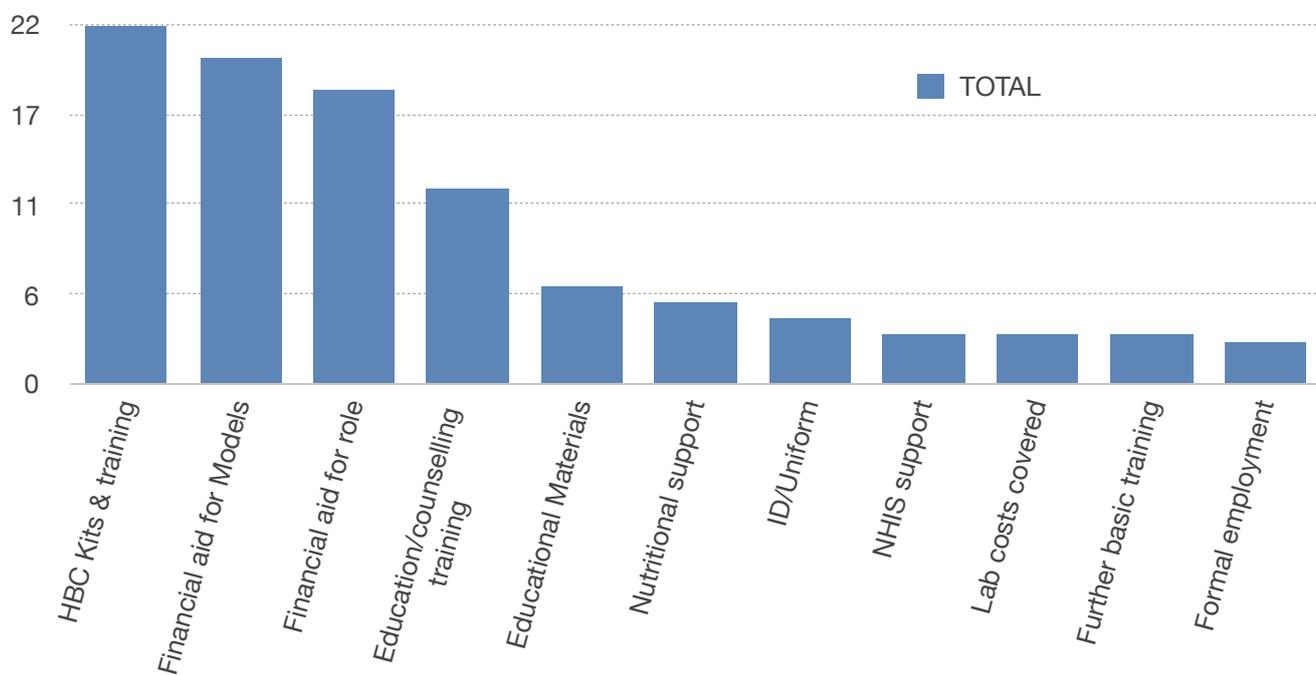
18 Models cited workshops or training from NAP+ at quarterly meetings, but generally commentary on this was reported neutrally, as Models explained that while they did receive this support, improvements could be made.

Only 1 site supplies gloves and other HBC items (cleaning supplies, disinfectant, basic first aid materials) to their Model, although other Models reported that if they require these items they take them from the facility along to their HBC client visits. 4 Models cited that they have been provided educational materials from NAP+, however stated that these come from Ghana AIDS Commission and that NAP+ is not able to print or supply these themselves. One Model complained that no staff visit the site itself, while another was confident in NAP+ because they assisted when there was an ARV shortage.

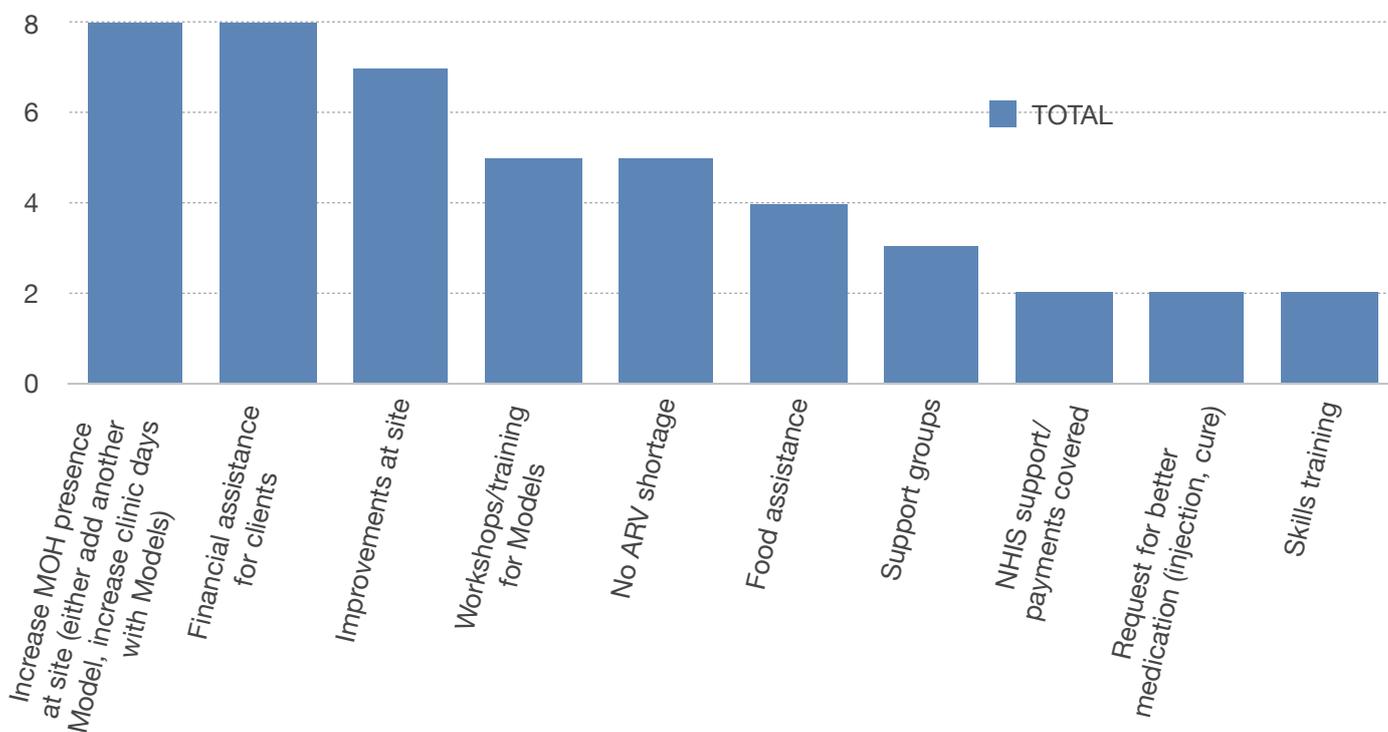
Models outlined the following five areas as most necessary to improve upon in the future: HBC Kits & training; Financial aid for Models; Financial aid for role; Education/counselling training; Educational Materials (Figure 2). For clients (Figure 3), increasing the Model presence at sites, through either more clinic days or including more Models in the program, was cited as most needing improvement. An equal number of clients responded that financial assistance for clients should be improved. Improvements to ART sites was requested, with workshops or training for Models and no shortage of ARV medications also requested by clients.

Contrary to a study by Tulloch et al (2015) of volunteer co-providers in Thailand, where co-providers exhibited low confidence in their abilities, Models of Hope in Ghana have high confidence in their abilities. Like the Models, co-providers in Thailand felt that they needed a clearer system and to receive more training (Tulloch et al 2015). Co-providers in Thailand complained of a lack of skills such as grant or proposal writing to apply for extra funding or further demonstrate their value (Tulloch et al 2015). This is also an area of opportunity for MoH, as Model capacity can be increased for those inclined to learn such skills. One Model stated that they would continue providing services even without their allowance, but would look for alternative funding. Without specific skills however, the options to search for other funding would be limited.

**Figure 2:**  
**Models: Suggested Improvements**  
 (number of times improvement was mentioned)



**Figure 3:**  
**Clients: Suggested Improvements**  
 (number of times improvement was mentioned)



## Governance, Funding & Future of the Program:

100% of Models view their work as volunteer work. However, the volunteer status of the co-provider Model role can be problematic. One Model attempts to *“recruit younger Model of Hope PLs to replace old ones, but they always want to know how much it pays. They get discouraged. I don’t know if this Model thing can be sustained”*. Another Model knows it is voluntary, and stated that without being able to see impact she wouldn’t do it. She successfully recruited someone to work in the program. Another stated that *“if we don’t disclose and do this, there would be more defaulters and more problems, but new people cannot do Models of Hope without incentive so future of project is now a concern”*. However, many Models cited the allowance as a way NAP+ has improved their governance of the program, suggesting financial motivation through the allowance does exist.

Although there is some financial motivation, when asked of their future plans if funding ends, Models overwhelmingly stated that they would voluntarily continue their work at facilities. *“First they didn’t pay us, but we came. From my experience, the money will come back”* stated one Model from GAR. In Eastern region, a Model explained that they would still come but without money for transportation each day they cannot come for every clinic day. Within these responses, Models reported that continuing work is contingent on their personal health and whether their facility would allow them to continue. Responses suggested a high level of obligation to continue assisting newly diagnosed PLHIV. Models explained that: *“I can’t stop because clients are looking up to me”* and *“because I want to help people become better as I am”*. This sense of obligation is a strong motivation, however, Models should not receive inadequate compensation or support, nor be taken advantage of by facilities through increasing their workload to mimic that of paid facility staff. Many Models revealed that they pay out-of-pocket expenses for themselves and also provide small amounts of financial assistance to their more vulnerable clients. Facility staff confirmed this, stating that some Models, nurses or administrative staff at times feel obligated to provide vulnerable clients with small amounts of money for transportation or food costs. While Models understand that their role is voluntary, there seems to be a lack of broader interest in ensuring that there is continued and sustainable funding that ensures the Models can maintain an adequate standard of living themselves. This lack of broader motivation to reward and care for co-providers is also present in the management of the Thailand program (Tulloch et al 2015).

When Models discussed NAP+, they often referred to the regional staff. This often did not refer to the NAP+ organisation overall nor to the head office executives. One Model respondent described NAP+ as *“the umbrella, so without them how can the Models do the work?”*. Many Models have experienced the project being governed by multiple different organisations, but appear to understand the need for, and desire, structure and governance. There seemed to be limited confusion surrounding current structure and Models understood how the project was situated between NAP+, WAAF, and CSS Project.

When asked if the capacity of NAP+ had increased, 37 Models responded ‘yes’ while providing detailed and often critical responses; 1 responded ‘no’; and 3 provided neutral responses. The neutral responses included the comment: *“Prior NGOs did better with extra funds for emergencies and management of funds”*, with other Models stating that before CSS Project funding for MoH was in a similar state. One stated *“They can do better, doing well but should provide more and better training; bring back support groups to stop defaulters”*.

Detailed responses included Models stating that:

- there are issues with sustainability of the project, and concerns about NAP+ because of low allowance, including fears for recruitment of future Models;
- since CSS there is allowance and improved workshops; there have been good outreach programs, refresher training, and staff/executives are better than previously;
- NAP+ capacity at first was not good and that WAAF provided them structure;
- the CSS team don't ever check-in at facilities, only the NAP+ regional staff check-in;
- the allowance increase helped, but data collection makes it too difficult to track clients for defaulter tracing/follow-up, a small computer system or similar would help;
- due to the motivation [allowance], Models now have the power to 'stand up' [for clients], disclose and provide support.

One Model expressed disappointment with their 'no' response, stating that NAP+ is *"Not good because allowance is small; spoke with them but no resolution or improvement. Capacity has improved a little. Matron [of facility] provides food supplements, NAP+ doesn't"*. Another said their capacity had increased but not as expected, and cited financial issues and no direct funding alongside a lack of transparency as problems; they continued by saying donors should encourage NAP+ to put what they've learned into practice, but that there are issues because the executive committee doesn't let the structures work, such as informing relevant stakeholders. Another Model doesn't trust NAP+ in finances because of previous staff, and wants to set future money aside for emergencies like children's hospital bills. Other respondents stated *"It should be better than this"*, *"NAP+ is all about the support group so without that they are not good"*, and that the *"problem is zero cash, without money you can't move"*. One Model was particularly critical, stating that while NAP+ capacity has improved, *"Those at the bottom work and get nothing, and those at the middle and top get so much, keep it for themselves"*. Expectations for NAP+ are high but not unrealistic, and suggest that there is still a way to go in terms of adequate structural and financial management.

29 Models believed they could go to NAP+ for complaints or suggestions, while 6 did not. As one Model elaborated: *"Not for anything. Who is there to complain to? There's no extra allowance or funds"*, while another reiterated this by saying they *"Leave it because NAP+ always says there's no money to do anything extra"*, with a third confirming that it is possible to contact them *"but they always say they don't have any money to help you"*. This emphasis on lack of financial assistance may be related to the type of requests, such as emergency payments for vulnerable clients. One Model took issue with their regional executive never visiting, and even though they complained to NAP+, nothing was resolved and the executive still does not visit. Those who have had positive experiences with NAP+ stated that they requested workshops which were added; a NAP+ staff member spoke with nurses who had discriminated; or that they assisted with ARV shortage issues.

A similarity shared between the Thai volunteer co-providers and Ghanaian Models of Hope is one of project financing, as both programs have at times experienced lack of a funding mechanism or sustainability, even though there is public recognition for volunteer PLHIV workers as a valuable healthcare resource (Tulloch et al 2015). In Thailand, minimal funding is supplied by central or localised government, however, co-providers reported that insufficient budgets were a recurring concern despite the integral role the co-providers played (Tulloch et al 2015). The concerns with NAP+ often focus upon financial aspects of governance and the view by some respondents that funds can be mismanaged. Requests for assistance appear to go unfulfilled due to lack of an emergency pool of funds to draw from.

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## A.R.T SITES & FACILITY STAFF

The research team attempted to interview facility staff members holding a higher position within each site, such as the in-charge nurse or administrator, although when this was not possible, a nursing or other staff member provided the interview. At only one site did the staff refuse to cooperate to provide an interview, while at multiple sites staff could only provide a limited timeframe, and some questions were omitted during interviews because of pressure to keep interview time to a minimum. HIV Testing and Counseling (HTC) - previously called Voluntary Counselling & Testing (VCT) which is still in use across multiple facilities observed during data collection, as VCT Centres - has been recognised as key to HIV prevention and treatment programs (Koku 2011), although uptake of testing is still considered to be low. To encourage voluntary testing, individuals must not fear consequences such as stigma if their diagnosis is HIV-positive. Many of the MoH ART sites were labelled as VCT Centres.

Comments from Models regarding the state of facilities included:

- no privacy at site, clients mix with other departments' clients in waiting rooms;
- staff share an office, so little privacy for counselling which they often cannot do;
- at another site, stigma is an issue amongst wider hospital staff and training is now in action to stop it;
- it is difficult to request anything for sites, it has minimal private space (only one open room for all activities).

The financial constraints faced by Models are apparent in many of their comments throughout the case study. One Model stated: "Young nurses should be trained to replace Models, they get financial reward so should be doing it". However, the general constraints at ART sites are significant, and influenced by the lack of wider support for the sites and staff at such facilities. Facility staff were asked to detail the types of support offered at the ART site and to the MoH specifically. The term 'support' was used to refer to financial assistance, on-site or workplace training, and printed educational materials or supplies used by Models in their everyday activities (such as HBC supplies of hand sanitiser or minor first aid supplies).

It was revealed that only 5 facilities offer extra regular financial support to their Models (in addition to these Models receiving the allowance provided under the CSS project). Two facilities in the ER responded that the *"hospital sometimes pays 40 cedis per month to each Model"* and that there are *"bonuses only, no regular incentives"*, respectively. One facility in the WR provides 200 cedis per month to their Model, gives them training and workshops and invites their Model to monthly meetings within the hospital. This facility sets a good example with their inclusion of the Model of Hope into their regular activities, and provides a high level of care to their PLHIV clients.

14 facilities confirmed that no financial support in any form was provided to Models. In the AR, one staff member clarified that: *"they've fought the hospital for support but no luck"*. Such responses indicate that facility staff are aware of broader issues with hospitals not actively supporting ART site activities, and particularly in relation to management infrequently supporting Models of Hope as co-providers within their facilities. Staff at one facility in the WR explained that *"management don't see Models as such good things"*.

Significant issues exist in the ways that hospital management staff view the MoH, whilst simultaneously taking advantage of their role as co-providers within their ART sites. It is possible

that there has not been enough advocacy on behalf of the MoH from governing organisations to enhance the views of management staff who may not have knowledge of the Models' day-to-day contribution. The study by Tulloch et al (2015) provides further evidence that co-providers provide beneficial interventions to PLHIV such as peer support and solidarity, sharing of experiences, education, and alleviating feelings of isolation; they also reduced the workload of facility staff.

Almost all facility staff in all regions responded that they receive the 50 cedis per month from the CSS project. There were very few complaints of it being late. Most facilities employ these funds for phone credit to complete follow-ups and defaulter tracing, however some facilities utilise it for other tasks such as: emergency travel costs for clients; NHIS renewals, and food supplementation. There were minimal instances of the in-charge being unaware of such funding, but occasionally the pharmacist or data officer received the funds and were uncertain of what was done with the money.

15 clients had accessed HIV and AIDS services at another healthcare facility; from this, 5 respondents in GAR cited negative experiences at other facilities; 5 respondents in GAR had positive experiences at other facilities. 1 respondent reported a neutral experience at another site, while 1 respondent explained that while not experiencing stigma at other sites, individual people can be either rude or helpful. Client in AR provided no responses to this question. In ER, 1 respondent stated that the other site visited provided a negative experience because there you "must hold onto your own folder" (registration folder containing your details at the site), while at this new ART site you did not. 1 respondent in WR answered that at one of the large teaching hospitals they had to move between many departments, therefore they had a negative experience. Many of the negative experiences referenced issues with the ART site itself, either because there was increased fear of stigma due to the process, or experienced stigma from staff. It was common for clients to discuss problems with the site that prevented privacy, such as having to utilise a waiting room with clients from different departments, or having to collect their medications from a shared main pharmacy.

### ***Laboratory Costs:***

Distinct discrepancies were found across all ART sites relating to the costs of laboratory testing. Newly diagnosed clients must undergo a range of initial tests to confirm their HIV status and uncover the state of their infection, however PLHIV who have defaulted must also retake such tests to ensure correct medications and care are obtained. Respondents reported that at some facilities, presentation of NHIS cards results in discounted laboratory tests. However, standard testing ranges from free to 300 cedis for 'baseline labs' (explained by the majority of participants to be inclusive of liver-kidney function test and full blood count test). Other testing, including viral load testing and immune system function testing (for CD4 count) were reported to be an additional cost, and are often unable to be completed at many sites due to possessing only a basic laboratory setup. Many of the ART sites visited during data collection had an on-site laboratory. Sites that do not must refer their clients to another facility, increasing the likelihood that these clients will be lost during the process. High costs of labs contributes to clients being LTFU, or defaulting, because of the challenge to pay out-of-pocket for these expenses.

There are discrepancies when Models or staff inform clients of laboratory costs, potentially contributing to LTFU. It was particularly worrying that in GAR, sites that do not have access to an on-site laboratory refer clients to Korle-Bu Teaching Hospital for testing, telling clients that this will cost 90 cedis (reported by multiple Models and Facility staff across GAR). However, at Korle-Bu it was reported that clients find they must pay upwards of 200 cedis for baseline labs, a significant

increase in cost. Such a discrepancy in the dissemination of information would increase the chances of such clients not obtaining their laboratory tests, and therefore these clients would not be enrolled onto ARV treatment.

### ***Key Population:***

There were three situations revealed for key population (KP) clients such as men who have sex with men (MSM) or female sex workers (FSW). Firstly, some facility staff explained that when aware of KP clients, there is no special treatment required and they reported good relationships with these clients. Secondly, some facility staff reported that their KP had requested specific clinic days or times, and sometimes this is possible for the facility to accommodate, however sometimes it is not. Thirdly, there were some reports that facilities 'do not have such clients', which could be attributed to multiple reasons, including the KP clients not visiting these facilities or not confiding in any staff members.

4 staff members across 4 facilities reported KP clients requesting a different clinic day, which only 3 of these facilities organised such a day. One staff member in ER told us that KP often don't confide in staff, but that "Everybody who comes here deserves service" and FSW are provided condoms if they are known to the staff. 3 staff interviewed stated that KP clients come with monitors, often from an NGO. One facility staff member of Ashanti region stated she doesn't "let them mingle with a lot of the staff for fear of stigma". Several staff members mentioned that targeted training for KP exists, but it appears that many current staff have never received such training. Stigma was mentioned by multiple staff, with one stating "*We stigmatise, some people, without getting close, you must know. But you cannot refuse health service to any of mankind*". This shows a desire on behalf of some staff to provide adequate care to all PLHIV, but there is an awareness that not all staff are this way inclined.

Processes for KP are facility-specific but also specific to the staff (their training and expertise but also personal disposition). This case study did not focus on KP, and therefore there are no significant findings to be reported. Areas for further study include examining individual staff attitudes towards KP, existence of stigma at facilities, and capacity of the facility to provide extra or specific support to KP clients.

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## HARDSHIPS & CHALLENGES: BARRIERS TO ADHERENCE

Hardships include barriers to care and personal challenges that affect healthcare-seeking behaviour and ability. This affects clients but may also be experienced by the Models themselves. Costs incurred throughout HIV treatment can include extra medications for infections or other illnesses; fees for laboratory tests; transportation costs to and from facilities to collect ARVs or to visit a doctor or pharmacy; and the cost of nutritious food (Kwansa 2010). There are conflicting reports regarding the cost of ARV medications. Some state the ARVs cost USD\$5 per month, or that some ARVs are covered by the National Health Insurance Scheme (NHIS) (Kwansa 2010). Other facilities appear to charge 5 cedis per month. There is anecdotal evidence that many facilities provide ARVs free of charge without the NHIS, while other facilities still charge a fee.

Across Sub-Saharan Africa, there is a distinct relationship between HIV and AIDS and embedded social inequalities such as food insecurity and malnutrition, and poverty (Mensah, Okyere & Doku 2015). There is currently a lack of data to understand how HIV-positive Ghanaians and their affected households cope with the infection and accompanying costs (Laar et al 2015). However, there is evidence to suggest that because the number of female PLHIV is higher than males (at least those who are known through testing and treatment), there is a gender divide that negatively affects the wellbeing and security of HIV-positive women and their children (Mensah, Okyere & Doku 2015; Poku et al 2017). This is because women potentially have restricted power in Ghana, affecting their ability to negotiate condom use and financial dependence, but also because of increased likelihood of their male partner having multiple other sexual partners (Mill & Anarfi 2002; Anarfi & Owusu 2011; Poku et al 2017).

Gyasi et al (2016) investigated the reasons behind both urban and rural people seeking traditional and alternative health treatments, uncovering that there appear to be certain factors 'pulling' clients in, and other external factors 'pushing' clients to alternative treatments. Some of the pull factors included the appeal of natural remedies over chemical medicines; the belief that natural alternatives have fewer side effects; and beliefs surrounding the spiritual nature of illness (Gyasi et al 2016). Push factors included negative client experiences of hospitals, such as long wait times, distrust of medical professionals, and considering biomedicine a foreign, and therefore less desirable, system (Gyasi et al 2016). Studies have shown that patient distrust of medical personnel is rooted in health professionals having inappropriate attitudes and inadequate knowledge which contributes to a breakdown of patient-professional relationship (Aziato & Adejumo 2014). The study by Gyasi et al (2016) found that pull factors relating to personal beliefs and values were more influential than external factors pushing individuals to seek alternative treatments.

It can be determined from the responses gathered within this case study that such hardships, barriers and challenges contribute to and explain why PLHIV default from their medications.

Clients were asked about the challenges they faced before regular contact with their Model. Health issues were mentioned by 13 respondents, and related directly to HIV symptoms but also to experiencing other illnesses. One client admitted that he couldn't walk on his own before, and was very sick before his HIV diagnosis. After diagnosis and referral to the current site, he was in denial and didn't understand, before the Models counselled and helped him. Another client stated that she was in a *"bad state, was very sick; taking herbal medicine with bad nutrition"*. A client from ER explained that *"Before, I had to come early to pick folder then go to OPD and see doctor. Now, work is shared by Models and staff and is quicker"*. Models assisting in ART sites alleviates

pressure from existing staff and can contribute to better outcomes for clients. However, care may need to be taken that Models are not covering staff tasks instead of attending to clients in their capacity as Model of Hope. Another client reported that she experienced skin rashes and health problems, before starting to adhere to her medications with her Model. A client of WR shared that *“people don’t understand HIV, so when first diagnosed I didn’t know how to tell anyone; had malaria on and off, loss of appetite”*. It is clear that Models are able to assist their clients through education, encouraging them to take better care of themselves and increasing their confidence to live with HIV.

Issues with the facility were mentioned 12 times, with financial challenges only mentioned 3 times. The low frequency of client responses of financial challenges contradicts the findings in Figure 4 where 87.5% of clients explained that financial difficulties had affected their health. This supported the researchers’ initial assumptions that respondents would emphasise economic challenges. Many clients actually held current employment (at the time of interviewing): 1 client held informal work; 28 held full-time employment, and 10 clients were unemployed. The findings suggest a bias, and that significant personal financial challenges may not be as commonly experienced as are reported. The findings suggest an increase in reporting of financial challenges at certain times, such as to Models or facility staff, to increase the likelihood of receiving assistance. This is discussed further within the next section on adherence and defaulting.

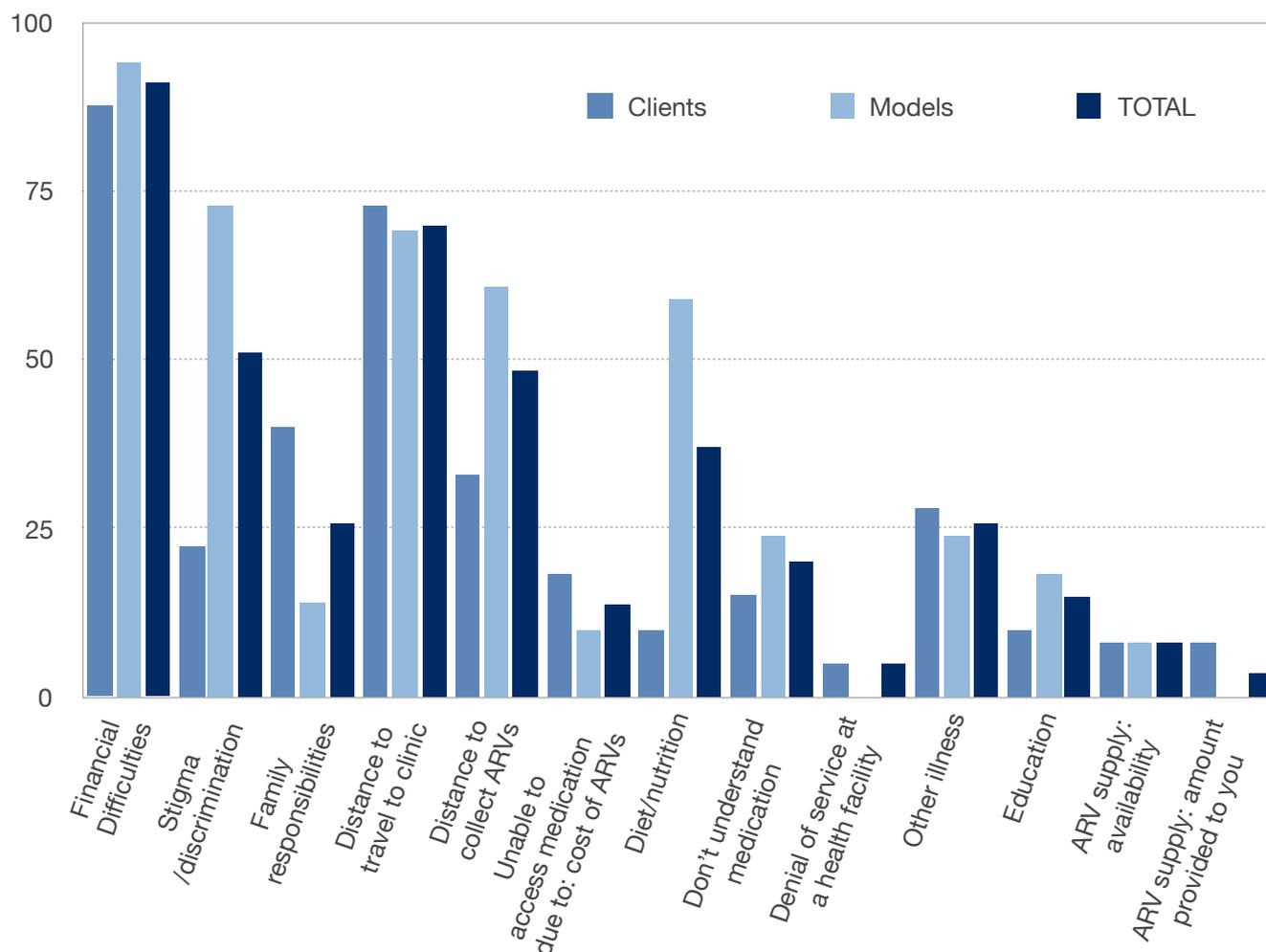
### ***Challenges to Adherence & Links to Defaulting:***

Several questions were asked to determine the challenges that clients face when adhering to their medications, but also the challenges that Models face through adherence counselling and tackling their defaulting clients. Figure 4 (below) were able to compare the responses from Models and clients. It was expected that the general category of Financial Difficulties would be most reported, by both Models and clients, therefore this was included as a control category.

Distance to Travel to Clinic was most frequently reported by both Models and clients (70.7% of 89 respondents, Figure 4); and Distance to Collect ARVs was second most frequently reported by both groups (48.3% of 89 respondents, Figure 4). These are the only two categories where responses from both groups coincided as affecting the health of PLHIV most frequently. Other Illness was reported as a challenge for 25.8% of 89 respondents (Figure 4), and was close to being equally reported by both respondent groups. Therefore, this is considered the third largest challenge for PLHIV in regards to their health. These three categories are agreed upon as most important by both clients and Models. That other categories had variations in responses indicates that Models perhaps have limited understanding of some of the challenges facing clients, but it is also likely that clients report different challenges to Models during their visits because of other motivations.

Many clients reported travelling long distances to visit an ART site that they feel comfortable with, or to avoid meeting people they may know at nearby facilities. This increases financial strain due to higher transportation costs. Family Responsibilities were reported as a challenge by 40% of clients (Table 6). This could indicate financial strain for PLHIV when supporting a family, or personal and mental hardship related to non-disclosure of status yet having family responsibilities that are challenging for those of poor health. According to Laar et al (2015), the burden of HIV falls hardest on women, as in Ghana they carry responsibility in a household to care for the sick, and face more difficulties than men when attempting to engage in economic activities outside the home. If the HIV-positive person within a household is female, the economic, physical and mental

**Figure 4:  
PLHIV Challenges (%)**



burdens on that individual could increase the likelihood of economic pressure on the entire household. However, it is worth noting that Family Responsibility was reported as a challenge for 14 of the 31 female client respondents (45%), and 3 of 9 male client respondents (33%). Further investigation would be required to determine the extent of differences in experience for male and female PLHIV.

There were differences when comparing Models' responses with clients. Family Responsibilities was highly reported by clients (40%) and low for Models (14.2%). The Stigma/Discrimination category was highly reported by Models (73.4%) with lower figures for clients (22.5%). This is a significant difference which would need to be further investigated, but could be due to multiple factors including over-reporting by Models, or inability to identify stigma or discrimination on behalf of clients. Diet/Nutrition as a challenge for clients was reported by 59.1% of Models, however by only 10% of clients (Figure 4). This is an interesting category, as nutrition is often related to the clients' ability to afford an adequate diet to stay healthy. This indicates that adequate nutrition may not generally be a challenge for PLHIV, and this correlates with the client demographics (Table 1)

These points highlight some of the challenges, and can inform future training for the Models, particularly in relation to Models being able to understand client bias. Clients may complain about particular challenges during counselling with their Model, however, their true challenges may in fact be different. An example of this may be a client complaining of a lack of money for food that day, or being unable to afford food that week for the family. However, during their interview, this same

client may have responded that Diet/Nutrition is not an issue for them, but rather another challenge is their main concern during their time living with HIV. There could be motivation on behalf of some clients to over-report to Models their struggles with finances, especially if Models or facilities have previously set the expectation that there is a possibility of financial assistance. One facility in-charge provided an example of this: *“Sometimes clients who have received money or support for things tell other clients “Oh just tell them you don’t have money”. They talk together at clinic days, sometimes for support but other times it has bad results”*. This highlights some of the challenges to obtaining accurate, reliable data from PLHIV in Ghana. They can be motivated to emphasise different aspects of their experiences to benefit, sometimes financially. The researchers attempted to account for this by incorporating the Financial Difficulties category first, and as the example provided to respondents, eliciting this response immediately and showing awareness of economic challenges.

Currently, data is taken for HBC clients when they enrol in HBC and when they become healthy and exit. HBC clients appear to frequently be those who default from their medications, but are not routinely monitored to determine their reasons for defaulting. Models were asked: *‘Do clients who become healthy (and therefore exit the program) ever return to poor health and need to re-enrol in the program?’*. An example scenario was provided to most respondents as ‘a client who becomes ill - either requiring admission or HBC, who then recovers, but falls ill again’. 43 Models responded ‘yes’ while 4 responded ‘no’, and many provided specific examples of recent clients to illustrate the difficulties in maintaining client adherence.

With regards to clients defaulting multiple times, and needing HBC, Models revealed that other illnesses such as malaria and STIs, as well as side effects of ARV medications, caused defaulting most often. Models provided further explanations through anecdotes of clients who had defaulted multiple times. One Model explained that clients *“Come to hospital, are admitted and take meds and feel OK again, then stop meds again and so on”*, indicating that it is difficult for some clients to come to terms with having to take medication everyday while they may feel healthy. Another Model reported that clients have *“stubbornness to disclose and so stuck in this cycle because lack of family support. One female client, 40, refused disclosure [to family], but was educated, and had to have HBC for five months but died”*. Although stigma was rated second (often perceived stigma or self-stigma) it will be discussed in more detail in the Disclosure, Stigma and Discrimination section). Clients also default because of obligations, particularly for funerals involving long-distance travel, but also gaining permission from work for time off, and general difficulties remembering or coming to appointments. One Model had a client suffering from an illness, who *“started taking meds again but two months later defaulted again due to travel, but now doing well”*, - a positive outcome.

Alternative treatments such as seeking pastor advice, attending prayer camps, or seeing herbalists contribute to defaulting and reasons for clients requiring HBC or admission to hospital. One Model stating that *“Especially when pastors advise”*, it is problematic, *“clients get adherence counselling but some have defaulted again, some died”*. In regards to alternatives, another Model divulged that a *“32 year old lady came to hospital and was admitted again, stopped meds because pastor gave her herbal ‘cure’ and she later died”*. Another client defaulted multiple times because he prioritised herbal medicine over taking ARVs. A Model has one client who is a pastor, who they traced and although he returns, he defaults often because of stigma and self-stigma, which has been occurring for 4 years. Another client defaulted multiple times because he prioritised herbal medicine over taking ARVs.

One client who was previously a Model of Hope herself was very sick, and other Models went for home visits with her until admitting her to the hospital where she recovered. However, she defaulted again and became sick and died. The Model recounting this story said there is no reason to default, but clients are tired of taking medications. This story shows that even with a high level of education, adherence is still a choice that can be affected by other factors. Other illnesses and side effects of ARVs appear to be a major factor, as one Model explained: *“One man defaulted 2 times; 3 weeks ago he was admitted and I realised he was old client but opportunistic infections were too much and he died”*. Another Model claimed he currently had multiple defaulting clients which was mostly from ignorance, and that PMTCT mothers often did not return to clinic.

**Figure 5:  
PLHIV Reasons for Defaulting (number of responses)**

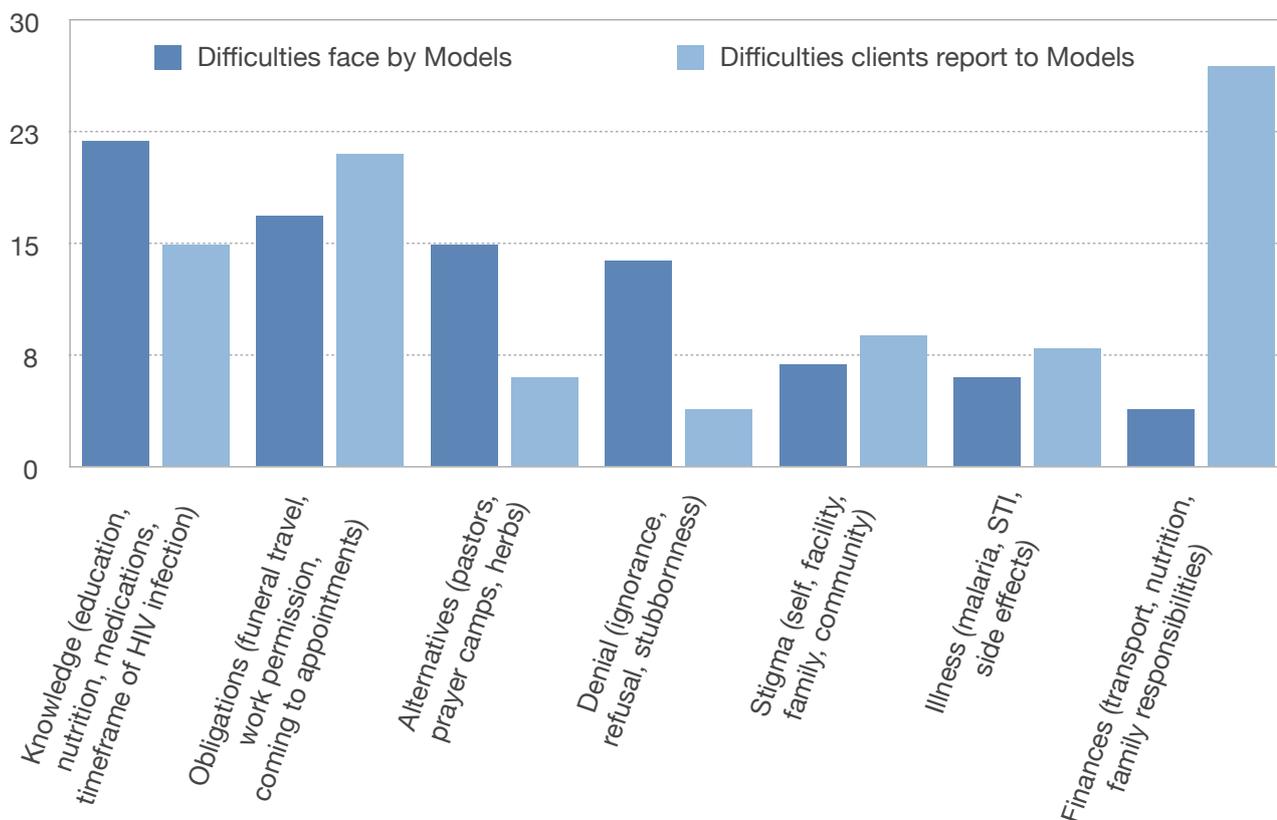


Figure 5 shows findings from two questions asked of Models to determine reasons behind defaulting: *‘What difficulties do you face in helping clients with adherence to medication?’*, and *‘What are the difficulties that clients most often report to you, in regards to adherence?’*.

As already discussed, there may be differences in what Models observe of their clients, and what clients most often report to them. Here, it can be seen that clients most often report financial challenges to their Model, while Models considered Finances to be the least challenging factor when encouraging clients to adhere. Models considered level of client knowledge the most challenging aspect of their role. For both questions, Obligations was referenced second, which includes challenges surrounding clients often travelling long distances and for extended periods of time to attend funerals, but also issues with clients remembering appointments or being able to obtain permission from their workplace for time off to attend clinic and collect ARVs. Obligations relate to their clients’ responsibility in managing their lifestyle and health.

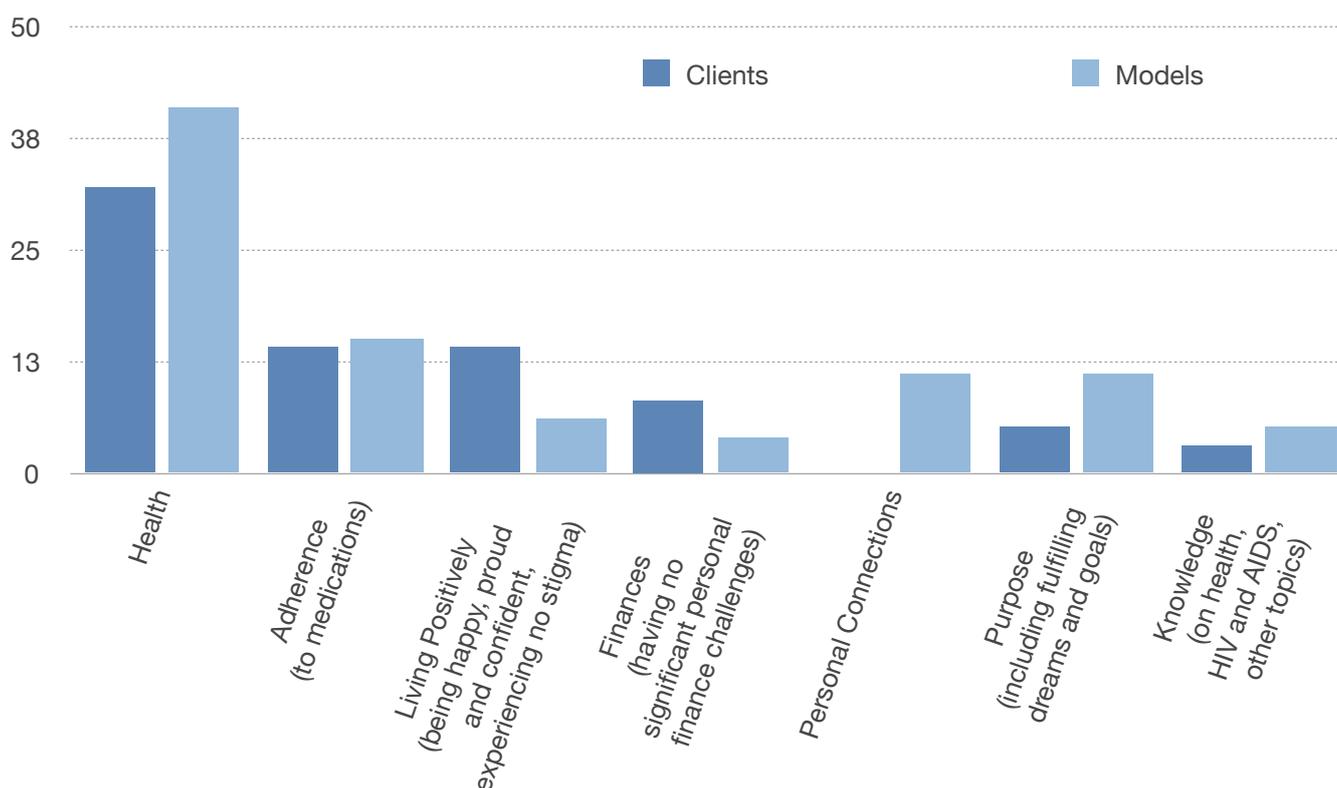
# WELLBEING OF PERSONS LIVING WITH HIV & AIDS

## Quality of Life:

Quality of life is a concept often mentioned in healthcare settings. It is used as a way to measure a patient’s personal wellbeing Finn & Sarangi (2008). Quality of life (QoL) is considered to be a “measurable outcome of health policy, health-seeking behaviour and overall life satisfaction” (Finn & Sarangi 2008, p. 1568), and in relation to HIV and AIDS, peer co-providers are important in contributing to their clients’ quality of life (Tulloch et al 2015). The role of social support has more recently received more attention in developing countries (Bajunirwe et al 2009; Folasire, Irabor, & Folasire 2012; Avornyo 2013; Anafi, Mprah & Asiamah 2014; Abrefa-Gyan, Cornelius & Okundaye 2016; Poku et al 2017), including a focus on the concept QoL for PLHIV and stigma reduction. “Yet, there is a plethora of evidence in Europe, Asia, and North America indicating social support as the strongest predictor of overall [quality of life] of people living with HIV and AIDS” (Abrefa-Gyan, Cornelius & Okundaye 2016, p. 206). This case study revealed that PLHIV in Ghana define quality of life through factors such as a person’s physical and psychological health, including their ability to adhere to medications; social relationships, their personal beliefs, values and being able to fulfil personal goals or dreams; their financial situation; and the environment in which they live.

Clients were asked questions regarding what QoL means to them. Respondents were at times prompted using the phrase ‘living positively’, due to familiarity with this phrase and belief that the

**Figure 6:**  
**Quality of Life (number of times category mentioned by respondents)**



essential meaning is closely tied to that of 'quality of life'. Respondents answered these questions from a personal perspective from their own experiences and knowledge.

Both Models and clients prioritised Health and Adherence as the two most important factors in having good QoL (Figure 6). However for clients, Adherence was tied for second with Living Positively. The third highest priority for Models was Personal Connections, while for clients it was Finances. The collective sample size of Models and Clients (89 respondents) means that 82% of respondents prioritised Health as the most important factor of having good quality of life as a PLHIV. 32.5% of collective PLHIV respondents believe Adherence is an important factor, while 22.4% value Living Positively. Only 13.4% of PLHIV respondents valued Finances as important to QoL. This seems to contradict responses regarding personal challenges where Financial Difficulties (including for transportation costs and cost of a healthy diet) were ranked highest (Table 6 and 7).

Clients overwhelmingly responded that their QoL had improved since contact with their Model. When asked to elaborate, clients responded: *"Whenever they're [Models] around they make you happy and forget about the problems you have"*; *"Because Model is now a role model it is easy to understand how to live"*; and *"Now I know how to take care of myself by taking medications and not take alcohol and herbal medicine and to eat good balanced diet"*.

With regards to the two clients responding 'no', they provided the following detailed explanations: (1) Because of his age, it [QoL] hasn't improved but stayed the same. He is unsure if that is because of his age or the disease; (2) Health has not been the best, talking to doctor about problems today. These responses indicate that their QoL has been affected by other health concerns beyond their HIV status, but that they may indirectly relate the lack of improvement to their QoL with the MoH program. For the 1 'undecided' response, the client reported the following: (1) Not as she used to be since medicines started. Education has improved her life and she has had HIV negative babies. Here, it can be seen that through the MoH education she has seen improvements, but that she potentially has concerns about the medication side effects which are not related to the program. Many clients who reported a positive increase in their QoL directly related this increase to their MoH.

All Model respondents stated that their QoL had improved because of their role as a Model, particularly through the gaining of knowledge. One Model stated *"Yes in terms of knowledge it [QoL] has improved"*; while another explained that through education she has learnt to be able to live her own life as she wants, and adhere and protect others. One respondent was eager to *"learn more and gain knowledge, and apply it"* because she had gained wisdom to share with other PLHIV. One Model admitted that initially, she didn't encourage herself to live well, but now knowledge has given her the ability to support her children. Having knowledge on HIV, on the medications and general health is empowering to PLHIV, allowing them to take control over their health and lives. It also allows them to feel confident when disclosing, as educating others is an important aspect of disclosure. The act of sharing knowledge with peers and others through education or counselling is therefore considered to be the most empowering aspect of being a Model of Hope. Personal attitudes and feelings, such as acquiring confidence, being happy, proud or bold are also considered important by many Models. One Model stated that most of his contacts are clients; when he counsels he feels good, he likes to educate, and people respect him at his site. Another Model has helped some clients to have a better life, and explained that anytime she disclosed her status to client it motivates them to adhere and understand how to live with the virus.

The personal connections made during their time in the role and sense of purpose they felt as a Model were also important, as they can now confidently participate in community life. Literature has found a positive relationship between QoL and overall social support (Sun et al 2013; Peter et al 2014; Abrefa-Gyan, Cornelius & Okundaye 2016). The findings show that PLHIV value personal connections, and support from others is key, whether it provides a monitor, peer or family support, or financial assistance when needed. Models indicated that having purpose increased their quality of life *“Because people are looking up to you”*. For Models of Hope, having a purpose through the role allows them to feel fulfilled, and fulfil other personal dreams and goals.

Gaining confidence through the role was important to Models, as this allowed them to support, advocate for, and protect PLHIV. One Model said that at first he had self-stigma and was shy, but now is bold and counsels others, and stands publicly; while another stated that when people don't accept her she can stand up; it *“changed [her] bad attitude to do good”* and she now follows steps to protect others. She also stated that the allowance is used to pay for her children's school fees. A Model in AR was once sick, and another PLHIV assisted her as a monitor so she wanted to do the same to others; she reported that she is happy with the work and feels proud. Another revealed she cannot read or write, but learnt so much from the role through training and education. Before she *“was not doing anything, but now I wake up, dress up, and go to counsel someone”*. One Model in GAR feels confident now, is building relationships, and is sociable, and professionally has been taught a lot through the role. Another Model feels happy and proud of helping those who may have killed themselves, and has clients always calling her. One Model said: *“Being at home leaves you to think too much so feel happy coming to be a Model and encouraged to talk with a lot of people; financial incentive is able to help with transportation; stopped self-stigma and I gained knowledge and purpose, happy to encourage others”*.

Such improvements made to the lives of Models can also be imparted to clients through the program. By educating clients and their families, and working towards ways for clients to find purpose too, PLHIV in Ghana can also be provided with knowledge and purpose. Having good quality of life means overcoming factors such as denial, hopelessness, poor health, lack of familial support and even financial constraints. However, these can, to an extent, be tackled through better education and imparting knowledge.

The main motivations for Models to continue working in their role were obligation to others, and a desire to help or impact others. Many Models had experienced a particular personal event where another PLHIV supported or impacted them, providing fuel for their desire to do the same for others. Only 3 Models cited the financial allowance as part of their motivation, indicating that Models have a strong commitment to the role regardless of financial compensation.

The majority of Models interviewed had participated in a support group in the past (44 respondents), often external to the MoH program. Interest in reviving support groups was high, as respondents explained that such groups were helpful and provided positive experiences, including more opportunity for education. For clients, only 6 had participated in support groups run by a MoH. Within this, 5 clients had been enrolled with their MoH for 5 - 10 years, while the average enrolment is 3.5 years, suggesting that MoH support groups had not been active for at least 1 year. Specifically, PLHIV who attended NAP+ support groups for longer time periods reported higher QoL (Abrefa-Gyan, Cornelius & Okundaye 2016). However, one of the major barriers to sustainability of support groups is related to the current expectation that attendees are paid a small amount for travel or food. Setting this expectation potentially damaged the integrity of such groups,

as PLHIV only attend when there is funds to access, rather than attending for benefit in areas of peer support, education, and gaining knowledge.

Some key stories shared by clients who had attended support groups included: learning how to use condoms and prevent STIs; learning about family planning, nutrition and living positively. There is evidence that support groups have been helpful to PLHIV, especially groups with multiple functions such as being sources of education and advice on personal and more generally shared experiences (Tulloch et al 2015). Clients who had not attended any support groups showed interest, particularly if the location was convenient, and expressed interest in further learning on HIV topics; one client stated they would join so long as attendee names would not be publicly advertised.

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## DISCLOSURE, STIGMA & DISCRIMINATION

Stigma and discrimination still remain barriers to prevention and treatment of HIV and AIDS (Fenny, Crentsil & Asuman 2017). Many PLHIV can be hesitant to engage in informative discussions because of stigma and discrimination, which still remain major challenges to the prevention of HIV transmission, as well as acting as barriers to treatment in Ghana (Adej, Danso-Bio, & Diko, 2012). Stigma can manifest as an experience of stigma and discrimination in everyday life, as self-stigma, and 'anticipated stigma'. 'Anticipated stigma' occurs when a PLHIV perceives a high chance of social rejection upon disclosure, while others may experience internalised stigma - more colloquially known as self-stigma - and also suffer poor psychosocial wellbeing (Earnshaw & Chaudoir, 2009; Dako-Gyeke et al 2015). Stigma mechanisms for PLHIV are related to their psychological, behavioural and health outcomes, particularly as they encourage a secrecy surrounding diagnosis that negatively affects prevention and treatment (Rankin et al 2005); those who experience stigma or discrimination from others may experience equally lowered wellbeing and distress as those who experience anticipated stigma (Dako-Gyeke et al 2015; Poku et al 2017). Anticipated stigma has the potential to affect PLHIV behaviour and wellbeing, including healthcare seeking behaviour, disclosure and adherence to medication. Self-stigma leads to isolation, self-blame and loneliness (Herek, Gillis & Cogan 2009; Anafi, Mprah & Asiamah 2014).

A common perception in Sub-Saharan Africa is that HIV infection is a consequence of immorality (usually sexual) or punishment from God, and therefore PLHIV are considered responsible for their infection (Anafi, Mprah & Asiamah 2014; Dako-Gyeke et al 2015). This cultural conception of the cause of HIV can influence the fear of blame and stigma, as well as the likelihood of another person enacting stigma against PLHIV. When stigma is enacted, it manifests through discrimination, and can occur through loss of employment, physical or verbal violence, and social rejection (Letamo 2004; Earnshaw & Chaudoir, 2009; Anafi, Mprah & Asiamah 2014). All of these manifestations were described throughout this case study, although enacted stigma was most often present for Models at home, while for clients it was at healthcare facilities.

### *Disclosure:*

Of 40 client respondents, 15 knew of their Models' status, while 21 did not know. This was sometimes contradicted through other responses, as clients would say that their Model often did group education or counselling and discussed their status. This could be explained through client denial and disbelief of their Models' disclosure, and warrants further investigation to understand. A prominent feature of the MoH program is the act of disclosure to give hope and peer support. It was explained to us by several Models that disclosing is stressful and emotional, thus you cannot disclose to every client. At some facilities, the in-charge staff member we spoke to clarified that Models are at times only brought in to disclose and counsel when staff are faced with a particularly difficult client.

46 Models had revealed their status to family or friends. Models revealed a variety of reasons and experiences for this question, including: 36 disclosed to gain a monitor or for support; 3 experienced external disclosure of their HIV status to a third party without their permission; and 2 experienced family neglect after disclosure. 1 respondent admitted self-stigma, while 2 explained that they could not be stigmatised due to their level of self-care and self-assuredness. One Model

stated that “I know my rights, you can’t stigmatise me” and explained that now she has the knowledge to help herself.

The high rate of Models disclosing appears to be in line with the expectation that Models are more willing to disclose their status to others. However, clients seemed equally as willing to disclose to their family or friends, indicating that the need for family support outweighs the potential risks for disclosing.

### ***Experienced Stigma & Discrimination:***

11 clients had experienced stigma or discrimination; 35 of 40 had disclosed to family or friends. However, when asked if they had discussed their experiences with their Model with other PLHIV, family or friends, there were equal numbers who had discussed and who had not, suggesting a limited desire to disclose details of personal experiences with others. Clients experienced stigma in a healthcare facility (5 respondents) more often than in their community (4) or at home (3). Clients often did not wish to discuss in detail their experience of stigma or discrimination, however, 2 respondents explained that someone who knew their status disclosed the clients’ HIV status without the clients’ permission. 1 respondent revealed being neglected by family after disclosing. 2 respondents answering ‘no’ mentioned self-stigma; while they had not experienced external stigma, they were aware that they stigmatise themselves.

32 Models revealed that they had at some time since their HIV-positive diagnosis experienced stigma or discrimination. For them, this occurred in the following locations: 14 in the home; 12 in a healthcare facility; and 9 in their community. There was no reported self-stigma. In their explanations, 5 Models cited experiencing family neglect; 5 Models experienced external disclosure of their HIV status to a third party without their permission; and 3 cited maintaining a good level of self-care that allowed them to not be stigmatised by others.

The Models who answered ‘no’ to experiencing stigma reported a strong level of self-care, where they would not allow others to stigmatise them. One respondent stated: *“I won’t give in to that”*, while another stated that no one can stigmatise her because she always discloses. One Model said *“I realised stigma was the thing killing me not the infection. Now I’m free”*, and stated that they disclose freely to all, while another answered that *“Because I accept my status you cannot stigmatise me”*.

Neglect from family was reported from both Models and clients, as was disclosure to a third party without the permission of the HIV positive person, either through a family member disclosing to other family or even to the wider community. For Models who had positive experiences, the reasons cited for this included the person disclosed to having a higher level of prior education or knowledge of HIV and AIDS, which contributed to their positive, supportive reaction. Families are the main source of care and support for ill family members in Ghana (Anafi, Mprah & Asiamah 2014; Dako-Gyeke et al 2015), emphasising the distress felt by PLHIV when stigmatised or discriminated against by a family member. A positive attitude from family members towards PLHIV can be beneficial to that person’s wellbeing. One Model respondent stated that the *“issue of AIDS is not one person, you need support, finances”*, and emphasised that it is not easy as there is lack of education.

One client revealed disclosing to her parents for support and financial aid, however doesn’t wish to disclose to anyone else because *“People don’t understand HIV, they won’t support you”*. Another

disclosed to her husband who has been very supportive, and they now have 3 children who *“think its a normal sickness like any other sickness”*, indicating that the education provided has helped. One woman had sought testing because her husband disclosed to her as HIV-positive; after her HIV-positive diagnosis she has not been on good terms with him because she is unaware of how he became infected.

For those clients who had not disclosed to anyone, their reasons included: living in a small community, so increased fear that if one person knows her HIV status, it will spread to others; another client admitted that she *“doesn't trust anyone else for fear of stigma”* while another stated *“They will stigmatise you”*, and revealed that they must lie about collecting ARVs. This client stated that the community needs more education but also said she doesn't want MoH to educate anyone she knows personally. The fear of stigma can be quite high, particularly for PLHIV living in more rural communities, and this fear strongly influences the actions they take with regards to living their life with HIV. These actions can be attributed to anticipated stigma and stigma avoidance.

### ***Stigma Avoidance, Anticipated Stigma & Self-Stigma:***

Stigma avoidance is illustrated by how many clients choose to visit an ART site far from their local area, sometimes within different regions, and often beyond their financial means in terms of transportation costs (distances travelled are outlined in Client Demographics, Table 1). The average travel time for clients of GAR sites was 1 hour 30 minutes; average for AR clients was 2 hours 30 minutes; ER was 1 hour 10 minutes; and WR was 45 minutes. Further investigation would be required to better understand the reasoning behind long-distance travel to a clinic and the relationship with stigma avoidance. However, observations made by the research team have been compared with interview responses. GAR travel times are concerning, considering the relatively smaller size of the region. Traffic congestion is a factor to consider, and there may be other motivations for PLHIV to select a site outside their immediate area. This was particularly apparent in AR, where clients travelled an average of 2 hours 30 minutes to their chosen ART site.

One client from WR had two facilities close to her, but prefers to visit a rural site; a client at AR cited the same but prefers the site in Kumasi because the Models are good, however, she takes three cars over 4 hours to clinic. In ER, 3 of 6 respondents had one or more ART sites closer to them but preferred visiting one further afield. A client visiting a site in western GAR lives in ER, but prefers to visit Accra to ensure she does not meet family members whilst accessing treatment; another GAR client travels 4 hours to her ART site. Another GAR client chooses to travel from her home in WR for several hours, however, she is aware that Winneba Hospital is closer and she has visited for unrelated illness while disclosing her status to staff. This indicates a strong avoidance-taking measure more closely related to stigma from a known person (family, friend or community) than fear of stigma from facility staff.

The majority of sites visited during this case study were considered to be poor by the research team; this included higher instances of reported stigma amongst facility staff, and reports of poor quality of facilities by respondents accompanied by observations of inadequate facilities by the researchers. Many facilities did not provide adequate seating for waiting clients, with one facility providing no seating and clients were observed sitting on the floor and steps outside. Many facilities did not provide private spaces for counselling and education, resulting in a lack of personal time between clients and Models or facility staff which potentially contributes to inadequate care provision. Lack of privacy may increase instances of stigma, as discussion of HIV

can be overheard by staff members from other departments and the general patient population. Model respondents from 4 ART sites in AR mentioned previously or currently encountering issues of stigma and discrimination with facility staff members.

While Models reported that Stigma/Discrimination was the challenge most often reported to them by clients (73.47% of respondents; Table 6), Stigma/Discrimination was reported by only 22.5% of clients (Table 6). The low score on stigma contradicts what has been reported by Models, as their reporting of clients who have experienced stigma is much higher. This could indicate a potential bias on behalf of the Models, which would influence them to remember stories of stigma. But there could also be a further connection between the length of time Models have been HIV positive and taking ARVs, and that clients have known their status for a shorter time. Another possibility is the tendency of Models to more open and public disclosure, increasing the likelihood of more people knowing their status which increases the chance of experiencing stigma or discrimination. Further research would be required to better understand stigma. When asked directly *'Have you experienced stigma or discrimination?'*, this figure was slightly higher with 27.5% of respondents answering 'yes'. However, client respondents may have focused on actual experienced stigma rather than self-stigma or predicted stigma relating to potential future stigmatisation (potentially by meeting family or a community member at the ART site). While actual experienced stigma is lower for clients than is reported by Models, stigma avoidance is a motivation that brings specific challenges to PLHIV.

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## CONCLUSION & RECOMMENDATIONS

The absence of comparative, detailed qualitative data and measurable indicators resulted in an inability to properly evaluate the current state of the MoH activities. However, the research team endeavoured instead to build a more holistic picture of all activities across the 4 CSS implementing regions, to better understand the interaction between Models, their facilities and clients.

Walk-ins for initial testing were highest at the facilities visited, with referrals second most common. This suggests that people do enter a facility seeking voluntarily for HIV testing. However, clients also reported entering hospital for a different illness and undergoing an HIV test, with limited or no consideration that their visit will result in a positive HIV test. It is unclear from these findings the extent of 'true' walk-ins for voluntary testing. Seeking care for a different illness yet receiving an HIV diagnosis could be a contributory factor for denial, due to the unexpected nature of the diagnosis. Better understanding of this is required, however it could be sufficient grounds to address the processes for testing. Reasons for referrals are difficult to determine, as these can be attributed to limited resources or capacity at the initial contact clinic, or that suspicion of HIV requires referral to a different ART site.

Denial and related attitudes are a significant challenge for staff and Models, and a barrier to receiving timely care for clients. The description of 'stubbornness' is a concept that would need further research to understand the cultural specifics before recommendations can be made as to how to better attend to denial. This is also related to alternative treatment options and the reasons behind clients choosing such alternatives - even after experiencing negative effects from herbal treatments. Reasons behind why clients pursue alternatives or cease adherence after short-term but successful adherence to ARV medications requires further research as well. If client beliefs do attribute HIV and illness to supernatural causes, there needs to be better understanding of how to communicate with clients about the benefits of ARV adherence and the potential for alternative treatments as complementary options. When safe, options such as spiritual healing or prayer could create better outcomes for clients. The conversation around public knowledge and client education initiatives needs revising to include current research surrounding alternatives such as Gyasi et al (2016), and to be restructured in a manner that is sensitive to the realities facing PLHIV in Ghana.

The provision of counselling and education to the majority of client respondents, and that clients consider education and adherence support to be the most important services received from Models, indicates a high level of effectiveness. The current state of the MoH concept can also be considered to be contributing to positive outcomes for PLHIV because Model and client respondents widely reported improvement to their lives through MoH activities, specifically due to education, adherence support, and overall improvements to health.

The two most common barriers to treatment for newly diagnosed clients included client attitudes, such as denial, and the desire to seek alternative spiritual or herbal treatments. Education is also a significant barrier through client literacy and understanding of HIV and health. Suggesting for future improvements from Models and clients included: HBC kits & training; financial aid for Models; increasing the Model presence at sites, through either more clinic days or including more Models in the program; and more education or counselling training. Other barriers included distances travelled to a clinic or to collect medications, and other illnesses, while stigma

and discrimination were a significant barrier in terms of self-stigma and stigma avoidance. Avoidance of perceived or anticipated stigma was high and greatly affects healthcare-seeking behaviour and health choices made by PLHIV. Models exhibited concern regarding the current governance of the program and how funds had been managed, and expressed doubts about the sustainability and future of the program.

While types of services provided by Models varied across facilities, due to shortage of facility staff and other constraints, Models perform many administrative tasks. Models conduct home-based care and visits for unwell or defaulting clients, and clients who default often do so multiple times and require home-based care due to severe illness. As volunteer co-providers, with limited skills and training, Models should not be exploited by facilities. The quality and frequency of training needs revising.

### ***Better Recognition, Training and Support of Model of Hope Co-providers***

As a social solution to a healthcare issue, the MoH concept can be strengthened through social and cultural theories as well as medical knowledge. Particularly because of the individual experience of living with HIV in Ghana, it is a recommendation that stakeholders maintain awareness of the specific experiences of PLHIV that contribute to personal challenges. Personal challenges contribute to the vulnerability of an individual, and in turn affect healthcare-seeking behaviour, treatment adherence, and the level of knowledge of PLHIV and the wider population.

De Santis and Barroso (2011) created a theory of vulnerability for people within the HIV and AIDS context, entitled 'Living in Silence', consisting of:

- confronting mortality and illness;
- struggling with change;
- encountering a lack of psychosocial support; and
- experiencing vulnerability.

This theory of vulnerability emerged from three themes:

- individual dimensions - networking, social relations and health factors;
- social dimensions - stigma, discrimination and social support; and
- programmatic dimensions - government and healthcare services and healthcare access (De Santis & Barroso 2011).

This case study has covered all three dimensions for both Models and client respondents, and recommendations are influenced by these. Programmatic dimensions would be an area of opportunity for improving the position of MoH within their embedded facilities through better definition of their role. Further investigation would be required at facilities to determine whether Model involvement with all new clients from initial consultation would be more beneficial. The high level of denial and subsequent difficulties faced by facility staff and Models could be improved by taking advantage of the Models' ability to facilitate disclosure. The expectations around the Model role within facilities could be streamlined to ensure consistency and better care. The role of a Model could also be better defined at facilities. This would allow for thorough evaluation in the future by providing measurable indicators and data collection options.

The issue of confronting mortality is embedded within experiences of denial for newly diagnosed. 'Struggling with change' can be seen through attitudes to initial treatment (what Models describe as 'stubbornness' or denial), but also in the difficulties that PLHIV face when

understanding the lifelong nature of the illness. So long as there is difficulty understanding that a PLHIV might feel well yet still be HIV positive, defaulting will remain a problem. Other struggles with change and reasons behind defaulting include adjustment to medications (and the potential experience of side effects), diet and lifestyle changes, and the concept of disclosing. The lack of psychosocial support relates to the difficulties faced when disclosing to friends or family, including others' reactions and potential for stigma or discrimination, but also to how PLHIV are treated within ART sites that lack facilities, and services, such as private areas for counselling and education or adequately trained staff. All of these factors contribute to an overall experience of vulnerability for those living with HIV and AIDS in Ghana.

### ***Support Groups***

Better organisation of regular group meetings would alleviate some of the pressure on the Models, while also strengthening the peer support network for PLHIV. Support groups seem to currently be the responsibility of NAP+.

It is important to set the right expectations with new clients, emphasising that groups are for social support and connection, education and group counselling. The previous expectation of financial reward for attending should not continue if support groups are to be sustainable.

### ***Consistent & Accurate Information Regarding Laboratory Costs***

Laboratory testing costs should be accurately relayed to clients. This could help with lost-to-follow-up clients, in particular those who are referred to Korle-Bu for '90 cedis labs' only to discover the actual fees may be upwards of 200 cedis. Having accurate cost information, and a better process to follow to ensure new clients are enrolled in the NHIS to get discounted/free labs will be essential to minimising lost-to-follow-up and defaulters.

### ***New Indicators & Qualitative Data Collection***

Future evaluation of MoH activities requires the development of new indicators that capture the 'why' and 'how' behind the current existing indicators. For example, while collecting statistics on the defaulting clients provides evidence of the numbers of defaulters, there is little chance of preventing new defaulters without understanding why defaulting occurs. Similarly with HBC, if it is evident that clients default and require home-based services multiple times, data should be collected on these clients' reasons behind defaulting.

Qualitative data collection is needed to be included with the current data collection tools. With such data it is possible to construct more effective prevention initiatives and services that result in better outcomes for PLHIV.

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