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Trust in faith-based HIV/AIDS care: the importance of “uninterruptable courage”

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An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
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Abstract

Trust in faith-based HIV/AIDS care: the importance of “uninterruptable courage”

By Emily Griswold

Introduction:

The relationship quality between clients and staff may strengthen clients’ commitment to HIV treatment, which is critical for a successful health outcome. Trust may affect this relationship and the quality of care that clients receive. Faith-based organizations may have unique features that promote trust. This qualitative study investigates the role of trust in faith-based HIV clinics in Kenya.

Methods:

Using a grounded theory approach, we conducted and analyzed 26 in-depth interviews with clients and staff across three comprehensive care clinics supported by the Christian Health Association of Kenya. Interviews were transcribed verbatim and analyzed to produce themes. The themes were compared to produce an overarching process framework describing the nature and role of trust, perceptions of HIV care, and opinions of faith-based health services.

Results:

Participants described trust in terms of confidentiality, honesty, meeting needs and expectations, and empathy. Trust stemmed from and was reinforced by reliable, holistic, multidisciplinary, collaborative, and patient-centered care provided to clients. Staff made extraordinary efforts to meet clients’ unique needs, developing partnerships with them through good rapport. Clients then demonstrated their trust through honesty, commitment to care, and expectations of high-quality services; staff reciprocated and strengthened this trust through kindness, respect, and empathy.

Institutions encouraged these processes by supporting and trusting staff as well as through continuous capacity building. Faith-based status was perceived to enhance rapport between clients and staff; it also conveyed a reputation for and expectation of quality services. Although these sites were well known for providing quality services, which helped create trust, trust independently signified a particular kind of quality—care that was reliable, comprehensive, individualized, and humane.

Conclusion:

Generators of trust and quality of care function in a mutually reinforcing cycle. Nurturing each of these serves to enhance the other—a process which could greatly improve adherence and outcomes in HIV. This study thus has implications for the manner in which HIV care, and potentially other health services, is provided in Kenya.

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Chapter 1: Introduction

1.1 Background

In 2011, there were about 1.6 million people living with HIV/AIDS in Kenya.[1] In the context of HIV/AIDS in sub-Saharan Africa, referral to and retention in care plays a crucial role in reducing morbidity, mortality, and drug resistance.[2] Retention rates vary substantially by program and population, but loss to follow up is an ongoing concern.[3-5]

Responses to the HIV/AIDS epidemic have been diverse. Many approaches attempt to increase clients' engagement in care, often through shared decision-making with providers,[6,7] peer treatment support,[8,9] system enhancements like referral mechanisms,[10] and integrating treatment of comorbidities or other health concerns.[4,11] Community-based treatment programs often focus on cultural and contextual barriers to treatment.[12,13] Faith-based organizations are actively involved in these efforts.

Faith-based organizations (FBOs) have provided health care in sub-Saharan Africa since the colonial period. They still occupy a significant portion of the health-care landscape through entities ranging from small, community-based organizations to large, national networks.[14,15] Many people perceive them as having distinct features and operating differently than other kinds of health facilities.[16] Most commonly, FBOs are said to have greater reach into rural areas, skill at providing psychosocial and spiritual support to patients, and continuity of services over time.[15]

Trust is thought to play a significant role in the operation of health systems, equitable access to health care, and successful patient-provider interactions.[17-22] Studies of trust in people living with HIV focus on their unique needs as sufferers of a chronic, infectious disease who often face stigma and social disadvantages. Stigma and breaches in confidentiality have been experienced by HIV patients even in formal care settings, leading many to prefer segregated, specialized care.[23,24] Because of their increased vulnerability and sensitivity to stigma and unwanted disclosure, HIV patients may have a higher need for trust in their health care relationships than patients with other chronic diseases.

By many accounts, FBOs’ efforts in HIV prevention, care, and treatment is growing in scope and importance.[25,26] FBOs’ widespread presence and growing influence in this field make them worthy of study in their own right;[27] many also state that communities trust FBOs more than other health providers.[28,29] If this trust both exists and contributes to improved retention in care, FBOs could have comparative advantages over other health providers in terms of outcomes. Therefore, studying trust in a faith-based environment generates evidence both for HIV care provision and begins to validate any claims made by FBOs to distinctive and superior care.

1.2 Purpose

Since people living with HIV potentially face decades of often intense connection with health systems, the factors that influence successful interactions should be explored in order to enhance treatment experiences and improve outcomes. Trust, generated by the moral and ethical standing purported as a unique advantage of faith-based organizations (FBOs), may serve as an important mediator in the relationship between patients and providers.

Our study sought to understand (1) how trust mediates referral and retention to HIV/AIDS care in a Kenyan FBO and (2) how trust influences perceptions of Kenyan FBOs’ health services. To achieve this understanding, we conducted a cross-sectional qualitative study consisting of in-depth interviews with staff and beneficiaries in three Comprehensive Care Clinics in Kenya.

Chapter 2: Literature review

2.1 HIV/AIDS in Kenya

Approximately 430,000 people are on antiretroviral therapy (ART) in Kenya,[30] yet some estimates put ART coverage at under 50%, largely due to lack of testing.[1] Most people with HIV welcome ART, but in the sub-Saharan context, Kenya included, transport and food costs, unfriendly and confusing health systems, and stigma are major barriers to referral to and retention in care.[31-33]

Comprehensive Care Clinics (CCCs) are one method of delivering HIV/AIDS services. These clinics provide a multi-faceted, multi-disciplinary approach to helping patients, particularly in matters of adherence.[34] By including pharmacists, social workers, counselors, and others on the team, CCCs aim to boost adherence and address structural and contextual barriers to care.[11] Some features of the program are home visits, support groups, active defaulter tracing, and increased counseling, which have been shown to improve retention in Kenya.[8,35-37]

Barriers to ART initiation may be profound in sub-Saharan Africa.[32,38] High-quality counseling characterized by good communication (rapport)[39,40] and flexible care (less frequent visits, negotiation of transport, etc…) are critical to patients' success in this setting, where economic status can be a profound barrier to accessing care. [62,6341] Negative interactions with staff can indeed affect initiation into treatment.[42] On the other hand, kindness, understanding, confidentiality and acceptance (i.e., treating HIV patients like normal people) can increase patients' commitment to treatment in sub-Saharan contexts.[43]

Patients can recognize when they are receiving quality, comprehensive services, and respond accordingly through provider choice and adherence.[44-46] Comprehensive, community-based care attempts to encourage this behavior, and can improve long-term adherence by meeting psychosocial needs in a culturally appropriate manner.[47,48]

Emphasizing adherence to ART has obvious health benefits and unsurprisingly tends to drive counseling. Yet dogmatic insistence on perfect adherence can undermine patients' attempts at compliance, causing them to lie about their behavior or cease treatment altogether.[49] Patients want to maintain the trust of their physicians, hoping to ensure they continue to receive good care. Patients may also comply with medical directives out of a sense of obligation to health workers rather than in the interests of their own health.[33] While such behavior probably undermines health status, it further stresses the need for compassionate, comprehensive, and forgiving care for people with HIV.

Trust in the context of HIV/AIDS

The results of many studies on trust in the context of HIV primarily focus on adherence to ART. Trusting ART as well as physicians is important to maintaining long-term adherence.[50,51] Furthermore, low trust is not only associated with poor adherence, but also with riskier behaviors,[52,53] while higher trust in providers correlates with better adherence.[45,54-57] Trust can be instrumental or it can confound other variables, such as age and ethnicity, in increasing adherence to ART and other medications.[58-60] In terms of outcomes, studies showed that higher trust in providers was associated with better quality of life and improved physical and mental health.[57,58] Trust forms a hallmark of long-term relationships between patients and providers in HIV care.[61] Evidence supports the importance of trust in HIV/AIDS care; to understand why, one must explore what trust *is* and *how* it operates.

2.2 Trust

What is trust and what does it do?

To trust someone is “a *voluntary* action based on expectations of how others will behave in relation to yourself in the future.”[21] Thus, there is always an element of uncertainty in trust; the results of trusting behavior cannot truly be known at the time trust occurs. The role of trust ranges from building relationships, legitimacy, morale and motivation, and inter-dependence. Trust can be viewed morally—that is, based on altruistic motives or moral duty.[62] Trust, either interpersonal or impersonal (trust in previously unknown persons) can be based on calculation (risk assessment), knowledge (past experience), or identification (instinct, shared values, societal norms, etc…).

At the heart of the health system rests the interaction between the patient and the provider, which is by definition often marked by profound vulnerability. Trust may drive the way health systems interact with patients and the broader society.[21] Thus, trust can be a useful proxy for the underlying values and organizational cohesion within a system. And because health systems have direct impacts on society at large, trust *of* and *within* these institutions must be nurtured for the system to function optimally.[63,64]

How is trust measured?

A variety of methods are used to evaluate trust within the health system context. Trust is usually measured quantitatively through a variety of scales.[65-75] Approximately half of these scales were developed using qualitative methods and the majority were created in the United States.[76] Some suggest that trust is too seldom studied qualitatively, leading to unclear frameworks and misunderstandings.[77]

Because trust is multi-dimensional dependent on the context and the topic in question,[78] assessments cover a range of domains and conceptual frameworks. Ozawa and colleagues, in a 2013 systematic review of the literature on trust in health contexts, focused on the following domains, in decreasing frequency:[76]

- Communication (quality of information exchange)
- Honesty (integrity, openness of relationship)
- Confidence (reliability)
- Competence (perceived ability, qualifications, reputation)
- Fidelity (duty to help patients beyond self-interest)
- System trust (belief in institutions and processes)
- Confidentiality (privacy)
- Fairness (perceived treatment of the disadvantaged)

Hall and colleagues, in an earlier review, found similar domains but added the category of “global,” which covers matters such as trust in decisions, assumptions that parties prioritize the best option rather than the most expedient, and overall trust.[18] The authors also explored predictors and effects of trust, identifying a variety of positive outcomes as well as a prioritization of the state of anxiety and vulnerability that characterizes most interactions within the health system as the context for trust, rather than patients’ or physicians’ personal characteristics. While these latter issues form many of the variables of trust studies, vulnerability is important as it can be the genesis of trust or mistrust, depending on how one is handled within the health system.[22]

As Ozawa et al identified, trust research has been scant in low- and middle-income countries.[17,76] Many of the worst features of health systems in the developing world—long lines, corruption, supply chain breakdowns, rudeness, and overworked staff—all influence patients toward distrust,[17] and can increase feelings of social exclusion and disconnection.[79] There is some evidence that trust may be established and conceptualized differently in low-resource settings,[80] but there is disagreement on this matter.[20]

Patients' trust of providers

Trust has long been held as a critical component of effective caregiving relationships.[81,82] Detailed explanations of trusting relationships are offered by qualitative research. In the context of HIV, qualitative studies found that common components critical to retention in care were relationships that were: caring (being concerned and interested in the patient, not judging them, providing personal care, being open and honest with patients, spending more than a few minutes with them), informative (involving patients in their care by teaching them/helping them learn, learning about side effects), and competent (remembering details about patient, being on top of latest research, familiar with HIV in "the real world"). Clients described the "ideal" health care provider as one who was caring, competent, and respectful; someone who was interested in their everyday life, and developed a comfortable and relaxed relationship that helped build trust. Ideal relationships were ones where the provider "was able to gain honest information from the patient that is accessible only in a trusting relationship, while the patient is able to receive the best care possible."[83]

Earlier research in urban settings found that trust was supportive to patients and possibly crucial to the provider's job satisfaction.[61] Better communication and shared decision making, key components of trust, were also associated with adherence.[84] More convenient care that was comprehensive (addressed more than HIV); a patient-focused orientation resulting in trust, listening, empathy, and respect from staff, and shared power and responsibility drove facility choice for many participants.[85]

Providers' trust of patients

Providers' trust of patients has powerful implications for a collaborative approach to care.[86] Patients' honesty, respect for the physician (or other health worker) as a professional and as a person, and adherence to treatment plans are common dimensions.[75] When patients sense that trust between themselves and their providers has broken down, they may react in ways that they assume will give them what they need, often by lying or omitting personal information in an attempt to preserve the relationship and its benefits.[49] Compliance with medical directions—adherence—positively influences providers' commitment to their work,[43] suggesting that trust building involves reciprocal processes.

Trust of health systems

The role of the health system in the community has profound consequences in terms of access and equity. Responsive institutions that are closely tied to the surrounding community and adept at generating trust may succeed at increasing access to health care and empowerment.[21,87-90]

Health systems are also important objects of trust to patients, as they contextualize the experience of the provider-patient relationship.[72] [91] [92] In terms of outcomes and behaviors, trust (or distrust) of institutions can negatively affect patients' self-rated health, care seeking, acceptance of care, and provider choice.[93-95] Negative experiences with either staff or institutions can affect trust of both.[96]

Trust within institutions

Evidence suggests that trust of leaders within an institution improves job satisfaction.[97] Effective complaint and accountability systems contribute to trust both of and within the health system.[20,97] Decentralizing health care, increasing emphasis on evidence-based decision making, and building trust within systems had positive outcomes in Uganda.[98] An enabling work environment created by good management that is responsive to employees' needs, communicates well, and fosters teamwork has been shown to both improve motivation and counteract destabilizing forces at the national level in Kenya.[99] Motivation is a key player in many conceptual frameworks of trust, and as such must be considered when examining trust within a health system.

Good leaders can inspire trust through competence, kindness, and honesty, which can simultaneously increase autonomy and decrease turnover.[100] While good leadership is essential for both building trust and well-functioning teams, attention must be paid to all levels within the team, not just senior staff.[101]

2.3 Faith-based organizations

Overview

Faith-based organizations (FBOs) have a long history of providing health care, particularly in the developing world.[102,103] Partnering with FBOs by governments, community-based organizations, and international donors is common,[104] although these relationships are not entirely unproblematic.[105-108] Partners perceive many advantages in working with faith communities—and by extension, facilities linked to such communities. Purported advantages include influence on multiple aspects of health-related behavior, cultural relevance,[109-112] perceived higher quality of care,[102] and a focus on the root causes of poverty and ill health.[113]

FBOs have a longstanding involvement in sub-Saharan Africa.[27,114] Approaches vary, but many FBOs' health services are designed to be more equitable than government or other private providers by reaching far into rural areas and disregarding profit in an attempt to serve the impoverished.[115-117]

Another perceived advantage of faith-based models is supposition that they are well-trusted by their communities. Associations between trust and FBOs include reliability and quality of services, ethical staff and management,[116] access to disadvantaged populations,[105] and historical authority.[118] The direct connection between the faith-based mission and trust is frequently stated but seldom explicitly explored.[28,29,114,119]

Although the advantages of the faith-based model are highly touted, assumptions that faith-based care is somehow better are largely speculative or not entirely supported.[102,120,121] Methodological issues across these studies contribute substantially to our lack of understanding of FBOs' performance,[92,107,121,122] but there are clearly many successful programs.[27,122-126]

FBOs and HIV/AIDS

Faith-based organizations have been involved in HIV/AIDS care to varying degrees in the developing world.[29,127,128] Their work has been lauded,[28,129] but not without controversy, especially surrounding condom use, stigma, and care for particular risk groups.[127,130-132] Efforts have been made to reverse the stigmatizing policies earlier embraced by many FBOs.[132,133] Some faith-based models have shown good results in HIV care, often reaching people in marginalized communities, opening new channels for prevention messages, or providing home-based palliative care.[12,28,132,134-136]

The Christian Health Association of Kenya (CHAK), through its member health facilities, provides comprehensive HIV/AIDS prevention, care, and treatment services throughout Kenya.[137] As a major provider of services in Kenya and a leader in faith-based health care in East Africa, it is a particularly interesting environment in which to examine the issues of trust and relationships in initiation and adherence to HIV care and treatment.

The HIV/AIDS program sponsored by CHAK offers comprehensive services for free to HIV-positive patients. This approach aims to reduce some of the barriers facing clients in their utilization of care; similar programs have had strong impacts on impoverished communities.[117,136]

2.4 Objectives

The literature suggests that trust may be essential to healthful outcomes in HIV/AIDS care and that faith-based organizations may be well placed to provide such care. Drawing on doctrines of compassion and reputations for trusting relationships, which are important both for health care more generally but particularly for HIV/AIDS, FBOs might well have an advantage over other health systems in this field. These advantages, however, are not well studied.

The process through which the forces of trust and faith operate on HIV patients do not appear to have been studied qualitatively or in a Kenyan context, where a substantial proportion of care is provided by faith-based organizations and HIV affects more than 6% of the population. More broadly, this study fills a gap in addressing some of the factors that may affect patients' care preferences in an African setting.[138] Trust in the context of ART adherence has been studied in Ethiopia and Uganda, but in this study, trust was a resulting theme rather than the subject of the research.[41] Other qualitative research in Africa has focused on what forces impact adherence, how patients perceive care, and worker satisfaction within health systems.[31,33,38,42,43,48,132,139-141] No studies appear to have qualitatively explored trust as a potential driver of referral and retention to HIV care in Africa.

Therefore, this study sought to understand:

1. How trust mediates referral and retention to HIV/AIDS care in a Kenyan FBO, and
2. How trust influences perceptions of Kenyan FBOs' health services.

These questions address key gaps in the literature. The results from this study offer qualitative explanations for how trust is defined in this setting, what causes it, what it does, and why. In addition, the study adds needed detail to the literature on FBOs, suggesting what features may constitute their comparative advantages over other health systems as well as where they may fall short.

Chapter 3: Methods

3.1 Study sites

Three CCCs were chosen as sites for this study by CHAK management after consultation with the Emory University team. The sites were selected because they were deemed both reasonably representative of CHAK HIV programs as a whole and diverse in culture, geography, language, and socio-economic background. The three sites each had between 2000 and 5000 patients enrolled in HIV care and treatment.

Site A was a large Catholic hospital situated in an industrial area of Nairobi. Site B was a Protestant facility located in a semi-urban region near Nairobi. Site C was a Catholic hospital located approximately 100 kilometers north of Nairobi, surrounded by largely rural farmland.

3.2 Questionnaire development

Interview guides for staff and clients were developed first. Similar studies and literature reviews were examined for potential questions and subject matter. The works of Hall et al. were instrumental in this process.[18,65] The authors described dimensions of trust, such as fidelity, competence, honesty, and confidentiality. They intended to evaluate trust in the context of a quantitative scale, so I rephrased these statements into open-ended questions, editing them to fit the study context. There was no predominant theory among the studies used to develop questions. The following topic areas emerged as key to investigations of trust in health care settings and are shown in Table 1.

Table 1: Thematic areas in trust research used to develop questionnaires

Topics	Literature support (first author and year)
Fidelity/Dependability (provider cares about patient, prioritizes their needs)	Anderson 1990; Hall 2001; Ozawa 2013
Competence/Confidence in knowledge and skills	Anderson 1990; Hall 2001; Ozawa 2013
Honesty	Anderson 1990; Hall 2001; Ozawa 2013
Confidentiality	Anderson 1990; Hall 2001; Ozawa 2013
Global (all others; undefined)	Hall 2001
Adherence to advice	Anderson 1990
Familiarity with issues	Anderson 1990
Trust within an institution	Goudge 2005

Additional questions were developed to assess the quality of care, behaviors needed to ensure good care, the uniqueness of the facility, the institutional environment, and at-risk populations within the community. Morgan et al, for example, was helpful for questions about organizational structure and the role of religious principles at the hospital.[130] Probes were drafted to address potential sub-topics within the larger framework. The final interview guide contained 22 questions for staff and 27 questions for clients, plus probes. As the study progressed, some questions were consolidated with others or skipped entirely, depending on the context of the interview.

The written and oral consent forms were translated into Kiswahili by CHAK staff. No formal back-translation occurred, but the translations were checked by multiple CHAK staff fluent in both languages.

3.3 Recruitment and study procedures

The target population was staff and clients at the three CCCs. Staff were eligible if they were directly involved in providing HIV care and treatment to clients. Diverse perspectives were sought, such as those of social workers, nurses, counselors, etc… Clients were eligible if they were above the age of 18 and regularly receiving services at the clinic. No distinctions were made between those who were new to the clinic and those who had attended it for years. Clients were eligible if they had time and wished to be interviewed; no restrictions were made on gender, background, stage of HIV illness, etc… The only requirements for English fluency for clients were at Site A because no CHAK staff were able to interpret during that week. Otherwise clients needed only to be conversant in Kiswahili or Kikuyu.

A staff person was designated at each site to recruit patients. These staff included the receptionist, the lead triage nurse, and a head nurse. Recruiters were provided with copies of consent forms and a brief summary of the study. Participants were asked if they wished to talk with an interviewer unaffiliated with the clinic. Recruiters were instructed not to interfere with the patient's scheduled services at the clinic. Staff were recruited for interviews via convenience sampling based on availability.

At Site A, interpreters were unavailable due to scheduling conflicts. Thus recruiters purposively selected patients likely to be proficient in English. Interpreters were available at Site B and Site C, as such consenting clients could be interviewed regardless of their English proficiency. At Site B, the recruiter made some effort to obtain diverse participants. This is reflected in the diversity of ages from this site; this was also the location of the study's sole male client.

We took great care to ensure that we did not interfere with clinic visits, work, or errands. Each participant was fully briefed about the study and promised complete confidentiality. Participants were not provided with incentives.

Data collection

Interpreters were provided with English and Kiswahili versions of the consent forms, interview guides, and briefed about the research topic. At Site B, the interpreter was present during clients' interviews but only played a supporting role, as all the clients chose to respond in English. The interpreter at Site C actively participated in the interviews with clients.

Interviews lasted about one hour including time spent discussing the study and the consent process. The tape recorder was turned on only after the participant agreed, seemed relaxed, and asked any questions they had about the study. In order to build rapport, the interviewer spent several minutes asking about how the interviewee was feeling, how their day had gone, their family, etc… Interviews were semi-structured; in general, questions followed a basic order and were asked similarly overall. However, adjustments were made to follow the respondent's train of thought, interests, and any topics that developed naturally during the conversation. Probes were used to solicit more details and nuance. Questions were rephrased, consolidated, or skipped to more closely align with what had already been said. As the study progressed and certain concepts reached saturation, the interview process became more focused with fewer questions and more probing. The interviewer took notes for reference purposes, but note-taking decreased over time during the course of the study. Detailed notes were taken on the few occasions where the digital recorder failed to function.

Extremely limited demographic information was collected to protect interviewees' confidentiality. However, both staff and clients were asked to describe the duration of their relationship with the clinic, how it had arisen, and what the nature of this relationship was, particularly in relation to their other experiences (other daily activities for clients, the broader hospital for staff). This was done not only to gain insight into people's relationships with the health facility but also to potentially develop categories of reliance on and integration with the CCC across participants.

3.4 Ethical considerations

Consent

Once a participant agreed to be interviewed, s/he was sent to a private room where I then explained the nature and purpose of the study and the time commitment involved. I emphasized the voluntary and confidential nature of the activities and interviews. Participants were given the opportunity to ask questions about the procedures, nature of the study, myself, CHAK, etc… They then gave verbal consent. I also explained the purpose of the tape recording and what would happen to the recording and the transcripts. All participants were provided with a copy of the consent script in either English or Kiswahili. All interviewees agreed to be recorded.

Review

Study documents were sent to staff at Emory University's Institutional Review Board, who determined that the study was non-research. Nonetheless, consent procedures were followed: participants were assured of complete confidentiality, informed of what would happen to the information they provided and the recordings of the conversation, offered the opportunity to ask questions, and told they could leave at any time or refuse to answer any questions. Only first names were collected by me for record-keeping purposes in a personal notebook. Recordings were stored on a digital recorder that remained in my possession at all times, and then transferred to a password-protected laptop. Transcripts were completely de-identified and not shared beyond the research team and research advisors.

Permission to conduct the study was granted by the director of CHAK's HIV/AIDS program, CHAK's director, and CCC managers at each site.

3.5 Data analysis

The study design, data collection, and data analysis were developed in accordance with the principles of grounded theory.[142,143] The analysis sought congruencies between the provision and acceptance of HIV services, practical and theoretical conceptions of trust, and the imagined and actual role of the religious mission in the facilities' services. Any insights into the process of choosing a facility, the interpersonal relationship between caregivers and patients, community norms and perceptions, and institutional motivations were exceptionally useful.

I transcribed and de-identified all interviews that were predominantly in English. Any spot translation needs were handled by CHAK staff or the Emory translator, a Kenyan graduate student fluent in Kiswahili. Recordings in local languages were translated and transcribed simultaneously to produce and English transcript. I subsequently de-identified all transcripts and checked them periodically for accuracy.

Transcripts were loaded into MaxQDA 11 (VERBI GmbH, Berlin, Germany, http://www.maxqda.com/). The text was annotated with memos and coded both inductively and deductively (using themes from the literature and the data collection instrument). An initial codebook was developed using interviews from two clients and two staff from Sites A and B. A second reviewer then used the codebook to code an additional client interview for validation. This process was done to ensure the definitions were clear, that all codes were useful, and that sufficient codes had been developed to address the research question. The second coder's work was merged with the mine, resulting in a final codebook that was used to analyze all subsequent transcripts.

Coded segments were retrieved and examined for breadth, depth, nuance, and context. Themes were developed through thick descriptions and constant comparison using a combination of deductive and inductive codes. Emerging themes were collected to develop categories which fed into conceptual frameworks. These frameworks were then used to interrogate additional aspects of the data. These answers were in turn used to create additional dimensions of the framework. Responses, themes, and categories were compared across participant variables such as gender, site, role, and inductive groups (e.g., types of behaviors needed to secure trust). Memos were created throughout this process to note emerging issues and contextualize data. These analyses were combined to generate a theory on the role of trust in the HIV programs of three Kenyan FBOs.

Chapter 4: Results

Interviews were conducted in July of 2013. Twenty-seven people were asked to participate; only one person could not complete the interview due to other obligations. Interviews lasted between just under half an hour to nearly an hour and a half, with an average recording time of 42 minutes. All interviews were conducted by me. An interpreter was present for the interviews of ten clients, five of whom nonetheless responded almost entirely in English. The other five responded in a mixture of Kiswahili, Kikuyu, and Kimeru. Interpreters were fluent in Kiswahili and Kikuyu, and conversant in languages similar to Kimeru. All staff interviews were conducted in English.

4.1 Participants

The breakdown of the 26 participants by role, gender and site is provided below in Table 2. On one occasion, clients were interviewed on maternal and child health day at the clinic. This fact, combined with the generally higher HIV prevalence among women in Kenya, resulted in a heavily female participant makeup.

The 13 clients ranged in age from just completing secondary school to the elderly. They included those who acquired HIV as infants, mothers with both positive and negative children, and those in discordant or concordant partnerships. Four clients volunteered as peer educators or community health volunteers for their CCC, conducting outreach, community mobilization, and serving as health educators and treatment supporters. Some clients were only on prophylactic antibiotics (cotrimoxazole) and multivitamins while others were on first- or second-line ART. Their most recent CD4 levels ranged from 50 to over 800. Some clients had experienced a variety of opportunistic infections, some even requiring lengthy hospital admissions. A few had had tuberculosis (TB) in the past. Some were recent enrollees, while others had been enrolled since 2005, the first year of the CHAK program. Several had known their HIV status as early as 2001.

The 13 staff worked as nurses, counselors, social workers, pharmacy technicians, community health team members, and clinical officers. A few had recently joined the clinic, while others had been working at the study sites for over a decade.

Table 2: Participant characteristics

Site	Participants' role	Gender breakdown	
		Female	**Male**
Site A	Client	3	-
	Staff	2	2
Site B	Client	4	1
	Staff	4	1
Site C	Client	5	-
	Staff	3	1
TOTAL		**21**	**5**

4.2 Overview

The results of this study begin by describing the meaning of trust to participants. They then delve more deeply into how clients and staff view trust and its role in HIV care. The outcomes and structural instigators of trust are described, followed by the role of religious missions in these processes. External environmental factors supporting trust and threats to its maintenance are noted. Finally, a theoretical framework linking the themes is presented.

4.3 Critical domains of trust

Clients and staff similarly spoke of trusted people as those who kept secrets, were reliable in times of need and happiness, were ones to whom people could share openly, were able and willing to help, and were highly motivated and concerned about others' welfare. One had absolute confidence that a trustworthy person would be supportive under any circumstances, a belief phrased by one participant as “uninterruptable courage.” Participants’ definitions of trust were often framed by the sense that in order to trust someone, you must yourself be a person who could be trusted. This phenomenon of accountability and reciprocity plays a significant role in the trust framework that emerged from this work. Many clients framed their commitment in terms of a “promise” to the staff; they in turn expected this promise to be returned with quality care. The next sections detail the nuanced differences in valuations and definitions of trust as they were described by clients and facility staff.

Client perspectives

Developing rapport and personalizing care

As expected, keeping secrets, providing emotional support and ensuring consistent, reliable interactions were straightforward pathways to trust for clients. Additional contributors to trust came from developing personal relationships. Personal relationships with staff were held in high regard by clients, who indicated they were often built through mentorship, home visits, and ultimately friendships. Lastly, clients were highly attuned to how staff interacted with other clients and used this to inform their degree of trust in providers. Seeing someone treated poorly or hearing their secrets divulged were almost guaranteed to prevent the establishment of or disrupt existing trust between that particular staff member and a client. This distrust could, in some cases, be generalized to the entire clinic.

Good rapport that facilitated trust between clients and staff was described as a unique feature of these facilities by the vast majority of participants. Good rapport was essential to making clients comfortable. One example from a female client describes how poor rapport, even in the context of brief exchanges, could prevent her from being truthful and open with her care provider:

Interviewer: "How do you know when you can [trust a health worker]?"

Participant: "It depends. Someone's approach, you know? If you approach me in a nice way, I will tell you anything. And if you're concerned about me, I will tell you everything. But if I get into the room and you're, like you're writing or stony-faced towards me, and, "habari yako? [how are you?] You're ok? Yes." So I wouldn't talk much about [myself to] you, I'll even tell you, "yes, I'm ok," [unless] there's something… observable. So, it depends on how you're going to approach me and, whatever… it depends on how someone is going to handle you. If you handle me nicely, if you're concerned about my health, if you're concerned about everything I am going through… I trust you." (Female client)

Rapport allowed clients to trust staff, which helped them become more open and honest. They shared private information which was often unrelated at first glance to their HIV status; rather than discount these revelations, staff welcomed them. This indicated that they were trusted by clients—a source of motivation to staff in and of itself.

Trust from clients allowed staff to develop more personalized, comprehensive care, expanding beyond HIV. For example, discussing a client's work could reveal opportunities for income-generating activities (based at the CCC or through its partners) to help stabilize their finances. Staff could discover potential scheduling issues that could lead to conflicts with antiretroviral (ARV) regimens, or conflicts within the family that would benefit from counseling. Staff could agree on alternative locations for delivering drugs to clients, often meeting outside of regular business hours to ensure confidentiality or to overcome transport barriers. Discussing family and friends helped clients feel like they were supported and cared for, further enhancing trust.

The breadth of services at CCCs (e.g., support groups, educational seminars, spiritual guidance, and counseling) allowed clients to commit more fully to care. The goal of this involvement was to help patients take control of their treatment and thrive; since they were more involved, the assumption was that more of their issues would be resolved, thereby removing barriers to adherence, causing better retention in care, and improving outcomes.

The following example shows how a typical medication counseling session might proceed:

"…The problem is always the ARVs, the Septrin is kind of not that big, but for the ARVs… Ok, I said to <clinician's name> I was very afraid. So I sat down with her, she took me through, she explained everything. So she told me… if you're working it's good to take either before you go to work because that would be much easier; you might get to work, you are late, you start doing your work, time passes, you are not taking, so it's good you put a time when you are not going to work. Or if you are not going to work that early you might set a time, that time finds when you are already asleep. By the time you wake up, the time has passed. So she told, it's as if I'm going to work, then let me consider that, and if I'm not going, it will help." (Female client)

In this interaction, the clinician walked the client through several scenarios to help her find her own strategy for taking her medications. Further discussions yielded other potential issues she might face, which they worked through together to find relevant solutions.

Underneath the personalized aspects of this program was a commitment to achieving good outcomes. Clients welcomed the kindness they received from staff, but they understood the importance of the medical aspects of their care as well.

"There's a difference because here you can't be given ARVs for all of 5 months. But in other places they will give you drugs for up to even 6 months. When you have all those drugs and

never go to the clinic for checkup the drugs can't be monitored, the doctor testing you might not be the same, the adherence to the medication might not be as good, and people will take the drugs any which way. Because there is no follow-up for adherence." (Female client)

Balancing trust in sensitive situations

Home visits were a key yet sensitive component of the active follow-up efforts of this program. Visits typically lasted between 30 minutes and 2 hours. Clients recognized that a home visit could be extremely useful for staff, and many appreciated the interest shown by staff in their day-to-day lives. For them, home visits represented a partnership between them and the CCC. It made them feel honored and supported. For other clients, home visits were problematic. They worried that their neighbors would discover their HIV status or stigmatize them for being ill. Other clients saw home visits as intrusions and signals of mistrust on the part of the health workers. In these circumstances, it was crucial for staff to be sensitive to clients' circumstances and preferences, respecting their opinions and need for confidentiality—crucial for maintaining trust.

Trusting relationships with staff could help clients overcome stigma. Though lessening by many accounts, stigma still exerts a powerful influence on the lives of people with HIV in Kenya. Stigma could influence the choice of a health facility, sometimes pushing clients to travel over 100 kilometers to reach their preferred clinic. Many described difficulties with initiating treatment because they had not fully accepted their status. Stigma compounded the already difficult economic and social circumstances facing many clients. Many gradually overcame stigma through the program's educational seminars, support groups, counseling, and outreach activities. Acceptance, kindness, empathy, and understanding—the rapport that characterizes trusting relationships—were crucial for such clients to feel comfortable at the CCC.

The CCCs had high standards for client retention, raising the stakes of missed appointments. But presuming clients were defaulting and then not asking them for explanations (essentially de-individualizing them) could have very negative consequences, as described by one young woman:

"…if you fail to [come to] the clinic… you're not taking your drugs. So to an extent you're like… you're trying your level best not to even forget taking that drug, you know? Then someone else tells you that you're not taking your drugs, you feel like, 'what the hell is this person telling me?' You try not to… to some extent you find that you can even give up. Just the same, I'll quit. I'll not even need to take those drugs because if I'm taking and, if I go to the clinic they're telling me I'm not taking drugs, then, there's no need? You know? As in it can lead me to bad, that as if I'm not, I personally lie, 'I don't take it,' if I take it seriously, how will they handle this?" (Female client)

Here, an experience of rudeness became a breach in empathy and kindness, and could have pushed a client to become dishonest and give up on treatment.

Staff perspectives

The role of trust in staff-client interactions

Staff knew that clients trusted them from a mixture of behaviors. Staff could tell they were trusted by the openness of clients' relationship with them. Such staff often used reciprocal honesty to help build trust with patients, telling stories about their own lives to help build rapport. These staff would trust clients precisely because clients trusted them. Another way staff knew they were trusted was when clients would ask for them specifically by name. Many clients would do this even if the staff person's role was poorly matched to the client's need. In most cases, staff would try to accommodate such requests, referring the client to teammates when needed but ensuring that the transfer of trust occurred and that the client understood the reasons for the referral.

While some staff said they trusted a healthy majority of their patients, others saw it as their job not to trust them, preferring to read into clients' stories and look for proof of good behavior. Adhering to medications and reliably attending appointments were prerequisites for some staff to trust patients, both generally and before allowing clients extra leeway with medication refills, for example. This skepticism could not however be expressed as rudeness or a lack of caring. Staff knew they had to balance looking for good behavior with supporting clients. They knew that clients often expected kind, empathetic care, and to not receive it would lower their trust in the staff. Clients wanted staff to listen and ask good questions, but they wanted to be believed and understood, not interrogated. Staff therefore had to meet these expectations even if they did not yet fully trust the clients.

Staff recognized that home visits were a delicate issue, with a substantial minority of patients disliking them. Staff said they would always ask if it was acceptable to talk in the patient's home and always respected this decision. Sometimes staff would pretend to be Jehovah's Witnesses or salespeople in case they were questioned by neighbors. The program vehicle, with its AIDS Relief logo, was particularly problematic. Staff had to ask clients about this independently. If the client wished to be visited but not with the program vehicle, staff would be dropped off far from the homestead and then walk the remaining distance.

Maintaining trust in difficult circumstances

To allay clients' fears about admitting personal, sometimes embarrassing information (a profound state of vulnerability), staff instilled a sense of honest, transparency, and accountability. Staff were candid and emphatic about the measures taken to ensure confidentiality. Sometimes they would take clients aside and show them the records room to explain how and when files were moved and information was shared. These actions helped educate clients and lessened uncertainty around the clinic's procedures, which contributed to an atmosphere of respect toward clients and their time. It also worked to lessen the power differential between staff and clients, making partnerships easier and trust more bi-directional. Most staff said that they would even admit their own mistakes to clients, using the opportunity to model honesty, educate the client, and diffuse tension. As expressed by one male staff, *"[you must] just be very frank to them, yes. And tell them, 'this happened, but it was not expected to happen so… this is what was expected to happen and now we are doing it this way,' yes."* Some staff however preferred not to admit mistakes to clients. Several staff noted that clients would grow to be quite confident with staff, freely telling them when they did something wrong and if another staff was rude or inattentive.

When clients did not adhere to treatment or were dishonest about something, the vast majority of participants said that staff were not punitive. Instead, they simply counseled clients and strove to better understand their circumstances. Staff (and many clients) felt that patients lied out of fear (of retribution, denial of services, or revealing embarrassing information), stigma, denial of HIV status, and struggles in their personal lives. This called for increased empathy from staff. The policies of these CCCs were to not turn anyone away, and staff frequently reminded patients that they would be committed to them under any circumstances. Staff indicated that clients were not chastised for being dishonest. Rather staff indicated that they simply counseled clients again, kindly and humanely, on the importance of staying in care and being honest:

Interviewer: "How do you treat them when you suspect that they're not being honest"?

Participant: "Ok we try, [based] on the kind of services and the experience we've had, we tend to understand them on the fears they had and um… Most of them on that level they open up. So, you cannot just… push them away because they've opened up, we tend to understand, and think of the best way to, they can be supported."

Interviewer: "So you, it's almost like you forgive them for that?"

Participant: "Yeah, we forgive them for that, and we move ahead. And it helps us for planning. So that others, proper vetting of other clients, and being more comfortable from the first contact made we, we try to explain to them the importance of [being honest]… so that in future they don't get problems in case they need support. Yeah, and even quote some examples, [[]], tend to open up better." (Male staff)

Clients confirmed this approach, noting that staff would "correct very kindly:"

"The way they interact with the patients you will never hear an insult or an unkind word. Even if you are wrong, they have to explain in a courteous manner. They count the drugs and explain to you kindly about resistance and how your medication should be taken. Even if you take alcohol, they will never say anything about it or deny you the medication, because some of them [other clients] even come for testing when they are drunk... and they explain to them slowly and courteously until they understand." (Female client)

Clients commonly made mistakes with their treatment regimens. This often caused them to lie in an attempt to please staff or ensure access to the program (although the sites' policies were to deny no one care), and staff were prepared for this. By being patient, staff helped clients view missteps in adherence as ordinary mistakes rather than failures:

"Once a patient is new and enrolled we try to tell them. Because now we've learnt from previous lies that other patients tell and the outcomes, eh? So we tell them that 'if you think that you'll please me by making things look better for me, eventually you'll be the person to be affected. So it's good that you tell me the truth, we correct early enough.' So now they are trying to believe 'you mean you'll not accuse me if I do this, but you'll tell me what is correct?' So… sometimes I see some patients and, 'you know what? I want to tell you the truth. Because I know the first I'm with you and you told me this, and I don't want it to go this way.' So you'll find some of them have just become friends, not just clients, but we are friends and they tell the truth, yeah." *(Female staff)*

Being patient and forgiving was seen as particularly useful for clients experiencing stigma. Some staff felt that home visits were particularly useful for such patients because of the extra time they allowed, while others focused on their rapport with clients. Staff knew they had to be patient, kind, and non-judgmental:

"Because you see when they come and you're there, you're laughing, you're catching up, 'how've you been?' you see now they feel appreciated like, they feel normal again. But initially before they came they are scared—'how will I be treated?'—then you tell them, they don't want to disclose but you… push them slowly, tactically, then eventually they do it and it's a weight off their shoulders. So that one helps now even, even if they come, they have a complaint, they are

not scared of telling you. They open up; they tell you everything even if it's not related to their condition, so it helps a lot. Yeah. They feel free and appreciated, yeah, if they're always happy." (Male staff)

Partnership and living positively

Personalized care and trust enabled the development of a partnership between staff and clients. Partnership also made clients feel as though they had made a "promise" to staff to do well on treatment. Staff described the ongoing care relationship as a "journey" that they walked together with clients. Though clients remained vulnerable and dependent on staff, the power differential was lessened between the two parties.

Partnership and trust helped clients commit to more than better adherence and supportive care. Many clients adopted an attitude called "living positively." Living positively meant fully accepting one's status and embracing hope for the future. Clients stopped feeling stress about their diagnosis and became optimistic. This shift in perspective was most strongly expressed by the clients who also volunteered as peer educators or support group leaders. They talked about the "blessing" of ARVs and the supportive staff at these sites, which helped free them from fear. One woman described the process of internalizing one's diagnosis and finding a way to move on:

"If you were to get tested and you were positive, first you go to the hospital. The doctor will advise you well on how to live, continue with your life. After that, a short period, you will get back to your drugs. Once you've known how to take your drugs daily without missing, without even skipping times or minutes or seconds, you'll just be like, life will continue from there… Because with us we were very down. But as you see us today you can't imagine even if we are positive!" (Female client)

Institutional strategies to foster trust

Personalized care was a hallmark of these CCCs. Participants' narratives abounded with examples of unique, fully comprehensive paths taken to help clients succeed with their treatment. Described in one site as a "wheel," this care encompassed far more than simply treating HIV.[i] In an effort to improve lives and remove barriers to adherence and living positively, these CCCs adopted various strategies to tackle psychosocial, spiritual, economic, educational, and cultural issues facing clients. While there were of course patterns of care, intense efforts were made to find the right mixture of interventions for each client. Interventions should also benefit the community as well; for example, selling liquor in the slums, however lucrative, was not supported. Personalized care met the needs and expectations clients had of their care and, when executed successfully, was built on a foundation of trust.

Staff felt that management trusted them and was committed to building their capacity. As said by a female staff member, *"This is because they feel that as far as we are giving out we also need to receive, so that as we give out, we give out what is quality."* Staff felt they had the space to grow and challenge themselves, handling clients with minimal supervision. Management was there to support and assist, but did not interfere with day-to-day operations unless there was an express need or if targets were not being met. Staff viewed this as trust being placed in them by the facility, which motivated them to do their best. This autonomy was maintained by strong teamwork and transparent operations. The focus was on the patient; for example, if lines got particularly long in the CCC, staff drew on additional human resources from outpatient services to ensure that clients were well attended. They also noted that they felt, with the exception of

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[i] In the "wheel" model, the client is placed at the center with different aspects of his or her life serving as spokes. The team works together to attend to each spoke so that the client is served holistically.

family planning services at Catholic facilities, that they had every option available to them to serve clients.

The CCCs made a variety of adjustments to keep clients in care. Working clients who had difficulties getting time off were sometimes given extremely short appointments (15 minutes) or longer windows after missing an appointment before staff would call to check in on them. Staff would also advise them which times of day or days of the week would be best. In some of the sites, staff would make arrangements to meet on the weekends (when the CCC was closed) or to meet clients in town to deliver medications.

The client-focused approach at these sites was developed over time and through evidence-based practices. One female client described particularly well how the clinic had adapted over time to meet both the needs of its clients and stay on top of adherence:

"I can say that they have improved the services in triage. At times they used to keep people too long but we would always assume that they were probably new and didn't understand the procedures. At first when we were in the other facility, nurses didn't want people to wait at all. They would come and give you your drugs as soon as you came out of the doctor's office, then you could go happily on your way. By the time they changed the Administrator we found some friction in the running of things. It became harder to understand the staff as a patient and it was like they didn't get along with us. Perhaps you had to ask for permission at your workplace to come to the clinic and pick up your drugs, they didn't want to know. But <the nursing team's leader> resolved that misunderstanding and now that is not the case. They serve people quickly and will consider it on a case by case basis. If you are unavailable on weekdays they will create

a slot for you on the weekend for you to collect your ARVs and go back to your business." (Female client)

4.4 How the "faith-based" status enhanced trust

Clients equated FBOs with kind, "God-fearing" staff. The mission was seen to augment the professional educations of staff by honing their interpersonal skills. Some clients thought that all the staff belonged to the same church as the facility, and many expected the staff (and clients as well) to refrain from drinking, smoking, and other immoral behaviors. Staff said that everyone aligned with the mission of the facilities, regardless of faith; one's "good heart" would drive him or her to help, to be compassionate and merciful. The religious mission was said to strengthen the empathy that staff felt for clients.

Participants thought the facilities had strong links to the community, with particularly close ties to churches. Clients thought that the facilities were well positioned for advocacy within the community, particularly surrounding myths and misconceptions surrounding HIV. Staff noted how the moral standing held by the facilities allowed them to challenge the stigmatizing actions of key figures such as chiefs or government officials. Many clients brought their children to the facilities for educational sessions and coming-of-age ceremonies.

There was a strong perception among staff that the facilities were fulfilling their objectives both medically and philosophically. These "mottos" varied, but all placed the patient squarely in the forefront. The facility adjusted to ensure the patients were helped as much as possible, taking advantage of all available resources. One male staff member described this well:

"…Basically what happens here that might be one, an example in that is, uh, you find that other people who've failed treatment elsewhere and you find that that facility is not able to give that

kind of treatment that they ***should*** *be put on next, when they're referred to other facilities, other facilities as well reject them. But when they come here, we absorb them in, even if we do other tests that require other drugs that we don't have here, we'll have to do a purchase for that, so that we make sure that that life is saved and is brought to better, [[]] existence."*

Interviewer: "So the system will adjust to the patient?"

Participant: "Yes, yes. And it is majorly so because, objectively, the institution accepts so." (Male staff)

Many other staff described acts of charity undertaken by themselves or their colleagues to ensure clients succeeded. Common examples included paying for transport fare out of pocket, purchasing crafts or vegetables from clients, or offering particularly impoverished clients odd jobs at the clinic.

Many clients expressed that the CCCs seemed devoted to making clients happy and seeing them live better lives. This commitment was expressed in small details like asking about families and greeting babies, as well as larger differences like not having long lines. Clients noted that staff often apologized when lines grew long, demonstrating respect for clients' time. These facilities are supported in the latter by their reputations as faith-based hospitals; private hospitals are frequently perceived (rightly so) as having expensive services. Although all services in the CCC were free, this perception was seen to limit the number of enrollees to manageable levels.

4.5 Enabling factors supporting the process of trust building

The trusting relationship between clients and staff was undergirded by several enabling factors. The first was the role of PEPFAR, CHAK, and CDC as major donors, who were largely responsible for the widespread availability of free ARVs, other medications, and services within these programs. The second was the influence of the strength of the CHAK health system itself, characterized by the faith-based supply chain management organization MEDS, a partner organization of CHAK, that ensured adequate and timely delivery of supplies. Clients noticed and appreciated the differences they saw between their CCCs and other facilities, noting that the enhanced services (such as free CD4 tests and active follow-up), sense of community and teamwork, and reliability of services contributed to their trust in the facility and its staff.

"And to trust the clinic also, when I come I won't be told there's no medication, there's no medicine around. And also to trust it when I come, let's say I have a… I have a social, a problem, I trust the clinic if I know when I go there, I get the best person there to help me. So if you know that when you have an issue, you go, you find all those people. You find the medication, you are, they, it's about people with that, patients have something in common like here… when you come here everyone is like you so that makes feel more at peace." (Female client)

The three study sites shared an intense focus on providing resources to staff and clients through capacity building and health education. Staff received frequent trainings, which they greatly appreciated. These trainings were diverse and multidisciplinary, allowing each staff member to expand their skills in different areas. For example, everyone received training in counseling, the medical aspects of HIV/AIDS care, and strategies for monitoring and evaluation, regardless of their specific role within the team. Staff thought these trainings greatly assisted their interactions with clients and their careers. Training opportunities were an important factor in their ongoing motivation.

Mission hospitals were some of the first to provide health care in Kenya and for many years promised the best care available. This has yielded a reputation that is well known: when one attends a mission hospital, one should expect to meet kind staff, expect that all needed services will be available, and be ensured of competent, high-quality care. Religion is also held in high regard in Kenya, bolstering FBOs' reputations. The religious mission was thought to strengthen staffs' interpersonal skills which enhanced good rapport. It was also seen as a powerful motivating factor for staff, both by clients and the health workers themselves. Prayer and hymns were commonly heard throughout the day; one client described morning prayers as "breakfast" for staff, while a nurse said that every day that began with prayer would "be bright." These attitudes of hope and optimism were very helpful to clients, particularly in times of worry and uncertainty.

An additional motivating factor for staff was the culture of teamwork and sense of united purpose. The organizational culture at these facilities was characterized by highly autonomous teams with supportive management. Management and staff worked together to continuously develop strategies to better meet patients' needs.

Interviewer: "How well do you think this facility lives up to its values and its goals?"

Participant: "Ok at least with values according to the kind of work we are doing, we are offering quality services, just going, not going for quantities, and it has committees that are put in place that are vetting most of the activity that we're doing. Like we have adherence committee who normally tells [us that] we, we're giving quality services. We have a quality improvement committee which normally tells, most [[]], make sure we're giving clients quality services. Like after every, ah, every month we do a mortality analysis—we want to see why we are having more *numbers of mortalities and be able to move in and address the issue. Also in terms of quality, ah… when our client misses appointment, we call them. We want to make sure they are having their pills. We move in for house visits, we address issues that they are having and ah, I think through that, the value of quality…" (Male staff)*

Threats to the system

Trust can be damaged when a facility is unable to offer all the services a client requests. There was some tension between offering all needed services (the professional ideal) and adhering to the mission, mostly in terms of offering family planning services at Catholic sites. Staff addressed these restrictions through creative workarounds or referring to community organizations, but the restrictions remained a tension for many. In every case they were honest about the restrictions. Clients did not seem to be worried by these restrictions, but it if their definition of a trusted facility was one that offered everything they needed then this is a potential weakness. As such, the success of this model is highly dependent on the availability and adequate delivery of drugs and training. CHAK's emphasis on capacity building was highly appreciated, and the use of a separate supply chain for medicines was seen as an enormous advantage over government facilities. However, changes in donor priorities could seriously hamper these successes. If the reliability of these services were to be threatened, both trust and the reputation for quality services would suffer.

Although staff and clients were quick to assert that everyone was treated equally at these sites, some participants acknowledged the potential for judgment due to the faith-based mission. Staff and clients could both feel pressured to behave more "properly" because they were affiliated with a religious hospital. Both groups admitted that some people might not wish to attend faith-based facilities for this reason.

Usually, the faith-based mission was a source of motivation for staff, but it could also be a source of stress and demoralization. Many staff felt that the salaries they received at these sites were not commensurate to the quality of care they provided. One woman described the positive and negative aspects of her work environment in the following excerpt:

"Ah, positively, people are able to work under minimal supervision, because your employer is direct with you. So you know you have to work. And, again, I'll talk about passion. People are driven by passion. You work, you know you came to work for the good of the patient. So, with the passion and with the daily prayers… yeah, people are, are able to work well. Ah, negatively… for every work there is a reward. And you'll find that maybe with, there is a lot of staff turnover because of the salaries. You'll find that the government have better working terms, ah, conditions like in terms of salaries, they pay well other than in mission hospitals. So you'll find that there is a lot of staff turnover. Yeah. And, maybe other NGOs, NGOs pay well, eh? So you'll find that, people term this one as an NGO, it, it is an NGO. So you'll find that they say that an NGO should be paying well. You see? But I understand with the hospital policies, the, the pay comes with the hospital policies. So you'll find that it's a bit challenging, yeah." (Female staff)

4.6 Themes and theoretical frameworks

The framework in Figure 1 below summarizes the discussed themes and how they interact with the trust phenomenon. It also demonstrates how trust contributes to quality services in these CCCs. This framework represents the views of both clients and staff.

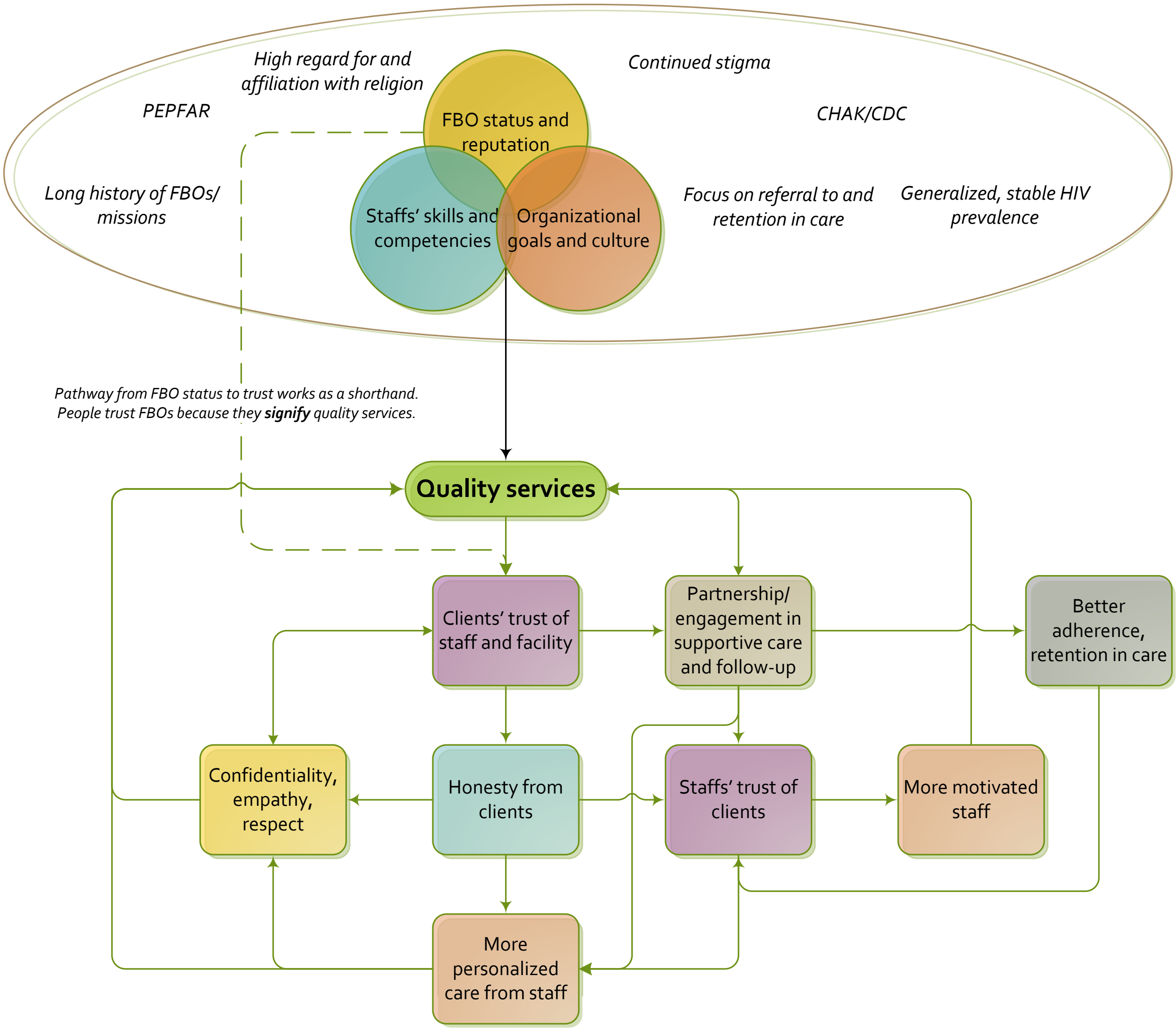

Figure 1: Conceptual framework showing how trust arises from and reinforces quality services. Enabling external factors influence the organization culture, FBOs' status and reputation, and the skills and competencies deployed by staff. Together, these forces define "quality services," which cause and are subsequently reinforced by trust.

Environmental factors (shown at the top of the model in italics), program characteristics, and institutional priorities combine to create the phenomenon of "quality services." Quality services were defined as offering the best options to patients, good relationships and communication with patients, smooth and timely flow within the clinic, and highly motivated staff. In these settings, quality took on an additional dimension of holistic care and a mission to uplift lives, which was supported by the faith-based nature of the institutions.

Quality services were an overwhelming generator of trust and a major determinant of facility choice. Trust then caused honesty and commitment from patients, which helped motivate staff and develop partnerships in care. These in turn contributed to better outcomes, but more importantly, they fed back into the phenomenon of quality services. Trust therefore served as an indicator of quality, one that was both structural (staff, supplies, accountability) and relational (rapport, partnership). This feedback loop was summarized well by a male staff member:

Interviewer: "Do you think they have a connection, a relation, those three factors [trust, the religious mission, and the quality of services]?"

Participant: "Between the three? Mm, what I would say is, it is a challenging question to answer, but let me try. Ah, that's to say, any quality of the service, or being in a faith-based institution, you are ensured of getting those services, and this has been on the onset from the very beginning. So patients used to know that if you go to that facility, you'll be able to get quality service. And at the same time, the confidentiality and all that… and therefore they had the trust. This one was set from the early days of the missionizing in Kenya. So… that's the point of inception, yes. And up today, those who came in after, they had to uphold that…"

Interviewer: "Reputation?"

Participant: "Yeah, that position, and even making it, making it better, yeah." (Male staff)

Chapter 5: Discussion

This study describes how trust arises and is reinforced by environmental factors and the interpersonal interactions within the clinic and beyond. When this process falters, trust breaks down quickly and the connection between the client and the CCC becomes fragile. Conversely, careful attention to the factors that create trust increases both its strength and clients' relationship with the CCC. This relationship begins to resemble more of a partnership than a simple service-provider-recipient interaction. The data strongly suggest that the presence of trust in this situation enables adherence to treatment and retention in care. These findings are novel in that they describe not only barriers and facilitators to retention and referral, but they also describe processes and meanings for these factors.

Trust, however, does not mediate referral and retention to HIV care on its own. Rather, trust is thickly entwined with the paradigm of quality services. Generators of trust and quality services are so closely aligned as to be inextricable. What participants considered quality services were those they trusted. Deviations from these perceptions could easily be deemed breaches of trust in some way. But attending to aspects of trust can sometimes, but not always, overcome lapses in quality.

FBOs are perceived as trusted entities because they offer excellent care. Staffs' best qualities (kindness, fairness, humaneness, etc…) are reinforced by the faith-based mission. The mission, at least in this context, contributes to a work environment in which staff are well trusted by management, thus motivating them to work harder and better. While targets are clearly important, the staff have focused on the people that become the data. Clients do not feel like numbers in a system. Care is individualized and staff develop long-term, friendly relationships with clients, going out of their way to make time for education and counseling. This focus on quality over quantity drives the care at these CCCs, supporting high standards for results and evidence-based practice.

In trusting a facility, clients have in effect made a promise to follow its advice. The care team has in turn made a promise to give clients everything they need and respecting them. A variety of small, simple acts as well as an pervading ethos of commitment demonstrate that staff were dedicated to treating their clients humanely and holistically.

5.1 Alignment with the literature

The components of trust described by the participants align well with the frameworks proposed by Hall et al and Ozawa et al.[18,76] These dimensions were all mentioned by participants at some point. Confidentiality factored highly in their descriptions, more so than in the studies reviewed by Ozawa and colleagues, which is perhaps unsurprising considering the vulnerability and stigma people with HIV face in Kenya. The quality of communication between parties in these clinics was a key generator of trust, as was the perceived competence of the caregivers. Confidence was expressed in clients' expectations of receiving needed medications and professional attention.

As was found in Tibandebage and Mackintosh's article on Tanzanian health systems, the faith-based mission of these hospitals was thought to engender trustworthiness in their staff and services. The findings in the present study diverged from theirs in that staff did not feel they were closely monitored by management.[116] Problematic management hierarchies and misguided human resource allocations have been described by stakeholders at other FBOs, but these views were not expressed by these participants.[15]

Threats to competence in Hall's model include a sense that the caregiver is not paying full attention to the client's needs. This threat was validated in one client's case, where a clinician had been rude to her and openly doubted the veracity of her statements. The client then felt that the staff were no longer interested in her as a person and was ambivalent about remaining at the facility. This finding concurs with others who have found that quality relationships between staff and clients improve satisfaction and plans to stay in care.[44,56]

Participants' responses suggest that trust plays a substantial role in successful initiation and maintenance of ART.[50] By enabling partnerships with staff, trust helped clients take full advantage of the services offered to them, which helped improve their quality of life.[51,57,58] As with Tugenberg et al, clients and staff agreed that clients needed care that was specific to their needs; to do otherwise would run counter to the importance staff placed on developing concerned partnerships with clients.[49,144] Other studies from Kenya showed that a lack of patient-centered, respectful care can deter people from seeking treatment,[13] lending additional weight to the sites' focus on rapport. The good rapport described by these participants, with its emphasis on shared decision-making, information, and commitment has much in common with models of health-care empowerment.[145] These elements of engagement and empowerment have facilitated adherence and retention in HIV care elsewhere.[6,7,146]

The CHAK focus on capacity building appears to address many of the building blocks that are hampering the growth of health systems in developing countries and improving providers' comfort and competence in HIV care.[147,148] The focus on training and supportive management holds promise for motivating and retaining skilled health workers, as has been found in other developing-country settings.[149,150]

In contrast to research in neighboring Tanzania,[101] staff in CHAK's program were overwhelmingly positive about their jobs, deriving great satisfaction and motivation from their work in the CCC. While many said their work was difficult, they expressed very little, if any, stigma or resistance towards interacting with HIV patients. Other similarities included concerns about growing lines in the waiting room and infrastructure issues, namely the lack of consultation rooms and the co-location of TB treatment rooms in the HIV ward, which many staff worried greatly increased HIV patients' (many of whom were immunocompromised) risk of TB infection.[101]

5.2 Strengths and limitations

Qualitative methods, particularly those based in grounded theory, allow material to develop naturally during the course of data collection. This limits the extent to which the researcher's preconceived notions influence the data. Saturation was reached on key themes and concepts.

The interviewer was able in most cases to develop a good rapport with participants. They were relaxed, attentive, and willing to correct misunderstandings on the part of the researcher. Procedures were also adapted to better suit the context of a particular interview.

There are numerous limitations with this study. First, the research "team" consisted of me only. This meant that substantial analysis could not occur before additional rounds of data collection, as is commonly done in grounded theory studies. Adaptations were made, but based on initial perceptions and field notes rather than on true emerging themes and categories. The fieldwork schedule, with multiple consecutive interviews, also made adaptation difficult.

Good rapport between myself and the respondents was evident in most transcripts, however it was clear that some staff were hesitant to discuss personal matters or were worried about my sharing their responses with management; many asked what I would do with the information or if their name would be shared anywhere.

While every attempt was made to limit bias in data collection, there were shortcomings in this process. The presence of CHAK staff during some interviews was extraordinarily helpful, but it may have limited interviewee’s impulses to explain seemingly self-evident concepts or processes. At Site C, the presence of a CCC staff member during portions of two interviews may have inhibited these respondents. Data from these segments were treated with extreme caution.

The role of the interpreter in research settings is complicated. In some situations, my interpreter helped clarify concepts and probed for depth and nuance. In others, it is clear from the transcript that their phrasing of some questions was not as open-ended and neutral as intended.

My position as an outsider was both helpful and a barrier in this study. Participants were usually happy to explain procedures, relationships, and geography to me. I am a young white woman, which I believe engendered both feelings of deference and a desire to be instructive among participants. I also represented an American university and an organization that could be perceived as funding or having control over operations at the clinic. Participants were told repeatedly that their opinions would be kept confidential and that the study would not directly affect services. Nonetheless, social desirability bias may have played a role in many interviews.

These findings are not generalizable beyond CHAK. They may hold resonance for similar CCC programs, but because this style of treatment is fairly unique according to the participants, they should not be freely extrapolated to the framework of other types of HIV/AIDS programs. Interviewees described their experiences at other facilities, mostly with criticism; these criticisms included other FBOs. Thus, it is important to remember that these results pertain to these sites and this program only. While the term “FBO” or “mission hospital” may generally carry a positive reputation in Kenya, it is not a guarantee of quality services according to the experiences of these participants.

5.3 Implications for policy and practice

Trust and quality of services were symbiotic in this study, although quality took precedence. Trust could augment and hone overall service quality. Therefore, trust is an excellent indicator of overall service quality. Fostering trust within HIV clinics, and health systems more generally, could serve to improve and hone the quality of services. This has positive implications for equity and access.

The atmosphere of respect and trust present at these sites is in direct opposition to numerous experiences of health care in sub-Saharan Africa. Many studies describe oppressive hierarchies that result in rudeness, or even abuse and violence, towards patients.[140,151,152] Fear of rude and disrespectful staff has direct consequences on patients’ care seeking behaviors.[153-158] In this study, such attitudes and behaviors were rare. Staff had largely shifted their attitudes from detached paternalism toward collaborative partnerships with clients, a profound shift in power dynamics. Some staff members were less trustful than others, but they nonetheless stressed how important patience and encouragement were to clients. These findings suggest that respectful, patient-centered care is both possible and successful.

Numerous implications for policy and programming arise from these results. On a structural level, reliability of drugs, staff, and services is crucial for maintaining public trust in a health system.[21,23,153,159] When clients know that what they need will be available, their attitude toward the entire encounter becomes more positive. Attitudinal shifts can help clients commit to services and adhere to treatment.[7] Reliable supply chains also alleviate a potential source of frustration for staff and allow them to function at their best, further motivating them as professionals. These factors have significant potential for increasing uptake of health services, both in the realm of HIV/AIDS and elsewhere.[23,159-162] For example, poor quality of services and unreliable access to drugs prevent many women in Africa from utilizing maternity services, often leading to morbidity and mortality for both mothers and infants.[163,164]

Programmatically, the CHAK system succeeds because it expects and encourages good care through capacity building. The program is tailored at each site to meet each and every client's needs, addressing many barriers to care. In addition to activities like support groups and health education sessions, the program capitalizes on the emotional and interpersonal strengths of its staff to support and uplift clients. While the faith-based status helps in this regard, other programs could follow suit by attending to the spirit in which services are delivered, not just the content. With the proliferation of HIV programs throughout Kenya, clients are becoming savvy as to which programs offer which benefits. Rudeness and oppressive hierarchies in staff were not apparent in this environment, and clients expected to be treated well. Kind, professional, and respectful staff are just as much an advantage as any other service. Such staff operate in a supportive team environment; management listens to their frustrations and takes steps to address their concerns. Programs should work to ensure that all levels of staff are supported in care provision and professional development, and that they are satisfied with their ability to positively affect their work environment.

5.4 Areas for further research

The findings of this study are specific to patients in care within a well-supported CCC system. Obvious areas for future work would be to study trust among patients not in care or staff and clients in another kind of health system, such as government facilities. This sample was also predominantly female, so it would be prudent to include more men in future studies. Because trust was so closely linked to quality services in these data, future research should attempt to deconstruct these concepts in different environments to isolate their unique effects.

The framework describing the interrelationship of trust and quality services could be useful in understanding other health conditions where referral and retention to care are important. In sub-Saharan Africa, antenatal care and maternity services are an obvious choice for future research. This is an area with high burdens of morbidity and mortality yet persistently low uptake of services. Programmatic approaches that generate trust and improve service quality could have substantial impact.

Participants noted that some groups might feel judged by religious facilities. These sentiments could be validated with further research, helping facilities tailor their programs to better meet the needs of everyone in their communities. This holds particular relevance for groups like commercial sex workers, men who have sex with men, adolescents, and migrant workers. Some of these groups are often highly stigmatized, particularly for moral reasons, which could be problematic in a religious environment.

5.5 Conclusion

This study adds a small piece to the immense gap in trust research in developing countries.[76] It describes trust's origin and effects in a health system purported to have particular advantages in this area. The intertwined nature of trust and quality services suggests that they improve and support each other. When one falters, the other can serve to keep HIV patients in care and committed to living positively.

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Appendix A: Interview guide for clients

INTERVIEW GUIDE—CLIENTS

INTRODUCTION

[Read this section to participant. ***Informed consent MUST be done before beginning!*** *Ensure door is closed (if available) and that others know you are not to be disturbed. Make sure you have extra paper and pens/pencils. Chat about neutral topics until participant is comfortable, then introduce research.]*

Thank you again for agreeing to be in this study! Before we begin, I need to describe the study a little more. I would like to ask you about your experiences with HIV treatment at __________ facility and what the idea of “trust” means to you. I would like to know about your relationships with the staff, how you are treated, and what you think of the facility. While I’m most interested in HIV care, please feel free to talk about other experiences you have had. Your opinions are important, and so are your experiences. We hope to use them to improve these programs and those at other facilities. Our discussion will last about one hour.

If you don’t want to answer any question, just say so. You can leave at any time. I will not share any information that identifies you—the staff at this clinic will never know what you personally think of them. When I write up the results of this study, I will remove any information that identifies you.

In order for me to make sure I catch everything you say I have to use this recorder. Your name won’t be on the recording. The only other people who will hear it are on the study team. They will not share it outside themselves. The recording will be destroyed after we are done with the study. However, it is your choice if you want me to record our conversation. Is it ok if I record our conversation?

[If participant ***does not agree****, politely ask why they are worried. Describe privacy protections more thoroughly. Note that recorder is there to help you, not to trap the participant. Stress voluntary and confidential nature of participation.]*

[If participant still ***refuses*** *to be recorded, thank them and ask them if they would like to talk anyway. Make sure recorder is turned off and put it away. Continue the interview if they agree, just take notes.]*

[If participant ***agrees****, turn on recorder. Check that it is working before proceeding. Place recorder near participant but close enough so that your voice is heard too. It may be helpful to hide the recorder among other objects if participant seems intimidated by it.]*

QUESTIONS

[Begin by asking participant to describe their day, their favorite hobby, food, etc. Gradually introduce questions on the participant's background and life in order to establish context. Once participant is comfortable, begin more formal questions.]

I'd like to start by talking about your experiences.

HIV treatment

1. What is your experience with the HIV services at this clinic?
    a. Did you come to this facility before you had HIV?
        a. If so, how has your relationship/experience changed?
            a. Probes: interactions, privacy, etc.
        b. What was your first experience here like?
    b. Optional probes: understanding, accessibility, appropriateness, relationships with staff, etc.
2. Describe the treatment plan you've made with your doctor/nurse.
    a. How well does it fit with your lifestyle?
    b. What are some problems with this plan?
    c. How involved were you in this decision?
    d. How well do you think you've done following this plan?
    e. Are there any gaps in care?
3. If you're worried about something, what could your doctor/nurse do to lessen your worry?
4. How long do you plan to continue your relationship with this facility?
5. Should other facilities in your community follow this one's example?

Opinions of health facility (staff and institution)

6. What motivates the staff here?
    a. What are their priorities?
    b. How does your care fit in this list?
    c. How well does everyone live up to their values/goals?
7. What makes a good doctor/nurse?
    a. Which of these qualities does the staff have here?
    b. How do these qualities affect your trust in the staff?
8. If your doctor/nurse made a mistake, what do you think would happen?
9. What typically happens when you ask questions about your treatment?
10. How well does the staff here meet your medical needs?
    a. Probe: Psycho/social, spiritual, etc
11. Why did you choose to come to this facility?
    a. Why do you stay?
    b. How loyal do you feel?
    c. What are its best/worst qualities?
    d. Probe: differences between this and other facilities, services, populations missed, etc
12. How qualified do you think the staff here are?

13. How careful/thorough/attentive is the staff when they work with you?
14. How much confidence do you have in your doctor’s decisions?
15. How well does the staff here keep your HIV status secret, if that’s your wish?
    a. Is confidentiality important to you?
    b. How well do they respect your wishes in general?

Trust

16. What does it mean to trust someone like a neighbor?
17. How do you know when you trust someone?
18. What do you mean when you say you trust a health worker?
    a. What about a health facility?
19. How much trust do you have in your facility? In its staff?
20. How has trust affected your relationship with this facility? (referral, retention)
    b. How do you think it affects stigmatized populations?
    c. Probes: MSM, CSWs, IDUs, women infected by husbands, adolescents, etc.
    d. Probes for all questions: behaviors and attitudes associated with trust, health worker’s motivations and priorities, competence, honesty, confidentiality, respect within the community, etc…
    [Try to touch on as many as you can]

FBO status

21. What does it mean to you when you hear that a health facility has a religious mission?
22. How do you think this affects the services they offer?
    a. Probe: type, quality
23. How do you think this affects the staff?
24. How do you think having a religious mission or affiliation affects your trust in a health worker/facility?
    b. Probe: different behaviors for different types of facilities.
25. Did you know that this facility is an FBO?
    c. Does that change your opinion at all?

CLOSING

So we’re coming to the end of our time together. I have a couple more questions, but first is there anything else you’d like to share?

26. If you could change one thing about your health care here, what would it be?
27. How comfortable would you be recommending this facility to a friend?

Thank you so much for your time! This has been really valuable. You have my contact information if you need to get in touch.

[Answer any final questions. Reiterate privacy, confidentiality, importance of their opinions to research, etc. Do not turn off the recording until it is clear that the interview is over.]

Appendix B: Interview guide for staff

INTERVIEW GUIDE—STAFF

INTRODUCTION

[Read this section to participant. ***Informed consent MUST be done before beginning!*** *Ensure door is closed (if available) and that others know you are not to be disturbed. Make sure you have extra paper and pens/pencils. Chat about neutral topics until participant is comfortable, then introduce research.]*

Thank you again for agreeing to be in this study! Before we begin, I need to describe the study a little more. I would like to ask you about your experiences with HIV treatment at __________ facility. I would like to know about your relationships with the other staff and patients, how you are treated, and what you think of the facility. While I'm most interested in HIV care, please feel free to talk about other experiences you have had. Your opinions are important, and so are your experiences. We hope to use them to improve these programs and those at other facilities. Our discussion will last about one hour.

If you don't want to answer any question, just say so. You can leave at any time. I will not share any information that identifies you—the staff at this clinic will never know what you personally think of them. When I write up the results of this study, I will remove any information that identifies you.

In order for me to make sure I catch everything you say I have to use this recorder. Your name won't be on the recording. The only other people who will hear it are on the study team. They will not share it outside themselves. The recording will be destroyed after we are done with the study. However, it is your choice if you want me to record our conversation. Is it ok if I record our conversation?

[If participant ***does not agree****, politely ask why they are worried. Describe privacy protections more thoroughly. Note that recorder is there to help you, not to trap the participant. Stress voluntary and confidential nature of participation.]*

[If participant still ***refuses*** *to be recorded, thank them and ask them if they would like to talk anyway. Make sure recorder is turned off and put it away. Continue the interview if they agree, just take notes.]*

[If participant ***agrees****, turn on recorder. Check that it is working before proceeding. Place recorder near participant but close enough so that your voice is heard too. It may be helpful to hide the recorder among other objects if participant seems intimidated by it.]*

QUESTIONS

[Begin by asking participant to describe their day, their favorite hobby, food, etc. Gradually introduce questions on the participant's background and life in order to establish context. Once participant is comfortable, begin more formal questions. NOTE: Probe throughout to differentiate between staff and institution, where applicable.]

I'd like to start by talking about your experiences.

HIV services

1. Which HIV services do you personally provide at this clinic?
2. How would you describe your relationship with your patients, generally?
3. What are some of the challenges facing your work in this field?
    a. What could you do better?
4. How do this facility's policies affect your ability to do your job?

Opinions about facility (staff and institution)

5. What motivates the staff here?
    a. What are their priorities?
    b. How well does this facility live up to its values/goals?
    c. Probes: decision to work here, best/worst qualities, differences with other types of facilities
6. What makes a good doctor/nurse?
    a. Which of these qualities does the staff have here?
    b. How do these qualities do you think affect trust?
7. If a doctor/nurse made a mistake, what do you think would happen?
8. What typically happens when patients ask questions about their treatment?
9. How well does the staff here meet your patients' needs?
    a. Probes: Psycho/social, spiritual, etc.
10. How well does the staff here keep patients' HIV status secret, if that's their wish?
    a. How well do they respect patients' wishes in general?
11. What do you think draws patients to this facility?

Trust

12. What does it mean to trust someone like a neighbor?
13. How do you know when you trust someone?
14. What do you mean when someone says they trust a health worker
    e. What about a health facility?
    f. How much trust do you have in your facility? In your patients?
        i. Compare those with HIV to those without.
    g. How does this trust apply to different kinds of patients, like those who experience stigma, those who don't, etc?
    h. Probes: MSM, women infected by husbands, adolescents, etc.

        i. Probes for all questions: health worker’s motivations and priorities, competence, honesty, confidentiality, respect within the community, etc…
        [Try to touch on as many as you can]

15. How much do you think patients trust you and your facility?
    a. Probes: behavior, attitudes, etc.

Now I’d like to talk a little more about this type of health facility.

FBO status

16. What does it mean to you when you hear that a health facility has a religious mission?
17. How do you think this affects the services they offer?
    c. Probe: type, quality
18. How do you think this affects the patients?
19. How do you think having a religious mission or affiliation affects your trust in a health worker/facility?
    a. Probe: different behaviors for different types of facilities.
20. Did you know that this facility is an FBO?
    d. Does that change your opinion at all?

CLOSING

So we’re coming to the end of our time together. I have a couple more questions, but first is there anything else you’d like to share?

21. How comfortable would you be recommending this facility to a friend?
22. What is the best part about working here?

Thank you so much for your time! This has been really valuable. You have my contact information if you need to get in touch.

[Answer any final questions. Reiterate privacy, confidentiality, importance of their opinions to research, etc. Do not turn off the recording until it is clear that the interview is over.]

Appendix C: Consent script

VERBAL CONSENT SCRIPT

Researcher's script

We are asking you to take part in a research study. It is funded by the United States Centers for Disease Control and Prevention, but is being arranged by the Christian Health Association of Kenya and Emory University, a large university in the United States.

This study involves an interview with a researcher. We would like to know your opinions about HIV/AIDS care at this facility. We also want to know what is important to you in a health worker and a facility. The researchers will keep everything you say confidential. The interview will last about one hour.

You don't have to answer any question you don't want to and you can leave at any time. Participating in this study will not affect your health care, your rights, or your relationship with this facility in any way. You will not receive payment for participating, however there are snacks available.

Also, we would like to tape record the discussion so we can collect your ideas accurately. The recording will not be shared with anyone outside of the study and will be destroyed once we have analyzed it.

Would you like to join the study? If so, please agree to the following statement:

Participant's statement

I agree to participate in this research study and discuss my experiences with HIV/AIDS care at this facility. I understand that none of my private information will be shared by the researchers. I can refuse to answer any question and can leave at any time. Participating in this study will not affect my job or my health care in any way.

Do you agree to have the discussion recorded? ☐Yes ☐No

Researcher's signature

Signature: ____________________ Date: __________ *(dd/mm/yyyy)*

Name: ____________________

Witness's signature

Signature: ____________________ Date: __________ *(dd/mm/yyyy)*

Name: ____________________

Participant received copy of a consent form for his/her personal records: ☐