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End User Perception of Antiretroviral Therapy (ART) Services in Public and Private Health Facilities in Anambra State, Nigeria: Lessons for Scale Up of Quality Private Sector Services

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Abstract

End User Perceptions of Antiretroviral Therapy (ART) Services in Public and Private Health Facilities in Anambra State, Nigeria: Lessons for Scale Up of Quality Private Sector Services

By Chika Egbunike

Background

Since the emergence of HIV and AIDS in Nigeria in the early 1980s, the country's health care system has struggled to provide care and support to the growing number of adults and children living with the disease. Government-managed public health facilities serve the vast majority of people seeking HIV and AIDS care and support services. As government resources for health care are stretched to a breaking point by HIV and AIDS and other demands, policy makers and health officials are looking to the private sector to take on more responsibility for providing ART and other HIV and AIDS services for millions of infected Nigerians.

Purpose: This study aimed to examine the perceptions of end-users of ART services provided through programs at private and public health facilities in Anambra State. Anambra State's 8.7% HIV prevalence rate[1] is among the highest of Nigeria's 36 states and the Federal Capital Territory. Anambra State also has one of the country's highest per capita income levels and also has a large number of private healthcare providers. The State provides an important opportunity to understand the perceptions and expectations of people living with ART about services provided by government run and privately operated health facilities.

Methods: A qualitative and descriptive research design was used for the study. Semi-structured focus group discussions were conducted amongst 84 participants in 4 health facilities (2 public and 2 private) in Anambra State. Participants were recruited through purposive sampling of end users receiving ART services in the health facilities. Qualitative data analysis, based in grounded theory, addressed inductive and deductive themes.

Results: The perceived needs of patients affect how they view quality services. Workforce performance stands out as the most important factor influencing end user perceptions of ART services, followed by patient values, health benefits, stigma and support systems.

Conclusion: An understanding of how ART end users evaluate their care may help to identify deficiencies and inform improvements to ART services. This understanding will help render ART services in health facilities more patient centered.

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[1] National HIV/AIDS and Reproductive Health Survey (NARHS plus II) of 2012

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Discussion of Findings

Chapter 1

1.1 Introduction

The HIV/AIDS epidemic remains a major public health challenge across the globe with about 35 million people in the world estimated to have died of AIDS related diseases by the end of 2015. Each year new infections occur in Africa with a large proportion of these occurring in Nigeria.

Nigeria's HIV infection rate of 3.2% appears low in comparison to countries in southern Africa; however, with a population of more than 173 million, the country has the second highest disease burden behind only South Africa. Despite efforts by government to establish antiretroviral therapy (ART) programs at public and private health facilities, only about 600,000 of those infected are currently receiving ART. Early in the epidemic, interventions focused on setting up structures separate from hospital programs.

Less than 10 percent of private health facilities provide ART services, with the vast majority of end users receiving services at government health centers (Abt Associates, October 2014). Costs and wider availability of services and drugs at public facilities are important factors in patient decisions. However, quality concerns have also limited use of private health facilities. A study on ART patient experience conducted in central Nigeria showed that patients on ART in public health facilities spent significantly less time to collect drugs compared to patients in private health facilities. Additionally, mean satisfaction scores of patients were higher for patients who used public health facilities. Dissatisfaction with antiretroviral services in private health facilities threatens efforts to expand services to reach the millions more needing ART (Osungbade,2013)

Additional research is needed to understand end user perceptions of ART services at private facilities and address gaps in perceptions and patient expectations. The present study seeks to provide such an opportunity for research on this issue. It is hoped that the research results will inform government and FHI 360 efforts to increase the role private health facilities must play if Nigeria is to serve its citizens living with HIV and AIDS.

1.2 Problem Statement

Healthcare services in Nigeria have been found not to meet end users' requirements and expectations (Chiegil et al, 2014). Research which examines end users' perceptions of antiretroviral therapy services in Nigeria healthcare facilities is quite limited. As such this study aimed to examine the perceptions of end users of ART services at selected private and public health facilities in Anambra State. Such knowledge can help health professionals, government and FHI 360 identify gaps and inform service improvement to meet end users' requirements and to address adequately the treatment needs of the more than 3.4 million Nigerians currently living with HIV and AIDS and the more than 220, 000 additional people contracting HIV annually (UNAIDS 2014). It has also been found that satisfied end users are more likely to participate in their own care, continue using the health facility services and stay with health care providers even when they have different options (Udoh, Eze & Okeji 2011).

1.3 Purpose Statement

Despite efforts by the Nigerian government to establish ART programs at public and private health facilities, only about 600,000 of those infected are currently receiving ART. Less than 10 percent of private health facilities provide ART services, with the vast majority of end users receiving services at government health centers. Additional research is needed to understand end user perceptions of ART services at private and public health facilities and use findings of the research to make recommendations to Anambra State Ministry of Health for service improvement.

1.4 Research Questions

1. What are end user perceptions of antiretroviral therapy services in public and private health facilities in Anambra State, Nigeria?

2. What are the similarities and differences between end user perceptions and experiences of ART services in public and private health facilities in Anambra State, Nigeria?

1.5 Significance Statement

This study will inform a better understanding of end user perceptions of ART services in public and private healthcare facilities in Anambra States. If utilized, these have the potential to inform efforts to improve the overall quality of ART services in health facilities in Anambra State and thus improve the health outcomes of end users.

1.6 Definition of terms

End User: The Advanced Learners' Dictionary (2000) defines end user as the person who actually uses a product (or service) rather than one who makes or sells it, especially the ones for whom the product or service has been designed. In this study, end users refer to the ultimate consumers of antiretroviral therapy services in public health facilities in Nigeria. These are people living with HIV and AIDS and attending ART services in public health facilities in Nigeria.

Public Health Facility: Public health facility (external environment) is a clinical setting established and managed by the government of Nigeria, to meet the health care needs and expectations of end users attending ART services. The environment comprises both the physical (antiretroviral therapy clinic and resources) and social (health care workers) dimensions. In this study "environment" refers to the factors/conditions (social or cultural) that influence the end user either directly or indirectly in his/her involvement in the antiretroviral therapy services in public health facilities in Nigeria (Chiegil et Al 2010).

Private Health Faculty: In this study, a private health facility (external environment) is a clinical setting established by faith-based organizations. It is a hospital that aims to meet the health care needs of end users attending ART services. Federal, state, and local health authorities provide regulatory oversight of private health facilities. The environment comprises both the physical (antiretroviral therapy clinic and resources) and social (health care workers) dimensions. In this study "environment" refers to the factors/conditions (social or cultural) that influence the end user either directly or indirectly in his/her involvement in the antiretroviral therapy services in public health facilities in Nigeria (Chiegil et Al 2010).

Antiretroviral Therapy: According to the WHO (2006:9) ART refers to the delivery of antiretrovirals as part of care interventions, including the provision of co-trimoxazole prophylaxis, the management of opportunistic infections and co-morbidities, nutritional support and palliative care. In this study, ART refers to the prescription and taking of antiretrovirals, at the correct time intervals, on a daily basis for one's entire life. Also, laboratory monitoring and management of opportunistic infections, adhering to food prescriptions, and taking generally good care of one's health. ART also involves keeping follow-up clinic visits and maintaining available supplies of antiretrovirals.

Perceptions: is defined as an idea, a belief or an image you have as a result of how you see or understand something (The Advanced Learners' Dictionary 2000). Chow et al (2009:436) assert that perception is purely subjective, as the perception that end users have of ART service provision affects their expectations greatly, and in turn, their satisfaction. Different end users have differing perceptions of ART service provision, which has been shown to predict overall end user satisfaction (Chow et al 2009:436).

Chapter 2

Literature Review

Introduction

This chapter provides a detailed analysis of reviewed literature on end user perceptions of ART services in public and private health facilities in Anambra State, Nigeria.

Health service provision refers to the way inputs such as money, staff, equipment and drugs are combined to allow the delivery of a series of interventions or health actions (WHO 2000). Many factors determine the quality of health services delivered. These factors include personal factors of the provider and the patient, and factors pertaining to the healthcare organization, healthcare system, and the broader environment (Mosadeghrad, 2014).

This study explores end user perception of ART health services, realizing that these perceptions could shape the choice and usage of available health care facilities. End users' perceptions are increasingly being used in the assessment of the competency of health care facilities and quality of care. When designed and administered appropriately, patient experience provides robust measures of quality (Manary M et al, 2013). An understanding of how end users view their care may help to identify gaps in service delivery and help inform improvements. This chapter further discusses the framework that was used for the study which is the Chronic Care Model.

End User Perceptions of Quality ART Services

Various end user perspectives, desires and priorities must be considered in any effort to define, measure, and improve quality of healthcare. Several studies have identified the health service quality factors that are important to patients. A study conducted in a private health facility in Thailand (Hasin et al, 2001) identified the following quality factors: cleanliness; service of doctor (quick response to request for service, intention and attention of doctors in listening to an end user, diagnosing method, treatment explanation, and courtesy); service of nurses (quick response to request for nursing service, help and attention of nurses, and courtesy); service of health care providers, i.e. staff (quick response to request for financial service, quick response to request for laboratory, pharmacy services including courtesy).

These findings are in keeping with a study by Chiegil (2010) conducted in Taraba State of Nigeria. The study sought to explore the factors relating to quality of care and their influence on antiretroviral adherence among end users in Nigeria. The factors that kept end users satisfied with care included clean and attractive service environment and courtesy of doctors, nurses and other health care providers. The following factors prevented end users from achieving their expectations for quality care: frequent stock out of cotrimoxazole and multivitamins; non-routine laboratory tests; sub optimally skilled health care workers; high fees for services and disharmony between health facility and community based support group members.

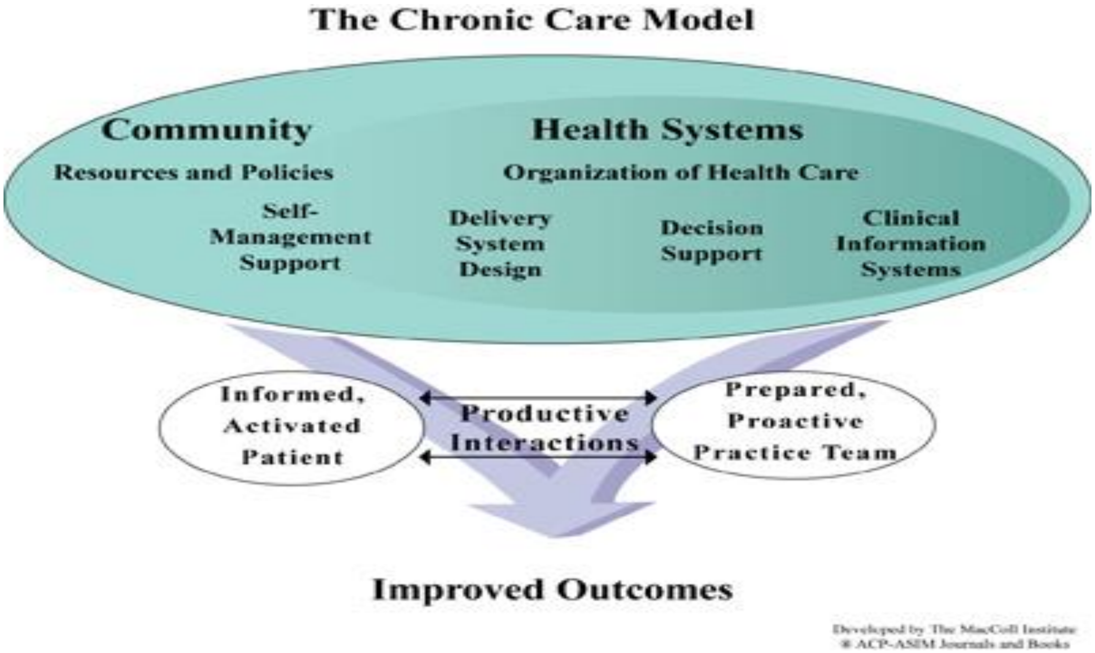
In a similar study by Onwujekwe et al (2016) investigating client perception and attitude to decentralization of HIV and AIDS treatment services to primary health centers in three Nigerian states, it was found that HIV and AIDS clients appeared to be generally satisfied with the ART services offered to them at their health care facilities. It was also noticed that their level of satisfaction for key services, such as counselling and testing, antiretroviral drugs and prevention of mother-to-child transmission (PMTCT), was mostly very good. However, long waiting time was seen to be a major contributor to clients' dissatisfaction with their current delivery mechanism.

The influence of long waiting times on end user perception of quality of health services was also a significant finding in another study conducted by Ogunfowokan et al, (2012) at the National Hospital Abuja. The study found a significant relationship between clients' satisfaction with ART services and the amount of time they spend in the doctor's office. Several studies have highlighted the crucial role of health personnel attitudes on end user perception of the quality of health services. In Chennai India, a study was organized by India's National AIDS Control Organization to help inform development of interventions to enhance ART access. In this study barriers to free Antiretroviral Therapy access at government Antiretroviral Therapy centers for injecting drug users living with HIV were explored. Health-care system barriers found included actual or perceived unfriendly hospital environment and procedures such as requiring proof of address and identity from PLHIV, including homeless injecting drug users; provider perception that injecting drug users will not adhere to Antiretroviral Therapy, resulting in Antiretroviral Therapy not being initiated; actual or perceived inadequate counseling services and lack of confidentiality; and lack of effective linkages between Antiretroviral Therapy centers, needle/syringe programs, and drug dependence treatment centers (Venkatesan et al, 2014).

Research findings indicate that end users’ perception of quality of health services is also influenced by services they receive in the facility ART pharmacy and laboratories. In studying perceptions of end users concerning quality of pharmacy services in public health facilities, Karunamoorthi et al (2009) sought to determine end users' level of satisfaction and their expectations with pharmacy services at specialist ART units in the government hospitals of Addis Ababa, Ethiopia. Results of the study showed that end users were dissatisfied with the pharmacy services. The major area of dissatisfaction was long waiting time in the pharmacy.

Similar studies undertaken in seventeen HIV treatment centers in Nigeria indicate that the perception of participants regarding the appearance of pharmacy was positive while that regarding the pharmacists' efforts to solve patients' medication related problems was negative. The participants' rating of satisfaction with the waiting time to access pharmaceutical services was negative; the satisfaction decreases with increasing waiting time. However, the satisfaction with the overall quality of pharmaceutical services received was rated as positive; 90.0 % reported that they got the kind of pharmaceutical services they wanted; 98.2 % would come back to the pharmacy if they were to seek help again and would recommend services to others. (Agu, et al, 2014).

In studying the perception of end users concerning quality of antiretroviral therapy laboratory services in public health facilities a study conducted in Tanzania by Mfinanga et al. (2008) sought to equate end users' satisfaction with the laboratory services received. The study's findings show that about 15.0% to 34.8% of end users were not satisfied with waiting time, privacy, results notification, cleanliness and timely instructions. End users who visited private health facilities were less dissatisfied with cleanliness and privacy of ART laboratory services than those who visited public health facilities. Also, end users with higher education were more likely to be dissatisfied with privacy and waiting time in both private and public health facilities.



The Chronic Care Model (CCM) is a framework that deals with care for people with long-term conditions or chronic diseases. Models of ART services are context specific and reliant on a range of factors, including patient barriers to retention in care, HIV and AIDS prevalence, and health service capacity. For this study the chronic care model was used. The CCM identifies the essential elements of a health care system that encourage high-quality chronic disease care. These elements are the community, the health system, self-management support, delivery system design, decision support and clinical information systems. Evidence-based change concepts under each element, in combination, foster productive interactions between informed patients who take an active part in their care and providers with resources and expertise.

The Chronic Care Model was developed by Edward Wagner, Director of the MacColl Center for Health Care Innovation at Group Health Research Institute in 1998. Based on more recent evidence, five additional themes were incorporated into the CCM namely: Patient Safety (in Health System); Cultural competency (in Delivery System Design); Care coordination (in Health System and Clinical Information Systems) Community policies (in Community Resources and Policies); and Case management (in Delivery System Design).

The CCM was used as the framework of this study due to the fact that the model has features that look at the total needs and expectations of the end user and ensures that their needs are integrated and coordinated into a whole.

Chapter 3

Methodology

3.1 Introduction

This section provides systematic and detailed information on the steps taken to implement the research study. It gives a detailed description of the key population and sample, including the inclusion and exclusion criteria used in the study. It also presents the ethical considerations used in the study for the protection of human subjects. It provides a detailed description of methods and steps used to collect data, and conduct data analysis. The study was conducted in four health facilities (two public and two private) located in Anambra State of Nigeria. Twelve focus group discussions (FGDs) and twelve key informant interviews (KIIs) were conducted. A total of 84 participants were interviewed from these health facilities, comprising end users of ART services and key health facility staff.

3.2 Population and Sample

The study population for this study was made up of end users of ART services who were HIV positive and met the following inclusion criteria: enrolled and receiving services for at least six months in the four targeted (two private or two public) health facilities in Anambra State; was a registered support group member of the health facility; between the ages of 18 - 50 (adults) and 11-17 (adolescents); and willing to provide oral consent (this was to avoid identifying subjects who are HIV positive) to participate in the study. Twelve FGDs were conducted and these were stratified by gender and age. For each facility visited 6 adult males, 6 adult females and 6 adolescents participated in the FGDs, which lasted between 50 - 70 minutes each. This ensured adequate time to explore relevant issues with participants. There were 84 participants in total. Key informants provided information on ART service standards, expectations and performance of public and private health facilities. A total of twelve KIIs were conducted. Key informants met the following inclusion criteria: were staff of the health facility; had worked in the ART section of the health facility for at least six months; must be a doctor, a pharmacist and a laboratory technician; and within the ages of 18- 50. For each health facility, the researcher interviewed a doctor, a pharmacist and a laboratory technician who were providing services in the hospital.

Study Area

The study was carried out in two (2) public health facilities and two (2) private health facilities in Anambra State (See Figure 3.1)**.** The health facilities selected were representative of health facilities in the state; they were purposively selected from a pool of existing health facilities supported by Family Health International (FHI 360) in Anambra State. The criterion for selection was based on high prevalence of HIV infection in each health facility; the health facility had received support from FHI360 and was registered with the Federal or Anambra State Ministry of Health as an ART service provider. The health facilities therefore had common standards and ART services. The researcher went to the four study sites to see the natural setting, and to understand the context.

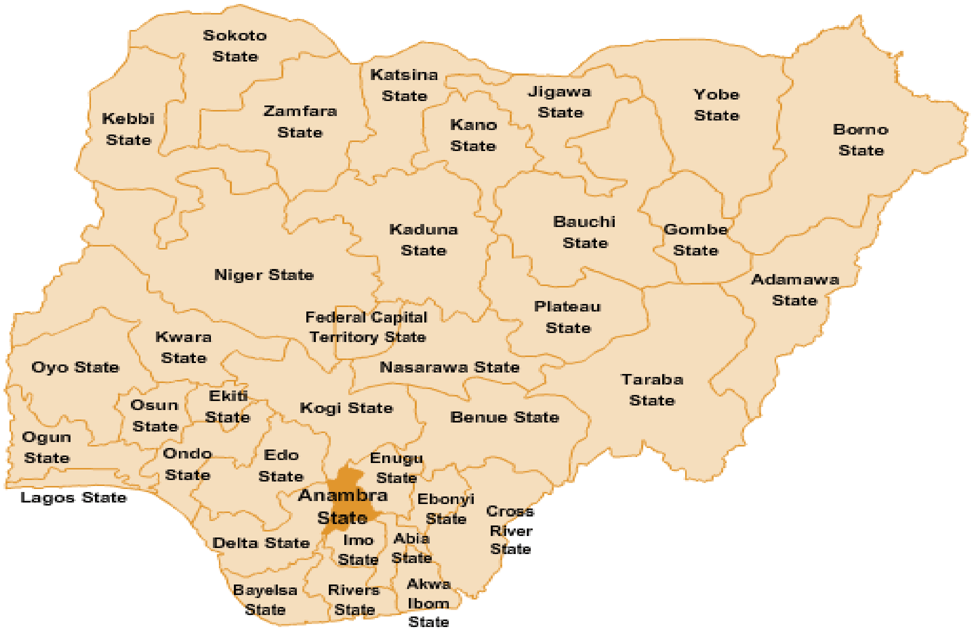


Figure 3.1 Map of Nigeria showing Anambra State where the two public and two private health facilities which were research sites for this study were situated.

3.3 Research design

The study used a qualitative and descriptive research design to collect rich contextual data. FGDs and KIIs were used to collect qualitative data on the perceptions of end users of ART services at two public and two private health facilities in Anambra State. FGDs were conducted in each facility; categories were adult male, adult female and adolescents. Each FGD had 6 participants. A total of twelve FGDs and 12 KIIs were conducted. The FGDs and Interviews took between 50 - 70 minutes. Additionally, there was a desk review of relevant research reports on ART services in private and public facilities.

Table 3.3.1 Inventory List of data collected

	Type of data	Name of Hospital	Type of Hospital	Ownership	Location	Language	Gender	Age
Women FGD 1	FGD	Hospital 1	Public	Government	Nnewi	Igbo	F	36-50
Women FGD 2	FGD	Hospital 2	Private	Faith-based	Onitsha	Igbo	F	26- 50
Women FGD 3	FGD	Hospital 3	Public	Government	Ekwulobia	Igbo	F	32-50
Women FGD 4	FGD	Hospital 4	Private	Faith-based	Awka	Igbo	F	29-48
Men FGD 1	FGD	Hospital 1	Public	Government	Nnewi	Igbo	M	36 - over 50
Men FGD 2	FGD	Hospital 2	Private	Faith-based	Onitsha	Igbo	M	36 - over 50
Men FGD 3	FGD	Hospital 3	Public	Government	Ekwulobia	Igbo	M	29-over 50
Men FGD 4	FGD	Hospital 4	Private	Faith-based	Awka	Igbo	M	32-49
Adolescent FGD 1	FGD	Hospital 1	Public	Government	Nnewi	Igbo	M & F	Under 25
Adolescent FGD 2	FGD	Hospital 2	Private	Faith-based	Onitsha	Igbo	M & F	Under 25
Adolescent FGD 3	FGD	Hospital 3	Public	Government	Ekwulobia	Igbo	M & F	Under 25
Adolescent FGD 4	FGD	Hospital 4	Private	Faith-based	Awka	Igbo	M & F	Under 25
Dr. KI 1	IDI	Hospital 1	Public	Government	Nnewi	Igbo	M	36-40
Dr. KI 2	IDI	Hospital 2	Private	Faith-based	Onitsha	Igbo	F	31-35
Dr. KI 3	IDI	Hospital 3	Public	Government	Nnewi	Igbo	M	36-40
Dr. KI 4	IDI	Hospital 4	Private	Faith-based	Onitsha	Igbo	F	36-40
Pharmacist KI 1	IDI	Hospital 1	Public	Government	Nnewi	Igbo	F	31-35
Pharmacist KI 2	IDI	Hospital 2	Private	Faith-based	Onitsha	Igbo	F	31-35
Pharmacist KI 3	IDI	Hospital 3	Public	Government	Nnewi	Igbo	M	36-40
Pharmacist KI 4	IDI	Hospital 4	Private	Faith-based	Onitsha	Igbo	F	31-35
Lab scientist KI 1	IDI	Hospital 1	Public	Government	Nnewi	Igbo	F	41-45
Lab scientist KI 2	IDI	Hospital 2	Private	Faith-based	Onitsha	Igbo	F	36 -40
Lab scientist KI 3	IDI	Hospital 3	Public	Government	Nnewi	Igbo	M	36-40
Lab scientist KI 4	IDI	Hospital 4	Private	Faith-based	Onitsha	Igbo	F	31-35

3.4 Procedures

Data collection was conducted in three phases namely the planning phase, implementation phase and conclusion phase. During the planning phase the researcher collected information that would aid her in the study via desk reviews of documents in the health facility, ministry, and FHI360. The two review guides (Focus Group Discussion and In-depth Interview), and demographic form were developed for the study. During the implementation stage, the interviewer travelled to Anambra State which was the site of the study and identified three colleagues form FHI 360 who were experienced in qualitative methods and would assist her in collecting data as research assistants. The researcher then gave them a one-day training on ethical considerations and skills necessary for the study. Because of the rapport FHI 360 had with the health facilities it was easy for the research assistants who were already known in the facilities to approach the management of the hospitals and request to meet with support group leaders, who were asked to make announcements to members to enroll if they were interested in participating in the study. The leader of the support group was asked to collect contact details of those wishing to participate for follow up calls by the researcher who then fixed the date for the various FGDs.

Recruitment

Participants were purposively approached and recruited from the existing health facility support groups. The population for this study were end users of ART services who were HIV positive, in Anambra State and who met the following inclusion criteria: has been receiving ART in a government designated center in a public health facility or a private health facility in Anambra State; at least 18 years old (adults) and 10-18 years (adolescents); has been attending the ART program for at least 6 months on a continuous basis; and willingly provided verbal consent to participate in the study.

Key informants were approached individually based on their subject matter expertise and were invited to participate in the study. Key informants had the following inclusion criteria: must be a staff of the health facility; has worked in the ART section of the health facility for at least six months; must be a doctor, a pharmacist and a laboratory technician; within the ages of 18-50; and willing to provide written consent to participate in the study. `

Key informants provided information on ART service standards, expectation and performance of public and private health facilities. For each health facility, the researcher interviewed a doctor, a pharmacist and a laboratory technician providing services in the hospital (a total of 12 participants).

Informed Consent Process:

The researcher gained informed consent from participants prior to commencement of the FGDS and interviews, including parental consent and child assent for minors aged 17 and under. The consent form contained information which explained the procedure for the FGDs and KIIs, an overview of the study and issues about confidentiality, risk, compensation, voluntary participation and benefits. The researcher allowed time for questions, and allowed the potential participants to summarize the material to confirm understanding. Four consent documents were made available: adult participant consent, parental consent for minors, child assent for minors and key informant consent. Oral consent was provided (this was to avoid identifying subjects who are HIV positive).

Potential Risks/Discomforts to Study Participants and measures to prevent occurrence:

Participants were informed that some of the focus group discussion questions could make them uncomfortable or upset. They were informed that they were free to decline to answer any questions they did not wish to or to leave the group at any time. All participants were asked to respect the privacy of other group members; and not to disclose anything said within the context of the discussions.

Benefits:

Participants were informed that the study was not designed to benefit any participant directly; but was designed to learn more about the perceptions and opinions of end users of ART services in private or public health facility. The study results would be used to improve quality of ART services in these health facilities.

Data Collection

Data was collected from primary sources through FGDs and KIIs in English and Igbo (local language in Anambra State). Data collection was conducted over four weeks from July to August 2016. A total of 84 people participated in the FGDs and KIIs in the four health facilities identified for the study.

3.5 Instruments

The instruments used for the study were FGD and KII guides. The researcher created guides to elicit information on issues surrounding ART services in health facilities. The questions were open-ended, which allowed participants to respond freely based on their knowledge, experiences, and feelings. Most questions included probes that allowed the researcher to clarify specific details and gather more detailed information on central topics. The researcher used the FGDs because it was an excellent approach to generate rich contextual data; and it allowed for participant interactions which drew out latent issues until the point of saturation. KIIs were used for experts in their field (doctors, laboratory scientist, and pharmacist). The developed draft FGD and KII were taken to the field for pilot testing prior to the main discussions and interviews. The guides were then reviewed and finalized based on feedback from the pilot testing. The instrument are in Annex B.

Box 1: Focus Group Discussion Sample Questions

1. How would you all describe the appearance of this health facility?
   Probes:
   "How would you describe the space in the hospital"?
   "How would you describe the cleanliness of the hospital"?
   "What do you like most about the health facility"?

2. What do you all think about the support given by staff at this health facility"?
   Probes:
   "What is the typical wait time before you see a Doctor"?
   "How did you feel about how the doctors attended to you (courtesy)"?
   "How knowledgeable are the Doctors about your needs (treatment explanation)"?

3. Describe the counselling services in this health facility?
   Probes:
   "How has counselling affected your adherence to treatment"?
   "How would you describe the treatment education you received during counselling sessions"?

Box 2: Key Informant Interview Sample Questions

1. In your own words what do you think quality ART service provision means?
   Probes:
   "What do you think are the most critical components"?
   "How would you describe the state of ART services in this health facility"?

2. How does your health facility ART services compare with those of Public/ or Private health facilities?
   Probes:
   "Describe this in terms of quality
   "Describe this in terms of cost
   "Describe this in terms of wait time
   "Describe in terms of availability of drugs

3. What do you think are patient's expectations regarding quality of ART services in this health facility?
   Probe:
   "Can you describe how feasible this is"?

Plans for data Analysis

Data Analysis was conducted by the researcher upon return to Emory University. Data collected from FGDs and KIIs were transcribed and entered into MAXQDA qualitative data analysis software. The data were categorized, coded and counted to identify frequent responses and themes to determine most relevant findings. A codebook of prominent themes was developed and the data were labeled with these codes. Data labeled with individual codes were analyzed to describe the treatment of specific themes across the data and in transcripts from public versus private health facilities and in male versus female and adult versus adolescent FGDs. The analysis was contextualized using findings from related research, policy, standards and reports from the desk review.

All data collected were stored and protected from physical damage in a safe place. Privacy and anonymity were assured by replacing names and other information with encoded identifiers. Confidentiality was maintained as only the research team members had access to study records.

3.7 Ethical considerations

Ethical approval to undertake the study was obtained from the Emory University Institutional Review Board and from the Nnamdi Azikiwe University Teaching Hospital Ethics Committee, Anambra State, Nigeria. Participants were assured that participation was voluntary and were free to leave if they did not wish to be part of the discussions.

3.8 Limitations and delimitations

Only four health facilities (two public and two private) in Anambra State were used for purposes of this study so the findings cannot be generalized beyond these four health facilities.

CHAPTER 4

RESULTS

4.1 Introduction:

This chapter presents the findings of this qualitative study. In order to answer the research questions of this study twelve FGDs and twelve KIIs were conducted in four Anambra State health facilities (two public and two private). A total of 84 participants were interviewed from these health facilities, comprising end users of ART services and key health facility staff.

This chapter firstly displays the research participants' demographic characteristics per study site (Table 4.1). The results showed that most participants (n=46; 54.8%) were female, compared to (n=38; 45.2%) male participants. Most of the participants were employed (n=78; 92.9%) compared to (n=6; 7.1%) who were unemployed. The highest proportion of participants fell in the "less than 25" age range (n=24; 28.6%), while the lowest proportion of participants fell in the "46 years and above" age range (n=18; 21.4%).

Most participants had attended school (n=79; 94.1%), while few (n=5; 5.9%) stated they had not attended school. Most participants live in urban and semi urban areas (n=67; 79.8%) compared to those that lived in rural areas (n=17; 20.2%).

This is followed by a presentation of the findings that address the research questions. The chapter also presents the five main thematic areas that emerged from analysis of the data with regard to end user perceptions of ART services in Anambra State. The thematic areas were categorized and discussed by the researcher.

4.2 Demographic data of participants

Table 4.1 Demographic data of participants (n=84)

Category	Number of participants per site													
	Public Hospital 1			Public Hospital 2			Private Hospital 2			Private Hospital 2			Total	%
Gender														
	FGD	KII		FGD	KII		FGD	KII		FGD	KII			
Male	8	1	**9**	8	2	**10**	10	0	**10**	7	2	**9**	38	45.2%
Female	10	2	**12**	10	1	**11**	8	3	**11**	11	1	**12**	46	54.8%
Total	18	3	**21**	18	3	**21**	18	3	**21**	18	3	**21**	84	100.0%
Age														
Less than 25 years	6			6			6			6			24	28.6%
26-30	0			2			2			2			6	7. 1%
31-35	1			5			3			4			13	15.5%
36- 40	4			0			4			3			11	13.1%
41-45	5			1			3			3			12	14.3%
46 years and above	5			7			3			3			18	21.4%
Total	21			21			21			21			84	100.0%
Occupation														
Student	3			6			5			6			20	23.8%
Civil Servant	3			4			5			4			16	19.1%

Self employed	13	10	8	11	42	50.0%
Unemployed	2	1	3	0	6	7. 1%
Total	21	21	21	21	84	100.0%
Highest Level of Education						
Primary school	5	3	3	5	16	19.1%
Secondary school	8	10	12	10	40	47.6%
University degree	3	6	4	6	19	22.6%
Post-graduate degree	2	1	1	0	4	4.8%
Other	3	1	1	0	5	5.9%
Total	21	21	21	21	84	100.0%
Area of residence						
Urban	13	13	12	14	52	61.9%
Rural	4	7	2	4	17	20.2%
Between urban and rural area	4	1	7	3	15	17.9%
Total	21	21	21	21	84	100.0%

4.3 Presentation of themes

The results of the study are presented under the themes that were drawn from the analysis of the qualitative data. Through the review of detailed notes and interview transcripts a series of inductive codes/themes were created. This process allowed the investigator to gain a broader understanding of the views and perceptions of focus group participants and key informants. Codes were developed through the inductive process of reviewing notes and transcripts from interviews and developing common themes that were discussed in multiple interviews and FGDs. In total, five codes/themes were created which helped to organize and categorize the information collected from the participants. Quotes that are applicable were supplied to substantiate relevant results. Also relevant literature was used to validate the key findings of the study.

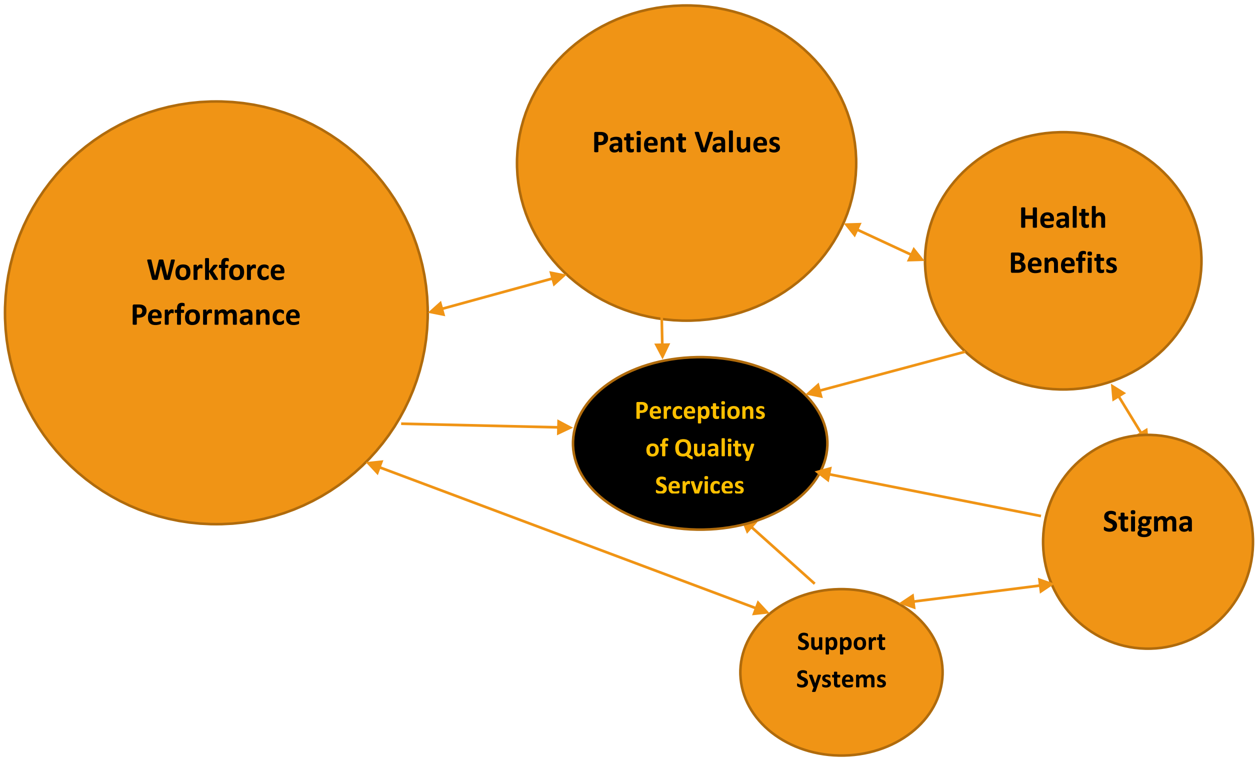


Figure 4.2: Factors influencing patient perceptions of Quality ART Services in Anambra State Nigeria.

4.4 THEME 1: WORKFORCE PERFORMANCE

One of the primary goals of this study was to ascertain ART end users' perceptions of the services they received at the health facilities in order to ensure their overall good health. From the discussions with participants it was seen that most participants found workforce performance to be the key factor that would ensure quality of ART services in the four health facilities used for the study. Participants were asked questions to describe the quality of ART care received in the facilities. These questions included questions on competence, responsiveness and availability of staff in the facilities. Some participants detailed how good interpersonal skills; knowledge of HIV and AIDS treatment; efficiency while carrying out services; and professionalism were necessary requirements for workforce performance.

Competency of health care facility staff and knowledge of HIV and AIDS treatment: the participants from both the public and private health facilities FGDs agreed that the staff were competent and knowledgeable.

A male participant from private hospital 2 was happy with the services he had received from the doctor that usually took care of him:

> *"The doctor I am seeing is taking care of me. He sees me well. He does not waste time. He is very competent and caring"*

A female participant from public health facility 1 expressed her confidence in the quality of treatment she received from staff and gave this example:

> *"After two months, three months, they check your CD4 count, just to see how your health is faring and then they're always sure to administer proper drugs to you if they find out you are not doing too well"*

Interpersonal skills: most female participants from both public and private hospitals had issues with poor interpersonal skills of nurses, while the male participants from both public and private hospitals had no problems with the interpersonal skills of any staff.

A male participant from public hospital 1 described how the doctors treated him and other patients as if they were family:

> *"Regarding how the doctors treat us, they treat us well. They have manners. They take us like their brothers"*

A female participant from public hospital 2 said that the nurses were very rude and unprofessional while caring out their duties:

> *"Instead of the nurse to answer my question she ignored me and when she eventually acknowledged me started shouting on me as if I was not a human again……They should try and work on most of their nurses because some of them are very saucy"*

While a female participant from public hospital 1 was impressed with how one of the nurses worked:

> *"A particular nurse is really good, nice and caring. She treats very well. We know her as aunty sharp sharp"*

4.5 THEME 2: PATIENT VALUES

This finding relates to the preferences, concerns and expectations of patients when they come to the health facility which they would want incorporated into health facility decision making to better serve them. The participants expressed a need to improve end user focused care in the health facilities. These needs included:

Length of waiting time: which was seen by a lot of participants as being too long. A male participant from a public health facility stated:

> *"Pharmacy department takes a lot of time. Sometimes, I stay up to two hours before I can be given my drugs".*

Not all participants saw waiting time to be a challenge as said by a male participant in private hospital 2:

> *"You know they don't waste time, everything depends on the time you're here"*

Being treated courteously and with dignity: Most female participants in the four health facilities we're not happy with how they were being treated especially by the nurses, a female participant from public hospital 1 was very upset about how elderly patients were being treated and said:

> *"Do you think it's fair for the old men who didn't go to school to be forced to pronounce the names of drugs. Sometimes it gets so bad that even when an elderly man doesn't know how to pronounce the name of their drug, they tell him off and it's not fair"*

Whereas a male participant from the same public health facility 1 said:

> "*What makes me come here is the way the doctors and nurses here assess us"*

Attention to physical environmental needs: when participants were asked questions related to the physical environment and attention to detail of the health facilities, most participants expressed satisfaction. It was observed that the female participants were the one who paid more attention to detail than their male counterparts who were more interested in the physical structure.

A male participant from public hospital 2 said:

> *"They are always keeping here clean. They also encourage us patients to be neat and clean as well"*

While a female participant in private hospital 2 said:

> *"The English man said cleanliness is next to Godliness, so this environment is clean. I give them 99 percent"*

Adequate space: During discussions with participants regarding space, they acknowledged that space was important to them including the aesthetics. Most of the participants, both male and female, wanted spacious, clean and attractive clinics that had adequate seats for end users. Some participants in public hospital 1 were not happy with the ART clinic being situated in the front of the building and requested that it would be better if they are situated at the back of the hospital because he felt people could identify them and listen in to their conversations. A participant from public hospital1 was not happy with the space and said:

> *"That place where they keep us to wait does not have space, the chairs are set too tightly together. They need to give us some more space"*

Coordination of services: During discussions with participants all acknowledged that coordination of services was good but also acknowledged that the participants sometimes caused confusion while receiving services. The participants recommended that the health facilities standardize health care processes and procedures. A participant said:

> *"The only problem we encounter is that you might have come here very early and some of the patients and workers here will cheat and overtake us, thereby making those of us who come early to end up going late."*

All participants stated that they would like to spend less time in the health facilities so that they could go about their daily activities on time:

> *"I think they should make the process in taking drugs very shorter than…… from one file to another, from one office to another."*

Cost of services: All participants in the health facilities used for the study complained about the cost of registration, folders for their documents, and getting identification cards. Some participants complained of the transportation cost to get to the facilities; others complained of cost of laboratory services. A participant from public health hospital 2 said that:

> *"They should reduce the cost here. The price of folder here is more expensive compared to Ihiala which is N150 and here is N600."*

Another participant from private hospital 2 said that:

> *"Most of us do not earn up to N6,000 where we work. The expense we do at home are high. They should reduce the cost."*

During discussions, a participant from public hospital 1 recounted her experience when she had no money:

> *"Like today, they just said I should pay N2,050 for nutritional drugs, and I don't have it, you understand...... so I can't take the drug now"*

Religion: During discussions with participants it was noticed that all participants from both the private and public hospitals were religious. Participants insisted that the researchers started with prayers before proceeding with the FGDs. A lot of the participants expressed their faith in God during discussions and usually thanked God for keeping them alive:

> *"I also like the chapel here. When you come, you can go there to pray to your creator. This is good because although they provide drugs to help us, it is only the Lord who truly has power of life."*

4.6 THEME 3: HEALTH BENEFITS

This theme refers to the perceived health benefits of ART services to participants. This included ART education and support; availability of drugs; and a sense of well-being;

ART education and support: When participants were asked questions regarding counselling they received, all of them acknowledged that they were satisfied. They stated that the counselling increased their understanding of requirements for their care. They also stated they were satisfied with how the health workers in the counselling department did their work.

Female participant private hospital 2:

> *"When I ask them, questions pertaining my health also, they take out time and explain it thoroughly and calmly."*

Male participant private hospital 1:

> *"When you get to the place where you are to take your drugs, they explain what you need the drugs for and how you should take them."*

Female adolescent participant public hospital 2 :

> *"When it comes to their counselling, they advise you on things to eat and things to avoid in order to improve your health. And if you follow their instructions, you find out that everything they tell you is true."*

Availability of Drugs: Most participants were happy with the uninterrupted supply of drugs in both public and private health facilities. Some participants said that for the few times they came to collect drugs and the hospital had run out of stocks, the pharmacists told them to wait or return the next day as they would collect the drugs from other facilities nearby.

A female participant from private hospital 2 said:

> *"Whatever drug you want; you will get it here."*

A male participant from private hospital 2 also said:

> *"The quality of the drugs is ok, it's nice, it helps to prevent the virus."*

A female adolescent participant from private hospital 1 said:

> *'There is never a time you find here, a scarcity of drugs nor will they ever tell you to go back.*

Sense of well-being: The participants had feelings of happiness and a sense of well-being with how they looked physically and adduced this to the care and drugs they were receiving in all the health facilities. They were very positive about their prospects of surviving and living a normal life. A female participant from a private hospital 2 said:

> *"So since 2005 till date, we bounced back to our normal body system. In fact, since 2005 till date, I don't even know how headache looks like"*

A male participant from public hospital 2 said:

> *"the benefit I get here is that my hope is being restored"; "since I started coming here my body is agile".*

Another male from Public hospital 2 said:

> *"Since I started coming here, I do not have high temperature and any other sickness any more. Sometimes I ask myself whether I still have the infection."*

4.7 THEME 4: STIGMA

Stigma remains the most unpleasant aspect of being an end user of ART services. It was seen to be the main reason many of the participants were afraid to see a doctor to determine their status or even receive treatment. Stigma and discrimination associated with HIV and AIDS are seen as one of the greatest challenges for HIV infection (Parker and Aggleton 2003). Stigmatization from the disease deeply damages the person's personality from a whole to an ordinary and finally to a stigmatized human being (Gaudine et al 2010). Analysis of the FGDs showed that participants expect health care providers to provide a stigma free environment where they will not have any feelings or experiences of being stigmatized including being shy of their status or being ashamed. Participants narrated the trauma which victims of stigmatization face.

Health care providers expose end users to stigma: Female participants from public health facility1 and 2 expressed concerns about feeling stigmatized and discriminated against by nurses: Participant from Public hospital 1:

> *"There are some nurses that whenever you ask questions it will be as if when they reply you, the virus we are suffering from will be transferred to them. They will do as if you are irritating to them. When they want to give you something, they put hand as if they touch you, they will be infected."*

Participant from Public hospital 2:

> *"There are places you go to in the hospital, and they cover their mouths noses and say that they can't communicate with us."*

An adolescent male from a private hospital said:

> *"Those collecting the lab paper bottle are wicked and uncaring. They act as if they talk to us they will be infected with the virus."*

Self-stigmatization: Some participants in both the public health facilities admitted to self-stigmatization. They admitted seeking services in faraway hospitals where they would not be recognized by family and friends. Some participants were ashamed of what people would say about them. A female participant said she felt that people would say she was promiscuous. Some male participants from a public hospital said they were afraid of their community reaction and so chose to receive ART services far from home.

A female participant from public hospital 2 said:

> *"I was hiding myself so people would not see me and judge me."*

A male participant from public hospital 2 said:

> *"People think that anybody that has the disease is the worst person on earth and so it made me somehow shy…... was hiding myself so people would not notice me and judge me."*

A male participant from public hospital 1 said:

> *"This is because if you go to the ones closer to where you live and people see you, they begin to stigmatize and discriminate against you."*

Social Stigma: Some participants expressed shame about letting their families and friends down

> *"I would not want my family or relations or members to know I am infected with HIV"*

4.8 THEME 5: SUPPORT SYSTEMS

This code captures any reference to individuals that encourage, provide emotional support and empathy to the plight of patients. This included mentions of family members, pastors, and health care providers. It was observed from discussions with both private and public health facility participants that a lot of participants were already very sick before they sought medical attention. Most of the participants were referred to the hospitals by pastors and family members. Participants also mentioned that they were happy with health providers that encouraged them and showed empathy towards their plight. Most participants from private hospitals which were faith based also appreciated the free drugs they were given monthly and equated this with quality of services they received in private hospitals.

A male participant from public hospital 1 said:

> *"I began to fall ill then my pastor now prayed for me."*

A male participant from public hospital 2 said*:*

> *"They help me a lot because at times they will be counselling me that I should not leave my drugs, that I should always take my drugs at the right time."*

A female participant from private hospital 1 said:

> *"They also have some good Reverend Fathers and sisters who help and encourage you, strengthen you when it is like your heart is down."*

A female participant from private hospital 2 said:

> *"Sometimes they give us free supplements to suck on in order to help build our immune System."*

RESULTS KEY INFORMANT INTERVIEWS

All health workers interviewed agreed that their patients were always satisfied with their services. The majority of the health workers indicated that they needed more professional support in form of training to improve their performance. All the health care workers knew what quality ART service provision meant. A doctor in public health facility 1 described it as:

> *"Quality ART service to me is service that meets the demands of the program, making sure that the patients that come have less waiting time and they get the right drugs in the right proportion and for the duration that was prescribed and also every aspect of the chain of management of the patient right from records, to the table where the nurses are, where the vital signs are taken, to the seat of the doctors, that everything moves like a flow. When that is done and patients leave happily, I think that we've achieved our aim and I can say we've given the patient quality care."*

One respondent from private hospital 1 felt that the quality of ART service provision was better in the public health facilities than in the private hospital where he worked. He said he had worked in a public health facility before and things were meticulously done but in the private hospital where he is currently working things were not being done as well. All the respondents interviewed complained about lack of health personnel in their facilities. A pharmacist in private hospital 2 gave an example of their daily workload and its implications for them:

> *"last month, we saw patients within the range of 180 to 200 every day and you can imagine how many pharmacists that we are to attend to these patients. It's really challenging and when it comes to offering pharmaceutical care services to these patients, it hinders us in a sense, because you will not have enough time. We are meant to spend quality time with a patient if you have to counsel the patient well."*

When participants where asked questions about barriers they had faced while providing ART services a Laboratory technician from public hospital 2 said:

> *"The barriers we've experienced is not only limited to this health facility. Health systems*

> *in the country are not good…... incessant strikes from health workers, this period, next period, tends to militate against the quality of health services that are being provided."*

He further went on to say that:

> *"the causes of the strike are not far- fetched, it's eh…. inability of the government to keep agreements so if governments could keep their own side of agreements. I think these strikes will be a thing of the past."*

A doctor in public hospital 1 suggested a recommendation to management with regards to space and said:

> *"We will need an expansion because our patients are increasing and the space we have is not enough, so I would recommend that we have a bigger space where we can do our work."*

CHAPTER FIVE

DISCUSSION/ CONCLUSION

5.1 INTRODUCTION

This chapter focuses on the discussion of the results and is guided by the study objectives described in the first chapter, parts of Wagner chronic care model and themes that emerged from the analysis of FGDs and KIIs. The researcher discussed implications of the findings to public health in Anambra State, tying the implications to existing literature, to enhance the credibility of the interpretations of the findings.

Overview of study discussions

This study sought to describe the perceptions of end users of ART services in public and private health facilities in Anambra State. Five major themes were identified from the study, namely:

Theme 1: Workforce Performance

Theme 2: Patient Values

Theme 3: Health Benefits

Theme 4: Stigma

Theme 5: Support Systems

The themes described in this paper raise the question of whether the perceptions of end users of ART can help inform service improvement to meet end users' requirements and to address adequately the treatment needs of HIV and AIDS patients in Anambra State. The researcher noted that some perceptions were more influential than others and that there was a reciprocal nature to the interconnectedness of the components and their influence(s) on end users' perceptions of quality services. The theme with the most influence was workforce performance and the theme with least influence being support systems.

5.2 DISCUSSION

THEME 1: WORKFORCE PERFORMANCE

The concept that all participants mentioned most consistently and was key to their perception of quality ART services was that of workforce performance. The World Health Organization (WHO) defines the performance of health workers in terms of four dimensions that include responsiveness, productivity, competence and availability. Both male and female participants from all the health facilities noted that responsiveness such as respect towards the ART patients was crucial. But it was noticed that female participants from all health facilities had the view point that female nurses were more unresponsive than doctors and other health professionals, like pharmacists, laboratory technicians and counsellors. In one facility where a male nurse was present female participants said they did not like male nurses talking to them. Most of the female patients said they had refused to talk to the male nurse because they were uncomfortable with him. From this finding, it may be that the characteristics of the nurses themselves, including their gender, background, knowledge and motivation play a factor in how they are viewed by end users. Also noticed by the female participants was that the nurses who were unresponsive were newly employed or transferred nurses.

The male participants both adult and adolescent in the four health facilities had no reports about being treated unresponsively and were happy whether they were treated by a male or female.

It was also noted by adult male participants in the two public health facilities, that they observed that job professional values were not being maintained. The participants complained that on several occasions they had noticed participants who were late to the ART clinic exchange money with staff to ensure they got to the beginning of the queue, hence making the people that came early go late. Participants were upset with this development and felt they could not voice their concerns because of fear of victimization.

All participants also complained about the length of time it took them to see doctors and other key personnel and felt that it was due to the large number of patients whom were registered in the health facilities to receive ART care. They also noted that some doctors in the health facilities resumed work late; hence making them wait for hours before seeing them on clinic days. During the FGDs it was noted the adults gave better feedback to the questions asked than the adolescent FGDs in all facilities. Maybe more youth friendly questions should have been designed for the adolescent FGDs.

In conclusion, it is noted that health workforce performance is key because it has an immediate impact on health service delivery and ultimately on population health. A well-performing workforce is one that works in ways that are responsive, fair and efficient to achieve the best health outcomes possible, given available resources and circumstances (World Health report 2006).

THEME 2: PATIENT VALUES

The participants expressed hope that their preference, concerns and expectations when they come to the health facility would be incorporated into health facility decision making to better serve them. They expressed the need for shorter waiting time; being treated courteously and with dignity; better coordination of service; reduction in cost of services; and adequate space and attention to physical environmental needs.

This finding suggests that if efforts are made to coordinate and include end user needs some part of the care process will meet their needs and preferences. This supports the CCM element which supports an integrated and coordinated care process that is user focused.

THEME 3: HEALTH BENEFITS

It was noted that participants saw ART educational support; availability of drugs; and a sense of wellbeing as what constituted their most important health benefits. Participants were happy due to receiving their drugs when needed at the health facilities. The physical implications of taking the drugs and adhering to counselling received also impacted on the participants and gave them a sense of wellbeing. This finding relates to the CCM element “delivery systems” which supports delivering effective and uninterrupted services, such as uninterrupted ARV drug supplies.

It was also found that empathizing with and encouraging the participants while counselling improved the participants’ sense of wellbeing and hence improved their quality of life. The participants felt satisfied while they were being counselled and hence felt free to share confidential information with the counselors. This is the self-management element of the CCM and helped to instill confidence in the participants. Participants were also happy with the knowledge they gained about their health condition from all health care providers in the health facilities. This empowered them and allowed them to take more responsibility regarding their health.

THEME 4: STIGMA

It is important that end users of ART services find themselves in a stigma free environment. Some participants expressed their views that where their ART clinic is situated is at the front of the hospital and does not afford them privacy. There is need for health facility management to ensure that health care infrastructure is designed in such a way as to promote confidentiality and stigma reduction. Study participants complained about health care providers that still stigmatized and discriminated against them during visits to the health facilities. There is obviously a need to reeducate public health care providers on stigma and discrimination. Stigma and discrimination needs to stop completely in the health facilities before we expect it to stop in the communities. The CCM has a “community resources” component which will help remove organizational boundaries in addressing the total requirements and expectations of the end user.

THEME 5: SUPPORT SYSTEMS

From the findings, it is obvious that the community plays a large part in supporting end users that are receiving ART services. It was seen that most participants showed up for care only when they became very sick. There is therefore a need to strengthen the linkages between community based organizations for wrap around services that will benefit the end users and the community as a whole. Each health facility has a support group for end users, these support groups need to also meet regularly with community based organizations to express their needs and seek any necessary assistance. When the community and health facilities work together, it is believed that health care quality would be improved. A good referral mechanism should be put in place so that as many end users as possible are referred to health facilities for treatment.

5.3 PARTCIPANTS' RECOMMENDATIONS FOR IMPROVING ART SERVICES

As part of the FGDs and KIIs participants were asked to make recommendations to the management of the different health facilities. The following list outlines the most important to them.

1. There is need to employ, train and retrain more health care workers to meet the increasing demand for ART services
2. There is need to put a cap on the number of patients that health facilities can see. Currently they are overwhelmed with the patient turnout and can no longer attend to patients as well as they would wish to.
3. Private health facilities do not receive any money from the government and are expected to source funds for their activities. They should be linked to non-governmental organizations that can sponsor some of their needs.
4. The cost of registering for attendance at the health facilities should be reduced.

5.4 CONCLUSION

The study sought to answer the question "What are end user perceptions of ART services in public and private hospitals in Anambra State Nigeria". In answer to this question, five themes emerged, namely workforce performance, health benefits, stigma, support systems and patient values. An understanding of how ART patients evaluate their care may therefore help to identify deficiencies and inform improvements. This understanding will help to render health care programmes in a more patient centered manner, and to increase their efficiency in a context of scarce resources (Wouter et Al 2008).

5.5 Recommendations

From the findings workforce performance was seen to be the greatest influence on how end users of ART perceived services relating to them. From this it is obvious that the performance of health workers, in terms of both competence and responsiveness need to be a priority if we are to ensure that end users of ART get quality services. Health workers are expected to conduct themselves with integrity and selflessly. But it was seen in two health facilities that the realities of life may make them betray that image. For example, collecting bribes from patients to put them at the head of the cue has been seen to be a coping strategy that some health workers employed to boost their income. Participants recommendations to change the situation included: improved working conditions, informing the population about such practices, and appeals to people’s personal and professional values.

The Government of Nigeria needs to ensure appropriate remuneration and regularity of payment. Health workers must be paid reasonably for the work they do. They also need to believe that the wage is commensurate with their responsibilities. This will also help prevent the incessant strikes that occur in the Nigerian Health sector.

There is need to ensure adequate information and communication to the health work force. Evidence shows that having information does help health workers to do their jobs better, as long as certain provisos are met: the information must be relevant to the job and available when needed, and workers must have a degree of confidence in the information’s quality and understand what it is “saying” (WHO,2006*)*. There is need to have continuous and regular education of the health work force.

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Annex A:

Socio-demographic form

Date of Focus Group: _ _/_ _/ 2016

Focus group participant information

Thank you for joining today's discussion. Please fill in your answers to these questions to help us understand who we are talking to.

Circle the option that best represents you or write in your answer.

Are you male or female?

Male Female

How old are you?

under 25 26-30 31-35 36-40 41-45 46-50 over 50

How many children do you have?

1 2 3 4 5 6 more than 6

How old are your children? (circle the ages of all your children)

0-5 6-8 9 10 11 12 13 14 15 16 17 18 over 18

What is your occupation? _________________________ **(**e.g. teacher, driver, seamstress, businessman)

What is the highest level of school you have attended?

Primary school Secondary school University degree (Bachelor's)

Post-graduate degree (Master's/ Doctorate)

What is your religion?

Christian Muslim Other I am not religious

Generally, how often do you attend a religious service?

More than once every week.

At least once every week.

At least once a month but not every week.

Less than once a month.

I never attend religious services.

Where do you live?

In Awka town (urban area) Close to Awka town (between urban and rural area)

Outside Awka town (rural area)

How many mobile phones are in your household?

0 1 2 3 more than 3

Are your children allowed to use a mobile phone?

Yes, they use mine/ another adult's.

Yes, my children have their own mobile phones.

No, my children are not allowed to use a mobile phone.

Annex B: Focus Group Guide

Research question: What are end-user* Perceptions of Antiretroviral Therapy(ART)

Services: Lessons for Scale-Up of Quality Private Sector Services.

Study Population: 6-8 participants (a group of men, a group of women and a group of adolescents) that are HIV positive and belong to health facility support groups in private (if applicable public) health facilities in Awka, Anambra State, Nigeria. They must be within the ages of 18-50 (adults) and 11 - 17 (adolescents); and have been attending the ART program for at least 6 months on a continuous basis. (***Note** People Living with HIV who have been accessing Antiretroviral Therapy (ART) in this Health facility for the purposes of this interview I will refer to them as "end users").

Supplies: Tape recorder, 8 pens, 8 note pads, Flip chart paper and stand

Total Participant time required: 60 minutes

Introduction (5 minutes)

We would like to welcome and thank you all for your participation in this study. My name is Chika Egbunike and I am a Global Health student from the Rollins School of Public Health (RSPH), Emory University. We would like to talk to you about the perceptions and experiences of people while accessing ART services in public/ private health facilities in Awka. We appreciate you all taking out time to participate in this focus group discussion. Your opinions are very valuable to us.

Let me tell you a little about how we will conduct the group discussion today. Your participation in this group is voluntary, so if you prefer not to be part of this discussion you are completely free to leave. However, we value all of your opinions and hope that you will stay and share your views. Whatever we discuss today will be confidential and used only for this research project. I would like to say that there are no right or wrong answers. We will simply be asking for your opinions and experiences, so please feel comfortable to say what you really think. We would like to hear as many different points of view as possible, so feel free to disagree with someone else and share your own view, but please also respect the views of others. We will not be going around the circle, just join in when you have something to say or you want to respond to someone else's point, but it is also important that only one person talks at a time so that we don't miss anything.

During the discussion_____________ will be taking notes. However, so that s/he does not have to worry about writing every word on paper we would also like to record the whole discussion. Because we will be on tape, please be sure to speak up so that we don't miss your comments. All responses will be kept confidential. This means that your responses will only be shared with research team members and we will ensure that any information we include in our report does not identify any of you as the respondent. The recording will be deleted after we transcribe the information. Is it ok with everyone to record this discussion? Remember, you don't have to talk about anything you don't want to and you may end the interview at any time. All comments both positive and negative are welcome. This discussion will probably last an hour.

Are there any questions? If not can we begin?

Introduction/Warm-up (5 minutes)

Let's begin by taking a few minutes to introduce ourselves. I would like to go around the circle and have each of you tell everyone your first names and your favorite food. Now that we have introduced ourselves, let's get started.

A. Opening questions: (5 mins)

1. How did support group members hear about ART services in this health facility?
   Probe:
   "Can you describe your initial reactions when you heard about ART services in this health facility?

2. What factors influenced your decisions to register for ART services in this health facility?
   Probe:
   "How did this being a private health facility (or public health facility if applicable) affect your decision to register here"?

B. Key Questions (30 mins):

So now that we've gotten some background information about how support group members registered at the health facility for ART services, I would like to talk about the quality of ART care received in this facility.

3. How would you all describe the appearance of this health facility?
   Probes:
   "How would you describe the atmosphere in the hospital"?
   "How would you describe the space in the hospital"?
   "How would you describe the cleanliness of the hospital"?
   "What do you like most about the health facility"?

4. What do you all think about the support given by staff at this health facility"?
   Probes:
   a. *"What is the typical wait time before you see a Doctor"?*
   "How did you feel about how the doctors attended to you (courtesy)"?
   "How knowledgeable are the Doctors about your needs (treatment explanation)"?

b. *“What is the typical wait time before you see a nurse”?*
“How professional are the nurses”?
“How knowledgeable are the nurses to your needs”?

c. Explain how you all feel about the Laboratory services in the health facility”?
“What is the typical wait time before you see the Lab technician”?

“How did you feel about how the Lab technicians attended to you”?

“How would you describe the equipment in the Laboratory”?

d. Explain how you all feel about the services received in the Pharmacy”?
“What is the typical wait time before you see the pharmacist”?
“How did you feel about the explanation the pharmacist gives you on how to take your š”?
“How would you describe availability of drugs in the hospital”?
“How would you describe the availability of medical supplies in the hospital”?

e. Describe the counselling services in this health facility?
“How has counselling affected your adherence to treatment”?

“How would you describe the treatment education you received during counselling sessions”?
“Where does counselling take place”?

5. How do your ART clinic experiences compare to your experiences of other health care services you have received previously?
Probes:
“How would you describe staff attitude during your treatment?
“How did you feel about the treatment received on the different occasions”?

6. How does HIV and AIDS status affect care in this health facility”?

7. How is confidentiality handled in this health facility?
Probe:
“What advice would you give the health facility management regarding confidentiality”?

8. Describe the reasons you all come to this health facility to access ART services.
Probe:
“What were some benefits encountered while receiving ART services”?
“What were some barriers encountered while receiving ART services’?

Ranking Activity (10 minutes)

Note to moderator: Ask the participants to take a sticky note and on a scale of 1 to 5, rate the following areas of ART services at this facility?

a. Quality of the ART services
b. Appearance of the facility
c. Cost of the services
d. Convenience/Accessibility

Ask the following questions once they have completed the ranking aspect of the activity.

9. Thinking of your ratings above, how does the facility meet your expectations for ART services?
   a) Why do you think _____________ are the most important things about the facility for members of the support group?

   b) Why do you think _____________ are the least important things about the facility for members of the support group?

C. Closing Questions (5 mins):

Finally, I would like to discuss overall recommendations on the ART services received at this facility

10. What recommendations do you have for staff in this facility about their ART services?

Conclusion

We would like to thank you all very much for your time and your willingness to participate in this discussion. Your experiences and opinions are very valuable to us and will assist us in understanding your perceptions about ART services in this health facility.

Description of Ranking Activity

Purpose

The purpose of this activity is to ensure all participants are involved in the activity and to generate additional information/ data to understand end user's perceptions and experiences while accessing ART services in the private/ public health facilities. The activity also encouraged more discussion and allowed us to begin to identify themes that were major priorities for support group members. This was achieved through the ranking method.

Instructions on how to do the activity

1. The moderator should give the participants a large sheet of poster paper, several markers and a pad of sticky notes and ask the participants to select a note-taker.

2. The moderator should ask the participants to take a sticky note and on a scale of 1 to 5, rate the following areas of ART services at this facility?
   a. Quality of the ART services
   b. Appearance of the facility
   c. Cost of the services
   d. Convenience/Accessibility

3. The moderator should then ask the two following questions.

Thinking of your ratings above, how does the facility meet your expectations for ART services?

c) Why do you think _____________ are the most important things to support group members about the facility?

d) Why do you think _____________ are the least important things to support group members about the facility?

How activity will generate data on the research question

This activity will generate more data that is relevant to the research question and allows us to prioritize or rank answers. Everyone is made to free list their ideas which also helps us get more varied opinions about the most and least important things to support group members. The ranking activity will allow the research team to understand what are most important and least important to support group members (end users).

Annex C: Key Informant Interview Guide

Research Question: What are health care worker perceptions of quality Antiretroviral Therapy (ART) services provided in the health facility

Study Population: Private/Public Health facility staff members (a Doctor, a Laboratory Technician and a Pharmacist) that are working with HIV positive people who are on ART.

Introduction

Thank you for agreeing to an interview today. My name is Chika Egbunike and I'm a student from the Global Health department at the Rollins School of Public Health, Emory University. I would like to talk to you about your perceptions of quality ART services provided in this health facility. I appreciate your taking out time to participate in this interview.

There are no right or wrong answers, so feel free to share any thoughts you may have about the experience. Your views are valuable to us, and we are here to learn from you. I have a list of topics that I would like to discuss but feel free to bring up any topics you feel are related to our discussion. I would like to add that your participation is completely voluntary, and if at any time, you feel uncomfortable and would like to discuss something else or even stop our discussion, please don't hesitate to tell me right away.

If it's ok with you, I'd like to audio-record this interview, so I can refer back to what you said later. Your participation in this project will be completely confidential. After our interview, I will transcribe our conversation while ensuring the removal of any personal identifying information, and then I will erase the recording. This means that your interview responses will only be shared with our research team members, and we will ensure that nothing links you to the information you provide. I'll take all possible precautions to protect your privacy.

Do you have any questions about the tape recording or privacy? If not, is it ok for me to record the interview? Our interview will last about 60-90 minutes. We're interested in your personal experiences, so there is no right or wrong way to answer a question and you can say whatever you're thinking. Do you have any other questions or concerns? If not, can we begin?

Opening Questions

To begin our conversation, I would like to begin by asking you some questions about your current job here in the health facility.

1. Can you describe to me your work here at the health facility?
   Probes:
   "What is your position in the health facility"?
   "What are your major responsibilities in your current position"?

"How long have you worked in this health facility"?

2. Can you tell me about your experiences while working with HIV positive people?
   Probes:
   "Describe your typical workday
   "How many HIV positive people do you see in a day"?
   "How long does it take you to attend to the patient"?
   "How do you dialogue with your patients"?

3. Describe how the health facility management identifies training needs of staff.
   Probes:
   "What in service trainings related to HIV/AIDS are planned for the next six months?

   "Tell me about the trainings you have received"?
   "How did you feel about the trainings"?
   "How often do you attend trainings"?

Key Questions

So now, I would like to get your opinion about the concept of quality as it relates to ART service provision in this facility

4. In your own words what do you think quality ART service provision means?
   Probes:
   "What do you think are the most critical components"?
   "What do you think is the ultimate goal of quality ART services"?
   *"*How would you describe the state of ART services in this health facility"?

5. How does your health facility ART services compare with those of Public health facilities?
   Probes:
   "Describe this in terms of quality
   "Describe this in terms of cost
   "Describe this in terms of wait time
   "Describe in terms of availability of drugs

6. What do you think are patient's expectations regarding quality of ART services in this health facility?
   Probe:
   "How feasible is this"?

7. Describe any barriers this health facility has faced in providing ART to people living with HIV and AIDS
   Probes:
   "What were the causes"?
   "What could be done to prevent this"?

8. How does HIV and AIDS status affect care in this health facility?
   Probe:
   “*What factors do you think contribute to HIV and AIDS related stigma*

9. Describe how confidentiality is handled in this health facility?

10. How can healthcare workers contribute to quality of ART service provision?
    Probes:
    “What will facilitate this”?
    “What will challenge this”?
    “What do you consider to be the best practices in quality ART service provision”?

Closing Questions:

So, we’re nearing the end of our interview. Before we go our separate ways, I’d like to talk about some of your overall impressions regarding quality ART services in this facility.

11. How do you feel overall about your experiences while providing ART services in this health facility?

12. In your opinion what would be your recommendation to the hospital management about ART services in this health facility?
    Probes:

    “How feasible is this”?
    “What would facilitate this”?
    “What would hinder this”?

Conclusion

We are now reaching the end of the discussion. Is there anything else that you would like to add about any of the topics that we’ve discussed or other areas that we didn’t discuss but you think are important?

Thank you for your time and participation in this interview. The information that you provided to us will be very helpful.

Annex D: Emory University

Consent to be a Research Subject

Title: End-User Perception of Antiretroviral Therapy (ART) Services: Lessons for Scale-Up of Quality Private Sector Services

Principal Investigator: Chika Egbunike, Global Health Department

Funding Source: None

If you are the legal guardian of a child who is being asked to participate, the term "you" used in this consent refers to your child

Introduction

You are being asked to be in a research study. This form is designed to tell you everything you need to think about before you decide to consent (agree) to be in the study or not to be in the study. **It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study.**

Before making your decision:

- Please carefully read this form or have it read to you
- Please ask questions about anything that is not clear

You can take a copy of this consent form, to keep. Feel free to take your time thinking about whether you would like to participate. By signing this form, you will not give up any legal rights.

Study Overview

The purpose of this study is to understand your thoughts and experiences while receiving ART services in public/ private health facilities in Awka.

Procedures

If you decide to participate, you will be in a group of 6-8 support group members. Your participation is voluntary. Your decision whether or not to participate will not affect your relationship with (insert name of health), FHI360 or your support group. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time without penalty.

Whatever we discuss today will be confidential and used only for this research project. During the discussion, we will be taking notes. However, so that we do not need to worry about writing every word on paper we would also like to record the whole discussion. This discussion will probably last an hour. We will serve you with light refreshments during the discussion.

Risks and Discomforts

Some of the focus group discussion questions may make you uncomfortable or upset, but you are free to decline to answer any questions you do not wish to or to leave the group at any time.

Everyone will be asked to respect the privacy of other group members. All participants will be asked not to disclose anything said within the context of the discussion but this cannot be assured. As with all research, there is a chance that confidentiality could be compromised; however, we are taking precautions to minimize this risk.

Benefits

This study is not designed to benefit you directly. This study is designed to learn more about the perceptions and opinions of people receiving ART services in (insert health facility name). The study results may be used to help others in the future.

Compensation

You will not be offered payment for being in this study.

Confidentiality

Certain offices and people other than the researchers may look at study records. Government agencies and Emory employees overseeing proper study conduct may look at your study records. These offices include [the Office for Human Research Protections, the funder(s), the Emory Institutional Review Board, the Emory Office of Research Compliance]. Emory will keep any research records we create private to the extent we are required to do so by law. A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results.

Study records can be opened by court order. They may also be produced in response to a subpoena or a request for production of documents.

Voluntary Participation and Withdrawal from the Study

You have the right to leave a study at any time without penalty. You may refuse to do any procedures you do not feel comfortable with, or answer any questions that you do not wish to answer.

Contact Information

Contact Chika Egbunike at 0802 306 1033:

- if you have any questions about this study or your part in it, or
- if you have questions, concerns or complaints about the research

Contact the Emory Institutional Review Board at 404-712-0720 or irb@emory.edu:

- if you have questions about your rights as a research participant.
- if you have questions, concerns or complaints about the research.
- You may also let the IRB know about your experience as a research participant through our Research Participant Survey at http://www.surveymonkey.com/s/6ZDMW75.

Consent

Please, print your name and sign below if you agree to be in this study. By signing this consent form, you will not give up any of your legal rights. We will give you a copy of the signed consent, to keep.

____

Name of Subject

____ ______________

Signature of Subject Date Time

____ ______________

Signature of Person Conducting Informed Consent Discussion Date Time

EMORY UNIVERSITY

ASSENT FORM FOR MINOR SUBJECTS

Study Title: End-User Perception of Antiretroviral Therapy (ART) Services: Lessons for Scale-Up of Quality Private Sector Services

Principal Investigator: Chika Egbunike

This page to be filled out by research team at time assent is obtained:

Subject's Age: _____years (If the child is **younger than 6 years old,** assent is not required.)

Subject's Name: ______________________________

Check one box:

☐ **This child is 6 to 10 years old** — must obtain subject's verbal assent (subject's signature not required)

____

Signature of person soliciting assent of 6 to 10-year-old subject Date Time

---

☐ **This child is 11 to 17 years old** — must obtain subject's signature on page 2 of assent form to document assent

---

☐ In my opinion, this child is unable to provide informed assent for non-age-related reasons, and the PI for this study has been informed of this determination.

- Reason(s): ____

____ ____

Signature of person soliciting assent (if above box is checked) Date Time

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EMORY UNIVERSITY

ASSENT FORM FOR MINOR SUBJECTS

Study Title: End-User Perception of Antiretroviral Therapy (ART) Services: Lessons for Scale-Up of Quality Private Sector Services

Principal Investigator: Chika Egbunike

INFORMATION ABOUT THIS STUDY:

- **What is a research study?**

A research study is when people like me ask people questions about a certain thing to find out more about it. Before you decide if you want to be in this study, it's important for you to understand why we're doing the research and what's involved.

- **Why is this study taking place?**

We are doing this study to understand the thoughts and experiences of adolescents that are receiving ART services in (insert name of health facility). We're inviting you to take part because you go to a support group where we're doing the study and you are between 11-17 years. You can choose whether or not you want to participate. Whatever we discuss today will be confidential and used only for this research project. During the discussion, we will be taking notes. However, so that we do not need to worry about writing every word on paper we would also like to record the whole discussion. This discussion will probably last an hour. We will serve you with light refreshments during the discussion.

- **What will happen to you if you take part in the study?**

If you agree to be in the study and your parents say it's okay, we will ask you to: Be part of a discussion with 6-8 adolescents where I ask you about your perceptions and experiences of ART services in this health facility. I will audiotape (record what we're saying) if you give permission. This will take about an hour (60 minutes).

- **Will any part of the study cause pain or make me feel uncomfortable?**

You might get bored or upset and decide that you don't want to finish the study activities or the interview. If so, just tell us that you want to stop. You can leave at any time. A possible risk for any research is that people outside the study might get hold of confidential study information. We will do everything we can to make sure that doesn't happen.

Everyone will be asked to respect the privacy of other group members. All participants will be asked not to disclose anything said within the context of the discussion but this cannot be assured.

- **Who can you ask if you have questions about this form?**

You can contact us if you have questions about the study, or if you decide you don't want to be in the study any more. You can talk to me, or your parents, or someone else at any time during the study. My phone number is *080 230 61033 or chika.egbunike@emory.edu*.

If you have questions regarding your rights as a research subject, please contact the National Ethics Committee, Federal Ministry of Health, Abuja. You will be offered a copy of this form to keep.

- **Do you have to be in this study even if you don't want to?**

You do not have to participate in this study. Research is something you do only if you want to. No one will get upset with you if you don't want to be in the study. And whether you decide to participate or not, either way will have no effect on your relationship with (insert name of health facility), FHI360 or your support group.

For subjects 11 to 17 years old: if you agree to be in this study, please sign your name below.

Signature of 11 to 17-year-old Subject Date Time

Signature of person soliciting assent of 11-17-year-old Subject Date Time