



國立臺灣大學公共衛生學院全球衛生碩士學位學程

碩士論文

Global Health Program  
College of Public Health  
National Taiwan University  
Master Thesis

奈及利亞東南部埃努古州年輕愛滋感染者的社會心理健康：

質性探勘研究

The Psychosocial Health of Young People Living with HIV/AIDS in  
Enugu State—Southeast Nigeria: A Qualitative Study

Elochukwu Ernest Uzim

指導教授：李柏翰博士

Advisor: Po-Han Lee, Ph.D.

中華民國111年6月

June, 2022

國立臺灣大學碩士學位論文  
口試委員會審定書

National Taiwan University  
Verification Letter from the Oral Examination Committee for Master's Students

論文中文題目

奈及利亞東南部埃努古州年輕愛滋感染者的社會心理健康：質性探  
勘研究

論文英文題目

The Psychosocial Health of Young People Living with HIV/AIDS in  
Enugu State—Southeast Nigeria: A Qualitative Study

本論文係 Elochukwu Ernest Uzim 君 (學號 R09853014) 在國立臺  
灣大學全球衛生碩士學位學程完成之碩士學位論文，於民  
國 111 年6月27日承下列考試委員審查通過及口試及格，特  
此證明。

This Thesis is written by Elochukwu Ernest Uzim (R09853014) studying in the  
graduate program in the Global Health Program. The author of this thesis is qualified  
for a master's degree through the verification of the committee.

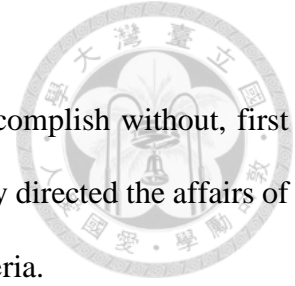
Potlan Lee 尊教授簽名 (Advisor Signature)

口試委員 Committee Members:

官長怡

Poyao Huang

## Acknowledgment



Dear reader, the thesis you are now reading was almost impossible to accomplish without, first and foremost, the benevolence of the *Divine Intelligence* that has constantly directed the affairs of my life. It was a nigh 18-month journey to finally arrive Taiwan from Nigeria.

“*Give it up, Elo,*” I thought many times; but you see, I am cut from a different kind of tough material—akin to Odysseus’ fabric! However, where the Greek lord sailed, I walked, walked, and then walked some more: through multiple visa delays, an exhausting pandemic, 2am classes in my dark room with poor internet, a full-time job, and ageing parents that needed me.

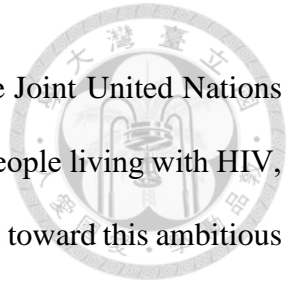
So here goes my heartfelt gratitude towards: Aliyu Zakayo, for the convo that begun my journey into *global health studies* proper; my family, sibs, and collateral kins for their unwavering support through it all; the kindest HIV nurses in Enugu who time and time again, assisted me through the field data collection processes; the YPLHIV in the state who trusted me with their stories—in the hopes of effecting a change in their treatment procedures. Hope I have not failed you.

Then, of course, there is the OIA & GHP Offices here at NTU who were never hard on me for my constant petitions and requests for assistance; my classmates, who held on from speeding up their graduation just so they could get to welcome me to Taiwan in person...after so long interacting virtually! My program Director, Dr Lin, who’s made sure that I settled in smoothly and regularly checks that I “enjoy the food”; and to all my excellent tutors here as well, thank you so much!

OK. *Po-Han*. Reader, this here is the one name that made all the difference. You see, he *is* my advisor, mentor, and friend; and I have no practical intentions of ever giving him up! No way.

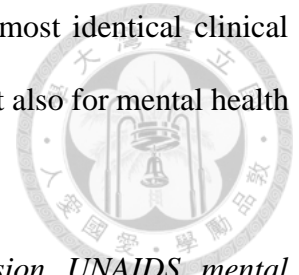
And so whilst this journey here seems to be like an end; in some quarters at the UN offices abroad where my desk is being prepared for me, it has only begun. To *Frost* and to *the road taken*, cheers!!

## Abstract



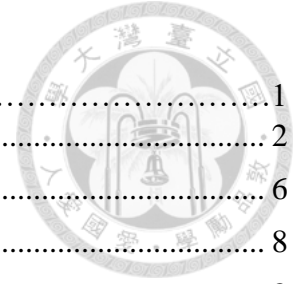
By 2030, Nigeria expects to achieve one of the ambitious targets set by the Joint United Nations Programme on HIV and AIDS (UNAIDS), namely, 95% of the country's people living with HIV, receiving treatment, and suppressing viral load. National efforts to strategize toward this ambitious goal have been underway since the turn of the 21st century. One vital aspect of such coordinated efforts has, however, remained ignored: the *psychosocial health of young seropositive people*. As one of the “higher HIV burden states” in the country, Enugu state in southeast Nigeria has an HIV prevalence rate of 1.9%—higher than 1.3%, the national average. A significant proportion of this population (15-49 years) has suffered interruptions in treatment at least once in the last two years (either as missed appointments or loss-to-follow-up patients). These people's clinical disruption is related to their worsening mental health and even suicidal ideation. A qualitative study has thus been conducted, including focus group discussions and in-depth interviews with 20 young people living with HIV (YPLHIV, aged 20-30 years) in the state from four different health facilities. The interviews focused on their emotional and mental health, their coping strategies in managing the factors that affect their lives, and strategies to recall and retain all YPLHIV with suicidal ideations back to care. Interviews were also conducted with the *antiretroviral*-providing clinicians across four health facilities to explore health providers' observations and perspectives on YPLHIV. The study finds that HIV-related stigma contributes to their suffering, resulting in self and social isolation, inability to develop intimate relationships, clinical abuse, and financial and nutritional stressors leading to virologic failure. However, interestingly, the shared experience of stigmatization has also motivated their resilience in the face of clinical angsts. The “sero-kinship”, a web of social relationships between YPLHIV, has connected and supported them in navigating their treatment regimens. Therefore, I argue that, in addition to de-stigmatization and provision of care that is not biomedically focused, it is also important to recognize and strengthen the

burgeoning sero-kinship between persons living with HIV, who share almost identical clinical experience and sense of survival—not only for medication maintenance but also for mental health promotion.



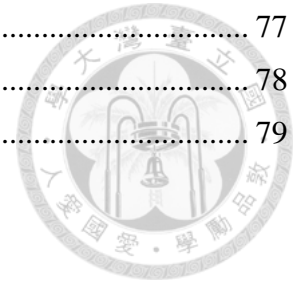
**Keywords:** *southeast Nigeria, psychosocial health, viral load suppression, UNAIDS, mental health, suicidal ideation, antiretroviral, sero-kinship.*

## Table of Contents



Acknowledgment.....	1
Abstract.....	2
List of abbreviations.....	6
<b>Chapter One. Introduction.....</b>	<b>8</b>
<b>Research Background.....</b>	<b>8</b>
<b>Research Questions and Objectives.....</b>	<b>10</b>
<b>Chapter Two. Literature Review, Theoretical Framework and Research Methods.....</b>	<b>13</b>
<b>Stigma.....</b>	<b>16</b>
<b>Psychosocial Theory.....</b>	<b>17</b>
<b>Research Design and Methodology.....</b>	<b>18</b>
<b>Chapter Three. Stigmatization of Young PLHIV.....</b>	<b>27</b>
<b>Non-Disclosure as a Cocoon against Stigma.....</b>	<b>28</b>
<b>Clinical-Related Stigma and Prejudice.....</b>	<b>31</b>
<b>Conclusion.....</b>	<b>34</b>
<b>Chapter Four. Mental Health of Young People Living with HIV/AIDS.....</b>	<b>35</b>
<b>Intimacy vs. Isolation on the Cusp of “Identity Crisis” among YPLHIV.....</b>	<b>35</b>
<b>Serodiscordance and Unmatched Relationships among YPLHIV.....</b>	<b>39</b>
<b>Financial and Nutritional Stressors as Precursors to Virologic Failure.....</b>	<b>40</b>
<b>Conclusion.....</b>	<b>44</b>
<b>Chapter Five. Sero-Kinship among YPLHIV.....</b>	<b>45</b>
<b>The Idea of <i>Clinical Affinity</i>.....</b>	<b>46</b>
<b>Disease, Loneliness, Togetherness, Hope.....</b>	<b>49</b>
<b>Conclusion.....</b>	<b>53</b>
<b>Chapter Six. Conclusion and Recommendations.....</b>	<b>54</b>
<b>Recommendations for the Nigerian Health Authorities.....</b>	<b>55</b>
<b>Limitations of the Study.....</b>	<b>57</b>
<b>References.....</b>	<b>58</b>
<b>Appendix 1. NTU IRB.....</b>	<b>68</b>
<b>Appendix 2. Ministry of Health, Enugu, IRB.....</b>	<b>69</b>
<b>Appendix 3. Research Participation Consent for Focus Group Discussion.....</b>	<b>70</b>
<b>Appendix 4. Research Participation Consent for In-Depth Interview.....</b>	<b>74</b>

**Appendix 5. Recruitment Poster ..... 77**  
**Appendix 6. Focus Group Discussion Guide ..... 78**  
**Appendix 7. In-Depth Interview Guide ..... 79**



## List of abbreviations



AIDS – Acquired Immunodeficiency Syndrome

ART – Antiretroviral Therapy

ARV – Antiretroviral

CD4 – Cluster of Differentiation 4 (used to determine the degree of weakness of the immune system from HIV infection)

COVID-19 – Coronavirus Disease 2019 (an infectious disease caused by the SARS-CoV-2 virus)

CSO – Civil Society Organization

DSD – Differentiated Service Delivery

EEGH – Enugu Ezike General Hospital

ESUTH – Enugu State University Teaching Hospital

FGD – Focus Group Discussion

HCW – Health Care Worker

HIV – Human Immunodeficiency Virus

HTS – HIV Testing Services

IDI – In-Depth Interview

LTFU – Loss-To-Follow-Up

MA – Missed Appointment

mL – [copies per viral] Milliliter



MMD – Multi Month Dispensing

MMS – Multi Month Scripting

NEPWHAN – Network of People Living With HIV/AIDS in Nigeria

PEPFAR – United States President’s Emergency Plan for AIDS Relief

PLHIV – People Living With HIV

R1, R2, etc. – Respondent 1, 2, etc.

RADET – Retention and Audit Determination Tool

Tx – Treatment

TX\_CURR – Treatment Current

UGH – Udi General Hospital

UNAIDS – Joint United Nations Programme on HIV/AIDS

UNTH - University of Nigeria Teaching Hospital

USAID – United States Agency for International Development

USD – United States Dollar

VLS – Viral Load Suppression

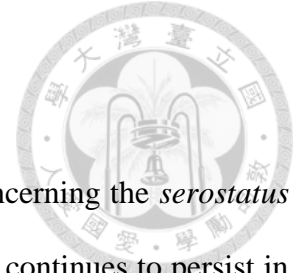
WHO – World Health Organization

YPLHIV – Young People Living With HIV/AIDS



## Chapter One.

### Introduction



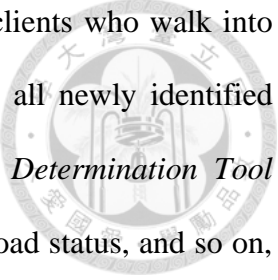
Through a qualitative study, this project aims to address the questions concerning the *serostatus* of young adults and their psychosocial health in Nigeria. The HIV burden continues to persist in the country, with an estimated 1.9 million people currently living with the disease, among which young adults aged 15-49 years account for a 1.3% prevalence rate of the entire country's HIV millstone (UNAIDS, 2019). Even though Nigeria is adjudged to be *on track* to achieving viral load suppression (VLS) for all HIV positive people in the country by 2030 (UNAIDS, 2021), it is still needful to refocus resources at all local levels where HIV care and support are sought from.

### Research Background

In Enugu State, one of the five states that make up the southeast geopolitical region,<sup>1</sup> the HIV strain in the state, as revealed in findings from the *Nigeria HIV/AIDS Indicators and Impact Survey, NAIIS*, is 3,736 of the total state population; this represents 1.9 % HIV positive prevalence rate (1.2% for males and 2.4% for females) among similar age band of 15-49 years in the state (see Federal Ministry of Health, 2018). This number is higher than the national average for the same age band, pegged at 1.3%. Following from this emergence, public health institutions in the state, including two high-volume tertiary hospitals such as the University of Nigeria Teaching Hospital (UNTH) and the Enugu State University Teaching Hospital (ESUTH), are equipped with antiretroviral therapy (ART) treatment-providing wings to cater to the needs of these seropositive populations as well as other out-of-state seropositive visitors (in most cases, categorized as “transferred-in,”), as circumstances dictate.

---

<sup>1</sup> The other states in the region are Abia, Anambra, Ebonyi, and Imo States, respectively.

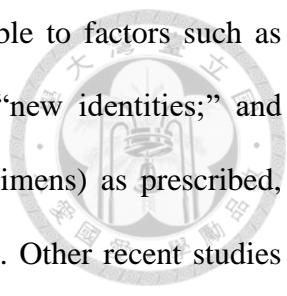


In this context, the treatment procedure involves counselling all untested clients who walk into these ART centers, prior to testing. This, in turn, is followed by linking all newly identified seropositive clients into a database known as the *Retention and Audit Determination Tool (RADET)*, through which their addresses, appointments, drug refills, viral load status, and so on, are tracked. With regard to the *RADET*, it is important to mention that, through data gleaned from this database by the service providers, the health facility backstop staff decry compelling evidence of *loss-to-follow-up (LTFU)*, which, usually at first, starts as a missed appointment (i.e. skipping appointment dates for *antiretroviral drugs* [ARVs] refills) and eventually, lapsing into LTFU after 28 days (see PEPFAR, 2019).<sup>2</sup> It is, thus, my interest in exploring some of the factors that give rise to this trend of discontinuity from care—and the mental health challenges that ultimately lead to it—that this research begins.

Relatedly, as a not-for-profits organization worker involved in community HIV health strengthening in Enugu state around 2020, I learned, from my informal conversations with ART adolescent focal persons at some select facilities within the state, that health professionals had drawn conclusions that the increase in numbers of both LTFUs and HIV-related deaths might be attributed to some still *unmet needs*, such as inadequate HIV funding, in the state. The monthly HIV report returned by the health facilities to the funders regarding their activities in the state (which I was privy to, due to my position as a monitoring and evaluation support personnel for one of such organizations), bears similar highlights of such issues. This situation of rising

---

<sup>2</sup> This points to the Monitoring, Evaluation, and Reporting Indicator Reference Guide, one of the “*process-to-impact*” strategic information tools, developed by the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) as a metric to assess PEPFAR’s programmatic impacts. The Guide (periodically updated) aims to support host country government (e.g., Nigeria) to achieve, for example, the goals of Joint United Nations Programme on HIV/AIDS (UNAIDS) regarding testing and treatment in view of viral suppression.



appointment attritions, according to these facility ART staff, is attributable to factors such as poverty, stigma, depression, loss of means of livelihood due to their “new identities;” and increasing disinterest in sticking to their medications (i.e., treatment regimens) as prescribed, following how Lightfoot and colleagues (2005) also identify such factors. Other recent studies have equally shown a link between seropositivity and negative psychosocial trends such as suicidal ideations (see, for example, Gizachew et al., 2021; Lavery et al., 2001; Necho et al., 2021; Ophinni et al., 2020; Schlebusch & Govender, 2015). These signs shared by the scholars, such as refusing ARV intake and refills, further exacerbated by missed appointments, as I have surmised, often lead to thoughts<sup>3</sup> around deliberately terminating one’s life among people living with HIV (PLHIV). Closely examined, these health behaviors are also not different from those *expressed* by the same seropositive cohorts, in public ART facilities found in Enugu State.

### **Research Questions and Objectives**

The study on the psychosocial health of PLHIV has been planned and pursued in the context in which interruption of ART (say, LTFU situation) and mental health, are conceivably connected. Also, considering the 95-95-95 Goals pronounced by the Joint United Nations Programme on HIV and AIDS (UNAIDS), the last 95 seeks to achieve 95% viral load suppression among PLHIV by 2030 (see UNAIDS, 2020). Presently, Nigeria has shown great strides with the initial conception of these *Goals* of 90-90-90 targets, which upon review at the end of 2020, showed that the country’s progress in each of these landmarks stood at 73-89-78—i.e., diagnosis-treatment-to viral suppression— (UNAIDS, 2021). Notably, an unclosed gap still lingers between treatment and

---

<sup>3</sup> Do note that the term “suicidal ideation(s),” as relating to the poor psychosocial health of PLHIV as I shall be using it throughout this discourse, also follows the *statist definition* of such concept i.e., as the potential outcome of interruptions in treatment manifesting either as missed appointments and/or loss-to-follow-up (as cued from PEPFAR, 2019). The present study shall not further abstract this meaning.

achieving viral suppression heading into 2030. Therefore, it is highly critical to explore potential risk factors in relation to suicide—demonstrably, a deterrent to said “goals”—among young adults living with HIV in Enugu, one of the top-ten states with a high prevalence of HIV infections in Nigeria (see Federal Ministry of Health, 2018) in order to also unanimously promote the landmark vision, by 2030.

It is against this background on which this qualitative research has embarked, that I conceptualized the following research questions which are intended to guide this study:

1. What are some of the factors that contribute to suicidal ideations among young PLHIV in Enugu State, southeast Nigeria?
2. Given that the mental health of young PLHIV may be affected by the social knowledge about, and attitudes towards the disease, what are the best possible approaches to preventing/tackling this?
3. Most importantly, how can all seropositive individuals with *suicidal ideations*—rising from MAs (missed appointments) & LTFUs—be recalled, and retained into care in line with the UNAIDS last 95 Goal?

By addressing these questions at the heart of this explorative research, are, therefore my aims to, first, explore, through qualitative means, potential factors that contribute to suicidal ideations among young PLHIV (aged 20-30 years). Secondly, this study can inform a more locally anchored approach to managing the mental health of young PLHIV. And finally, I would like to explore, together with the study participants who are PLHIV, their strategies to recall and retain more seropositive clients from *loss from care* (manifesting either as missed appointments or LTFU) by

providing robust mental health support, through including their own voices, experiences, and perspectives, in this study<sup>4</sup>.



---

<sup>4</sup> Let me here mention that another interesting way to have begun this study would have been by a *critique of the HIV cascading framework* in Nigeria—such as: exploring how the continuum of care begins first at diagnosis, linkage to care, then retention drives, followed by the adherence drives around ART, and finally, viral suppression; thereafter, further exploring how PLHIV “experience the care continuum” just as Kay et al. (2016), had done; or, elsewhere by Hillier et al., (2020). One advantage of such a critique being in unraveling how many individuals disproportionately “fallout” from each of these chains, and what factors that give rise to them. However, doing this would be further expanding the scopes of the present study to accommodate for broader factors different from *psychosocial health* only—which, originally, is the working premise of this current explorative study. Having now established that I am not oblivious to a multi-background approach to research of this kind, I shall presently continue with the background as here conceptualized.

## Chapter Two.

### Literature Review, Theoretical Framework and Research Methods



Extant work in the field of HIV/AIDS case management continues to excite researchers to explore the links between serostatus and suicide. However, while the focus of most of the studies in this field remains highly positivist (quantitative studies), other ongoing efforts in the area of HIV research continually strive to take a more qualitative and, thus, holistic perspective, on related issues—by using methods such as in-depth interviews, focus group discussions, key-informant interviews and so on (e.g., Adjetey et al., 2019; Atanuriba et al., 2021; Dzinamarira et al., 2019; Mutumba et al., 2015; Nyongesa et al., 2022; Salad et al., 2019).

However, few of these qualitative studies are produced by Nigerian researchers—especially in serostatus-related mental health studies—so, this vital issue, relevant to the overall healthcare of young PLHIV, is largely ignored in the country. For example, Salad and others (2019) focus their study on stigma and the resulting discrimination due to seropositive status in conflict-context Somalia. Undoubtedly it is a very important study, which, however, does not mention at all the overall mental health of *actual* seropositive persons in Somalia. They attribute this knowledge gap to the conflict situation in the country, stating that “due to the ongoing conflict [in Somalia], HIV sentinel surveillance cannot reach most of the affected areas” (2019, p. 46). This indicates that undiagnosed seropositive cases in such areas are at a higher risk of passing the virus to others on the one hand, and on the other, suffering untimely death due to other untreated opportunistic infections. Even though this is not the major focus of this study, it does merit urgent attention. Also, Nyongesa and colleagues (2022) explored the psychosocial and mental health challenges faced by emerging adults (18-24 years) in rural Kilifi, Kenya. An important study about the

Kenyan health system, but nonetheless, not directly relatable to Nigeria. The important point worth noting, however, is the overall rising interests in this field of study.

Other researchers, such as Dzinamarira and others (2019), who also based their studies in Africa, focus on how feeding practices regarding nutrition have affected adults living with HIV in Kigali, Rwanda. Their study says nothing regarding suicidal ideations among the same cohorts of interest except that HIV infection is attributable to poor nutrition, which is, however, not linked to mental health. As a mitigation measure, nonetheless, the authors suggest that “support efforts... [should] incorporate nutrition management” (Dzinamarira et al., 2019, p. 83). Notwithstanding, in their study, they do not consider how nutrition, or the lack thereof, may be related to the mental health of PLHIV in Kigali.

A little closer to Nigeria, Adjetey and others (2019) look at a very important aspect of HIV care and treatment—namely, differentiated service delivery (DSD), which makes for an interesting *connection* as to why some seropositive persons discontinue care without a trace. I also examined DSD through focus group discussions and in-depth interviews with some of the study participants in the current project by asking the respondents what kind of support they would like to see incorporated into their treatment regimen—to help them cope with their mental health needs. However, Adjetey and others (2019), in their study, had sought to find out the possible predictors of community-based treatment among PLHIV receiving treatment at an ART facility in Ghana through focus group discussions. They learned the respondents’ “concerns about stigmatization and abandonment in the community upon inadvertent disclosure of [their] status” (Adjetey et al., 2019). This study has also informed me of possible contributing factors, such as stigma and neglect, to the increase of LTFUs in Enugu State. DSD, on its own, is an important person-centered model designed to optimize retention in HIV care for a longer period, which should be adequate

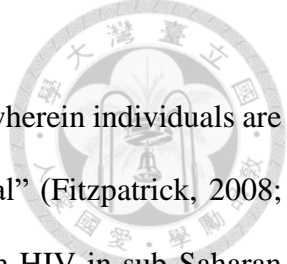


to achieve viral load suppression, especially in low-resource settings such as Nigeria (Roy et al., 2019). Examples of such a model would be community refills, extended work hours, multi-month scripting and dispensing of medications (MMS & MMD) to clients enrolled in ART facilities to extend the supply of their ARVs as far as they have met the certain viral loads threshold, etc. Yet, Adjetej and his colleagues find that “Participants expressed preference for facility-based service provision with the construct that, it ensures *comprehensive health checks* before provision of necessary medications” (2019, para. 3, emphasis mine).

Were such “comprehensive health checks” also inclusive of crucial mental health assessment of all seropositive clients who visit their healthcare centers in Enugu, I believe that a more robust lifestyle would have been encouraged devoid of all the anxieties that ultimately build up to not just suicidal thoughts only, but overall psychosocial meltdown. However, knowledge about whether such a rapport (positive or negative) exists between the HIV positive clients and the facility attendants has been explored in the analytical sections of this research, including the *quality* of such service. More so, possible ways such relationship can be further used to strengthen and enhance continuity in care and treatment (as one of this research’s objectives), in line with the UNAIDS 2030 goals, becomes even more expedient. As would be shown, the fifth chapter of this study is extensively devoted to how *a new form of relationship* emerges from *clinical resilience*.

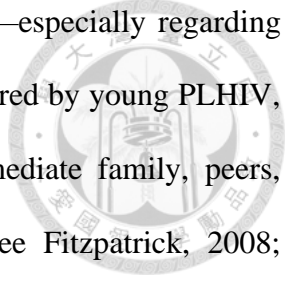
Therefore, informed by this review of recent studies in this field of health research, some important theories helped frame the understanding of this current study. Presently, the stigma and psychosocial theories have formed the two major conceptual frameworks to further guide this research. One important reason (for the choice of these theories) is that they are both beneficial *reflective tools* (van Luenen et al., 2017) in understanding some of the conceptual shifts (Stutterheim & Ratcliffe, 2021) by young PLHIV towards their treatment.

## Stigma



According to the sociologist, Erving Goffman, stigma denotes an attribute wherein individuals are disqualified from full social acceptance of what society considers “normal” (Fitzpatrick, 2008; Goffman, 1986). In a literature review of the stigma of people living with HIV in sub-Saharan Africa, Mbonu and others (2009) found that stigma stymies the delivery of efficient socio-medical care, affecting the patients’ adherence to ART. This is largely attributable to the cultural constructs through which seropositive people in southeast Nigeria are viewed, as I have come to conceptualize it, “sexually unruly.” Owing to this negative stereotype, they are, therefore, *rightly* treated as “scapegoats” (Gilmore & Somerville, 1994). Gilmore and Somerville (1994) have, therefore, made a compassionate appeal to a more humane approach to the disease and its bearers, based on which the society should recognize that everyone carries *in* them the burden of HIV and that several individuals are either *infected* or *affected* by it. Following the analysis of collected field data, therefore, I have also found out (as will be shown later in the analytical section) the extent of the weighted effects of HIV on the bearers, both *infected* and *affected*.

Consequently, where society seems indifferent towards this *viral* disease and those infected by it, self-stigma (among seropositive persons) remains, by itself, a pervasive phenomenon even with the availability of such support groups as the network of people living with HIV/AIDS in Nigeria (NEPWHAN). Notwithstanding, this self-immolation continues to rear forth as a form of personal chastisement (Chime et al., 2019). The end results? Left unchecked, this trend develops to morph into discontinuity from care. Hence, I consider that the pervading menace of missed appointments and LTFUs in public ART hospitals in Enugu State is attributable, in part, to this largely ignored risk factor: stigma and its related attributes.



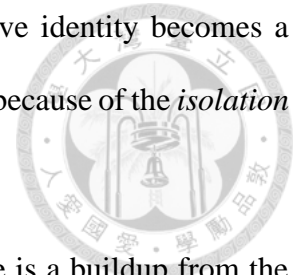
In this regard, I believe that stigma (both self-imposed and from others—especially regarding status disclosures) is at the heart of most of the mental health ordeals suffered by young PLHIV, oftentimes, with an increasing disconnect between them and their immediate family, peers, religious community, work colleagues, and healthcare professionals (see Fitzpatrick, 2008; Gilmore & Somerville, 1994; Gizachew et al., 2021; Salad et al., 2019). As stated earlier, it is because of some of the cultural constructs regarding the mode of transmission of the disease (with “sexual promiscuity” often taking precedence over all else) that gave rise to the disqualification of the disease bearers from full social acceptance by other members of society (see Goffman, 1986). Implicitly, the theoretical implications of the concept, “stigma,” formed a significant part of the topic-guided questions of the focus group discussions and in-depth interviews.

### **Psychosocial Theory**

With HIV emerging—and remaining persistently so—as a highly stigmatized disease, the psychosocial theory may enable us to better understand the psychological dimensions of the disease as it, in part, further explains dynamisms in self-understanding, social relationships, as well as an individual’s relationship to society throughout life’s stages (Newman & Newman, 2020), as a new form of seropositive identity is assumed (Seeley et al., 2011).

Erik Erikson (1902–1994), a protégé of Sigmund Freud, is considered the originator of this theory—of course, heavily influenced by his mentor’s seminal classic on psychoanalysis. He believes that psychosocial development follows a graded process, which he grouped into eight ascending stages: *Trust versus Mistrust; Autonomy versus Shame and Doubt; Initiative versus Guilt; Industry versus Inferiority; Identity versus Confusion; Intimacy versus Isolation; Generativity versus Stagnation; Integrity versus Despair* (Vogel-Scibilia et al., 2009). For this project, it was at the 6<sup>th</sup> Stage: Intimacy versus Isolation, characterized by young adulthood, 19-

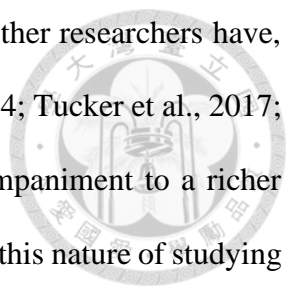
40 years (Cherry, 2020), that I started to examine how a *new* seropositive identity becomes a “shattering” of one’s *intimacy* with society, leading up to suicidal ideations because of the *isolation* that follows from assuming such a new identity.



To further expand his theory, Erikson goes on to state that each new stage is a buildup from the one preceding it, and that progress to the next stage is achieved by dealing with the conflicts present in each stage (Malone et al., 2016). Hence, for seropositive persons, the transformation from the ability (identity) to the inability (confusion) to form strong relationships with other members of society is a precursor to loneliness, depression, and anxiety. Informed by this theory of psychosocial dynamics, I considered that, for the seropositive population of Enugu State, the disinterest in keeping up to their therapy appointments stemmed from the identity/confusion conflict passing to the intimacy/isolation that ultimately happens. It is, perhaps, one such classic example of “identity crisis” which was a term coined by Erikson (see Erikson, 1970), to illustrate this bleak period of unfriendliness from other members of society, that helps one better understand some of the mental health challenges faced by young people living with HIV in Nigeria.

It is therefore my estimation that the points made above would greatly benefit *enhanced adherence counselors* in the treatment and care of young PLHIV. To this end, the in-depth interviews (which involved the focal persons providing ART-related services in the health facilities studied) was expanded to also ascertain the quality of therapy available to this closed group (see the third analytical chapter for why I classify them as a “closed group”), both within and outside of the health facilities in Enugu, southeast Nigeria.

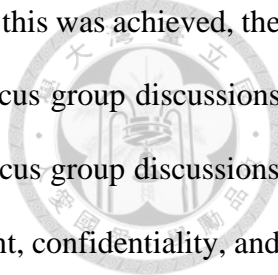
## **Research Design and Methodology**



To better understand the biomedical interventions that exist in HIV care, other researchers have, elsewhere (see, for example, Stutterheim & Ratcliffe, 2021; Syed et al., 2014; Tucker et al., 2017; Wilson et al., 2015), theorized that qualitative research is a pivotal accompaniment to a richer socio-behavioral understanding of the HIV disease. Informed, therefore, by this nature of studying the psychosocial effects of stigma and social isolation on, in this case, young PLHIV, this research also pursued both group discussions and individual interviews to collect qualitative data. Topic-guided focus group discussions have been conducted between the seropositive persons recruited for this study. Also, I conducted in-depth interviews with ART focal persons in the four public health facilities including: University of Nigeria Teaching Hospital (UNTH), Enugu State University Teaching Hospital (ESUTH), Udi General Hospital (UGH), and Enugu Ezike General Hospital (EEGH). The choice of these public hospitals was not arbitrary. All of them shared two important attributes that I considered necessary for this study. They are, firstly, high-volume<sup>5</sup>ART sites (with an est. *TX\_CURR* >200—namely, total seropositive clients currently on treatment in those facilities); and, secondly, reflecting on balancing both the urban and rural representations, a dimension that I also considered very important for the study design. For example, the two tertiary institutions are mostly accessed by urban dwellers, while UGH and EEGH are predominantly rural. At first, I aimed to recruit at least six “vulnerable” respondents aged 20-30 years from each facility mentioned above, through the facility focal persons (convenience sampling, although this was advertised in a recruitment poster). By “vulnerable,” I mean individuals who had missed their appointments in the last twenty-four months or had ever been considered an LTFU patient. This was further determined from the appointment registers available in such facilities. Participation

---

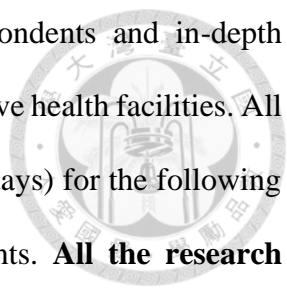
<sup>5</sup> In Enugu state, these two tertiary hospitals and the additional general hospitals cater for most of the total in-state PLHIV population, due to their wider diagnostics facilities compared to other health centers within the state.



was completely **voluntary** in so far as the inclusion criteria were met. Once this was achieved, the facility staff (preferably a nurse in the ART unit) so recruited for these focus group discussions were also pre-trained (where I was unable to be present and conduct the focus group discussions by myself; however, this eventuality did not happen) on the ethics of consent, confidentiality, and how to administer open-ended focus group discussions. Audio recording facilities were used to record the discussions, which were conducted in Igbo (a major Nigerian language spoken in the entire southeast of Nigeria, including Enugu State), Pidgin-English (where preferable), and most of the time, a mixture of both. Notes were taken at different stages of the data collection process, which were eventually transcribed, verified, and thematically analyzed. In turn, the facility attendants, on their part, formed part of the in-depth interviews I conducted (hence, they did not need further recruitment through a poster), to examine the quality of mental health care/support that is available to their seropositive clients; and their opinion regarding how to strengthen the systems that provide these treatments/therapy.

### ***Regarding research ethics and consent***

At first, I obtained ethical approval from the Enugu State Ministry of Health (**Ref. No. MH/MSD/REC21/213**) for the study to be conducted in the state; and an additional clearance from the National Taiwan University Institutional Review Board (**NTU-REC No. 202108HS020**). Both review boards, whose concerns regarding “non-violations of the emotional wellbeing of the study participants” was pertinently addressed by recruiting trained HIV testing services (HTS) counselors also in the facilities to be a part of the FGD processes. Additionally, extra care was taken to phrase the discussions as non-invasively as possible with the choice to skip any question(s) which the participants felt uncomfortable to respond.




Altogether, I conducted focus group discussions (FGDs) with 20 respondents and in-depth interviews (IDIs) with 4 service-providing clinicians, each from the respective health facilities. All interviews were conducted in and around the hospital premises (on clinic days) for the following reasons: convenient recruitment and cost-effectiveness for the participants. **All the research participants consented** to be part of the study and further expressed personal gratitude towards me for, in their own words, “*showing genuine concern about our mental health,*” for which, as I later came to understand, they had yet to get such elaborate discussions on. Overall, there were more women than men participants (17:3), which turned out beneficial to the study as the women were more *expressive* and showed greater empathy to the research trails (e.g., they contacted me to be sure I was coming to the discussion after all... *it’s almost like they wanted so much to speak to an outsider*). They were all aged 20-30 years. Age for IDI respondents were not elicited; years of clinical experiences, however, was.

### ***Eligibility criteria***

This study considered all young people living with HIV in Enugu State aged between 20-30 years who are enrolled for treatment (but had **ever** been considered as—at any point in time since inclusion into **Tx**, i.e., treatment, at the facility—an LTFU, or previously missed an appointment within the last 24 months) at one of the four ART facilities including UNTH, ESUTH, EEGH, and UGH. Seropositive status and age were determined (for confirmation) from the enrollment register in the facilities. In the same vein, all ART specialists active for more than two years within the facilities were eligible for in-depth interviews.

### ***Inclusion criteria***



PLHIV who are linked to the facilities under study and are aged between 20-30 years were targeted for focus group discussion recruitment. They were also on record as having missed appointment(s) within the previous 24 months, or were ever considered an LTFU case, that is, stayed >28 days without honoring their last appointment, before being tracked back to care again. Furthermore, the in-depth interviews were conducted with ART staff members who have had more than two years full-time experience providing care and treatment at the facilities.

### ***Exclusion criteria***

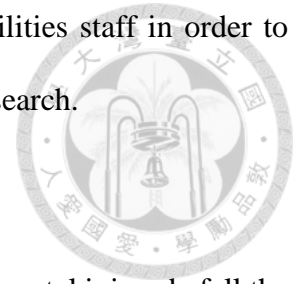
All seronegative people did not qualify to be part of this research; also, all seropositive people aged <20 years or >30 years old **did not** qualify for this study, even though they were linked to the treatment facilities of interest. Furthermore, all **non-current** ART staff in the facilities with or without the requisite years of care and treatment experience (i.e., >2 years) did not qualify for the in-depth interviews. By the same token, other staff members, even those currently employed in the ART unit but with active HIV case management experience of fewer than 24 months, were not interviewed.

### ***Research timetable***

Following ethical approval, data collection for this study started in October 2021 and lasted through December of the same year, one facility per time, across the four public hospitals under review. This data collection, therefore, lasted for a period of two months as I was careful to adjust the schedules in line with the 2019 SARS-COV-2 (COVID-19) regulations set by the Nigerian government throughout the year. Following data collection was another period which involved data cleaning, verification, and transcription of audio that ended in March 2022. Data analyses



followed thereafter with occasional contacts with some of the health facilities staff in order to confirm any incongruities or seek additional information relevant to the research.



### ***Risks/benefits to participants' wellbeing and finance***

In keeping with the Helsinki Declaration, no personal harm or physical or mental injury befell the research participants, as a core part of the consent-seeking process was non-binding **voluntary** participation in the research. This research also did not financially benefit the participants except where specifically requested—for example, providing consumables such as snacks and beverages for the study participants during field data collection.

### ***Conflict of interests***

Both myself as the principal investigator and my advisor at National Taiwan University have no conflicting interests in this research.

### ***Regarding my positionality and reflexivity***

I was already a “familiar face” at these health facilities as they were places, I had also previously worked (especially regarding HIV uptake services for pediatrics and adolescents) as a monitoring and evaluation support personnel for Catholic Relief Services (an NGO involved in the health space at Enugu state). However, I have no prior knowledge of all the FGD participants in this study. That said, whilst I visited these facilities during data collection, I was equally doing a participant observation of both my study location and potential subjects. I noted the following:

- At almost all the facilities visited, patient’s waiting time prior to being attended spans several hours (~ 2-8 hours!).

- Sanitary facilities in the hospital are mostly padlocked and cannot be assessed by the patients.
- The FGD respondents *felt* I was the “guy from the government” who would “fix things” for them. I made certain to clear this misconception and empathized with them.
- A part of me, whilst interacting with them, also *wanted to be HIV positive* as I felt I had “a stronger voice” to make outbursts, especially regarding their waiting times at the clinics.
- I almost always *felt broken* at the end of every discussion.
- The clinicians were modest and *genuinely appeared* like they wanted to see changes (esp. regarding the mental health of their patients), but they are all equally overwhelmed by things generally. Some trek a long distance to come to work. *They also indicated interest that they, too, wanted to be counseled.*
- Some recordings of “no response” in the transcribed data weren’t for lack of things to say by the respondents; sometimes, non-verbal cues such as slumped shoulders, a nod, lack of eye contact, nail-picking, and so on, were in some ways, *actual responses* to some questions.

### *Notes about the field data*

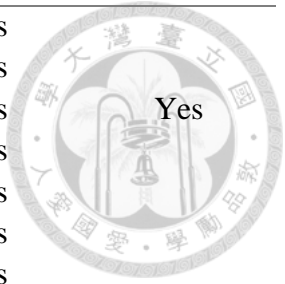
In the following three chapters, the discourse focuses on analyzing three important **themes** and **sub-themes** that have emerged—both from the research proposal as well as the field data collected. The three main themes that make up each chapter are: Stigma, the Mental Health of PLHIV, and the Sero-Kinship among YPLHIV, respectively. Note that where the notation “R1, R2, R3, etc.,” are used within the transcripts, they are simply Respondent 1, 2, and so on. Another point bears

noting that: given the COVID-19 pandemic in Nigeria at the time, there were also cases of rising armed conflicts struggles across entire southeast Nigeria (including the study location) between nationalist agitators in the region for self-autonomy. The present government had proscribed them (the *Indigenous People of Biafra, IPOB*) and arrested their leader, which further led to escalated civil unrest throughout southeastern Nigeria and continues to survive to this day. This condition, therefore, might have affected the overall “moods” of the study participants as they were equally Igbo (and, by extension, *Biafrans*) living in the southeast as well. Lastly, where the reader notices a wider difference in the genders of the FGD respondents, it is, firstly, reasonably within bounds of the HIV prevalence rate among both genders in the state (1.2% among males; and 2.4% among females; both representing 3,736 of Enugu HIV pop. aged 15-49 years, see FMOH, 2018). Secondly, women might be getting more tested than men due to pregnancy, antenatal visits, and so on; hence, females becoming disproportionately represented as the “gender with greater HIV prevalence” than men (consider related findings in this field elsewhere in Africa by DiCarlo et al., 2014).

***Demographic information of the study participants***

Facility	Date collected	Respondents	Sex	Age	Years HIV+	Clinical interruption within previous 24 months?	IDI Conducted?
<b>UDI GH</b>	28/10/21	1	M	29	4	Yes	Yes
		2	F	27	3	Yes	
		3	F	28	10	Yes	
		4	F	26	1	Yes	
		5	F	28	1	Yes	
		6	F	29	10	Yes	
<b>ESUTH</b>	29/10/21	1	M	30	3	Yes	Yes
		2	F	30	5	Yes	

		3	F	29	8	Yes	
		4	F	30	15	Yes	
<b>EEGH</b>	3/12/21	1	F	30	15	Yes	Yes
		2	F	29	1	Yes	
		3	F	20	20	Yes	
		4	F	20	6	Yes	
		5	F	30	8	Yes	
		6	F	24	2	Yes	
<b>UNTH</b>	21/12/21	1	F	22	7	Yes	Yes
		2	F	21	21	Yes	
		3	F	21	7	Yes	
		4	M	22	3	Yes	



## Chapter Three.

### Stigmatization of Young PLHIV

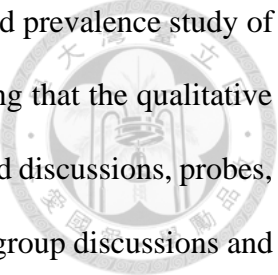


HIV remains a highly stigmatized disease in Africa (Mbonu et al., 2009; Rankin et al., 2005; Winskell et al., 2011; Winskell et al., 2015). Consider that, for example, in Nigeria, factors such as religion (Speakman, 2012), socio-cultural beliefs (Muoghalu & Jegede, 2013) as well as misperceptions about modes of infection (Agu et al., 2020) have been demonstrably explored by these researchers as having links to the stigmatization of young people living with HIV (YPLHIV). It also follows then that this present study has aimed to investigate the phenomenon of HIV stigmatization, potentially as a *discreditable trait* (consider for example, Chaudoir et al., 2013) which has continued to play a huge role in how issues pertinent to the mental health of the disease bearers are addressed. For example, I sought to understand how the young individual living with HIV has reacted<sup>6</sup> to the stigma *enacted* on him/her by society (as deriving from their serostatus), and how said individual also *internalizes* such stigma by feelings of shame and self-loathing (Chaudoir et al., 2013). Recall that Goffman had conceptualized stigma to denote an attribute with which individuals are disqualified from full social acceptance of what society considers normal (see Goffman, 1986; Fitzpatrick, 2008). The “society” for us, in the present study, is Enugu State in southeast Nigeria.

As mentioned in the Introduction, Enugu was considered one of the “HIV burden states in Nigeria” with HIV prevalence rate of 1.9%, shown to be higher than the national average of 1.3 percent

---

<sup>6</sup> Chaudoir and colleagues (2013) delineated three ways which an individual reacts to stigma as comprising: *anticipatory, enacted, and internalized*. With the first, the individual *expects* to be the victim of discriminatory behavior from society; with enacted, it is the degree to which the individual has *actually suffered* stigma in the past; and finally with the third, it represents the degree to which the individual *feels shame or despises oneself* because of the stigma. In this research, we shall also see how the YPLHIV in Enugu state progresses through these stages.



(among people 15-49 years old), according to the national HIV incidence and prevalence study of the Federal Ministry of Health (2018). It was within this geographical setting that the qualitative data for this present study was conducted—during which several topic-guided discussions, probes, and overall clinical settings observations obtained (mainly during the focus group discussions and in-depth interviews) were used to understand stigma as a “non-normal” reaction to young people living with HIV/AIDS in Nigeria. I, therefore, approach the issue of *stigma among YPLHIV* as Pescosolido and colleagues also argued (in 2008) that it is a condition that gives rise to prejudice and discrimination; in this case, among young people living with HIV/AIDS.

This theme of stigma and associated sub-themes (two important ones which will also be reviewed below) show that this psycho-social “mark separating individuals from one another” (Pescosolido et al., 2008, p. 431) is a contributing factor towards suicidal ideation as well as the manifestation of poor psychosocial health among YPLHIV in southeast Nigeria. This was notably explored across the four public health facilities sampled for this study, such as the UNTH, ESUTH, UDI GH, and EEGH, respectively, and the 20 respondents from the focus group discussions (FGDs) as well as the 4 ART clinicians in-depth interviewed (each from one of the health facilities). The 20 respondents of the FGD (17 females and 3 males) aged 20-30 years (with average age = 26.25 years) are all seropositive (with the range of the period of initial diagnosis ranging from birth, i.e., 1-21 years, respectively). All of them have remarked on how they *perceive* that other people discriminate against them due to their serostatus both within and outside of the clinical setup. As the respondents showed, prejudice follows these young people when they share their HIV status with non-HIV positive people, conceived by them as *others*. Hence, to preserve their mental health from the effects of stigma, these young would rather let no one know their serostatus.

### **Non-Disclosure as a Cocoon against Stigma**

Following the idea of “preserving their mental health,” all the respondents from the FGD clearly expressed anxiety over disclosing their serostatus to other people, even close family members. At UGH, for example, a 29-year-old female respondent who has been HIV positive for 10 years (initially diagnosed in 2011) answered, upon being asked whether she thinks anything had changed in her relationships with others due to her status that:

[Prior to being diagnosed] I was *scared* of going to the clinics...because... anyone who returned from the hospitals and had *boils* on their skin or you're very *slim* or *dry* would clearly be avoided because not only does she have HIV, but she's carrying AIDS! (R6, UGH FGD, 28/10/21, *emphasis* mine).

Her statement demonstrates that other individuals generalize the overall physical conditions of an ill person as *attributable* to the HIV strain present in that person; hence, existing ties with the individual, with the entrenchment of stigmatization, are cut. In order not to “suffer twice” the rejection of close family members such as children or her parent because of being HIV positive, she decided not to disclose her status. When probed on how she coped with the stigma from others and even self-stigma, she continued:

In the beginning, somebody like me, I was *looking for death*...I had lost my husband the same year (2011). I was *always praying for death* until I finished that dosage...but I look at my children and feel helpless. *My mother did not know* why I was taking those drugs and kept asking me questions about it. *I refused to tell her*.... My mother is now dead. My children continue to support me to take my drugs even though *they do not know why I am taking them* in the first place but are merely satisfied that my health conditions have improved (R6, UGH FGD, 28/10/21, *emphasis* mine).

At ESUTH, a response from another female respondent, aged 30 years and who had been seropositive for half the time (diagnosed in 2006), replying to a similar question goes:

*My health status is private* to me; the only person who knows about my status is *my husband who is equally HIV positive*.... My husband and myself found out about our serostatus the same time; that helped making disclosure easier, and *we both agreed to keep the news between us from our children* (R4, ESUTH FGD, 29/10/21, *emphasis* mine).

It had been earlier theorized in the introductory part of this study that there are those *infected* with HIV and those *affected* by the disease (see Gilmore & Somerville, 1994); it is my position, therefore, that *those infected by the HIV disease*, in a bid to avoid stigma, but more so to “protect” close family members such as parents, spouse, or children (for more on the latter, consider, Gilborn, 2002), erect a protective envelope (of non-disclosure) that shields their loved ones also from stigmatization. This “protective envelope” equally extends to the younger people *infected* by HIV. Again, the following remarks by yet another female respondent, aged 20 years and who has lived with HIV since birth, merit attention:

I am *not as happy as everyone else* whenever we play... There are 8 of us in the family (siblings), and *I am the only person who was diagnosed of HIV amongst all of my siblings*; up to today; *the rest of my siblings, besides my mother, do not know why I take the drugs I take*. They have asked questions severally and tired out from asking. My mother tells them it is for “hormonal corrections” ...but I am just tired of the whole thing, honestly. *My father still does not know I am HIV positive* (R3 EEGH FGD, 3/12/21, *emphasis mine*).

Her remarks show how much additional sadness this burden of non-disclosure contributes to her declining mental health. Yet again, other respondents also share similar stories such as hers. For example, an older male respondent, this time, at a different health facility, aged 29 and has been HIV positive for 4 years (diagnosed in 2017), says:

My friends do not know what is happening to me... *because I do not want them to know!* Even till date, *people refuse to eat at the service of songs or burial wakes of some of our village people who are thought to have died of HIV* (R1, UGH FGD, 28/10/21, *emphasis mine*).

This statement above lends further credence as to why most HIV survivors would rather not disclose their status to other people seeing, to what extent, such discriminatory behaviors from others could reach. Just in case the reader starts to wonder what could possibly happen were these individuals to disclose their status, again, the respondents share some of their experiences:



In terms of being in a relationship, a guy I met for about a few months insisted that we go run a test (being that he had already started discussing marriage) ... I didn't want to run the test, so I opened up to him and told him about my status. That was the end of the relationship (R3, 21 years, UNTH FGD, 21/12/21).

Elsewhere at ESUTH, another female respondent replies:

*I feel lonesome and rejected...*, and I am still having the pains. For example, in terms of marriage, *I would have been married and happily wedded a long time ago*; but when my suitors (at least two in the last one year) learn about my status (because I don't want to hurt them...*I tell them the truth*), they run away. Nobody, not even my siblings who visited me earlier get to visit me again because of my status (R2, 30 years, ESUTH FGD, 29/10/21, *emphases mine*).

At a personal level, young people living with HIV are stigmatized. Therefore, they decline to share their seropositive status with other people, considered outsiders, with whom they feel vulnerable relating their serostatus to. However, what of the conditions of the mental health of YPLHIV within the healthcare facilities where they come for clinical appointments? Do these vulnerable populations consider the clinic settings as having enough safety net for their wellbeing? The answer is generally negative, as the reader would get to infer.

### **Clinical-Related Stigma and Prejudice**

I chose the health facilities as the preferred location for the FGDs and IDIs, mainly for convenience among the study participants. But for an equally undisclosed reason was my intention to observe the general clinical setup of the ART units, the timeliness of clinicians to the facility, and the patient-physician relationships. I intended that these would also form crucial insights into understanding how stigma is enacted on the HIV positive people by their service providers.

However, it is important to set clear records about some precedence which are that: health services funding in Nigeria is sub-optimal (Abubakar et al., 2022); there are ~1.9 million HIV positive people in Nigeria (UNAIDS, 2019), which places an additional burden on health care workers (HCWs) in terms of the quality of care available; and that the clinicians providing ART services,

on their part, are overwhelmed with a system that does not recognize nor sufficiently reward hard work. Yet, *they do really care about their patients' wellbeing* notwithstanding.

Having stated the above, I consider that these observations further help place in the context the nature of the clinical-related stigma and prejudice YPLHIV associates with the health facilities.

Consider the following responses when the FGD discussants were asked if they had ever had any bad experiences at the health facility where they received ART services? At ESUTH, all the four respondents, with a median age of 30 years and an HIV diagnosis range of 12 years, remarked:

R1: The nurses here are rude.

R2: Yes. I just don't like *here*.

R3: They *don't usually treat us as normal* human beings.

R4: *They are harsh to me when I come late* for my clinic visits. They will usually *give me a penalty by not collecting my card early*, thus delaying me. When one misses appointments again, they will shout at one.

(ESUTH, FGD, 29/10/21, *emphases mine*.)

When checked against responses to the same question at another tertiary health facility, UNTH, the following responses from the respondents (median age = 21.5 and range of diagnosis = 5 years) are equally notable:

R1: I have been shouted [on] at the facility before.

R2: No bad experience on my part.

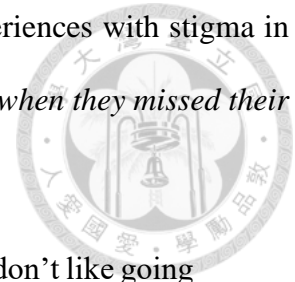
R3: *I feel insecure* about other people finding out about my status whenever I visit the clinics... my neighbor is one of the cleaners in the hospital and she nags quite a lot at home.

R4: No negative experiences at the hospital... I volunteer there, and they treat me as a colleague.

(UNTH FGD, 21/12/21, *emphasis mine*).

Regarding the above, R2 and R4 responses (that they have no negative experiences in the clinical setting) particularly, also provide intriguing insights to a follow-up question. R2 is a 21-year-old

female. In response to the question regarding what she *felt* given her experiences with stigma in their homes and the health facility and if these made her *feel sad or happy when they missed their ART appointments*, she replied:



*I feel very happy! Whenever I miss my appointments, I feel happy! I don't like going there, and whenever I do, I try as much as possible to finish on time and leave that place, especially on my viral load-count test days; it doesn't give me joy being there. I also feel happy when I miss my drugs* (R2, UNTH FGD, 21/12/21, *emphases mine*).

As I have shown, the above statement further sets upsetting precedence towards the emergence of suicidal ideations as a challenging hurdle to a sustainable *retention drive* among YPLHIV. How do the clinicians themselves react to such reckoning? Consider some of their responses to what they want to see changed about HIV services in Nigeria:

Yeah, just *the attitudes to the patients* here; our attitudes, the way we talk to them, respecting them, providing privacy, attending to them timely, you know, this time is very, very important, because *the waiting time of patients is sometimes big or high....* It matters a lot. If patient is talking to you and you are not talking or responding, it means that the patient may feel dejected or rejected. The person may start asking, *is it because I'm HIV positive?* (UNTH IDI, 21/12/21, *emphases mine*).

This clinician's account tells half the story. Another clinician at UGH provides a much more looming insight into the nature of HIV services in Nigeria and how it reflects negatively on the mental health of YPLHIV in Enugu State. He mentioned that:

HIV/AIDS interventions in Nigeria are '*numbers driven*' against real change. So, in Nigeria, as far as HIV/AIDS is concerned, *it is about targets and the number of people reached*; but then, *there is little or no emphasis on the quality of service provided* for these people....Because there's a theory that if more people are reached...there's...higher chance of epidemic control; however, those people that are reached, most of them don't even receive tailored services (UGH IDI, 3/12/21, *emphases mine*).

These interviewees' responses further corroborate the FGD respondents' account of a largely unmet mental health need (stigma-free clinical services). This phenomenon tends to stifle the funding and resources provided by both the Nigerian government as well as international funders

(e.g., the Global Fund, UNAIDS, and the United States Agency for International Development [USAID] etc.) towards HIV services in the country, especially regarding retention drives.



## **Conclusion**

This chapter has considered the effect of stigma as reflecting negatively on the mental health of YPLHIV and how it tilts the seropositive people into *suicidal tendencies* such as missing their clinical appointments, ARVs, and ultimately, left unchecked, discontinuing from care. Relatedly, I have shown how YPLHIV resist sharing their serostatus with even close family members (and potential intimate partners!) as a way of preserving their mental health from additional jeopardy. In the following chapter, I will identify other factors that, in addition to stigma, build up suicidal ideas among YPLHIV.

## Chapter Four.

### Mental Health of Young People Living with HIV/AIDS



In the last chapter, I have demonstrated the construct of stigma and its effects on the mental health of young PLHIV in Enugu State, southeast Nigeria, aged 20-30 years, by analyzing the issues concerning stigma, such as the *perceived* negative attributes that follow serostatus disclosure and the nature of clinically related mental health burdens on the seropositive population. In this chapter, I will relate the mental health issues of YPLHIV to Erik Erikson’s psychosocial development theory (especially on the sixth stage of *Intimacy vs. Isolation* relationships), on one hand. On the other hand, the mental health of these HIV survivors would also be related to the ideas of financial and nutritional stressors, and how they lead up to virologic failure among YPLHIV within the state.

#### Intimacy vs. Isolation on the Cusp of “Identity Crisis” among YPLHIV

For contextual clarity, recalling Erikson’s theorization of psychosocial development following a graded process which he categorized into eight ascending stages (Cherry, 2020; Vogel-Scibilia and colleagues, 2009) of:

1. *Trust vs. Mistrust*—Infancy stage. Can I rely on the world, and would my needs be met?
2. *Autonomy vs. Shame and Doubt*—the struggle to control one’s world in early childhood.
3. *Initiative vs. Guilt*—the autonomy to pursue new tasks, pre-school, is conceived.
4. *Industry vs. Inferiority*—build self-esteem via skills acquisition throughout school age.
5. *Identity vs. Confusion*—what values and concepts do I possess as an adolescent?
6. *Intimacy vs. Isolation*—the development of shared intimacy with other young adults.
7. *Generativity vs. Stagnation*—Life’s goals are accomplished throughout middle adulthood.

8. *Integrity vs. Despair*—looking back on lived life’s experiences as a fully mature adult.

I now go on to examine how the 6<sup>th</sup> stage of Erikson’s psychosocial development—intimacy versus isolation—characterized by young adulthood of 18/19-40 years (Cherry, 2020; Mcleod, 2018), has led to a shattering of the *intimacy* that seropositive people have with society especially upon *assuming a novel identity* associated with HIV. Also, how does the new identity ultimately build up to one’s *isolation* from others (referred to the stigma discourse) and *self*? In this regard, Mcleod (2018) considers a factor of loneliness, depression, fear of commitments to new relationships, and depression, all of which, as I shall demonstrate in this discourse, are attributed to the individual’s serostatus.

At the FGD with the recruited participants, they were asked if, because of their serostatus, they felt lonesome, depressed, or rejected? The responses, across multiple sites, varied considerably. Consider this 26-year-old female respondent (living with HIV for 10 years) at UGH who says:

Yes, I feel lonely as a result of my HIV status.

(R4, UGH FGD, 28/10/21).

And another female, aged 29 years—also a decade long into her seropositive status, responding to the same question, says she felt:

Both [depressed and rejected] when I was first diagnosed and... *was looking for death* initially, but...now managing my life (R6, UGH FGD, 28/10/21, *emphasis mine*).

To better understand how these above issues relating to *isolation* measure up against other responses to the same question, a quick overview of the responses of EEGH discussants sheds further insight. The respondents, all females with a median age of 26.5 years, and a range period of initial diagnosis ranging from 1 to 20 years (with one of them being HIV positive from birth) answered that:

R1: I feel lonely...mostly when I am idle. I have also felt depressed when a suitor rejected me because of my status.

R2: Whenever I *reflect* on my condition, I feel lonely and depressed as well.

R3: I feel lonely and depressed because I am always by myself. Also, people I would have been playing with also rejected me.

R4: I feel lonely all the time...depression sets in at the mention of HIV to my hearing.

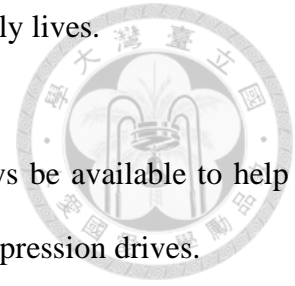
R5: Whenever I return from the market where I go to sell wares, in the silence of the house, I start to feel lonesome.

R6: I feel depressed and tired *whenever it is time to take my drugs because I hate taking them.*

(EEGH FGD, 3/12/21, *emphases mine*).

Reflecting on Erikson's sub-theory of *intimacy versus isolation*, the mental health of young adults living with HIV/AIDS in southeast Nigeria is negatively impacted by the seclusion they suffer from an intimate relationship with self and others. However, of further consideration is the heightened burden of the "identity crisis", namely a developmental event that makes an individual question what place they occupy in the world, according to Erikson (1970). As shown above, R6 particularly (24 years of age and living with HIV since 2019), felt completely challenged by the need to adhere to her antiretroviral treatment (ART). Unattended to, one is easily left to wonder what state her mental health assumes in the next decade and beyond, if she continues to feel this way. It follows then that further attention to the mental health of YPLHIV is particularly imperative. One of the ART clinicians at EEGH had mentioned the failure of clinicians to fully prepare their patients for the treatment process due to a deferential focus on targeted testing, without firmer approaches to ensuring that the treatment processes remain uninterrupted throughout the patient's lifetime. I agree with the clinician's position that the points raised above about treatment preparation are *primus inter pares*, the logical step towards initiating ART. For example, there is more need to remind the patients that:

- i. For the time being, ARVs would form a consistent part of their daily lives.
- ii. Viral load suppression is contingent on treatment adherence.
- iii. And that a dedicated adherence counselor/personnel would always be available to help them navigate any challenges that might thwart their viral load suppression drives.



Regarding this last point, some of the ART clinicians were directly observed in the clinical setting, as part of my informal data gathering. I saw someone shouting at a patient for being late for their appointment and further threatening to delay the patient for a longer period as a *lesson* for others. Relatedly, the participants at ESUTH, responding to an earlier question about receiving negative behaviors from other people because of their serostatus, replied thus:

R3: Even at the hospital here, they do exhibit discriminatory practices...often shouting at us from a distance and shooing us back and forth...they will just be treating us as some trash *or whatever*.

R4: You cannot even cough anywhere close to the nurses without being shouted at. It's that bad for us.

Again, when directly asked about their experiences in the clinical setting, you would recall these previous responses such as that:

R1: The nurses here are rude.

R2: Yes. I just don't like *here*.

R3: They don't usually treat us as *normal* human beings.

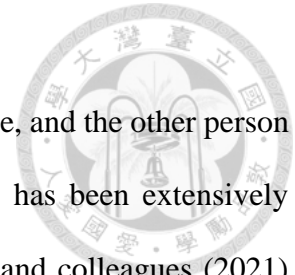
R4: They are harsh to me when I come late for my clinic visits. They will usually give me a penalty by not collecting my card early, thus delaying me. When one misses appointments again, they will shout at one.

(ESUTH FGD, 29/10/21, *emphases* added).

The two most enduring factors which directly contribute to why some of the patients either miss their appointments in the first place, or come a little later than scheduled, would form the next section of this discourse. Before then, however, one other critical point merits urgent attention.



## Serodiscordance and Unmatched Relationships among YPLHIV



I define serodiscordance here as a case where one individual is HIV positive, and the other person (intended to be a relationship partner) is not. This aspect of HIV study has been extensively researched, and newer works continue to emerge. For example, Chihana and colleagues (2021) have studied the HIV cascade of care among serodiscordant couples across multiple sites in the African Sahara region, finding that low HIV-status awareness was a major driver for the person-to-person transmission of HIV. Another recent study that examines the mutual support between different couples was conducted in Tanzania, exploring whether the idea of “solidarity” is related to treatment outcomes at the dyadic level of HIV infection as “two people’s secret” (Fonner et al., 2021).

In Nigeria, however, among this present study’s respondents, serodiscordance leads to an inability to find matching intimate relationships with others who are not seropositive. This means that such individuals cannot fully explore, and benefit from, shared intimacy/bonding with other would-be partners—for fear of “suffering twice” should they be rejected because of their serostatus. One female respondent at UNTH, aged 22 and living with HIV since 2014, expressed her anxieties about the issue:

Sometimes...you know that when we are growing, we fall in love; so, thinking about having a relationship with this guy now, how will I let him know that I am HIV positive? I feel so depressed thinking about it all. What would my life become of if he goes?

Asked if she could suggest what needed to be done, she replied:

...matching and pairing up HIV-positive clients for marriage would be a much welcome idea (R1, UNTH FGD, 21/12/21).

It might interest anyone wondering about this to know that even though the PLHIV population have an organization known as the Network of People Living with HIV/AIDS in Nigeria

(NEPWHAN), established in the country in 1998, little is known (at the time of this writing) about partner-pairing among its network of members who seek intimate relationships.



### **Financial and Nutritional Stressors as Precursors to Virologic Failure**

Virologic failure is not the primary study purpose of this research. However, it does bear mentioning that the mental health-related challenges that derive from the unmet financial and nutritional stressors faced by YPLHIV, if ignored, might lead to the virologic failure of seropositive people in southeast Nigeria. With this understanding then, the WHO (2003) considers nutrition among PLHIV as meriting renewed focus at all programmatic levels in-country, particularly in Nigeria, where HIV is currently endemic. Quite upsetting, though, nutrition requires robust funding (see Nutrition International, 2021); for a country like Nigeria, therefore, with ~40% of its millions of populations living below the poverty line (137,430 naira or \$381.75) annually as per its 2019 “Poverty and Inequality” report (see World Bank Group, 2020), the effects of this on the young HIV positive people of southeast Nigeria add a further strain on their mental health. For example, most of the sampled population of the FGD consistently cited financial and nutritional needs as two of the major barriers to accessing their treatment. Further linked to out-of-pocket expenses, the issue becomes clearer as to why they might miss their clinical appointments or become LTFU patients, over time. Funding, therefore, is a contentious challenge to treatment uptake among YPLHIV in southeast Nigeria.

With the above in mind, in-country HIV programmatic procedures become worrisome when the young adults, un/semi-employed, are further required to withstand the worst of an additional portion of their treatment services, such as out-of-pocket expenses. How do the people who are directly affected react to this? This was what I hoped to find out when the focus group discussants

were asked about the challenges they faced in making it to their appointments? They responded in the following ways.



UGH:

R1 (male, aged 29 and HIV positive since 2017): Money is a really big challenge for me personally; transportation, feeding, and household needs can all be solved with money...and I don't have that.

R3 (female, aged 28 and HIV positive since 2011): Sometimes, it is mostly money-related issues for transportation to this place.

R6 (female, aged 29 and HIV positive since 2011): As a widow, money for transportation to this place as well as feeding my children is a huge problem for me.

(UGH FGD, 28/10/21).

Udi is a rural community in Enugu state. I make this point to show how, regardless of where one lives (rural or urban), as the urban respondents from ESUTH show (below), the stressors are felt equally.

At the ESUTH:

R1 (male, aged 30 and HIV positive since 2018): ...transportation costs...challenges.

R2 (female, aged 30 and HIV positive since 2016): At my workplace, I do not usually get a permit from my employer to come for my clinic visits because they do not know my status; I am equally terrified of disclosing my status as I'd automatically lose my job. *I have to lie to them.* I usually give excuses that my eye is itchy so they can allow me to come to the hospital.

R3 (female, aged 29 and HIV positive since 2013): When I travel, sometimes getting my drug refills might be difficult.

R4 (female, aged 30 and HIV positive since 2006): It is transportation money for me.

(ESUTH FGD, 29/10/21, *emphasis mine*).

Note how these responses above relate to those mentioned earlier from the UGH, EEGH, and UNTH, in similarity.

At the EEGH:

R4 (female, aged 20 and HIV positive since 2015): I have no financial support available for me to continue coming here to receive my treatment.

R5 (female, aged 30 and HIV positive since 2013): I *feel traumatized* that I cannot confidently disclose to my relations about where I come to for my treatment.

R6 (female, aged 24 and HIV positive since 2019): I travel a far distance to this place for my appointments and it is equally costly.

(EEGH FGD, 3/12/21, *emphasis* mine).

The community where this health facility is situated, known as Enugu Ezike, and the eponym of the general hospital in that locality, is a rural community of mostly crop farmers, where the HIV positive young adults share similar financial and nutritional stressors with their sero-kins—see next chapter for an explanation of this novel term! —in urban, tertiary health facilities.

At the UNTH:

R1 (female, aged 22 and HIV positive since 2014): My school activities, transportation challenges...are major challenges that hinder meeting up with my appointments at the facility.

R2 (female, aged 21 and HIV positive from birth): Transportation challenge.

R3 (female, aged 21 and HIV positive since 2018): Transportation challenge for me is a huge issue.

(UNTH FGD, 21/12/21).

What we learn from all these preceding statements is twofold:

1. Due to the distance between the YPLHIV homes and the health facilities they go to receive uptake services, it is increasingly difficult to keep up with clinical appointments. The gap is where the *differentiated service delivery* (DSD) model, which is specifically focused on meeting the needs of the individual—as against the hither-to “one-size-fits-all” approach—

could be further used to address such issues (such as direct home delivery of ARVs to the patients; community ART pickup, etc.).

2. Again, the *truth* about one's HIV status can be burdensome. Resonating with the idea of “non-disclosure as a cocoon” developed in chapter 3, R2 at ESUTH had to navigate through her clinical appointments by telling an untruth to her employer about what she comes to do at the ART clinic. This demonstrates clinical resilience. However, how long until this *untruth* is discovered, and what implications it may have for her health outcome, remains the dilemma here.

Again, at ESUTH, the ART clinician mentioned during the in-depth interview that, prior to commencing treatment, incidence patients must pay for a part of the services, noting that:

*Some patients are not economically fit to pay for even a folder. This is a huge detraction from even enrolling into care in the first place. If government can make this aspect of HIV services free, I believe it'd also go a long way in retaining more clients in care and treatment. Since this year (2021), they pay as high as 2,500 naira (as a result of the inflation) from the initial 500 naira which they paid before. Even though this is a one-off payment, in my opinion, it is still high (ESUTH IDI, 29/10/21, emphases mine).*

The amount quoted is ~\$6 USD from the initial \$1USD (parallel exchange market rate as of Dec 2021); this is quite costly for young unemployed HIV positive people to have to pay, for a folder. For trustworthiness purposes, I had attempted to confirm if the rates were the same across the board when I contacted other facilities such as UNTH, EEGH, and UGH after this interview. Notably, they only mentioned that some civil society organizations (CSOs) within the state sometimes paid for the newly diagnosed positive cases, linked to the health facilities, through their office. How much exactly this amounted to, they did not say. This, however, is not the only financial cost these young adults have to bear, considering that their service providers are not oblivious of these challenges. At Udi GH, the ART clinician had said:

Most of these people are poor people; and I am mentioning this because most of the people who think of suicides are: hungry, not taking care of themselves, have no money to even come here in the first place, and so on... thank goodness for *tenofovir disoproxil, lamivudine and dolutegravir (TLD)* which is a little bit mild compared to when they were taking the *efavirenz combination* which, in my opinion, *is suicidal on its own* when taken without meal because *it is hallucinogenic* which makes them think they are going mad or something. *There is really a nutrition gap*. Poverty is a big challenge that these people are having—the money to take care of themselves and all of that is not available.

The interviewee went on to add:

A woman here died and left her 10 kids, four of whom were also reactive. We are just saddened that we cannot help all of them as the kids resorted to eating scraps here and there. The last of those four kids also died last week. Before now, we also had “*plumpy nuts*” that was a nutritional supplement that come with the drugs; sadly, such things are not available anymore and they were quite nutritious while we had them for these patients (UGH IDI, 28/10/21, *emphases added*).

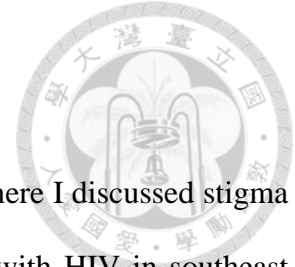
Deducing from the above statement, holistic ART health financing could have gone on to further boost retention drives among people who are already diagnosed with HIV/AIDS and enrolled in, HIV treatment services.

## **Conclusion**

I have shown in this chapter how the psychosocial health of YPLHIV is affected by their inability to find intimate relationships; and the roles that finance and nutrition play on further worsening their mental health. Notwithstanding these shortcomings, however, an interesting phenomenon emerges at this point in the study, which shows how these patients have weaved a strong web of adherence mechanisms that, increasingly, helped them continue their treatment uptakes. It is the idea of *sero-kinship*, which will be showcased in the next chapter. I theorize it to be the *thread* holding most of the YPLHIV together and helping them navigate the associated mental health difficulties relating to their serostatus.

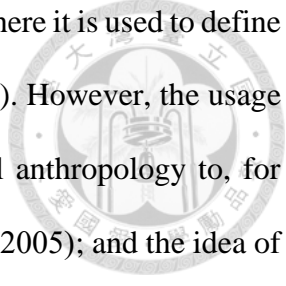
## Chapter Five.

### Sero-Kinship among YPLHIV



This final analytical chapter builds up from the last two preceding ones where I discussed stigma and the overall mental health of young people aged 20-30 years living with HIV in southeast Nigeria. Despite the effects of mental health issues (e.g., fear of disclosing status to others, appointment skipping, intentional drug under-dose) existing among the participants, the HIV positive young adults, nonetheless, continue to show strong clinical resilience and devotion to their treatment regimen. This idea of *trying* to find ways to live with HIV despite all the frailties associated with its treatment in Nigeria (already evaluated in detail in the preceding two chapters) is what I conceptualize as *sero-kinship* in this study.

On its own, kinship is a *précis* term that both medical sociologists and medical anthropologists have long theorized in research; here, it connotes the significance of social life in relation to group therapy or survivorship. Additionally, sero-kinship is further located in the conceptual context of “necrosecurity”, proposed by Martha Lincoln (2021). As a medical anthropologist, in her seminal study of the COVID-19 pandemic in the United States, Lincoln (2021) explores the idea of “managing shared existential dangers” (p. 46) especially by the US government’s “attempts to secure life by allowing death to flourish selectively” (p. 50). She conceived necrosecurity as emerging, firstly from Foucault’s idea of “*biopower*,” and subsequently, Achille Mbembe’s challenge of this Foucauldian notion by reconceptualizing it into necropower (i.e., entailing power to decide over another’s life and death). Presently, I only rely on this idea to understand how these *shared existential dangers* (HIV) *are managed* in relation to HIV *survivorship* in Nigeria, by comparing it with COVID-19 in the US context.



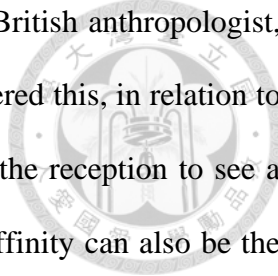
Conceivably, *kinship*, as a term, has strong roots in cultural anthropology, where it is used to define intersecting social relationships between individuals in society (Holy, 1996). However, the usage of the term has also long shifted from the domains of social and cultural anthropology to, for example, the politics of “optimal size,” in political anthropology (Hammel, 2005); and the idea of reciprocal altruism, in the anthropology of religion (MacIntyre, 2004). Kinship has also been applied to describe how people with mental health challenges navigate complex social dynamics with kin relationships forming the mainstay of support in the situations in which state services are weak, such as in urban South Africa (MacGregor, 2018). Both Lincoln’s “shared existential dangers” (2021), and MacGregor’s “intersection between mental health and kinship” (2018), therefore, set notional precedence for me to also associate *kinship* in my study of the mental health of young people living with HIV/AIDS.

Operationally, hence, *sero-kinship*, as proposed in this study, derives from bodily fluids diagnostics for antibodies—more formally known as *serological testing*, through which the HIV antigen is identified in the body. To follow, the kin-relation is captured by the web of social relationships existing among a group of people (*kin*) who are, in this case, *seropositive* (i.e., tested positive for the HIV antigen). I take this extra care to explain what this new term, “sero-kinship,” means in the context of this study, to describe an important phenomenon discovered during the data collection with the recruited participants.

### **The Idea of *Clinical Affinity***

To better understand the idea of sero-kinship, I need to introduce another term, *clinical affinity*, which designates the *bonding* between two or more individuals who share a similar or relatable clinical condition (in this case, HIV); it could also be thought of as an un/natural relationship that emerges between a physician, caregiver(s), and a patient(s) which becomes an integral part of the





treatment process. Hence, it is akin to the *forging of relatedness* that the British anthropologist, Janet Carsten (2000), employed in her study of kinship. I have also considered this, in relation to the exchange of pleasantries between two individuals who are waiting at the reception to see a physician and may have had no prior knowledge of each other. Clinical affinity can also be the exchange of looks between two pregnant women as they are wheeled separately into different labor rooms, recognizing, between them, “a shared experience,” in their contractions. Or it is even the “We-Are-In-This-Together” nods of sympathy between two bald cancer patients in the chemotherapy room. Words may not necessarily be exchanged, yet each recognizes in the other a *shared experience* that unites them. Therefore, where this *bonding* or *exchange* is sustained, formed by and for the people involved, a tendency to commit to their treatment regimen is forged, as I have learned from my study participants. This would be amply demonstrated below.

Thus, clinical affinity is an important feature of the sero-kinship between young seropositive people in Enugu, southeast Nigeria. As to why I theorized such behaviors to be *sero-kinship* and not, say, “acts of friendship” or “solidarity action” between two *surviving* individuals, it is because, for the YPLHIV, they are not saddled with the discomforting thoughts of disclosing their status to one another since the *one*, is already aware of the HIV status of the *other*. Hence, there are no pretensions to the nature of the relationship, which springs from the notion that: we can help each other in surviving.

Relating from the above, an *affine*, in cultural anthropology, is one related to the other by marriage (Murphy, 2021; Weller, 1981). In this study, I make an extension of this definition to capture the meaning conveyed by the relationship that exists when two or more individuals are *married* to the same health condition. In its simplistic form, this is exactly what *clinical affinity* is all about. Both the focus group discussants and the ART clinicians interviewed are *related* due to some aspects of

their serostatus condition that further convey this meaning. For example, when the discussants were asked if they feel sad or happy whenever they miss their appointments, the respondents at ESUTH all echoed “sad!” Asking them why they felt so, one, female aged 30 years, replied:

I feel more relaxed when they give me my drugs; also, *being here gives me the opportunity to interact and mix more with other people like me* (R2, ESUTH FGD, 29/10/21, *emphasis mine*).

The opportunity to interact and mix more “with other people like me *here*” when she comes for her ART appointments at the health facility is evidence of the idea of clinical affinity. R2’s comment above becomes even more relatable when we examine her answer to an earlier question about whether she feels lonely, depressed, or rejected because of her serostatus. She provided us with an additional narrative which I consider helpful in further substantiating these abstract concepts, when explaining that:

Sometimes at home, yes, *I feel lonesome and rejected...*and I am still having the pains. For example, in terms of marriage, I would have been married and happily wedded a long time ago; but when my suitors...learn about my status...they run away. Nobody, not even my siblings who visited me earlier get to visit me again because of my status (R2, ESUTH FGD, 29/10/21, *emphasis mine*).

Coming to the health facility, therefore, is her way to escape the depressive conditions at “home”, where she is periodically confronted with the sadness of being out of the dating circle of seronegative suitors. Hence, her earlier response that “being here [at the health facility] gives me the opportunity to interact and mix more with other people like me” is proof her dependency on others (*clinical affines*) who share similar serostatus as hers, helps her negotiate through her treatment and maintain her viral load suppression (VLS) drive. Again, at UGH, another respondent, male aged 29 years, who was also responding to the question of sadness or happiness over missing his ART appointment, responded thus:

I feel sad whenever I miss my appointment because those are the same days I meet some of my friends who also come here to take their drugs (R1, UGH FGD, 28/10/21).

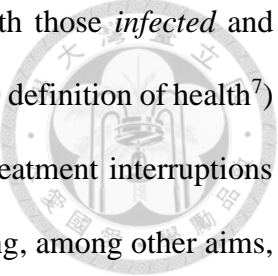
It is important for us to understand that these “friends” of his are equally people who are either the service providers at the health facility or other seropositive patients who come to the same health facility also to receive treatment for HIV. I group all of them as his sero-kins.

The foregoing are not the only examples that help us better understand the idea of *clinical affinity* as it exists among *sero-kins*. Consider also what this 30-year-old female respondent at EEGH says when asked about her experiences encountering unfriendly reactions from others because of her serostatus? She recalls:

One of the days when I came here to this clinic, I met someone I know; I was in distress...but eventually, it turned out he was also HIV positive and that has calmed me down more. Otherwise, *I don't know what I would have done...* (R1, EEGH FGD, 3/12/21, *emphasis mine*).

As I observed at the respective health facilities, PLHIV, on clinic days, are seen “reserving” seats for one another in a crowded waiting lounge at the hospital, making small talks, doing *group thinking*, and oftentimes, offering each other a ride back home in their vehicles or motorcycles, and functioning, overall, as a closed group. They *feel safe among themselves* because entry into this group is limited to *kins* or *affines* who are either HIV positive, or involved in their treatment provision services, such as the clinicians. This “sense of safety,” therefore, between two or more people who share similar health conditions should be thoroughly encouraged among seropositive people to help them counter some of the suicidal ideas associated with their serostatus. This idea forms the next section of this discourse.

### **Disease, Loneliness, Togetherness, Hope**



HIV is a disease that exerts hard mental health costs on the sufferers (both those *infected* and *affected* by it). Without a holistic spectrum of care (consistent with the WHO definition of health<sup>7</sup>) involving sufficient mental health provision to all involved, the spate of treatment interruptions would, undoubtedly, continue to stultify the UNAIDS 2030 goal of achieving, among other aims, 95% viral load suppression among the global seropositive population (see UNAIDS, 2020). If mental health remains ignored, viral loads among YPLHIV might continue to increase. A concerted effort by all involved in the treatment process should, therefore, be optimized. The UNTH clinician so interviewed about the clinician’s views on bridging these unmet mental health gaps faced by the young seropositive adults of Enugu state, reaffirms that this:

Issue of teamwork...needs to be significantly improved on [across board] because in teamwork, if this person does not do this [addressing our patients’ mental health needs, for example] and there is a gap, some other person tries to fill it immediately; so, it reduces burnouts and stagnation in the workflow. Even the cleaner, gateman, and all of us here are all important for the mental health needs of our patients. It is a concerted effort, and we need to keep improving on them continuously... (IDI UNTH, 21/12/21).

This “togetherness” is a call to action, especially in these days of the COVID-19 pandemic, which competes for available resources due to the unprecedented speed of its spread among persons across the world (see United Nations, 2022). Consider, therefore, what this pandemic means for Nigeria, where donor funds (which hitherto accounted for most of the HIV funding in the country) have now shifted to COVID-19 financing to curtail its spread. As Oladele and colleagues (2020) demonstrated in their findings, the intended consequence is that HIV incidence and treatment

---

<sup>7</sup> According to the World Health Organization (WHO) Constitution which was adopted by the International Health Conference held in New York from 19 June to 22 July 1946, signed on 22 July 1946 by the representatives of 61 States and entered into force on 7 April 1948, they defined health as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (WHO, 1946).

interruption across the country might, they say, record an increase. One hopes this does not become the case.

Regarding this grasp on *hope*, the respondents entrusted their most intimate information to me *with the hopes that* it would help improve the overall treatment condition of PLHIV in Enugu state. On this “trust”, I have also acted as *their sero-kin*; to speak through their voices as one who is interested in seeing an uptake in HIV services in Nigeria by improving the mental health conditions of its survivors.

Finally, I consider it important to mention that the idea of “*sero-kinship*” was only observed in a limited setting—within the clinical environment only. One of the limitations of this present study, however, regards the uncertainty concerning the extension and continuity of such *bonding* between the PLHIV outside of the hospital. And, even if so, the nature of such relationships outside (i.e., whether the relationship outside of the clinical setting compromise “kinship” as theorized here) remains unaddressed. For example, do they provide post-clinical counseling to one another (especially the newly diagnosed who are still struggling to come to terms with their serostatus)? Or do they equally form an “adherence group” reminding each other, for example, about their subsequent ART appointments, ARVs intake, and so on? We do not know at this stage of the study. However, one other interesting observation bears noting: oftentimes, in the clinical setting, PLHIV provide co-counseling services with the ART clinicians for other seropositive people with psychosocial support needs. When I asked the clinicians during the IDI how they would counsel a seropositive person with suicidal ideations? At UGH, the interviewee notes:

[Here at Udi General Hospital] we have peer groups we match with each other (we call them *survivors*), and they are usually the ones who share their stories with the rest and inspire them in peer education. We have, sadly, had a guy who drank *sniper* (mosquito repellent!) when he was told his HIV status was reactive. He was a young graduate. However, this story further inspires the young ones (to continue

treatment) than frightens them. At least, that's my opinion on the matter. Honestly, the best approach for us is to invite them into meetings—support group meetings—and merge them with the others who are already on treatment (UGH IDI, 28/10/21, *emphases added*).

Note the interviewee's opinion that such "support group meetings" serves an important need for those requiring additional psychosocial support. I theorize that it is equally possible that this practice further strengthens these patients to foster new relationships among themselves, which is essentially what the concept of *sero-kinship*, as I have earlier argued, is all about. At ESUTH, the IDI respondent also answered similarly:

Here, for a patient that has a suicidal idea, usually, we normally bring other patients that are taking drugs, *especially the treatment supporter team*, to talk with them; we also tell them that *this* is not the end of their lives—that having HIV is not a death sentence. We also show them some of our workers that are on treatment who go on to lead *normal lives* and have gone on to continue achieving their potentials; we also link them up to support groups where they can be getting support from others.

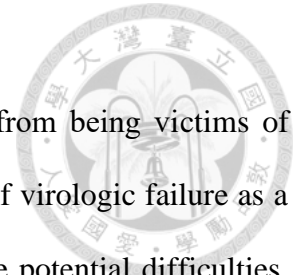
Continuing about what the "support groups" so mentioned consist of:

[The] support group...is made up of people living with HIV who (male and female) come together, monthly, to discuss about issues that pertain to *them* and find a way to make their lives easy. It happens once a month, and the turn-up is quite reasonable, with as many as 30-50 persons turning up every month for the activity. *I strongly believe support groups have improved ART services in this facility* because some patients that had earlier withdrawn from treatment, through such support group meetings, have been able to return to treatment and develop more self-confidence (ESUTH IDI, 29/10/21, *emphases mine*).

I now conclude by letting the reader know that some of the young PLHIV in Enugu state also work as volunteers at the ART clinics. Some of them noted that they were unpaid, but are relentless, nonetheless, in using the opportunity to "assist themselves" and hope that the government would recognize such services and formally incorporate them as staff at the clinics. They argue that *patients-as-service-providers* might overturn aspects of the clinical-related abuses that PLHIV suffer at the health facilities (such as patient delays at the clinics, discrimination from seronegative staff, and so on). However, the merits of this argument are not part of this present study.

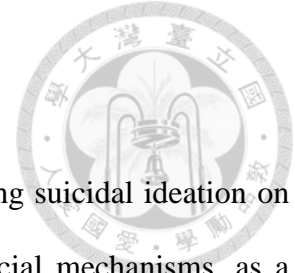
## Conclusion

In this analytical section, we followed the young PLHIV's experience from being victims of stigmatization because of their serostatus, to becoming potential victims of virologic failure as a result of their unmet nutritional and financial needs. Yet, amidst all these potential difficulties, they have strengthened their resolve to continue their treatment processes by weaving a new form of interconnectedness (called "sero-kinship"). Therefore, their individual aspirations become further enmeshed in this novel form of clinical collectivism, that is primarily aimed at viral load suppression.



## Chapter Six.

### Conclusion and Recommendations



In this research, I have presented the issue of HIV and mental health, using suicidal ideation on the one hand, as an exploratory metric; and on the other, the psychosocial mechanisms, as a theoretical framework to understand how seropositive young people, aged 20-30 years in Enugu state, southeast Nigeria, are affected by the disease. The HIV impact assessment study of the Federal Ministry of Health (2018) had found that young adults 15-49 years old in Enugu have an HIV prevalence rate of 1.9%, higher than the national average of 1.3%. I, therefore, focused on a subset of this population who receive antiretroviral therapies at four of the ART-providing health facilities in the state (EEGH, ESUTH, UGH, and UNTH), with a known history of treatment interruptions (either as missed appointments or loss-to-follow-up patients). To do so was to explore whether these treatment interruptions might have been a factor of their *unmet* psychosocial health needs.

Using focus group discussions and in-depth interviews with 24 respondents (20 FGDs & 4 IDIs) spread across the four study sites, I understood that YPLHIV in the state suffer stigmatization from others (who are not HIV positive like them), such as close family members, friends, and in some cases, their service providers at the health facilities. Given all of these, they lose ties with some of their social circles and become lonely, depressive, and sometimes, *feel* dejected, because of their serostatus.

In addition, the costs of transportation to their respective clinical appointments and lingering nutritional gaps further exacerbate the risks of virologic failure among these patients. Yet,



notwithstanding all of these, these young adults have retained a *forging of relatedness*<sup>8</sup> between themselves, which has helped them commit to their treatment regimens. Moreover, as the UNAIDS ambition to achieve ~95% viral load suppression among the global HIV population approaches (by 2030), it is now more imperative<sup>9</sup> than ever to expedite all actions vital to Nigeria also becoming successful in this stride. These, therefore, form the kernel of my recommendations.

### **Recommendations for the Nigerian Health Authorities**

Drawing on this study, I have three recommendations for both mental and sexual health authorities.

1. Stigma, prejudice, and discrimination against young people living with HIV in Enugu state are increasing causes of mental health breakdowns that these vulnerable populations suffer, both within and outside the clinical environments. Therefore, there is a heightened need to expand the counselling units of the HIV Testing Services (HTS) of health facilities in Enugu to accommodate properly-trained counseling psychologists who can better *prepare* the patients to *last through their treatment cycle*. Some patients (as have been confirmed during this research) are not yet mentally prepared to understand that their treatments (e.g., ARV intake, meeting up appointments, CD4 counts, etc.) would remain a lifelong process (until at least, a lasting cure for HIV has been found). Understandably, health professionals in Nigeria are not adequate to cater to the needs of the population, but that should not

---

<sup>8</sup> A term I borrowed from the British anthropologist, Janet Carsten in her epic “Cultures of Relatedness: New Approaches to the Study of Kinship” (2000), to explain how the idea of *clinical affinity* (i.e., the “forging of relatedness” between two or more individuals who share similar or relatable clinical conditions) is embedded in the larger theme of *sero-kinship* which I conceptualized in this study, as denoting the web of social relationships that exist among a group of people who are HIV positive.

<sup>9</sup> Regarding this “urgency,” it is also worth mentioning, here, that a full *critique of the HIV cascading framework* in Nigeria to better understand how all other issues, besides *psychosocial health*, contribute to declining viral load status among YPLHIV, would make for a greater starting point to a holistic reimagining of the HIV programming space in the country. Understandably, this is a farther-reaching scope that is beyond the framing of the present study. Future research along these lines is therefore, highly encouraged.

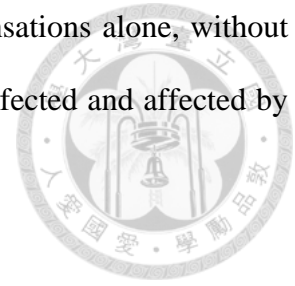
further impugn the need to train the ones available to match up to the pressing demands of the country's health economy (see the arguments of Abubakar et al., 2022).

2. Where evidence for its use has been proved, PLHIV with credible educational backgrounds and *sustained* viral load suppression history (i.e., < 1000 copies/mL of the HIV antigen in their body over time) should be placed under the employ of the government as *critical assets* vital for the viral load suppression (VLS) goals of the country. This is because of the following reasons:

- i. They have been shown to be instrumental in assisting the service providers as *quasi-counselors* for members of their cohorts who have demonstrated clinical restraints in committing to their treatments by, for example, sharing their own personal experiences with the treatment as a way of motivating others *not to give up* even as they face deeply rooted personal challenges.
- ii. They might be more motivated to serve the needs of their fellows who, in the hands of some other seronegative staff, are subject to clinical abuses.

3. I have successfully argued that *sero-kinship* plays an important role in supporting and promoting better clinical outcomes among YPLHIV; however, there are more ways its usefulness could be elaborated. For example, it should be further encouraged by practices such as promoting *intra-relationship-matching* between HIV patients who have shown interest in this, abuse-free clinical settings, and greater participation by everyone involved in the entire clinical spectrum—from the gate security to the backstop staff behind the RADET computer monitors—in order to further expand this “web of social relations” by making it more sustainable, and useful, both within and outside of the clinical environment. As I have demonstrably shown in this research, the HIV treatment process should be

holistic and not merely centered around drug scripting and dispensations alone, without sufficient regard for the wellbeing of the mental health of those infected and affected by HIV.

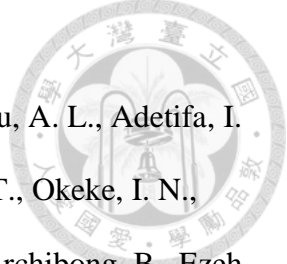


### **Limitations of the Study**

This study was conducted mainly in 2021, a COVID-19 pandemic year in Nigeria following its declaration in the country as a “health emergency” of great concern by the Federal Government (see NCDC, 2022). It follows then, therefore, that this prevalent emergency may have also contributed to the increasing interruptions in treatment recorded among YPLHIV in Enugu state, thereby influencing the “tone” of some of the research respondents as “intrinsically negative” toward their treatment. Expectedly, the outcomes may have been different without the prevailing circumstances of the COVID-19 situation at the time of the study. Therefore, more research in this field—the intersection between mental health and HIV—in the future (when the pandemic situation can be significantly shown to have ceased to affect the Nigerian healthcare industry) is further encouraged.

Secondly, and most importantly, I did mention that the idea of *sero-kinship* was only observed within the clinical environments. Therefore, it is presently unknown what nature this “web of social relationships” assumes outside of the health facilities among YPLHIV. Is it continuous or dismantled? Does it produce new meanings to people who are, and are not, involved in the network? This present study cannot satisfactorily answer these questions at this time. Hence, the need to further explore this field is vital for its grounding in social medicine.

## References

- 
- Abubakar, I., Dalglish, S. L., Angell, B., Sanuade, O., Abimbola, S., Adamu, A. L., Adetifa, I. M. O., Colbourn, T., Ogunlesi, A. O., Onwujekwe, O., Owoaje, E. T., Okeke, I. N., Adeyemo, A., Aliyu, G., Aliyu, M. H., Aliyu, S. H., Ameh, E. A., Archibong, B., Ezeh, A., . . . Zanna, F. H. (2022). The Lancet Nigeria Commission: investing in health and the future of the nation. *The Lancet*, *399*(10330), 1155–1200. [https://doi.org/10.1016/s0140-6736\(21\)02488-0](https://doi.org/10.1016/s0140-6736(21)02488-0)
- Adjetey, V., Obiri-Yeboah, D., & Dornoo, B. (2019). Differentiated service delivery: a qualitative study of people living with HIV and accessing care in a tertiary facility in Ghana. *BMC Health Services Research*, *19*(1), n/a. <https://doi.org/10.1186/s12913-019-3878-7>
- Agu, I. C., Mbachu, C. O., Okeke, C., Eze, I., Agu, C., Ezenwaka, U., Ezumah, N., & Onwujekwe, O. (2020). Misconceptions about transmission, symptoms and prevention of HIV/AIDS among adolescents in Ebonyi state, South-east Nigeria. *BMC Research Notes*, *13*(1). <https://doi.org/10.1186/s13104-020-05086-2>
- Atanuriba, G. A., Apiribu, F., Boamah Mensah, A. B., Dzomeku, V. M., Afaya, R. A., Gazari, T., Kuunibe, J. K., & Amooba, P. A. (2021). Caregivers' Experiences with Caring for a Child Living with HIV/AIDS: A Qualitative Study in Northern Ghana. *Global Pediatric Health*, *8*, n/a. <https://doi.org/10.1177/2333794x211003622>
- Carsten, J. (2000). *Cultures of Relatedness: New Approaches to the Study of Kinship* (Illustrated ed.). Cambridge University Press.
- Chaudoir, S. R., Earnshaw, V. A., & Andel, S. (2013). “Discredited” Versus “Discreditable”: Understanding How Shared and Unique Stigma Mechanisms Affect Psychological and

Physical Health Disparities. *Basic and Applied Social Psychology*, 35(1), 75–87.

<https://doi.org/10.1080/01973533.2012.746612>

Cherry, K. (2020, June 26). *Understanding Erikson's Stages of Psychosocial Development*.

Verywell Mind. Retrieved May 2, 2021, from [https://www.verywellmind.com/erik-](https://www.verywellmind.com/erik-eriksons-stages-of-psychosocial-development-2795740#citation-1)

[eriksons-stages-of-psychosocial-development-2795740#citation-1](https://www.verywellmind.com/erik-eriksons-stages-of-psychosocial-development-2795740#citation-1)

Chihana, M. L., Conan, N., Ellman, T., Poulet, E., Garone, D. B., Ortuno, R., Wanjala, S.,

Masiku, C., Etard, J. F., Davies, M. A., & Maman, D. (2021). The HIV cascade of care

among serodiscordant couples in four high HIV prevalence settings in sub-Saharan

Africa. *South African Medical Journal*, 111(8), 768–776.

<https://doi.org/10.7196/samj.2021.v111i8.15489>

Chime, O. H., Arinze-onyia, S. U., & Ossai, E. N. (2019). Examining the effect of peer-support

on self-stigma among persons living with HIV/AIDS. *Pan African Medical Journal*, 34,

n/a. <https://doi.org/10.11604/pamj.2019.34.200.17652>

DiCarlo, A. L., Mantell, J. E., Remien, R. H., Zerbe, A., Morris, D., Pitt, B., Abrams, E. J., & El-

Sadr, W. M. (2014). 'Men usually say that HIV testing is for women': gender dynamics

and perceptions of HIV testing in Lesotho. *Culture, Health; & Sexuality*, 16(8), 867–882.

<https://doi.org/10.1080/13691058.2014.913812>

Dzinamarira, T., Pierre, G., Habtu, M., & Okova, R. (2019). Nutrition And HIV/AIDS: A

Qualitative Study on Perceived Factors Affecting Feeding Practices among Adult People

Living with HIV/AIDS in Kigali, Rwanda. *Nutrition & Food Science International*

*Journal*, 9(4), n/a. <https://doi.org/10.19080/nfsij.2019.09.555767>

Erikson, E. H. (1970). Autobiographic Notes on the Identity Crisis. *Daedalus*, 99(4), 730–759.

<http://www.jstor.org/stable/20023973>

Federal ministry of health, FMOH. (2018). *Nigeria HIV/AIDS indicator and impact survey (NAIIS) technical report*. UMB. <https://www.ciheb.org/PHIA>



Fitzpatrick, M. (2008). Stigma. *British Journal of General Practice*, 58(549), 294.1-294. <https://doi.org/10.3399/bjgp08x280092>

Fonner, V. A., Ntogwisangu, J., Hamidu, I., Joseph, J., Fields, J., Evans, E., Kilewo, J., Bailey, C., Goldsamt, L., Fisher, C. B., O'Reilly, K. R., Ruta, T., Mbwambo, J., & Sweat, M. D. (2021). "We are in this together:" dyadic-level influence and decision-making among HIV serodiscordant couples in Tanzania receiving access to PrEP. *BMC Public Health*, 21(1), 720. <https://doi.org/10.1186/s12889-021-10707-x>

Gilborn, L. Z. (2002). The effects of HIV infection and AIDS on children in Africa. *Western Journal of Medicine*, 176(1), 12–14. <https://doi.org/10.1136/ewjm.176.1.12>

Gilmore, N., & Somerville, M. A. (1994). Stigmatization, scapegoating and discrimination in sexually transmitted diseases: Overcoming 'them' and 'us.' *Social Science & Medicine*, 39(9), 1339–1358. [https://doi.org/10.1016/0277-9536\(94\)90365-4](https://doi.org/10.1016/0277-9536(94)90365-4)

Gizachew, K. D., Chekol, Y. A., Basha, E. A., Mamuye, S. A., & Wubetu, A. D. (2021). Suicidal ideation and attempt among people living with HIV/AIDS in selected public hospitals: Central Ethiopia. *Annals of General Psychiatry*, 20(1), xx. <https://doi.org/10.1186/s12991-021-00335-5>

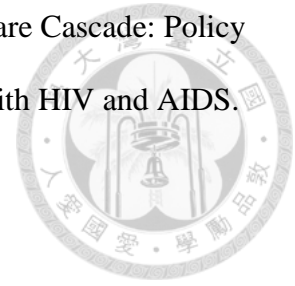
Goffman, E. (1986). *Stigma: Notes on the Management of Spoiled Identity* (Reissue ed.). Touchstone.

Hammel, E. A. (2005). Kinship-based politics and the optimal size of kin groups. *Proceedings of the National Academy of Sciences*, 102(33), 11951–11956. <https://doi.org/10.1073/pnas.0504647102>

Hillier, S. A., Winkler, E., & Lavallée, L. (2020). Decolonising the HIV Care Cascade: Policy and Funding Recommendations from Indigenous Peoples Living with HIV and AIDS.

*International Journal of Indigenous Health*, 15(1), 48–60.

<https://doi.org/10.32799/ijih.v15i1.34001>



Holy, L. (1996). *Anthropological Perspectives on Kinship (Anthropology, Culture and Society)*. Pluto Press.

Kay, E. S., Batey, D. S., & Mugavero, M. J. (2016). The HIV treatment cascade and care continuum: updates, goals, and recommendations for the future. *AIDS Research and Therapy*, 13(35). <https://doi.org/10.1186/s12981-016-0120-0>

Lavery, J. V., Boyle, J., Dickens, B. M., Maclean, H., & Singer, P. A. (2001). Origins of the desire for euthanasia and assisted suicide in people with HIV-1 or AIDS: a qualitative study. *The Lancet*, 358(9279), 362–367. [https://doi.org/10.1016/s0140-6736\(01\)05555-6](https://doi.org/10.1016/s0140-6736(01)05555-6)

Lightfoot, M., Rotheram-Borus, M. J., Milburn, N. G., & Swendeman, D. (2005). Prevention for HIV-Seropositive Persons. *Behavior Modification*, 29(2), 227–255.

<https://doi.org/10.1177/0145445504272599>

Lincoln, M. (2021). Necrosecurity, Immunosupremacy, and Survivorship in the Political Imagination of COVID-19. *Open Anthropological Research*, 1(1), 46–59.

<https://doi.org/10.1515/opan-2020-0104>

MacGregor, H. (2018). Mental Health and the Maintenance of Kinship in South Africa. *Medical Anthropology*, 37(7), 597–610. <https://doi.org/10.1080/01459740.2018.1508211>

MacIntyre, F. (2004). Was Religion a Kinship Surrogate? *Journal of the American Academy of Religion*, 72(3), 653–694. <https://doi.org/10.1093/jaarel/lfh063>

Malone, J. C., Liu, S. R., Vaillant, G. E., Rentz, D. M., & Waldinger, R. J. (2016). Midlife

Eriksonian psychosocial development: Setting the stage for late-life cognitive and emotional health. *Developmental Psychology*, 52(3), 496–508.

<https://doi.org/10.1037/a0039875>



Mbonu, N. C., van den Borne, B., & de Vries, N. K. (2009). Stigma of People with HIV/AIDS in Sub-Saharan Africa: A Literature Review. *Journal of Tropical Medicine*, 2009, 1–14.

<https://doi.org/10.1155/2009/145891>

McLeod, S. (2018, May 3). *Erik Erikson's Stages of Psychosocial Development*.

<https://www.simplypsychology.org/Erik-Erikson.html>. Retrieved April 26, 2022, from

<https://www.simplypsychology.org/Erik-Erikson.html>

Muoghalu, C. O., & Jegede, S. A. (2013). Perception of HIV/AIDS among the Igbo of Anambra State, Nigeria. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, 10(1), 1–13.

<https://doi.org/10.1080/17290376.2013.807052>

Murphy, M. D. (2021, November 3). *Kinship Glossary*. Anthropology. Retrieved May 10, 2022, from <https://anthropology.ua.edu/student-resources/kinship-glossary/>

Mutumba, M., Musiime, V., Tsai, A. C., Byaruhanga, J., Kiweewa, F., Bauermeister, J. A., &

Snow, R. C. (2015). Disclosure of HIV Status to Perinatally Infected Adolescents in Urban Uganda: A Qualitative Study on Timing, Process, and Outcomes. *Journal of the Association of Nurses in AIDS Care*, 26(4), 472–484.

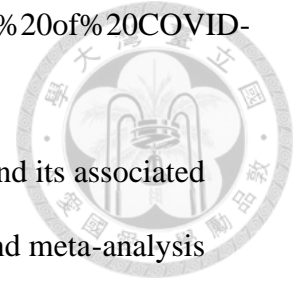
<https://doi.org/10.1016/j.jana.2015.02.001>

NCDC. (2022). *Nigeria Centre for Disease Control*. [Ncdc.Gov.Ng](https://ncdc.gov.ng). Retrieved May 18, 2022,

from



<https://ncdc.gov.ng/diseases/sitreps/?cat=14&name=An%20update%20of%20COVID-19%20outbreak%20in%20Nigeria>



Necho, M., Tsehay, M., & Zenebe, Y. (2021). Suicidal ideation, attempt, and its associated factors among HIV/AIDS patients in Africa: a systematic review and meta-analysis study. *International Journal of Mental Health Systems, 15*(1).

<https://doi.org/10.1186/s13033-021-00437-3>

Newman, B. M., & Newman, P. R. (2020). Psychosocial theories. *Theories of Adolescent Development, 149–182*. <https://doi.org/10.1016/b978-0-12-815450-2.00006-1>

Nutrition International. (2021, January 18). *Nigeria: Increasing development and productivity through better nutrition*. Retrieved May 23, 2022, from <https://www.nutritionintl.org/our-work/our-global-projects/africa/nigeria/>

Nyongesa, M. K., Nasambu, C., Mapenzi, R., Koot, H. M., Cuijpers, P., Newton, C. R. J. C., & Abubakar, A. (2022). Psychosocial and mental health challenges faced by emerging adults living with HIV and support systems aiding their positive coping: a qualitative study from the Kenyan coast. *BMC Public Health, 22*(1). <https://doi.org/10.1186/s12889-021-12440-x>

Oladele, T. T., Olakunde, B. O., Oladele, E. A., Ogbuaji, O., & Yamey, G. (2020). The impact of COVID-19 on HIV financing in Nigeria: a call for proactive measures. *BMJ Global Health, 5*(5), e002718. <https://doi.org/10.1136/bmjgh-2020-002718>

Ophinni, Y., Adrian, Siste, K., Wiwie, M., Anindyajati, G., Hanafi, E., Damayanti, R., & Hayashi, Y. (2020). Suicidal ideation, psychopathology and associated factors among HIV-infected adults in Indonesia. *BMC Psychiatry, 20*(1), n/a. <https://doi.org/10.1186/s12888-020-02666-1>

PEPFAR. (2019, September). *Monitoring, evaluation, and reporting indicator reference guide* (MER 2.0 (Version 24)). U.S. President's Emergency Plan for AIDS Relief.

Pescosolido, B. A., Martin, J. K., Lang, A., & Olafsdottir, S. (2008). Rethinking theoretical approaches to stigma: A Framework Integrating Normative Influences on Stigma (FINIS). *Social Science & Medicine*, *67*(3), 431–440.

<https://doi.org/10.1016/j.socscimed.2008.03.018>

Rankin, W. W., Brennan, S., Schell, E., Laviwa, J., & Rankin, S. H. (2005). The Stigma of Being HIV-Positive in Africa. *PLoS Medicine*, *2*(8), 702–704.

<https://doi.org/10.1371/journal.pmed.0020247>

Roy, M., Bolton Moore, C., Sikazwe, I., & Holmes, C. B. (2019). A Review of Differentiated Service Delivery for HIV Treatment: Effectiveness, Mechanisms, Targeting, and Scale. *Current HIV/AIDS Reports*, *16*(4), 324–334. <https://doi.org/10.1007/s11904-019-00454-5>

Salad, A. M., Mohamed, A., Da'ar, O. B., Abdikarim, A., Kour, P., Shrestha, M., & Gele, A. A. (2019). Sick and solo: a qualitative study on the life experiences of people living with HIV in Somalia. *HIV/AIDS - Research and Palliative Care*, *Volume 11*, 45–53.

<https://doi.org/10.2147/hiv.s185040>

Schlebusch, L., & Govender, R. D. (2015). Elevated Risk of Suicidal Ideation in HIV-Positive Persons. *Depression Research and Treatment*, *2015*, 1–6.

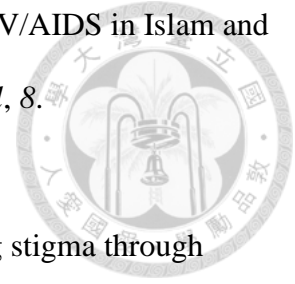
<https://doi.org/10.1155/2015/609172>

Seeley, J., Mbonye, M., Ogunde, N., Kalanzi, I., Wolff, B., & Coutinho, A. (2011). HIV and identity: the experience of AIDS support group members who unexpectedly tested HIV negative in Uganda. *Sociology of Health & Illness*, *34*(3), 330–344.

<https://doi.org/10.1111/j.1467-9566.2011.01384.x>

Speakman, S. (2012). Comparing the Impact of Religious Discourse on HIV/AIDS in Islam and Christianity in Africa. *Vanderbilt Undergraduate Research Journal*, 8.

<https://doi.org/10.15695/vurj.v8i0.3490>



Stutterheim, S. E., & Ratcliffe, S. E. (2021). Understanding and addressing stigma through qualitative research: Four reasons why we need qualitative studies. *Stigma and Health*, 6(1), 8–19. <https://doi.org/10.1037/sah0000283>

Syed, I. A., Syed Sulaiman, S. A., Hassali, M. A., Thiruchelvum, K., & Lee, C. K. (2014). A qualitative insight of HIV/AIDS patients' perspective on disease and disclosure. *Health Expectations*, 18(6), 2841–2852. <https://doi.org/10.1111/hex.12268>

Tucker, J. D., Tso, L. S., Hall, B., Ma, Q., Beanland, R., Best, J., Li, H., Lackey, M., Marley, G., Rich, Z. C., Sou, K. L., & Doherty, M. (2017). Enhancing Public Health HIV Interventions: A Qualitative Meta-Synthesis and Systematic Review of Studies to Improve Linkage to Care, Adherence, and Retention. *EBioMedicine*, 17, 163–171. <https://doi.org/10.1016/j.ebiom.2017.01.036>

UNAIDS. (2019, March 14). *New survey results indicate that Nigeria has an HIV prevalence of 1.4%*. Retrieved April 29, 2021, from [https://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2019/march/20190314\\_nigeria](https://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2019/march/20190314_nigeria)

UNAIDS. (2020, July 6). *UNAIDS report on the global AIDS epidemic shows that 2020 targets will not be met because of deeply unequal success; COVID-19 risks blowing HIV progress way off course* [Press release]. Retrieved April 30, 2021, from [https://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2020/july/20200706\\_global-aids-report](https://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2020/july/20200706_global-aids-report)

UNAIDS. (2021, March). *Putting people at the centre brings good results in Nigeria.*

[https://www.unaids.org/en/resources/presscentre/featurestories/2021/march/20210305\\_people-at-the-centre-nigeria](https://www.unaids.org/en/resources/presscentre/featurestories/2021/march/20210305_people-at-the-centre-nigeria)

United Nations. (2022, February 10). *Fast-spreading HIV variant doubles rate of immune system decline.* UN News. <https://news.un.org/en/story/2022/02/1111372>

van Luenen, S., Garnefski, N., Spinhoven, P., Spaan, P., Dusseldorp, E., & Kraaij, V. (2017).

The Benefits of Psychosocial Interventions for Mental Health in People Living with HIV: A Systematic Review and Meta-analysis. *AIDS and Behavior*, 22(1), 9–42.

<https://doi.org/10.1007/s10461-017-1757-y>

Vogel-Scibilia, S. E., McNulty, K. C., Baxter, B., Miller, S., Dine, M., & Frese, F. J. (2009). The Recovery Process Utilizing Erikson's Stages of Human Development. *Community Mental Health Journal*, 45(6), 405–414. <https://doi.org/10.1007/s10597-009-9189-4>

Weller, R. P. (1981). Affines, Ambiguity, and Meaning in Hokkien Kin Terms. *Ethnology*, 20(1), 15–29. <https://doi.org/10.2307/3773359>

WHO. (1946). *Constitution of the world health organization.* Who.Int. Retrieved June 9, 2022, from <https://www.who.int/about/governance/constitution>

WHO. (2003, May). *Nutrient requirements for people living with HIV/AIDS: report of a technical consultation, World Health Organization, Geneva, 13–15 May 2003.* World Health Organization.

<https://apps.who.int/iris/bitstream/handle/10665/42853/9241591196.pdf>

Wilson, P. A., Valera, P., Martos, A. J., Wittlin, N. M., Muñoz-Laboy, M. A., & Parker, R. G. (2015). Contributions of Qualitative Research in Informing HIV/AIDS Interventions

Targeting Black MSM in the United States. *The Journal of Sex Research*, 53(6), 642–654. <https://doi.org/10.1080/00224499.2015.1016139>

Winskell, K., Hill, E., & Obyerodhyambo, O. (2011). Comparing HIV-related symbolic stigma in six African countries: Social representations in young people's narratives. *Social Science & Medicine*, 73(8), 1257–1265. <https://doi.org/10.1016/j.socscimed.2011.07.007>

Winskell, K., Holmes, K., Neri, E., Berkowitz, R., Mbakwem, B., & Obyerodhyambo, O. (2015). Making sense of HIV stigma: Representations in young Africans' HIV-related narratives. *Global Public Health*, 10(8), 917–929. <https://doi.org/10.1080/17441692.2015.1045917>

World Bank Group. (2020, May 28). *Nigeria releases new report on poverty and inequality in country*. World Bank. Retrieved April 27, 2022, from <https://www.worldbank.org/en/programs/lsmis/brief/nigeria-releases-new-report-on-poverty-and-inequality-in-country>

# Appendix 1.

## NTU IRB



### 國立臺灣大學 行為與社會科學研究倫理委員會

Research Ethics Committee  
National Taiwan University  
No. 1, Sec. 4, Roosevelt Rd., Taipei, Taiwan 10617, R.O.C  
Phone: 3366-9956 Fax: 2362-9082  
審查核可證明

許可日期：2021年10月13日

倫委會案號：202108HS020

核可證明之有效期限：2021年10月13日至2022年10月12日

計畫名稱：奈及利亞東南部埃努古州年輕愛滋感染者自殺意念探討：質性探勘研究

校/院/系所/計畫主持人：國立臺灣大學/全球衛生碩士學位學程/研究生Elochukwu Ernest Uzim

計畫文件版本日期：【研究計畫書，2021年9月12日】、【知情同意書，2021年9月12日】、  
【招募文宣，2021年9月12日】、【訪談大綱，2021年9月12日】

上述計畫業於2021年10月13日通過國立臺灣大學行為與社會科學研究倫理委員會審查，符合研究倫理規範。本委員會的運作符合國立臺灣大學行為與社會科學研究倫理準則與規範及政府相關法律規章。

本案需經研究經費補助單位核准同意後，該計畫始得執行。

計畫主持人最遲應於本核可證明到期前的6周，提出持續審查申請表，本案需經持續審查，方可繼續執行。在計畫執行期間，若有計畫變更或嚴重不良反應事件，計畫主持人須依國內及國立臺灣大學相關法令規定通報本委員會。

行為與社會科學研究倫理委員會主任委員 鄭麗珍

Handwritten signature of Li-Chen Cheng in black ink.

### Ethical Review Approval National Taiwan University

Date of approval : October 13, 2021

NTU-REC No. : 202108HS020

Validity of this approval: from October 13, 2021 to October 12, 2022

Title of protocol : Suicidal Ideations among Young People Living With HIV/AIDS in Enugu State—Southeast Nigeria: A Qualitative Study

University/College/Department/Principal Investigator : National Taiwan University/Global Health Program, College of Public Health/MSc Student Elochukwu Ernest Uzim

Version date of documents : 【Research Protocol, September 12, 2021】 , 【Informed Consent Form, September 12, 2021】 , 【Recruitment Advertising, September 12, 2021】 , 【Focus Group Discussion Guide, September 12, 2021】

The protocol has been approved by the Research Ethics Committee of National Taiwan University and has been classified as expedited on October 13, 2021. The committee is organized under, and operates in accordance with, Social and Behavioral Research Ethical Principles and Regulations of National Taiwan University and governmental laws and regulations.

Approval by funding agency is mandatory before project implementation.

Continuing Review Application should be submitted to Research Ethics Committee no later than six weeks before current approval expired. The investigator is required to report protocol amendment and Serious Adverse Events in accordance with the National Taiwan University and governmental laws and regulations.

Chairperson Li-Chen Cheng  
Research Ethics Committee

Handwritten signature of Li-Chen Cheng in black ink.

Appendix 2.

Ministry of Health, Enugu, IRB



**ENUGU STATE MINISTRY OF HEALTH  
RESEARCH ETHICS COMMITTEE**



Ref. No.: MH/MSD/REC21/213  
Date: 29<sup>th</sup> June 2021.

The Reseacher,  
Elochukwu <sup>Uzima</sup> ~~Izum~~,  
Global Health Program,  
College of Public Health,  
National Taiwan University,  
Taiwan.

Sir / Ma,

**Re: Suicidal Ideations Among Young People Living With HIV / AIDS in Enugu State, Southeast Nigeria – A Qualitative Study**

I refer to your request for permission to carry out a study / research on the above health issue and to inform you that approval has been granted to you.

**Ethical Guideline**

1. You are to keep to the principles of informed consent by obtaining a signed/ thumb printed informed consent of subjects, parents/ legally accepted representative.
2. You are to deposit one (1) copy of the result of your study to the research ethics committee of the State Ministry of Health.

A handwritten signature in black ink, appearing to read 'Ifeanyi Godwin Chukwu', is written over the ethical guidelines.

**Dr Ifeanyi, Godwin Chukwu.**  
**Chairman,**  
**Research Ethics Committee.**

### Appendix 3.

#### Research Participation Consent for Focus Group Discussion



**Lead Discussant reads:**

**What language do you prefer for our discussion today?**

...English

...Igbo

#### **Suicidal Ideations among Young People Living with HIV/AIDS in Enugu State, Southeast Nigeria.**

Hello. My name is **Elochukwu Uzim**. I would like to invite you to take part in this focus group discussion (hereafter FGD) about HIV and mental health in Nigeria. It is a core part of my thesis research at the National Taiwan University, Taipei, Taiwan.

#### **Purpose of the FGD**

This FGD will help us know how to support the mental health of young PLHIV in Nigeria who have HIV and need mental health support services. It will also tell us about people's risks for developing mental health issues injurious to their antiretroviral drugs intake. We plan to invite about 6 participants to take part in this FGD. If you take part, you will help make mental health services better in the country.

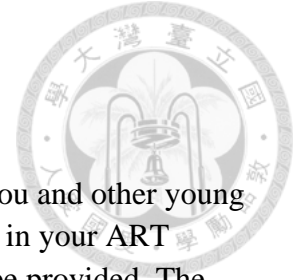
#### **FGD Procedure**

If you agree to take part in this FGD, you will be invited to take part in about two hours' (maximum) discussion during which we will ask you some questions related to your mental health. These discussions will be recorded (and later transcribed) without any direct mention of your actual name(s) in order to preserve your anonymity.

#### **Potential Risks/Discomfort**

Some of the questions may make you feel uncomfortable. You are free to skip a question and continue. The information you provided will be protected in a secure place by the Principal Investigator. Access to the information will be minimized and limited to ONLY persons directly involved in this research (in this case, my thesis supervisor in Taiwan).





### **Potential Benefits**

You may or may not benefit by taking part in this study. If you take part, you and other young PLHIV may directly benefit from improved mental health support services in your ART facilities. In addition, a light refreshment (such as snacks and drinks) will be provided. The answers you give is expected to help improve the health services of young Nigerians living with HIV.

### **Alternative to Taking Part**

Your alternative is not to take part. If you choose not to take part, no direct harm or charges will be brought upon your person. Participation is completely voluntary and free.

### **Costs to Person Taking Part in the FGD**

It will not cost you anything to take part in this study other than your time.

### **Payment to Person Taking Part in the FGD**

You will not receive any payment for taking part in this FGD.

### **Confidentiality and Access to Records**

Maximum efforts will be made to protect your personal information and your responses to the FGD. An alternative name will be used instead of your name to identify the responses you give. Any answers included in the final report will not have your name or personal details on it. The information we collect from you will not be released outside of the Principal Investigator and his supervisor in Taiwan. If you feel any concerns towards your safety or violations of the confidentiality agreement, please contact:

Enugu State Ministry of Health,  
Research Ethics Committee,  
State Ministry of Health Complex,  
PMB 1034, Enugu, Enugu, Nigeria.  
Phone: 042-255642; +234-8035580802

**OR**

Federal Ministry of Health,  
Federal Secretariat Complex Shehu  
Shagari Way,  
Garki, Abuja  
P.M.B. 083 Garki Abuja  
Tel: +234-803-586-8293  
E-mail: info@nhrec.net



### **Refusal to Take Part and Right to Withdraw**

Your taking part in this FGD is voluntary. You do not have to take part in this FGD. You are free to change your mind at any time and stop taking part. Refusal to take part or stopping to take part will not affect the health services you or any member of your household already receive at the ART clinics. If you decide not to take part or stop taking part, we will ask your permission to give us the reasons and the information you gave will not be included in analysis.

### **Removal from Research**

The Principal Investigator in charge of this research can remove any part of your response that is not related to this research without your consent. We will notify you if this happens. You will have a chance to ask questions.

### **Do you want to ask me anything about the survey?**

### **Consent Statement**

I have read this form and/or someone has read it to me. I was encouraged to ask questions and given time to ask questions. Any questions that I had have been answered satisfactorily. I agree to take part in this FGD. I know that after choosing to be in the FGD, I may withdraw at any time. My taking part is voluntary. I have been offered a copy of this consent form.

Do you agree to do the FGD? 'YES' means that you agree to do the discussion. 'NO' means that you will NOT do the discussion.

\_\_\_\_\_Yes \_\_\_\_\_No

Name of participant \_\_\_\_\_ Date: \_\_\_\_/\_\_\_\_/2021

**[For illiterate participants]**

Signature of witness \_\_\_\_\_

Date: \_\_/\_\_/2021

Printed name of witness: \_\_\_\_\_



Signature of person obtaining consent \_\_\_\_\_

Date: \_\_/\_\_/2021

Printed name of person obtaining consent:

\_\_\_\_\_

## Appendix 4.

### Research Participation Consent for In-Depth Interview



**Lead Discussant reads:**

**What language do you prefer for our discussion today?**

...English

...Igbo

### **Suicidal Ideations among Young People Living with HIV/AIDS in Enugu State, Southeast Nigeria.**

Hello. My name is **Elochukwu Uzim.** I would like to invite you to take part in this in-depth interview (hereinafter IDI) about HIV and mental health in Nigeria. It is a core part of my thesis research at the National Taiwan University, Taipei, Taiwan.

#### **Purpose of the IDI**

This IDI will help us know how to support the mental health of young PLHIV in Nigeria who have HIV and need mental health support services. It will also tell us about people's risks for developing mental health issues injurious to their antiretroviral drugs intake. If you take part, you will help make mental health services better in the country.

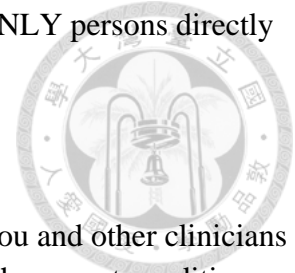
#### **IDI Procedure**

If you agree to take part in this IDI, you will be invited to take part in about two hours' (maximum) discussion during which I will ask you some questions related to your understanding of mental health support/services for young people living with HIV in Enugu State. These discussions will be recorded (and later transcribed) without any direct mention of your actual name(s) in order to preserve your anonymity if you so prefer. Else, your name will be used.

#### **Potential Risks/Discomfort**

Some of the questions may make you feel uncomfortable. You are free to skip a question and continue. The information you provided will be protected in a secure place by the Principal

Investigator. Access to the information will be minimized and limited to ONLY persons directly involved in this research (in this case, my thesis supervisor in Taiwan).



### **Potential Benefits**

You may or may not benefit by taking part in this study. If you take part, you and other clinicians involved in ART services may directly benefit from improved mental health support conditions for young PLHIV in your facilities. In addition, a light refreshment (such as snacks and drinks) will be provided.

### **Alternative to Taking Part**

Your alternative is not to take part. If you choose not to take part, no direct harm or charges will be brought upon your person. Participation is completely voluntary and free.

### **Costs to Taking Part in the IDI**

It will not cost you anything to take part in this study other than your time.

### **Payment to Person Taking Part in the IDI**

You will not receive any payment for taking part in this IDI.

### **Confidentiality and Access to Records**

Maximum efforts will be made to protect your personal information and your responses to the IDI. An alternative name (if you so prefer) will be used instead of your name to identify the responses you give. Any answers included in the final report will not have your name or personal details (should you so prefer) on it. The information we collect from you will not be released outside of the Principal Investigator and his supervisor in Taiwan. If you feel any concerns towards your safety or violations of the confidentiality agreement, please contact:

Enugu State Ministry of Health,  
Research Ethics Committee,  
State Ministry of Health Complex,  
PMB 1034, Enugu, Enugu, Nigeria.  
Phone: 042-255642; +234-8035580802

**OR**

Federal Ministry of Health,  
Federal Secretariat Complex Shehu  
Shagari Way,  
Garki, Abuja  
P.M.B. 083 Garki Abuja  
Tel: +234-803-586-8293  
E-mail: info@nhrec.net



### **Refusal to Take Part and Right to Withdraw**

Your taking part in this IDI is voluntary. You do not have to take part in this IDI. You are free to change your mind at any time and stop taking part. Refusal to take part or stopping to take part will not affect the health services you or any member of your household already provide at the ART clinics. If you decide not to take part or stop taking part, we will ask your permission to give us the reasons and the information you gave will not be included in analysis.

### **Removal from Research**

The Principal Investigator in charge of this research can remove any part of your response that is not related to this research without your consent. We will notify you if this happens. You will have a chance to ask questions.

**Do you want to ask me anything about the survey?**

### **Consent Statement**

I have read this form and/or someone has read it to me. I was encouraged to ask questions and given time to ask questions. Any questions that I had have been answered satisfactorily. I agree to take part in this IDI. I know that after choosing to be in the IDI, I may withdraw at any time. My taking part is voluntary. I have been offered a copy of this consent form.

Do you agree to do the IDI? 'YES' means that you agree to do the interview. 'NO' means that you will NOT do the interview. \_\_\_\_\_Yes \_\_\_\_\_No

Name & signature of participant \_\_\_\_\_ Date:  
\_\_\_\_/\_\_\_\_/2021

---

Printed name, date & signature of person obtaining consent:

## Appendix 5.

### Recruitment Poster



### Research Volunteers Needed for Study on Mental Health and Infectious Disease

Nation  
al  
Taiwa  
n  
Univer  
sity

Are you interested in contributing to the improvement of the mental health of young people living with HIV/AIDS in Nigeria? Do you identify as a member of this seropositive population and wish to see your mental health support merit more attention as part of your clinical care? If **YES**, then you may be eligible for a focus-group discussion in your health facility.

#### YOU MAY BE ELIGIBLE IF YOU

- ❖ Are HIV positive and receive ART care in Enugu State
- ❖ Are between the ages of 20-30
- ❖ Have **EVER** been considered a loss-to follow-up (LTFU) patient
- ❖ Have missed an appointment at least once in the last 24 months

#### POTENTIAL BENEFITS

Participating in this research may drive a policy change towards robust mental health support for PLHIV and further promoting the UNAIDS last 95 Goal: viral load suppression and retention.

#### PARTICIPATION INVOLVES

- ❖ A maximum of 2 hours focus group discussion with other participants (six over all with mixed groups of males and females)
- ❖ Exchange of topic-guided views and opinions
- ❖ Willingness to allow your views be anonymously recorded

#### LOCATION

Within this ART facility. Light refreshment will be provided for your time.

#### FOR MORE INFORMATION

Please contact the PI: Elochukwu Uzim at +234-8153909341, email [R09853014@ntu.edu.tw](mailto:R09853014@ntu.edu.tw) or visit [www.ghp.ntu.edu.tw](http://www.ghp.ntu.edu.tw)



## Appendix 6.

### Focus Group Discussion Guide



1. Kindly state your age and sex, please?
2. How long have you been HIV positive?
3. Throughout the period of your seropositive status, have you ever felt stigmatized by others as a result of your serostatus? How did/do you cope with this, would you like to share? (Probe for any other coping mechanisms or lack thereof.)
4. Do you feel lonesome, depressed, or dejected when your loved ones fail to return intimate affections (love) towards you as a result of your status?
5. Do you consider the social isolation that you encounter from others to be the product of the immediate environment in which you live? In other words, do you feel “more socially accepted” in the urban areas than in the rural areas and vice versa?
6. Have you ever experienced discriminatory behavior from the health facility where you receive ART services?
7. When you miss your ART appointments, do you feel sad or happy? (Probe for why they feel either way.)
8. Follow up to 7 above, is this as a result of any economic challenges like poverty, loss of means of livelihood, etc.?
9. What kind of mental health support would you like to be incorporated into your treatment regimen?
10. Are there any other things you would like to share?

**END**



## Appendix 7.

### In-Depth Interview Guide



1. Kindly state your name and years of clinical experience in ART services?
2. What would you like to see changed about HIV services in Nigeria?
3. Given the opportunity to incorporate mental health care (such as listening to the patients talk about themselves, expression of anxieties, depression, and mood swings; counselling sessions; etc.) as part of the ART services available to patients, would you adopt it?
4. How would you counsel a patient with suicidal thoughts/ideations?
5. Have you ever lost a patient to suicide, if so, how did you feel?
6. Any other thing you would like to share about HIV services generally in Nigeria?

**END.**