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# The Influence of Community-Based Interventions on Behaviors of HIV+ Persons in Congo-Kinshasa

Max Ebengho Bokelo  
*Walden University*

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# Walden University

College of Health Professions

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Max Ebengho-Bokelo

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Walden University  
2021

Abstract

The Influence of Community-Based Interventions on Behaviors of HIV+ Persons in

Congo-Kinshasa

by

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MPH, Kinshasa School of Public Health, 2004

MD, University of Kinshasa, 1995

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health – Community Health Track 2

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## Abstract

Sub-Saharan African communities bear the highest burden of HIV/AIDS in the world. Because of identifiable cultural links and local beliefs, people are more likely to engage in sexual mores that could negatively impact their lives. Starting in early 2000, Congolese HIV+ patients have undergone a variety of inputs designed to decrease HIV risk behaviors among people. The purpose of this inquiry was to understand the impact of those actions within the community. Data grounded on the socioecological model were collected regarding any changes in (1) behavioral rejection of condoms, (2) Kintwidi phenomenon, (3) levirate and (4) sororate marriage, (5) sexual cleansing, (6) stigma and discrimination, (7) sexual gender-based violence and female genital mutilation, and (8) unprotected receptive vaginal or anal intercourse throughout a decade of community-based interventions (CBIs) implemented since 2004. Out of the holistic approach employed to tackle HIV in communities, the main query was to understand the meaning and impact of the comprehensive strategy in the Democratic Republic of Congo (DRC). From snowball sampling, nine in-depth interviews, three focus groups, and two key-informant interviews were conducted in DRC. Data collected in Kinshasa and Bandundu cities were coded, synthesized, and analyzed through NVivo R1 and Microsoft Excel. All eight key-cultural components above were stated to be significant negative sentiments for Congolese people living with HIV (PLHIVs) under CBIs. Findings could be used to inform further preventive activities to alleviate any HIV individual and community burdens in sub-Saharan Africa, leading to positive social change and better lives for PLHIVs, family members, and their communities.

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November 2021

## Dedication

I would like to dedicate this dissertation to three important people in my life who passed away: (1) my lovely mother Honorine Matuli Moongo who struggled as a single mother to raise three children in the context of extreme poverty in Africa, (2) my aunt Odette Bolumbu Moongo, who had shown true love to my children before leaving this human earth, and (3) my beloved uncle Joe Nembetwa Ndie-Boteya, who made me leave poverty by dragging my attention toward the schooling dream. May all your souls Rest in Peace.

Also, I would like to warmly dedicate this work to my beloved Colette Lompoko Bambondo and our children, for all your sacrifices during this immigration process in the United States and the COVID-19 pandemic lockdown. I am proud and grateful to be your husband/father.

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## Chapter 1: Introduction to the Study

The World Health Organization (2019) thinks that 32 million people have died from the human immunodeficiency virus (HIV) since the beginning of history. According to their database, almost 75 million individuals have been infected, even though several inputs have been provided as hypothetical responses to that emerging disease in Africa (WHO, 2019). In this research, the main goal was to understand the impact of community actions organized with health partners to alleviate the burden of the disease. For instance, Bakeera-Kitaka et al. (2019) wanted to identify factors influencing the risk of becoming sexually active among HIV infected adolescents in Kampala and Kisumu in the Eastern Africa. The authors revealed that out of 2.1 million HIV infected adolescents aged between 10 and 19 years, 80% were living in sub-Saharan Africa. This burden might impact the future of Africa; therefore, understanding how people behave in the region could provide a way to solve this issue. Zihindula and Maharaj (2015) highlighted the growing awareness and concerns regarding a particular type of behavior in Congo-Kinshasa, especially behaviors associated with sexual violence against women.

Kagaayi and Serwadda (2016) suggested that the delay between a possible early detection of HIV among some African migrants in Belgium in 1983 and the recognition of the disease had negatively impacted the sub-Saharan Africa epidemics. This was mostly due to stigma and perception of fear in African communities. For Probst et al. (2016), South Africans from low socio-economic status are more likely to die from HIV at over 50% of risk than others. Ahmed et al. (2019) thought that educational interventions, self-management, peers, and community supports could be counted as



major pillars of positive social improvement for people living with HIV (PLHIVs). Consequently, a behavior such as a safe male circumcision could be suggested to reduce the risk of HIV transmission (Kagaay & Serwadda, 2016). Today, nobody knows if other Congolese cultural behaviors such as cultural marriages influence the prevalence of HIV/acquired immuno-deficiency syndrome (AIDS), particularly how community actions could play a role in HIV prevention. Results from this study could become a powerful social and transformative instrument designed to generate positive sociocultural behaviors to shape healthy communities in Congo-Kinshasa.

The following part of the chapter presents the background of the study by summarizing the research literature, the gap in knowledge, and the main reason of performing this study. This first portion will lead to the problem statement as the evidence of the relevance of the problem and its significance. The research paradigm will be proposed through the purpose of the study, with a description of the phenomenon of interest while trying to understand the influence of community-based interventions (CBIs) on behaviors of HIV+ persons in the Democratic Republic of Congo (DRC) since 2004. Some fundamental research questions will be asked prior to explaining the nature of the study, its limitations, the potential contributions of the inquiry, and a summary of the chapter.

### **Background**

This literature review surveys articles addressing behavioral issues of HIV+ individuals among different communities, especially those using CBIs as one of the principal approaches for HIV epidemic control in a specific cultural context. The scope of

the study was based on selecting articles and publications designed to frame the understanding of eight key concepts: levirate marriage, sororate marriage, Kintwidi phenomenon, sexual gender-based violence (SGBV) and female genital mutilation (FGM), cleansing, poor condom usage for cultural reasons, unprotected receptive vaginal or anal intercourse, and discrimination and stigma. For instance, Hile et al. (2018) employed in-depth individual and group interviews from 42 participants to identify factors that could be incorporated to promote positive HIV-related behavior and self-management in New York City. Further, Zhang et al. (2018) suggested new directions for African American men who have sex with men (MSM) as elements to inform HIV programs and positive behavioral intervention to reduce community risks of HIV transmission.

Focusing on Latino population, Martinez et al. (2016) explored local data from male couples to adapt evidence-based behavioral HIV prevention interventions by performing combination approach. Conroy et al. (2018) wrote about creating an overlap between integrating sociocultural approaches and empowering women to take the dyadic environment and men's perspectives. Two years before, Mataboge et al. (2016) proposed how teaching community members in coaching teenagers could support each other in order to bridge strategies and increase HIV/AIDS prevention in South Africa. In 2015, Wekesa and Coast experimented reproductive health services, including HIV prevention and needs of PLHIV regarding contraceptives in Nairobi, Kenya. However, Pretorius et al. (2016) did not find significant differences in HIV-Stigma reduction programs

targeting PLHIVs and their family members in South African between rural and urban areas, but the intervention showed positive results in both cases.

Meanwhile, some mixed studies have been also reviewed. For example, Gorofalo et al. (2018) performed a project life-skills randomized clinical trial targeting behavioral intervention among young transgender women who showed a greater reduction in condomless sex acts for one year. But two years before, Collins and Sapiano (2016) wrote about the diffusion of the effective behavioral interventions as an opportunity for other large evidence-based projects. Likewise, Ahmed et al. (2016) outlined PLHIV patients' beliefs and their behavior when facing complementary and alternative medicine. Authors suggested community interventions towards medication adherence in younger adults with higher income and syndrome of depression. Mandumbu and Mariga (2017) provided non-material intervention with suited strategies to improve agriculture for PLHIVs and elderly farmers in security in sub-Sahara Africa.

A number of scholars have approached this topic from different angles and with different focuses. Sun et al. (2018) focused on a socio-ecological perspective using intersectionality theory in HIV care to reach the incidence reduction through community-based approaches. Mustafa (2018) published an article on U.S. Black men living with HIV regarding prevention among special communities such as fishermen, teenagers, and inmates. Meanwhile, Zhou et al. (2018) illustrated that more attention is needed in different Chinese communities. Indeed, different places identified as high, medium, and low levels provided different levels of condom use and HIV/STD prevalence in heterosexual transmission mode. Similarly, Wang et al. (2018) investigated targeted risk

behaviors regarding HIV/AIDS among female sex workers in Yunnan border, China. In 2018, Lu et al. compared behavior changes among female sex workers in Asia and newly diagnosed HIV-positive men having sex with men around the same location.

The same year, Ousley et al. (2018) found that HIV fishermen in Myanmar have a higher risk of hepatitis C co-infection, because they disproportionally engage in drug injection use and higher risk transactional sex than other patients. Screening people's attitude, Sharma et al. (2018) outlined the high-risk behavior regarding drug users and co-infection with hepatitis C virus risks among inmates. On a different point, Leddy et al. (2018) showed that food insecurity was associated with poor health among PLHIVs in the United States of America. In summary, more than 75 articles focusing on CBIs have been reviewed, including those written by Gilbert et al. (2015), Bhatta et al. (2018), Yang et al. (2018), Merlin et al. (2018), Burman and Aphane (2017), Mahvu et al. (2017), Belmar and Stuardo (2017), and Poku and Bonnel (2016).

According to the U.S. President's Emergency Plan for AIDS Relief (PEPFAR, 2017), Congolese HIV+ patients have received bi- and multilateral assistances from different health partners for HIV diagnosis, treatment, and community interventions. In 2019, PEPFAR underwent multiple difficulties in tracking progress when assessing the impact of a project and the threshold gap from making a significant improvement toward a needed change. However, despite post-2000 funding activities to control HIV via the Global Funds, World Bank, World Health Organization (WHO), UNICEF, Department for International Development (DFID), and local Congolese partners, nobody knows if

the provided CBIs were significantly impactful for PLHIVs themselves and their family members while facing their own cultural barriers.

This study took the opportunity to motivate a scientific attention to consider the missing link between some highly country funded programs as in Congo-Kinshasa and the lack of evaluated results for further improvements in similar or parallel programmatic activities. For Shi and Johnson (2013), cultural behaviors as barriers could be mistakenly ignored, but people need to know how, when, where, and with whom to partner for specific, attainable, measurable, relevant, and time-bound results. The idea is to be building key ingredients in DR Congo and elsewhere for successful HIV epidemic control (PEPFAR, 2019). This qualitative ethnographic study finally occurred in two cities of the DR Congo in 2020, instead of three as previously planned.

### **Problem Statement**

WHO (2018) warned against behaviors and conditions that increase the risk of contracting the human immunodeficiency virus (HIV), especially in the African region. Meanwhile, Casale et al. (2018) demonstrated that improving several social supports in the clinic and CBIs among South African adolescents who are HIV-infected may prevent them from specific health issues. Patra and Halsall (2016) suggested that unprotected receptive intercourse, lack or improper condom use, poor prevention of maternal HIV transmission, shared injecting drug use, certain beliefs, and sociocultural practices such as alcohol consumption with higher sexual risks and FGM are a set of health determinants negatively influencing the HIV prevalence in Uganda. Quinn et al. (2018) explained how AIDS beliefs influenced behavior by decreasing the rate in condom use.

According to PEPFAR (2014), the Congolese HIV prevalence is twice as high in urban than in rural areas; however, sociocultural behaviors impacting the spread of HIV among Congolese people, or the impact of HIV on sociocultural behavior, has never been explained. Likewise, nothing was found in my literature review describing the effects of CBIs on sociocultural behaviors among Congolese PLHIV and their family members. Indeed, no one has described a substantial cultural understanding of the Congolese HIV/AIDS spread in communities and the risk brought by the high rate of unintended juvenile pregnancies (Chae et al, 2017), culturally approved marriage among youth, and a variety of other identifiable local cultural rituals. In fact, an important group of HIV+ patients have been under a regimen of socioeconomic, psychological, and medical asset of activities for years, but no one knows at what level these actions were impactful on transformative behaviors to create healthy people.

### **Purpose of the Study**

The aim of this unique study is to investigate the extent to which the introduction of CBIs impacted lives of individuals infected with HIV, their family members, and their community through a compound of gender-based sociocultural behaviors in Congo-Kinshasa. Thus, an ethnographic research study was conducted using observations and interviews to explore and understand the following Congolese sociocultural behaviors among PLHIVs: (1) the custom of marrying a widowed brother-in-law with a matrimonial cousin, known as levirate marriage, (2) getting married to a dead wife's sister or sororate marriage (Malungu, 2001; Westreich, 2004), (3) unprotected receptive vaginal or anal intercourse (WHO, 2018), (4) rejection of condom use for cultural

reasons, (5) mores culturally tolerating incest among an uncle and his own nieces identified as the “Kintwidi phenomenon” (Shan & Cui, 2018), (6) SGBV and FGM (Fawole, 2018; WHO, 2019), (7) stigma and discrimination, and (8) sexual cleansing (Vera et al., 2018), or a Mongo tribe’s mores spiritually setting free a widow by having unprotected receptive sex with another widow or a mentally disabled person.

Because partners stopped providing food to several Congolese PLHIVs in communities according to their goals, I proposed to evaluate outcomes of a comprehensive CBI composed of: (1) home visits and (2) outreach and Voluntary Counselling Test (VCT) programs applied since 2004 within Congolese provinces (PEPFAR, 2017). Even though data collection was held at one time, this qualitative study analyzed reports of each particular sociocultural behavior at different times, before and after the intervention. The aftermath of CBIs among HIV infected individuals’ behavior was screened at the intrapersonal and interpersonal levels in DR Congo, comparing results of people who have been into a program to those who never been.

### **Research Questions**

RQ1 - In what ways has participation in CBIs impacted sexual behaviors among Congolese PLHIVs and the community in general?

RQ2 - What is the meaning of CBIs for family members?

RQ3 - What are the detailed sociocultural behaviors impacted at the end of the projects?

### **Theoretical / Conceptual Framework**

The theoretical basis of this qualitative study was the socioecological model (SEM) because I sought to understand how much a decade of CBIs from 2004 impacted thousands of Congolese HIV/AIDS patients' lives and their family members. According to the United Nations International Children's Fund (UNICEF; 2019), SEM can be used as a framework for prevention. My study applied this model to a group of multileveled sociocultural challenges in DR Congo (Glanz et al., 2015; Harris, 2018; Ravitch & Carl, 2016). When describing the SEM, Glanz et al. (2015) highlighted five principles impacting health behavior stating: (1) the multiplicity of levels of influence, (2) the significance of determinants, (3) the interaction of influences of behaviors across levels, (4) the specificity of SEM on a particular behavior, and (5) the fact that multilevel interventions should be most effective in shaping behaviors as desired.

The conceptual framework of this study can be viewed at five levels. The first stage is the individual level, explained by biological and personal historical factors that lead to the behavior (UNICEF, 2019). The second stage is the interpersonal level, made of the social network and the social support system around the individual (UNICEF, 2019). The third stage is related to the community, involving organizations, institutions, and informational networks within defined boundaries (UNICEF, 2019). The fourth stage is composed of organizations and institutional holding rules and regulations that have impact on people's life (UNICEF, 2019), and the fifth stage is located at the policy level, enabling the environment at local, state, national, and global laws and policies that influence behaviors (UNICEF, 2019). In this study, Congolese sociocultural practices



were screened through this theoretical lens in order to provide specific information describing how beneficiaries understood the influence of CBIs on their own behaviors, as further described in Chapter 2.

### **Nature of the Study**

This research project is a qualitative ethnographic study, with the intention to detect the potential impact of the multiform CBIs on the current behaviors of PLHIVs in all the Congolese provinces involved during the last decade (Ravitch & Carl, 2016). Based on individual beliefs and personal environment, ethno-anthropological values could provide a sharp understanding of eight key-concepts through in-depth interviews, focus groups, and some key-informant interviews. This inquiry was based on the deep understanding, questions, and participative observation to decipher sociocultural meaning of potential behavioral changes consecutive to the Congolese CBIs achievement (Ravitch & Carl, 2016). This strategy was rooted in analyzing data collected through the SEM of health behavior. Data were gathered from focus groups, in-depth structured interviews completed over the telephone with a research assistant on the ground, and Skype interviews in selected geographically inaccessible Congolese provinces.

### **Definitions**

Some key cultural concepts need to be explained in this qualitative study in order to better present the topic. These include:

#### **Community-Based Interventions (CBIs)**

Petridou and Antonopulos (2017) suggested that CBIs are related to multicomponent activities that usually combine individual and environmental change

strategies across several settings to prevent dysfunction and feature well-being among population groups in a specific local community. Most of the time, a whole community such as a Congolese city, a county, or a sole neighborhood can be considered as a unit of the targeted intervention (Petridou & Antonopoulos, 2017). Several community interventions were presented as culturally driven and seem to be responding to the need of their partners, rather than those of HIV+ patients.

### **Cultural Behaviors**

In 2017, Legare suggested that human beings live in a complex and variable culture that is unmatched by other species. Our lives are made of extrasomatic niches with artifacts, skills, beliefs, and inherited practices that have been cumulatively modified over time, called cultural behaviors (Lagare, 2017). These extragenetic characters, such as the requirement of condom use for Congolese HIV+ patients, have an objective influence on the behavior of individuals and the human society.

### **Female Genital Mutilations (FGM)**

The United Nations Funds for Population (2019) defined FGM as all practices involving the intentional injury to the genital organ of a girl or a woman for non-medical reason. As in SGBV, this is associated with coercion and threats of violence, and it can be physically harmful. I am seeking to know how Congolese HIV+ patients and their community members culturally understand certain behavioral changes through CBIs.

### **Kintwidi Phenomenon**

According to the Research Directorate, Immigration and Refugee Board of Canada (2003), the Kintwidi phenomenon is a type of a cultural sexual violence or forced

marriage where a girl or a woman is required to get married with her grandfather, her nephew, or her cousin in the Yansi tribe in Bandundu, DR Congo.

### **Sexual and Gender-Based Violence (SGBV)**

According to the United Nations Refugee Agency (UNHCR; 2019), any act that is perpetrated against a person's will and based on gender norms and unequal power relationships is considered to be SGBV. Because SGBV is often associated with coercion, threats of violence, and actual violence, it can be harmful due to its physical, psychological, emotional, or sexual impact on the victim (UNHCR, 2019).

### **Sexual Cleansing**

Vera Cruz et al. (2018) defined sexual cleansing as a common African cultural ritual, especially in Mozambique, where a supposedly "impure" because widowed woman is expected to have unprotected sexual intercourse with a relative of her deceased husband or a stranger in order to be "purified."

### **Socioecological Model (SEM)**

The SEM is a theory-based framework designed to understand the multifaceted and interactive effects of individual and environmental factors on behavior (Glanz et al., 2015). Owen and Fisher (n.d.) explained that the ecological model of health behaviors emphasizes (EMHB) the policy and the environmental context of behavior, while inserting psychological and social influences. The EMHB leads to different levels of health influence in guiding the development of more comprehensive interventions, including individual factors, interpersonal factors, institutional and organizational factors, community factors, and public policy factors (Sallis Neville Owen & Fisher, n.d.).

## **Stigma and Discrimination**

WHO (2019) defines stigma as an attitude or belief that leads to rejection or avoidance of other human beings perceived as different. This feeling causes exclusion of others and consequently discrimination (WHO, 2019). HIV+ patients are potentially subject of many types of rejection within communities, especially in developing countries with the level of education and cultural mindsets.

### **Assumptions of the Study**

Sivhabu and Visser (2019) performed a qualitative study in Limpopo, South Africa by exploring mores in sexuality among young people of Venda. They used multiple focus groups, suggesting that constructions of sexuality and cultural practices can be used rather to promote context-specific HIV prevention programmes. The following sexual risk behaviors were found: the male sexual drive discourse (meaning sex is unavoidable and natural), rite passage, discourse of hegemonic masculinity (enhance sex to prove masculinity), consider sex as a commodity, normalization of HIV (AIDS to be seen like flu), and non-adherence to cultural practices (Sivhabu & Visser, 2019). In DRC, sexual cleansing is culturally meant to set widows free from bad spirits after the death of their spouses. However, that seems to be a harmful cultural practice composed of several unprotected sex intercourses with a stranger partner that could lead to HIV contamination if that person was infected. But nobody can scientifically explain how the widow would be purified after having sex.

At the same time, Kintwidi phenomenon is another harmful cultural practice that can lead to the spread of HIV among people. While many Congolese are still believing in

it as a valuable cultural practice, there is however a rise in understanding how much communities have been affected by this cultural ritual. Charlier et al. (2018) described the belief of “virgin cleansing” as a magical argument for most people living in sub-Saharan African countries. These hetero-aggressive sexual practices are grounded at the medical anthropology level where people believe in cleansing by virgins based on the fact that the patient is usually dirty by the disease, so he needs to be cleaned (Charlier et al., 2018). Many studies have suggested to challenge all cultural practice that negatively influence health (Sivhabu & Visser, 2019). For instance, in Mongo culture, any nightmares or bad dreams from widows who avoid that sexual ritual is interpreted as a haunted spirit from the dead person. They are therefore motivated to undergo the ritual process.

### **Scope and Delimitations**

Nobody has explained if the growing interest in tackling HIV/AIDS within community assets found an answer through CBIs implemented in early 2000. Some specific actions through home visits, income generating activities, and other inputs are visited in this study to understand if CBIs among HIV+ patients brought any expected change in behavior among PLHIVs and their communities. This inquiry describes the way HIV+ patients understand eight 8 key cultural behaviors in sub-Saharan Africa, especially in DR Congo.

Because I aimed to illustrate how HIV+ patients understand these concepts, I used a comparative research pairing data between non-HIV tested people on one side (supposed HIV free), then PLHIVs and their family members under CBIs on the other side. So, focus groups, in-depth interviews, and the key informant approach were used in

non-discriminatory gender fashion for data collection excluding individuals less than 18 years old and people proven mentally unable to undergo the study. A middle school level education was the minimum requirement for all participants from Kinshasa, Mbandaka, and Bandundu. Both wing-parts of this inquiry were conducted at the end of 2020 for its pioneer part, and the beginning of 2021 for the remaining portion of it based on CBIs implemented from 2004 to 2018 using the SEM.

Limitations of the StudAschengrau and Seage (2014) argued that some limitations of similar studies include selection bias due to data missing from dead patients, given the high mortality rate of PLHIVs in the past (WHO, 2019). Information bias can also occur due to memory loss from interviewees. At the same time, “healthy worker survivor effect” can be found among family members of PLHIVs, influencing their outcomes because totally omitting the risk exposure by sticking on their previous HIV serostatus (Aschengrau & Seage, 2014). Data collected from self-assessment could not generate generalizable conclusions through understanding the exposure of Congolese sociocultural behaviors and HIV/AIDS, since CBIs were applied upon different and inconstant community action package.

Also, involving people who have never been in a CBI program may generate some selection biases, especially because of low literacy in Africa, where people are more likely to never had heard of such complex assistances targeting special populations. Conversely, data from health workers or public health practitioners could generate biases because of their background awareness regarding information on HIV/AIDS. Meanwhile, the study will be limited due to the lack of quantitative or objective information related to

the knowledge, attitudes, and practices of PLHIVs, compared to identified non-HIV communities where CBIs were not applied. In the future, a comparative study should be planned on HIV matter, pairing Congolese CBI communities with non-CBI communities.

### **Significance of the Study**

The outcome of this research project fulfills the gap in understanding the consequent detailed behavioral changes among PLHIVs in Congo-Kinshasa. Results suggest potential practices and encourage alike CBIs capable to benefit other targets. The originality of this study is based on potential inward sociocultural mores' diversity, and possible information spread of benefits identified from CBIs if found significantly able to transform community's behaviors. Consequent results are more likely resourced from a multiplicity of changes potentially observable in sociocultural behaviors, shaped by more than 700 languages spoken within over 200 Congolese tribes while fighting to control the HIV infection with a variety of cultural beliefs. This research could support strong professional practices by suggesting culturally adapted tools to address HIV spread through cultural behaviors such as levirate or sororate marriage and sexual cleansing (Vera et al., 2018).

Thus, further local community outreach strategies could be planned accordingly, as Sentell et al. (2018) broadly described the promotion of a sustainable culture of prevention in Albania using a specific thematic known as "Si Je." For Crankshaw et al. (2016), promoting similar dyadic relationship elements underlying couple-counseling frameworks for successful HIV risk reduction coordination would be significant. Durevall and Lindskog (2016) and Fielding-Miller et al. (2015) suggested that a

culturally adapted SGBV reduction plan among intimate partners and married women could be beneficial in sub-Saharan Africa. Consequently, a sociocultural ecological data-driven study in a future healthy Congolese community could transform sociocultural behaviors and lead to reduction in current high sexual violence rates while diminishing the exposure of women living at risk of HIV/AIDS in Congo-Kinshasa.

### **Summary**

In this chapter, HIV/AIDS has been viewed as one of the main public health threats among Congolese communities that have undergone CBIs as a part of the holistic response starting in 2004. Using an ethnographic approach, I outlined my interest in understanding how HIV+ patients make sense of eight cultural key-concepts when employing five different stages of the SEM. The purpose of the study is to seek for any consequent behavioral changes that could have benefited the target population since nobody has explained the influence of CBIs among Congolese PLHIVs. Based on their beliefs, some other respondents might have different assumptions, beyond the delimitation of this study in the geographical space and time, including where we investigated in Bandundu, and Kinshasa. Data collection began at the end of 2020 in a pilot study, while focus groups, in-depth interviews, and key informant person interviews continued in the remaining city of Bandundu. Outcomes from this study could be used for a further quantitative inquiry to inform other similar activities in the HIV/AIDS field.

The following chapter will be based on a wide literature review, describing the conceptual framework and the theoretical foundation for understanding the influence of CBIs on behaviors of PLHIVs in Congo-Kinshasa. I will also describe in detail each of



the eight concepts, providing a deep cultural understanding of the information. Indeed, a conceptual framework will be suggested prior to providing a strategic literature review related to those culturally integrated concepts, and the method chosen in this inquiry is a qualitative approach screening every single information regarding different levels of SEM on the subject.

## Chapter 2: Literature Review

### Introduction

According to the WHO (2017), Africa is the most HIV-infected region in the world, bearing almost 70% of all HIV-affected individuals. Meanwhile, Rosenberg et al. (2017) suggested that older PLHIVs in rural hyperendemic communities of South Africa had sexual behaviors consistent with high HIV transmission risk status. Studying risky sexual behaviors among in-school adolescents and HIV risk perception in Ghana, Afriyie and Essilfrie (2019) proposed that adolescents did not perceive themselves to be at risk of HIV infection despite their risky behavior. Whittle et al. (2019) suspected that food insecurity may be associated with a range of poor mental health results among women at risk of HIV in the United States of America. MacLean and Wetherall (2021) found a bidirectional relationship between mental depression and stigma. They figured out that female and young PLHIVs are more likely to develop adverse effect to stigma (McLean & Wetherall, 2021). This statement highlights the particular interest of organizing social interventions within communities.

WHO (2017) reported that more than 25.7 million people were living with HIV in Africa, out of 36.9 million globally. However, in a systematic review involving four databases, Fearon et al. (2019) were not able to present conclusive evidence regarding the role of peers in adolescent sexual behavior among vulnerable sub-Saharan Africans. When studying risk and resilience regarding the nature of HIV among indigenous people in Ecuador, Dao et al. (2019) found that the identified risk factors of HIV/AIDS were interconnected within a mosaic of syndemic relationships. They demonstrated that,

among indigenous communities, the mutually reinforcing individuals' risk level of sexual behavior, violence, and substance abuse increased the risk of HIV (Dao et al., 2019). However, I found nothing in my review of the literature regarding a likelihood in a change of attitude obtained from the influence of any CBI project in Congolese sociocultural behaviors.

The purpose of this ethnographic research is to understand whether Congolese PLHIVs have undergone any changes in sociocultural behaviors as a consequence of the CBIs previously planned to alleviate the burden of HIV/AIDS in different communities. For instance, Techasrivichien et al. (2016) demonstrated that Thai sexual norms were drastically changing with their lifestyle and practices, creating a significant gap between the older generation and young Thai people. Besides the antiretroviral treatment approach, the U.S. President's Emergency Plan for AIDS Relief (PEPFAR; 2017) tracked the Congolese community-based response addressing the HIV/AIDS crisis through home visits, then outreach and VCT programs within 26 provinces. Unfortunately, nobody has explained whether, during the implementation process, patterns of Congolese sexual behaviors and gender-based sociocultural attitudes have been modified throughout CBIs while addressing HIV/AIDS.

Listing a selected group of gender-based behaviors of interest, this inquiry will be focused on (1) HIV/AIDS stigma and discrimination, (2) levirate marriage (i.e., the custom decreeing that a woman marry a widowed brother-in-law as a matrimonial cousin), (3) sororate marriage (i.e., the custom whereby a man marries a dead wife's sister; Malungu, 2001; Westreich, 2004), (4) unprotected receptive vaginal or anal

intercourse (WHO, 2018), (5) rejection of condom use for cultural reasons, (6) mores culturally breaking incest among an uncle and his own nieces identified as the “Kintwidi phenomenon” (Shan & Cui, 2018), (7) SGBV and FGM (Fawole, 2018; WHO, 2019), and (8) sexual cleansing (Vera et al., 2018) or a Mongo tribe’s mores spiritually setting free a widow through unprotected receptive sex with another widow or a mentally disabled person. How did Congolese PLHIVs under CBI’s understanding of high-risk sexual behavior change follow the implementation of different ongoing community projects?

To better understand the relevance of the problem, Omori and Abu-Raddad (2016) strived to depict the missing links in sub-Saharan Africa HIV prevalence and the population’s sexual behaviors through 25 countries using the Demographic Health Survey data. That socioecological study revealed that population behavior was not predictive of HIV infection (Omori & Abu-Rabbad, 2016). Paradoxically, data from the Kaiser Family Foundation (2017) suggested that DR Congo is the only country in the central African region holding less than 1% of HIV prevalence among individuals aged 15 to 49 years. According to the United Nations’ AIDS organization (UNAIDS; 2018), all the neighboring countries have a higher incidence of HIV/AIDS than what DR Congo bears, including 11.5% of prevalence for Zambia, 7.9% for Uganda, 3.1% in Congo-Brazzaville, 2.7% in Rwanda, and 1.9% in Angola. Could sociocultural behaviors explain the low HIV serostatus in DR Congo?

Conroy et al. (2019) established a relationship between food insecurity and sexual violence. For instance, an observational study from UNAIDS (2017) reported that 49.2%

of Congolese would never buy vegetables from shopkeepers living with HIV. That isolated fact may be understood as a sign of stigma and discrimination against PLHIVs. Meanwhile, CBIs have been applied since 2004, and for CDC (2017), the World Bank (2018) suggested that 0.8% of Congolese adults between the ages of 15 and 49 are HIV infected out of 78,736,153 inhabitants. Besides CBIs, antiretroviral treatments (ART) administration is employed for 122,268 people under treatment since 2015, because there are more than 19,000 people at risk of death in the country (CDC, 2016). For this study, I used in-depth interviews, key-informant person interviews, and focus groups to collect and compare qualitative information from living HIV+ people and their family members who have been in the program in order to understand the behavioral impact of the CBIs in at least three of the following provinces of DR Congo: Kinshasa Haut-Katanga, Bandundu, Kongo Central, Kasai, and Equateur.

### **Literature Search Strategy**

I used multiple literature search strategies to conduct my literary review: (1) searching appropriate data from the Internet, (2) reading books from my personal library, (3) searching bibliographic databases, (4) scanning bibliographies of existing reviews and eligible studies, (5) searching key journals, (6) searching for seminal articles, and (7) contacting scholars working in the area. Faryadi (2018) suggested that the literature review is the second stage of the Ph.D. thesis writing process, and that it should use a systematic approach using published and accredited scholar articles and/or publications. Also, Rudestam and Newton (2015) advised dissertation writers that the review of literature is the lengthiest portion of the research proposal. The influence of CBIs on

behaviors of HIV+ people living in Congo-Kinshasa proved to be a broad research topic for the literature review. This chapter provides not only information regarding the main interest of the inquiry and its context, but also the relationship to previous publications related to the topic (Rudestam & Newton, 2015).

In the same way through the Walden University Library, I found that Poku & Bonnel (2018) offered an opportunity to understand how funding CBIs may prevent HIV by delivering gender-sensitive interventions. I systematically consulted several websites, library databases, and research engines in this process, such as advanced search on PubMed engine using NCBI resources, Google Scholar engine with random search, online database and physical consultation at Pierce County Library in Lakewood, WA, home reading books from my personal library as recommended by Walden University, ScienceDirect engine using personalized messages, and Walden University Library through Thoreau multi database search. For all online searches performed in general, the main inputs were based on key terms as follows: community-based interventions, sociocultural behaviors, and socioecological model in PubMed database. However, I used other terms in different search engines, such as literature review and HIV/AIDS, HIV/AIDS, and Behaviors at Walden University Library with EBSCO. I used community-based interventions, HIV, and behavioral changes for qualitative research inquiry with Google, PubMed, and Yahoo engines.

In the search of key journals, most of the articles collected throughout the prospectus process were either quantitative or mixed studies. Because my goal was to understand a transformative natural phenomenon from its environmental setting in ways

that could be contextualized and reflect how Congolese PLHIVs make sense themselves of the influence of CBIs in their life (Ravitch & Carl, 2015), it became imperative to perform a qualitative study instead of a quantitative one as previously chosen. Ferthman and Allensworth (2015) suggested the use of Community Toolbox for community needs assessment in the literature review, but primary data methods and ad hoc tools were proposed. For instance, it is widely encouraged to use key informant interviews, focus groups, survey questionnaires in health promotion programs as data collection methods (Ferthman & Allensworth, 2015). Salazar et al, (2015) found that qualitative modes differ from quantitative ones in the fundamental assumptions made regarding (1) the generation of facts, (2) the purposes of the study, (3) the approach adopted, (4) the type of needed data, and (5) the role of the researcher. I will engage as a researcher in seeking facts that can generate information designed to understand that influence of behaviors among Congolese PLHIVs.

The literature review is where a researcher's critical ability to perform a study becomes a piece of evidence (Rudestam & Newton, 2015). Scholarly data are usually drawn from original source materials. Thus, Rubin and Rubin (2012) suggested that accuracy to record and report data, as Rudestam and Newton (2015) recommended: "careful inspection of design, analysis, and results from the primary source material" (p.72). Indeed, it has been stated by Rubin and Rubin (2012) that qualitative interviewing is the art of hearing data. The authors recommend a naturalistic approach, guided by a wide social construction approach that focuses on the way subjects interpret their own worlds as for CBI influence among PLHIVs, and the key facts of understating their own

environment (Rubin & Rubin, 2012). Rudestam and Newton (2015) thought that the use of a library is a critical piece of the dissertation process. The scarcity of Congolese behavioral data in HIV depicts then a real need for information in this case.

After reading bibliographies of existing reviews and eligible studies when back to the diverse existing software databases, I realized that most of the information collected regarding HIV, community interventions, and behaviors in this inquiry are online-based data-driven up to July 2019. For instance, using cultural behavior, HIV/AIDS, and community-based interventions as keywords to search the ScienceDirect engine revealed an interesting article written by Wagman et al. (2017). That study was an evaluation of a process preventing intimate partner violence and HIV infection using Safe Homes and Respect for Everyone (SHARE) program in Rakai, Uganda. The above cohort's qualitative study involving 1407 participants suggested that two-third of them felt positively influenced in behavioral change through SHARE program (Wagman et al., 2017). Thus, the use of multiple and synchronized actions potentially contributed to positive behavior changes.

Forwarding citation search of seminal articles, Awad and Abu-Rabad (2014) proposed a convincing narrative stating that the decline of HIV prevalence in sub-Saharan Africa (SSA) would have been driven by the decrease of sexual risk behavior in communities. Their finding offers support to the hypothesis that evolution in sexual behavior happened in the 1990s and must be taken as a dominant driver of recent inflections of sub-Saharan African HIV prevalence (Awad & Abu-Rabad, 2014). Using the same keywords with PubMed, I found out that for Lim et al. (2018), a culturally



adapted intervention offers a better STI/HIV prevention tool to foreign female workers in Singapore.

According to Audet et al. (2017) in rural Mozambique. with identical keywords, PubMed page offered a systematic adaptation of evidence-informed interventions and provided with high-quality results, based on the delivery of actions in low-literacy populations, using theater-based performance. Audet et al. (2017) thought that generating discussions on sociocultural aspects of the issue while implementing a project provides more benefits than using traditional healers and community health workers to improve the quality of life for PLHIVs.

### **Theoretical Foundation**

This study was framed by the SEM. The self-assessment of CBIs was based on the SEM as understood by PLHIVs. In 2015, Glanz, et al. (2015) suggested that environmental contexts were significant determinants of health behaviors. Authors highlighted the behavioral influence of SEM at multiple levels (Glanz et al., 2015). Similarly, Galiano (2016) performed a second study with a purpose of understanding how living with HIV in Sao Paolo, Brazil, as an adolescent was affecting personal growth, and how the treatment adherence was important for them. He recruited 20 adolescents between 13 and 20 years old from a group of 268 preselected candidates infected by HIV through mother-to-child transmission at birth from a longitudinal study organized by Adoliance (International alliance) in April 2009 (Galiano, 2016). Interviewees demonstrated ambivalent feelings regarding the efficacy and confidence in treatment

adherence, or the complexity of living with HIV as “a different person” when serological status was disclosed.

Fertman, et al. (2017) thought that the ecological health perspective helps to explain multiple levels of influence regarding an individual’s behavior and acknowledges that an individual both shapes and is shaped by the environment. Olakunde et al. (2019) used a cross-sectional ecological study to share the basics of the economic influence of HIV in sub-Saharan African countries. Multiple HIV programs in African countries were exclusively funded by their foreign partners (Olakunde et al., 2019). However, because family members in this study needed to understand that they are at an environmental risk for HIV/AIDS with potential heavy consequences, opinions were compared with independent groups of respondents.

In fact, the history of the SEM is rooted on Lewin’s study in 1951, when he described ecological psychology as the impact of the outside environment on a person (Glanz, et al., 2015). Indeed, that history evolved significantly when Watson suggested the stimuli-response theory in 1925, then the cognitive theory was explained by Tolman in 1932 and Lewin in 1951. Later on, (1) Bronfenbrenner’s work came on systems theory in 1979. One year later, (2) the Moos’s study took place in 1980 with the description of social ecology. After six years was born (3) the Barker’s study in 1986 when seeking to understand the environmental psychology. This field evolved to (4) the model of community food environments developed by Glanz in 2005 (Glanz, et al., 2015). (5) The ecosocial model from Glass and McAtee was suggested in 2006, prior to (6) Bandura’s

1986 models designed to guide behavioral interventions such as social learning and social cognitive theory.

Also, Gullion (2016) defines ethnographic as an interdisciplinary tool used by scientists to delve into a variety of social groups to culturally make sense of concepts. For Ugwu (2017), antique ethnography is believed to be rooted in Herodotus writings between 484 and 425 BCE. However, several scholars who hold onto the view that Morgan pioneered formal ethnography and Malinowski systematized participant observation seem to be gathering significant information (Ugwa, 2017). In fact, modern tendency started in the twentieth century with Bronislaw Malinowski who was credited with the development of the in-depth scientific inquiry (Gullion, 2016). In 1922, Malinowski wrote the *Argonauts of the Western Pacific* considered as the pioneering fieldwork of ethnographic studies (Gullion, 2016).

Before the cardinal method in ethnographic fieldwork with Malinowski, Frank Cushing finished own fieldwork from 1879-1884 (Ugwa, 2017). Ethnography widely evolved from the colonial era through the landscape of Western and non-Western scholars to investigate on a matter involving traditional societies. Ugwa (2017) argued that some old European scholar writings signed by antique philosophers such as Khaldun (1332 – 1406), Montesquieu, Auguste Comte, Spencer, and Emile Durkheim must be understood as leading to ethnographic dynamic. Ugwa (2017) noticed that a French polyglot Jesuit missionary known as Joseph-François Lafitau wrote on the Iroquois and the comparative anthropology, based upon own theology training, humanities, and rhetoric knowledge. Based on constructivist theories applied to human behavior, this

ethnological study is a positivistic inquiry observing an occurring contextual phenomenon, with an emphasis on an inductive exploration of potential behavioral changes in Congolese HIV+ patients under CBI for more than 10 years (Rudestam & Newton, 2015).

For Glanz, et al. (2015), the Ecological perspectives on health behavior posits on 5 principles: (1) There are multiple levels of influence on health behaviors, (2) Environmental contexts are significant determinants of health behaviors, (3) Influences on behaviors interact across levels, (4) Ecological models should be behavior-specific, and (5) Multilevel interventions should be most effective in changing behaviors. To improve the components of health promotion programs within communities, Fertman and Allensworth (2017) suggested health education and environmental actions to support the conditions of healthy living. Authors establishes that improving health among PLHIVs under CBIs in DR Congo through EHM includes advocacy, environmental change, legislation, policy mandate, resource development, social support, financial support, community development and organizational development (Fertman & Allensworth, 2017).

Ravitch and Carl (2017) sustain in this case that a qualitative inquiry seeks the discovery and the description of how people share their daily routine, and the main understanding of their life experiment. Because every Congolese CBI approach was built according to PLHIVs' needs and their environment, the SEM was selected as a culturally adapted theory to perform the inquiry. The U.S. Department of Health and Human Services [HHS] (2019) suggests that the Ecological Model recognize multiple levels of

influence on health behaviors including: (1) intrapersonal or individual factors, (2) interpersonal factors, (3) institutional or organizational factors, (4) community factors, and (5) public policy factors.

Theoretically, the SEM would help understand in what ways participation in CBIs has influenced sexual behaviors among Congolese PLHIV, but also potential detailed cultural behaviors to be impacted at the end of the project. For instance, because SEM should be behavior-specific (principle 4) (Glanz et al, 2015), it would help understand in what measures CBIs influenced SGBV in Congo, stigma, and discrimination, unprotected receptive vaginal or anal intercourse (WHO, 2018), any rejection of condom uses for cultural reasons, ‘Kintwidi phenomenon’ or cultural mores breaking incest among an uncle and his own nieces (Fawole, 2018).

### **Conceptual Framework**

Ravitch and Carl (2017) wrote that a conceptual framework is designed to make the case for why an inquiry is significant and relevant. Thus, the appropriate conceptual framework for this study will be based on constructs of SEM. This theory will help understand why the influence of CBIs among HIV+ patients is important on behavioral change in order to build potential actions not only for understanding the gap between DRC and neighboring countries, but also to decreasing the prevalence of HIV. Initially, the study will be grounded on the construct of the SEM. Indeed, working on the HIV field in developing countries makes public health practitioners feel the level of hopelessness of HIV+ patients during their lifetime.

They need strong support, and nobody will know what they are thinking of if people do not dig into their intrapersonal level of understanding their disease and their environmental world. Exploring interactions between the subject and family members could be done through SEM using interpersonal level of knowledge (Glanz et al., 2015). The behavior will be tailored at the community level since there will be some household activities, occupational activities in the active living domain (Glanz et al., 2015). Access and characteristics of behavior settings will be observed in the neighborhood, home environment, during transportation, in the school environment, or in daily routine activities in patients' community (Glanz et al., 2015). Fertman and Allensworth (2017) suggest the use of the policy environment to understand patient issues and address societal problems.

This positivistic inductive study is designed to make sense of how Congolese HIV+ patients understand their own probable sociocultural behavior change under CBIs applied from 2004 (Ravitch & Carl, 2016). As a systematic ethnographic inquiry, this qualitative reflexive-iterative study is significant because in-depth interviews, focus groups and key-informant approaches using NVivo 12 for data analysis would rigorously offer ways in which participation in CBIs has impacted sexual behaviors among Congolese PLHIVs and the community in general, the meaning of CBIs for family members, and the detailed sociocultural behaviors impacted at the end of projects in different environment.

The significance of this socioecological study based on the expected behavioral change on HIV+ patients under CBI lies on how Congolese PLHIVs understand their

own dynamic cultural behavior on (1) unprotected receptive vaginal or anal intercourse, (2) rejection of condom use for cultural reasons, (3) levirate marriage, (4) sororate marriage, (5) mores culturally breaking incest among an uncle and his own nieces known as ‘Kintwidi phenomenon’, (6) SGBV and FGM, (7) stigma and/or discrimination, and (8) sexual cleansing. Beliefs and cultural behaviors of people with low education may lead to risky sexual behaviors due to poor capacity of understanding risks of contracting HIV; however, education may not be fully granted of healthy behavior credit. Framing this reasoning on ecological perspectives would explain cultural behaviors that impact the current spread of HIV.

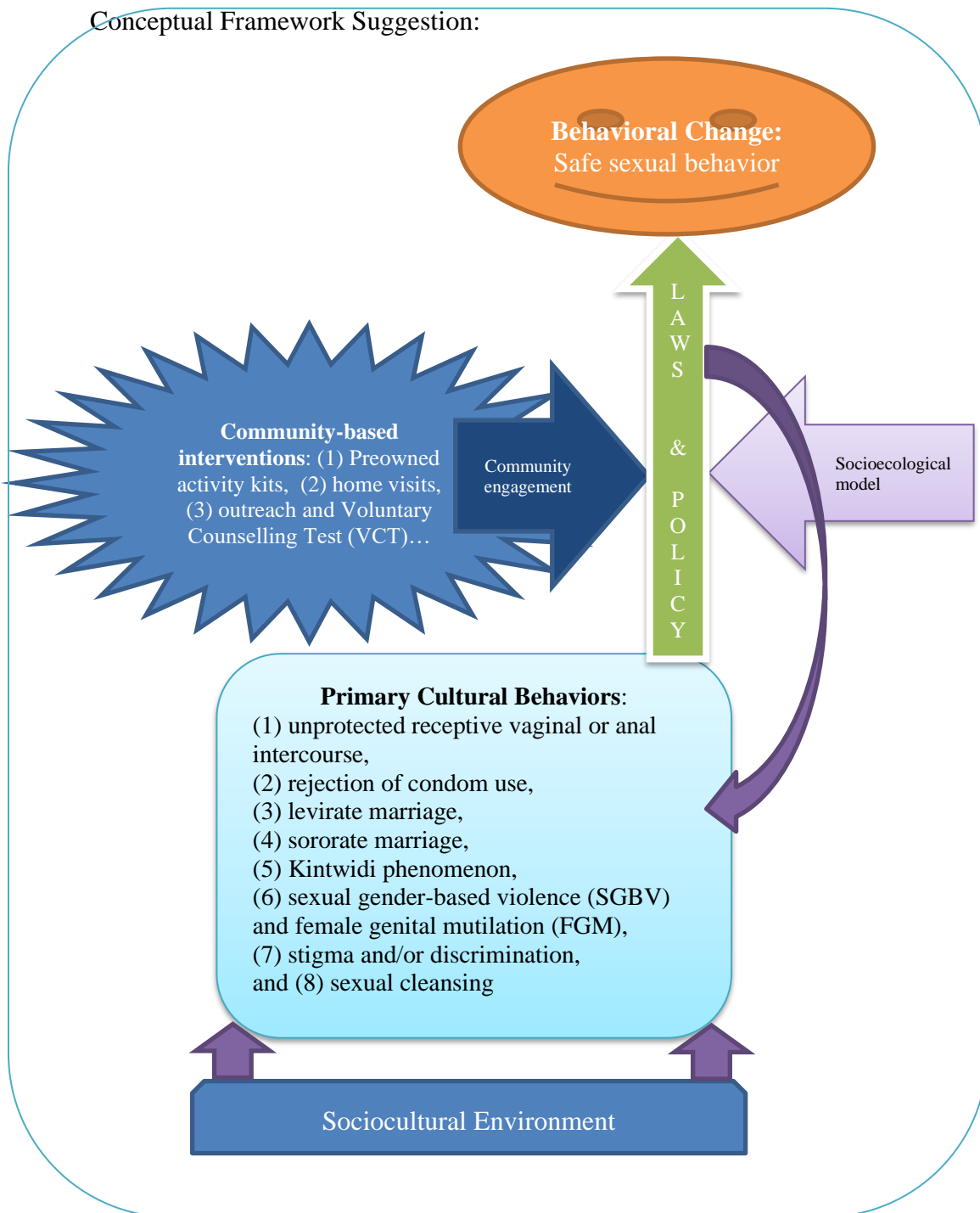
According to Rojas et al. (2019) when reading Bogenschneider’s theory, the conceptual framework of SEM is based on the importance of family and relationships in the life of the individual. In fact, in this study, constructs related to multiple levels of the SEM will be interchangeably used in iterative, systematic, and inductive reasoning to provide the overall core structure of behavioral changes of Congolese PLHIVs under CBIs as understood by each individual (intrapersonal) in programs, his environment (interpersonal, family, community, society/law). Edmonds and Kennedy (2017) suggest a deep screening of relationships among cultural features to build a scientific framework of a topic.

In this study, the principal researcher will be used as a primary tool of data collection and analysis, even in Mbandaka, DRC where a second researcher is planned to be associated and help proceed data collection for bias prevention purpose, according to the fact that the main researcher had been a part of CBI implementation for seven years in

one of the three selected target provinces. Creswell and Creswell (2018) found that using reliability and reflexivity in qualitative research from a natural setting is a sustainable and intensive experience with participants. In general, research can be carried out from individuals (in-depth interviews & key-informants) to groups of people (focus groups) for real CBI project impact data collection purpose (Ravitch & Carl, 2014). Glanz, et al. (2015) suggest that socioecological theory (Klassen et al, 2019) inform a research topic on how changes occur through interaction with people's environment.



**Figure 1**  
*Conceptual framework of sexual cultural behaviors*



### **Literature Review Related to Key Variables and/or Concepts**

The key variables that need to be investigated in this study are the following: (1) the unprotected receptive vaginal or anal intercourse, (2) rejection of condom use, (3) levirate marriage, (4) sororate marriage, (5) Kintwidi phenomenon, (6) SGBV and FGM, (7) stigma and/or discrimination, and (8) sexual cleansing. In 2017, Nedjat-Haiem et al., conducted a prospective Ecological study to determine the feasibility of implementing an Advance Care Planning Intervention (ACP-I) among seriously sick older Latinos of at least 50 years having one or more diseases such as cancer, hypertension, or HIV/AIDS. Authors employed the *intrapersonal level* of knowledge from Latino-Hispanic participants and time to completion of tests to depict variations, they found that not only the ACP-I Plan was feasible, but it was also perceived as extremely helpful by respondents based on enrollment and intervention completion rates (Nedjat-Haiem et al, 2017). At the *interpersonal level*, a SEM study performed by Grau et al. (2017) from 49 Southern New England participants using drug and alcohol demonstrated that the most important HIV care continuum (HCC) challenges regarding PLHIVs under substance abuse issues included linking and retaining people having several co-morbidities and meeting their daily basic social needs.

The first of these eight key variables under the study is the *unprotected receptive vaginal or anal intercourse*. In 2016, CDC suggested that Men who have sex with men (MSM) are more likely to contract HIV than other social layers in the U.S. with an estimated new infection around 62% among gay and bisexual men. MSM usually have unprotected receptive anal sex, and African Americans ethnic/racial group bears the most

important burden of HIV and AIDS in the nation (CDC, 2016). Studying perception and use of condom among seronegative gay men in Canada on nineteen semi-structured interviews using SEM, Klassen et al. (2019) concluded that messages only based on safety and risk when speaking of condom usage are biasing other prevention methods' visibility. Strategically, enabling gay men's skills for self-advocacy and setting interventions in communication would have potential positive contributions (Klassen et al., 2019).

Otherwise, using intrapersonal and interpersonal determinants of SEM constructs as a syndemic risk affecting women with, and at risk of HIV in poor urban communities of Bronx, New York, Batchelder et al. (2019) suggested that effective multilevel interventions may decrease perceived financial hardship and risk of violence. For Batchelder et al (2019), self-worth may be understood as a principal driver of HIV vulnerability and the way the infection is affecting the vulnerable population. In summary by similarity, unprotected receptive vaginal intercourse is the common risky sexual practice culturally used in DR Congo. This study would deliver a compound of understandable messages from Congolese PLHIVs and their family members regarding a decade of actions implemented into CBI, and what would have been done to reduce their risky sexual behaviors according to their thoughts. Nothing is scientifically known about their understanding of the anal unprotected sexual behavior at this point.

The second variable to be analyzed in the study will be the *rejection of condom use*. Lacey (2017) presented a study outcome guided by the SEM on perception of Gusii women that women are not to be conducting any public sex conversation with men,

especially on taboo matters such as in condom use when performing sexual health education in Kenya. The author found that female empowerment and bringing the message promoting the use of condom could be done using a culturally sensitive approach. Also, there is a need of building a trusted messenger approach with complex and fluid outsider identity using trainings to replace the old model. Analyzing data results with a comparison group would be an important research tool.

Similarly, Yang and Thai (2017) wanted to know sociocultural factors of spousal HIV transmission as described interfered by the experiences of HIV + Cambodian men. Researchers suggested that men involved with sex workers perceived their attitude as a natural behavior and married men never used condoms during sex with their spouses prior to their HIV diagnosis because according to them, sex is a part of life's pleasures. In fact, condom use is culturally conceived as a barrier to sexual pleasure. Assuming that many Congolese HIV+ patients and HIV- people would've culturally choose sexual intercourse without a condom, an abrupt integration of it could generate questionings and mistrust in a couple. SEM would provide information related to condom use in the Congolese community, and make people understand that cultural behavior needs to be adapted to integrate the condom use with confidence as a daily routine protective tool.

The third variable in the study is known as the *levirate marriage*. The gap in the literature review on this topic is really perceivable. Westreich (2019) highlights the position of Jewish law on posthumous reproduction and its mutual interaction related to the bioethical and legal discussion on that matter. Reading Malungo (2001), levirate marriage or widow or widower inheritance known as *Kunjilila Mung'Anda* in Zambian

cultural mores has come to be implicated in the transmission of HIV/AIDS. The author found that other sociocultural factors are also associated to the spread of HIV in Zambian communities (Malungo, 2001). Some Congolese cultural behaviors are to be identified in order to understand the influence of CBIs within our communities. In fact, from Zambia to DRC, the HIV test is not required prior to the levirate marriage, and the voice of vulnerable widows does not count when it comes to inheritance of a widowed woman after the death of her husband. This study provides a unique opportunity to hear what they think, especially what is the influence of CBIs regarding that cultural behavior in the HIV prevention field. The present study attempts to provide data regarding what is the understanding of a group of HIV+ patients and their family members after more than 10 years of community accompaniment program known as CBIs.

The fourth potential influence variable to be screened in this study will be the *sororate marriage*. Of 5,159 topics retrieved in the literature review performed by Haseli et al. (2019), 82 were qualitative studies associated with infidelity using the SEM . Incompatibility of interpersonal characteristics was found more likely associated with infidelity than incompatibility of intrapersonal characteristics. Similarly, Uchudi, et al. (2019) conducted a multilevel analysis of the determinants of high-risk sexual behavior in sub-Saharan Africa. Authors found on ecological arguments that involvement with several partners is determined by cultural norms and social changes (Uchudi et al., 2019). They suggest from this 20-African country study that health behaviors are shaped and determined by identifiable societal conditions (Uchudi et al., 2019). Sororate marriage needs to be understood as involved in the influence of CBIs.

In this risky cultural practice, widowed men are allowed to take their sisters-in-law in marriage when the spouse is dead. As in levirate marriage, HIV test is neither a requirement prior to the marriage consumption. Unspoken cheating sexual practice generally occurs between the man and his partner even before that cultural event. The practice is culturally accepted in Ngbandi and Mongo tribes in Equateur, DR Congo, with a high probability of condomless usage because of promiscuity. Nevertheless, people from the Congolese culture tend to believe that sororate marriage is a good way of making sure that children are safely taken care of by the sister of a dead woman. This study would provide genuine thoughts from PLHIVs and their siblings, then explain what the influence of a decade of CBIs within Congolese communities was made of.

Shan and Cui (2018) defined the Kongo sociocultural mores known as *Kintwidi phenomenon* as the fact of culturally crediting incest among an uncle and his own nieces. In 2003, the Immigration and Refugee Board of Canada (IRBC) wrote about forced marriage occurring in Yansi tribe in Bandundu, DR Congo, where women are supposed to be protected by a tribal law that makes them stay in the clan. Culturally, people believe that women grow family by giving birth. So, even young girls aged 12 are forced to marry their cousin, uncle, nephew, or grandfather by the tribe elder's decision (IRBC, 2003). This phenomenon never benefited from sustainable documentation, especially when it comes to understanding the sexual vulnerability of teens, CBIs applied in Bandundu province and risks of HIV/AIDS.

By analogy, it appears clearly that Kintwidi phenomenon is a twin-concept of a culturally tolerated forced marriage. In this situation, HIV is not the only risk disease

factor, but also because of consanguinity and biological risk factors, other morbidity occurrences could affect the offspring from a Kintwidi marriage. Consequences of a permanent widow status for a young, widowed lady could be perceived as the offered spouse would grow older. For the widow, the old man might die just a couple of years after the first loss. Now, how do PLHIVs under CBI understand the influence of CBI after 10 years of the program? And how family members think of the consequences in the community. This inquiry would suggest some comparable answers to those questions through HIV+ patient interviews, focus groups and key informant opinion.

The sixth variable to be understood using SEM ,will be *sexual gender-based violence (SGBV) and female genital mutilation (FGM)*. Palma and Parr (2019) used SEM through eighteen semi-structured interviews to understand the HIV vulnerability of Filipino prisoners. Using the framework analysis at the individual, community and social levels, findings revealed the increased vulnerability of Filipino women prisoners to HIV in the sample interviewed shaped by low knowledge (Palma & Parr, 2019). As noticed in the Yansi tribe example above, forced marriage is an SGBV and can be traumatizing. A data analysis performed by Shahabuddin et al. (2017) in Bangladesh from explaining maternal health-seeking behavior regarding married adolescents suggest that four levels of SEM factors need to be taken into consideration. All because adolescent girls illustrated very little decision-making autonomy, but interpersonal and family levels played an important role (Shahabuddin et al., 2017).

A twined factual situation related to SGBV and FGM suggests that these entities are not only traumatizing, but also a smooth transmission means for HIV particles.

Twenty years of armed conflict in DRC might have generated many HIV+ cases in the community. Listening to what PLHIVs think and trying to understand what their family members say through 10 years of CBIs could provide scientific information on their understanding. Mswela (2010) focused on trying to understand the connection between HIV/AIDS, sexual inequality, sexual violence, especially FGM and other cultural practices. Once again here, the twined factors SGBV and FGM will be examined with rigor and scrutiny as a qualitative study.

Chronologically, *stigma and/or discrimination* for HIV/AIDS are/is going to be the seventh variable of this study. As with Placek et al (2019), Amzel et al. (2018) studied negative effects of interrelated factors on the psychosocial wellbeing of children with HIV, such as disclosure, stigma, and discrimination. Authors suggested that a CBI with family-centered support around a free-stigmatization environment is more effective and provide strong psychosocial support to the individual (Amzel et al., 2018). Williams (2014) highlighted a community-wide discrimination of PLHIVs in South Africa, making HIV + patients more likely to experience rejection and discrimination. Indeed, people undergoing HIV stigma and discrimination tend to hide. They decrease important contacts such as with community organization supports, health support institutions, and social networking contacts. They feel banned and rejected by their own community, then consequently tend to depress in solitude. HIV+ patients and other family members living around them would provide potential answers of the impact of CBI through a qualitative methodological study questioning.



The eighth and the last variable to understand will be *sexual cleansing* (Vera, et al., 2018). According to IRBC (2003), the inheritance of widows is practiced in more than 100 Congolese tribes. That belief supports that, widowed girls or women are a property of the family when husbands die, since her family was given a dowry. Because widowed bear evil spirits from their died spouses, they need to be cleaned up. The special ritual process that consists of getting rid of those impurities is to be forced to sleep with a chosen man in the society (IRBC, 2003), or an intellectually disabled person in the community. In the article written by Vera et al (2018), sexual cleansing is a risky practice found beyond Congolese borders. The man supposed to help the widow get rid of the bad spirit will never be tested for HIV prior to that unprotected sexual contact. Conversely, nobody would know the serological status of the widowed person if no tested. In most of those ritual contacts, sexual risk of HIV transmission could be stated bidirectional, because the man can transmit HIV to his sexual partner and the other one could also do the same, depending on the individual vulnerability.

Confirming the practice of sexual cleansing in Africa, Malungo (2001) suggested that some cultural rituals promote the transmission of HIV/AIDS as in Zambian communities by their practices. For example, sexual cleansing is culturally meant to set a widowed woman free from bad spirits after the death of her spouse. This is a dangerous cultural practice composed of several unprotected sex intercourses that could potentially lead to HIV infection. Coming in physical contact with a semi-nude person can be viewed as a normal sexual intercourse in their mindset (Malungo, 2001).

In this chapter, a total of fifty-six topics have been reviewed with forty-five qualitative articles, combined with one mixed study on top of nine books. All the books were informative regarding the Socioecological model, or this selected qualitative method with an emphasis on ethnography. Otherwise, because of its interest in the conclusion, one syndemic study (Dao et al, 2019) was willingly integrated here, showing the interrelation of mutually reinforcing risk factors of HIV/AIDS among indigenous highland communities in Ecuador. The literature review with both theories helped identify individual factors impacting the human behaviors regarding HIV, and extra-individual factors with the SEM related to the environment in which the person is living (Glanz et al, 2015). Some articles provide details on sociocultural factors having an impact on human behavior; however, no one of them is designed to decrypt any potential behavioral influence on Congolese PLHIVs from all CBIs implemented.

Mullerschon et al (2019) wrote about a survey performed in Germany from January 2015 to February 2016 among sub-Saharan African migrants regarding their knowledge, attitude, behavior, and practice (KABP). Authors revealed that introducing health insurance within that migrants' community increased the odds of having done the HIV test. It is also well known that leaving the community for work, unprotected sex, barriers to healthcare, and substance abuse such as alcohol & drug consumption have a mutual reinforcement with HIV/AIDS rate among the indigenous highland communities in Ecuador (Dao et al, 2019). In order to understand the Congolese issue at the individual level, the SEM best fit in this study to explain how PLHIVs understand the influence of

CBI applied in Congo, because other stages of the SEM would take care of describing the relationship with people's sociocultural behavior.

### **Summary and Conclusions**

Major themes treated in the literature review of this cross-sectional research targeted risky sexual behaviors, cultural facts, and mores in poor communities, and then CBIs implemented in different social layers to improve the quality of life among PLHIVs. The reasoning framework chosen is based on the SEM of understanding by similarity and through the existing literature, the probable social impact of CBIs as applied in DRC. For instance, a systematic review of 33 studies regarding health benefits from positive reappraisal copying (PRC) with Finkelstein-Fox, Park, and Kalichman (2019) suggests that depending on the contextual factors, the PRC approach is beneficial on PLHIV when working on the implications of a potentially traumatic diagnosis.

However, nobody knows how much the influence of each CBI components is on transforming PLHIV's behavior in DR Congo. Data collection from in-depth interviews, key informants, and focus groups will depict group-centered information regarding community HIV-driven programs and patients' point-of-views. It will ultimately attempt to explain the gap in HIV rates between DRC and its surrounding countries. Participants will be selected by *snowball sampling method* from at least five important cities of DR Congo in order to conduct a pilot qualitative study self-reporting the influence of the CBI program implemented since 2004. Chapter 3: Research Method

## Introduction

The purpose of investigating potential behavioral changes among Congolese PLHIVs is to understand whether CBI programs implemented in the DR Congo have had a real impact on people's sociocultural behaviors as expected, since such programs were previously designed to decrease the incidence of HIV among Congolese communities. This qualitative study was an ethnography one, synchronically employing a few in-depth interviews, key informant techniques, and focus groups around at least two Congolese provinces where CBIs had been applied in HIV+ communities since 2004. Investigation of several cultural factors enabled this research in (1) FGM and SGBV (Fawole, 2018; WHO, 2019), (2) unprotected receptive vaginal or anal intercourse (WHO, 2018), (3) condom rejection use for cultural reasons, (4) levirate marriage, or the custom decreeing the marriage of a widowed brother-in-law to a matrimonial cousin, (5) sororate marriage, or getting married to a dead wife's sister (Malungu, 2001; Westreich, 2004), (6) the "Kintwidi phenomenon," or the Kongo tribe's mores of incest between an uncle and his own nieces (Shan & Cui, 2018), (7) sexual cleansing, or a Mongo tribe's mores spiritually setting free a widow by having unprotected receptive sex with another widow or a mentally disabled person (Vera, et al, 2018), and (8) stigma and discrimination.

In practice, a comprehensive CBI with the following parts took place in Congolese communities since 2004 as follows: (1) outreach and VCT programs applied in the 11 old provinces (PEPFAR, 2017), (2) home visits for known patients, and (3) IGAs to help PLHIVs reintegrate their previous natural occupation. Thus, the significance of this enquiry is to fill the gap in the understanding of the impact of CBIs

among HIV+ individuals' behavior at the intrapersonal and the extra personal levels in DR Congo during the decade starting in 2004. Because no researchers have been able to explain why the Congolese HIV rate is so low – less than 1.3% (Ministry of Plan, 2014) compared with other countries in the central African region – cultural approaches could represent a problem-solving outlet, based on existing ways PLHIVs and their family members understand the HIV crisis in sub-Saharan Africa. The expected results of this qualitative research would be suggested as an alternative to improve the quality of life for other Congolese HIV+ people.

In this chapter, I will provide the main research questions of the study. Also, the role of the researcher will be described, explaining different ways of avoiding biases and ethical issues because of personal relationships with participants. Then in the methodology section, the sampling strategy and selection criteria will be provided prior to understanding the specific data collection instrument, its appropriateness, and the data analysis plan. The credibility, dependability, hypothetical transferability, confirmability, and reliability of this study will be described to understand the trustworthiness of the enquiry, and I will discuss the ethical procedures involving the IRB. This chapter will close with a summary, but the starting point is the research design and its rationale in the following section.

### **Research Design and Rationale**

Three main research questions will guide this 10-year *cross-sectional* social study among HIV+ persons living in DRC and their family members:

RQ1: In what ways has participation in CBIs impacted sexual behaviors among Congolese PLHIVs and the community in general?

RQ2: What is the meaning of CBIs for family members?

RQ3: What are the detailed sociocultural behaviors impacted at the end of different CBI projects?

As the main concept of the study, *behavioral change* is the phenomenon under study that leads all observations from the initial behavior status. However, as previously stated, when using a self-report approach in this context, participants provide their own opinion for research purposes. Because all of the participants in the study are HIV infected, this could potentially be the starting point of the HIV spread within and outside the community if they do not behave positively where they live. That is why a control group was used as a comparing scientific tool. According to Davis, et al. (2015), theories of behavior have a linearity that explains why behavior may occur after considering a number of predictors associated with one another having a probable impact on a particular attitude. SEM is believed to provide comprehensive frameworks to understand the variety and interacting determinants of health within and outside of social layers (Salazar et al., 2015). To make connection with practice, Hickson et al. (2015) suggested a Minority HIV/AIDS Research Initiative (MARI) to understand the rationale of sexual behaviors and HIV/STI among 800 African American MSM in the southeastern United States. The traditional HIV environmental riskscape has shown empirical evidence that HIV transmission risk among a targeted population of African American MSM is highly affected in the deep south (Hickson et al., 2015). As a tool for digging into people's

tradition, ethnography was an interesting, well-suited tool to support this study, as cultural behaviors are involved when it comes to understanding individuals' thoughts regarding sociocultural mores among Congolese HIV+ persons.

### **Role of the Researcher**

My role as the main researcher was to conceive the primary study-frame designed to help HIV+ patients understand the meaning of diverse sociocultural concepts involved in CBIs. Framing a study involves suggesting not only data collection tools, but also making sure beyond methodology appropriateness that ethical issues are considered and data are analyzed as required. To understand how much a decade of CBIs more likely impacted thousands of Congolese HIV+ patients' lives and their family members (Fertman & Allensworth, 2017), I used the SEM as a bias-free approach, standing as the theoretical foundation for this ethnographic study in Congolese communities.

Because of the Coronavirus (COVID-19) pandemic, a remote collaborative data collection approach was chosen. As Mbandaka was unselected for bias prevention purpose, a trained research assistant was used to monitor and gather data when the Internet connection dropped off. According to Salazar et al. (2015), in inquiries and practices involving behavioral issues and interventions, researchers must consider the principles of ethical practices. Therefore, two Congolese provinces participated in the project to ensure the equilibrium and the flow of the information without any external influence. In fact, the high frequency of African patients dying from HIV and multiple patients away from ART medications would suggest a purposive patient-centered selection sampling method, based on snowball sampling technique. But using this

technique runs the risk of selection bias. For instance, personal relationships with patients may alter the quality of interviews if performed only by the main researcher, producing information bias. According to Babbie (2015), relationships involving power over the participants lead to ethical concerns, especially in research on human sexuality. Involving a research assistant in data collection was my first choice since travelling to DRC requires quarantine and multiple administrative inquiries. The alternate option was to withdraw Mbandaka from the study and organize the remote data collection with Kinshasa and Bandundu. This would impact personal research goals because I wanted to know objectively if something has changed in my community after 10 years of CBI actions in terms of behaviors.

Thus, increasing the number of sites from one to three and having a comparison group reduced bias risks. Aschengrau and Seage (2014) defined bias as a systematic error occurring in a design or conduct of inquiry that leads to an erroneous association linking the exposure to the illness. In the literature review, epidemiologists distinguish two types of biases: *selection biases* and *information biases*. A selection bias is an error resulting from the manner employed to select subjects and from factors having an influence on participation in the study (Gerstman, 2015). Indeed, more than 50 types of selection biases have been identified. An information bias occurs from a systematic difference in the way that the exposure or result is measured between compared groups (Aschengrau & Seage, 2014). Choosing both to collect data from Mbandaka and stay as data collector would not be a selection bias, because we have planned to potentially gather correct data with written and audiotaped interviews from the prospectus. However, collecting



information from known patients with personal relationships could generate information biases. Also, the teamwork should avoid *self-selection* bias and decrease *loss to follow-up* (Aschengrau & Seage, 2014). The number of participants, their age, sex, and other socio-demographics may impact outcomes regarding self-reporting influence of CBIs among PLHIVs.

Throughout the data collection process, focus groups could be potentially viewed as less offensive because of the number of participants, since one of the group members can answer several questions (Rubin & Rubin, 2012), but at a certain point in-depth interviews and key informant approach could generate a high rate of information biases because I could face old patients or identifiable PLHIVs from Mbandaka. That situation could shape recall biases from the patient, because emotionally forgetting what happened in the past, or interviewer biases led by an underappreciation of the patient's health conditions after being in the program for so many years (Aschengrau & Seage, 2014). At the end of the interview, misclassification bias could also occur either from the participant or from the interviewer by misunderstanding a question.

Another intrusive factor that could disturb the research process is confounding. Indeed, confounding can be confused with bias, but it is known as a distortion fact in an association between an explanatory variable and the response variable provided by the influence of extraneous factors (Gerstman, 2013). Fundamentally, questions related to HIV and AIDS must be understandable at the very low education level in order to meet the level of participants. People who never been involved in a CBI are more likely to get less information than others, but the education level could be a compensatory factor.

Meanwhile, voluntary participation and informed consent were the guiding principle of this study. Salazar et al. (2015) suggested an exclusive integration of the Belmont report when performing a study on human beings. The authors stated that respect for persons, beneficence and psychosocial risk, and justice must apply to ensure the reasonable and nonexploitative research procedure (Salazar et al., 2015). Finally, I opted for self-removal from data collection in Mbandaka because the IRB would probably never allow me, who previously worked in that site, to collect information from Equateur, DRC. But that risk of bias could be minimized by the research assistant who will play a great role in checks and balances in data collection.

## **Methodology**

### **Participant Selection Logic**

This is a cross-sectional study collecting 10 years of information using a community HIV-centered approach. Rudestam and Newton (2015) highlighted that data gathered in qualitative studies are expressed in words, the reasoning is inductive, and depending on the topic analyzed, the phenomenon of study could be naturally occurring or contextual. In fact, three important groups of people are targeted in this study: (1) eligible middle school education level (or above) HIV+ patients under CBI from 2004 to 2020 in three of 26 provinces of DR Congo, (2) adult family members of PLHIVs who lived with them for at least 6 months under the CBI program, and (3) HIV negative people or unknown serostatus individuals who never been in any CBIs for comparison reasons. The selection logic was done with no gender, no religious, and no social class discrimination, and all participants needed to provide proof of identification and be at

least 18 years old on the starting day of data collection. Also, at least two of the following cities using CBI with HIV treatment centers would be selected to conduct the study:

Bandundu, and Kinshasa.

These qualitative data were remotely collected in late 2020 from DRC, after the Walden IRB approval, and under the guidance of the Congolese Ethics Association. Accordingly, the sampling method was purposive, since a qualitative researcher is more likely to deliberately seek knowledgeable respondents who can contribute significantly to the expected outcomes (Rudestam & Newton, 2015). Because HIV is a sensitive matter, participant selection was based on confidentiality, using informed consent and voluntary participation for either PLHIVs aged 18 and above under CBI project with at least middle school education level, or adult family members living with PLHIV for at least six months. Synchronically, groups of non-HIV people or unknown serostatus individuals composed a comparison group. Selected participants claimed to meet the criteria at their non-disclosure mode choice of communication, after the local committee board named selected participants in a confidential signed-coded list containing only identification initials of elected respondents for the study. Each site had two gender-based focus groups, six in-depth qualitative interviews, and six gender-based key informant persons.

Based on two chosen sites, four to six focus groups of eight to 14 people equally selected on gender basis resemblance occurred over two hours, with 18 in-depth qualitative interviews of one and half hours each, and 60 minutes of six key informant persons through the three selected sites. This was equally divided by study groups and comparison groups to avoid an initial unbalanced database. Data were audiotaped (Zoom

meeting), and depending on selected sites, focus groups took place either among PLHIVs or identified family members in order to have at least 20% of their opinion as outcome. This was the same for other data collection layers, and people who had never been in any program were also interviewed for comparison reasons. The in-depth interviews were semi-structured and unstructured (Robin & Robin, 2012). Semi-structured interviews were privileged, and the gap in literature review regarding the influence of CBI programs applied on PLHIVs in DR Congo and the difference in HIV seroprevalence with neighboring countries were emphasized as the rationale feeding this study. An existing local HIV+ patients' network was used to generate participants in each provincial coordination of the National HIV/AIDS Program known as Programme National de Lutte contre le Sida.

Around the research assistant, leaders of HIV+ patient groups were physically contacted, and snowball sampling approach took to integrate new participants. Fortunately, no pressuring cellphone call intervened for that purpose. Subjects will be suggested to make a choice for either in-depth qualitative interview or focus group if age-frame meets the local age interval chosen for no more than four years between the youngest and the oldest respondent. Participants had a choice to not integrate any group, and informed consent forms were available for those who accepted to voluntarily participate in the research. It was clearly stated that self-removal from interview could deliberately happen whenever the participant wants to. The education level was required in order to accede to an acceptable quality of outcomes when asked questions by the interviewer either in French or in Lingala (National language). Even though one focus

group by site should be enough, data collected need to be gender-based balanced in order to avoid bias. Indeed, saturation is used in qualitative research as a tool for discontinuing a data collection process or an analysis. An open-ended question was provided at the end of each interview to allow HIV+ patients freely speak out and make statements regarding potential changes from CBIs applied. The time limit scope of the interview was a benchmark guideline, at the same time saturation was supposed to be significant when collecting redundant information from all the eight or 14 participants of each focus group, or when critically starting to collect biased data from interviewees.

### **Instrumentation**

As Creswell and Creswell (2018) summarized, the researcher conducts face-to face interviews with participants in qualitative studies, and they could be also interacting in open-ended unstructured questions. The investigator has a choice to collect information using adaptive tools, such as audiovisual or digital materials (Creswell & Creswell, 2018). The use of in-depth interviews in this case is compatible with interview protocol and audiotape equipment to double record data. Focus group will benefit from genuine focus group protocol and audiotaping technique, and data from key informant persons will be also gathered in an audiotaping fashion using key informant protocol. A well-planned preparation of data collection is a key step for a successful research (Babbie, 2015). In this case therefore, each data collection instrument will be researcher produced. The author suggests that the impression you made on the informant, the way you established contact with him or her and the way you identify yourself designs your data

collection quality (Babbie, 2015). Some observation notes will be taken regarding the lifestyle of participants, and data recording will be done according to ethics and procedures.

With the research assistant, another important step in instrumentation usage would be in the use of qualitative documents. Most of data related to qualitative documents have been previously recorded by the institution. HIV+ patients and family members as well will be selected from a list established by an organization taking care of them, where they can be identified as benefiting from a CBI program. Failing to provide information regarding an HIV+ person is an exclusion criterion from the research group; however, the person could be selected in the comparison group of research. Therefore, private documents such as register books, meal distribution plans and monthly reports will be used for data collection purpose.

### **For Published Data Collection Instruments**

The Congolese Health System uses what is known as the National Information System or *Système National d'Information Sanitaire (SNIS)* in French. Internal qualitative documents would be the foundation of the official and the private tools, upon which the attention will be focused in this study. Starting by a contact with the Congolese Office of Ethics in the Ministry of Higher Education and Research, possible information will be requested starting from 2004 through 2015 at the Ministry of Health through the DLM (Direction de la Lutte contre la Maladie), PNMLS (Programme Multisectoriel de Lutte contre le Sida), PNLS (Programme National de Lutte contre le Sida), United Nation World Food Program (WEP) and INRB (the National Institute of Biomedical Research).

The second stage of action will be based on meetings with local partners such as DREAM (Sant Egidio), ACS AMO Congo, CORNERELA, Femme Plus, and different provincial health departments of selected provinces. All their 10-year registers will be screened by the researchers for possible qualitative data collection purpose with confidentiality and respectfulness of HIPAA requirements.

Some data collection tools have been used since the CBI program started to record information regarding activities for PLHIVs and orphans' vulnerable children (OVC). In this case, measuring a possible change in behavior after CBI (validity) and understanding the degree to which scale produces consistent changes in behavior matter (reliability). Indeed, showing that the data quality related to behavioral change is well founded and the fact that the expected result depends on that procedure means both validity and reliability (Rudestam & Newton, 2017). Assuming most information registered in those agencies are quantitative, an interview protocol will be made for qualitative data collection. However, data provided by the SNIS (the state tool) will go through a quality assurance process with all partners at the national level. The internal validity of this study will be screened (as validity of a causal inference), at the same time its external validity (as generalizability of findings), and finally the probable reliability of the existing Congolese HIV database. Cultural information will be mainly utilized as required the Congolese mores, and information regarding sexual statements will be kept confidential.

### **For Researcher-Developed Instruments**

This inquiry is a unique behavior cultural-driven study conducted at least a decade

after performing an activity devoted to addressing HIV/AIDS issues within Congolese communities. Because there is no reference in terms of instrument development prior to this inquiry, a *pilot study* was remotely conducted at 33.33% from one of the three preselected locations in 2020 (Rudestam & Newton, 2017), and 66.67% others will follow in 2020. Then, in-depth interviews, focus groups and key informant protocols will benefit from tests of instruments made up by the principal researcher. However, in open-ended interviews, a sole blank pen-to-paper approach is required, mixed with audiotaping procedure for data safety (Rudestam & Newton, 2017). It is known that content validity is related to how much a measure covers a range of explanation included within a concept (Babbie, 2015), and reliability is linked to the replicability of the results under similar inputs (Rudestam & Newton, 2017). After the data collection meeting, the main researcher proceeded with the validation of data collected through the Congolese National Information System (SNIS) throughout each selected province. Eighteen focus group protocols were printed out in both French (official language) and Lingala (one of the four national languages and the most popular) in order to be understood in the remote areas, then 36 printed protocols for in-depth interviews, and then twelve others for key informant person interviews.

### **Procedures for Pilot Studies**

In this research, the pilot study took place remotely to better experiment the option of having both a study group, and a comparison group as suggested. People who never have been in a group of Congolese CBI actions were randomly selected with unknown HIV serostatus to seek for behavioral change without any intervention in the



comparison group. In the comparison group, voluntary participation was based on a random selection of 3 interviewees, 3 key informant persons, and eight to 14 respondents of focus group through a list of volunteers. The pilot study will help fix potential ground issues and figure out how to improve the future main study. At the same time, the snowball sampling was the main technique of choosing HIV+ participants in the pilot study and their family members to be interviewed in the study group. All recruitment procedures in this study will be conducted by the main researcher, in full respect of the persons, the HIPAA and human beings in general. For Shi and Johnson (2013), the process of reflection in ethics is imaginative and analytical, it provides an opportunity for leaders to engage in building relationships with their communities. This will help to manage a generalizable experience in other two remaining Congolese sites of data collection.

### **Inclusion Criteria**

These groups of people are potentially registrable on the list of respondents: voluntary participants to be at the same time HIV+ patients under CBI project in one of the provinces of DR Congo for at least 6 months, who can also present either a state issued identification proving aged at least 18 the day of the inquiry or a proven genuine state birth certificate, middle school education level minimum, be a French speaker respondent or Lingala, respondent availability stated at the data collection day, or adult family members who had lived at least 6 months with PLHIV during CBI, and confidentiality in the study group. Being a participant in the comparison group does not require a serostatus identification; however, age and other criteria are the same.

**Exclusion Criteria**

This category of people would not be selected as respondents in the study: PLHIVs with less than 18 years, family members of less than 18 age, people currently sick, and PLHIVs with mental disability under Folstein Test or Mini-Mental State Examination (MMSE) testing the cognitive function below score 24. The Psychiatry & Behavioral Health Learning Network (n.d.) suggests five to 10 minutes MMSE test for detecting cognitive impairment, assessing severity, and monitoring cognitive changes over time.

Participants were selected after the initial partner meeting based on snowball sampling principles before January 2020 (Ravitch & Carl, 2017). In this case, respondents recruited their peers using confidentiality and dignity. Data for both the pilot and the main study were registered in the main researcher's computer and a movable memory tool will be kept safe at the personal strongbox. The pilot study was a sampling test of 33.3% of cases in one single city in December 2020, with data collection, synthesis, analyze and assessment with comments. Because favorable, the main study took place by implementing the remaining 66.7% of data collection. This third chapter is a part of five chapters composing my proposal that was submitted for IRB approval.

**Procedures for Recruitment, Participation and Data Collection**

Involving a research assistant, the selection of participants in study groups and comparison groups was done according to the principle of voluntary participation. HIV negative and unknown serostatus respondents of age 18 and older were selected in the comparison group, while HIV+ patients and family members of age 18 and plus were

selected into the study group. Respondents were informed regarding their all benefits and the expectations of the study, then it was clearly stated that self-withdrawal from participation in this enquiry could happen any time and whenever the person feels free to leave the study. All the respondents were asked to stay in touch with the researcher after data collection, because of possible return for follow-up interviews for clarifications.

The three following tables related to 3 research questions explain the procedures of recruitment of respondents, their participation in the study and data collection process according to the type of technique designed by the researcher.

**Table 1**

*Research Question 1 - In What Ways do Participation in CBIs has Impacted Sexual Behaviors among Congolese PLHIV and the Community in General?*

Data collection type versus process	In-depth interview protocol	Focus group protocol	Key-informant person protocol	Observation tool
From where	3 sites: 1.Kinshasa, 2.Bandundu, 3.Mbandaka	3 sites: 1.Kinshasa, 2.Bandundu, 3.Mbandaka	3 sites: 1.Kinshasa, 2.Bandundu, 3.Mbandaka	3 sites: 1.Kinshasa, 2.Bandundu, 3.Mbandaka
Data collector	Main researcher	Main researcher	Main researcher	
Frequency	Once per participant	Once per group	Once per respondent	
Duration	45 minutes	60 minutes	30 minutes	10 minutes
Recording	Paper sheet-based questions and audiotaping	Paper sheet-based questions and audiotaping	Paper sheet-based questions and audiovisual taping	Blank sheet and pens
Follow-up	Arranged home visit	Respondents replacement	Arranged home visit	Arranged home visit

**Table 2**

*Research Question 2 – What is the Meaning of Community-based Interventions for Family Members?*

Data collection type versus process	In-depth interview protocol	Focus group protocol	Key-informant person protocol	Observation tool
From where	3 sites:	3 sites:	3 sites:	3 sites:

Data collector	1.Kinshasa, 2.Bandundu, 3.Mbandaka 1,2 and 3: Main researcher	1.Kinshasa, 2.Bandundu, 3.Mbandaka 1,2 and 3: Main researcher	1.Kinshasa, 2.Bandundu, 3.Mbandaka 1,2 and 3: Main researcher	1.Kinshasa, 2.Bandundu, 3.Mbandaka 1,2 and 3: Main researcher
Frequency	Once per participant	Once per group	Once per respondent	
Duration	15 minutes	30 minutes	15 minutes	10 minutes
Recording	Paper sheet-based questions and audiotaping	Paper sheet-based questions and audiotaping	Paper sheet-based questions and audiovisual taping	Blank sheet and pen Pictures
Follow-up	Arranged home visit	Respondents replacement	Arranged home visit	Arranged home visit

Table 2 to continue

**Table 3**

*Research Question 3 - What are the Detailed Sociocultural Behaviors Impacted at the End of the Projects?*

Data collection type versus process	In-depth interview protocol	Focus group protocol	Key-informant person protocol	Observation tool
From where	3 sites: 1.Kinshasa, 2.Bandundu, 3.Mbandaka	3 sites: 1.Kinshasa, 2.Bandundu, 3.Mbandaka	3 sites: 1.Kinshasa, 2.Bandundu, 3.Mbandaka	3 sites: 1.Kinshasa, 2.Bandundu, 3.Mbandaka
Data collector	1,2 and 3: Main researcher	1,2 and 3: Main researcher	1,2 and 3: Main researcher	1,2 and 3: Main researcher
Frequency	Once per participant	Once per group	Once per respondent	
Duration	30 minutes	30 minutes	15 minutes	10 minutes
Recording	Paper sheet-based questions and audiotaping	Paper sheet-based questions and audiotaping	Paper sheet-based questions and audiovisual taping	Blank sheet and pen Pictures
Follow-up	Arranged home visit	Respondents replacement	Arranged home visit	Arranged home visit

Self-withdrawal of participants is one of the guiding principles of social studies (Salazar et al, 2015; Babbie, 2015). In fact, respondents were clearly explained that they are free to exit the study anytime they want in a simple procedure. Meanwhile, respondents prescheduled in this study for an interview could be revisited if any valid reason occurs while implementing data collection. For instance, a natural disaster

occurring, an unexpected sickness, a hospitalization of a child, a war, or any other acceptable reason that could prevent a participant from attending on time data collection site. Follow-up procedures was planned to occur in physically meeting the person at home, of after the individual decided to reach out to the team. Missing a focus group will potentially not affect the study project, until the sample size decreases below six (Babbie, 2015).

### **Data Analysis Plan**

Collecting data related to the influence of CBIs on behaviors of HIV+ persons under the program required the use of computer-assisted qualitative data analysis software (CAQDAS). Fortunately, self-report is based upon what the individual knows and ultimately what has changed so the coding process was used as the main way of getting qualitative data ready for analysis with CAQDAS (Rudestam & Newton, 2017). Saldana (2016) warned researchers about one of the most frequent concerns that they usually feel overwhelmed by the wide array of coding methods to choose for data analysis. For instance, magnitude coding allowed a choice to a respondent between 3 = high, 2 = medium, 1 = low, and 0 = none (Saldana, 2016).

### **Table 4**

#### *Data Analysis Process*

Recherche questions versus data analysis	RQ1. In what ways do participation in CBIs has impacted sexual behaviors among Congolese PLHIV and the community in general?	R.Q2. What is the meaning of Community-based Interventions for family members?	RQ.3. What are the detailed sociocultural behaviors impacted at the end of the projects?
Connection of data	Interview, focus group, key informant transcripts	Interview, focus group, key informant transcripts	Interview, focus group, key informant transcripts

Type and procedure of coding	Transcripts Microsoft Word, then Excel using double cycle <i>magnitude</i> coding	Transcripts Microsoft Word, then Excel using double cycle <i>magnitude</i> coding	Transcripts Microsoft Word, then Excel using double cycle <i>magnitude</i> coding
Software in use	QRS NVivo 11	QRS NVivo 11	QRS NVivo 11
Manner of treating discrepant cases	Avoid descriptive coding approach	Use selective code repeatedly	Subsume codes into broader codes or categories

Table 4 to continue

### Issues of Trustworthiness

Yanget al. (2016) performed a qualitative study collecting information on the validity of the culturally embedded risk factors for Cambodian husband-wife HIV transmission in Phnom Penh, Cambodia. Authors used 15 in-depth interviews from women becoming infected with HIV from their HIV+ husbands (Yang, Lewis, & Wojnar, 2016). Interviews were conducted in Khmer, and trustworthiness of study outcomes was protected through peer debriefing, coding process to consensus and maintaining an audit trail (Yang et al, 2016). That is why in order to increase data trustworthiness in this study and obtain the IRB approval, informed consent, minimal risks, anonymity, confidentiality, trustworthiness, voluntary participation, and guaranty of withdrawal every time while organizing the research were required (Babbie, 2015).

Qualitative *validity* referred to the scale measuring exactly what the tool is supposed to measure (Salazar et al., 2015). Multiple validity procedures were engaged to establish the credibility of this study, such as (1) *triangulating* different data sources instead of collecting information from one single site, (2) *member checking* approach by comparing obtained results from participants' information, (3) *rich, thick description* or detailed descriptions of the setting with site transportation possibility, (4) *bias* clarification from self-reporting with an attention on social desirability bias, inaccurate

recall bias, selective recall bias, (5) *discrepant information*, (6) spending *prolonged time* in the field for data collection verification purpose, (7) using *peer debriefing* to improve the accuracy of the account, and (8) employing *external auditor* to review the entire project of the study (Creswell & Creswell, 2018).

The reliability of this study was checked through documentation related to the procedures of using self-report to understand the effects of CBI among HIV+ persons in DRC. The database set up must reflect information collected from the respondents (Creswell & Creswell, 2018). This will be done by (1) checking the transcripts, (2) removing drifts from code definitions, coordinating the communication among coders through regular documented meetings and sharing analyses, (4) cross-checking codes from other searchers (Creswell & Creswell, 2018). Probable transferability or external validity will be assumed by providing enough contextual data related to CBI and framing for outsiders to be fully able to contextualize the study (Salazar et al., 2015). Also, the dependability will be based on audit trails and triangulation approach, according to the fact that this qualitative study has a pioneering inquiry collecting information regarding how respondents understand the effects of their own sociocultural facts (Creswell & Creswell, 2018; Salazar, 2015). The counterpart to objectively observing cultural facts would define the confirmability of this qualitative study, checking if someone around provided similar results to an identical study (Ravitch & Carl, 2016). At the end of the data collection process, it would be imperative to make sure the conclusion reflects information as provided by the intra-and intercoder chain.

## **Ethical Procedures**

One of the major responsibilities of any researcher is to act always in the ethical manner when working (Rudestam & Newton, 2015). Social research is a naturally person-centered approach of understanding and explaining different phenomena occurring around the world, so the authenticity of the relationships between researchers and respondents is fundamental (Ravitch & Carl, 2017). Conducting a research on human beings is delicate and requires high standard ethics usually managed at universities by the Institutional Review Board (IRB) (Babbie, 2015). University IRBs formalize research ethics and institutionalize procedures to guaranty that the *informed consent* of the participant is freely obtained prior to entering any research project (Rudestam & Newton, 2015, Salazar et al, 2015). Therefore, the IRB agreement must be obtained prior to any field contact with respondents, based on potential ethical issues linked to HIV worldwide and the current COVID-19 pandemic.

After the Walden IRB approval, the Congolese Committee of Ethics (CCE) will be contacted with the Walden approval document in order to proceed with data collection under the agreement of the Congolese Research and Health Ministries as required by the law in DRC. These agreements will guide all contacts with the National Program addressing HIV/AIDS (PNLS) and participants. The treatment of human participants in this study will respond to the following principles: (1) voluntary participation using the golden rule of informed consent, (2) no harm to the participants, (3) anonymity and confidentiality (Babbie, 2015). So, I will need: (1) the IRB approval, (2) a CCE permission, (3) a letter of the Ministry of research, (4) an authorization of the Ministry of



Health, (5) a PNLs Approval, and (6) the individual informed consent letter before starting data collection.

The recruitment was done using PNLs Bandundu and other institution registers (General Referral Hospital of Bandundu and ACS AMO Congo) with the research assistant under the supervision, but snowball sampling will be used for homogeneity and fluidity in communication between peers. The initial group of selected respondents will receive a briefing related to confidentiality and the anonymous character of data collection (Babbie, 2015). The main elements of informed consent were based on time commitment, benefits to be expected, potential risks and how to handle them, explain the voluntary participation in the study, advise the participants of payment, explain the limits of confidentiality, and inform them about the debriefing (Rodeham & Newton, 2015). The use of audiotape (PLHIVs and siblings) and audio taping (key informant) was explained to the participants. Self-withdrawal could occur anytime, and allow questions before, during and after data collection. Ensure a permanent confidential plan of communication with participants whenever they want.

Under the main researcher guidance using the virtual technology, data collection was done anonymously on interview protocols, focus group protocols and key informant protocols. Confidentiality was the main principle, data collected are kept on paperwork, the Sony audiotape device, and CDs at the main researcher's office with a coding identification system. Currently, a double secure system using lockers is employed. Only the main researcher has access to it. Then information dissemination will be done according to the legal process, and data will be systematically destroyed after 10 years

storage if no more needed. The use of data collected for audit reason will be possible since PNLN is the National organization taking in charge all database related to HIV/AIDS, but I will manage different ethical issues related as applicable, and I will be accountable for data collected, especially because of the virtual data gathering. Only paperwork from the main researcher is kept, but all information collected from the ground will be shredded at the KSPH after quality assurance work with both documents.

### **Summary**

This cross-sectional ethnographic and qualitative study grounded on *Socioecological Model* is meant to facilitate self-report on the Influence of Community-Based Interventions on Behaviors of HIV+ Persons in Congo-Kinshasa. A literature review based on the following approach has been used to design the research pathway: searching data from Internet, reading personal books from home, physically searching from bibliographic database, scanning bibliographies of existing reviews and eligible studies, handing search key journals at Pierce County Library and the Tacoma Public Library, forwarding citation search of seminal articles, and contacting scholars working in the area. Indeed, fifty-six HIV topics have been reviewed with forty-five qualitative articles, combined with one mixed study on top of nine books read. The study screened some African risky sexual behaviors, cultural facts, and mores in poor communities, and then how CBIs have been implemented in different social layers to improve the quality of life among HIV+ persons. Ethical principles and the research framework designed the way the researcher will implement activities in partnership with participants.

To conclude this chapter, eight main variables are being examined using SEM through this plagiarism and bias-free writing, such as: levirate marriage, sororate marriage, Kintwidi phenomenon, unprotected receptive vaginal or anal intercourse, cultural rejection of condom use, sexual gender-based violence (SGBV) and female genital mutilation (FGM), stigma and/or discrimination, and sexual cleansing. However, two main ethical issues are to manage when performing social science research, especially (1) to obtain the fully informed consent of participants, and (2) to imperatively keep the experience unharmed. Meanwhile, because this study was done in a wide unknown field of seeking behavioral change among PLHIVs in DRC after a new program implementation identified as CBI, it became imperative to organize that pilot study. This reinforced the validity of the research, measure the competency of the researcher, illustrate de beneficence of the research, and help fix some eventual field issues (Rudestam & Newton, 2015). Remotely performing the pilot study opened ideas about settings, demographics, data collection, data analysis, evidence of trustworthiness, and potential expected results of the study.

## Chapter 4: Results

Through this qualitative, ethnographic study, I addressed whether the introduction of specific CBIs in Congo-Kinshasa among PLHIVs from 2005 impacted their behaviors as well as their family members and their surrounding communities. I used in-depth interviews, focus groups, and some key-informant person interviews to collect culturally specific and noticeable information. Starting with a pilot study in December 2020, data were remotely gathered from Congo-Kinshasa out of two settings: with a nonprofit organization known as ACS AMO Congo in Kinshasa and in Bandundu around the Urban Health Zone of Bandundu in Kwilu province. While performing this inquiry, I answered three major research questions:

1. In what ways has participation in CBIs impacted sexual behaviors among Congolese PLHIVs and their community in general?
2. What is the meaning of CBIs for family members?
3. What are the detailed sociocultural behaviors impacted at the end of the projects?

This chapter will describe the pilot study performed during this COVID-19 pandemic, different settings involved in my data collection, some demographics describing the selection of interviewees, and the whole data collection process. Data analysis with NVivo R1 and Microsoft Excel will also be described. The chapter also includes evidence of trustworthiness and my final study results.

### **The Pilot Study**

The current COVID-19 pandemic brought several changes to my plan for my dissertation. The first one was the impossibility of travelling to Congo-Kinshasa in 2020 because of the lockdown restrictions. The second was authorization from the Walden IRB to proceed with a new data gathering method because of the travel ban, and the third was the IRB approval extension from the Kinshasa School of Public Health (KSPH), switching to the remote data collection approach since nobody was allowed to travel. On November 23, 2020, the KSPH granted my study an approval (authorization number ESP/CE/187/2020) for 12 months after working with the Walden IRB.

Even though I did not travel, focus groups and other interviews were still conducted in person while following CDC COVID-19 guidelines. A research assistant named Dr. Super Jeremy was selected on December 15, 2020, in a collaborative strategy with Dr. Mukumbi Henri from the KSPH. Dr. Super was trained by me from December 17th to December 19th, 2020, using WhatsApp after locally printing all the paperwork required. A Sony audio recorder number ICD-BX140 was also provided to collect information. Then on December 23, the first audiotaped training occurred as a triangulation between Dr. Mukumbi and Dr. Super. I also selected Mr. Michel Manoka, a known HIV community volunteer with 20 years of experience working with the target to connect with PLHIVs in Kinshasa by snowball sampling. On December 27, 2020, the first focus group occurred with a total of 12 female PLHIVs from 2:00 a.m. to 3:30 a.m. PT. I remotely explained to all of them how participating in the focus group was based on personal willingness to be a part of the group and then explained the interest of signing

the informed consent form if they agreed to be a part of that qualitative study. All respondents were also told that they were free to withdraw from the study any time. To help interviews evolve smoothly, snacks, drinking water, and \$10 transportation cards (20,000 Congolese Francs) were provided as a stipend to each participant.

Before proceeding with the focus group, some clear ground rules were set around the exact timing of each question (Ravitch & Carl, 2016). Participants were also encouraged to express their thoughts and assured that there were no wrong answers (Ravitch & Carl, 2016). Answers were recorded via audiotape and notes. The first female focus group started at 10:50 a.m. and ended at 11:50 am local time in Congo-Kinshasa. The second focus group of six male PLHIVs occurred from 2:30 p.m. to 3:30 p.m. with Dr. Mukumbi and Dr. Super Eloko. As with the female group, the informed consent signing process was the priority before engaging in interviews. Because of the high quality of the information that I collected in Kinshasa on the first day, I decided to move forward and include data gathered to the main study. Both focus groups for female and male PLHIVs helped to collect accurate data, since the risk of developing a severe COVID-19 infection while gathering a large amount of HIV infected people several times was higher. All data were collected in two different steps.

### **Settings Description**

#### **Organizational Conditions That Influenced Participants or Their Experience at Time of Study That May Influence Interpretation of the Study Results**

As stated, data collection was conducted in two major steps. The first session occurred in Kinshasa, DR Congo from December 23rd, 2020, to February 28th, 2020.

The second one occurred on January 2021 in the city of Bandundu, DRC. On December 27, 2020, I virtually gathered 12 female PLHIVs social-distanced in the multipurpose meeting room of ACS AMO Congo at 10:30 a.m. local time or 2:30 am Pacific Time. Then the second focus group occurred with six male PLHIVs in the same location. Socially distanced interviewees responded to questions circle-sited in a wide, ventilated room with 22 seating chairs and one table.

On January 6, 2021, the second step of data collection was focused on individual interviews. It started with three voluntary female participants after the informed consent form was signed. Then, two male respondents were interviewed one at a time. Respondents were informed that they were free to leave the interview anytime they wanted. Safe drinking water, a transportation card, and a few snacks were offered. Data were recorded on both paper in Kinshasa and with a SONY recorder ICD-BX140. All audiotaped data served as a support to the written information gathered, then written data were later translated into English either from French or Lingala, one of the four national languages. However, the female key-informant person contacted for the interview from Kinshasa in December 2020 and January 2021 declined the offer.

The first data collection organized in Bandundu occurred on January 21, 2021, with a focus group of 13 PLHIVs. Patients were selected by the Central Health Zone office through the nurse supervisor. Then women from 30 to 55 were selected for in-depth interviews regarding their perception of the influence of CBIs in their community as PLHIVs. One male respondent and three female PLHIVs were interviewed on in-depth-questionnaire basis. Here, as in Kinshasa, where the former provincial director

ACS AMO Congo had a better understanding of the situation, the Bandundu team also selected a key-informant person to be interviewed.

## Demographics

### Present Participant Demographics and Characteristics Relevant to the Study

This qualitative study involved a total of 42 respondents as follows: two men as key-informant persons, 12 female and six male participants questioned separately in a focus group, five in-depth interviews, and 13 PLHIVs in a focus group for Kinshasa. Additionally, Bandundu-city offered a data collection of four in-depth interviews with one male and three female PLHIVs. The following table depicts demographics of all participants in this study.

**Table 5**

#### *Gender and Tribe Participation*

Number	Tribe/gender	Male	Female	Total	Province
1	Kusu	0	1	1	Maniema
2	Lokele	1	1	2	Tshopo
3	Luba	1	4	5	Kasai Central/Oriental
4	Lubakat	1	0	1	Tanganyika
5	Manianga	1	1	2	Kongo Central
6	Mbala	0	2	2	Kwilu
7	Moboma	1	0	1	Mai-Ndombe
8	Ndibu	1	1	2	Kongo Central
9	Ngbandi	1	1	2	Sud-Ubangi
10	Ngoli	0	1	1	Kwango
11	Ntandu	0	1	1	Kongo Central
12	Pende	1	0	1	Kwilu
13	Sakata	1	1	2	Mai-Ndombe
14	Sona	0	2	2	Kongo Central
15	Songye	1	0	1	Eastern Kasai
16	Suku	0	1	1	Nord Kivu
17	Tetela	2	0	2	Sankuru
18	Yaka	2	3	5	Kwango
19	Yansi	1	3	4	Kwilu
20	Yombe	1	3	4	Kongo Central
Total		16	26	42	

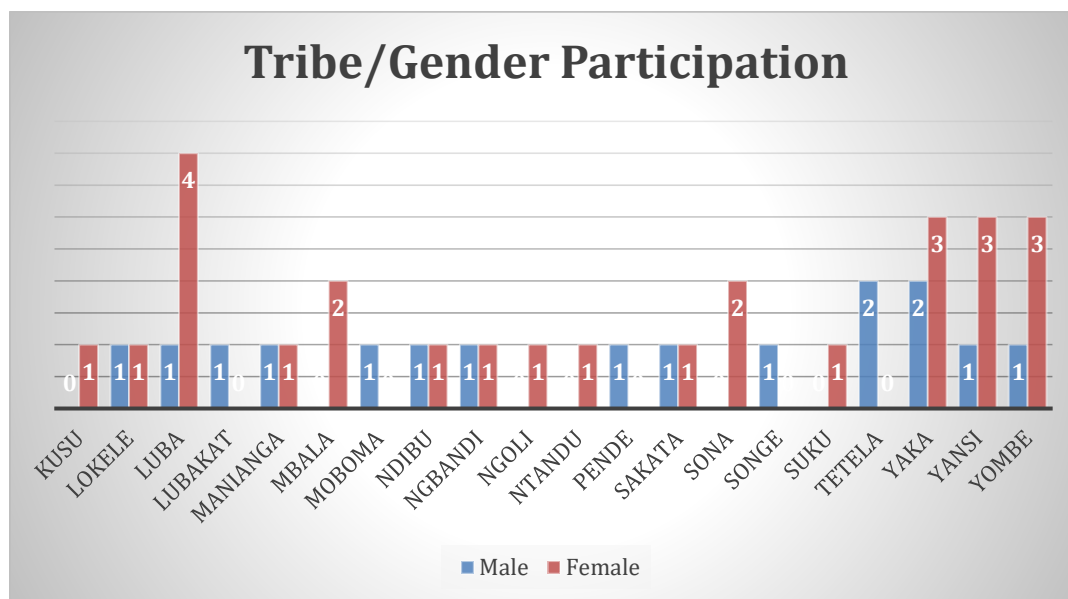
Table 5 to continue



Because of the cultural diversity, several tribes were involved in this qualitative study. This would more likely have a positive impact of the results. This inquiry included at least 13 of the 26 major provinces in Congo-Kinshasa as described in Figure 1. Data collected show that not only was female participation about 61.9% higher but also Luba and Yaka tribes had the highest participation with 11.9% each, followed by Yansi and Yombe tribes with 9.52% of participation each. There were more Luba women than others in this study for 9.52% in terms of participation.

**Figure 2**

*Tribe Versus Gender Participation*



## Data Collection

### Number of Participants from Whom Each Type of Data Was Collected

As stated, 42 PLHIVs remotely and physically responded to three different types of interviews from Congo-Kinshasa. Data were recorded on a SONY ICD-BX140 audiotape from their voluntary participation to this qualitative study designed to understand if CBIs as applied in DR Congo have had an impact on behaviors of Congolese PLHIVs. Table 2 describes the details of the data collection.

**Table 6**

*Data Collection Type, Location, and Respondents' Demographics*

#	Activity	Respondents	City	Location	Age	Gender	Date
01	Focus group	12	Kinshasa	AMO Congo	27-50	F	12/27/20
02	Focus group	6	Kinshasa	AMO Congo	32-55	M	12/27/20
03	Focus group	13	Bandundu	BCZS-BDD	30-55	F/M	1/20/21
04	Key-informant	1	Kinshasa	AMO Congo	57	M	2/28/21
05	Key-informant	1	Bandundu	Kingston, NY	57	M	2/27/21
06	In-depth interviews	5	Kinshasa	AMO Congo	27-50	4 F/1M	1/03/21
07	In-depth interviews	4	Bandundu	BCZS-BDD	30-55	3 F/1M	1/21s-22/21
	Total	42	2 cities	2 locations	Years	26F/16M	12/20-3/21

Table 4 to continue

### Location, Frequency, and Duration of Data Collection for Each Data Collection

#### Instrument

As stated, two Congolese cities were involved to gather information. The first part of data collection started in Kinshasa from December 2020 to February 2021, and the second part occurred in Bandundu in January 2021 before remotely interviewing the last key-informant of Bandundu in February 2021. The following table depicts the location, the frequency, and different duration of data collection from the field.

**Table 7***Type of Data Collection and Timing*

#	Data collection	Participants	Location	Frequency	Duration
1	Focus group 1	12	Office of ACS AMO Congo Kinshasa	1	92 minutes
	Focus group 2	6	Office of ACS AMO Congo Kinshasa	1	73 minutes
	Focus group 3	13	Meeting room of the Health Central Office Bandundu	1	110 minutes
2	Key-informant interview 1	1	Office of ACS AMO Congo Kinshasa	2	62 minutes
	Key-informant interview 2	1	Kingston, NY	1	55 minutes
3	IG In-depth interview	1	Office of ACS AMO Congo Kinshasa	1	56 minutes
	KR In-depth interview	1	Office of ACS AMO Congo Kinshasa	1	60 minutes
	MR In-depth interview	1	Office of ACS AMO Congo Kinshasa	1	56 minutes
	NP In-depth interview	1	Office of ACS AMO Congo Kinshasa	1	58 minutes
	SA In-depth interview	1	Office of ACS AMO Congo Kinshasa	1	52 minutes
	MG In-depth interview	1	Meeting room of the Health Central Office Bandundu	1	50 minutes
	NYA In-depth interview	1	Meeting room of the Health Central Office Bandundu	1	51 minutes
	PNM In-depth interview	1	Meeting room of the Health Central Office Bandundu	1	50 minutes
	RN In-depth interview	1	Meeting room of the Health Central Office Bandundu	1	48 minutes

Table 7 to continue

## **Data Recording Process**

This data recording process was completed according to qualities and values of qualitative interviews (Ravitch & Carl, 2016). As soon as the research assistant was selected from a collaborative way with the KSPH, he started working daily with me and Dr. Mukumbi from Kinshasa on December 17, 2020. Dr. Super visited the meeting room of ACS AMO Congo before practicing with the materials that would be used when interviewing such as the audiotape recorder and the laptop to remotely connect with me. After discussing with Dr. Mukumbi and selecting PLHIVs in Kinshasa by a snowballing purposive approach, we planned the first focus group with a separate group of women and men in the meeting room of ACS AMO Congo on December 27, 2020, at 10:00 a.m. and 2:00 p.m. to avoid crossing contacts between them because of the COVID-19 pandemic.

On December 26, 2020, Dr. Super (the research assistant), Dr. Mukumbi (the KSPH representative), Manoka Michel (the ACS AMO Congo community worker), and I had a 55-minute meeting to get an overview of the data collection process. After receiving the signed informed consent forms from 12 female PLHIVs aged 27 to 50 years old, the first focus group started at 2:30 p.m. on December 27, 2020. I asked direct questions to participants after a brief presentation of myself, the project, and the compensation they were supposed to receive during and at the end of the interview. A snack of juice, sandwiches, and safe drinking water was offered while answering questions. Because I was trying to understand change in behaviors from norms, rules, or values of particular cultures (Ruben & Ruben, 2012), the SONY audio recorder ICD-

BX140 was set in the middle of the circle, and Dr. Super wrote every answer below asked questions. The first instructive focus group recording 12 women PLHIV ended at 4:02 pm Kinshasa-time, with transportation cards handed to each interviewed participant.

After disinfecting the room and social distancing with the first group, a group consisting of male PLHIVs 32–55 occurred at 4:27 pm. This focus group started with a 20-minute process of voluntary participation with the individual informed signing consent form after loudly reading it to the group. Because of that time-consuming process and the lockdown stated in Kinshasa by state authorities from 8:00 pm, a snack and drinking water were offered to participants, then open-ended questions were asked. Each respondent received a transportation card. At the end of the day, a 30-minute meeting was organized between Dr. Super, Dr. Mukumbi, Mr. Manoka, and me as the daily data gathering synthesis.

The next data collection was scheduled for January 3<sup>rd</sup>, 2021, with in-depth individual interviews. As planned, Dr. Super showed on the field on 01/02/2021 to make sure that the site was ready for interviews. He came back on 01/03/2021 at 8:10 am, reorganizing the meeting room for one-on-one interviews after signing the informed consent form. Out of 10 PLHIVs invited, only 5 of them were present and voluntarily accepted to be interviewed. The first interview of the day with a Luba ethnic female PLHIV target-person occurred at 8:50 am, it ended at 9:48 am. She was given a snack, some drinking water, and a transportation card as motivation. Then the second female respondent from the Yombe tribe entered the room social distancing with the previous one. She was explained the consent form in French before starting with her interview at

10:09 am. Her interview also ended at 11:09 am with a snack, some drinking water, and a transportation card. At 12:18 pm, we received another Luba respondent lady following the same process up to 1:14 pm. The fourth respondent was from the Tetela tribe, a male PLHIV who underwent the same procedure from 1:27 pm - 2:19 pm, before closing the day with a Yaka male from 3:04 to 4:00 pm, each of them holding a transportation card when leaving the site. They were all recorded the same way, both on paperwork and with an audiotaped approach while responding.

The second step of data gathering intervened across a challenging 6-day roadway journey in Bandundu-city versus 48 usual hour-trip for the research assistant. He left Kinshasa from Limete station on 1/13/2021 but arrived in Bandundu-city later on 01/19/2021. He met with the HIV/AIDS Provincial medical coordinator the same day, before being invited to plan all research activities with the Health Zone Medical Doctor of Bandundu health zone. As suggested, Dr. Super Jeremy and the Nurse supervisor planned and met with the first group of 13 PLHIVs in the meeting room on 01/20/2021. The consent form signing process occurred at 12:50 pm, then the first heterogeneous focus group occurred at 2:15 pm. It lasted 110 minutes around nine tribes. Several open-ended questions were asked, answers were recorded on paperwork while everything was audiotaped. A snack was provided with water, and a transportation card for each. Also, a second wave of four PLHIVs met for successive in-depth interviews at the same location the following day. They received their snack, then questions were asked by turn as data were gathered and the last debrief related to the whole process of data collection took place on 1/21/2021. A second money transfer was made for Bandundu, and Dr. Super left

Bandundu-city by autocar on 01/23/2020 after providing stipends to the local staff involved in that research.

### **Variations in Data Collection from the Plan Presented in Chapter 3**

In 2020, Liu, Kuo, and Shih wrote about the first documented coronavirus pandemic in the history. They explained how highly contagious the virus was and how it could be quickly spreading in the world, coming from animals with human-to human contact (Liu, Kuo, & Shih, 2020). That is why before the current COVID-19 pandemic, this data collection was supposed to be completed from the field with a trip in Congo-Kinshasa through partnership in Bandundu and Kinshasa the capital. The COVID-19 pandemic brought a worldwide crisis with border closings and shutdowns, making impossible any movements from a country to another one, even from a city to another one within the same country mostly in 2020. Because the IRB approval letter from the KSPH number ESP/CE/306/2019 of 12/24/2019 was supposed to expire on 1/2/2021, the Office of Ethics Committee of the KSPH was solicited for a data collection period extension. Another approval letter number ESP/CE/187/2020 was assigned to this study on 11/23/2020 up to 1/2/2022.

At the beginning of this process, an informing email was sent to the representative of the local World Health Organization to let him know that a study was planned to take place in Bandundu-city. Five days later, a researcher assistant was assigned to the study, as initial data collection settings for the whole inquiry went from three to two research sites for bias prevention purposes. This decision was made because I mainly worked in Mbandaka for seven years as the director of the local site. Initially, I was supposed to

have 12-18 in-depth interviews, three key-informant person interviews, and six focus groups in total for the remaining two sites. At the end of the process, I rather remotely collected data as following: nine In-depth interviews in total, three focus groups, and two key-informant person interviews as below declined in the table. All data were collected in remote mode with a trained research assistant on the ground. The depiction below will illustrate how I collected over 60% of all expected qualitative information on PLHIVs in Kinshasa and Bandundu-city.

**Table 8**

*Different Interviews by Setting Locations*

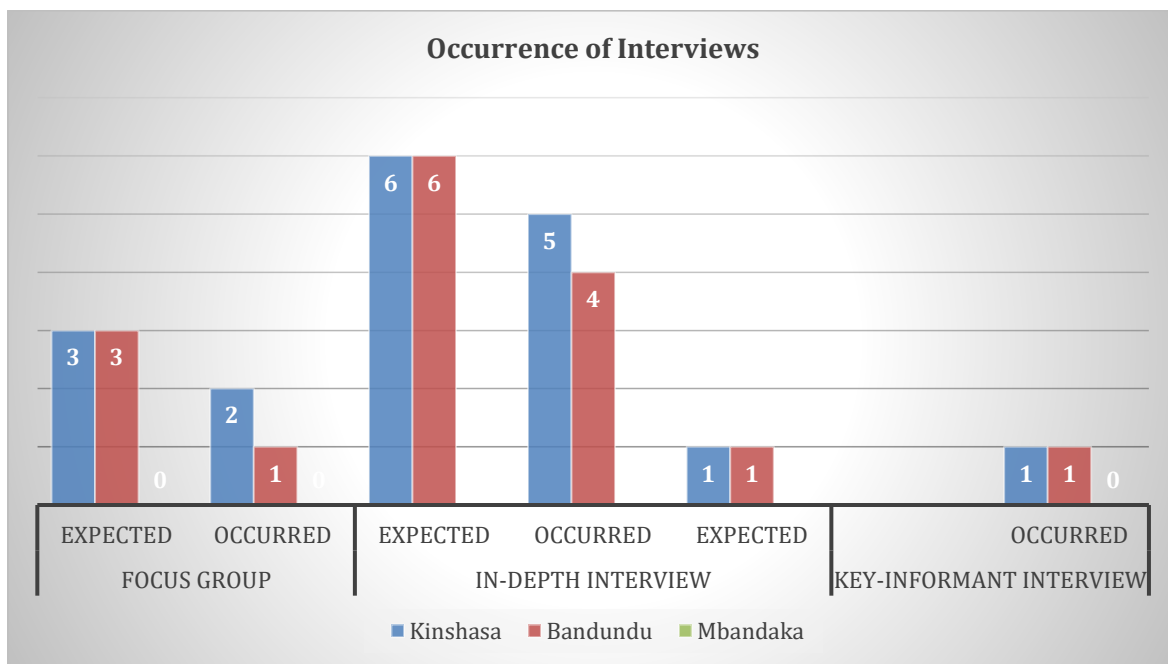
Number	Focus group		In-depth interview		Key-informant interview	
	Expected	Occurred	Expected	Occurred	Expected	Occurred
Kinshasa	3	2	6	5	1	1
Bandundu	3	1	6	4	1	1
Mbandaka	0	0	0	0	0	0
Total	6	3	12	9	2	2

Because of the cancellation for bias prevention, Mbandaka did not have any interviews.

**Figure 3**

*Depiction of Interview Occurrences by Location.*





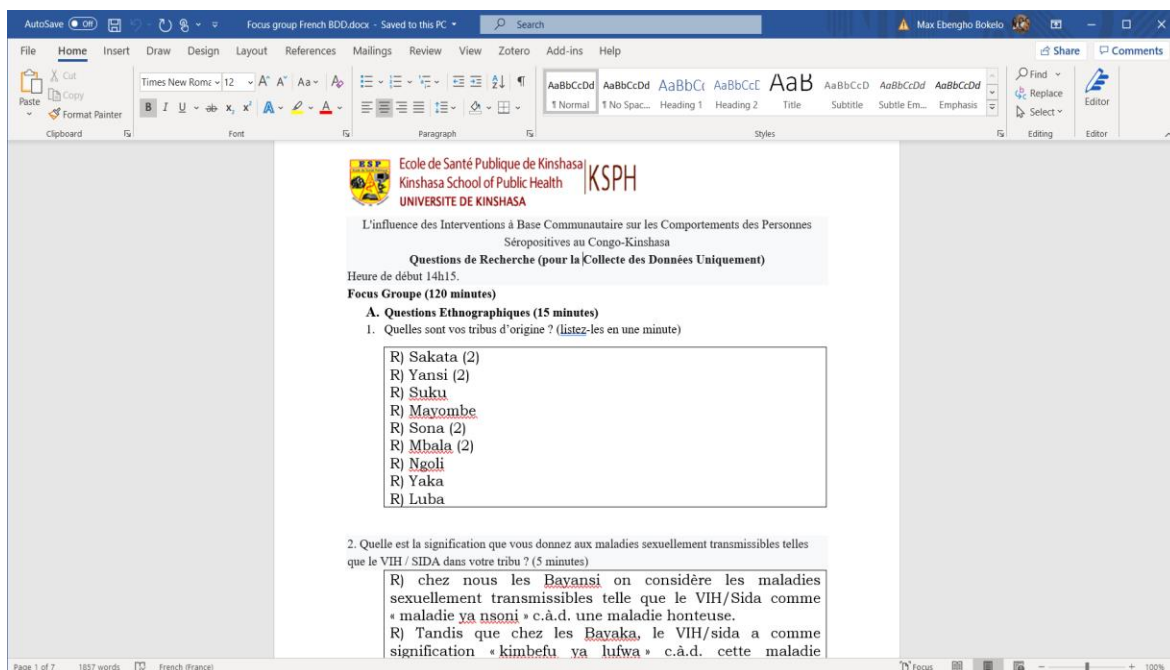
### Any Unusual Circumstances Encountered in Data Collection

The COVID-19 pandemic caused this major unusual change while gathering my qualitative data. One of the main circumstances was the use of masks while recording information with social distancing. In the meantime, in Kinshasa, the lockdown decided by the local government prevented this study from getting an important flow of respondents, according to the fact that every Congolese citizen was supposed to be home before 8:00 pm. Also, because of the curfew, we did not have enough men involved in their own focus group. Thus, I engaged to have three male PLHIVs mixed with 10 ladies scheduled to be interviewed on 01/20/2021 in the meeting room of the Health Zone. The Internet was so slow that almost all interviews planned in Bandundu were conducted in-person by the research assistant. Another fact noticed at the beginning of my data collection was the use of Microsoft Teams for the first interview in Kinshasa. This occurred because Zoom was not operating correctly.

Meanwhile, I was supposed to have my data collected and transcribed from the SONY ICD-BX140 audiotape to the written form. Unfortunately, most of the discussions were done in Lingala language, meaning I needed a double translation from Lingala to English via French. The unusual circumstance here was the manual translation in French from Lingala, without any automated transcriptions. Then all interviews were translated in English, trying to mean exactly what each respondent was explaining without any biases. Also, this study was performed with personal funding. Out-of-pocket money sent to Congo-Kinshasa came from my own savings, and the Internet disruption in DRC made things even harder. I took longer to remotely record some information when a simple talk was needed locally. Except tribes listed on the first page of the French version, snapshots found below on the following pages illustrate how I went from my French version to the English translation.

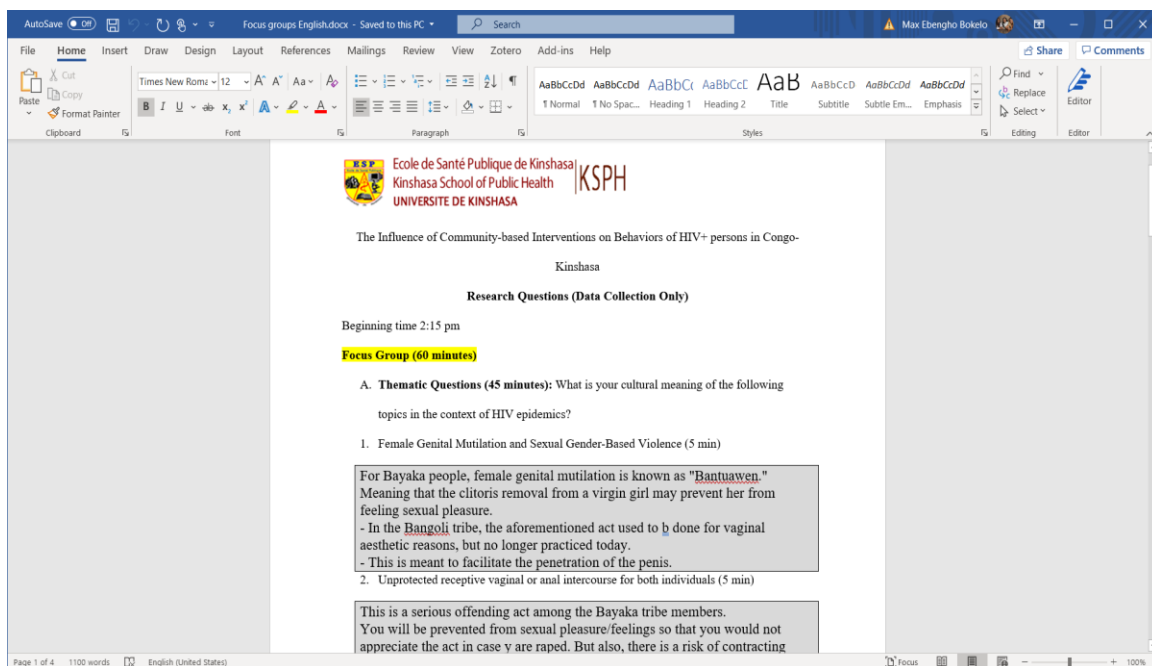
**Figure 4**

*French Data Collection for Tribes Involved in the First Female Interview in Kinshasa*



**Figure 5**

*English translation of the first female interview from ACS AMO Congo Kinshasa.*



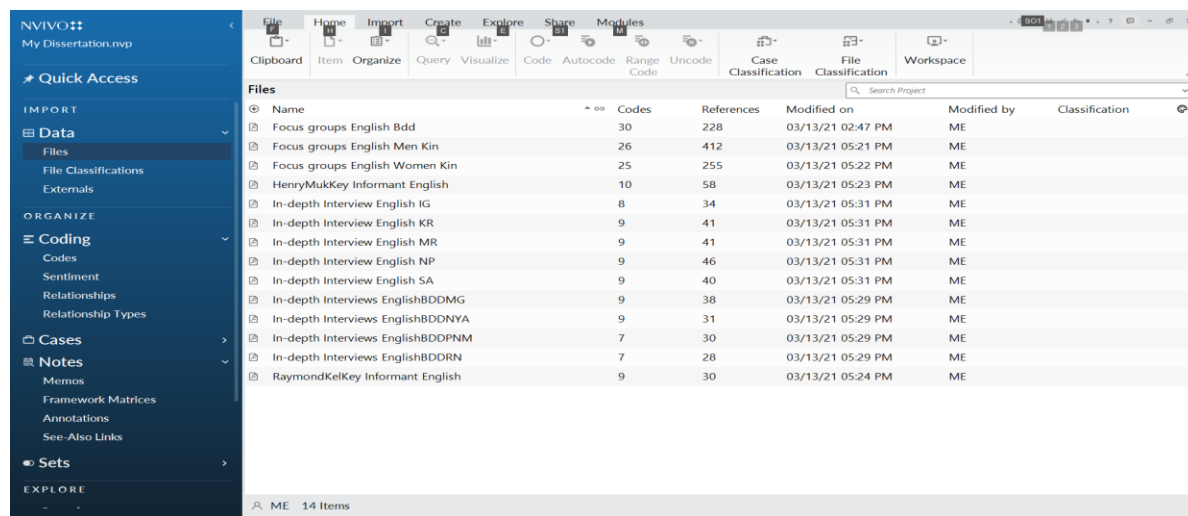
## Data Analysis

### Process Used to Move Inductively from Coded Units to Larger Representations Including Categories and Themes

Because of the need to arrange data in a systematic order with the purpose of synthesizing closer answers provided by respondents, the last version of NVivo R1 was used, and all data were coded from In-depth interviews, focus groups and key-informant person interviews. Qualitative data were entered by file as follows: focus group English BDD, focus group English men Kin, focus group English women Kin, Henry Muk Key informant English, In-depth interview English IG, In-depth interview English KR, In-depth interview MR, In-depth interview English NP, In-depth interview SA, In-depth interview English BDD MG, In-depth interview English BDD NYA, In-depth interview English PNM, In-depth interview English BDD RN, and Raymond Kel Key Informant English.

#### Figure 6

#### *NVivo Coding Process Illustrating Cases (files) Recorded*



Name	Codes	References	Modified on	Modified by	Classification
Focus groups English Bdd	30	228	03/13/21 02:47 PM	ME	
Focus groups English Men Kin	26	412	03/13/21 05:21 PM	ME	
Focus groups English Women Kin	25	255	03/13/21 05:22 PM	ME	
HenryMukKey Informant English	10	58	03/13/21 05:23 PM	ME	
In-depth Interview English IG	8	34	03/13/21 05:31 PM	ME	
In-depth Interview English KR	9	41	03/13/21 05:31 PM	ME	
In-depth Interview English MR	9	41	03/13/21 05:31 PM	ME	
In-depth Interview English NP	9	46	03/13/21 05:31 PM	ME	
In-depth Interview English SA	9	40	03/13/21 05:31 PM	ME	
In-depth Interviews EnglishBDDMG	9	38	03/13/21 05:29 PM	ME	
In-depth Interviews EnglishBDDNYA	9	31	03/13/21 05:29 PM	ME	
In-depth Interviews EnglishBDDPNM	7	30	03/13/21 05:29 PM	ME	
In-depth Interviews EnglishBDDRN	7	28	03/13/21 05:29 PM	ME	
RaymondKelKey Informant English	9	30	03/13/21 05:24 PM	ME	

Cases entered in NVivo were coded using multiple patterns. The first one was ‘cultural meanings’ with components such as: condom rejection for cultural reasons, female genital mutilation, Kintwidi phenomenon, levirate marriage, sexual cleansing, sororate marriage, stigma and discrimination, and unprotected receptive vaginal or anal intercourse.

### Figure 7

*Depiction of Coding Cultural Meanings of Traditional Concepts*

The screenshot shows the NVivo software interface with a list of codes. The table below represents the data shown in the screenshot.

Name	Files	References	Created on	Created by	Modified on	Modified by
Community-based Interventions	11	34	03/14/21 10:03 PM	ME	03/15/21 09:25 PM	ME
Community-based Interventions for family members	14	25	03/16/21 05:01 PM	ME	03/16/21 09:15 PM	ME
Cultural meanings	14	343	03/13/21 05:46 PM	ME	03/14/21 06:27 PM	ME
Condom rejection for cultural reasons	3	6	03/14/21 08:31 PM	ME	03/14/21 09:43 PM	ME
Female Genital Mutilation	3	16	03/14/21 08:27 PM	ME	03/14/21 09:43 PM	ME
Kintwidi phenomenon'	3	6	03/14/21 08:34 PM	ME	03/14/21 09:44 PM	ME
Levirate marriage	3	12	03/14/21 08:32 PM	ME	03/14/21 09:38 PM	ME
Sexual cleansing	3	11	03/14/21 08:35 PM	ME	03/14/21 09:25 PM	ME
Sororate marriage	3	22	03/14/21 08:33 PM	ME	03/14/21 09:37 PM	ME
Stigma and discrimination	2	5	03/14/21 08:36 PM	ME	03/14/21 09:21 PM	ME
Unprotected receptive vaginal or anal intercourse	3	14	03/14/21 08:28 PM	ME	03/14/21 09:42 PM	ME
Date	12	13	03/13/21 05:35 PM	ME	03/13/21 07:28 PM	ME
Gender	0	0	03/14/21 08:13 PM	ME	03/14/21 08:13 PM	ME
Location	13	15	03/13/21 05:40 PM	ME	03/13/21 07:28 PM	ME
Sociocultural behaviors impacted	14	39	03/16/21 09:02 PM	ME	03/16/21 09:46 PM	ME
Tribe	5	21	03/13/21 06:06 PM	ME	03/13/21 06:19 PM	ME
Understanding of Sociocultural Behaviors Impacted	12	23	03/16/21 09:59 PM	ME	03/16/21 10:19 PM	ME
Ways participation in CBIs Impacted	3	14	03/16/21 09:36 PM	ME	03/16/21 09:44 PM	ME

When observing social actions, every data collection must be performed with scrutiny, recording qualitative information either by quantitating data collected, or coding alphanumeric data (Saldana, 2016, p. 26). If the table above depicts 8 components of cultural meanings ending with unprotected receptive vaginal or anal intercourse to illustrate a part of respondents’ cultural meaning, the second code related to this NVivo R1 data recording was ‘gender.’ Gender coded as ‘F’ for female and ‘M’

for male, with this screenshot example given while organizing focus group in Bandundu-city data collection:

**Figure 8**

*Screenshot Illustration of Gender as Coded for Female and Male.*

The screenshot shows the NVIVO software interface with a list of codes. The 'Codes' pane is open, displaying a table with columns for Name, Files, References, Created on, Created by, Modified on, and Modified by. The 'Gender' code is expanded, showing sub-codes for 'Female' and 'Male'.

Name	Files	References	Created on	Created by	Modified on	Modified by
Community-based Interventions for family members	14	25	03/16/21 05:01 PM	ME	03/16/21 09:15 PM	ME
Cultural meanings	14	343	03/13/21 05:46 PM	ME	03/14/21 06:27 PM	ME
Condom rejection for cultural reasons	3	6	03/14/21 08:31 PM	ME	03/14/21 09:43 PM	ME
Female Genital Mutilation	3	16	03/14/21 08:27 PM	ME	03/14/21 09:43 PM	ME
Kintwidi phenomenon'	3	6	03/14/21 08:34 PM	ME	03/14/21 09:44 PM	ME
Levirate marriage	3	12	03/14/21 08:32 PM	ME	03/14/21 09:38 PM	ME
Sexual cleansing	3	11	03/14/21 08:35 PM	ME	03/14/21 09:25 PM	ME
Sororate marriage	3	22	03/14/21 08:33 PM	ME	03/14/21 09:37 PM	ME
Stigma and discrimination	2	5	03/14/21 08:36 PM	ME	03/14/21 09:21 PM	ME
Unprotected receptive vaginal or anal intercourse	3	14	03/14/21 08:28 PM	ME	03/14/21 09:42 PM	ME
Date	12	13	03/13/21 05:35 PM	ME	03/13/21 07:28 PM	ME
Gender	0	0	03/14/21 08:13 PM	ME	03/14/21 08:13 PM	ME
Female	8	9	03/13/21 05:38 PM	ME	03/13/21 07:28 PM	ME
Male	5	6	03/13/21 05:39 PM	ME	03/13/21 07:23 PM	ME
Location	13	15	03/13/21 05:40 PM	ME	03/13/21 07:28 PM	ME
Sociocultural behaviors impacted	14	39	03/16/21 09:02 PM	ME	03/16/21 09:46 PM	ME
Tribe	5	21	03/13/21 06:06 PM	ME	03/13/21 06:19 PM	ME
Understanding of Sociocultural Behaviors Impacted	12	23	03/16/21 09:59 PM	ME	03/16/21 10:19 PM	ME
Ways participation in CBLs Impacted	3	14	03/16/21 09:36 PM	ME	03/16/21 09:44 PM	ME

I had only two handful data collection locations in DRC, the first one known as ACS AMO Congo in Kinshasa, and the second one identified as the Central Office of Health Zone known as the BCZS of Bandundu-city.

**Figure 9**

*Location coded for ACS AMO Congo and BCZS Bandundu.*

The screenshot shows the NVIVO software interface with a list of codes. The table below represents the data visible in the screenshot.

Name	Files	References	Created on	Created by	Modified on	Modified by
○ Cultural meanings	14	343	03/13/21 05:46 PM	ME	03/14/21 06:27 PM	ME
○ Condom rejection for cultural reasons	3	6	03/14/21 08:31 PM	ME	03/14/21 09:43 PM	ME
○ Female Genital Mutilation	3	16	03/14/21 08:27 PM	ME	03/14/21 09:43 PM	ME
○ Kintwidi phenomenon'	3	6	03/14/21 08:34 PM	ME	03/14/21 09:44 PM	ME
○ Levirate marriage	3	12	03/14/21 08:32 PM	ME	03/14/21 09:38 PM	ME
○ Sexual cleansing	3	11	03/14/21 08:35 PM	ME	03/14/21 09:25 PM	ME
○ Sororate marriage	3	22	03/14/21 08:33 PM	ME	03/14/21 09:37 PM	ME
○ Stigma and discrimination	2	5	03/14/21 08:36 PM	ME	03/14/21 09:21 PM	ME
○ Unprotected receptive vaginal or anal intercourse	3	14	03/14/21 08:28 PM	ME	03/14/21 09:42 PM	ME
○ Date	12	13	03/13/21 05:35 PM	ME	03/13/21 07:28 PM	ME
○ Gender	0	0	03/14/21 08:13 PM	ME	03/14/21 08:13 PM	ME
○ Female	8	9	03/13/21 05:38 PM	ME	03/13/21 07:28 PM	ME
○ Male	5	6	03/13/21 05:39 PM	ME	03/13/21 07:23 PM	ME
○ Location	13	15	03/13/21 05:40 PM	ME	03/13/21 07:28 PM	ME
○ ACS AMO Congo	1	1	03/14/21 08:19 PM	ME	03/14/21 09:49 PM	ME
○ BCZS Bandundu	1	2	03/13/21 05:37 PM	ME	03/13/21 05:37 PM	ME
○ Sociocultural behaviors impacted	14	39	03/16/21 09:02 PM	ME	03/16/21 09:46 PM	ME
○ Tribe	5	21	03/13/21 06:06 PM	ME	03/13/21 06:19 PM	ME
○ Understanding of Sociocultural Behaviors Impacted	12	23	03/16/21 09:59 PM	ME	03/16/21 10:19 PM	ME

Then, came later on, a few key meaningful codes of sociocultural behaviors impacted prior to coding the ‘understanding of sociocultural behaviors,’ the ‘understanding of Community-based Interventions,’ ‘ways that participation in CBIs impacted sexual behaviors among Congolese PLHIV,’ the ‘understanding of the detailed sociocultural behaviors impacted at the end of CBI projects at different levels,’ and ‘tribes and the meaning of STDs in their tribe.’

### **Specific Codes, Categories, and Themes that Emerged from the Data Using Quotations as Needed to Emphasize Their Importance**

#### ***Responses provided***

Condom rejection for cultural reasons:

#### ***Codes.***

‘Condom rejection’

### **Figure 10**

*Depiction of Cultural Meanings and Condom Rejection Recorded as Cultural Reasons.*

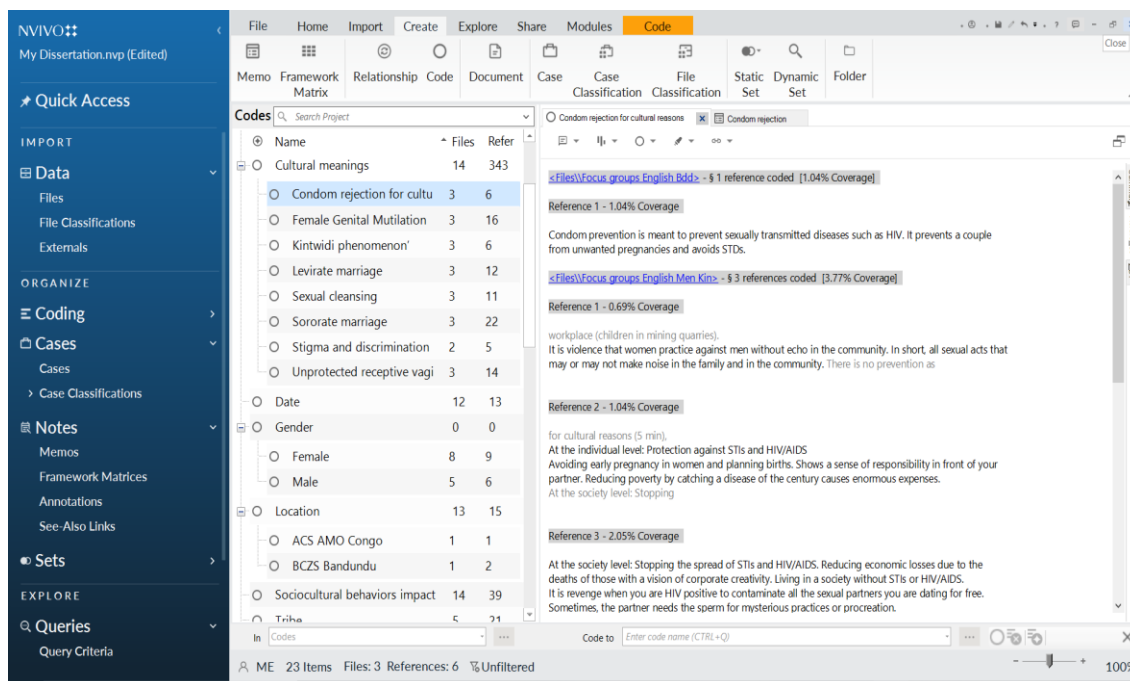


Figure 10 to continue

### *Group answers*

### *Categories*

This group of answers was divided into two categories, categories understood here as feeling, especially in magnitude coding as moderate or very marked sentiment/feeling.

Positive sentiment

4. Moderately positive

3. Very positive

Negative sentiment

2. Moderately negative

1. Very negative

### **Figure 11**

*Coding 'Sentiment' as a Positive or a Negative Feeling .*



Name	Files	References	Created on	Created by	Modified on	Modified by
Positive	3	32	03/12/21 07:27 PM	ME	03/12/21 07:27 PM	ME
Negative	3	55	03/12/21 07:27 PM	ME	03/12/21 07:27 PM	ME

Sentiment or respondent's feeling will further be divided in moderate or very marked feeling every time, whether while being positive or negative. This is defined as a significant key-component of this study, because the goal of the research was to understand how participants in CBIs felt the influence of community actions implemented on their behaviors.

### ***Group themes***

Thematic questions

Ethnographic questions

Impact questions

### ***Themes***

3. Culture and behaviors

2. Tribes and understanding

1. CBIs and impact

### **Qualities of Discrepant Cases and How They Were Factored into the Analysis**

Understanding this coding process was quite difficult, because if positive sentiments are meant to explain an attraction to the respondent's feeling, this could be disturbing when a participant has an attachment to a supposed harmful traditional practice. For instance, when a respondent presents a positive sentiment to the Kintwidi phenomenon or the levirate marriage, this must be understood as a negative attraction to a bad cultural behavior. That is why I had to personally handle this coding process, because I am the only researcher who could understand traditional facts in regards with questions asked and how each participant responded. Also, from 'moderate' to 'very positive' or 'negative' sentiments, answers provided by respondents were the key-component of the whole coding process.

Indeed, I had gradually worked as a 'lone wolf coder,' being flexible with concepts, dealing with ambiguities in conformity with an extension of vocabulary (Saldana, 2016). Every paperwork was treated with scrutiny and rigor in order to reveal what were the thoughts of all respondents either from group interviews or individual responses. Answers obtained have been grouped into either positive sentiment coding for 'moderately positive' and 'very positive,' or negative sentiment understood as 'moderately negative' and 'very negative.' For example, for discrepant cases such as sociocultural behaviors, they seemingly impacted the end of the project for males, and same feelings for females were compared separately from different focus groups implemented.

### **Evidence of Trustworthiness**

In qualitative studies, the researcher is committed to a set of diverse standards to assess the trustworthiness of the inquiry compared to quantitative studies. Standards to assess the validity of any qualitative studies resume in credibility, transferability, dependability, and confirmability (Ravitch & Carl, 2021, p. 188). Based on what I went through despite the global COVID-19 crisis, trustworthiness was the cornerstone of this study. An extension of the KSPH's IRB approval was required and obtained since the first one expired in January 2021. Signed informed consent forms, very minimal risks, anonymity, confidentiality, voluntary participation with guaranty of withdrawal anytime were the socle before, when, and after data collection of this study in Kinshasa and Bandundu-city (Babbie, 2015).

### **Describing the Implementation of and / or Adjustments to Credibility Strategies Stated**

From Kinshasa to Bandundu-city, some complex patterns were sometimes not completely explained either in Lingala, or in French. I faced the paradigm of dealing with the English translation, not excluding to interfere with meaningful traditional information explaining some phenomenon such as sexual cleansing understanding in Mongo community, or Kintwidi phenomenon found in Yansi tribe. A recursive research design was engaged while collecting information through in-depth individual interviews, comparing different focus groups and key-informant person interviews. The credibility of this study was well established by the scale of measuring exactly what the instrument (questionnaire) was supposed to measure from the field (Salazar et al., 2015). One of the

approaches used was triangulation. It was used to collect the high standard quality of responses from questions asked to participants.

For instance, the same question in the interview was asked to the whole group when organizing focus groups, and each of the participants was able to provide his understanding of the concept. This included multiple strategic key-components, such as the triangulation approach cited above, member checking strategy with a comparison of different answers, a thick description of ACS AMO Congo Kinshasa site and BCZS in Bandundu-city, bias reporting especially when translating traditional or cultural information in English, discrepant information described above, prolonged data collection time from 2019 to 2020 due to the COVID-19 pandemic, in finally using a peer debriefing approach with the Kinshasa School of Public Health personnel, and having a researcher assistant while remotely gathering data (Creswell & Creswell, 2018).

### **Describing the Implementation of and / or Adjustments to Transferability Strategies**

The concept of transferability has a closer understanding with external validity (Ravitch & Carl, 2016). A qualitative study does not stand alone as an inquiry willing to provide true statements as generalizable information from a group of tribes to another one. This study occurred with a goal of developing a set of descriptive context-relevant cultural statements explaining ‘a possible influence’ of CBIs in behaviors of PLHIVs in Congo-Kinshasa, with a significant cultural side point of view at the individual, community, organizational, societal, and law levels. For instance, levirate or sororate marriages are known differently in diverse tribes interviewed, and Kintwidi phenomenon

seems to be applicable among Tetela versus Yansi, with the exception of not involving a grandfather.

### **Dependability: Implementation of and / or Adjustment to Consistency**

The major question explaining dependability is, ‘are these data provided in Kinshasa or Bandundu stable?’ That concept was widely explored by explaining the consistency of arguments, illustrating the relationship between what was provided in different focus groups and in-depth interviews. At the same time, I am engaging to be comparing city-information from different types of arguments. For instance, answers provided by Tetela people from Kinshasa meant the same with Tetela in Bandundu-city. Personal audit trails and the triangulation approach were the cornerstone strategy when questioning respondents. Thus, each individual was asked the same question in order to compare different answers using multiple approaches. In fact, answers from focus groups were richer than in-depth individual interviews, and key-informant person interviews provided significant point of views in different concepts, widely tending to rebuild constructs of the current study.

### **Confirmability: Describing Implementation of and / or Adjustment to Consistency Strategies**

When objectively observing cultural facts, it is strategically important to cross-check around and figure out if someone else provided similar answers to the same questions. I have tried this difficult exercise, but because of the uniqueness of this study, no consistent answers were found to explain the influence of CBIs in behaviors of PLHIVs either in Congo, or in Africa. However, some cultural studies explained concepts of

Kintwidi phenomenon, levirate marriage, sororate marriage or sexual cleansing phenomenon. For example, one respondent stated that his own father was raised in a levirate marriage. Data collected is a proof that some of interviewees have experienced cleansing phenomenon and were able to describe consequences of cultural laws at the individual level, community level, organizational level, societal level, and laws.

As a researcher here, I meant to collect confirmable information from Kinshasa and Bandundu-city, with a relative freedom and neutrality (Ravitch & Carl, 2016). Triangulation strategies were involved with reflexivity. The same question was asked differently to the same persons and different ones. Answers were compared while using NVivo R1, taking in account the fact that some of them were positive, not meaning the respondent agreed with, and other negative not meaning that the participant disagreed with it. Every answer must be conceptualized and exactly explain what the question meant. That is why I had to solely code my information.

## **Results**

### **RQ1 - In What Ways Has Participation in CBIs Impacted Sexual Behaviors Among Congolese PLHIV and their Community in General?**

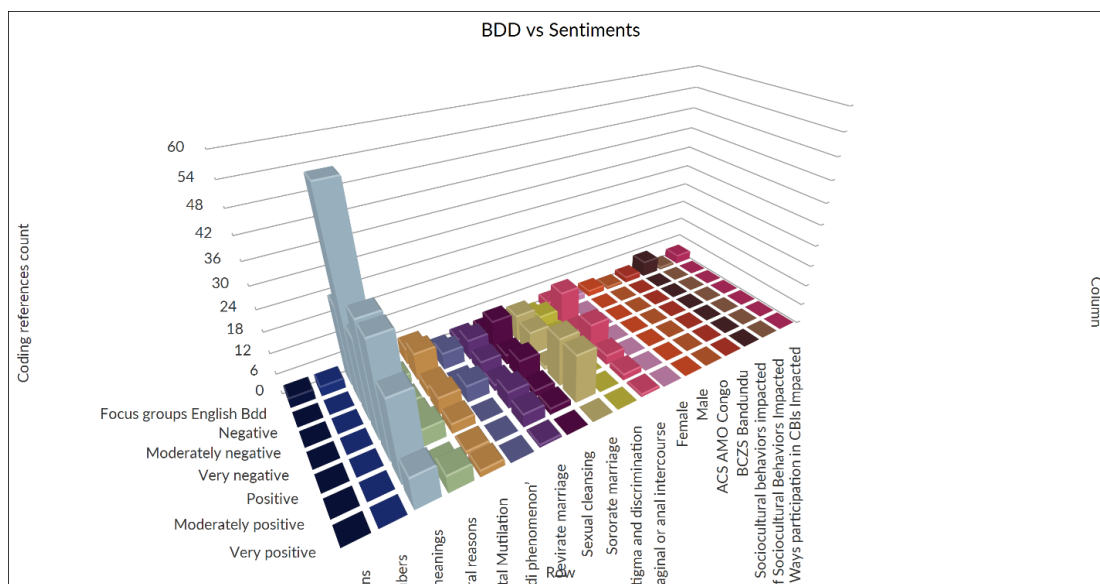
#### ***Focus Group Answers***

Throughout this research, several questions were asked to respondents in order to meet my goal. After the informed consent form signing process and their voluntary participation, they were asked for instance: ‘What is the meaning of CBIs such as VCT, HV, GIA at your level?’, ‘In what ways has participation in CBIs since 2004 has impacted your sexual behaviors among Congolese HIV+ persons, families, communities,

organizations, and societies?’, ‘what is your understanding of the detailed sociocultural behaviors impacted at the end of CBI projects considering the personal, family, community, organizational and societal (law) level?’

**Figure 12**

*Cultural Concept without Impact Answers versus Type of Sentiment*



Data entered in NVivo R1 software were reduced, synthesized, and analyzed to provide answers to those different questions. The above NVivo R1 graph depicts different qualitative answers offered as positive or negative suggestions.

The following table built from each cultural concept generates the frequency of answers’ occurrence and the type of sentiment provided per question.

**Table 9**

*Concepts and Frequency of Sentiment*

Concept/Magnitude Sentiment	Focus groups English Bdd	Negative	Moderately negative	Very negative	Positive	Moderately positive	Very positive
-----------------------------	--------------------------	----------	---------------------	---------------	----------	---------------------	---------------

1. Community-based Interventions	3	0	0	0	0	0	0
2. Community-based Interventions for family members	3	0	0	0	0	0	0
3. Cultural meanings	23	55	23	32	32	23	9
4. Condom rejection for cultural reasons	1	3	1	2	5	0	5
5. Female Genital Mutilation	5	8	3	5	3	1	2
6. Kintwidi phenomenon'	1	5	0	5	0	0	0
7. Levirate marriage	2	6	4	2	5	4	1
8. Sexual cleansing	2	9	3	6	2	2	0
9. Sororate marriage	2	8	7	1	14	14	0
10. Stigma and discrimination	1	5	3	2	0	0	0
11. Unprotected receptive vaginal or anal intercourse	3	10	2	8	3	2	1
12. Female	2	0	0	0	0	0	0
13. Male	2	0	0	0	0	0	0
14. ACS AMO Congo	2	0	0	0	0	0	0
15. BCZS Bandundu	1	0	0	0	0	0	0
16. Sociocultural behaviors impacted	3	5	2	1	6	1	5
17. Understanding of Sociocultural Behaviors Impacted	1	2	0	2	13	2	11
18. Ways participation in CBIs Impacted	3	0	0	0	11	1	10

Table 9 to continue

**Ways Participation in CBIs Impacted Their Behaviors.** Three main answers came out of that theme in focus groups regarding that question. For instance, a group of PLHIVs stated, “CBIs have played an important role, mainly in how to have responsible sex by correctly using condoms<sup>1</sup>. CBIs have helped us through counseling and practical advice<sup>2</sup>. They have also contributed to access to medicines<sup>3</sup>. CBIs allowed PLHIVs to get married, because in the past we thought PLHIVs could never get married<sup>4</sup>.” Another focus group suggested that ‘we live positively with responsible sex and giving birth to



HIV-free children<sup>5</sup>. There are laws passed in the Congolese parliament that protect us<sup>6</sup>.”

The last focus group stated that “CBIs have been effective in ending discrimination and stigmatization of our sexual partners through awareness<sup>7</sup>. CBIs played a significant role in advocating for policy makers to pass laws protecting HIV-positive people in Congo-Kinshasa<sup>8</sup>. CBIs enabled Congolese HIV-positive people to know their rights and duties<sup>9</sup>. CBIs have allowed us to have responsible sex intercourse using condoms or abstaining ourselves<sup>10</sup>. CBIs enabled us to give birth with a regular follow-up at PMTCT<sup>11</sup>.”

**Understanding of Sociocultural Behaviors Impacted.** A thorough description of answers suggests from the first focus group the following statement: “... I do not have free access to medicines<sup>12</sup>. I cannot live an independent life, I miss HIV counselling<sup>13</sup>, I have difficulty getting positive advice like in the past<sup>14</sup>.” The second focus group thought as “It made us PLHIV accepting ourselves as we are<sup>15</sup>, then we regained our leadership with hope of living longer<sup>16</sup>. Laws protecting us systematically promote our integration into society<sup>17</sup>.” And the last focus group spoke broadly as “... I had pain thinking how difficult it would be for the future generation to live without this project<sup>18</sup>. At the end of AMO Congo, we were abandoned with no supervision, all the expertise designed to take care of HIV-positive people was vanished<sup>19</sup>. Because life is sacred, my view of HIV/AIDS has totally changed for nothing can be taken lightly anymore<sup>20</sup>. CBIs enabled me with some sustainability in planning my future<sup>21</sup>, extending my life without relying on anyone who could influence it negatively<sup>22</sup>. We are urgently asking all those who can financially intervene and provide support to the comeback and continue beyond all AMO CONGO HIV/AIDS activities.”

**Understanding of Sociocultural Behavior Concepts Impacted.** The initial focus groups suggests as answers, “The VCT is the voluntary screening center: it is where everyone goes to look to find out their HIV status<sup>23</sup>. During Home Visits, health workers would come to visit us at home with food, needed medicines and counseling to strengthen us<sup>23</sup>. IGA means income-generating activity. This helped us to be independent in our society<sup>24</sup>. The second group thinks that “VCT is an activity that allows HIV-positive people to know their serological status<sup>25</sup>. The VCT is only the voluntary counselling and testing that has broken the ice at all considerations of the disease to access antiretroviral treatment<sup>26</sup>. However, HV are home visits organized by community care technicians to help them learn about lives of HIV-positive people or people affected by HIV/AIDS<sup>27</sup>. IGAs are income-generating activities that allow infected and affected people to get away from the concept of "SO.PE.KA" which means in the local slang of people living in Kinshasa ‘sombela ngai’ (buy for me), ‘pesa ngai’ (give me), and ‘kabela ngai’ (offer me gifts)<sup>28</sup>. IGAs did not come to make us rich people, help us to become financially and economically self-sufficient or stable<sup>29</sup>.

The third one stated, “The VCT is voluntary counselling and testing. It enabled us to be confirming our HIV serological status<sup>30</sup>, then benefit from healthcare workers and specialists in the field with sensitive vital advice<sup>31</sup>. A VCT is a specialized setting-core assisting a community with HIV test/search through the human blood. Home visits are routine activities that allow HIV/AIDS technicians to organize a tour at home to an agreed location with anyone infected or affected to understand the reality of their life<sup>32</sup>. Home visits can also be seen as strategic field activities performed by HIV/AIDS

technicians to act on behalf of an affected or infected person<sup>33</sup>. Income Generating Activities are activities that generate individual or collective income for self-care for a person infected or the whole family of the individual affected by HIV/AIDS<sup>34</sup>. IGAs are income-generating activities of a PLHIV (person living with HIV/AIDS) for financial and economic independence<sup>35</sup>. The IGA is a technique that aims for a PLHIV to avoid the "SO. PE.KA, i.e., Sombela ngai, Pesa ngai, Kabela ngai" which means into an easy English: "buy this for me, give this to me, and constantly shop for me anytime."<sup>36</sup>

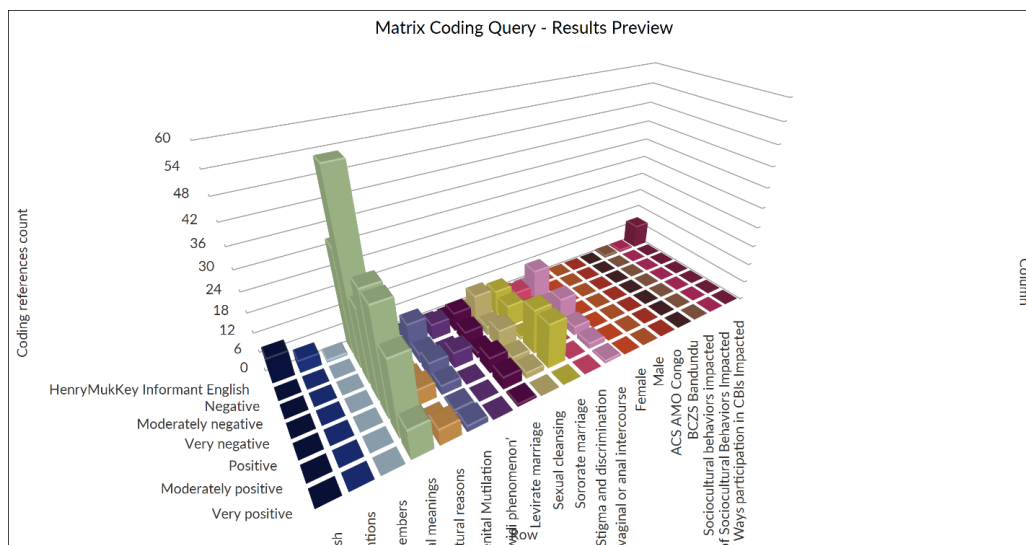
The second interview stated that "... this helped save many lives<sup>38</sup>. Especially the AGR have allowed women to have a self-determination in society. These interventions focused on HVs and GIAs allowed them to become responsible again and be pro-active<sup>39</sup>. In Bandundu, we have data where women have learned to implement a limitation of risky relationships<sup>40</sup>."

### ***Key-Informant Interview Answers***

**Ways Participation in CBIs Impacted Their Behaviors.** In this study, two key-informant interviews occurred. One in Ngaliema-Kinshasa and another one in Bandundu-city as shown below.

### **Figure 13**

*Concept Questions without Impact Answers versus Sentiments*



In the first interview above from Kinshasa, I learned that “Community-based interventions are those activities designed to improve prevention and management of health or food or economic assistance carried out by family members directly, or those of the community (neighbors, friends, members of a social club ....), without necessarily going through a state facility such as the hospital or the nutritional center<sup>41</sup>.”

**Table 10**

*Concepts Discussed versus Sentiments.*

Concept Questions/Sentiment	Key Informant English	Negative	Moderately negative	Very negative	Positive	Moderately positive	Very positive
1. Question key-informant person	8	0	0	0	0	0	0
2. Community-based Interventions	4	0	0	0	0	0	0
3. Community-based Interventions for family members	1	0	0	0	0	0	0
4. Cultural meanings	32	55	23	32	32	23	9
5. Condom rejection for cultural reasons	1	3	1	2	5	0	5
6. Female Genital Mutilation	1	8	3	5	3	1	2
7. Kintwidi phenomenon'	1	5	0	5	0	0	0
8. Levirate marriage	1	6	4	2	5	4	1
9. Sexual cleansing	1	9	3	6	2	2	0

10. Sororate marriage	1	8	7	1	14	14	0
11. Stigma and discrimination	1	5	3	2	0	0	0
12. Unprotected receptive vaginal or anal intercourse	1	10	2	8	3	2	1
13. Female	0	0	0	0	0	0	0
14. Male	1	0	0	0	0	0	0
15. ACS AMO Congo	1	0	0	0	0	0	0
16. BCZS Bandundu	0	0	0	0	0	0	0
17. Sociocultural behaviors impacted	1	0	0	0	4	0	4
18. Understanding of Sociocultural Behaviors Impacted	1	0	0	0	7	0	7
19. Ways participation in CBIs Impacted	1	0	0	0	1	0	1

Table 10 to continue

**Sociocultural Behaviors Impacted.** From this interview, it was stated that “... these community interventions provided a comprehensive solution to the problems PLHIVs faced in our society. This is the holistic response to the Congolese PLHIVs’ situation. Indeed, when we talk about the management of AIDS patients (PLHIV), we tend to consider only the medical aspects (medical care needs of PLHIV patients, treatment of opportunistic infections, and the anti- retroviral treatment....)<sup>42</sup>. It is often forgotten that the PLHIV face several challenges on daily basis other than health-related issues, including psychological challenges such as: Isolation, social withdrawal, stigma, discrimination. These can be solved with social resiliency<sup>43</sup> by well-performing community-based activities such as a good VCT (Voluntary Counseling and Testing, Effective Counseling), home visits (HV), group exchanges or groups of storytelling, community activities such as community meals.

There are also some economic challenges. For instance, a seriously ill person sees his economic productivity widely reduced in one hand, and on the other hand his

spending on finance increased. As a result, the individual ends up losing income quickly. That person quickly becomes economically dependent with multiple social needs. This causes a decrease in self-esteem, a kind of social humiliation, a social stress that also reinforces in the long run of the immuno-depression in the PLHIV. These kinds of situations (challenges) are in short-term solved through the fact of granting an income-generating activity (IGA), a productive activity of money...<sup>44</sup>.”

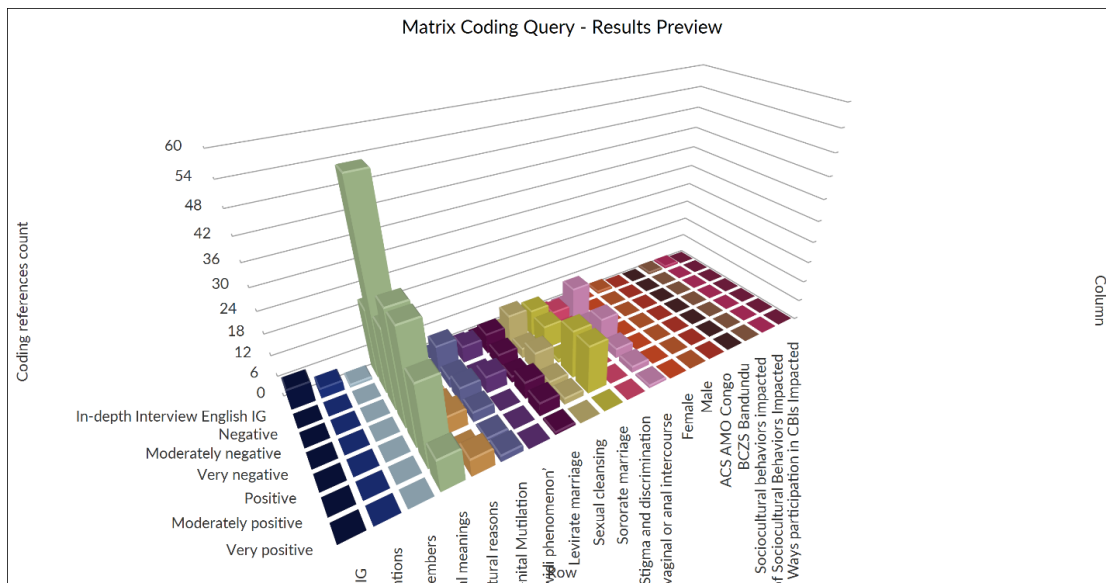
**Understanding of Sociocultural Behavior Concepts Impacted.** The key-informant interview suggested that “this project may have influenced certain behaviors in the community such as, social acceptance of the PLHIV as a patient<sup>45</sup>, the reduction of rejection and stigma towards PLHIV<sup>46</sup>, the organization of the care of AIDS orphans by the community<sup>47</sup>, the practice of home visits to PLHIVs by community members<sup>48</sup>. reducing the financial dependence of some VPPs through economic support activities (RMAs or income-generating activities)<sup>49</sup>. regular attendance of PLHIV at the hospital for treatment and follow-up ARV<sup>50</sup>, increased HIV testing in the community (especially among young people, before marriage, etc.)<sup>51</sup>, AIDS has ceased to be a mysterious and taboo disease in the community<sup>52</sup>.

#### *In-depth Individual Interview IG*

**Ways Participation in CBIs Impacted Their Behaviors (IG).** This respondent was the blinded acronym related to the first interview that occurred with the graph below.

#### **Figure 14**

*Concepts without Impact Responses versus Sentiment*



For this interviewee, “CBIs have contributed more to my development by knowing how to distinguish between what is right and what is wrong.<sup>53</sup>”

**Sociocultural Behaviors Impacted (IG).** Data collection from Kinshasa revealed that “VCT is understood as voluntary counseling and testing done in order to know the HIV status<sup>54</sup>. HV is home visits designed to strengthen someone who is sick and no longer comes to the health center<sup>55</sup>.”

**Understanding Concepts of Sociocultural Behaviors Impacted (IG).** For this interviewee, “CBIs have provided me some value, leading to a positive life, working with community members<sup>56</sup>.”

**Table 11**

*Concept Components versus Sentiment*

Concept components/Sentiment	In-depth Interview English IG	Negative	Moderately negative	Very negative	Positive	Moderately positive	Very positive
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1. In-depth Interview English IG	6	0	0	0	0	0	0
2. Community-based Interventions	3	0	0	0	0	0	0
3. Community-based Interventions for family members	1	0	0	0	0	0	0
4. Cultural meanings	20	55	23	32	32	23	9
5. Condom rejection for cultural reasons	1	3	1	2	5	0	5
6. Female Genital Mutilation	1	8	3	5	3	1	2
7. Kintwidi phenomenon'	1	5	0	5	0	0	0
8. Levirate marriage	1	6	4	2	5	4	1
9. Sexual cleansing	1	9	3	6	2	2	0
10. Sororate marriage	1	8	7	1	14	14	0
11. Stigma and discrimination	1	5	3	2	0	0	0
12. Unprotected receptive vaginal or anal intercourse	1	10	2	8	3	2	1
13. Female	0	0	0	0	0	0	0
14. Male	1	0	0	0	0	0	0
15. ACS AMO Congo	1	0	0	0	0	0	0
16. BCZS Bandundu	0	0	0	0	0	0	0
17. Sociocultural behaviors impacted	1	0	0	0	1	0	1
18. Understanding of Sociocultural Behaviors Impacted	1	0	0	0	2	0	2
19. Ways participation in CBIs Impacted	1	0	0	0	1	0	1

### ***In-depth Individual Interview KR***

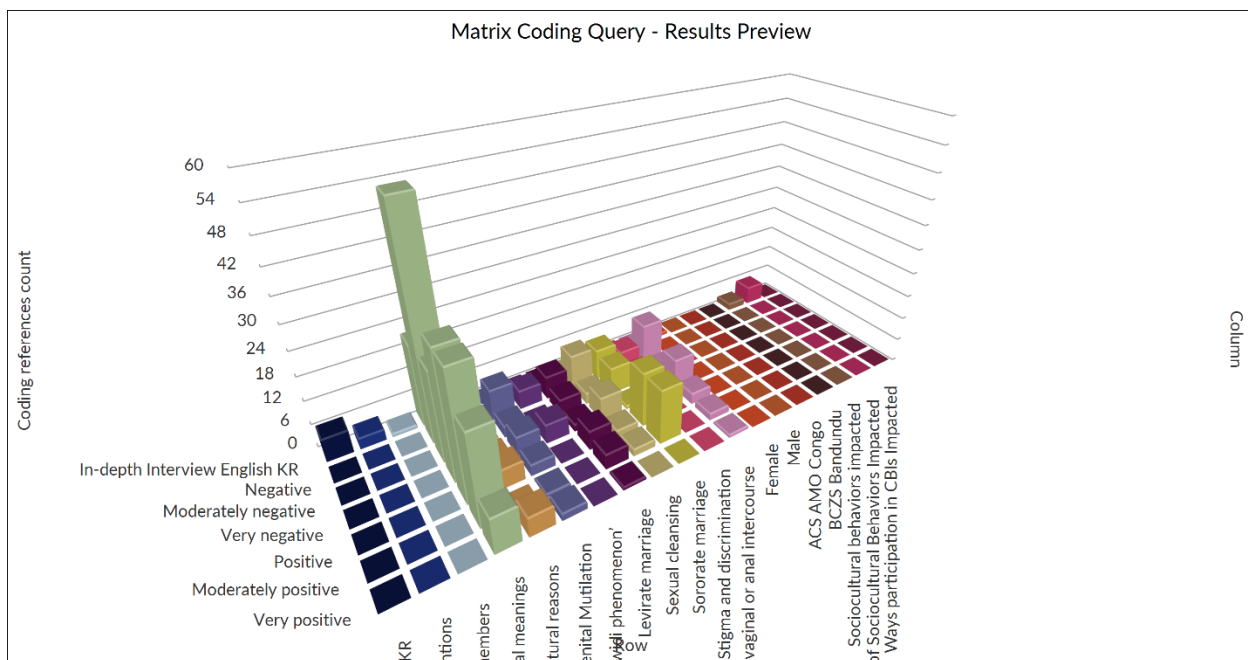
#### **Ways Participation in CBIs Impacted Their Behaviors (KR). He**

stated, “my sexual behavior was shaped since I did not find a faithful partner<sup>57</sup>.”

### **Figure 15**

*KR Case Components without Impact Responses versus Sentiment*





**Sociocultural Behaviors Impacted (KR).** It was stated in this question for “VCT, I do not remember anymore. HV is related to home visits were done with HIV/AIDS volunteers and social workers to find out what were our needs<sup>58</sup>. GIAs: helped me a lot in small business and satisfy my needs.<sup>59</sup>”

**Table 12**

*Case Component versus Sentiment*

Case components/sentiment	In-depth Interview English KR	Negative	Moderately negative	Very negative	Positive	Moderately positive	Very positive
1. In-depth Interview English KR	6	0	0	0	0	0	0
2. Community-based Interventions	3	0	0	0	0	0	0
3. Community-based Interventions for family members	1	0	0	0	0	0	0
4. Cultural meanings	21	55	23	32	32	23	9
5. Condom rejection for cultural reasons	1	3	1	2	5	0	5
6. Female Genital Mutilation	1	8	3	5	3	1	2

7. Kintwidi phenomenon'	1	5	0	5	0	0	0
8. Levirate marriage	1	6	4	2	5	4	1
9. Sexual cleansing	1	9	3	6	2	2	0
10. Sororate marriage	1	8	7	1	14	14	0
11. Stigma and discrimination	1	5	3	2	0	0	0
12. Unprotected receptive vaginal or anal intercourse	1	10	2	8	3	2	1
13. Female	1	0	0	0	0	0	0
14. Male	0	0	0	0	0	0	0
15. ACS AMO Congo	1	0	0	0	0	0	0
16. BCZS Bandundu	0	0	0	0	0	0	0
17. Sociocultural behaviors impacted	2	0	0	0	2	0	2
18. Understanding of Sociocultural Behaviors Impacted	5	0	0	0	5	2	3
19. Ways participation in CBIs Impacted	1	0	0	0	1	0	1

Table 12 to continue

### Understanding Concepts of Sociocultural Behaviors Impacted (KR).

#### Data collected

revealed this statement, “at the personal level, I recovered the social consideration I had lost before<sup>60</sup>. At the family level, no one thinks of my death anytime soon<sup>61</sup>. At the community level, self-support group friends continue to hang out with me<sup>62</sup>. At the organizational level, I manage not to be dependent<sup>63</sup>. For the law, I know my rights and my duties now<sup>64</sup>.

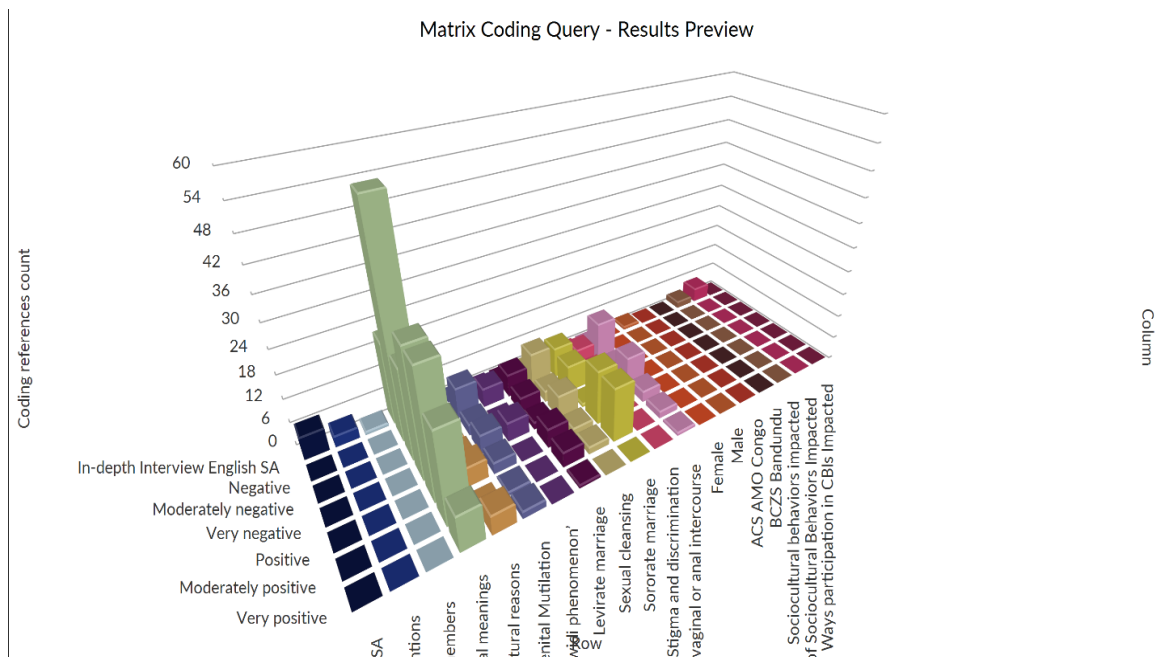
#### *In-depth Individual Interview SA*

**Ways Participation in CBIs Impacted Their Behaviors.** This interviewee offered an answer to the question stating, “I have changed the way I have sex with sharing experiences<sup>65</sup>. Being elderly in the family, I had a new insight in terms of

leadership<sup>66</sup>. Regarding the laws, I understood my rights and duties of an HIV-positive person<sup>67</sup>.”

**Figure 16**

*Concept Components versus Sentiment*



**Sociocultural Behaviors Impacted.** For this question, answer suggested were, “VCT is the advice and voluntary testing of anyone who wants to know his ORHR status for free<sup>68</sup>. HVs are home visits of the "bana ya membre" (PLVIHs) to understand living standards in order to intervene differently<sup>69</sup>. A IGA is the income-generating activity I received from AMO CONGO in order to support my family<sup>70</sup>.”

**Table 13**

*Concept Components versus Sentiment*

Concepts/Sentiment	In-depth Interview English SA	Negative	Moderately negative	Very negative	Positive	Moderately positive	Very positive
1. In-depth Interview English SA	6	0	0	0	0	0	0
2. Community-based Interventions	3	0	0	0	0	0	0
3. Community-based Interventions for family members	1	0	0	0	0	0	0
4. Cultural meanings	21	55	23	32	32	23	9
5. Condom rejection for cultural reasons	1	3	1	2	5	0	5
6. Female Genital Mutilation	1	8	3	5	3	1	2
7. Kintwidi phenomenon'	1	5	0	5	0	0	0
8. Levirate marriage	1	6	4	2	5	4	1
9. Sexual cleansing	1	9	3	6	2	2	0
10. Sororate marriage	1	8	7	1	14	14	0
11. Stigma and discrimination	1	5	3	2	0	0	0
12. Unprotected receptive vaginal or anal intercourse	1	10	2	8	3	2	1
13 Female	0	0	0	0	0	0	0
14. Male	1	0	0	0	0	0	0
15. ACS AMO Congo	1	0	0	0	0	0	0
16. BCZS Bandundu	0	0	0	0	0	0	0
17. Sociocultural behaviors impacted	1	0	0	0	3	0	3
18. Understanding of Sociocultural Behaviors Impacted	1	0	0	0	4	0	4
19. Ways participation in CBIs Impacted	1	0	0	0	3	0	3

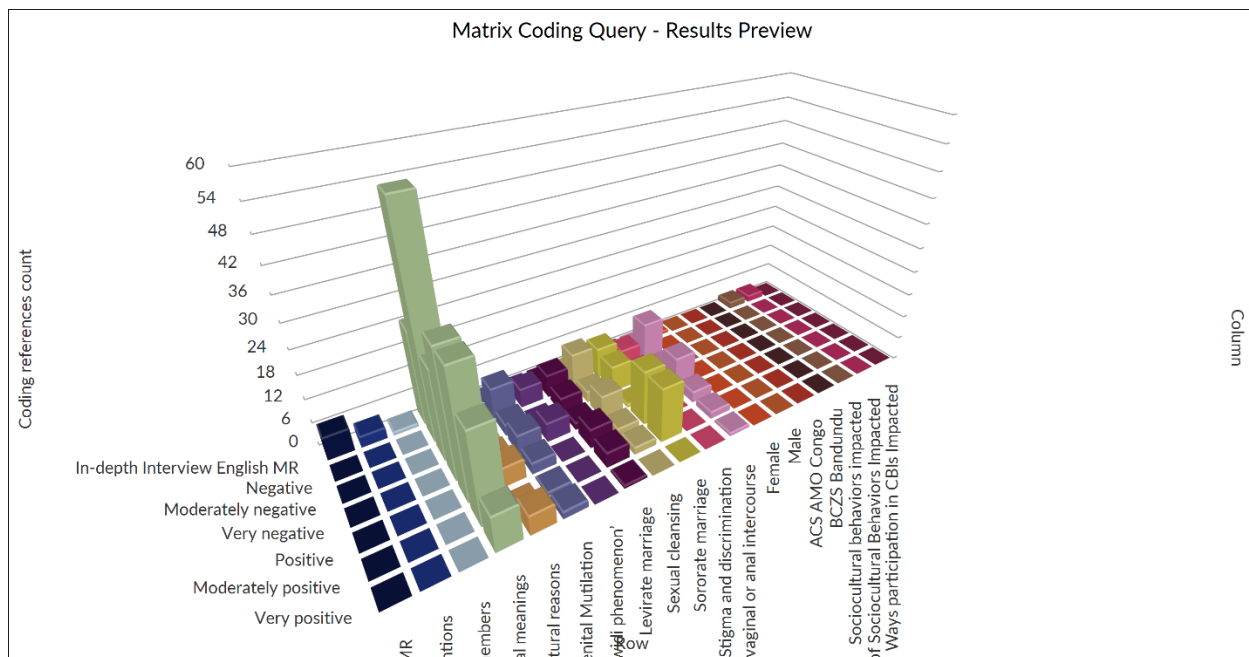
**Understanding Concepts of Sociocultural Behaviors Impacted.** He responded here, Since I was shown the way forward, I no longer have health problems<sup>71</sup>. No one talks about me in the wrong way because I am the one who contributes more to my family members<sup>72</sup>. In the community, I participate in HIV/AIDS activities<sup>73</sup>. In regard to laws, I know how to use my rights and duties as a good citizen<sup>74</sup>.

***In-depth Individual Interview MR***

**Ways Participation in CBIs Impacted Their Behaviors.** I live straightforward with my family and my community in terms of behaviors<sup>75</sup>.

**Figure 17**

*Concept Components without Impact Responses versus Sentiment*



**Sociocultural Behaviors Impacted.** The interviewee stated, “I came out of hiding. I finally got in touch with the world again<sup>76</sup>.”

This is the only answer to the important question provided by the individual, and the response explains how PLHIVs were able to get out of the clandestinity. That reverse behavioral observation could likely have a relationship with the fact that significant information was given to the individual for behavioral change.

**Table 14**

*Concept Components versus Sentiment :*

Concepts / Sentiment	A : In-depth Interview English MR	Negative	Moderately negative	Very negative	Positive	Moderately positive	Very positive
1. In-depth Interview English MR	6	0	0	0	0	0	0
2. Community-based Interventions	3	0	0	0	0	0	0
3. Community-based Interventions for family members	1	0	0	0	0	0	0
4. Cultural meanings	24	55	23	32	32	23	9
5. Condom rejection for cultural reasons	1	3	1	2	5	0	5
6. Female Genital Mutilation	1	8	3	5	3	1	2
7. Kintwidi phenomenon'	1	5	0	5	0	0	0
8. Levirate marriage	1	6	4	2	5	4	1
9. Sexual cleansing	1	9	3	6	2	2	0
10. Sororate marriage	1	8	7	1	14	14	0
11. Stigma and discrimination	1	5	3	2	0	0	0
12. Unprotected receptive vaginal or anal intercourse	1	10	2	8	3	2	1
13. Female	1	0	0	0	0	0	0
14. Male	0	0	0	0	0	0	0
15. ACS AMO Congo	1	0	0	0	0	0	0
16. BCZS Bandundu	0	0	0	0	0	0	0
17. Sociocultural behaviors impacted	2	0	0	0	1	0	1

18. Understanding of Sociocultural Behaviors Impacted	2	0	0	0	2	0	2
19. Ways participation in CBIs Impacted	1	0	0	0	1	0	1

Table 14 to continue

### **Understanding Concepts of Sociocultural Behaviors Impacted.** The

interviewee stated, “VCT

is the voluntary counseling and testing that health care workers do to understand how

PLHIVs live<sup>76</sup>. HVs are home visits performed by care workers to learn about the social situation of HIV-positive people. IGAs are income-generating activities that we receive to become financially independent<sup>77</sup>.

#### ***In-depth Individual Interview NP***

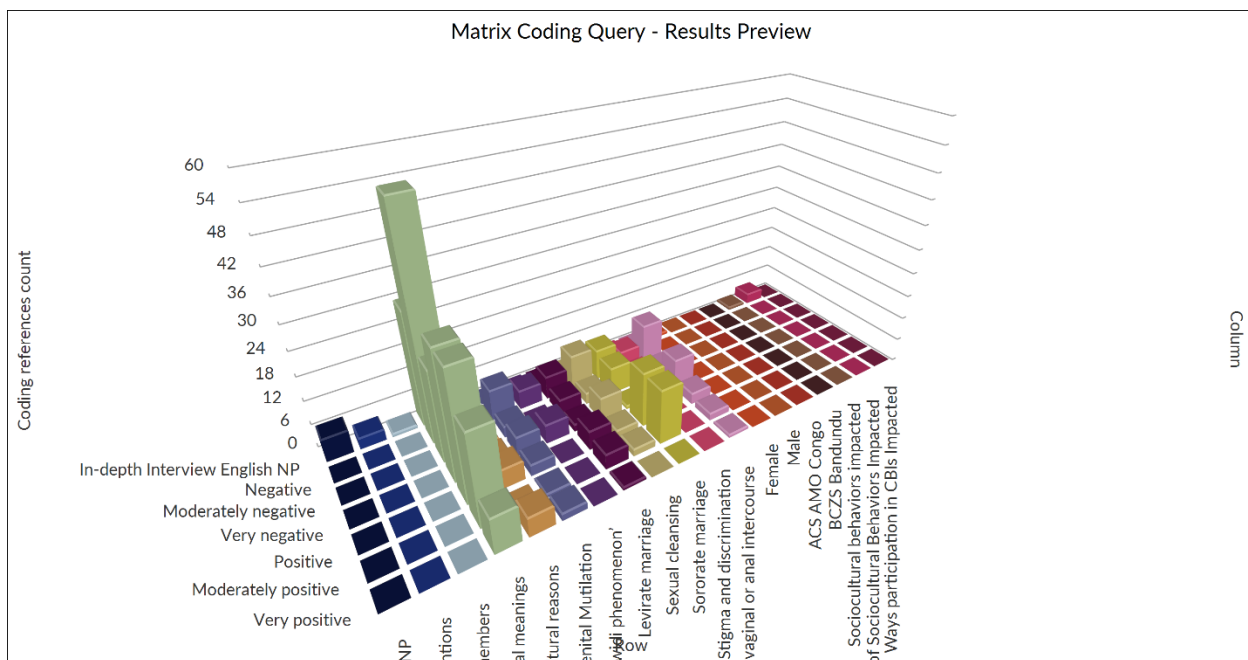
#### **Ways Participation in CBIs Impacted Their Behaviors.** “This helped me get

back

my societal consideration that I lost at the beginning of the disease<sup>78</sup>, and it assisted me acknowledge my rights and duties in the community<sup>79</sup>. I own several testimonies from CBIs in various groups regarding my HIV status, since its enabled lots of friends to rid of their fear<sup>80</sup>. Besides that, I regret how we lost the whole program of CBIs as performed in the past with institutions like ACS AMO CONGO<sup>81</sup>. My family is proud of me every time they figure out that I am healthy, and I am in track of my daily health.<sup>82”</sup>

### **Figure 18**

*Concept Components versus Sentiment*



**Sociocultural Behaviors Impacted.** “I benefited from the good advice to guide my life<sup>83</sup>. I know my rights and duties as a person with HIV-positive<sup>84</sup>. The community looks at me as a fearless person<sup>85</sup>.”

**Table 15**

*Concepts for NP versus Sentiment*

Concepts / Sentiment	In-depth Interview English NP	Negative	Moderately negative	Very negative	Positive	Moderately positive	Very positive
1. In-depth Interview English NP	6	0	0	0	0	0	0
2. Community-based Interventions	3	0	0	0	0	0	0
3. Community-based Interventions for family members	1	0	0	0	0	0	0
4. Cultural meanings	29	55	23	32	32	23	9
5. Condom rejection for cultural reasons	1	3	1	2	5	0	5
6. Female Genital Mutilation	1	8	3	5	3	1	2



7. Kintwidi phenomenon'	1	5	0	5	0	0	0
8. Levirate marriage	1	6	4	2	5	4	1
9. Sexual cleansing	1	9	3	6	2	2	0
10. Sororate marriage	1	8	7	1	14	14	0
11. Stigma and discrimination	1	5	3	2	0	0	0
12. Unprotected receptive vaginal or anal intercourse	1	10	2	8	3	2	1
13. Female	1	0	0	0	0	0	0
14. Male	0	0	0	0	0	0	0
15. ACS AMO Congo	1	0	0	0	0	0	0
16. BCZS Bandundu	0	0	0	0	0	0	0
17. Sociocultural behaviors impacted	1	0	0	0	3	0	3
18. Understanding of Sociocultural Behaviors Impacted	3	0	0	0	3	0	3
19. Ways participation in CBIs Impacted	1	1	1	0	4	0	4

Table 15 to continue

**Understanding Concepts of Sociocultural Behaviors Impacted.** “VCT is the voluntary testing of anyone who wants to know his HIV status from a healthcare center<sup>86</sup>. HVs are home visits are done by community healthcare to help us understand how to guide our life<sup>87</sup>. IGAs are only the income-generating activities that I used to receive to avoid the ‘SO.PE.KA meaning, sombela ngai, pesa ngai, kabela ngai’<sup>88</sup>. This can easily be translated into: ‘if you teach me how to fish, I will have more than charity for every day.’”

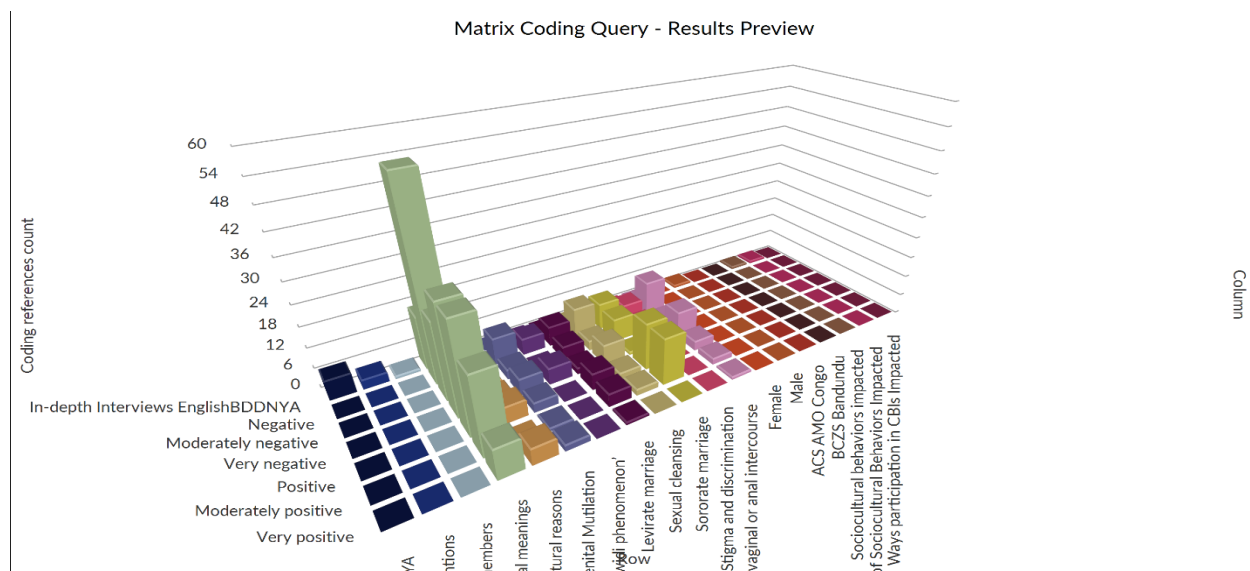
### ***In-depth Individual Interview NYA***

**Ways Participation in CBIs Impacted Their Behaviors.** CBIs implemented allowed to

educate the public about HIV by suggesting the use of condoms during every sexual intercourse<sup>89</sup>.

**Figure 19**

*Concepts without Impact Questions versus Sentiment*



**Sociocultural Behaviors Impacted.** I received preventive counseling and I have consideration in the society<sup>90</sup>. I am no more ashamed to declare out loud my HIV status<sup>91</sup>.

**Understanding Concepts of Sociocultural Behaviors Impacted.** For this PLHIV, “VCT is the Voluntary screening center, and this is where everyone will consult to find out their serological summer<sup>92</sup>. HV means home visit: so, health workers would come to visit us at home with food, medicine, and advice to strengthen us<sup>93</sup>. IGA: It was an income-generating activity that helped us to be independent in society<sup>94</sup>.”

**Table 16**

*Concept Components versus Sentiment*

Concepts / Sentiment	In-depth Interviews EnglishBDDNYA	Negative	Moderately negative	Very negative	Positive	Moderately positive	Very positive
1. In-depth Interviews EnglishBDDNYA	6	0	0	0	0	0	0
2. Community-based Interventions	3	0	0	0	0	0	0
3. Community-based Interventions for family members	1	0	0	0	0	0	0
4. Cultural meanings	16	55	23	32	32	23	9
5. Condom rejection for cultural reasons	1	3	1	2	5	0	5
6. Female Genital Mutilation	1	8	3	5	3	1	2
7. Kintwidi phenomenon'	1	5	0	5	0	0	0
8. Levirate marriage	1	6	4	2	5	4	1
9. Sexual cleansing	1	9	3	6	2	2	0
10. Sororate marriage	1	8	7	1	14	14	0
11. Stigma and discrimination	1	5	3	2	0	0	0
12. Unprotected receptive vaginal or anal intercourse	1	10	2	8	3	2	1
13. Female	0	0	0	0	0	0	0
14. Male	1	0	0	0	0	0	0
15. ACS AMO Congo	0	0	0	0	0	0	0
16. BCZS Bandundu	1	0	0	0	0	0	0
17. Sociocultural behaviors impacted	1	0	0	0	2	0	2
18. Understanding of Sociocultural Behaviors Impacted	1	0	0	0	3	0	3

19. Ways participation in CBIs Impacted	1	0	0	0	1	0	1
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Table 16 to continue

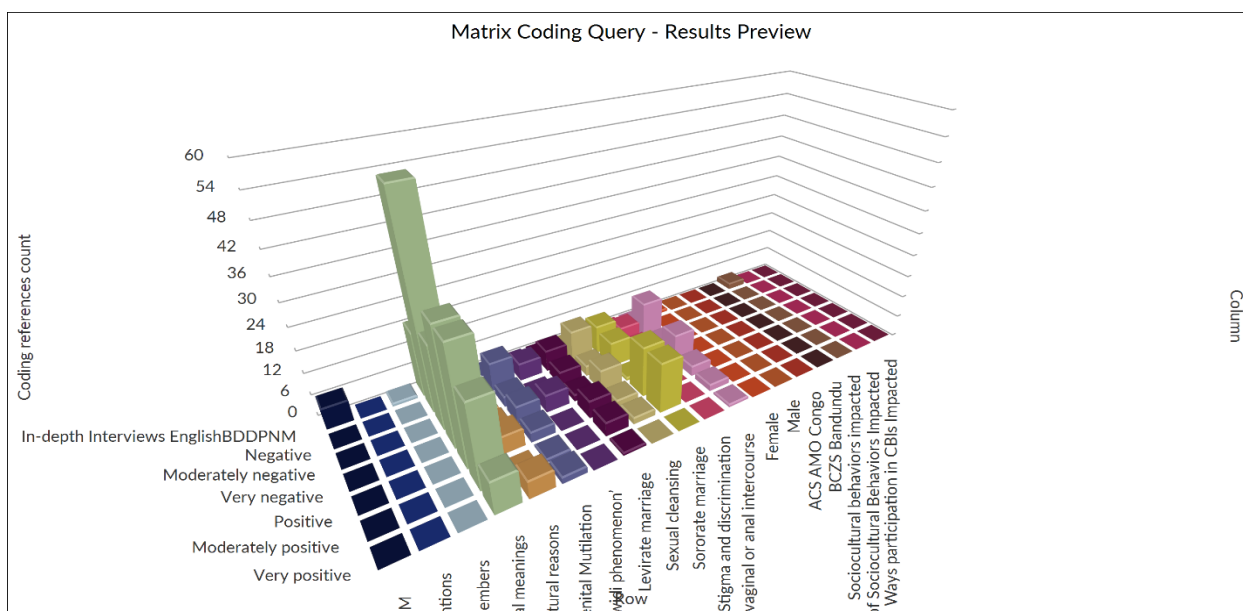
***In-depth Individual Interview PNM***

**Ways Participation in CBIs Impacted Their Behaviors. N/A**

The following graph illustrates how these PLHIVs from Bandundu distinguishes own sentiments with key-concept components, excluding information regarding the impact on sociocultural behaviors.

**Figure 20**

*Concept Components without Impact Questions versus Sentiment*



**Sociocultural Behaviors Impacted. N/A**

Table suggesting sociocultural behaviors impacted at the end of the project with ‘no answers’.

**Table 17**

*Concepts versus Sentiment*

Concepts / Sentiment	In-depth Interviews EnglishBDDPNM	Negative	Moderately negative	Very negative	Positive	Moderately positive	Very positive
1. In-depth Interviews English BDDPNM	6	0	0	0	0	0	0
2. Community-based Interventions	1	0	0	0	0	0	0
3. Community-based Interventions for family members	1	0	0	0	0	0	0
4. Cultural meanings	18	55	23	32	32	23	9
5. Condom rejection for cultural reasons	1	3	1	2	5	0	5
6. Female Genital Mutilation	1	8	3	5	3	1	2
7. Kintwidi phenomenon'	1	5	0	5	0	0	0
8. Levirate marriage	1	6	4	2	5	4	1
9. Sexual cleansing	1	9	3	6	2	2	0
10. Sororate marriage	1	8	7	1	14	14	0
11. Stigma and discrimination	1	5	3	2	0	0	0
12. Unprotected receptive vaginal or anal intercourse	1	10	2	8	3	2	1
13. Female	1	0	0	0	0	0	0
14. Male	0	0	0	0	0	0	0
15. ACS AMO Congo	0	0	0	0	0	0	0
16. BCZS Bandundu	1	0	0	0	0	0	0
17. Sociocultural behaviors impacted	1	0	0	0	0	0	0
18. Understanding of Sociocultural Behaviors Impacted	1	0	0	0	0	0	0

19. Ways participation in CBI's Impacted	1	0	0	0	0	0	0
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Table 17 to continue

**Understanding Concepts of Sociocultural Behaviors Impacted. N/A**

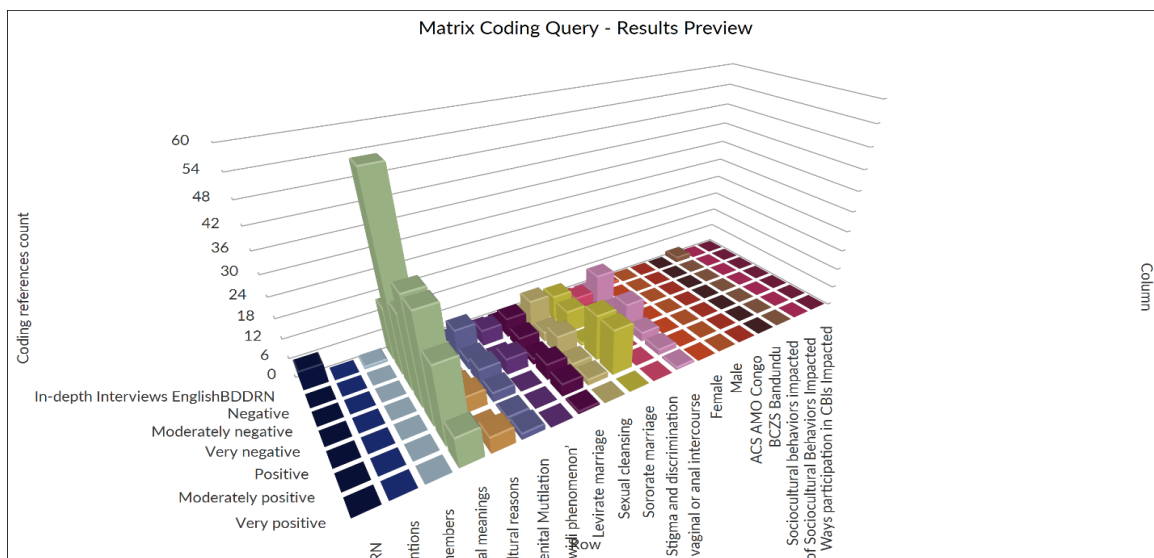
*In-depth Individual Interview NRB*

**Ways Participation in CBI's Impacted Their Behaviors. N/A**

No impact revealed here since the person did not answer that question.

**Figure 21**

*Concept Components without Impact Questions versus Sentiment*



**Sociocultural Behaviors Impacted. N/A**

**Table 18**

*Concept Components versus Sentiment*

	In-depth Interviews	Negative	Moderately negative	Very negative	Positive	Moderately positive	Very positive
Concepts/Sentiments	EnglishBDDRN						

1. In-depth Interviews EnglishBDDRN	6	0	0	0	0	0	0
2. Community-based Interventions	1	0	0	0	0	0	0
3. Community-based Interventions for family members	1	0	0	0	0	0	0
4. Cultural meanings	16	55	23	32	32	23	9
5. Condom rejection for cultural reasons	1	3	1	2	5	0	5
6. Female Genital Mutilation	1	8	3	5	3	1	2
7. Kintwidi phenomenon'	1	5	0	5	0	0	0
8. Levirate marriage	1	6	4	2	5	4	1
9. Sexual cleansing	1	9	3	6	2	2	0
10. Sororate marriage	1	8	7	1	14	14	0
11. Stigma and discrimination	1	5	3	2	0	0	0
12. Unprotected receptive vaginal or anal intercourse	1	10	2	8	3	2	1
13. Female	1	0	0	0	0	0	0
14. Male	0	0	0	0	0	0	0
15. ACS AMO Congo	0	0	0	0	0	0	0
16. BCZS Bandundu	1	0	0	0	0	0	0
17. Sociocultural behaviors impacted	1	0	0	0	0	0	0
18. Understanding of Sociocultural Behaviors Impacted	1	0	0	0	0	0	0
19. Ways participation in CBIs Impacted	1	0	0	0	0	0	0

### Understanding Concepts of Sociocultural Behaviors Impacted. N/A

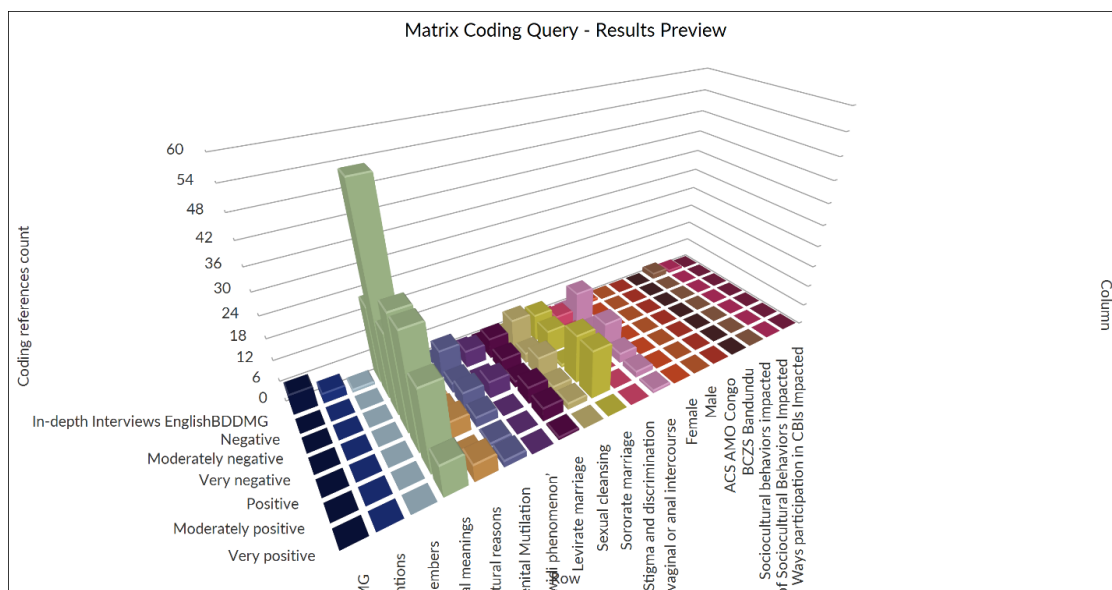
#### *In-depth Individual Interview MGB*

**Ways Participation in CBIs Impacted Their Behaviors.** On this step, the interviewee answered, “I developed personal skills in public speech ability, and I started openly talking about my HIV status without fear or shame<sup>95</sup>, I had the chance to send my

little brothers to school<sup>96</sup>. I completely changed the way I was understanding sex without a condom<sup>97</sup>, I would never accept to have any intercourse without condom. I became responsible and faithful.<sup>98</sup>”

**Figure 22**

*Concepts without Impact Questions versus Sentiment*



**Sociocultural Behaviors Impacted.** “I became almost an expert in this field, especially implementing outreach in HIV prevention<sup>99</sup>. But since this project left, we have had difficulty feeding our children and getting essential medicines.<sup>100</sup>”

**Table 19**

*Concept Components versus Sentiment.*

Concepts / Sentiment	In-depth Interviews EnglishBDDMG	Negative	Moderately negative	Very negative	Positive	Moderately positive	Very positive
1. In-depth Interviews EnglishBDDMG	6	0	0	0	0	0	0



2. Community-based Interventions	3	0	0	0	0	0	0
3. Community-based Interventions for family members	1	0	0	0	0	0	0
4. Cultural meanings	22	55	23	32	32	23	9
5. Condom rejection for cultural reasons	1	3	1	2	5	0	5
6. Female Genital Mutilation	1	8	3	5	3	1	2
7. Kintwidi phenomenon'	1	5	0	5	0	0	0
8. Levirate marriage	1	6	4	2	5	4	1
9. Sexual cleansing	1	9	3	6	2	2	0
10. Sororate marriage	1	8	7	1	14	14	0
11. Stigma and discrimination	1	5	3	2	0	0	0
12. Unprotected receptive vaginal or anal intercourse	1	10	2	8	3	2	1
13. Female	1	0	0	0	0	0	0
14. Male	0	0	0	0	0	0	0
15. ACS AMO Congo	0	0	0	0	0	0	0
16. BCZS Bandundu	1	0	0	0	0	0	0
17. Sociocultural behaviors impacted	2	0	0	0	0	0	0
18. Understanding of Sociocultural Behaviors Impacted	1	0	0	0	0	0	0
19.: Ways participation in CBIs Impacted	1	0	0	0	0	0	0

### Understanding Concepts of Sociocultural Behaviors Impacted. The

interviewee suggested,

“VCT: Voluntary screening center: this is where everyone will consult to find out their serological status<sup>101</sup>. HVs: home visits are organized so health workers would come to visit PLHIV at home with food, medicines, and counseling to strengthen them<sup>102</sup>. IGA: It was an income-generating activity that helped us to be independent in society.<sup>103</sup>” This

statement shows how mindful is this PLHIV in the way of understanding behavior impacted.

## **RQ2 - What Is the Meaning of Community-Based Interventions for Family Members?**

### ***KIP1***

Family members have their own opinion regarding CBI. This PLHIV stated, “based on the answer to the previous question, we understand that a PLHIV is in social and financial distress<sup>104</sup>. He is a very vulnerable person and seem to be exposed to the social risks of abandonment<sup>105</sup>, threats<sup>106</sup>, rape<sup>107</sup>, sexual violence<sup>108</sup>, stigma<sup>109</sup> .... Reading the impact on the individual: A PLHIV with a holistic or a comprehensive care is protected from elements of social vulnerabilities, as well: PLHIV with IGAs are not economically and not socially vulnerable<sup>110</sup>. They can professionally manage their sexuality and make safe decisions.

For instance, decline all paid unprotected intercourse<sup>111</sup>. From the family and community perspective: I would say thanks to the IGA granting activities, because many PLHIVs have found themselves well accepted and tolerated in their society, so that stigma and discrimination have significantly decreased within our families and communities<sup>112</sup>. From the Organizational and law perspective in general, community activities have enabled the implementation and development of global laws on behavior and attitudes that are favorable and secure for PLHIVs. This includes schools, churches, and markets<sup>113</sup>.”

### ***KIP2***

“There are different opinions for different individuals. This has enabled people to adopt positive attitudes towards HIV<sup>114</sup>. Nevertheless, community interventions allowed that the same action as a single individual would benefit, so that several individuals will benefit in a sustainable way at the Community level<sup>115</sup>. The right example is being thought the safe use of sharp objects among PLHIVs in order to reduce the risk of transmission at the community level.”

***FG BDD***

“It is meant to promote the social consideration within our respective families<sup>116</sup>. Initially, the family considered these interventions to be a derogatory act because, for example, when ACS AMO Congo was distributing food, people referred to us as people receiving food belonging to poor. We were called "madia ya ba pauvres", meaning a food for poor people<sup>117</sup>. These interventions had helped me live in peace, be comfortable and independent, the family was so happy for it<sup>118</sup>.” For FG, even though they’ve been criticized for consuming ‘foods of poor people’, CBIs brought a powerful insight in their life as a handful booster, getting all of them back on the working path.

***FG KIN Men***

“CBIs was enough powerful to strengthen my family and provide some consideration to my modest person because I am no longer weak as before<sup>119</sup>. CBIs gave me a strong hope to fight for my life by taking ARVs and work<sup>120</sup>. CBIs helped my medical, psychosocial, and spiritual care, it offered an opportunity to physically attend my church and pray<sup>121</sup>. CBIs have allowed my family members to consider me like

everyone else with respect.<sup>122</sup>” Family wise, CBIs settled back these PLHIVs as the main responsible of their families as they used to be, they understood the role of the medication and the community spiritual support.

***FG KIN Women***

“It means to me a legendary consideration, an honor, and the acceptance of HIV ill people in regards of proportional quantities of food that I used to receive from my healthcare facility<sup>123</sup>. At the beginning in my family, no one knew I was infected with HIV, since I was at risk of becoming homeless because being useless to them<sup>124</sup>. Community-based interventions that my daughter received at AMO CONGO as IGA (tailor training) have provided us with a value in our family<sup>125</sup>. This allowed the marriage of my daughter taking over to send her brothers and sisters to school<sup>126</sup>. Today I have literate children working and the whole family runs behind me to receive help. These interventions helped family members change the negative way everyone was looking at me. Even my own mother used to call me ‘a simple thing’ when she found out I was infected.<sup>127</sup>” Women interviewed in this focus group showed how they came out of the clandestinity, they got back to productive work and became again able to sustain others.

***In-depth Interview IG***

“My family members were delighted because there was no one in the family who could contribute to my life at that level.<sup>128</sup>” This person acknowledges the return of joy in her life through her family members.

***In-depth Interview KR***

“Community-based interventions were for my family members as a teasing response to me despite the improvement in my health<sup>129</sup>.” This is a proof of a negative sentiment because the family illustrates discrimination, it is a real family stigma.

***In-depth Interview MR***

It meant “Response to any changes, solidarity, and courage to HIV+ people<sup>130</sup>.”

CBIs stand as a strong approach to positively modify PLHIVs’ lives.

***In-depth Interview NP***

“As any act provided by a person deserves a thank you, these interventions have strengthened my life and relationships with my family members<sup>131</sup>.” This PLHIV is grateful for the positive change brought by CBIs in his life.

***In-depth Interview SA***

“A real relief because with my own strengths, I could not get out of it<sup>132</sup>.” CBIs are here qualified as a real pain reliever, a life-saving approach brought to her.

***In-depth Interview BDD MG***

“They were happy with these interventions because it helped me to live in peace and to engage in small business in order to send my children to school<sup>135</sup>.” CBIs made them go back to work and help them live in a peaceful situation with their households.

***In-depth Interview BDD NYA***

“My family was happy with these interventions, such as with the counselling, home visits, foods, medications because it helped me live well and longer<sup>136</sup>.” For this client, CBIs made her life, and her family recognized the interest of them.

***In-depth Interview BDD PNM***

“It was an interesting approach that helped my family lives in peace like everyone else, especially becoming, independent and my family was happy about it<sup>137</sup>.” CBIs were a way to get back to the normal life, according to this patient.

***In-depth Interview BDD RN***

“Because my family members thought that if they eat foods I was provided by ACS AMO Congo, they would also be infected with HIV as I did. So, they never ate that food<sup>138</sup>. In my family I was considered a thief, a worthless person<sup>139</sup> who usually goes to beg for food from AMO Congo.” This is also a part of negative sentiment I received from PLHIVs. Rejection and discrimination were a part of their life with no change sometimes.

**RQ3 - What Are the Detailed Sociocultural Behaviors Impacted at the End of the Project?**

***KI Kin Interview***

“This project may have influenced certain behaviors in the community such as: Social acceptance of the PLHIV as a patient<sup>140</sup>, the reduction of rejection and stigma towards PLHIV<sup>141</sup>. Also, the organization of the care of AIDS orphans by the community, the practice of home visits to PLHIV by community members<sup>142</sup>. It helped reducing the financial dependence of some VPPs through economic support activities (RMAs or income-generating activities)<sup>143</sup>, regular attendance of PLHIV at the hospital for treatment and follow-up ARV<sup>144</sup>. It increased HIV testing in the community (especially among young people, before marriage, etc.), AIDS has ceased to be a mysterious and taboo disease in the community.” Clear behavioral changes were noticed here: social acceptance of the society, reduction of stigma and discrimination around the PLHIV.

***KI BDD Interview***

“All activities carried out under the project have led to a significant change in socio-cultural behavior (outreach, screening, testing, etc.)<sup>145</sup>. This has enabled the acceptance of HIV like any other diseases<sup>146</sup>, there has also been a change in sexual behaviors by protecting CBIs: limitation to the routine partnership and in the management<sup>147</sup>... The information we received has enabled us to reduce risky behaviors, such as prostitution<sup>148</sup>. Also, we even abandoned negative behaviors. Meanwhile, some couples involved in CBIs became better welded and they self-determined their goals in the society with enhanced self-esteem gotten<sup>149</sup>.” This PLHIV admits personal behavioral changes such as the reduction of risky sexual behaviors and became proud of it.

***FG BDD***

“I fully understood and started practicing the use of condoms<sup>150</sup>. I became independent in my society, and I was able to send my children to school<sup>151</sup>. This became an opportunity to speak out without shame or fear<sup>152</sup>. It changed our sexual behaviors and prevented us from having several sexual partners<sup>153</sup>. We became faithful, we knew how to use the condom correctly and regularly. This prevented us from unprotected intercourses<sup>154</sup>.” Here, the condom use became the rule in their daily behavior if needed.

***FG Kin Men***

“I took the option of living positively by accepting my HIV status<sup>155</sup>. I have adopted a culture of law enforcement to protect myself and others<sup>156</sup>. I learned a good culture of living in a society despite my HIV status<sup>157</sup>. I understood that it is not good to have sex with anyone and, to do so you have to protect yourself<sup>158</sup>.” I learned from this

focus group that PLHIVs interviewed decided of protecting themselves and their whole community from getting infected with HIV.

***FG Kin Women***

“Sociocultural and sexual behaviors influenced by CBIs at the end of the project induced: the acceptance of our HIV status, resilience meaning the ability to cope with the situation<sup>159</sup>. My sociocultural behavior has totally changed despite the fact that some family members have disclosed my HIV status. Anyway, I am no longer ashamed or afraid of telling my HIV status<sup>160</sup>. Regarding sexual intercourse, once in front of a gentleman who wants sex with me, wearing a condom is a requirement<sup>161</sup>. To make a long story short, the behavior has changed a lot and thanks for being a part of ACS AMO Congo program beneficiaries.” According to this focus group, the resilience, and the acceptance of the HIV+ status were the major changes, beside safe condom utilization.

***In-depth Interview IG***

“Not so much big change but, I live like everyone else. My sexual life was strengthened and I becoming very faithful to my wife<sup>162</sup>.” This PLHIV acknowledges changing her sexual behavior, but at the same time does not recognize undergoing as much changes as he expected through the project.

***In-depth Interview KR***

“Whenever I was increasing weight, I gave birth to dead babies in Boma, and my husband sent me back to my family for proper care in Kinshasa with my older brother. My brother brought me to ACS AMO CONGO office where HIV/AIDS was diagnosed. Since then, I became like a normal woman who lives with a discipline better than before.



I became responsible for my life to live alone as I have not yet found a partner<sup>162</sup>.” For this PLHIV, CBIs were a life-saving approach, because she is no longer giving birth to dead babies, and she knows now that HIV was the main cause of her health issues.

***In-depth Interview MR***

“Before the illness, I never understood what to do. However, when I became ill, I had self-control in terms of behaviors. I organized myself differently and finally, I was concerned when AMO Congo project ended. I brought moral comfort to two friends who became self-reliant today<sup>163</sup>.” The behavioral change can be found in his understanding of the issue, at the same time self-control in her community is a great asset.

***In-depth Interview NP***

“Sociocultural and sexual behaviors have totally changed, and thanks to the many tips received to strengthen my life and that of others<sup>165</sup>.” This PLHIV is grateful for CBIs, and she emphasizes that these actions were a great support to their lives in general.

***In-depth Interview SA***

“My moral side is strengthened. I feel like newly born with hope of life. I understood how to live and safely continue my sexual life since it will always be protected<sup>166</sup>.” For her, CBIs changed her life back to normal with a strong mental.

***In-depth Interview BDD MG***

“These interventions had helped me a lot in my love life. I started using condoms to avoid contaminating others, and I also started educating others to prevent HIV infection<sup>167</sup>.” CBIs led this PLHIV to healthy condom use and safe HIV outreach.

***In-depth Interview BDD NYA***

“I have totally changed and started to use condoms to protect my partner<sup>168</sup>.”

Hence, CBIs made her ready to prevent others from getting infected with HIV.

***In-depth Interview BDD PNM***

“I completely changed my sexual behavior. I started using condoms to protect myself and my sexual partners<sup>169</sup>. I safely use all the skills I received from my counseling, and I stopped cheating<sup>170</sup>.” I read a transformative life led by CBIs with a positive behavior within her community in Bandundu.

***In-depth Interview NR***

“I changed my sexual behavior. I became reliable with only one person and began even counseling others how to protect themselves from HIV/AIDS<sup>171</sup>.” As in the last interview, all data collected describe detailed sociocultural behaviors impacted at the end of the project from the individual to the societal level, bringing a special accent on sexual behavior as HIV/AIDS had spread among different Congolese communities.

**Data to Support Each Finding (Quotes from Transcripts, Documents, etc.)**

***RQ1 - In What Ways Has Participation in CBIs Impacted Sexual Behaviors Among Congolese PLHIV and their Community in General?***

According to data collected, the majority of respondents suggested that CBIs consist of a package of holistic activities for PLHIVs starting from the outreach to their social assistance. Some of the meaningful features of that approach are VCTs, HVs, and Income-Generating Activities (IGA). Those known iconic activities are the cornerstone of social actions designed to strengthen medical aspects of the long walk through the

HIV-disease journey. For instance, one of the focus groups suggested that “CBIs have played an important role, mainly in how to have responsible sex by correctly using condoms. CBIs have helped us through counseling and practical advice, they also have contributed to access to medicines. CBIs allowed PLHIVs to get married, because in the past we thought PLHIVs could never get married.”

I also learned from this unique qualitative study that besides addressing stigma and discrimination, CBIs implemented during this decade helped PLHIVs to really become responsible and take care of their family members beyond their own children. As community heroes, PLHIVs became a living testimony of their own previous sexual behaviors. Consequently, other community members could learn from their social situation and adopt positive sexual attitude based on multiple socioeconomic outputs of HIV affecting working parents. PLHIVs said for example, “we live positively with responsible sex, and we are able to give birth to HIV-free children.” This is a high level of understanding not only their rights, but also how it is possible for a PLHIV to have a ‘normal life’ while being socially committed into societal norms. Because my trial timeframe with NVivo R1 expired, a small part of my data was explored using Microsoft Excel.

However, one of the interviewees suggested that “there is not so much big change but, I live like everyone else now.” This answer can be confusing, but the idea was as stated above that in a married couple of PLHIVs, they can live a normal life. They can have unprotected sex intercourse with his/her partner for reproductive purpose and give birth to an HIV-free baby if subsequent measures are taken. Surprisingly, one of them

stated, “I became responsible for my life to live alone as I have not yet found a partner.” This means that this individual is potentially changed and willing to stay in control of what he/she does sexually, until he/she will find a partner to get married. The same respondent said, “condom is important for not getting contaminated by sexual transmitted diseases.” This interviewee clearly seems to attribute a protective effect against HIV/AIDS to the correct condom use any time you have sex with unknown partners.

Another respondent said, “I have changed the way I have sex while sharing experience.” At the same time, he/she stated regarding unprotected receptive sexual intercourse that, “It is very risky that we can become the freeway of infections such as HIV/AIDS and STIs.” Conversely, on condom rejection for cultural reasons, he/she suggested that without using a condom, “he is exposed to HIV and STIs without knowing it. If he has someone he can trust, *there is no danger*.” This twisted idea of trusting someone without knowing his/her serological HIV status is an issue in regard to the expected results after 10 years of being in CBIs. Rather than following the same avenue, another person suggested, “I completely changed the way I was understanding sex without a condom, and I would never accept to have any intercourse without condom. I became responsible and faithful.”

***RQ2 – What Is the Meaning of Community-Based Interventions for Family Members?***

Findings of the second research question can be viewed as externalities of CBIs. This means grasping PLHIV’s understanding of CBIs and their valuable multifaceted consequences of a decade of interventions among their communities in DR Congo. For instance, one of the respondents said, “my family was happy with these interventions

because it helped me to live in peace and to engage in small business in order to send my children to school.” Because of CBIs, this person was able to come back to the normal life, fight for survival and educate her children as school is not free in DRC. That made her a proud person in her family, because being a part of an impactful program.

However, some of them have a bad experience of CBIs, especially in regard to the way family members had been socially labeling them. For this interviewee, “community-based interventions were for my family members as a teasing response to me despite the improvement in my health.” This answer reminds stigma and discrimination, when looking at a person in a different way just because he/she is HIV infected or a beneficiary of any assistances because of the social status. This leads to the way a PLHIV implements response to changes. One of them thinks that “it is important to respond, “to any changes with solidarity, and courage regarding HIV-positive people.” Family members can be a discouraging factor if they do not support your fight.

In summary, the meaning of CBI was remarkably diverse. For example, one patient said, “... these interventions have strengthened my life and relationships with my family members.” It seems to be clearly showing that there is a strong bond between that sick person and his/her family members due to the support brought with CBIs. Following at the same direction, another patient stated that he got “a real relief because with my own strength, I could not get out of it.” This PLHIV suggested, “my family was happy with these interventions, such as with the counseling, home visits, foods, medications because it helped me live well and longer.”

***RQ3 - What Are the Detailed Sociocultural Behaviors Impacted at the End of the Project?***

Throughout this qualitative study, I learned that sociocultural behaviors may have changed due to a decade of the project implementation. This could be valid at least in terms of daily practice and skills. At the same time, PLHIVs seem to be stating what they do in their lives around family members. Talking about sexual intercourse, this PLHIV in Bandundu stated, “I safely use all the skills I received from my counseling, and I stopped cheating.” Due to CBI implementation, it is understood here that the person had changed his/her sexual behavior at the end of this project.

Because of the relationship between HIV in Africa and sexual behavior, one of them suggested that “I changed my sexual behavior. I became reliable on only someone and began even counseling others how to protect themselves from HIV/AIDS.” For this PLHIV, “my sexual life was strengthened, and I became very faithful to my wife.” This seems to be the main behavior said impacted by the project. Another PLHIV thought that “all activities carried out under the project have led to a significant change in socio-cultural behavior, such as outreach, screening, etc.” This PLHIV stated, “this became an opportunity to speak out without shame or fear. It changed our sexual behaviors and prevented us from having several sexual partners. We became faithful, we knew how to use the condom correctly and regularly. This prevented us from unprotected intercourses.”

From a diverse opinion, most PLHIVs took a decision of living positively by accepting their HIV + status. They adopted a culture of protecting themselves and other

measures targeting law enforcement. They learned a culture of living in a society despite their HIV status, and they understood how dangerous it is in having sex with anyone with no condom. This must be done because they need to protect themselves. One of the most important deliverables in this project was the resilience in solving their problems. This concept of resilience means here the ability to cope with their local situation.

### **Discrepant Cases / Non-confirming Data as Applicable**

The major discrepant case in this qualitative study came from a PLHIV who said he would be having sex with a partner without a condom only if he trusts the person. At the same time, the respondent sustains that only condom is a safe tool to be used when having sex with casual partners. This individual (SA) sustains that condom rejection for cultural reasons could be understood due to the fact that, “he is exposed to HIV and STIs without knowing it. If he has someone he can trust, there is no danger.” It is important to address that issue after a decade of being in a community-based intervention program designed to implement HIV prevention for others, self-autonomy, and resilience.

I also must highlight the fact that most positive opinions recorded do not mean the respondent agreed with it. For instance, when talking about female gender mutilation, the interviewee coded as SA suggested that “if the person is trained, mutilation can go well.” This person is proven to disagree with that practice because stating in that interview that, “it is also the fact of considering women as socially inferior to men.” For another respondent from Kinshasa, there is another practice in Luba tribe designed to prevent women from cheating. She said, “in my tribe of Bakwalondji in the Eastern Kasai, we do not talk about mutilation. We call ‘Tshibawu’ a known traditional ceremony to prevent a

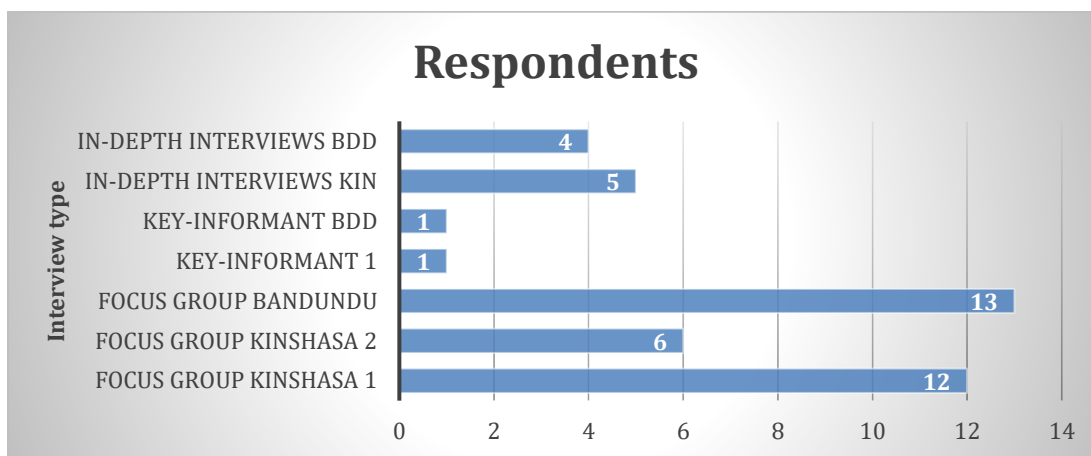
woman from cheating under the influence of a cultural law.” I am not able to say whether she agrees with that practice or not.

### Tables and Figures to Illustrate Results

From December 2020 to February 2021, all qualitative data gathered were reduced, synthesized, analyzed and results were kept in an authorized fashion. Tables below built contain data explaining how Congolese PLHIVs understand the influence of CBIs on their behaviors since the implementation of this program has started/ended. In each table/graph, information gathered illustrate outcomes of 3 focus groups, 2 key-informant person interviews and 9 in-depth interviews performed in Kinshasa and Bandundu-city. The following graphs will provide detailed data collected after reduction.

**Figure 23**

*Interview Types and Number of Participants*

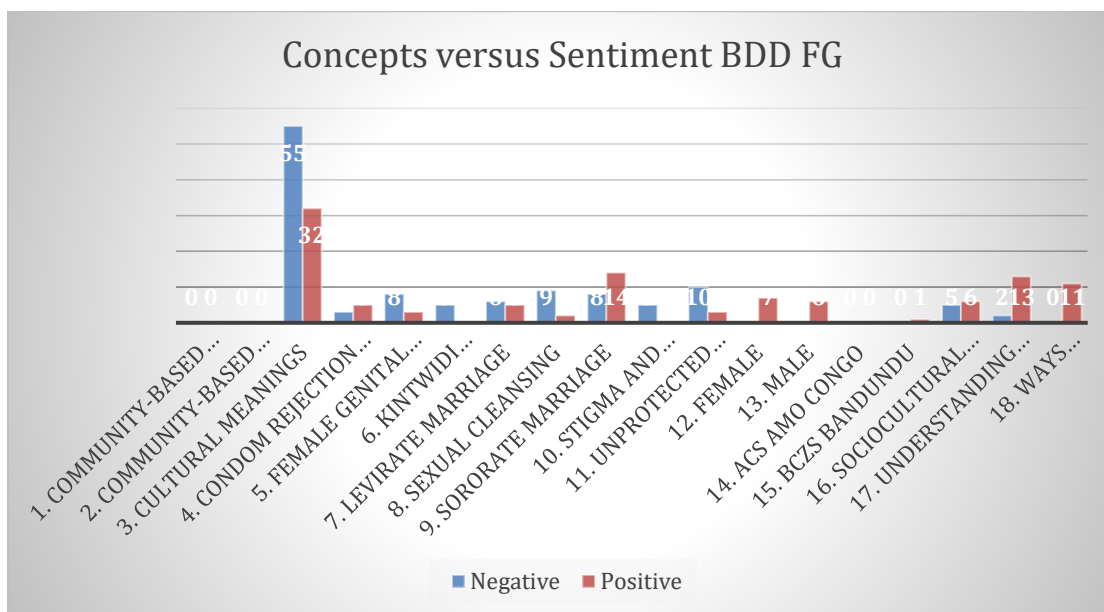


Most people were interviewed in focus groups from the female group built in Kinshasa, and from the focus groups set up in Bandundu-city.

**Figure 24**



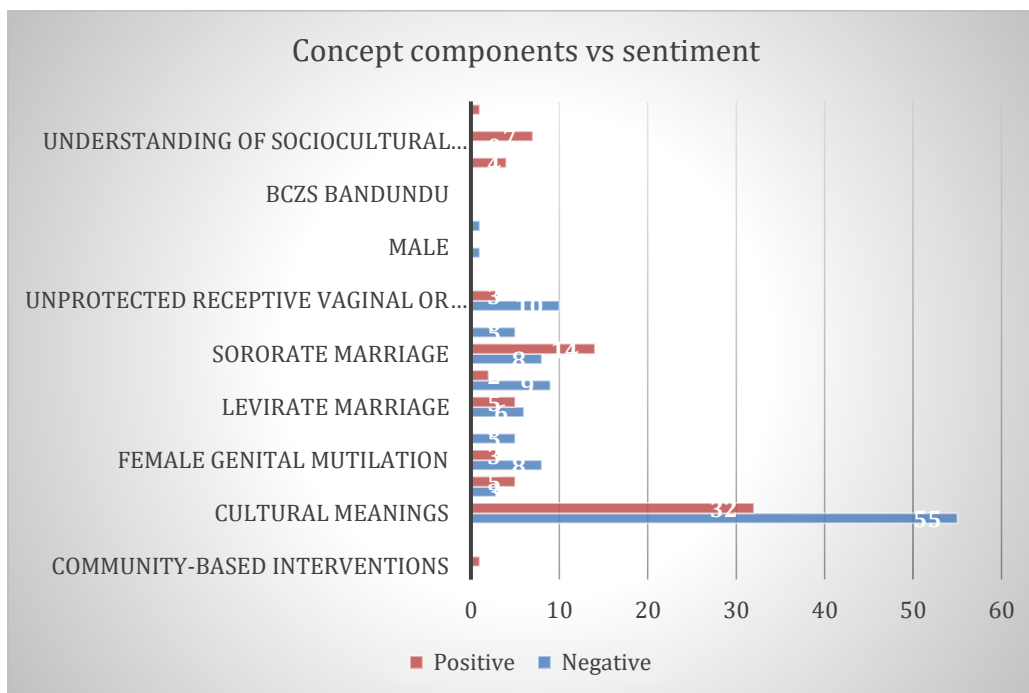
*Concept Components versus Sentiment from the Focus Group in Bandundu-city*



With 55 negative answers on cultural meanings, the message sent is meant to explain the disagreement of PLHIVs with several practices. Some of them are taken as positive arguments and support those cultural practices. For instance, when talking about stigma in Suku tribe, it is considered as a rejection by casting a bad look from someone. For Manianga people, it is a way of living differently with other community members. The Luba tribe thinks that stigma is a way to denigrate someone, lessen his community value. All these assessments are taken as negative value in the society.

**Figure 25**

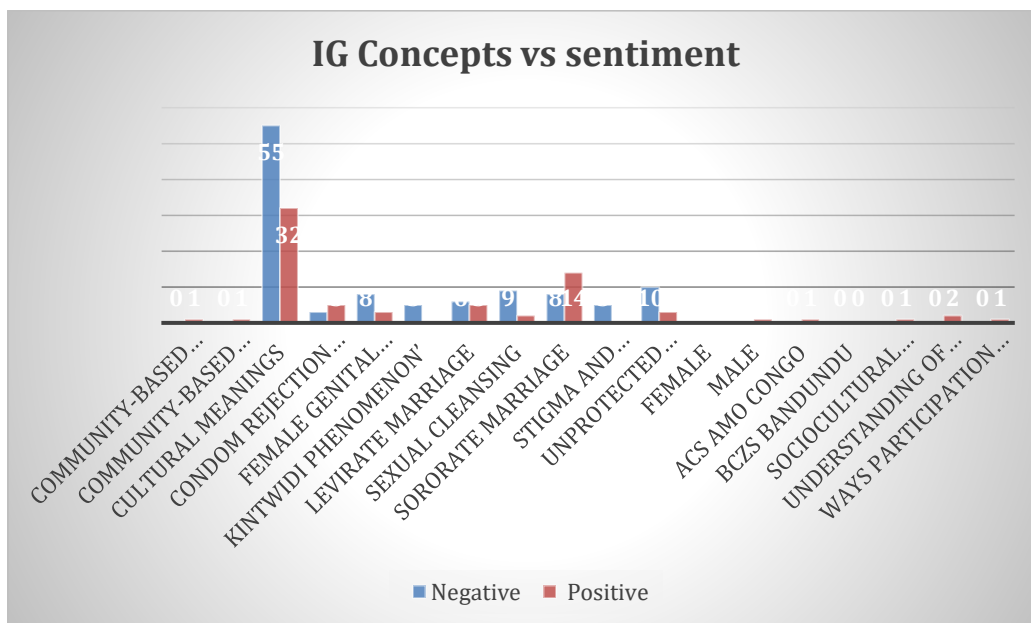
*Key-Informant person Kinshasa*



This graph shows that, negative opinions are far way larger than positive opinions regarding several practices in the community. For example, when talking about the Kintwidi phenomenon, he stated, “... this can be a risky behavior on not knowing their HIV status can lead to STI infection and HIV/AIDS; cause suicides and deaths when you don't agree with the old partner you are offered; you can also be stressed out for a marriage without consent.” He also said on the sororate marriage that, “the positive side of it is the decreasing of the orphan concept in the community or as a family.”

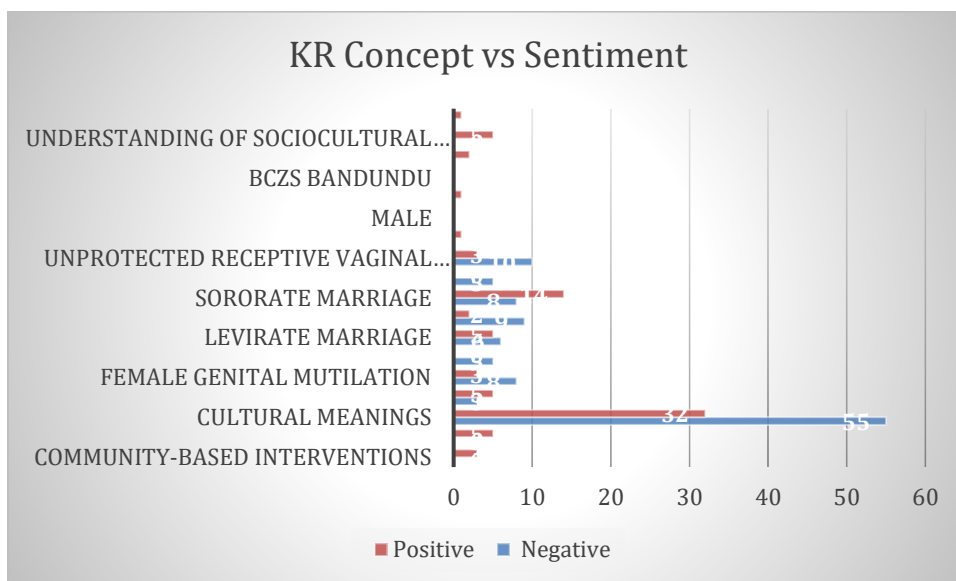
**Figure 26**

*IG interview Concepts vs Sentiment*



**Figure 27**

*KR Concepts versus Sentiment*

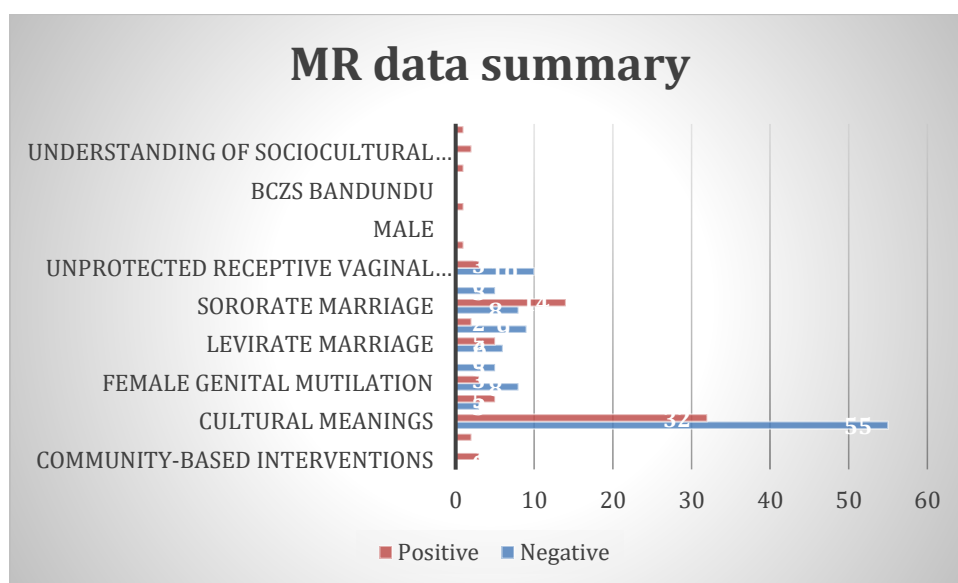


This interview was one of the richest data I have collected during my research. It provided the SEM backbone information regarding the influence of CBIs at each level. According to this interviewee, CBIs have impacted her life at different layers of her life.

At the personal level, she recovered the social consideration that she previously lost, at the family level, no one thinks of her death anytime soon, at the community level, self-support group friends continue to hang out with her, at the organizational level, she manages to be independent, and at the law level, she knows her rights and her duties.

**Figure 28**

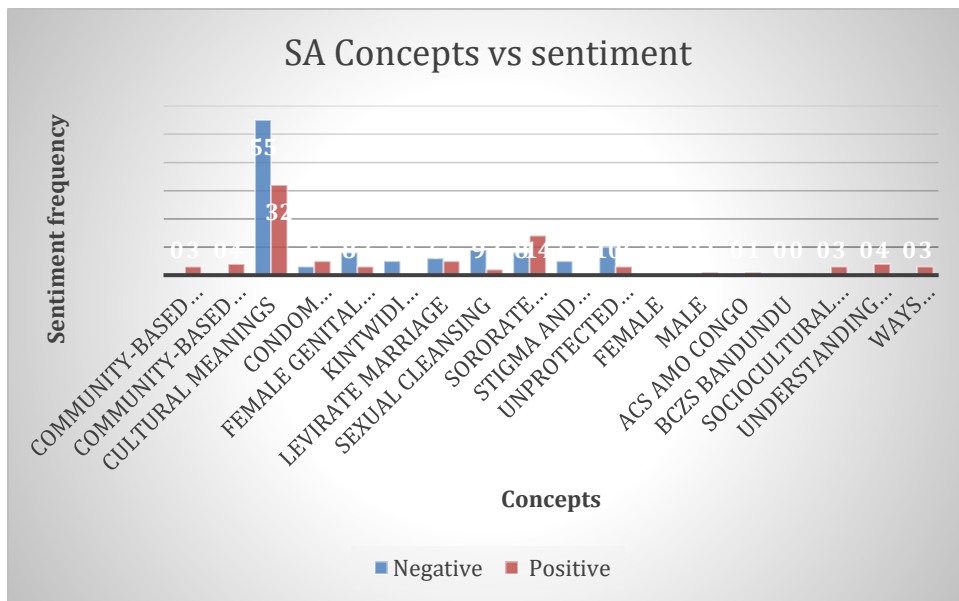
*MR Concept Data versus Sentiment*



Data collected from this interviewee indicated that the individual lives straightforward with her family and her community in terms of behaviors. She came out hiding and was back to normal life with strong contacts with her community. This is a significant change for that person because in her language they say, "Udi mupeta budi penshi ewu" meaning, whoever caught a deadly disease is locked in the house.

**Figure 29**

*SA Concepts vs sentiment*



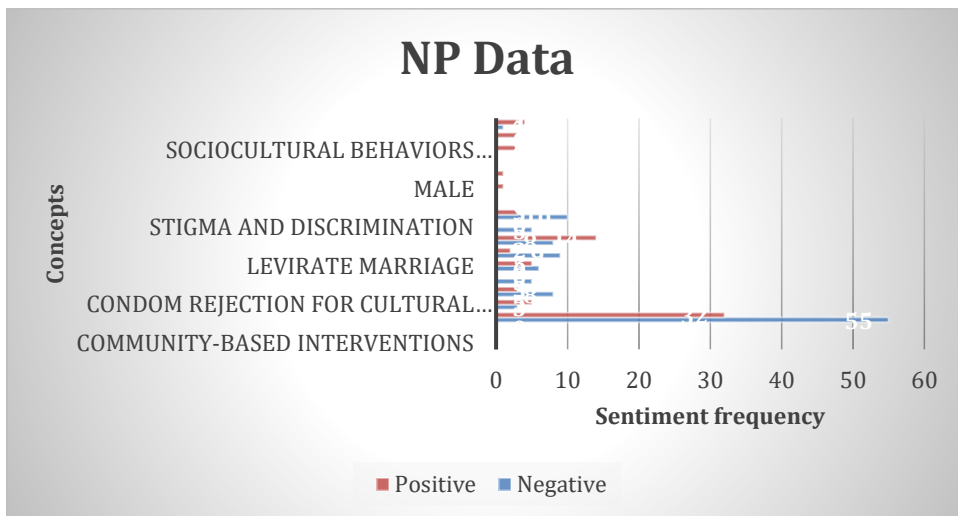
This

figure

illustrates from the Tetela tribe regarding the Kintwidi phenomenon that the marriage between an uncle and a niece has value in their culture because it is done to enhance the spirits of their ancestors. HIV/AIDS is known as “emoka soni”, meaning ashaming disease. However, in order to keep the spirit of the family among them, people should wisely prevent members from contracting HIV in traditional forced marriage.

**Figure 30**

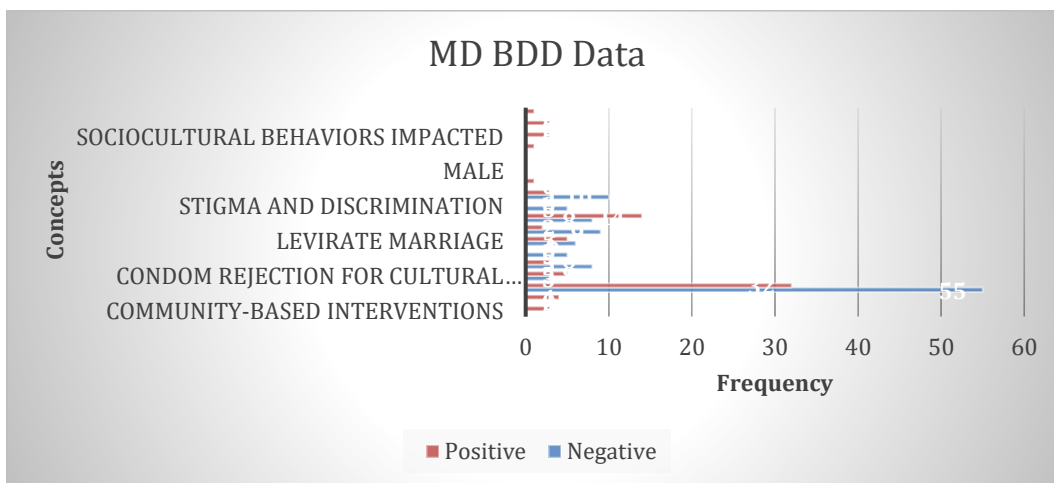
*NP Concepts versus Sentiment*



In this case, the interviewee explains several concepts and seems to disagree with them. For instance, she stated that Sexual Gender-Based Violence (SGBV) is known in her culture as "BANUANGATA KUBUKOLE", which means taking a woman by force to do whatever you want. In other words, a woman is considered as a simple thing using the expression "TSHINTU".

**Figure 31**

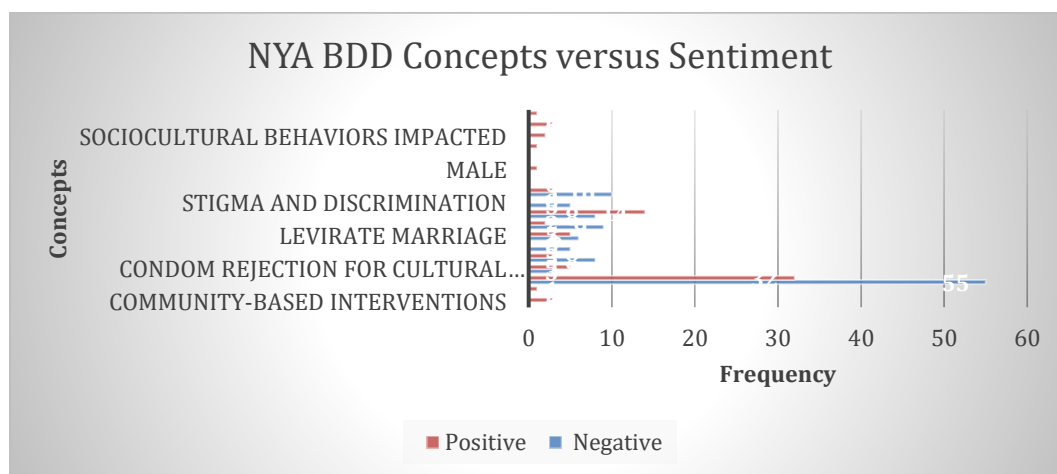
*MD Concepts versus Sentiment*



Talking FGM and SGBV, this respondent stated, “FGM can be the cause of infections such as HIV, especially if the materials used are not quite sterilized. And SGBV can also be the gateway to STIs like HIV, because it is done by forcing a woman.” She summarized that, “it is important to sterilize the materials but also to avoid any act of violence such as taking the woman by force.”

**Figure 32**

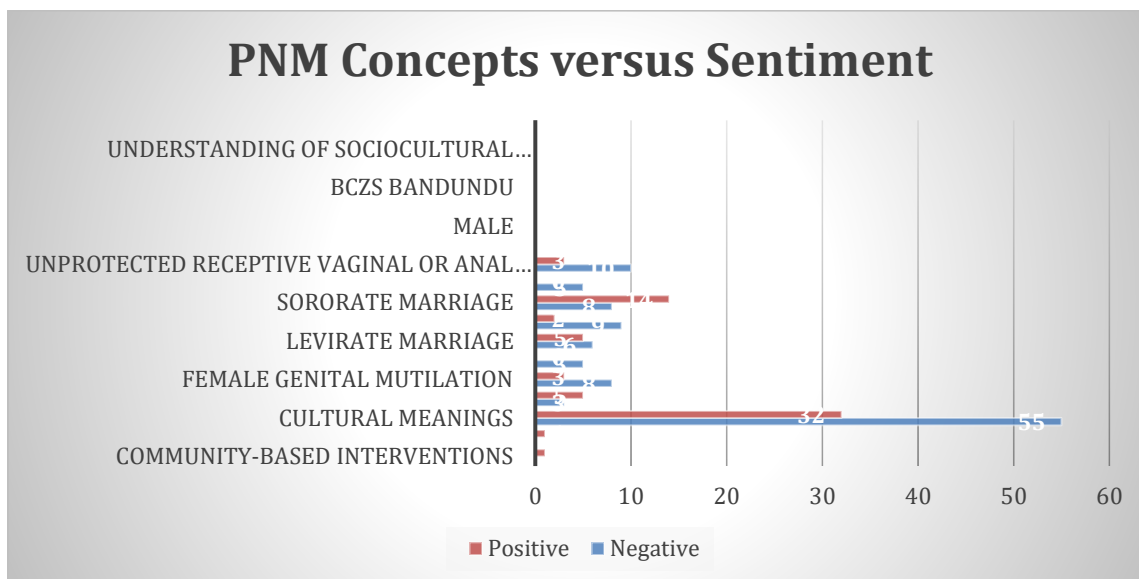
*NYA Concepts versus Sentiments*



According to this respondent, he was not using condoms in the past, because he thought that condoms can cause abdominal pain to a lady and other illnesses. In their culture, HIV/AIDS was known as the "kimbefo ya lufwa", meaning an incurable disease or a disease leading to death. The milestone with this interviewee is that CBIs have helped him understand the role of a condom and he is always correctly using it now.

**Figure 33**

*PNM Cultural Concepts versus Sentiment*

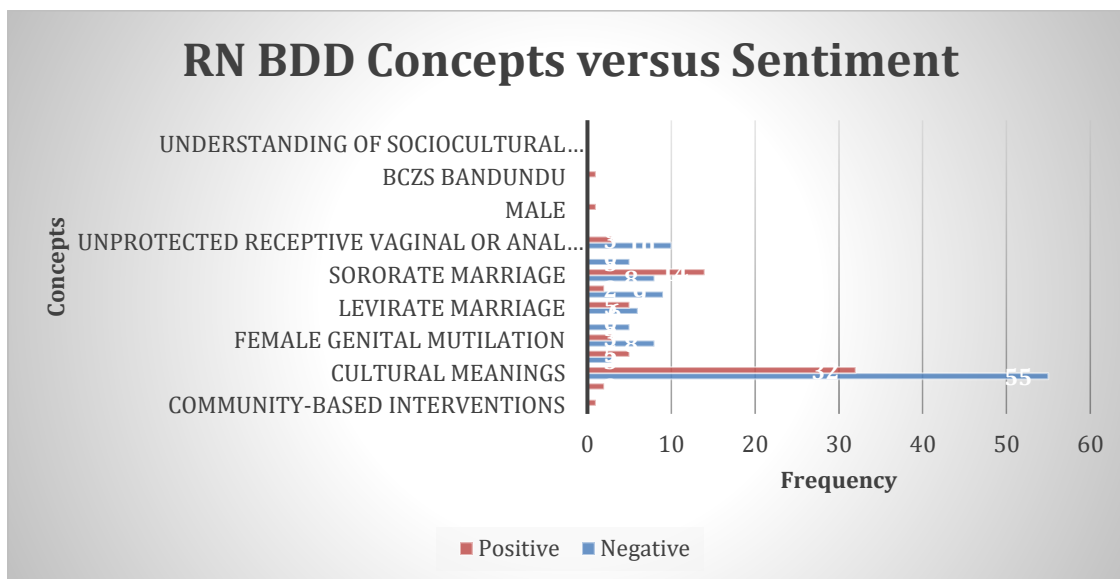


This respondent from Bandundu stated that receptive vaginal intercourse is done as unprotected when they trust their partners and especially for pleasure reasons. According to their culture, sexual intercourse performed by the anus is a risk factor of STIs. For them, people do not use the condom because of they think it causes pain, also they say they do not feel any pleasure when bearing it. They said that it is necessary to do it rather as "nitu na nitu" etymologically meaning, 'body to body' or without any barrier to make sure you feel the sexual pleasure. Fortunately, CBIs have changed his behaviors, now he can put on a balance the weight-interest between pleasure and his own life. He stopped cheating not only to protect his sexual partner, but also himself.

**Figure 34**

*RN Concepts versus Sentiment*





This person changed her personal behavior on using condom as she responded. However, she stated that her family members did not want to eat food provided by ACS AMO Congo, pretending to prevent themselves from contracting HIV (bias in their mindset). From a worthless or a thief in my family, I became worthy and started serving most of them as an example of addressing HIV issues. She stated, “I changed my sexual behavior. I became reliable on only someone and began even counseling others how to protect themselves from HIV/AIDS.” The respondent did not find any advantages on the cleansing phenomenon. According to her, their population needs to be mobilized regarding HIV prevention because FGM and SGBV drive to STIs, therefore they must be discouraged in their community.

### Figure 35

*The NVivo R1 Word Cloud from Data Collected*



analysis showing a broad point of view, with an ethnographic layer explaining sentiment regarding all key-concept components per interviewee.

For instance, while interviewing KR in Kinshasa, answers systematically targeted all five levels of the socioecological study design. This respondent (KR) suggested that at the personal level, she recovered the social consideration that she lost before getting sick. At the family level, no one thinks of her death anytime soon. At the community level, she reported that self-support group friends continue to hang out with her as long as she was involved in CBIs. At the organizational level, she manages now not to be dependent anymore. At the law level in DRC, she explained that she knows her rights now and all her duties in the context of HIV infection.

This chapter draws fundamentals of three major research questions of this ethnographic inquiry. I tried to suggest a problem-solving approach by which I would understand if CBIs implemented in DRC really have influenced behaviors of PLHIVs from 2005 up to 2015 as viewed by themselves. That scientific pathway primarily elaborates insights based upon understanding of CBIs for family members as the blueprint of PLHIVs' support. Otherwise, the chapter also suggests detailed sociocultural behaviors impacted at the end of the project, much as with ACS AMO Congo in Kinshasa and Bandundu-city. A few discrepant cases are described, and data supporting findings are here presented in tables are synthesized in figures.

### **Summary of Answers to Research Questions**

In general, I have learned from all 42 interviewees that their participation in CBIs may have influenced either positively or negatively their behaviors. Most of the

respondents stated having responsible sex intercourse after undergoing CBIs. They are more likely to use condom with all new partners and entertain safe relationships with current partners than the way it used to be. They have access to mother-to-child transmission prevention services and have the right to get married, thus even give birth to HIV-free children. Also, CBIs are stated to be effective in addressing HIV stigma and discrimination in their communities.

However, one ambivalent response emerged from wrongly acknowledging how to be faithful without a condom if you are 'confident' to your sexual partner. As with all PLHIVs, family members have experienced benefits of CBIs in different ways. They understood that voluntary counseling test (VCT), home visits, and income-generating activities (IGA) are key-components of CBIs in this community approach. This helped most of them not only stay adherent with antiretroviral treatment (ART), but also have access to vital foods when needed with other planned social activities. Consequently, PLHIVs have learned to become independent, they developed self-esteem and a significant decreasing interest in prostitution.

In fact, PLHIVs have been taught relevant approaches in building strong relationships with lawmakers and work in influencing the quality of their life. At the end of the project, they learned how to reduce risky behaviors at the individual level. At the community level, PLHIVs have learned how to apply supportive methods to reduce the community burden of HIV. They successfully applied measures conducting to self-determination and self-esteem when walking toward their organizational goals.

Congolese PLHIVs created their own societal mechanisms to address HIV issues with positive impacts on laws designed to improve the quality of their life.

### **Transition to Chapter 5**

From late 2020 to early 2021, a few samples qualitative data have been gathered using two key-informant interviews, three focus groups, and nine in-depth interviews in both Kinshasa via ACS AMO Congo and Bandundu-city. Because of the COVID-19 pandemic, data were collected remotely, and the idea was to understand if at least one of the CBIs implemented in Bandundu and Kinshasa among PLHIVs and their family members have had an influence on their sociocultural and sexual behaviors. This chapter contains field information collected, then reduced and synthetized in tables and graphs. Data gathered were technically analyzed step by step based on respondents' 'sentiment' through the last version of NVivo R1 software. Using the socioecological model, I closely looked at any possible influences of CBIs at the individual level, the interpersonal level, the community level, the organization level, and the public policy level.

This will help transition on key-findings of the study in the chapter 5, walking towards data interpretation. I will therefore assign the last chapter to providing the limitation of the inquiry, before sharing objective recommendations that would help improve the quality of the life for PLHIVs in DR Congo. Indeed, interviewees responded to a questionnaire, but in the meantime the cornerstone question below emerged when summarizing the body of this study. Would there be any social changes to highlight while HIV is being a heavy burden for most of the African counties? The following chapter will help draw a conclusion in terms of implication, at the same time provide a field-based

conclusion related to information collected from PLHIVs and their family members as responses related to a probable influence of CBIs in their behaviors for an impactful social change.

## Chapter 5: Discussion, Conclusions, and Recommendations

This research was an ethnographic qualitative study designed to understand whether a number of CBIs applied in developing counties such as in Congo-Kinshasa have had an impact on preventing PLHIVs from negative behaviors. Grounded in the SEM, with this study I addressed different layers of the Congolese society regarding CBIs implemented among PLHIVs since 2004. All components in CBI programs were set up to provide PLHIVs with an independent life. My goal was to understand the influence of CBIs at the intrapersonal level, the interpersonal level, the community level, the organizational level, and the societal/policy level (laws). Trying to understand cultural values by questioning not only PLHIVs, but also stakeholders as community partners, I conducted nine in-depth interviews, three focus groups, and two key-informant interviews to obtain information needed to answer research questions.

Open-ended questions were asked in different ways to determine whether participation in CBIs had impacted sexual behaviors of PLHIVs. Family members were also asked what their understanding of CBI concepts was for each key-component. Those questions addressed main sociocultural behaviors impacted by CBI projects either in Kinshasa or in Bandundu-city. A total of eight key-component factors were deeply explored, such as the levirate marriage, sororate marriage, Kintwidi phenomenon, sexual cleansing, unprotected receptive vaginal or anal intercourse, SGBV and FGM, rejection of condoms for cultural reasons, and stigma and discrimination against PLHIV. Data were collected, transcribed, synthesized, and analyzed in NVivo R1 during the trial period, and Microsoft Excel. This study was designed to investigate the extent to which

the introduction of CBIs impacted lives of individuals living with HIV, their family members, and their communities through the compound of gender-based sociocultural behaviors in Congo-Kinshasa.

### **Summarizing Key Findings**

In this ethnographic qualitative study, I asked open-ended questions to 42 respondents in three major categories in order to explore the gap in understanding the influence of CBIs on behaviors of Congolese PLHIVs. At the intrapersonal level, most PLHIVs admitted accepting the use of condoms to prevent themselves from being infected with new serotypes of viruses. CBIs had helped PLHIV understand risk factors and strengthened them in taking ARTs daily. At the interpersonal level, CBIs opened new avenues and strong collaborative means of sharing preventive information with family members regarding food security and voluntary counseling and testing. At the community level, beyond group supports, African culture was the bond designed to boost mutual assistance among PLHIVs and their community. Also, CBIs were impactful for those included in the program. Monthly community meal sharing or school bag distributions with peers had positively transformed their lives.

Findings revealed at the organization level that new group supports were developed and a culture based on regular flow of communication with true HIV preventive messages was established, embedded on local organizations such as UCOP +, OACA-PVVs Bandundu, ACS AMO Congo, or Femme Plus in Kinshasa. These Congolese organizations became the foundation of the CBI implementation strategy, transforming the entire Congolese society. At the law level, PLHIVs were protected by



the law number 08/11 as of July 14, 2008, providing free healthcare. The “confidentiality” became a law, and disclosure exception could be decided only by a judge. Anyone who deliberately transmits HIV to another person will be in detention. Also, blood screening before blood transfusions became a law, and Congolese PLHIV have the right to give birth or get married. Having sex with someone younger than 18 years of age is illegal. FGM and SGBV are also prohibited and punishable by the law.

### **Interpretation of the Findings**

As indicated in the literature review, in addition to antiretroviral treatment, CBIs performed through home visits, formal and informal outreach activities, and VCT (PEPFAR, 2017), yet researchers had not examined whether the strategy applied to address HIV issues had impacted PLHIVs’ sexual behaviors within all 26 provinces of DRC. Prior studies on sub-Saharan African HIV prevalence and the population’s sexual behavior through 25 African countries did not reveal any HIV infection prevalence predictions using the SEM (Omori & Abu-Raddad, 2016). Similarly, even though the Congolese PLHIVs who participated in CBIs had suggested behavioral changes in their statements, a new confirming KAP study was needed to establish an existing link between the increasing prevalence of HIV in Congolese communities and CBIs implemented from 2004.

Given the strong relationship between food insecurity and sexual violence (Convoy, 2019), a persistent lack of basic foods in low-education households may explain how uncontrolled prostitution led to a certain level of HIV contamination among Congolese PLHIVs. The focus groups, key-informant interviews, and in-depth individual

interviews provided words affirming a certain sexual behavioral change from PLHIVs when CBI components were implemented in Congo. PLHIVs used to receive a food package, money, and IGA, setting them away from being a burden to the community. Conversely, Pour et al. (2020) demonstrated in a subnational study that there is a substantial increase in prevalence of HIV in the large population of Kinshasa. That transversal study included data from 1,240 healthy mothers seeking prenatal care, with 11% of HIV prevalence. Those results were widely contrasting with PEPFAR outcomes that suggested 2.86% HIV prevalence among pregnant women (Pour et al., 2020).

Congo-Kinshasa used to be around 1% HIV prevalence for people aged 15 to 49 years in contrast to the high HIV prevalence in neighboring countries such as Zambia with 11.5% (highest) and Angola with 1.9% (Kaiser Family Foundation, 2017). As stated above, new quantitative data confirmed an increasing HIV prevalence (Pour et al., 2020), while my qualitative study showed fewer sexual behavioral risks taken among PLHIV involved in CBIs with ACS AMO Congo in Kinshasa and Bandundu-city since 2004. My findings indicated that PLHIV through CBI are more likely to use condoms in new intercourse, but I did not confirm that PLHIV will always do it and do so correctly. HIV, sexual, community, family, and marriage were the most commonly used words in this qualitative inquiry. All cultural practices such as sexual cleansing, sororate marriage, levirate marriage, the Kintwidi phenomenon, inability to use condom for cultural reasons, FGM and SGBV, unprotected vaginal/anal intercourse, a stigma and stigmatization were reported as negative behaviors by Congolese PLHIVs. This finding suggests trends leading to positive change in behaviors for PLHIVs.

### **Interpretation of Findings in the Context of the Theoretical Framework**

The theoretical framework of this ethnographic study was the SEM (Glanz et al., 2015). Based on cultural understanding of eight key concepts, interviewees responded to a questionnaire in three methods: focus groups, in-depth interviews, and key-informant interviews. Self-assessment was the fundamental approach used to understand whether PLHIVs involved in CBIs for at least a decade were positively or negatively impacted by the program designed to make them independent in their communities. Because the SEM of health behavior posits five core principles, the findings of the current study need to be interpreted according to these principles (Glanz et al., 2015).

There are several levels of influence on health behaviors (Glanz et al., 2015). The focus group in Bandundu reported that VCT and home visits provided abundant information regarding the correct use of condoms and responsible sexuality. PLHIVs in Bandundu-city became proactive in providing preventive information to their peers. When PLHIVs learned about ART and the vertical transmission prevention method, they requested the right to get married and give birth to HIV-free Congolese babies. Two targeted levels by CBIs were sexuality with condom use at the individual level and general health through medication.

Another significant determinant of health behaviors is the environmental context in which they occur (Glanz et al., 2015). According to the focus group in Bandundu, the Kintwidi phenomenon is a cultural behavior found in the Yansi tribe in Greater

Bandundu. Providing information related to risky sexual behaviors in that community was the foundation of the approach among PLHIVs undergoing CBIs in Bandundu-city. The same approach will not provide similar results elsewhere because of different environmental contexts. In my study, HIV/AIDS interviewees were able to describe potential risks of diseases because this type of traditional marriage is dependent on the family tradition.

Third, as observed, behavioral changes occur with interaction across different levels (Glanz et al, 2015, p. 48). According to the focus group of men performed in Kinshasa, because their community had been through the negative impact of FGM (community level), individuals were able to decline any culturally designed FGM offers opposing even new Congolese laws made to promote health adolescents through a specific program (Programme National de la Santé de adolescent) in healthy communities. That group suggested that urban Luba PLHIVs and their community members refused to let girls be sexually mutilated for men's pleasure.

Fourth, when looking for social change, the ecological model always targets a specific behavior (Glanz et al, 2015, p. 49). Because of the poverty, most of our PLHIVs contracted the disease either when cheating on their spouse, or through unprotected sexual intercourse with prostitution. CBIs provided PLHIV with IGAs and home visits for follow-up. Most of them stopped engaging in prostitution with the income they started making, so they started sending children to school and never came back to that negative sexual behavior. As they have positively changed behaviors, people who were refusing to

take their daily medications in the past became peer mentors for new PLHIVs in Bandundu-city and ACS AMO Congo Kinshasa with community volunteers.

Fifth, because of their multiplicity in levels of a variety of interventions, this approach is set to be the most effective in behavioral changes in the community (Glanz et al, 2015, p. 49). Most PLHIVs in Kinshasa learned new jobs of their choice. School fees were paid for children, IGAs were given to parents, home visits were performed to make sure they had been complying with their daily medication around families, community groups have been created, UCOP+ was the major organization including all PLHIV, and contacts were established for follow-ups regarding laws protecting them.

In summary, the self-assessment of the multifaceted intervention provided by a decade of CBIs among PLHIV in Congo starting in 2004 seemed to positively impact the lives of the target population. They were able to accept their status as PLHIVs and willingly share information. The focus group of women in Kinshasa testified to their resiliency and suggests that they are accepted by their family members because they learned more about the disease. HIV no longer implies a shorter lifespan. One respondent from individual in-depth interviews in Kinshasa stated:

At the personal level, I recovered the social consideration I lost before.

At the family level, no one thinks of my death anytime soon.

At the community level, self-support group friends continue to hang out with me.

At the organizational level, I manage not to be dependent.

At the law level, I know my rights and my duties (KR Interview-Kinshasa).

### **Limitations of the Study**

One of the important limitations of this study is the selection bias due to the fact that I am providing a study summary related to a self-assessment as a snapshot on PLHIVs starting in 2005 (Aschengreau & Seage, 2014). Because of the mortality of HIV in Africa, large numbers of patients are dead, and multiple others did not attend the interview sites due to the COVID-19 pandemic. Also, the sample taken for this qualitative study cannot be stated to be representative of all the Congolese population. However, the snowball sampling selection could potentially decrease a chance of having strong speakers for high-quality performance (selection bias), but also due to the fact that information provided is from the past, there is a risk of recall bias in individual interviews. That is why triangulation and repetitive questioning were used in focus groups and all data collection approaches to obtain the best answers possible from each question.

This qualitative study does not have a previous baseline research comparison, as a database ready to be used as a gold standard study. Indeed, finding an existing primary study would have served as a comparison inquiry to better grasp the potential influence of CBIs among PLHIVs in Congo. Also, the easiest way to measure the impact of CBIs in terms of health should be the HIV testing process. Unfortunately, relevant approaches to evaluate the impact of specific interventions in qualitative studies are made of complex

components, including a gold standard of information from the same or a similar community. That referential loop does not exist in the central African region in terms of cultural behaviors, creating a need for the field innovation.

That is partly why I requested the IRB approval from the KSPH, after sharing information with the Walden IRB. The remote data collection was authorized in December 2020, and I trained the research assistant, before having pre-organizational meetings and field visits prior to each local interview. Useful forms and documents were printed out, respondents were selected and invited at the site for the interview. The informed consent form was read to each of them, letting them know that participation was voluntary, and they were free to leave the study anytime they wanted without any constraints. They signed two informed consent forms, keeping a copy for each of them and interviews occurred in confidentiality with a lunch provided, and a \$10-transportation card.

At the end, data collected were kept confidential and outcomes were shared with the KSPH. However, because of the difference in languages, data were collected in Lingala, then translated in French, before requesting the second English translation. This may potentially generate confirmation biases due to personal interpretations of information collected from respondents. Also, the lack of comparison studies would not help to reduce any potential gaps in the influence of CBIs as self-assessment is subjective. Finally, for example, conclusions gained from Bandundu-city regarding Kintwidi phenomenon would never be generalizable in the whole country, except for the Yansi people wherever they locate in DR Congo.

## Recommendations

This ethnographic qualitative research was based on self-assessment from PLHIVs who have been in CBIs for a decade starting 2004 in Kinshasa and Bandundu-city. A total of 45% of respondents involved in the program are culturally aware of community risk behaviors increasing the likelihood of spreading the disease in their environment. Involving Congolese PLHIVs in a Community-Based Participatory Research (CBPR) designed to draw their needs in Congo-Kinshasa is critical. Also, because this SEM study sets up the baseline of people's cultural understanding of the influence of CBIs in behaviors of PLHIVs, a quantitative study describing the magnitude and the geographical distribution of their issues needs to take place.

Talking about a possible quantitative study, the subset size of cases selected from the whole population must be representative of PLHIVs according to each region. That is why, I would rather recommend a stratified random sample due to the fact that DRC is divided in 26 provinces, several rural territories, and cities of more than 260 tribes. Also, a proportional sample may occur because of the inequality in interventions per region in CBIs, since Kinshasa, Katanga and Bas-Congo used to receive more funding than other regions when implementing the project. PLHIVs in high-level financed provinces may feel differently impacted than lower funded regions.

Indeed, those future studies must come out with a ready-to-go project involving mostly PLHIVs with greater needs. Also, randomly selecting subjects to any future studies will significantly decrease chances of any type of biases. At the same time, comparing data with information from people who have never been into a CBI program



would make a difference if taken as a reference to illustrate any existing gaps.

Furthermore, that projected study must be designed to minimize the risk of collecting self-assessed data. This will significantly reduce the risk of subjectivity and biases in analysis because using a rational data collection process.

### **Implications**

Realistic qualitative data are drawn from multiple useful approaches designed to depict the magnitude of any social issues amongst a group of the population (Restar, A. et al., 2020). In this ethnographic study, I employed several methods that support my suggestion. This suggestion states that there is a significant social change in the way of understanding how behaviors of PLHIVs could had been influenced by CBIs in Kinshasa and Bandundu-city, after a decade of the program since 2004. Using SEM in individual in-depth interviews, focus groups and key-informant interviews in both sites revealed a variety of potential impacts understood as positive social change. For instance, when studying multiple relationships and pathways across the SEM with PLHIVs, authors found that “interventions should be multicomponent and build and/or strengthen social capital and condom self-efficacy, as well as intentionally target prominent structural and environmental barriers to condom use” (Restar et al., 2020). Because CBIs were diverse, it appears at different layers that behavior-targeted tasks can lead to a meaningful dynamic goal, with an impactful social change as culturally self-assessed by PLHIVs. Several methods engaged in this ethnographic study support the prospect of significant social change at least in understanding how behaviors of PLHIVs could have been influenced by CBIs in Kinshasa and Bandundu-city, after a decade of the program since

2004. Individual prompted in-depth interviews, focus groups and key-informant interviews performed in both sites revealed a variety of potential impact, insight deeply understood as positive social change for PLHIVs.

At the intrapersonal level, even though there is no preselected gold standard of their skills, PLHIVs and other interviewees noticed a change in understanding risk factors and individual safe behaviors to prevent themselves from unhealthy acts. This is also valid for personal daily duties, including follow-ups for personal safety. For instance, each PLHIV knew that he/she must take his/her daily treatment, personal hygiene and the correct use of condom can prevent him/her from getting sick. Each PLHIV understood how risky all eight key-components in study are, and all negative consequences that can occur if he/she misapplies even only one of them. The present self-assessment also represents a strong rejection of risky cultural behaviors, such as levirate marriage, sororate marriage, Kintwidi phenomenon, FGM or SGBV, and others at the individual level after being a part of this program.

At the interpersonal level, a wide range of data from Congolese interviews suggested that family members behave now differently towards PLHIVs in Bandundu-city and Kinshasa. PLHIVs interact easily with family members than before, after being in CBIs. Besides meals sharing and understanding their own safety, family members are aware of risky behaviors. They seem more open in sharing information regarding HIV. For instance, everybody in some families became involved in sharp waste management. Some of them started helping ill siblings attend medical facilities for help when needed.

In the meantime, some PLHIVs under CBIs went back to their previous activities. They started taking care of their siblings with schooling.

At the community level, data collected suggested more openness in willingly sharing information with their community members. PLHIVs under CBIs felt more comfortable talking of their own HIV status. A closer look of highlights in interviews indicated that respondents were more likely to engage in positive and healthy practices in order to keep their community safe. Lots of them did not find any benefits in FGM and SGBV, they rather used the word ‘trauma’ when it comes to defining those concepts. For example, inbred illnesses are theoretically seen occurring as a consequence of the Kintwidi phenomenon in the community than the cultural misconception related to keeping the family wealth inside, because the dowry would not be paid out of the family.

At the organizational level, an emphasis in one of the focus groups was that the backbone of the strategy implemented to address HIV in different Congolese communities appears to be the organizational shape of the fight. ACS AMO Congo was born as a community organization, while a multi-sectorial boost came with the PNMLS and PNLS, creating some significant clusters with PLHIVs’ ground organizations such as UCOP +, Femme Plus, CORNERELA + fighting against stigma and discrimination in the Congolese community. Specific core components of the SEM were targeted to induce this outcome, stimulating needs of PLHIVs to create their own organization and independently address their daily issues.

At the societal/policy level, stakeholders, lawmakers, local authorities, and family members were involved in creating new laws when needed. Most importantly, they

committed in applying rules related to existing laws as their benefits. Currently, Congolese PLHIVs know their obligations and their rights. For instance, they know that they have the right to get married and give birth to HIV-free babies. At the same time, they know that they have the obligation to protect others from harm (HIV contamination), and they have right to a safe and healthy life themselves. Meeting the assumption of this qualitative study, they are more likely not to believe in sexual cleansing but consider having sex with minors rather a felony.

The main theoretical tool utilized in this qualitative study was the SEM. Based on the ethnographic approach, eight valuable cultural key-components were studied through three appropriate open-ended questions using interviews. Even though the self-assessment process could be confusing with a simple cognitive study, my goal was to assess a possible existing influence of CBIs in behaviors of Congolese PLHIVs interviewed. Data collected were confidentially synthesized, reduced and analyzed using NVivo R1. They have showed sentiments of each participant regarding CBIs as applied since 2004 in Kinshasa and Bandundu-city. In the future, a statistical effect-causality study will need to take place and establish the strength of that relationship between CBIs and its theoretically stated influence.

Connecting the theory to the practice, CBIs as applied appear to be a significant booster of knowledge and the framework leading their sexual behaviors into the community. As a result of their engagement with CBIs, PLHIVs know exactly what is wrong and what is correct in order to stay safe and healthy. However, they all seem to need more material and financial support to become really independent. Consequently, a

new startup community microproject assigned to up to ten PLHIVs needs to be conceived. This project will be designed with a goal of developing self-esteem from personal outcomes. For instance, because of the scarcity of safe drinking water in DRC, PLHIVs could be involved in delivering safe drinking water through independent rural/urban bicycle users. At the same time, a connected SMART cellphone-App startup project would be conceived to alert the exact time to take ARTs, follow-ups on remaining meds versus lab exams, the immunization calendar, and ultimately make money from owning a small community-safe drinking water business.

### **Conclusion**

Facing the COVID-19 pandemic, the humankind seems to be unwillingly lessening some previous major health concerns that he has been experiencing for more than three decades. In this ethnographic qualitative study, the socio-ecological model (SEM) with its five levels was utilized to understand a possible influence of community-based interventions (VCT, HV, and IGAs) on behaviors of HIV+ persons in Congo-Kinshasa. A literature review was engaged, and data were confidentially collected from December 2020 to March 2021 among 39 PLHIVs in Kinshasa and Bandundu-city. A total of 42 respondents provided qualitative data, using three focus groups, two key-informant person interviews, and nine in-depth individual interviews under the supervision of the Kinshasa School of Public Health (KSPH).

Data gathered from multicultural tribes were analyzed through NVivo R1 and Microsoft Excel, providing significant qualitative information on whether or not PLHIVs under CBIs have self-assessed any changes in their own sexual behaviors. In the primary

cultural behavior, one of the five core principles of the ecological perspectives regarding behavioral change suggests that multilevel interventions are more likely to be effective in changing behaviors (Glanz et al, 2015). In this ethnographic study, I acknowledge by self-assessment a much better understanding of all eight key-cultural components below listed with Congolese PLHIVs. In fact, levirate marriage, sororate marriage, sexual cleansing, Kintwidi phenomenon, FGM and SGBV, the ban of condom for cultural reasons, unprotected receptive vaginal or anal intercourse, stigma and discrimination are all stated to be very negative sentiments for Congolese PLHIVs under CBIs. This confirms my conceptual framework suggesting that using the SEM, a sociocultural environment might interfere with primary cultural behaviors and generate safe sexual behaviors through specific community-based interventions as understood in the Democratic Republic of Congo.

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## Appendix A: Interview Question Forms



Ecole de Santé Publique de Kinshasa | KSPH  
Kinshasa School of Public Health  
UNIVERSITE DE KINSHASA

**Annex 1: Interview Questionnaire**

The Influence of Community-Based Interventions on Behaviors of HIV+ Persons in  
Congo-Kinshasa

**Research Questions (Data Collection Only)**

Beginning time .....

**Individual In-depth Interview (60 minutes)****A. Thematic Questions (40 minutes)**

**(1) Female Genital Mutilation (FGM) and Sexual Gender-based Violence  
(SGBV) (5)**

1. What is the meaning of the Female Genital Mutilation for each individual?

2. What is the meaning of Sexual Gender-Based Violence in the family and the community?

3. Please describe how do you would understand to prevent HIV infection when facing FGM and SGBV in your community, organization, and laws?

**(2) Unprotected receptive vaginal or anal intercourse (5 minutes)**

1. What is your cultural understanding of the unprotected receptive vaginal intercourse?

2. What is your cultural meaning of the unprotected receptive anal intercourse?

3. How risky are the unprotected receptive vaginal and/or anal intercourse with HIV in your environment?

**(3) Condom rejection for cultural reasons (5 minutes)**

1. What is the importance of the condom for the individual and the society in general?

2. Culturally speaking, how would you understand why someone wouldn't use the condom when having sex?

**(4) Levirate marriage, or the custom decreeing the marriage of a widowed brother-in-law to a matrimonial cousin (5 minutes)**

1. How would you understand the fact of culturally getting married to your brother-in-law?

2. What is your understanding of the good societal side regarding levirate marriage?

3. What are the risks in levirate practices?

**(5) Sororate marriage, or getting married to a dead wife's sister (5 minutes)**

1. How would you understand the fact of culturally getting married to your sister-in-law?

2. What is your understanding of the good societal side regarding sororate marriage?

3. What do you think are the risks in sororate practices?

**(6) Kintwidi phenomenon (5 minutes)**

1. What is your understanding of the Kintwidi phenomenon?

2. What do you think can be the health risks in Kintwidi practice?

**(7) Sexual cleansing (5 minutes)**

1. What is your understanding of the sexual cleansing?

2. What is your understanding of the health risks in sexual cleansing?

3. What is the positive side of the cultural sexual cleansing?

**(8) Stigma and discrimination (5 minutes)**

1. What is your cultural understanding of stigma?

2. What is your understanding of discrimination?

3. How do you understand the influence of stigma and discrimination in the HIV field?

**B. Impact Questions (10 minutes)**

1. What is the meaning of Community-based Interventions such as VCT, HV, GIA... at your level? (3 minutes)

2. In what ways has participation in CBIs since 2004 impacted sexual behaviors among Congolese HIV+ persons, families, communities, organizations, and your laws in general?

3. What is your understanding of the detailed sociocultural behaviors impacted at the end of CBI projects, considering the personal, family, community, organizational and the societal (laws) levels? (4 minutes)



**C. Ethnographic Questions (10 minutes)**

1. What is your tribe? (1 minute)

2. What is the meaning of Sexual Transmitted Diseases such as HIV/AIDS in your tribe? (2 minutes)

3. What is the meaning of Community-based Interventions for family members? (3)

4. What are the detailed sociocultural behaviors impacted at the end of the projects? (4 minutes)

Ending time .....

Thank you so much for your answers in partnership with the KSPH.



The Influence of Community-based Interventions on Behaviors of HIV+ persons in  
Congo-Kinshasa

**Research Questions (Data Collection Only)**

Beginning time .....

**Focus Group (60 minutes)**

**A. Thematic Questions (45 minutes):**

1. What is your cultural meaning of the following topics in the context of HIV epidemics?
2. Female Genital Mutilation and Sexual Gender-Based Violence (5 min)

3. Unprotected receptive vaginal or anal intercourse for both individuals (5 min)

4. Condom rejection for cultural reasons (5 min)

5. Levirate marriage, or the custom decreeing the marriage of a widowed brother-in-law to a matrimonial cousin (5 min)

6. Sororate marriage, or getting married to a dead wife's sister (5 min)

7. The Kintwidi phenomenon (5 min)

8. Sexual cleansing (5 min)

9. Stigma and discrimination (10 min)

**B. Impact Questions (10 minutes)**

1. What is your understanding of Community-based Interventions such as VCT, HV, Food distribution, GIA...? (3 min)

2. In what ways has participation in CBIs since 2004 impacted sexual behaviors among Congolese HIV+ persons, families, communities, organizations, and your laws? (3 min)

3. What is your understanding of the detailed sociocultural behaviors impacted at the end of CBI projects, considering the personal, family, community, organizational and the societal (laws) levels? (4 min)

**C. Ethnographic Questions (5 minutes)**

1. What are your tribes and what is the meaning of Sexual Transmitted Diseases such as HIV/AIDS in your tribe? (1 minutes)

2. What is the meaning of Community-based Interventions for family members? (1)

3. What are detailed sociocultural behaviors impacted by the projects? (5 minutes)

Ending time .....

Thank you so much for your answers in partnership with the KSPH.



The Influence of Community-based Interventions on Behaviors of HIV+ persons in  
Congo-Kinshasa

**Research Questions (Data Collection Only)**

Beginning time .....

**Key-Informant Person Questionnaire (45 minutes)**

**A. Thematic Questions (30 minutes)**

1. What is your understanding of the FGM at the individual level and the SGBV at the community level? (3 minutes)

2. Unprotected receptive vaginal or anal intercourse (3 minutes)

3. Condom rejection use for cultural reasons (3 minutes)

4. Levirate marriage, or the custom decreeing the marriage of a widowed brother-in-law to a matrimonial cousin; (5 minutes)

5. Sororate marriage, or getting married to a dead wife's sister (3 minutes)

6. The 'Kintwidi phenomenon' (5 minutes)

7. Sexual cleansing (4 minutes)

8. Stigma and discrimination (4 minutes)

**B. Impact Questions (10 minutes)**

1. What is your understanding of Community-based Interventions such as VCT, HV, Food distribution, GIA...? (4 minutes)

2. In what ways has participation in CBIs since 2004 impacted sexual behaviors among Congolese HIV+ persons, families, communities, organizations, and your laws in general? (3 minutes)

3. What is your understanding of the detailed sociocultural behaviors impacted at the end of CBI projects, considering the personal, family, community, organizational and the societal (laws) levels? (3 min)

**C. Ethnographic Questions (5 minutes)**

1. What is your tribe? (1 minute)

2. What is the meaning of Sexual Transmitted Diseases such as HIV/AIDS in your tribe? (1)

- 3. What is the meaning of Community-based Interventions for your family members? (1 mi)

- 4. What are the detailed sociocultural behaviors impacted at the end of the projects? (2 min)

Ending time .....

Thank you so much for your answers in partnership with the KSPH.

## Appendix B: Kinshasa School of Public Health IRB Approval



REPUBLIQUE DEMOCRATIQUE DU CONGO  
Ministère de l'Enseignement Supérieur et Universitaire  
Université de Kinshasa  
ECOLE DE SANTE PUBLIQUE  
**COMITE D'ETHIQUE**

No d'Approbation: *ESP/CE/132/2020*

Kinshasa, le 23 novembre 2020.

Au Dr Max Ebengho Bokelo  
Investigateur principal  
Candidat Ph.D. en Santé Publique  
Walden University/USA

**Concerne :** Approbation de l'amendement et de la prolongation de votre étude intitulée :  
« **L'Influence des Interventions à Base Communautaire sur les Comportements des Personnes Séropositives au Congo-Kinshasa** ».

Docteur,

Le Bureau du Comité d'Ethique de l'Ecole de Santé Publique de l'Université de Kinshasa a reçu et examiné attentivement le courriel que vous avez envoyé, le 21 novembre 2020, en rapport avec la prolongation et le changement intervenu dans votre protocole de recherche dont le titre est repris en marge. Il en ressort clairement que la crise du COVID-19 vous a empêché de finir votre étude dans le temps imparti et vous oblige de changer la méthode de collectes des données et de prolonger l'approbation.

Ainsi, pour vous permettre de poursuivre normalement vos recherches doctorales, le Bureau du Comité d'Ethique autorise la collecte des données en ligne en utilisant un chercheur sur terrain qui vous servira de pont via Zoom/WhatsApp pour interviewer directement les répondants et vous aider à réaliser d'autres activités. Aussi, le Bureau du Comité d'Ethique approuve la prolongation de votre étude jusqu'au 02 janvier 2022 conformément de l'approbation initiale N°ESP/CE/306/2019 du 24 décembre 2019.

considération distinguée.

Veuillez agréer, Docteur, l'expression de notre



Professeur Dr Paul LUSAMBA DIKASA

Président du Comité d'Ethique