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Medication Adherence and People Living with HIV: A Qualitative Study

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Medication Adherence and People Living with HIV: A Qualitative Study

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Abstract

While significant strides have developed evidence-based preventions and treatments for people living with HIV/AIDS (PLWHA), only 26% percent of HIV-positive people in care achieve the treatment objective of viral suppression (Viral Suppression, 2018). While the literature has identified a positive relationship between patient-provider communication and optimum treatment adherence, nonadherence is poorly understood, and no evidence-based model for such communication exists. This study aims to examine the perspectives of HIV-positive patients and family/friend caregivers (FFC) related to treatment adherence, as most of the literature has been dominated by the clinician's point of view. Further, this work seeks to provide knowledge that will inform medication-taking behaviors so that future interventions can include patient-driven adherence discussions in treatment planning.

This project employs a grounded theory approach to analyze HIV-positive patient and caregiver interviews about treatment. A convenience sampling method drew participants from an HIV support organization in Memphis, Tennessee. Results indicate that medication adherence demands collaborative communication between patients, caregivers, and providers that prioritizes the patient's perspective. This communication approach requires the provider to respond to the patient's concerns first to achieve positive medication-taking practices and quality of life. Adherence communication also allows the provider to perform a holistic assessment of the patients'/caregivers' cognitive, emotional, behavioral, and environmental capacity to achieve treatment goals. Central to medication adherence is the discussion of supportive services.

Keywords: HIV, medication adherence, patient-provider communication, caregiver

Chapter I: Introduction

Inadequate health communication about disease management can seriously impact health outcomes. The botched handling of public health communication during the AIDS epidemic did great harm. Institutional failures contributed to the spread of HIV in two critical ways: (1) It created stigma by labeling those infected, and (2) The government allowed moral dilemmas to influence their willingness to fund AIDS research during the early days of the U.S. epidemic, which indirectly contributed to millions of preventable deaths and disease transmissions. The early lessons of the AIDS epidemics illustrate how detrimental health communication is to medicine, health science research, and research implications for public health interventions.

Early in the U.S. AIDS epidemic, public misperception about a health threat led to treatment failure. Today healthcare professionals (HCP) assume that patients are non-compliant and may avoid conversations about medication-taking attitudes, beliefs, and behaviors regarding chronic disease management. A greater understanding of medication nonadherence can help HCPs understand why patients don't take their medicines. Presumptive assumptions and the lack of communication between stakeholders lead to unnecessary barriers in the patient, caregiver, and provider relationships which directly impact treatment outcomes.

Patient/caregiver-centered communication has the potential to advance medical practice by translating knowledge into treatment success for laypersons self-managing chronic conditions such as HIV. First, HCPs and researchers must change how they approach medication nonadherence to achieve optimal treatment goals. Understanding why patients decide not to adhere to treatment, as well as why they adhere, are essential factors in improving medication adherence among those who are chronically ill.

This qualitative grounded theory study explores the adherence experiences of people receiving treatment for the human immunodeficiency virus (HIV). The purpose of the study is to explore the adherence experiences of HIV-positive patients and caregivers. Suboptimal medication adherence has been identified as the primary culprit of disease complications such as drug resistance, increased HIV-related comorbidities, and mortalities as well as new HIV infections (Ingersoll & Cohen, 2008; Lemstra et al., 2018). Recently, more and more studies are focusing on patient-provider communication as a viable means by which to improve adherence rates among people living with HIV (PLWH) (Archiopoli et al., 2016; Beach et al., 2015; Fehringer et al., 2006; Flickinger et al., 2016; Hurley, Emily A. et al., 2018; Zolnierek & DiMatteo, 2009). However, no studies have offered a model for adherence communication between patients, caregivers (e.g., unpaid, untrained family/friend supporting the care recipient), and providers. A thorough examination of the lived adherence experiences of patients and informal caregivers provides insight into adherence communication and its pivotal impact on adherence-related tasks.

In 2021 approximately 40 million people were living with HIV, and 650,000 died from HIV-related deaths (UNAIDS, 2022, September 15). While significant strides in medicine have decreased mortality and comorbidity among PLWH, nonadherence to antiretroviral therapy (ART) (e.g., a combination of HIV medicines) remains a principal determinant of new infections (Chaiyachati et al., 2014). In 2019, for instance, the Centers for Disease Control and Prevention (CDC) (2022) reported approximately 34,800 new HIV infections. In the U.S., legislators, health research institutions, and public health officials organized programs to mitigate the HIV pandemic. Currently, the Joint United Nations Program on HIV/AIDS (UNAIDS) and the World Health Organization (WHO) strive to achieve 90% treatment coverage for all HIV patients as

well as 90% virologic success in treated patients (UNAIDS, 2022, September 15). The aim is to stop the spread of the disease by 2030. While pharmaceutical companies are closer than ever to finding a cure and producing a vaccine to reduce the spread of the virus, treatment adherence to ART is currently the primary way for PLWH to suppress the virus for survival.

HIV and Associated Stigma

Since the announced discovery of the virus in the early 1980s, HIV has caused an estimated 40 million deaths worldwide (UNAIDS, 2022, September 15). The botched way public health officials, lawmakers, researchers, and federal agencies handled the health threat exacerbated the spread of the disease until it eventually became a worldwide health pandemic. Fears of contagion and social judgments about those who were infected were a formidable distraction from people from taking the appropriate measures to protect themselves from the disease. Had public health communication been delivered differently, HIV stigma could have been less of a barrier to HIV prevention, care, and treatment (Pulerwitz et al., 2010).

In 1981, the first initial reporting of AIDS occurred when the CDC described what they thought were five isolated cases of lung infection among previously healthy young gay men in Los Angeles, CA. On the same day as the CDC publication, reports of similar cases of lung infections and other opportunistic infections, such as a rare and unusually aggressive skin cancer common among older people, Kaposi's Sarcoma, were reported to the CDC (CDC, 2001, June 1). By the end of that year, medical sites reported 270 cases, 121 of which died that same year (HIV, 2022, September 15) . The disease was called GRIDS, or the Gay-Related Immune Deficiency.

Remembering the Early Days of HIV: "GRIDS," "Gay Cancer." Unfortunately, epidemiologists labeled the virus GRIDS before they understood that the disease was prevalent

among heterosexuals, intravenous drug users, people who received blood transfusions, and infants of infected mothers. When researchers figured out that the deadly infection was a health threat to the entire population, there were nearly 500 documented cases in 23 states (publichealth, 2022, October 12). *This is not unlike the media and press frenzy over the Monkey-Pox spread being reported during the summer of 2022.*

In 1981, men who had sex with men were disenfranchised people. When HIV came to the public health scene, gay men were still on the fringes of acceptable society. Gay people and members of the Queer-identifying community were demonized by religion and criminalized by law and policy. Gay men at this time did not have rights and lived a life of secrecy to avoid homophobia and discrimination. This marginalized group suffered chilling responses and little sympathy from society as they died untimely from what many perceived to be the consequence of living a lifestyle contradictory to traditional religious beliefs. One televangelist, Jerry Falwell, articulated the consensus of many conservative Americans by claiming that "God sent AIDS as retribution for the sins of drug-using and gay communities" (publichealth, 2022, October 12). These social and political factors created HIV-related stigma and unwarranted discrimination. As thousands of people died, the conservative presidential administration did not acknowledge or respond to the health crisis.

Reagan Administration's Chilling Response to the AIDS Crisis. Over five thousand documented AIDS-related deaths occurred before U.S. President Ronald Reagan mentioned the word "AIDS" in public in 1985-this was not a formal address but a response to a reporter's question. Reagan's failure to address the HIV crisis co-created structural violence that systematically denied social inclusion, civil rights, treatment, public empathy, and social support to those who were sick with AIDS. Then something changed the direction of public involvement;

Rock Hudson, a famous actor, died from AIDS-related complications in 1985. Hudson was the first well-known celebrity to die from AIDS in the U.S. The disease was no longer a silent epidemic. Although Hudson's public image epitomized the robust heterosexual male, he was privately a gay man — during a time in American history when being gay had severe consequences. Hudson faced the scandal of "coming out" in 1985 when he announced that he was dying from AIDS. While he had a personal relationship with the Reagans and requested their support so that he could receive treatment in Paris, Nancy Reagan declined. The AIDS-related death of an iconic white heterosexual male actor marked a significant turn in the history of the AIDS epidemic. In his 1987 book on the AIDS epidemic, journalist Randy Shilts wrote that AIDS in the U.S. occurred in two distinct phases: "AIDS before Rock Hudson and AIDS after" (Smithsonian, 2012, January 8).

From 1981 to 1985, the federal government denied funding for HIV research, public health education, and disease prevention (HIV, 2022, September 15). While the presidential administration stalled their involvement, the disease quickly became a pandemic that affected people beyond the gay community. Grassroots organizations mobilized efforts to provide much-needed social support services to the HIV-positive community to prevent new infections. Social support services included the provision of medical care, housing, and food.

A month after President Reagan mentioned AIDS publicly, the federal government allocated 190 million dollars to the Administration's budget for AIDS research (Smithsonian, 2012, January 8). By the time the government became involved, 5,636 people had died from AIDS. This type of labeling, ignorance, and prejudice violated the human rights of millions and gave birth to a palpable stigma that HIV-infected people still struggle with today. Stigma marks a particular circumstance, quality, or person with shame or disgrace. Stigma is an integral part of

the individual experience and the social treatment of PLWH (Sandelowski et al., 2004). According to Sandelowski, Lambe, & Barroso (2004), stigma carries the exact significance of biomedical symptoms and tremendously affects the patient's illness perception and experience.

Despite legal protection and increased public awareness about HIV, HIV-positive people in the U.S. and worldwide still carry the burden of stigma and discrimination. Many are still denied and fired from jobs, denied housing, and denied medical treatment (Anderson, 2009). Shockingly, healthcare personnel self-report that they stigmatize patients with HIV and provide substandard care. Family members often treat HIV-positive people differently once they disclose their diagnosis (Anderson, 2009). Ignorance about the primary modes of HIV transmission and moral judgment and prejudice against groups most affected by the virus fuels stigma and discrimination toward PLWH (Anderson, 2009). According to a 2009 national survey by the Kaiser Family Foundation, one-third of Americans believed that HIV could be transmitted by sharing a drinking glass, touching a toilet seat, or swimming in a pool with someone with the virus- all unfounded misconceptions (KFF, 2009, April 01). From that survey, 42% of respondents would be uncomfortable with a roommate who had HIV, 23% would be uncomfortable with a co-worker with HIV, and 35% would be uncomfortable if their child had a teacher with HIV (KFF, 2009, April 01).

HIV/AIDS Prevalence. Prevalence refers to the number of people living with the disease who need care and is an important aspect of ART adherence-related issues. In 2021 approximately 38.4 million people were living with HIV worldwide (UNAIDS, 2022, September 15). While the rate of new infections has reduced by 54% from its peak in 1996 with the use of HIV medicines, 1.5 million *new* infections still occurred in 2021 (UNAIDS, 2022, September

15). Of those infected, 28.7 million people accessed antiretroviral therapy, which is an improvement from 7.8 million in 2010.

National HIV statistics reveal that approximately 1.2 million people in the U.S. have HIV. In 2019, it was estimated that there were approximately 34,800 new HIV infections in the U.S. The populations most infected by the disease were minority groups, as the disease disproportionately impacts minorities, gays, bisexuals, and other men who have sex with men (MSM) (HIV, 2022). For instance, in 2020, black 71% of new infections in the U.S. were MSM, and 39% of those infections were among Black males (HIV, 2022, October 27).

Also, HIV is more prevalent in some areas of the U.S than others. Ten states account for 65% of HIV cases (KFF, 2021, June 7). Specifically, the South accounted for approximately half of HIV diagnoses in 2017 (KFF, 2021, June 7). The District of Columbia has the highest rate nationwide, but eight of the top 10 states were in the South. In 2015, Memphis, Tennessee, was eighth in the country for new HIV transmissions and twelfth for AIDS cases. In Memphis, HIV disproportionately affects Black American men and women (LeBonheur, 2017). Even more disturbing is that in 2017 most new HIV diagnoses occurred among youth ages 15-34 (LeBonheur, 2017).

Antiretroviral therapy has substantially reduced AIDS-related morbidity and mortality and the rate of new annual infections. Fifty-seven percent of PLWH are virally suppressed (KFF, 2021, June 7). Tennessee public health officials intend to decrease HIV prevalence through prevention: viral suppression via ART adherence and antiretroviral pre-exposure prophylaxis (PrEP) oral medicine for high-risk groups such as men having sex with men and intravenous drug users (LeBonheur, 2017). The goal is to prevent new infections by increasing viral

suppression among those infected with HIV, which also decreases the rate of new transmissions. Both interventions demand medication adherence.

HIV Treatment. The introduction of antiretroviral therapy (ART) transformed HIV treatment and improved the clinical course of the disease by reducing HIV/AIDS-associated morbidity and mortality (McComsey et al., 2021; Samji et al., 2013). Adherence, nevertheless, remains to be unsatisfactory and remains between 27%-80% across varying populations (Iacob et al., 2017). To achieve viral suppression, patients must take their medicines as prescribed 95% of the time to achieve maximal viral suppression (Haas et al., 2016; Turner, 2002). Research reveals that even modest nonadherence compromises the benefits of ART and results in viral replication, drug resistance, and other adverse virologic outcomes (Clutter et al., 2016).

The HIV Care Continuum. The HIV care continuum is a model of the dynamic stages of HIV care. While the literature uses the term interchangeably with the HIV treatment cascade, the continuum consists of five main steps: diagnosis, linkage to care, retention in care, adherence to antiretroviral therapy, and viral suppression (Kay et al., 2016). The cascade shows the proportion of PLWH engaged at each stage from diagnosis to suppressed viral load. Understanding how gaps in the continuum of HIV care affect virological outcomes in Memphis and the U.S. provides insight into how to improve adherence and, ultimately, increase viral suppression among the HIV-positive population (Gardner et al., 2011).

Diagnosis. The first step in the treatment continuum is diagnosis. Of the 1.2 million people living with HIV in 2019, 87% were diagnosed. This means that nearly 1 in 7 or 13% of people living with HIV were unaware of their serostatus, which means they were not seeking treatment to stay healthy and not taking measures to prevent transmissions (HIV, 2022, October 27). CDC guidelines recommend that all healthcare professionals offer all patients between the

ages of 13 and 64 an HIV test as an initiative to make HIV screening a routine rather than a risk-based practice in healthcare settings (Kay et al., 2016). All adults and adolescents should be tested for HIV infection at least once. Pregnant women should be tested, including those presenting at labor with an unknown HIV status. Individuals at increased risk for HIV infection, such as MSM, intravenous drug users (IDUs), and persons presenting with a sexually transmitted disease (STD), should be tested at least once a year (Bradley et al., 2014).

Linkage to Care. Once diagnosed, it is customary to be "linked" to an HIV care provider for treatment and prevention counseling to avoid disease progression to AIDS and to spread the disease to others. The CDC measures linkage to care as the percentage of PLWH who have had at least one CD4 or viral load test run by a healthcare professional in a given year (HIV, 2021). In 2019, it is estimated that 66% of PLWH received HIV treatment. Currently, the United States federal benchmark for linkage to care is that at least 85% of newly diagnosed PLWH will have their first clinical visit within 30 days of their diagnosis (HIV, 2019). In 2016, 75.9 % of people were linked to care in the first month and 85.2% within three months (Part, 2012)(HIV, 2019). Best practice recommends that all HIV-positive people initiate ART therapy as soon as possible, which happens in the next stage of HIV treatment, "retention" to care (AIDS, 2015; WHO, 2018).

Retention to Care. This next stage of the HIV treatment cascade is "retention" to care. In 2019, 50% of PLWH were retained in care. Retention in HIV medical care is defined as a patient's regular engagement in medical care at a healthcare facility after initial entry into the HIV care system (CDC, 2021). The CDC defines medical care as documentation of at least two CD-4 counts, or viral load tests performed three months apart for **the year of evaluation (HIV, 2022). This stage comes after that initial visit and helps patients to achieve** therapeutic goals

such as optimal adherence and lifestyle modifications. Patients are tested for viral loads and CD-4 counts to determine the efficacy of treatments. Medical appointments range from every 3-6 months (HIV, 2019) (Chapman & Bogle, 2014).

Since there is no cure for HIV/AIDS, PLWH people must engage in care for a lifetime to achieve and maintain viral suppression. Studies report that PLWHs retained in care are more likely to start ART, achieve viral suppression, and have a significantly lower risk of HIV transmission (Crawford, 2014; Robertson et al., 2015; Yehia et al., 2014). Also, studies have established that patients who are not retained in care are responsible for 43% of new transmissions and have approximately twice the long-term mortality rate as those who keep their medical appointments (Li et al., 2019; Mugavero et al., 2009).

Viral Suppression. According to the CDC (2022), viral suppression is having less than 200 copies of HIV per milliliter of blood. It is estimated 57% achieved viral suppression. People who achieve viral suppression maintain therapeutic CD-4 levels and an intact immune system. A suppressed viral load means the virus is undetectable in a patient's blood. Undetectable viral loads prevent sexual transmissions and transmissions from mother to child (CDC, 2022). While the virus is undetected in the blood, it is ever-present and demands constant self-management to keep viral replication in check (Shukla et al., 2016). Those who fail to reach viral suppression progress into a terminal form of HIV, AIDS.

Adherence to Antiretroviral Therapy. For optimally adherent, treatment is effective in more than 95% of cases (Vogel, M. et al., 2010). On the other hand, PLWHs with suboptimal adherence are approximately three times more likely to experience virologic failure than those with optimal adherence (Bezabhe et al., 2016; Paterson et al., 2000). To achieve optimal adherence, HIV-positive patients manage disease symptoms, medication side-effects,

comorbidities, long-term medical care, the psychosocial burden of having a chronic illness, and the burden of HIV stigma.

Side effects. People who take ART often experience side effects. Side effects are unwanted or unexpected reactions to a medication. Side effects range from dizziness to life-threatening conditions like a heart attack (FDA, 2018). Factors such as age, gender, allergies, metabolism, and interactions between other medications can cause side effects. When PLWH experiences side effects from taking the drug, they commonly report dizziness, nausea, and malaise. Medication-taking strategies such as eating smaller meals or taking medications before rest can mitigate the occurrence and intensity of adverse reactions to drugs (HIV, 2022).

Comorbidities. People who adhere to treatment live longer and sometimes develop comorbidities. Comorbidity is the presence of two chronic diseases or conditions in a patient. Comorbidity is associated with worse health outcomes and a more complex medical management (Valderas et al., 2009). PLWH who have been living with the disease for a long time commonly suffer comorbidities such as cancer, reproductive ill health, diabetes, kidney damage, heart disease, liver disease, and increased levels of fat in the blood (Lorenc et al., 2014). Comorbidities are significantly more significant among the HIV-infected population than patients with other chronic diseases. The chronic immune activation and inflammation caused by the presence of HIV cause the development of more comorbidities, at a younger age, among HIV-positive patients (Gallant et al., 2017; Guaraldi et al., 2011). In these instances, physicians suggest supplements support an individual's health.

The life expectancy of an AIDS patient is between 6-19 months without antiretroviral therapy (Knoll et al., 2007). An AIDS patient with a high viral load and virulent bodily fluids is highly infectious during acts such as unprotected sex, sharing needles during intravenous drug

use, breastfeeding an infant, and blood transfusions. AIDS-related complications ravage the human immune system until the infected person succumbs to opportunistic infection or other AIDS-related complications (The Antiretroviral Therapy Cohort Collaboration, [TATCC], 2008). Since there is no cure for HIV, medication adherence and disease management are the only means to survive the infection.

Another critical aspect of disease management outside of clinical settings is creating self-management (SM) support for the people grappling with the burden of being chronically ill. Many newly diagnosed patients experience ambivalence about their diagnosis, so advice-giving must match the patient's readiness to receive information and contemplate change. Collaborative interactions between patients and healthcare providers advance self-management through intentional behavior change to increase self-efficacy, which predicts the patient's ability to successfully self-manage medication-taking and symptom management. The literature has established that SM education that teaches skills is more effective than providing patient education in an information-only, advice-giving format (McGowan, 2012).

Chronic Disease Management

The Center for Managing Chronic Disease (2022) defines a chronic disease as a stable condition that can be controlled but not cured. Chronic disease is when a person's health deteriorates over time without proper management to mitigate symptoms, complications, and disease progression. Chronic diseases usually carry uncertain prognoses, adverse therapies, and more psychosocial burdens than acute diseases. Proper chronic disease management can improve the quality of life and predict an average life expectancy (Holman & Lorig, 2004; (McGowan, 2012). When an effective medication, such as ART in HIV care, extends life expectancy for people with an incurable disease and pushes symptoms into remission, the disease moves from

the acute care model to the chronic care model. The shift from acute to chronic illness requires self-management, demanding that patients play an active and informed role in decision-making. (Swendeman et al., 2009). The regular care model depends on patient-centered care and patient/caregiver/provider partnerships that work together to control symptoms and prevent disability (Knight & Shea, 2014; Jordan & Osborne, 2007; Bodenheimer et al., 2010; (Swendeman et al., 2009). The framework positions providers to play supportive roles in assisting patients in identifying problems, setting health goals, and self-managing symptoms (Swendeman et al., 2009). In this context, patients rely on providers to support their autonomy and self-determination to self-manage the disease and illness.

Self-Management. Viral suppression is primarily accomplished through effective self-management, including adherence to ART, abstaining from high-risk sex behaviors, and not sharing needles during intravenous drug use (Cohen, 2011; Paterson et al., 2000). Johnston et al. (2008) defined self-management (SM) as "an individual's ability to manage the symptoms, treatment, physical, psychosocial, and lifestyle changes inherent in living with a chronic condition" (p.5). In SM, patients are expected to use medications correctly, adopt lifestyle changes, and react to symptoms appropriately. Patients must also adjust to the social, economic, and emotional burdens of being sick (Areri et al., 2020; Swendeman et al., 2009).

Self-Management Interventions. The World Health Organization (WHO) (2001) identified self-management interventions (SMI) as evidenced-based practices for people self-managing a chronic disease (Welch, 2014; Swendeman, Ingram, & Rotherman-Borus, 2009; Michie, Miles, & Weinman, 2002). SMIs provide the patient with disease-specific information to guide decision-making for successful disease management (Warren-Findlow, Seymour, & Huber,

2011). Additionally, self-management support offers interventions to manage the psychosocial aspects of the disease, such as stress, anger, and depression (Areri et al., 2020).

Specific to HIV, self-management models emphasize the development of behavioral goals (Lee et al., 2021). HIV-specific challenges in self-management include the lack of direct self-monitoring of physical status (PLWHA can only be informed about their situation during medical visits, which are typically every 3 to 6 months in comparison to hypertension or diabetic patients being able to monitor biomarkers such as blood pressure or blood sugar several times a day at home between medical visits), stigma and disclosures, and the criminalization of HIV exposure. The Positive Self-Management Program combines health education with self-management skills to ensure that patients understand the risks and benefits and actively participate in medical decision-making in HIV care (NCOA, 2020). Numerous studies have demonstrated success in using self-management programs to change health-related behaviors for PLWHA, such as medication adherence, reducing risks of transmission, increasing self-care, emotional regulation, accessing social resources and support, reducing substance abuse, improving quality of life, and coping with social stigma (Swendeman et al., 2009).

In addition to health-related behaviors, many newly diagnosed patients experience a period of ambivalence in which they become frozen or use maladaptive coping strategies such as avoidance or denial before they accept the fact that they are chronically ill and begin to take action to manage the disease and illness. At this point, patient-provider communication moves the patient toward step by matching health education and skills building with the patient's readiness. Self-management education moves the patient through the processes of intentional behavior change to eventually adhere to treatment plans to achieve optimum health (Prochaska & DiClemente, 1983; Raihan & Cogburn, 2021).

Patient-Provider Communication

Extensive clinical research has delivered efficacious drugs to combat the disease; empirical research is still working to solve the behavioral problem of nonadherence among those infected. To maximize the impact of ART, PLWH must engage in care along the entire treatment cascade. To assist in this task, health communication promotes health for patients and caregivers living with HIV. To achieve treatment goals, patients must be "activated" to self-manage HIV autonomously. Considering that most providers are focused on controlling the disease, patients, and caregivers, are most concerned with managing the day-to-day experience of living with the symptoms of the disease and the side effects of taking the prescribed medicines (Graffigna, Barello, & Bonanomi, 2017). This dichotomy often presents discordance in the patient-provider relationship as the medical expert tends to focus on the disease, and the patient's focus is usually on the day-to-day experience of coping with the illness. Providers must use strategic adherence communication to bridge the worlds of real life and medicine.

The Illness and Disease Dichotomy. The perspectives of patients and providers come from two distinct concepts: disease and illness. Twaddle's seminal work (1994) defines disease as a health problem that consists of a physiological malfunction that results in an actual or potential reduction in physical capacities or a reduced life expectancy. According to Twaddle (1994), the disease is an organic phenomenon independent of the subjective experience or social conventions of illness that can be measured by objective means such as blood chemistry. This scientific perspective makes mechanical inferences to the human mind and body, effectively reducing the dysfunction or disease to a single dimension — ignoring the soul, mind, and environment that collectively create the illness experience (Carlos, 2005).

On the other hand, Twaddle (1994) defines illness as a subjectively interpreted undesirable state of health. More specifically, illness is an individual's subjective feeling or experience that represents a break from their body's normal function. In medical terms, this experience is referred to as a symptom. The concrete experience of illness, or a sign, has considerable influence on health-related behaviors, adherence, and the willingness of the layperson to cooperate with medical personnel (Seidlein & Salloch, 2019). To enhance patient-provider collaboration, communicative agreements must be established between the Lifeworld, and their voices must be integrated so that they can be on one accord to accomplish treatment success.

The Two Contrasting Voices of Patient-Provider Dialogue. In therapeutic relationships, the patient and provider speak from two distinctive voices: The Voices of Medicine and the Lifeworld. A helpful way of understanding patient-provider communication is through Mishler's (1984) theoretical concepts of contrasting dialectic frameworks that characterize the interaction. Mishler drew on Habermas' ideas of communicative action and applied them to the context of patient-provider communication. Mishler (1984) describes voices in the patient/caregiver/provider interaction in his work about medical consultations. Mishler (1984) explains that voice does not equate to a speaker but is a particular world orientation. The voice represents a relationship between the speaker and their worldview (George, 2010). A speaker may have more than one voice, or different speakers may share the same voice. According to Mishler (1984), the "Voice of Medicine" represents the technical and scientific assumptions of biomedicine, while the "Voice of Lifeworld" represents the individual's perceived experience of everyday life.

The "Voice of Medicine" (VOM). The VOM represents the technical rationality of systems and industry and tends to decontextualize personal experiences of health and disease (Barry et al., 2001). This voice is formed through formal education and is usually the practitioner's voice. The VOM serves the purpose of explaining symptoms and presentations of illness. Much of the clinical visit is controlled by this voice. While studies have shown that it takes the average patient or caregiver 92 seconds to complete their narrative, the VOM, on average, interrupts the report within the first 11 seconds of the interview. Which is highly focused on the disease, not the person. The VOM

The "Voice of Lifeworld" (VOL). The concept of the VOL came from the phenomenological sociology of Alfred Schutz (Barry et al., 2001). He worked to synthesize Husserl's study of consciousness, meaning, and the lifeworld with Max Weber's sociology of meaningful subjective action. Jurgen Habermas expanded this concept of the lifeworld in his social theory of communicative action. Habermas explains that the lifeworld is the "background" or environment of the actor and represents culture, behavior, and attitudes. The lifeworld describes the world as the individual has experienced it. Lifeworld, ultimately, is the difference between subjective and objective reality as it represents the reality of the individual's experience.

The VOL, while not deemed medically significant by some clinicians, largely influences patients' adherence to treatment. The VOL discloses the patients' behaviors, environment, and life situations. Many symptoms or disruptions in health reflect problems with living rather than disease. For example, headaches, rashes, dizziness, fatigue, stomach disorders, aches, chronic constipation or diarrhea, and weight fluctuations often reflect problems related to living rather than the underlying disease (Roter & Hall, 2006). The patient can tell you the diagnosis, whether it be a psychosomatic disorder or a physiological one. The VOL

The VOL also influences patients' and caregivers' perceived health status. While practitioners rely on medical data, patients and caregivers refer to the physical, functional, social, and emotional aspects of well-being (as cited by Roter & Hall, 2006). To explore these nuanced aspects of human existence, they must go beyond the biomedical voice to hear the living voice. In a study by Hall and colleagues, patients' perceived health status is related to their functional abilities, such as walking independently without a cane, rather than biomedical data or lab diagnostics (Hall et al., 1993). Perceived health status is a concept that influences patients' and caregivers' health-seeking behavior and determines whether they perceive their condition to be a threat. Whether their needs are met in the medical consultation can determine when and how they begin to take action to address present and future health risks. The lifeworld of symptoms and other illness experiences largely determines when and how they present to a doctor's office or an emergency room. How medications perform and how they fit into the patient's lifeworld ultimately determine whether or not the patient is willing and optimistic about adhering to the treatment (de Ridder et al., 2004). According to Ridder and colleagues (2004), health optimism is not unrealistic as people's expectations predict their self-care behaviors and treatment engagement and ultimately lead to improved health outcomes.

Typically, the "Voice of Medicine" dominates clinical interactions, unilaterally defining what is and is not relevant through closed-ended questions (Barry et al., 2001). The verbal dominance of the Voice of medicine contradicts the concepts of patient-centered communication and compromises the delivery of competent care. Infrequent interruptions from the VOM may reflect engagement on the provider's part. Unfortunately, clinical realities reflect frequent interruptions that redirect the conversation away from the patient and place it primarily on the disease. This interaction pattern is positively associated with patient dissatisfaction,

patient/provider discordance, and medication nonadherence. Conversations in which providers and patients speak the same voice or speak equally of medicine and the lifeworld are reported to be most effective by patients, caregivers, and providers. This communication pattern engages patient and provider to share power through direct communication in which the provider has established enough rapport and trust through effective communication to be able to broach the topic of adherence, nonadherence, and other important aspects of chronic care management. Clinical communication that ignores the lifeworld to achieve biomedical objectives contributes to poor patient satisfaction and suboptimal adherence outcomes. This communication pattern fails to elicit and therefore answer the patient's concerns.

Statement of Problem

The limited perspectives of HIV-positive patients and family/friend caregivers (FFC) related to treatment adherence restrict the therapeutic role it can serve. Identifying and sharing the patient perspective allows powerful insight into the patient's condition, life situation, and environment while providing the opportunity for the interactants to co-create meaning, outline treatment expectations, and facilitate a therapeutic relationship to achieve adherence goals.

Currently, the only way to survive HIV is to adhere to ART. While drug regimens have proven efficacy for preserving life, nonadherence among the US population remains prevalent, with less than half achieving viral suppression (The Foundation for AIDS Research). To achieve viral suppression, patient/provider teams must work together to achieve a 95% adherence rate (Iacob et al., 2017). This teamwork includes assessing adherence status, medication-taking behaviors, self-care behaviors, and barriers to adherence such as forgetting doses, lacking resources to obtain the medication, and functional health literacy, among other factors determining an adequate level of patient activation. Since HIV is a chronic disease,

communication about these and other topics must continue, ideally with HIV provider continuity, for a lifetime.

Providers and patients lack the structure and resources to discuss medication adherence (Bezreh et al., 2012; Kee et al., 2018). Patient and provider teams avoid discussing the topic of adherence (Bezreh, Laws, Taubin, Rifkin, & Wilson, 2012). Providers are poor assessors of adherence, and patients fail to disclose the reality of their medication adherence (Basu et al., 2019). Medication is the staple of chronic disease management, so nonadherence leads to many poor outcomes for the patient, the public, and the economy. To improve adherence, patients and providers must talk about the issue nonjudgmentally, providing empowering support to patients and caregivers learning to manage illness and treatment (Patel et al., 2018).

Nonadherence is a health problem of a striking magnitude that cuts across multiple chronic illness domains. Nonadherence correlates to increased expenditures for patients and institutions. In 2020, US healthcare costs exceeded 4.1 billion dollars (AMA, 2020). Consequences of nonadherence include wasted medication, disease progression, reduced functional abilities, lower quality of life, and increased use of medical resources such as hospital and emergency room visits (CDC, 2017a). Indirect costs include absenteeism from work, decreased productivity, difficulty maintaining employment, and expensive medications required to manage potentially fatal chronic conditions (Iuga & McGuire, 2014).

On the other hand, evidence shows that patients who persist in treatment realize positive health outcomes, including less frequent hospital visits, lower healthcare costs, and a decreased risk of having preventable and untimely disease complications and death (Iacob et al., 2017). While many disciplines (medical, nursing, medical anthropology, pharmacy, and health communication) have researched and applied several health behavior theories, none have created

a theory that can explain or predict behavior. The positive link between adherence and health outcomes is universal across multiple chronic disease domains. It needs to be investigated from varying perspectives, methods, and disciplines to advance the knowledge of theory and intervention.

   Nonadherence. Patients often explain nonadherence as a coping mechanism for managing symptoms, side effects, and the many challenges of living with chronic illness. While non-compliance to prescribed medications can be dangerous— as stated above, drugs, when taken correctly, have the power to manage symptoms and prevent disease progression— healthcare professionals must recognize that it is their right not to do so (Sandman et al., 2012). Thinking from this patient-centered perspective assumes that the patient has the agency to question medical advice, not simply comply with expert recommendations. As a nursing professional, I challenge the adherence/compliance/concordance framework that positions the patient not to question expert advice. I argue that patients are more adherent when they have the agency to question medical information. Patients who are informed, autonomous, and agree to the treatment are more likely to become activated to perform self-care and treatment management (Krist et al., 2017). I argue that this process goes far beyond the decision to take a pill. Patients go through different activation levels before consistently adherent (Yao et al., 2021). Therefore, collaborative communication is one of the most impactful interventions in the chronic healthcare model. Optimal medication adherence requires knowledge, skill, and confidence developed over multiple interventions beyond the initial medical visit. Building the capacity of both patients and providers to have collaborative communication regarding adherence has the most significant potential to improve treatment outcomes for PLWH (Iacob et al., 2017).

Nonadherence Prevalence among Disease Domains. The CDC attributes over 900,000 deaths annually to suboptimal prescribed medication adherence (CDC, 2017a). It is estimated that approximately 50% of American adults live with chronic disease and that only 50% adhere to the medication recommendations of their healthcare providers (. The top four leading causes of disease-related deaths are related to chronic diseases: cardiovascular disease, cancer, chronic lower respiratory disease, and stroke (WHO, 2017b). While adherence among the HIV population is the focus of this study, the prevalence of nonadherence among multiple disease domains warrants more research.

Cardiovascular Disease. Cardiovascular disease (CVD) is the leading cause of death in the U.S. and is linked to one in three overall deaths per year (Maningat et al., 2013; Roger et al., 2012). It is no surprise that adherence is a common challenge for patients living with CVD. In hospital post-cardiac events, 24% of patients did not fill their prescriptions one month after discharge, and 34% stopped taking their medicines within one month of release. Self-reported measures indicate that patients had 83% adherence to an aspirin; 63% for cholesterol-lowering agents, 61% for beta blockers in conjunction with aspirin; 61% for beta-blockers, 54% for aspirin plus beta-blockers; and 39% for regimens that required three medications- aspirin, beta blocker, and cholesterol-lowering medication (Singh, P., 2017). These findings prove that patients who adhere to treatments live longer and have fewer adverse events and hospital visits. Failure to take these medicines usually means failure to achieve blood pressure control. Poorly managed blood pressure increases the likelihood of having a myocardial infarction (heart attack) and stroke, introducing significant morbidity, disability, and mortality risks among this population (Singh, 2017).

Cancer. Cancer patients have similar nonadherence rates as other chronic diseases. Pharmacological agents have improved health outcomes in chronic malignant disorders such as myeloid leukemia. Among these patients, a quarter to one-third is non-adherent, resulting in suboptimal treatment response and poor prognosis, including disease progression and even death (Hugtenburg et al., 2013; Mahon & Etienne, 2014). Neugut et al. (2016) examined adjuvant hormonal pharmacotherapy for 21,255 women. Despite its ability to reduce mortality for non-metastatic breast cancer patients, over 15-60% of the participants were non-adherent in the adjuvant hormonal therapy (Sella & Chodick, 2020)

Chronic Respiratory Diseases. Chronic lower respiratory disease is the third leading cause of death in the U.S. Among the chronic obstructive pulmonary disease (COPD) population, poor adherence to drug therapy and treatment recommendations, such as smoking cessation, which increased emergency hospitalizations (Jimmy & Jose, 2011; Khdour et al., 2012). In 2015, Khdour et al. (2012) found that the COPD population often suffers multiple co-morbidities complicating medical management and that COPD has a steady disease advancement that results in health deterioration. These patients, consequently, suffer high rates of depression. Depression places respiratory patients at high risk for nonadherence to prescribed therapies. Davis et al. (2017) compared users and non-users of COPD maintenance medication to discover that adherence significantly lowered risks for frequent hospitalization and reduced Medicare expenditures. Yet nonadherence rates to these medications remain at 40-60% (Davis et al., 2017).

Stroke. Patients with uncontrolled high blood pressure are at risk for stroke and other vascular diseases such as heart failure, coronary heart disease, and renal insufficiency. Poor adherence to prescribed regimens in stroke care is an unrecognized risk factor (Yeo et al., 2020). Yeo and colleagues (2020) explained that suboptimal adherence to antithrombotics and statins

determines patient survival after stroke and cardiovascular events. Naik & Chakrabarty (2022) explained that nonadherence to health habits was present in over 76% of patients. Approximately 37% of patients were nonadherent in taking medicines (Naik & Chakrabarty, 2022). Kulkarni et al. (2021) reported that 40% of patients with uncontrolled blood pressure were nonadherent to antihypertensive regimens. Uncontrolled blood pressure is a leading risk factor for stroke and end-stage renal disease, heart failure, and diabetes (Kulkarni et al., 2021).

Purpose of the Study

This grounded theory study examines the perspectives of HIV-positive patients and family/friend caregivers (FFC) related to treatment adherence. Research findings will be discerned using communication theory and suggested as a guide for intervention development with patients, family-friend caregivers, and providers. I bring my constructivist orientation to this project and prioritize the voices and concerns of patient and caregiver narrative responses to interview prompts.

Importance of the Study

Weaknesses in adherence research have produced thousands of studies with little to no impact on adherence outcomes (Conn et al., 2016; Costa et al., 2015; DiMatteo, 2004; DiMatteo et al., 2002). Adherence research uses non-standardized measures, relies almost exclusively on self-report measures, and is subject to desirability bias. To move adherence science toward a theory that has the power to inform interventions, these shortcomings must be addressed in research and clinical practice. An exploratory study rooted in the real-world context of patient experiences has the potential to shed light on the phenomenon. The implications of these findings could address current limitations in adherence research by providing more insight into constructs most salient to patients and providers who are actors in adherence communication.

There is no "gold standard" to measure adherence outcomes (Chesney, 2006; Lam & Fresco, 2015; Simoni et al., 2006). Adherence variables are measured directly and indirectly. Direct measures include biological assays of drugs in the blood or urine, confirming drug ingestion but not adhering to therapeutic objectives. Indirect methods include self-report, clinician assessment, medical chart review, directly observed therapy (DOT), pill count, pharmacy refill records, electronic drug monitoring (EDM), and therapeutic impact markers such as HIV-1 RNA viral loads, CD4 lymphocyte count, which are much more accurate measures of adherence and reflect whether health outcomes are ultimately improved by adherence related tasks (Simoni et al., 2006). Unfortunately, of all these measures, self-report is used to assess patient adherence (Stirratt et al., 2015).

Self-report is the most common method for assessing adherence behavior in the research and clinical care (Stirratt et al., 2015). However, the validity and precision of these self-report surveys are under scrutiny. The NIH Adherence Network assembled a panel of adherence research experts from various chronic illness domains to review the validity of self-report medication adherence measures. These experts found that the standards varied substantially in questioning, recall periods, and response items (Stirratt et al., 2015). Furthermore, self-report is vulnerable to recall bias and to misreport from faulty memory and tends to overestimate adherence by 10-20% (Simoni et al., 2006; Stirratt et al., 2015). Consequently, the data produced by these tools poorly reflects medication-taking truths, which presents a barrier to finding real-world explanations for treatment failure.

Adherence rhetoric is the third limitation evident in adherence query and praxis. Rhetoric is defined as speaking or writing that is intended to persuade. This term is appropriate in this context as biomedical science has a history of blaming patients for treatment failure under the

25

oversimplified assumption that compliance equals optimum health outcomes and that the ill patient is nonadherent and, therefore, deviant. The dismissive labeling of patients as "noncompliant" lays the blame on the patient when evidence shows that 75% of unplanned readmissions to two facilities were due to gaps in care (Advisory, 2013). The care teams failed to schedule follow-up appointments, discharged patients with incomplete instructions or discrepancies on the patient's medication list, and could not demonstrate self-care procedures to patients and informal caregivers (Advisory, 2013). These factors convolute the root causes of poor treatment outcomes, complicating the solution process. By labeling patients as nonadherent or the problem as nonadherence, health science, scholars could be misrepresenting the situation, much like in the early days of the HIV epidemic. The result is wasted time, money, research, and, most importantly, poor quality of life, disease transmission, and preventable disability and death.

Theoretical Frameworks

Self-regulation, self-management, and other adherence-related tasks are discussed about the patient's ability to take their medicines as prescribed under different stressors and challenges over time. I will discuss behavioral theories to explore medication-taking and self-management tasks in HIV care. Additionally, I will discuss interpersonal communication theories that illuminate patient-provider and caregiver interactions. In Chapter II, I will discuss these frameworks in greater detail.

The most commonly used theories and models linked to medication adherence include the health belief model, social cognitive theory, transtheoretical model, and the self-regulation/common sense model (Conn et al., 2016). Conn et al. (2016) reported that interventions guided by these theoretical frameworks have a modest effect. However,

interventionists can use the tenets of these frameworks to understand adherence behaviors and formulate communication strategies best suited for mobilizing patients to achieve health goals.

Social Cognitive Models. The Health Belief Model (HBM) is one of the original health behavior theories in the public health field. The HBM's six beliefs motivate or discourage behavior modification (Parvanta, 2011). Evidence shows that identifying and addressing health beliefs during clinical communication improves adherence (Midence & Myers, 1998). Bandura's Social Cognitive Theory (SCT) translates health knowledge into health actions. SCT constructs, such as self-control, are precursors of adherence behavior. Bennet et al. (2018) found that providers can adjust patient education according to whether the person perceives themselves to have high or low self-control. Providers can tailor communication and patient education by assessing the patient's self-efficacy, perceived locus of control, and perceived self-control.

Motivation Models. The self-determination theory (SDT) (Ryan & Deci, 2000) is a framework of human motivation emphasizing autonomous behaviors—an essential distinction in self-management. The theory emerged in the 1970s and is key to understanding health behaviors related to self-management in chronic disease. The framework suggests that motivation to perform healthy behaviors is enhanced when individuals perceive themselves as competent to perform the behavior and choose to do so of their own free will and volition (Patrick & Williams, 2012; Ryan & Deci, 2000). The argument could be made that noncompliance and nonadherence work against patients' perception of autonomy to disagree with prescribed regimens (Russell et al., 2003). Williams & colleagues (2004) describe autonomously regulated behavior as those the person feels they have the freedom to choose as opposed to behaviors they would do under pressure or coercion.

The self-regulation model (SRM), also known as the common-sense model, views the patient as an active problem solver in the process of self-management. **The SRM examines the individual's illness perception to explain their health-seeking behaviors** (Leventhal et al., 1980). The SRM explains self-regulatory behaviors as responses to the cognitive representation of a health threat. People develop action plans for coping with symptoms, medication, side effects, and challenges associated with living with a chronic disease. This is consistent with many claims that intentional nonadherence is a logical decision. Depending upon the appraisal of the outcome, people develop patterns of behaviors for coping with a chronic illness (Midence & Myers, 1998). There is empirical evidence that illness representations and beliefs are related to medication adherence. For instance, treatment adherence was linked to the idea that treatment effectively controls the disease. Other illness representation constructs include illness coherence which is the patient's comprehension of the illness. The self-determination theory differs from the SRM in that it argues that patients' adherence behaviors improve when they perceive the action to be their own decision rather than a decision they are pressured to perform by a medical expert (Ryan & Deci, 2000)

The Health Locus of Control (HELOC) explores patients' perceptions about their ability to control behaviors to achieve health outcomes. A core construct of the HELOC is self-efficacy, but the framework focuses on individuals' expectations to achieve health goals. The Transtheoretical Model (TTM), also known as the Stages of Change Model (SOCM), is an integrative biopsychosocial model that conceptualizes the process of intentional behavior change (Prochaska & DiClemente, 1982). This model acknowledges that patients are at different cognitive and emotional stages of contemplating the disease. The consequent stage of change requires specific communication to move the patient to the stage where they can adhere to and

persist in self-management. Prochaska & DiClemente (1982) suggest that medical personnel use the framework to tailor communicative tactics for helping patients move toward the next stage.

    Interpersonal Communication Models. Habermas' theory of Communicative Action explains interpersonal communication between patient and provider. This theory posits a dialectical struggle between the voice of medicine and the voice of the real world (Haberman, 1984) (Barry et al., 2001). The voice of the lifeworld refers to the patient's contextually grounded experiences of events and problems in life. Depending on the patient's history and position in the world, the timing and significance of events shape the individual's experiences. In contrast, the voice of medicine reflects a technical interest and a scientific attitude. The meaning of events is provided through abstract rules that decontextualize events and remove them from personal and social contexts (Mishler, 1984). In the context of clinical communication, it is ideal to have communication that represents both worlds so that the patient can have their needs met and receive competent care.

    Since its inception in the 1970s, the Communication Accommodation Theory (CAT) has been a framework for understanding how speakers adjust their language to accommodate each other during interpersonal interactions. CAT focuses on how, when, and why speakers attune their messages to match their conversation partners. Thakerar, Giles, and Cheshire (1982) defined psychological accommodation as "individuals' beliefs that they are integrating with and differentiating from others, respectively, while objective linguistic convergency and divergence can be defined as individuals' speech shifts towards and away from others, respectively" (p. 222). Accommodative strategies such as convergence are used to adapt communicative behaviors such as accent, speech rate, smiling, gazing, pauses, and utterances to the person they are communicating with. CAT contends that communicators accommodate those they admire,

respect, and trust, and in this way, communicative differences are attenuated. This is a critical aspect of partnership building between patients, caregivers, and providers.

Summary

This study seeks to illuminate the lifeworld experiences of HIV-positive patients and caregivers regarding ART adherence. As most previous work on adherence experiences tends to focus on why patients are nonadherent or adherent, there is a knowledge gap about what communicative experiences have impacted patients' and caregivers' management of HIV treatment. The results of this study may serve multiple stakeholders, such as physicians, nurses, clinicians, health science researchers, and health communication scholars, as it has the potential to guide adherence resources and practices for providers, patients, and caregivers. Chapter II offers a review of pertinent literature regarding HIV disease, treatment, patient-provider interaction about adherence, and health communication theory. Chapter III details the methodological elements of the study. Chapter IV details the project's results, followed by an interpretation of the findings in Chapter V.

Research Questions

Research questions for this exploratory qualitative grounded theory study reflect "a problem-centered perspective of those experiencing a phenomenon and is sufficiently broad enough to allow for the flexible nature of the research methods" (Birks & Mills, p. 21). The research questions for this study include:

RQ1: How do HIV patients and family/friend caregivers (FFCs) define and understand the concept of adherence?

RQ2: How do patients and FFCs conceptualize the HIV disease process and treatment?

RQ3: What aspects of the medical world do HIV patients and FFCs identify as supportive and central to begin, adhere to, and persist in treatment?

RQ4: What elements of the lifeworld day-to-day lived experiences do HIV patients and FFCs identify as substantial determinants of beginning, adhering, and persisting in treatment?

RQ5: How are FFCs describing their role in the treatment and its adherence?

Since there is limited research on adherence communication experiences from the patient and informal caregiver perspective, as this is a human inquiry, adherence, after all, is a behavioral phenomenon that has many layers of complexity to examine. An exploratory approach allows the researcher to expand their ability to discover novel concepts regarding a complex socio-behavioral phenomenon. The qualitative methodology allowed me to explore the topic from the participants' worldview to examine relationships between variables. This pragmatic strategy permits a researcher to choose " 'what works' within the precepts of research to investigate, to predict, to explore, to describe, and to understand the phenomenon" (p.70) (Williams, 2007).

Constructivist grounded theory is the research methodology used in this study. This methodology is appropriate for formulating parsimonious theories grounded in the experiences of those involved and is, therefore, appropriate for this study (Walsh, 2015). The constructivist paradigm assumes that people can have varying motivations and challenges for adhering to treatment. This motivation can be influenced by the person's environment- family, friends, caregivers, or providers.

While my aim is not to develop or test a theory, it is to generate knowledge that can be applied to such an endeavor. Findings helped explain why people adhere to medicines, why they persisted in treatment and the processes in between. The knowledge acquired from this study has

implications for health communication praxis regarding the partnerships between patients, caregivers, and HCPs in chronic condition management.

Overview of the Research Design

An exploratory study was performed using grounded theory. Grounded theory methodology is an effective way to formulate ideas and discover novel insight into a poorly understood phenomenon such as medication-taking (Birks & Mills, 2015; Charmaz, K., 2006; Glaser & Strauss, 1967; Urquhart, 2012). Because the analysis is grounded in the data, it promises to deliver parsimonious answers to research questions regarding nonadherence, adherence, and patient perspectives. Findings helped explain why people begin to adhere to medicines, why they persisted in treatment, and the processes in between.

This study sought to investigate medication-taking from the real-world experiences of participants. In constructivism, the experiences of multiple people are explored according to her account and then interwoven to find connections between emerging concepts in the data (Charmaz, K., 2006). The study sample was drawn from a population of HIV-positive patients and caregivers who receive supportive services from a downtown Memphis, Tn, facility. Some people had linear adherence experiences, in which they were diagnosed, immediately sought treatment, and remained in care throughout their entire illness. Others had nonlinear adherence experiences in which they had periods of ambivalence before they accepted their diagnosis, decided to submit to treatment, and persisted until they achieved viral suppression. Adherence decisions were made from varying belief systems, barriers, and social motivators. When these themes and factors began to reoccur, I knew I had achieved data saturation.

Constructivist grounded theory methodology calls for the researcher to acknowledge when data saturation has occurred or when there are no new emerging concepts or theories from

the interview data (Birks & Mills, 2015; Urquhart, 2012). For this study, I anticipated a sample of 11 and 20 participants. The final sample was 28 participants. Chapter III provides more details about the study's specific design.

Definition of Terms

The following terms help the reader understand each word's context in this study.

Adherence: According to Ho & Associates (2009), adherence is the engaged, voluntary, and collaborative involvement of the patient in a mutually agreed upon course of behavior to produce a therapeutic health outcome (Ho et al., 2009)

Agency: Agency is the capacity of individuals to have the power to enact one's will and the ability to act on one's behalf

Biomedical Model of health care: The roots of the provider-dominated and disease-centered medicine approach. This model reinforced medicines' tendency to focus on the mechanism of the human body rather than the person's experiences. This depersonalization of medicine placed providers' foci on technologies such as diagnostic testing, among many other biomedical tools used to identify disease, instead of the patient's report or health narrative (Foss, 2002).

Biopsychosocial Model of Healthcare Delivery: The biopsychosocial model is an adaptation of the biomedical model that considers the biological, psychological, and social dimensions of human suffering (Borrell-Carrió et al., 2004; De Haes, 2006)

Concordance: Concordance is a communicative process by which the patient, caregiver, and clinician negotiate and agree upon clinical decisions from discordant perspectives (Bell et al., 2007).

Disease: A health problem that consists of a physiological malfunction that results in an actual or potential reduction in physical capacities or a reduced life expectancy (Twaddle, 1994).

Evidence-based Practices: EBPs are protocols from scientific evidence from randomized clinical trials. EBP treatment plans are depersonalized and designed from inferences made toward large populations rather than specific patient cases (Sur & Dahm, 2011).

Healthcare provider: A clinician is a trained medical professional such as a doctor, physician assistant, therapist, pharmacist, nurse, etc., who works directly with patients rather than in a laboratory or as a researcher. The clinician's core responsibility is to manage the patient and her illness, reducing the impact of the disease on the patient's life (Tumulty, 1970).

Illness: Illness is a subjectively interpreted undesirable state of health. More specifically, illness is an individual's subjective feeling or experience that represents a break from their body's normal function (Twaddle, 1994).

Illness Narrative: The patient's illness narrative explains how the patient experiences the disease. The narrative reveals the patient's beliefs, perceptions, attitudes, and expectations about the disease and treatment (Kleinman, 1988).

Informal Caregiver/Caregiver: an informal caregiver is any person, relative, partner, friend, or neighbor who has a significant relationship with an ill person and provides some unpaid, ongoing assistance to the "sick" person (caregiver, 2022).

Narrative Medicine: Charmaz (2006) describes narrative medicine as productive patient-provider interaction. Charon (2006) defines narrative medicine as a medical practice informed by the patient's disease experience. Narratives illuminate the social context of a person's health. According to Nelson (1992), patients' stories help develop healthcare practices that are ethical

and equitable as the narrative evokes empathy and enables the provider to relate to the patient as a person.

Nonadherence: The American Psychological Association (APA) (2022) defines nonadherence as an individual's failure to follow a prescribed therapeutic regimen. The APA clarified that nonadherence is often a matter of inadequate communication between the practitioner and the client or the result of adverse effects of the medication that is not being adequately addressed by the patient's healthcare team.

Patient activation: Patient activation is a concept that refers to the knowledge, skills, and confidence an individual has about making effective decisions to manage their health. Activation is developmental in nature and involves four stages: (1) believing the patient role is essential; (2) having the knowledge and confidence to take action; (3) taking action to maintain and improve one's health; and (4) staying the course even under stress (Hibbard et al., 2004).

Patient-centered Care: Patient-centered is characterized as care that is respectful of and responsive to individual patient preferences, needs, and values (Mead & Bower, 2000; Parsons et al., 2014).

Patient-centered Communication: A patient-centered communication approach that acknowledges the whole person's personality, lifestyle, and social structure, to come to a shared understanding of problems, goals, and barriers to treatment and wellness (Naughton, 2018).

Patient empowerment: A health promotion concept in chronic disease management by which people gain greater control over health decisions and actions(McAllister et al., 2012).

Patient Autonomy: The right of patients to make healthcare decisions without the influence or persuasion of an HCP. In this framework, professionals educate patients so they can make informed decisions (Schwab, 2006).

Self-determination: The concept that the patient should decide whether to accept the suggested treatment or care. The Patient Self-Determination Act is a federal law that protects a patient's right to self-determine healthcare decisions (Kelley, 1995).

Self-management: An individual's ability to manage symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition and to affect the cognitive, behavioral, and emotional responses necessary to maintain a satisfactory quality of life (Swendeman et al., 2009)

Self-regulation: Self-regulation is intentional acts to realize a goal. The process by which people initiate and adjust, thoughts, feelings, or actions to effect the realization of personal goals is an important aspect of self-management in chronic disease care (Heatherton, 2011).

Sub-therapeutic/Suboptimal adherence- A dose or concentration of a drug lower than usually prescribed to treat a disease effectively (Oxford, 2019).

Viral Suppression/Virologic Control- When ART reduces a person's viral load to an undetectable level (Avert, 2019).

The Voice of Lifeworld (VOL): Habermas defined the VOL as the "background" or environment of the actor and represented culture, behavior, and attitudes. The lifeworld describes the world as the individual has experienced it. Lifeworld, ultimately, is the difference between subjective and objective reality as it represents the reality of the individual's experience. The VOM represents the technical rationality of systems and industry and tends to decontextualize personal experiences of health and disease (Barry et al., 2001).

The Voice of Medicine (VOM): The VOM represents the technical rationality of systems and industry and tends to decontextualize personal experiences in the health and disease (Barry et al., 2001).

Undetectable – A person living with HIV is considered to have an 'undetectable' viral load when ART has brought the level of the virus in their body to such levels that blood tests cannot detect it. Being undetectable is not a constant state. If PLWHs do not take their medication correctly, their viral load will go back up (Avert, 2019). *Undetectable people* are not at risk of infecting other people.

Therapeutic Communication: The face-to-face interaction advances a patient's physical and emotional well-being. Therapeutic communication can be verbal or nonverbal.

Therapeutic Alliance: The relationship between a clinician and patient. Qualities of a good therapeutic alliance include mutual trust, respect, caring, general agreement on treatment goals, shared decision-making, and mutual engagement in the "the work" (Ardito & Rabellino, 2011).

Chapter II: Literature Review

Worldwide, poor medication adherence is a significant obstacle to healthcare. Currently, major barriers to compliance are thought to include complex medication regimens, poor health literacy, vague understanding of treatment benefits, poor patient preparation for medication side effects, low patient satisfaction with treatment, prescription medication costs, and inferior to non-existent communication between providers, patients, and caregivers regarding matters of treatment benefits, challenges, and medication adherence (Ha & Longnecker, 2010). I argue that before research can deliver a plausible solution to medication nonadherence, the perspectives of those living with the challenges of chronic illnesses should be elevated to focus. The narratives of this study can inform science and medical practice about the reality of medication-taking from the lived experiences of those managing HIV.

This literature review summarizes the construction of adherence concepts, the changing models of the U.S. healthcare system, and the communication-centric dynamics of patient-provider communication in treatment management.

The Construction of Medical Compliance

Around 400 B.C., Hippocrates was the first to record that some patients did not take their medicines as prescribed and explained that their treatment did not work. The first mention of adherence in modern medicine was by Robert Koch in 1882, who documented that noncompliant tuberculosis patients were "vicious consumptives, careless and irresponsible" (Hugtenburg et al., 2013; Vrijens et al., 2012). In the 1970s, at the McMaster University Medical Centre, Sackett & Haynes began the groundwork for compliance literature with the seminal book 'Compliance with Therapeutic Regimens.' The book was driven by a biomedical/pharmaceutical focus concerned

with empirical questions about patients' deviations from prescribed therapies and focused on the quantitative analysis of adherence behaviors (Vrijens et al., 2012).

Peer-reviewed studies in 1966 first reported the compliance and adherence terms. In the 1970s, scholars used the term compliance instead of adherence. Aronson (2007) explains that the term compliance is derived from "the Latin word *complire* and means to fill up and hence to complete an action, transaction, or process and to fulfill a promise." The Oxford English Dictionary offers this definition: "the acting in accordance with, or the yielding to a desire, request, condition, direction, etc.; a consenting to act in conformity with; an acceding to practical assent" (Aronson, 2007). In the compliance model, providers apply a benevolent, paternalistic approach to medicine in which the provider knows best and the patient submits to the recommendations of the medical expert. Rhetorically, compliance positioned the patient to be passive in health decision-making — trusting the benevolent doctor to make the "best" decision for their life (Pollock, 2016).

Initial compliance studies were not patient-centered, as they focused on the consequences of patients not following the doctor's recommendations. The patient's perspective was not a priority or, in many cases, a consideration. The biomedical approach positioned the physician as the absolute authority in clinical decision-making—wielding scientific expertise to perform the foremost Hippocratic duty to save and preserve life. Post-World War I and II, this paternalistic approach was deemed appropriate for treating acute illnesses, injuries, and communicable diseases (Pollock, 2016). Later, social medicine would push toward a more egalitarian medical practice in which all people are equal and entitled to human dignity, civil liberties, and rights.

Changing Healthcare Delivery Models

To address the many challenges of treating chronic disease, the present healthcare system will require a paradigm shift from episodic, acute illness to a model designed to care for patients suffering from chronic illness. This change is fundamental as it is the Hippocratic responsibility of the medical professional to adapt care systems to the changing needs, concerns, and conditions of modern society. To meet the health epidemic of chronic disease, a collaborative patient/caregiver-provider partnership is needed to expand the designs of coexisting medical paradigms: biomedical, biopsychosocial, and patient-centered care (Salmond & Echevarria, 2017). A collaborative partnership care model will require enhancing and developing patient/caregiver-provider communication in theory and praxis. Before exploring the concept of a collaborative healthcare delivery model, I will summarize the history of medicine and healthcare delivery to reveal the past and present characteristics of each system before exploring ways in which health communication can advance adherence theory and praxis in clinical practice and research across all chronic disease domains to include HIV.

The advancement of medical practice, throughout the centuries, from folk practice to rigorous scientific medical expertise, outlines the development of adherence concepts over time. During the early twentieth century, the biomedical system distinguished itself from folk medicine by becoming objective and scientific. In the 1930s, biomedicine tackled infectious diseases by discovering antibiotics (Lewis, 1976). As public health and medicine began to conquer the challenge of infectious diseases, chronic diseases became more prevalent among an aging population. These illnesses in the social medicine movement demanded a more humanistic approach that considered the patient and the condition when delivering patient care. Engel suggested that the biopsychosocial model of care delivery humanizes medicine. This model

emphasizes the social, psychological, and behavioral dimensions of illness. And finally, as chronic illness replaced acute illness as the most problematic health threat, patient preference and autonomy, the patient's choice became the central focus of the patient-centered care model. Each model speaks to the transformation of the patient's role in medical decision-making.

The Biomedical Model. The roots of the provider-dominated and disease-centered medicine approach can be traced back to Rene Decartes. Decartes described the body as "a machine, so built-up and composed of nerves, muscles, veins, blood, and skin, that even though there was no mind in it at all, would not cease to have the same function" (Foss, 2002, p. 37). Conceptualizing the body as a machine laid the foundation for biomedicine, emphasizing the body rather than the person. Intricately entwined with the technical aspects of medical management, this model still prevails today.

The Post-World War era was a crucial time for modern medicine. During this time, drugs such as penicillin revolutionized medicine leading to the development of chemistry-oriented health sciences such as biochemistry, pharmacology, microbiology, and immunology (Foss, 2002). This reinforced medicines' tendency to focus on the mechanism of the human body rather than the person's experiences. This depersonalization of medicine placed providers' foci on technologies such as diagnostic testing, among many other biomedical tools used to identify disease, instead of the patient's report or health narrative. The medical consultation became a scientific and objective meeting in which the provider dominated verbal communication and limited the patient to closed-ended questions.

In the biomedical model, the disease is the focus. Etiologies are reduced to purely physical defects without consideration of environmental or behavioral factors. While many have criticized the limitations of the biomedical model, it has been a highly productive model.

41

Biomedicine eliminated infectious disease as the leading cause of death in the United States and effectively increased the average human life expectancy with technologies such as antibiotics (Thomas, 1976). From this model, the pharmaceutical industry rose to deliver treatments such as insulin to diabetics, among many other medicinal therapies. The biomedical model is limited, however, as it takes a reductionist approach to understanding disease by primarily focusing on diagnostics and diagnosis rather than the human experience. Under this model, medicine primarily focuses on pharmaceutical consumerism (taking drugs) and treatment rather than prevention.

As biomedical science became sound knowledge that trumped folk medicine, common sense, and laypeople's knowledge, experts influenced health-related behaviors, often recommended ideal healthy living practices, and dominated clinical decision-making with a paternalistic communication approach. In the paternalistic or "expert knows best" interaction model, the patient is viewed as a passive recipient of care, not an active decision-maker. The compliance model is expert-centric— the expert identifies the problem rather than the patient, and the provider determines the health outcomes the patient should strive for. Currently, the medical community views the paternalistic patient-provider interaction model as the least ideal for chronic disease management. In this model, the provider decides which information to share. Initially, providers thought it was cruel to disclose bleak treatment prospects and, therefore, which treatment a patient should receive (Ha & Longnecker, 2010). Additionally, the biomedical approach demanded patient compliance as the disease was the primary concern.

While social medicine urged practitioners to employ patient-centered care, advances in technology and biomedical science moved medical practice towards implementing evidence-based practices (EBP) (Sur & Daham, 2011). EBPs are protocols derived from scientific

evidence from randomized clinical trials. Since medication is the central component of chronic care management, EBPs encourage providers and patients to comply with treatment courses identified, through research findings, to be most likely to deliver safe and reliable healthcare to achieve health goals. EBP pushed medical practice away from the subjective realities of each patient to apply a one-size-fits-all treatment course to many patients. For patient-provider communication, EBP mechanicalized medical practice to decontextualize questioning and interactions.

Formally introduced in 1992, EBP began a movement towards the systematic application of medicine over traditional practices. EBP treatment plans are depersonalized and designed from inferences made toward large populations rather than specific patient cases (Sur & Dahm, 2011). Evidence from scientifically rigorous randomized clinical trials argued that EBPs were the best and most rational treatment options. Patients who disagreed with EBPs were labeled and often treated as irresponsible or irrational when they simply exercised the agency to question those from whom they receive care (Pollock, 2016).

Biopsychosocial Model. In 1977, Engel offered the biopsychosocial model as an adaptation of the biomedical model that considered the biological, psychological, and social dimensions of human suffering (Borrell-Carrió et al., 2004; De Haes, 2006). In his critique, Engel did not deny that biomedicine had produced pivotal advances in modern medicine. Instead, he addressed three tenets of medical thinking responsible for dehumanizing care. First, Engel criticized the dualistic nature of treatment that assumed separation between mind and body. Second, he criticized the materialistic and reductionistic thinking of medicine that valued objectively observed signs that the provider can see, either through technology or their assessment, over the subjective experiences reported by patients. In his opinion, an empathetic

clinician legitimizes the human experience by hearing it. And finally, Engel argued that an effective provider could not remain objective (Borrell-Carrio, Suchman, &Epstein, 2004). Borrell-Carrio, Suchman, &Epstein (2004) emphasized this by comparing a technician to an expert clinician. A technician can report lab results, but a specialist clinician validates the human experience by witnessing it with empathy. In the final distinction, Engel emphasized the importance of the patient-provider relationship and its ultimate impact on treatment outcomes.

Patient-Centered Care Model. As early as 1957, scholars began to question medical paternalism and "disease-centered" care in favor of a more patient-centered approach that took the patient's autonomy from the periphery to the center of clinical decision-making (Deegan & Drake, 2006). This concept has gained the support of the medical establishment as the Association of American Medical Colleges (AAMC) (1984) stated, "every effort should be directed at developing and enhancing a patient-centered humanistic attitude in medical students." The medical community began shifting its ethos from the paternalistic model of medicine to the patient-centered approach that considered the patient a unique individual who should participate in the clinical decision-making (Mead & Bower, 2000).

The Institute of Medicine (IOM) defines patient-centered care as: "Providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions." Fundamentally, patient-centered medicine promotes the most egalitarian provider-patient relationship as it contrasts the conventional `paternalistic' relationship (Mead & Bower, 2000; Parsons et al., 2014). A statement issued by 21 leaders in medical communication asserted that a patient-centered or relationship-centered approach to care, which emphasizes the patient's disease and illness experience, is a fundamental communication task in quality care delivery (De Haes, 2006). Patient-centered interpersonal

interactions result in greater satisfaction for patients and providers. Satisfied patients who are happy with their provider's communication are reported less likely to file complaints or malpractice lawsuits and more likely to share pertinent health information, follow medical advice, and adhere to treatment recommendations (Hall & Roter 1981). Providers with satisfied patients reported greater job satisfaction, less stress, and less work-related burnout — which presents an ideal environment for facilitating trust and rapport-building between patients, caregivers, and providers (Ha & Longnecker, 2010).

To address the chronic disease epidemic, the medical community suggests a collaborative communication model in which the patient and provider are equally engaged in co-creating meaning for disease experiences. The patient is expected to collaborate with healthcare professionals as an engaged decision-maker, making informed decisions (Salmond & Echevarria, 2017). Providers are expected to empower the patient to become a self-healer. To shift current healthcare paradigms to this new model, health communication between providers, laypersons, and care professionals will be vital in providing holistic care. Effective communication will be the cornerstone of this integrative care model designed to treat the person, the disease, and the patient's Lifeworld.

Interpersonal Communication between Patient, Caregiver, and Provider

"*… communication is the most important tool health professionals have to provide healthcare to clients"* (Kreps & Thornton, 1992, p. 2).

The Department of Health and Human Services defined health communication as: "the study and use of communication strategies to inform and influence individual and community decisions that enhance health" (Parvanta, 2011, p.3). In 1993, William Roper, the Centers for Disease Control and Prevention director, defined health communication as "the crafting and

delivery of messages and strategies, based on consumer research, to promote the health of individuals and communities" (Parvanta, 2011, p.7). Health communication is central to the social process of care provision and the promotion of public health. It is paramount in treating, gathering, and sharing "health information" (Kreps et al., 1998). When transmitted and received by the targeted audience, health information has the power to prevent disease and promote health. Health communication inquiry often focuses on solving healthcare delivery problems (Kreps et al., 1998). This study is designed to explore the experiences of patient-provider communication regarding medication adherence. This study will reveal that patients have therapeutic alliances with their healthcare team and that interpersonal communication between the two groups largely influences treatment outcomes.

In the chronic care model, the patient-provider goal is to manage symptoms and prevent disability rather than curing the disease (Swendeman et al., 2009; Wagner et al., 2001). Originally this patient-provider interaction was one-sided, with the expert making the recommendations and the patient complying with them. Over time the model adapted itself to accommodate patient autonomy and self-determination. The patient is expected to execute treatment outside the clinical setting without expert supervision. Ideally, the patient should record their subjective response to medication and report this data to the clinician during a follow-up doctor's visit (Deegan & Drake, 2006). From this interactive feedback, the provider and patient should collaborate to adjust regimens to achieve patient-centered health goals. The patient's ability to persist (initiate and continue treatment recommendations) and achieve therapeutic objectives relies on the therapeutic alliance between the patient, caregiver, and provider (Deegan & Drake, 2006; Paige et al., 2016).

Patient Interaction Models. *Emanuel & Emanuel (2000) listed and compared four ethical patient-provider relationship models for providers and patients. These models attempt to balance competent medical care with patient autonomy and values and are appropriate guidelines for patient-provider interaction models (Borza et al., 2015). The paternalistic model is not ideal because it excludes the patient's perspective from treatment decisions. The informative model in which the clinician imparts information but does not contribute to decision-making is also inadequate in meeting the criteria for collaborative care and shared decision-making.*

The interpretative model is also problematic as it seeks to reform patient values to treatment objectives — a process that undermines patients' rights to self-determination. (Emanuel & Emanuel, 2000). And last is the deliberative model in which the collaboration of patient and provider plays a part in treatment decisions. According to Borza & Colleagues (2015), the deliberative model is the most ethical relationship model for the chronically ill as it includes the collaborative input of both patient and practitioner. Additionally, since the deliberative model includes engagement and participation from both parties, the disease and illness experiences are prioritized and treated as the providers incorporate patient preferences *into their care plans. When applied effectively, this interaction combines the strengths of the biomedical, biopsychosocial, and patient-centered care models to deliver a more holistic care model that is scientific, humanistic, and preferred by the patient. Ironically, the idealization differs from the compliance framework that assumes that treatment is the best option or that puts the expert and the disease at the center of all decision-making.*

Compliance Model. Adherence is the preferred term for the WHO, The American Pharmacists Association (APA), and the U.S. National Institutes of Health Adherence Research Network (WHO, 2003; APA, 2004; & Office of Behavior and Social Sciences Research, 2008).

47

While the literature suggests that adherence represents a more patient-centered ideology for patient-provider interactions than compliance, the terms' compliance and adherence are used interchangeably. The 2003 WHO definition of adherence is "the extent to which a person's behavior corresponds with agreed recommendations from a healthcare provider," which is identical to Haynes & Sackett's 1976 definition of compliance: "the extent to which the patient's behavior coincides with the clinical prescription" (Haynes & Sackett, p. 1-2). While the rhetoric attempts to change the structure of the compliance ideology over time, it is easy for scholars to focus more on the efficacy of treatment than issues that are more salient to the patient. Compliance denotes a paternalistic expectation in which the patient is expected to follow the provider's directions and trust that the provider knows best, without question (Pollock, 2016).

The reductionist belief that EBPs were the best decision for all patients and that patient compliance with EBPs would ensure the best patient outcomes made the concept of patient compliance a simple solution to the complex issues of health, disease, illness, and medication use. The pressure for patients to "comply" increased, and the research enterprise identified patient nonadherence as the number one problem of treatment failure when other sources have proven that there are systematic problems at play (Midence & Myers, 1998; Pollock, 2016). For instance, Midence & Myers (1998) found that pharmaceutical companies have recommended heavy medication dosages to patients to ensure the efficacy of drugs. The consequence of this practice, in large, has been medication side effects. Other causes of treatment failure include, but are not limited to, issues like misdiagnosis, treatment bias, lack of resources, and poor prescribing practices on the part of providers (Pollock, 2016). Whether a mechanism of biomedicine, which has a long history of patient blaming, or the manipulation of Big Pharma to make medication consumerism the perceived key to health, nonadherence became identified as a

problem, and researchers paid less attention to other plausible explanations for treatment failure (Chakrabarti, 2016). Over the years, different interaction models have been used to discuss and negotiate treatment plans. I will discuss historical models, current models, and an ideal model of patient-provider interaction.

Adherence Model. Adherence would emphasize the importance of a patient actively engaging in clinical decision-making. Recent literature has updated the adherence definition to mean the "active, voluntary, and collaborative involvement of the patient in a mutually acceptable course of behavior to produce a therapeutic result" (Ho et al., 2009). For chronic disease, the patient must be engaged as they have to self-monitor and perform tasks that prevent disease progression.

At a cursory glance, adherence research appears to be solely concerned with patient health. Ultimately, it also involves issues of professional control, power, and entrenched beliefs about patient-provider relationships (Russell et al., 2003). While adherence to some degree is necessary to survive the chronic disease, behaviors disconcordant with provider recommendations should not be the ultimate blame for treatment failure. HCPs see noncompliance as a challenge to their expert knowledge, beliefs, expectations, and norms (Playle & Keeley, 1998). The use of nonadherent or non-compliant as a negative label can deny the legitimacy of patient behaviors that differ from professional recommendations, ultimately undermining patients' autonomy and right to self-determination (Arrieta Valero, 2019). Before labeling patients as noncompliant, providers should assess and gain context of the person's life to design treatment plans to which patients can realistically agree.

Concordance Model. A joint working group assembled by the Royal Pharmaceutical Society of Great Britain formally introduced concordance in 1995 (Vrijens et al., 2012). The term

denotes a "meeting of the minds," agreement, cooperation, or a therapeutic alliance between providers, patients, family, and caregivers regarding medication management (Vrijens et al., 2012; Deegan & Drake, 2006). While some scholars have used concordance synonymously with adherence and compliance, others clarify that concordance is less about medication-taking and more about the communication process in conversations about the treatment (Jimmy & Jose, 2011). Concordance is a communicative process in which the patient and clinician negotiate and agree upon clinical decisions from conflicting perspectives.

The concordance ideology is a significant transformation in clinical communication as it was part of the movement that made it acceptable and even desirable for the patient to be more autonomous and disagree with the prescriber (Chakrabarti, 2014). The concordance framework acknowledges that the patient's beliefs, perceptions, and attitudes about medication management should influence treatment decisions just as much as the medical expert's (Chakrabarti, 2014). In the concordance model, the patient is encouraged to have the rhetorical agency to voice any concerns with the healthcare team without being judged or labeled non-compliant. According to Kenneth Burke's framework, rhetorical agency is the human capacity to act upon evaluations and questions. Rhetorical agency demonstrates the ability and power to challenge, negotiate, choose, and evaluate information. The informed and engaged patient who makes treatment decisions has self-efficacy and rhetorical agency. These self-managers report higher satisfaction with care delivery and better health (Hibbard, J. H. & Greene, 2013).

Deegan & Drake (2006) explain that the clinician's expectation to control the disease and the patient's hope to achieve some locus of control over the psychosocial dimensions of the illness experience will often cause patients and providers to have discordant objectives; therefore, expectations about treatment. At best, the clinician can inform and advise the patient

and the patient can either accept or reject the advice, in part or whole, as the patient must live with the consequence of treatment side effects and balance its benefits with its risks (Bell et al., 2007). Deegan & Drake (2006) assert that providers should expect a "clash of perspectives" (p.1637) between themselves and patients. Who, after all, "should have the privilege to judge that medication is working (Deegan & Drake, 2006, p.1637)"?

Research has established that patients are more adherent to treatment regimens to which they and their providers agree (Bell et al., 2007; Laws et al., 2012; Deegan & Drake, 2006). While the compliance model of medication management produces interventions that strive to mold patients' behavior to providers' recommendations, scholars and practitioners challenge providers who make decisions for patients and expect them to comply (Balint, 1957; Deegan & Drake, 2006). Balint (1957) emphasized the importance of patient-centered care and urged the medical community to move forward to a therapeutic alliance in which providers and patients work as partners through collaborative disease management and interactive communication called shared decision-making (Deegan& Drake, 2006).

Shared Decision-Making Model. In collaborative interactions, both parties have the right to agree or disagree. In social science, this construct is identified as agency. Agency is defined as the capacity of individuals to act independently, make their own free choices, and exert power in enacting them (Emirbayer & Mische, 1998). Shared decision-making (SDM) demonstrated an ideal communication model for clinical interactions (De Haes, 2006). The President's Commission supported the ideology for the Study of Ethical Problems in Medicine (1982), which included that "shared decision-making requires that a practitioner … develop reasonable alternatives to meet the needs of patients". The statement also emphasized the importance of patients engaging in this dialogue to self-determine their ideals of well-being (De

Haes, 2006). Charles et al. (1997) developed the most cited definition of SDM. The report includes four essential characteristics: patient and clinician are involved in all phases: sharing information, expressing treatment preferences, and reaching an agreement (Shay & Lafata, 2014). SDM is a crucial component of medication management as patient perceptions of SDM positively correlate with patient outcomes (Shay & Lafata, 2014).

Shay & Lafata (2014) asked patients to define SDM. All patients described SDM as a collaborative process in which the patient/provider exchange information, remain open-minded and mutually respectful to the other's ideas and suggestions, remain cognizant of the elements of patient self-advocacy, and co-creates personalized plans of care. The significance of this study is that patient perceptions of their participation in decision-making appear to be more impactful to health outcomes than any other phase of clinical communication. Ledford et al. (2010) found that patients vary in the degree of decision-making they wish to make. Most important to patients is that they are offered a role in decision-making (Shay & Lafata, 2014). Ultimately, providers should foster collaborative communication by eliciting the patient's narrative. In this process, the patient can share personal details about themselves, and the provider can learn about their social world. Studies have also established that narratives help providers relate to the patient on a human level, allowing them to empathize more with the patient's plight (Shay & Lafata, 2014).

What is Effective Patient-Provider Communication

According to Newell and Jordan (2015), effective communication occurs when the sender conveys the message's intent in a way that is understood and received by the receiver. In healthcare, communication is equally crucial as clinical knowledge and procedural skills (Warnecke, 2014). The quality of communication and interaction between healthcare providers, patients, families, and caregivers ultimately determine whether providers influence the patient's

healthcare status and state of well-being (Riedl & Schüßler, 2017). Studies have established that strong patient-provider relationships result in greater utilization of evidence-based therapies and healthcare resources (Okunrintemi et al., 2017)

Communication happens in an interactive two-way process in which two or more people exchange messages by nonverbal, verbal, face-to-face, or not face-to-face methods (Newell & Jordan, 2015). While some scholars argue that care processes are divided between the technical and humanistic aspects of care, others assert that they are interrelated. For example, the provider's ability to listen and collect a thorough medical history narrative directly influences their ability to assess and treat ailments (Larson et al., 2017).

Healthcare providers and patients perceive nonadherence as a contentious issue in clinical interactions. Evidence supports that both parties feel threatened by this topic (Midence & Myers, 1998). Providers think that their medical authority and expertise are being questioned, and patients feel that any admission of "non-compliance" could carry the consequence of being labeled and even withdrawn from the treatment (Midence & Myers, 1998). Both parties have expectations that are not met and react in ways that do not support therapeutic success.

The three main goals of patient-provider communication are to create a good interpersonal relationship, facilitate information exchange, and include patients in the decision-making (Ha & Longnecker, 2010). Effective patient-provider communication can enhance patient understanding of medical information and allows providers to identify patient/caregiver needs, perceptions, and expectations. Patients who report satisfaction with the providers' communication are more likely to be satisfied with the care, share pertinent information for an accurate diagnosis of their health problems, follow advice, and adhere to prescribed treatments

(Ha & Longnecker, 2010). Charmaz (2006) argues that narrative medicine is how productive patient-provider interaction occurs.

King & Hoppe (2013) denotes a decline in empathy and communication in medical education. Unsurprisingly, many patients report unmet informational and emotional needs during clinical provider interactions (King & Hoppe, 2013). Charmaz (2006) asserts that narrative medicine is one of the main elements lacking in modern-day medicine. Charon (2006) defines narrative medicine as medicine used with narrative skills to recognize, absorb, and interpret stories of illness. According to Gale et al. (2003), narratives are tools for an inquiry into the social, ethical, and therapeutic practice of client care…and are valuable means of exploration, interpretation, and a means of forming a consensus between clients, families, and practitioners" (p. 89). Nelson (1992) adds that patients' stories help develop healthcare practices that are ethical and equitable. The narrative evokes empathy and enables the provider to relate to the patient as a person. While compassion cannot be taught in medical school, the narrative allows providers to connect with their patients through empathy. Charon (2004) adds that "narrative" knowledge about patients, unlike scientific or epidemiological knowledge, provides insight into one individual's meaning of suffering and the human condition.

Medical anthropologist, Arthur Kleinman (1988), explained the importance of illness narratives among the chronically ill as they are how the sick person makes sense of their experiences. Kleinman (1988) describes these narratives as following three categories to organize events and meanings: restitution, chaos, or quest pattern. The restitution narrative views the illness as a temporary episode from which they hope to return to "normal" life and health. The chaos narrative sees the illness as a permanent and deteriorating illness with no hope of returning to normal. The third and most significant type of narrative is the quest narrative. The

quest narrative organizes illness experiences as an opportunity to transform oneself into a triumphant and capable "self-manager." Themes from narratives will allude to which narrative the patient can be in any of these narrative modes at one time or another during the trajectory of chronic illness.

The patient's illness narrative explains how the patient experiences the disease. The narrative reveals the patient's beliefs, perceptions, attitudes, and expectations about the illness and treatment (Kleinman, 1988). More importantly, patients have explained that the narrative helps them to organize their thoughts and experiences about the condition (Wittenberg-Lyles et al., 2013). The narrative allows the providers to assess the patient's literacy, knowledge, and capacity for problem-solving and coping (Charon, 2004). The patient's narrative also reveals the cultural aspect of the patient's thoughts, beliefs, and attitudes.

The more providers begin to know the patient beyond their body and disease, holistic care that treats the individual, not the disease, is likely to happen. Patient narratives also access the patients' knowledge about the disease and how such ideas are formed in the context of their culture, environment, and community. From mutual understanding, a therapeutic alliance between provider and patient can be created through the co-construction of meaning during their interactions.

Therapeutic Alliance. A therapeutic alliance refers to the bond between a clinician and a patient. The therapeutic alliance is an integral component of the patient-centered care model. Initially used in the context of psychotherapy, Sigmund Freud defined the partnership as having the function of providing a "sense of collaboration, warmth, and support between the client and the therapist" and denotes the rapport that is established between patient and provider (Ardito & Rabellino, 2011).

Deegan & Drake (2006) explain that the therapeutic alliance bridges empirical knowledge with the individual's concerns, values, and life context. In this model, the provider does not assume the efficacy of the medication. Providers and patients are co-investigators in learning what works best for the individual. In contrast to the traditional patient/provider relationship, medical authority respects the patient's right to informed choice and individualized treatment (Deegan & Drake, 2006). This frame of adherence communication supports greater rhetorical agency on the part of the patient and honors patient autonomy. As the patient realizes their decision is not judged as "non-compliant" or deviant, they are more likely to communicate their true feelings and thoughts regarding treatment and medication.

Barriers to Therapeutic Patient-Provider Communication

Effective patient-provider communication is one of the strongest predictors of medication adherence in the literature (Archiopoli et al., 2016). When assessing providers, people focus on the personality and the quality of the patient-provider relationship to determine whether or not the doctor is effective (McCarthy, 2014). Also, the literature has established a correlation between patient-provider communication quality and improvement in health outcomes (Calo et al., 2014). How providers communicate with patients can affect patient adherence and retention in the outpatient chronic care (Flickinger et al., 2016). Providers fail to meet the patient's and caregiver's needs in four areas: information exchange, rapport building, trust, and power-sharing in the patient/caregiver-provider interactions. These four components comprise the essential elements of patient-centered communication. For this section, I will discuss the common communication barriers exhibited by providers.

Clinician Roles in Patient-Provider Communication. A therapeutic patient/caregiver-provider relationship uses the clinician as an intervention to cope with the burden of illness

management. Collaboration between clinicians, patients, and providers is essential to overcoming challenges such as side effects, medication costs, lifestyle, scheduling, and other difficulties (Warnecke, 2014). The literature has established that patients and caregivers prefer providers who have a reasonable "bedside manner," who are active listeners, and who use an affiliation interaction style to establish therapeutic partnerships with the people for whom they provide care are active listeners and use an affiliation interaction style to establish therapeutic alliances with the people they provide care to. For this discussion, I will focus on the interactions between patients, caregivers, and providers.

Symptoms and disruptive life events often prompt patients to set a medical appointment or seek emergency care. Sometimes, this happens in the clinic and during an emergency room visit. In the medical consultation space, patient-provider communication involves the discussion of diagnostic inquiries, care planning, symptomology, treatment negotiation, goal setting, and medication management (Newell & Jordan, 2015). Providers all play a role in medication education. The doctor's scope is to diagnose and prescribe. The nurse's role in medication education occurs during routine patient care and discharge planning (Newell & Jordan, 2015).

Physicians. The physician's communication and interpersonal skills determine their ability to gather information for an accurate diagnosis, give therapeutic instructions, and foster therapeutic relationships with patients/caregivers (Ha & Longnecker, 2010). Ideally, physicians perform pre-prescription adherence communication, including information about the medication, what to expect regarding side effects, how to take the medicines, how to eat, how often patients/caregivers must pick up prescriptions, which drugs require refrigeration, etc.

When seeking medical expertise, patients have expressed greater satisfaction with physicians with a reasonable "bedside manner." The term "bedside manner" dates back to 1869

57

and refers to how a physician acts toward a patient (Person & Finch, 2009). When assessing a provider's performance, patients expressed that verbal communication skills are critical. Providers deemed good listeners had the best relationships with patients and the least complaints (Person & Finch, 2009). Receivers of care also reported that they appreciated physicians who engaged in nonmedical conversation, offered information freely and were attentive to the patient's needs and preferences. In this participatory interaction style, the physician seeks a mutual understanding and agreement on treatment plans. Most importantly, this interaction style supports patient autonomy so that the patient can become empowered and activated to self-determine their health status (Ha & Longnecker, 2010).

Nurses. Effective nursing communication serves a therapeutic function in healthcare (MacLean et al., 2017). The nurses' primary role in clinical communication is patient education and advocacy. In acute care settings, nurses are key health team members as they spend the most time with patients and perform multiple tasks such as medication administration, health procedures, and discharge education (Newell & Jordan, 2015). Nurses also act as a liaison between the patient and other healthcare professionals.

Riley (2008, p.20) reported that in "nurse-patient interaction, both nurses and patients bring individual knowledge, attitudes, feelings, experiences, and patterns of behaviors to the relationship." In training, nurses are encouraged to avoid medical jargon, be attentive and engaged listeners, and use appropriate nonverbal cues to facilitate patient trust and rapport. Newell & Jordan (2015) reviewed patient perceptions of nursing communication to determine that overwhelmingly, patients reported that nurses were poor communicators. Kwame & Petrucka (2020) described nursing communication behaviors as poor because nurses dominated conversations. The study explained that patients perceived nurse communication as impersonal,

nonprivate, rigid, uninformative, and authoritative (Kwame & Petrucka, 2020). Provider communication in the HIV care setting was described as collaborative and open, as providers were less dominant in the interaction process. This encouraged the patient/caregiver to participate and engage in clinical conversations to meet their needs and concerns. Specific to nursing practice, research has identified more extended visits and good communication skills as patients' and caregivers' favorite aspects of nursing care (Newell & Jordan, 2015).

Information Exchange. The Patient Charter of 1991 formally recognized the patient's right to receive information about the treatment (Pollock, 2016). The Patient Charter recognized that adequate information positively impacted disease prevention and reduction. This is especially true for medication management. While the pharmacy industry includes patient information leaflets with medications, scholars have widely criticized those materials for having industry and professional focus rather than a consumer one (Pollock, 2016). Derived from a biomedical guide, the materials emphasize compliance and displace any skepticism that may lead to the patient's deviation from professional recommendations. This factor increases the necessity for effective interpersonal communication between patients, caregivers, and healthcare personnel.

The information exchange consists of information-giving and information-seeking. Healthcare providers need information for diagnosis and treatment planning. Patients and caregivers need information for understanding, emotional coping, and informed decision-making. Along the continuum of chronic disease management, illness coping will perpetuate the patients'/caregivers' need for information (Pawlikowska et al., 2012). The same is valid for providers. As disease management adapts to the aging body, providers will continue seeking patient feedback to advance care plans and solve health challenges.

Provider Failure to Elicit the Patient/Caregiver Agenda. Many providers fail to learn a patient's agenda during clinical interactions before they dominate the interaction with biomedical questioning rather than active listening (Singh Ospina et al., 2019). This is especially detrimental in the chronic care model because success depends on the participation and engagement of the patient/caregiver (Spanjol et al., 2015). When attempting to co-manage illness with patients, providers fail to elicit patient concerns, expectations, and conceptions. Sing Ospina et al. (2019) discovered that patient agendas were only elicited during 36% of clinical encounters. This illuminates the fact that providers are very poor at eliciting patient/caregiver concerns and agendas. To mitigate this communication pattern, studies have suggested that agenda eliciting is a best practice used to improve patient satisfaction with patient/caregiver/provider interactions and clinical outcomes. Agenda eliciting is a communication skill taught to practitioners to create a better space for mutual understanding between patients/caregivers and providers (Hood-Medland et al., 2021)

Verbal Dominance and Provider Interruptions. To evaluate the quality of patient-provider interaction, researchers quantify verbal dominance. Interruptions and the amount of talk define verbal dominance. While interrupting can be viewed as a matter of engagement, interruptions limit a speaker's right to participate in the conversation (Matusitz & Spear, 2014). Interruptions also change the speaker's narrative, preventing a provider from hearing information outside their line of questioning. Researchers found that clinicians interrupted the patient after 11 seconds in 67% of encounters (Singh Ospina et al., 2019). Another study found that compared to the 67% of interruptions made during medical consultations, patients only interrupted the provider 33% of the time (West, 1998; Matusitz & Spear, 2014). Decreasing verbal dominance in

provider communication patterns could allow consumers more room to engage in clinical

conversations to improve adherence success.

The amount of talk is a standard descriptive measure of patient-provider communication

(Beach et al., 2015). Matusitz & Spear (2014) found that provider talk accounted for 60% of

clinical conversations. The amount of talk indicates social dominance, which contradicts the

patient-centered communication model in which the patient shares power with the provider

during a collaborative communication process.

Matusitz & Spear (2014) have described an impersonal communication approach used by

healthcare providers called scripted communication. Scripted communication is a formal

standardized communication applied universally to some situations. Ge et al. (2009) describe this

communication as the "automatic pilot" approach to provider communication. This is contrary to

patient-centered care and prevents patient/caregiver disclosures about challenges, preferences,

and concerns (Matusitz & Spear, 2014). A more personable communication approach that is

interactive between patient/caregiver and provider allows for social penetration. Altman and

Taylor (1993) developed the social penetration theory to explain how relationships grow and

how communication evolves from a formal, superficial, and impersonal state to a deeper state of

sharing meaning which is fundamental to collaborative communication and shared decision-

making in chronic illness management (Liu et al., 2022).

Rapport and Trust Building. Good rapport creates a close and harmonious relationship

with patients, caregivers, and providers. Lang (2012) suggests that establishing a connection

comes first in clinical communication. Rapport is found when people feel they have something in

common. In the short period of a medical visit, that commonality is most likely to occur in

language. This claim is validated by the communication accommodation theory, which will be

61

discussed in further detail in the theory section of this chapter. The accommodation theory says that individual differences can be minimized through accommodative communication. For example, a provider should pay attention to how a person experiences the world- whether the patient uses visual or auditory expressions. If a patient says, "That sounds great," and then a provider responds by saying, "I hear you," versus "I see," rapport ensues much faster as the patient's preference has been noted, not the provider's (Lang, 2012). The patient is empowered by expressing issues that are most salient to them. This form of communication is not dominated by one voice. It is not a one-way delivery. It is transactional communication that allows the patient/caregiver to voice their preferences and beliefs in concert with the provider.

Active Listening. Active listening is a communication quality patients and caregivers value (Jahromi et al., 2016). A key to self-managing is finding and understanding information. A provider actively listening can assess information needs and sense when patients/caregivers have lingering, unspoken questions or concerns. When providers actively listen, patients and caregivers feel they can relate to the provider (Smith et al., 2018). Studies have also established that patients associate active listening with empathy. Patients prefer empathetic providers who express interest in the patient's feelings, incorporate silence, and pause to attend to what the patient is saying (Matusitz & Spear, 2014). Aside from listening, patients judge the quality of provider communication by nonverbal cues that express interest and engagement (Jahromi et al., 2016).

Nonverbal Communication. Nonverbal communication is deemed the most influential factor in communication between interactants (Pawlikowska et al., 2012). The demonstration of facial expressions, head nodding, body position, and posture conveys interest, caring, reassurance, and support (Berman & Chutka, 2016). For instance, Larson and Smith (1981)

found that forward body position and attentive body orientation were associated with higher patient satisfaction. Other non-verbal communication qualities associated with positive patient experiences include neat appearance, body language, eye contact, posture, and tone of voice (Khan et al., 2014).

Another aspect of nonverbal communication vital to adherence management is emotion regulation. Experiencing, processing, and modulating emotional responses is necessary to manage emotional stressors common among patients living with chronic disease (Wierenga et al., 2017). While providers listen to patient situations and stressors, they must regulate how they respond to the information so that patients/caregivers will continue to fill at ease to disclose personal information and so that providers can help patients/caregivers to navigate through emotional stressors. Reframing and modifying perceptions about situations allows patients to adjust their frame of mind so as not to affect their social, psychological, physical, or spiritual state (Graffigna et al., 2017).

Power Sharing in the Patient/Caregiver-Provider Interaction. In the context of patient/caregiver-provider relationships, productive communication is patient-centered in a way that legitimizes the thoughts, beliefs, and experiences of the patient/caregiver (Newell & Jordan, 2015) Vogel et al. (2018) describe two provider interaction styles: provider dominant/active and affiliative. Some providers direct their communication behaviors toward maintaining control and the hegemonic power of being the expert in which they reprimand patients, which reduces disclosure and compliance (Schachner et al., 2021). Other providers use an affiliation interaction style that allows the patient to share power in the dyadic interaction to establish and maintain a positive and therapeutic relationship with the patient (Vogel, D. et al., 2018). Vogel et al. (2018)

found that affiliative interaction styles of communication reduced patient anxiety and promoted openness for disclosure for productive treatment management.

The patient's and caregiver's perception and satisfaction with the interpersonal skills of the provider largely determine whether a therapeutic alliance is formed to achieve optimum health outcomes (Dang et al., 2013). To help patients, caregivers, and clinicians achieve patient-identified treatment outcomes, more must be understood about the patient/caregiver experience and their documented expectations and preferences for provider communication (Berkowitz, 2016). Patients, families, and caregivers prefer friendly provider interaction styles that seek the patient's point of view. The provider interaction style enables patients to disclose pertinent information to providers and to adhere to prescribed treatments (Larson et al., 2017).

Adherence Dialogue between HIV Patients, Caregivers, and Providers

Communication between patient and provider is positively linked to medication self-efficacy. Unfortunately, these conversations rarely occur as both patients and providers fear adverse reactions from the other. Overall, the literature has established that HIV-positive patients prefer collaborative communication in which they feel their story has been heard (Peyre et al., 2016). HIV-positive patients prefer nonjudgmental communication without homophobia or stereotyping (Hurley, Emily A et al., 2017). The provider's capacity to elicit interactive communication through listening and engagement initiates a partnership of empathy and mutual respect from the initial visit (Peyre et al., 2016). Clinical communication can become a positive opportunity for patients to partake in ART education, medication management, problem-solving, and resource mapping for social support. The directive, judgmental communication that attributes nonadherence to the patient's fault without exception results in poor patient satisfaction and poor health outcomes (Peyre et al., 2016).

Providers treating the HIV-positive population, more specifically, concern themselves with whether the patient is ready to take the medication before the regimen begins (Azhar et al., 2020). HIV-specialists have reported discussing a range of possible antiretroviral medications available to the patient, the dosing requirements, and some education about the concept of viral resistance and its relationship to adherence before writing prescriptions (Callon et al., 2016). Some providers explained that they had to feel satisfied that the patient grasped the need for the medication before they prescribed it. Prescribers identified this disease knowledge as the patient's HIV IQ. Once providers are satisfied with the patient's readiness and capacity to adhere, some have gone as far as to sit down with patients/caregivers to write down a medication schedule based on their regular daily routine. Other providers described going a step further to have the patient/caregiver bring in all of their medicines before they began the pills so that the patient/caregiver could look at the medication labels together and write additional instructions (Callon et al., 2016).

During the second phase of adherence communication, HIV physicians explained that communication continues after the patient begins medicinal therapy. Providers performed routine check-in assessments with patients/caregivers to determine whether they were successfully adhering to the medication and used different approaches to inquire about medication-taking behaviors. For example, one physician asked general questions to assess adherence: "How are you doing with your medications?" . . . "how are you taking them?" . . . "are you having trouble taking them?" The questions might also be specific. A provider shared that he asked the patient about drug use or how often they missed doses (Roberts & Volberding, 1999).

Roberts & Volberding (1999) explained that providers used the information from the questions to troubleshoot problems with non-adherence. Providers asked questions to learn what

was causing them to fail at taking their medicines in the patient's life situations. Once the physician identifies the problem, they develop strategies for overcoming life barriers. Whether the patient was missing doses due to forgetfulness, medication costs, failure to pick up medicines at the pharmacy, or issues with medication beliefs, the provider expected to address the problem and move forward. For example, providers suggested using timers and phone apps and even worked with patients to reschedule dosing around their work schedule to optimize adherence results. In the process, these providers modeled effective problem-solving techniques to the patient.

Although medication nonadherence is a common practice among chronically ill patients, they rarely discuss this problem with providers during routine visits (Smithson et al., 2012). Additionally, providers avoid discussions about adherence and do not assess patients' experiences with the medication (Phillips et al., 2012). In HIV care, Weiser (2014) discovered that while 95% of HIV providers discussed adherence, only 60% provided information about tools to increase adherence, and only 54% of providers referred nonadherent patients to adherence support services.

Intentional vs. Unintentional Nonadherence

When addressing medication-taking behaviors, it is critical to understand whether the patient has intentional or unintentional non-adherence behaviors. Intentional non-adherence is deliberate and primarily associated with patient beliefs and motivation. Unintentional non-adherence is based more on the patient's inability to execute medical instructions (Molloy et al., 2014). Identifying the type of nonadherence helps clinicians design interventions most specific to the patient's needs.

Intentional Nonadherence. The intentionally non-adherent patient includes a person weighing the benefits and risks of treatment. Beliefs and perceptions about the seriousness of the illness, the perception of treatment efficacy and necessity, and the potential harm of taking medications underpin the rationale for intentional nonadherence (Weiss et al., 2016). The patient, at this point, considers the risk of adverse effects from treatment against potential health risks incurred without treatment (Hugtenburg, 2013). Intentional non-adherence is often related to un-mastered self-management skills, such as the inability to recognize and manage symptoms (Hugtenburg et al., 2013). Others fail because of their experience with medication side effects. Other patients view their illness as episodic and only take medicines when symptoms are present or stop taking medication because they feel better (Bae et al., 2016). Another commonly reported reason for missing ART doses was that the patient felt sick or ill from medication side effects and consequently felt the drug was toxic or harmful (Kalichman et al., 2021). Intentional nonadherence requires discussion between the provider and patient to determine how treatment can be redesigned to the autonomous patient's needs and preferences (Hugtenburg et al., 2013).

Unintentional Nonadherence. Unintentional nonadherence refers to unexpected behavior, such as forgetting or not understanding exactly how to take medicine (Hugtenburg et al., 2013). This nonadherence stems from the patient's inability to read or comprehend instructions or can be as unintentional as forgetting (Boretzki et al., 2017). Building the patient's capacity through interventions that increase health literacy, patient problem-solving, and decision-making are interventions that have successfully modified unintentional medication-taking behaviors. Self-management exercises that empower the patient to better fulfill treatment demands through improved coping and symptom recognition, for example, are interventions that will enhance unintentional non-adherence (Boretzki et al., 2017). Other interventions designed to

67

treat unintentional non-adherence are pharmacy texts, pill organizers, or technical reminders that help patients remember to take their medicines and better follow medical instructions (Hugtenburg et al., 2013).

Roberts and Mann (2003) conducted a qualitative study to understand better how patients conceptualized the differences between intentional and unintentional adherence using semi-structured interviews, narratives, and personal diaries. Roberts and Mann (2003) showed that each person's decision to adhere or not adhere is rational rather than irrational. Decisions were influenced by careful consideration of potential social consequences and implications for life values. The researchers also learned that these decisions were temporal and rarely final. Internal negotiations and renegotiations to adhere to were influenced by life activities and circumstances, including but not limited to spiritual or religious beliefs, physical health status, social relationships, and patient-provider communication. This study's findings captured the personalized decision-making process in the medication-taking (Johnston Roberts & Mann, 2003).

Theoretical Frameworks

Theories provide a framework for understanding the underlying mechanisms of health beliefs and behaviors. Since the most critical determinant of behaviors is beliefs, this understanding can inform health communication strategies providers use in clinical practice (Patrick & Williams, 2012). Parsimonious theories can identify and target critical mediators and moderators that create the most efficacious interventions for enhancing medication adherence among targeted populations and audiences. Additionally, theoretically guided interventions provide consistency and coherence to clinical guidelines and practices (Patrick & Williams, 2012).

Recent studies have used cognitive behavioral frameworks to explore disease prevention, health promotion, and health education (Farzadnia & Giles, 2015). Frameworks such as the health belief model, the social cognitive theory, and the theory of planned behavior have been used to explore medication-taking behaviors. Self-management theories in medication adherence include the common-sense model of self-regulation, the transtheoretical model of change, the self-determination theory, the social action theory, the health locus of control, and the patient activation model. The interpersonal dynamics of the patient-provider relationships are explored through the lenses of interpersonal communication theories: Habermas' theory of communicative action, the communication accommodation theory, and the goals-plans-action theory.

Social Cognitive Models (SCM). SCMs are theoretical frameworks for understanding health behaviors. They operate under a common assumption that attitudes and beliefs are significant motivations behind behavior. Many explain that health behavior is based on responses to health threats and that all decisions are based on expectancy beliefs and the subjective values placed on expected outcomes (Adefolalu, Adegoke O., 2018a)**. T**he limitation of these models is that they assume that health behaviors are based on logical rationale but in the case of medication-taking behaviors, that is not always the case. Medication-taking behaviors can be explained and predicted by social, cognitive, cultural, and behavioral determinants of the health (Scialli et al., 2021). This will become more evident when I discuss the common-sense model of self-regulation and its illness representations.

Health Belief Model (HBM). The HBM, one of the original theories in the field of public health, was introduced by Rosenstock (1974). The HBM hypothesizes that health behaviors depend mainly on an individual's wish to avoid illness and the belief that specific actions can prevent or alleviate health threats. The HBM has six tenets that influence health behaviors and

behavior outcomes. They include the following: perceived susceptibility, perceived severity, perceived benefits of interventions, perceived barriers or costs of interventions, cues to action, and self-efficacy to perform the behavior (Parvanta, 2011).

Scialli et al. (2021) argued that a person's decision to adhere to treatment is based on a cost-benefit analysis in which the person weighs the treatment's effectiveness against potential negative consequences of nonadherence, such as disruption of functioning or adverse side effects. Gao, Nao, Rosenbluth, Scott, and Woodward (2000), one of the first HBM investigations into ART adherence, investigated the relationship between disease severity, health beliefs, and medication adherence. The findings suggested that perceived susceptibility to illness and treatment barriers are significantly related to medication adherence. These findings were consistent with more recent studies that found people who believe in the efficacy of HIV treatment are more likely to adhere to the HIV treatment (Scialli et al., 2021). Once a patient's perceptions align with the realities of their condition, self-management can build coping and disease management skills (McCarley, 2009). Other HBM constructs such as self-efficacy and locus of control, also predict treatment adherence.

Social Cognitive Theory (SCT). The SCT translates health knowledge into health actions. The core determinants of SCT include the following components: understanding of health risks and benefits, perceived self-efficacy, outcome expectations that present costs or benefits depending on the behavior, the plans, and strategies used to realize health goals, perceived support systems, and obstacles (Bandura, 2004). Self-efficacy is a central concept of self-management as patients gain the confidence to manage their disease prognosis through appropriate health-promoting thoughts and behaviors.

Self-efficacy for treatment adherence has been identified as an essential correlate of medication adherence (Seyde Shahrbanoo et al., 2017; Turan et al., 2016)**. Consequently, self-efficacy is an essential construct in many health behavior theories**(Johnson et al., 2007; Michie et al., 2003; Swendeman et al., 2009)**.** Bandura (1994) defined "self-efficacy as a person's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives" (p.71). Bandura asserts, "Beliefs of personal efficacy affect health behavior both directly and by their impact on goals, outcome expectations, and perceived facilitators and impediments." (Bandura, pp145, 2004). Those with low self-efficacy are easily convinced of the futility of their effort in the face of difficulties.

Turan et al. (2016) describe self-efficacy as a modifiable interpersonal factor. Social experiences are the most effective way to create a strong sense of efficacy (Bandura, 2004). A resilient understanding of effectiveness comes from overcoming obstacles through perseverant efforts. Bandura (2004) explained that people with high efficacy expect to realize favorable outcomes. The second way to enforce self-beliefs about effectiveness is through the vicarious experiences of social models. In the case of HIV, a person who has achieved viral suppression through medication adherence would be a social model of self-efficacy. Social persuasion is the third way by which a provider can strengthen self-efficacy. Providers can mobilize and activate patients through education, skills-building, and social support (Archiopoli et al., 2016). And finally, the fourth way to modify self-efficacy is by reducing stress reactions, negative emotions, and misinterpretations about their life situation.

HIV Treatment Self-Efficacy. HIV treatment self-efficacy is defined as having confidence in one's ability to adhere to ART even in the presence of challenges such as side effects, daily schedules and time constraints, and other demands in life that conflict treatment

self-management (Adefolalu, Adegoke O, 2018b; Turan et al., 2016)The relationship between self-efficacy and better adherence outcomes has been established across multiple chronic diseases such as diabetes, hypertension, and HIV (Johnson et al., 2007). Psychosocial predictors of HIV treatment self-efficacy include lower depression, greater problem-solving skills, and effective coping skills (Archiopoli et al., 2016; Turan et al., 2016).

The Transtheoretical Model of Change (TTM). The TTM, also known as the Stages of Change Model (SOCM), is an integrative biopsychosocial model that conceptualizes the process of intentional behavior change (Prochaska & DiClemente, 1983). The five stages of change (SOC) include pre-contemplation (ambivalence), contemplation (recognition that change is needed), preparation (commitment to change), action (behavior modification), and maintenance (stable behavior change without relapse) (Arafat et al., 2019). A study about blood pressure management determined that SOC was a significant independent predictor of self-monitoring (Breaux-Shropshire et al., 2012). Genberg & Associates (2013) found that the stages of change can predict adherence rates among patients self-managing diabetes. Implications for this knowledge are that by identifying a patient's SOC, practitioners may be able to predict risks for medication nonadherence (Genberg et al., 2013).

The Common-Sense Model of Self-Regulation (CSM). Illness representations are illness experiences that shape motivations and decisions for a future action plan to achieve a health goal. Identifying deviations from normal functioning physical and somatic self is fundamental in the self-regulatory processes in which people must make decisions and take actions to restore or protect their state of health (Hagger et al., 2017). The model explains how patients cope with somatic sensations that deviate from "normal" function and how interaction with environmental cues such as observation, discussions of illness with others, and health

communication campaigns influence coping strategies such as medication adherence (Leventhal et al., 2016). Leventhal et al. (1980) developed the CSM to understand lay-person perceptions of illness threats and how those perceptions guide strategies to cope with illness. The team produced a psychometric instrument from qualitative and scaling studies called the illness perception questionnaire (IPQ) (Weinman et al., 1996).

The CSM was initially compromised by five dimensions of the cognitive representation of illness: identity, timeline, cause, consequences, and perceived control. The essence of the disease is identified through its symptoms and label. The timeline reflects the condition's onset, duration, and fluctuation rate. The cause represents causal antecedents of the disease, such as genetics, infection, aging, or other exacerbating factors. The consequences reflect beliefs about how the illness will impact life events such as work-life, family, and personal relationships. And finally, illness experiences determine how a patient's perceived control—whether the illness has been responsive to treatment defines perceived control (Hagger et al., 2017). Later, the sixth dimension, illness coherence which represents the patient's comprehension of the illness, was added to the IPQ-R (Moss-Morris et al., 2002). Relative to this study, this representation is influenced by interaction, communication with health providers, and interpersonal factors such as personality and individual differences (Hagger et al., 2017). Interventions to align patients' illness/treatment beliefs with medical knowledge and provide patients with adaptive understanding to manage their health are becoming increasingly prevalent in (Phillips et al., 2012).

Self-Determination Theory (SDT). SDT (Patrick & Williams, 2012; Ryan & Deci, 2000) is a theory of human motivation emphasizing autonomous behaviors. The idea emerged in the 1970s and is key to understanding health behaviors related to self-management in chronic

disease. The framework suggests that motivation to perform healthy behaviors is enhanced when individuals perceive themselves as competent to perform the behavior and choose to do so of their own free will and volition (Ryan & Deci, 2000). Williams & colleagues (2004) describe autonomously regulated behavior as those the person feels they have the freedom to choose as opposed to behaviors they would do under pressure or coercion.

Health Locus of Control (HELOC). The HELOC is the degree to which people believe they have control over the outcome of an event in opposition to external forces beyond their control (Morowatisharifabad et al., 2010). The framework was developed by Julian Rotter (1966) and is rooted in personality psychology. Rotter argues that a person's "locus" is conceptualized as an internal force of control over one's own life. In contrast, the external locus believes life is controlled by fate and other outside forces (Rotter, 1966). People with a strong internal locus of control believe life events can be directed or redirected by their actions. People with a strong external locus of control believe that the outcomes of circumstances are under the control of external forces. External HELOC increases by age, and internal HELOC increases by education level. HELOC has core elements like constructs such as self-efficacy. It is much different as the theory concerns expectations about the future rather than the perceived ability to complete a task (Rotter, 1966).

Patient Activation Model (PAM). Recent research examines factors and interventions influencing patients' ability to self-manage and adhere to treatment. Patient activation is considered the most reliable indicator of a patient's ability to manage their health autonomously (Graffigna et al., 2017). Activated patients are more likely to trust clinicians and less likely to experience adverse clinical events and hospital readmissions. Furthermore, activating patients is a critical strategy in making healthcare more sustainable by reducing healthcare-related costs.

74

Also, activated patients are more likely to take preventive measures to safeguard their health (Graffigna et al., 2017).

Developed by Hibbard and colleagues (2004), patient activation is a concept that refers to the knowledge, skills, and confidence an individual has about making effective decisions to manage their health. Activation is developmental in nature and involves four stages: (1) believing the patient role is essential; (2) having the knowledge and confidence to take action; (3) taking action to maintain and improve one's health; and (4) staying the course even under stress (Hibbard et al., 2004). The patient's role in managing their health and healthcare is promoted as an essential factor in improving treatment adherence in the United States. The notion is a foundational principle in the widely adopted Chronic Care Model (Bodenheimer et al., 2002).

The Patient Health Engagement Model (PHEM). The Patient Health Engagement Model (PHEM) is also a critical factor in enhancing the quality of care for chronically ill patients. The PHEM might act as a mechanism to increase patient activation and adherence. Although the concepts of engagement and activation may overlap in meaning, Graffigna et al. (2017) explain that they differ in linked phenomena. Studies have also established that patient engagement develops because of the complex sense-making process related to the patient's health status and perceived role in their healthcare journey.

The PHEM outlines four evolving phases: blackout, arousal, adhesion, and eudaimonic project. The 'blackout' phase denotes the stage in the care process in which the patient is overwhelmed and shocked. During this phase, the patient may be passive and delegate all decisions to providers. In the 'arousal phase,' the patient has evolved. They become hypervigilant in monitoring signs and symptoms and become disorganized in their activation,

75

which is dysfunctional to the clinical relationship with their care provider. As the patient obtains mastery of their illness and becomes more aware of the importance of their role in care management, they enter the 'adhesion' phase. In this phase, patients have greater health literacy and can follow medical instructions. During the 'adhesion' phase, they are activated but not autonomous in self-management. In the final step, the eudemonic project state that the patient is fully engaged in independent self-management and can see themselves beyond their disease. This empowered stage includes their ability to frame self-management in a positive light as they have gained confidence in their ability to self-manage the disease (Graffigna et al., 2017).

Graffigna et al. (2017) confirmed the importance of allocating time and effort to promoting patients' ability to self-manage and effectively adhere to treatment. The healthcare provider's ability to legitimize the patient's proactive role in their health directly impacts their ability to successfully self-manage illness and adhere to prescribed medications in chronic disease management.

Habermas' Theory of Communicative Action (HTCA). Habermas' theory of Communicative Action explains interpersonal communication between patient and provider. This theory posits a dialectical struggle between the voice of medicine and the voice of the real world (Haberman, 1984) (Barry et al., 2001). The voice of the lifeworld refers to the patient's contextually grounded experiences of events and problems in life. Depending on the patient's history and position in the world, the timing and significance of events shape the individual's experiences.

In contrast, the voice of medicine reflects a technical interest and expresses a "scientific attitude." The voice of medicine acts according to abstract rules that decontextualize events, removing them from personal and social contexts (Mishler, 1984, p.104). The HTCA brings into

perspective the importance of worldviews when communicating. This understanding can reduce discordant unproductive interactions (Bezreh et al., 2012).

The HTCA makes the distinction between strategic communication and communicative action. Strategic communication achieves the goals of actors but is not free of coercion. Contrarily, communicative action is free of pressure and merits cooperative behavior (Bezreh et al., 2012). The provider represents "the system," and the patient describes the lived world or "lifeworld." Communicating with these perspectives has great implications for patient/caregiver-provider interactions in chronic care and HIV intervention development in health science research. To provide prevention interventions for HIV-positive youth in Bali, a study addressed the mismatch between the "systemworld" and the "lifeworld" to reflect the identity, language, and interaction style of participants (Lubis et al., 2021).

Communication Accommodation Theory (CAT). Since its inception in the 1970s, the CAT has been a framework for understanding how speakers adjust their language to accommodate each other during interpersonal interactions. CAT focuses on how, when, and why speakers attune their messages to match their conversation partners. Thakerar, Giles, and Cheshire (1982) defined psychological accommodation as "individuals' beliefs that they are integrating with and differentiating from others, respectively, while objective linguistic convergency and divergence can be defined as individuals' speech shifts towards and away from others, respectively" (p. 222). Accommodative strategies such as convergence adapt communicative behaviors such as accent, speech rate, smiling, gazing, pauses, and utterances (Farzadnia & Giles, 2015). CAT contends that communicators accommodate those they admire, respect, and trust, and in this way, communicative differences are attenuated.

Pines et al. (2021) used the CAT to create communication interventions for HCPs dealing with verbal aggression from patients. The CAT intervention addressed group-level interactions and adjustments. The study found that there are robust associations between accommodative behaviors and positive health outcomes (self-efficacy, life satisfaction, and mental health), quality of HCP interaction (adherence, communication satisfaction, and persuasiveness), and relational solidarity (relationship satisfaction, trust, and intimacy) (Pines et al., 2021).

Research Questions

Research questions for this exploratory study reflect "a problem-centered perspective of those experiencing a phenomenon and is sufficiently broad enough to allow for the flexible nature of the research methods" (Birks & Mills, 2015, p. 21). Given the gaps in knowledge and research, this health communication project will examine the following questions as part of a conceptual network of inquiry:

RQ1: How do HIV patients and FFCs define and understand the concept of adherence?

RQ2: How do patients and FFCs conceptualize the HIV disease process and treatment?

RQ3: What aspects of the medical world do HIV patients and FFCs identify as supportive and central to begin, adhere to, and persist in treatment?

RQ4: What elements of the lifeworld day-to-day lived experiences do HIV patients and FFCs identify as substantial determinants of the beginning, adhering, and persisting in treatment?

RQ5: How are FFCs describing their role in treatment?

Since there is limited research on HIV adherence communication from the patient and informal caregiver perspectives, I approach this project as a behavioral phenomenon with many layers of complexity. An exploratory approach allows the researcher to treat this subject as a complex socio-behavioral phenomenon and explore the topic from the participants' worldview to

identify and examine relationship variables. This strategy permits me to choose " 'what works' within the precepts of research to investigate, explore, describe, and understand the phenomenon" (p.70) (Williams, 2007).

Constructivist research and grounded theory assume that people can have varying motivations and challenges for adhering to treatment. This motivation can be influenced by the person's environment- family, friends, caregiver, or providers. While my aim is not to develop to test a theory, it is to generate knowledge that can be applied to such an endeavor in the future. Findings will provide new knowledge about why PLWHV adhere to medicines, why they persist in treatment and the processes in between. The knowledge acquired from this study has implications for health communication praxis regarding the partnerships between patients, caregivers, and providers in chronic condition management.

Summary

Health communication strategies for the HIV-patient/caregiver/provider partnerships are needed to deliver quality healthcare to people with chronic conditions. Today, six in ten Americans will live with a chronic disease which requires patients, caregivers, and providers to effectively communicate about self-care and medication adherence as prescription drug therapy is the mainstay treatment for most chronic conditions (CDC, 2020; Scott & McClure, 2010). While randomized clinical trials may prove drug efficacy, they are not designed to explain or predict the personal, individualized process of patients adhering to medications in real-world environments and uncontrolled settings. Adherence communication research has many implications for medicine. Adherence communication between patients, caregivers, and providers could reveal ways to improve symptoms, medication-taking, and lifestyle

management. Significant outcomes such as mortality, hospitalization, and quality of life could be

improved for people living with HIV.

Chapter III:

Research Perspective

The research design collectively guides the components of shared beliefs and agreements between researchers to consider how problems should be addressed and understood (Kuhn, 1962). In this design, I identify the paradigm by which I pursue this project.

There is an affinity between beliefs about what constitutes reality and the choices one makes about methods that will develop and advance knowledge about that reality (Crotty, 1998). Researchers cannot view methods in isolation from the researcher's e ontological position (Dainty, 2008). Ontology is the nature of reality and what constitutes that reality (Hudson & Ozanne, 1988). A positivist believes the world is external and that any research phenomenon has a single objective reality regardless of its worldview or perspective (Carson et al., 2001). In contrast to the positivist view, the constructivist paradigm assumes the multifariousness of reality (Carson et al., 2001). Guba & Lincoln (1988) argue that these multiple realities depend on systems of meanings and not fixed facts (Neuman, 2000). Constructivist knowledge is socially constructed and not objectively perceived or determined and relies on qualitative methodology to pursue the knowledge (Hirschman, 1986). The constructivist argues that perceptions and the consequent actions of those involved create social phenomena and that meaning is subjective and dynamic (Bryman, 2012). The constructivist paradigm also dictates that the researcher interacts with study participants. The researcher is not objective and co-constructs the meaning of social phenomena through her interpretation. The constructivist researcher brings her worldview and experience, as well as the worldview and understanding of the participants, to the research process.

Epistemology is concerned with the generation of knowledge. Based on their goals and their assumptions of reality, for instance, a positivist takes a generalizing approach to research as they apply their findings to large numbers of people or settings. On the other hand, a constructivist approach is more concerned with seeking more subjective knowledge such as motives, meanings, reasons, understandings, and context-bound experiences by providing a thick description of a phenomenon (Hudson & Ozanne, 2008). In the social sciences, a thick description is a term first introduced by anthropologist Clifford Geertz. It denotes an explanation beyond a physical account of behavior by adding a subjective context given by an actor of the social phenomenon (Geertz, 2005). The constructivist researcher 's use of qualitative methods emphasize action over doctrine, making it appropriate for developing new knowledge toward intervention creation (Hudson & Ozanne, 2008).

The research produced here should reflect the experiences of those who participated. The group examined here are members of vulnerable populations using abductive reasoning to pursue truth and knowledge. This research addresses a detrimental gap in healthcare science: the phenomenon influencing medicine adherence and nonadherence. The voices of those at the project's center should be the results' governor.

Participant Protections

The advancement of medical knowledge tells a long history of research scandals (Rajendran et al., 2019). Under the positivist paradigm, scientists operated objectively and distanced themselves from research participants (Townsend, Cox, & Li, 2010). This approach operated under the assumption that scientific advancement was more important than human life and dignity. As a result, healthcare professionals' gross abuses of power resulted in atrocities, such as The Tuskegee Syphilis Study (1932-1972)- a research project in which scientists

recruited 400 black men into a medical study under a deceptive guise (Jones, 1993; Townsend, Cox, & Li, 2010). Researchers misled volunteers to believe they were treating them when they were only observing the course of the disease. Even as a cure became available, medical professionals denied treatment to follow the disease's trajectory until the participants' untimely deaths (Jones, 1993). The scientists only sought to satisfy scientific curiosity and offered no goodwill to study participants.

Governing bodies also criticized studies from the social sciences. For example, in 1964, The Milgram Shock Experiment raised ethical questions about research methods that inflict emotional or psychological distress on participants. In 1970, the Tearoom Trade study underwent scrutiny because the investigator misrepresented his identity and the research purpose and infringed on research participants' privacy. Unethical research projects have used deceptive guises to elicit participation, collect data, deny participants informed consent, and violate the participants' privacy and confidentiality. Without ethical and moral governance, these studies' investigators caused undue psychological distress and harm to the participants without considering what was beneficial or harmful to the people.

In response to these ethical violations, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research issued the *Belmont Report* to protect human volunteers' civil rights in research in 1979 (Vanderpool, 1996). The *Report* established three basic ethical principles: respect for persons, which states that researchers must be truthful and conduct no deception-protecting the autonomy of all people and treating them with courtesy and respect and allowing for informed consent; beneficence, which promises to "do no harm" and to maximize the benefits of the research project while minimizing risk to human subjects; and justice which promises the fair distribution of costs and services to potential research

participants equally, ensuring that reasonable, non-exploitative and well-considered procedures are administered justly (Koski, 2017).

The Declaration of Helsinki was written to provide operational principles to govern and define rules for research ethics. Those principles are still relevant to the content of research proposals. The plan of a research study had to provide a thorough scientific background of the research topic to show the relevance of the inquiry. In applying a proposed research study, investigators carefully assess risks and benefits to participants to argue a reasonable likelihood of an advantage to the person or population of observation. In the study plan, investigators summarize their qualifications to ensure study participants are protected as well as the integrity of the science. Finally, the governing body's research plan is subject to ethical review (DePoy, 2016). This study was approved by the Institutional Review Board (IRB) at the University of Memphis.

My Role

As a licensed registered nurse and medical anthropologist, I am qualified to question medication nonadherence from a unique position as I am an actor in this social phenomenon. I listen to patients and physicians explain challenges with medication adherence every day. Also, I am often present in the space of clinical communication between patients and other clinicians to see the real-world truth of patient-provider communication. I have witnessed the gaps in care delivery that can be addressed with well-guided health communication interventions. And finally, as a scholar, I am familiar with the biomedical, social, and behavioral sciences. I conducted my graduate studies in medical anthropology on medication adherence among the HIV population in Memphis, Tennessee, which concluded that health communication could improve medication non-adherence. I learned from interviews with patients and providers that medication

nonadherence requires collaborative communication in which experts share power in medical conversations with laypersons to achieve health goals. And finally, I can triangulate my academic knowledge with what I experience on the nursing floor, giving me a unique perspective. The advantage of triangulating theoretical knowledge with real-world experiences as a registered nurse where I engage patients in conversations about medications, disease, side effects, and many other topics that impact the human experience. This purview allows me to look at nonadherence from many angles to understand this phenomenon better.

Method

The research community recognizes the limitations of quantitative research when examining human experiences (Lucas-Alfieri, 2015). Using qualitative methods helps ground knowledge in human experiences to allow novel information to emerge. Qualitative research is beneficial when the researcher wishes to address gaps in the literature about the phenomenon, aims to expand the breadth of inquiry, to provide a better understanding of the research problem through the exploration of novel or poorly understood constructs and variables (Hanson et al., 2005). Treatment nonadherence remains a stumbling block to medicine as optimum treatment outcomes depend on how drugs are prescribed and taken. In-depth insight into barriers to optimum adherence could be a significant finding for improving healthcare delivery and health outcomes among those who, like people living with HIV, are chronically ill. For these reasons, qualitative methods are appropriate for this study.

Semi-Structured Interviews. According to Lucas-Alfieri (2015), interviews are a qualitative method of collecting descriptive, non-numerical data such as observations of behaviors or personal accounts of experiences. Interviews have a long history in the disciplines of anthropology and sociology. Distinct theoretical approaches such as symbolic interactionism,

phenomenology, and social constructionism, among many others, guide the use of narrative query (Demuth & Mey, 2015; Maxwell & Reybold, 2015). While many qualitative methods exist, the researcher must assign the most appropriate approach to fulfill the study's purpose.

Semi-structured interviews have many benefits for creating units of meaning for analysis. According to Bernard (1988), semi-structured interviews boast many advantages. Semi-structured interviews are appropriate when the interviewer only has one session with the participant. Preceded by observation, informal, and unstructured interviewing, interview guides allow researchers to use productive probes for collecting relevant information. Secondly, semi-structured interviews enable the interviewer to manage narrative data reliably. Answers can then be examined and compared as units between participants. Thirdly and most importantly, the semi-structured interview allows each participant the freedom to voice issues that are most salient to their lived experience, as the interview questions may be limited in scope or tainted with the underlining bias of the researcher. Collectively, these qualities allow empirical truths to emerge from the data, which makes this method well-suited for this study (Bernard & Bernard, 2013).

The interview guide included three distinct sections. The first topic covered disease and treatment conceptualization. Next, the second section asked HIV self-management questions to understand how people experience and manage symptoms and medication-taking challenges. The third and final topic of the interview protocol asked people about their greatest struggle in HIV self-management. These open-ended questions allow the participant to give rich answers that include their experiences with illness, self-management, and the socio-cultural environment of these occurrences. As a part of the iterative process of grounded theory methodology, I

adapted questioning. I added probes as needed to elicit pertinent information or to further explore reoccurring concepts in participant narratives.

Grounded Theory Methodology. This qualitative study uses the constructivist grounded theory methodology. Grounded theory (GT) is an emergent approach that does not seek to test an existing framework. Instead, GT allows themes to emerge from the data. This technique keeps theories rooted in a phenomenon (Glaser, 1978; (Marshall & Rossman, 1999). Glaser's definition of grounded theory is a "general methodology of analysis linked with data collection that uses a systematically applied set of methods to generate an inductive theory about a substantive area" (Evans, 2013)(Glaser, 1992, p. 16).

Developed by two sociologists, Barney Glaser, and Anselm Strauss, GT combines sociology, positivism, and symbolic interactionism (Ralph et al., 2015). In contrast to other hypothetic-deductive approaches in scientific inquiry, GT uses inductive and deductive reasoning to develop theories by discovering a reoccurring emergence in the data (Charmaz, Kathy, 2008). GT is appropriate for examining the nuanced meanings of lived experiences told through narratives elicited by semi-structured interviews. Influenced mainly by symbolic interactionism through symbols, such as language, GT is a valuable tool for framing qualitative data.

Since the introduction of GT into the research community in the 1960s, different GT genres have evolved. To better describe how I used GT in this study, I will provide a brief history of the methodology's evolution. I will outline how GT has expanded into three distinct genres over the last several decades.

History. Glaser and Strauss are the founders of classic grounded theory. Strauss was conversant in symbolic interactionism and Glaser in descriptive statistics. They co-conducted a

study examining the terminally ill (Chun Tie, Birks, & Francis, 2019). Throughout their collaboration, they developed a constant comparative method to produce a dying theory, which Glaser & Strauss described in *Awareness of Dying* (1965) (Chun Tie et al., 2019; Ralph et al., 2015). Glaser and Strauss (1967) wrote the seminal work *The Discovery of Grounded Theory: Strategies for Qualitative Research*. In this book, they argued that researchers could generate theory from the qualitative data (Chun Tie et al., 2019). At the time, the research community recognized quantitative methodology as the golden standard for rigorous science, a novel ideology for theory development. Through their new methodological approach, Glaser and Strauss established that qualitative research could be scientific and stringent through constant comparative analysis (Ralph et al., 2015).

Genres of GT: Glaserian, Straussian, and Constructivist. Glaser and Strauss began to branch into their separate versions of GT. The two produced independent works. Glaser published *Theoretical Sensitivity* (1978) and Strauss *Qualitative Analysis for Social Scientists* (1987). From the original conception of GT, three philosophical genres evolved: Glaserian GT (Glaser, 1992); Straussian GT (Strauss, Corbin, and Clarke, 1990); and constructivist GT (Charmaz, 2006)(Birks & Mills, 2015; Chun Tie et al., 2019). Ralph et al. (2015) argue that GT is a methodology of generations.

Glaserian. The first generation of GT, or Glaserian GT, proclaimed a realist ontological assumption that a single truth existed in the data and a positivist epistemological belief that knowledge emerges directly from the data (Glaser, 1992; Ralph et al., 2015). Glaser argued that classic GT's goal is to generate a conceptual theory that examines relevant or problematic behavior patterns for those involved in (Chun Tie et al., 2019). Glaser (1992: p.2) argued that

grounded theory's strategy is to interpret meaning in social interaction by examining "the interrelationship between meaning in the perception of the subjects and their actions."

Straussian. The second generation of GT, Straussian GT, was born when Strauss & Corbin coauthored *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* (Ralph et al., 2015)*.* Straussian GT took an interpretive epistemological claim that must include "the perspectives and voices of the people being studied" while also maintaining a realist ontological assumption by recognizing the threat of researcher bias and the consequent concern of maintaining objectivity (Strauss & Corbin, 1994, p.279; (Birks & Mills, 2015; Chun Tie et al., 2019). Weed (2009, 2010, 2017) explains that this realist perspective on objectivity underpins the differences between Glaserian and Straussian GT, which classifies the latter as a post-positivist approach to the Glaserian version of the theory (Layder 1993; Charmaz, 1995; Weed 2009, 2010, 2017). The third genre of GT, the constructivist-interpretive GT, rejected the notion of objectivity. Charmaz argued that constructivist assumptions were most appropriate for the grounded theory methodology (Weed, 2017).

Constructivist. In contrast to the first two generations of GT, constructivist GT rejects objective science in favor of constructive knowledge created by interpreting behaviors and actions (Weed, 2017; Charmaz, 1995). Founded by Charmaz (2000), constructivist GT is an interactive research practice in which the researcher does not remain objective or detached from research participants (Ralph et al., 2015). Charmaz (2006) established that the constructivist researcher interacts with participants and co-creates meaning about the reality they understand (Singh, S. & Estefan, 2018).

Charmaz's approach considers the personal and professional experiences of the researcher as well as their knowledge of existing literature (Charmaz, 2006). Charmaz (2014) argues that

this co-constructed meaning of social phenomena is necessary to challenge established viewpoints or to aid in a new understanding of a phenomenon. Charmaz (2014) suggested a holistic examination of people from their socially-constructed perspectives on the researched topic (Singh, S. & Estefan, 2018). Furthermore, Charmaz (2014) acknowledges the possibility of bias as the researcher's knowledge and expertise undoubtedly co-create meaning in interpreting the data.

While I agree with Birks and Mills (2015) that a non-partisan approach to GT is sometimes needed to maintain the core elements of the GT process, I adopted the constructivist approach to the GT methodology. I choose this GT variant because the knowledge I seek is subjective. I have conducted multiple literature reviews on adherence and have experience researching and treating the HIV-positive population. Also, the constructivist approach is appropriate as I am a researcher who advocates for this population; I am not objective about the phenomena or the participants I study. So, in that respect, my approach is constructivist as I am co-creating the nuanced meanings of ideas, concepts, and themes.

Surveys. I selected very brief qualitative surveys to gain additional in-depth information about people's underlying communication in the context of serious illness. These survey tools (one for patients, one for caregivers) may offer a deeper understanding of the conceptual network of questions explored in this study. The qualitative surveys do not aim to establish frequencies or other patterns but to reach a depth of understanding.

Family Caregiver Communication Tool Survey. The 10-item FCCT (see Appendix H) is a valid and reliable instrument (Cronbach's alpha of 0.80 and 0.67) used to collect data about family/friend caregiver communication patterns relative to the participant's illness, values, and beliefs. The FCCT is a "partial credit" Rasch model. The Likert-type scale has selections that

range from frequently to never for probes such as "My family talks about what might happen if treatment doesn't work." The FCCT provides a score interpretation of specific caregiver types based on each subscale (conformity and conversation), using 0-11 as low and 12-20 as high. Scoring instructions for the FCCT include 1. adding items 1-5 to calculate the conversation score and 2. Add items 6-10 to calculate the score for conformity. To interpret the FCCT score and determine caregiver type, use the median score as the cut-off point between the two subscales (0-11 low; 12-20 is high) and interpret the score. Scores categorize caregivers into four types: Lone Caregiver (Conversation low, Conformity low); Carrier Caregiver (Conversation low, conformity high); Partner Caregiver (Conversation high, Conformity low-; Conversation high), Conformity high- Manager Caregiver.

Identifying caregiver types allows providers to tailor communication to the primary caregiver's needs. Other studies have used the tool to assess the patient/caregiver's family environment for problematic communication, poor familial support, and risk factors associated with caregiver strain and burden (Wittenberg et al., 2017). For this study, data collected with this tool explores caregiver communication and its influence on participants' treatment-related behaviors such as medication-taking and treatment adherence.

The Family Caregiver Activation in Transitions Tool. The Family Caregiver Activation in Transitions Tool (see Appendix G) is a 10-item validated tool (person-separation reliability of 0.84) used to measure family/friend caregiver self-efficacy before, during, and after hospital discharge. The FCAT is a six-point Likert-type scale that offers answers ranging from strongly disagree to strongly agree for probes such as "I maintain an accurate list of my loved one's medication." Data collected with the FCAT can assess family/friend caregiver preparedness and

confidence to support adherence-related behaviors among loved ones living with HIV after hospital discharge.

The tool was developed with direct input from family caregivers and is relevant to their experiences. According to Coleman, Ground, & Maul (2015), five family/friend caregiver tenets were used to design questions in the scale: (1) FFCs' contributions to the care of their loved one is often dynamic, (2) FFCs may have different goals from those of the patient, (3) FFCs feel unprepared for post-discharge medication management, (4) FFCs need encouragement to assert an identity, and (5) FFCs often assume the responsibility for organizing post-hospital care plan tasks. Data from the measurement can be used to explore patient and family caregiver needs during transitions in care. Healthcare professionals can use this information to tailor communication to FFCs' needs.

Research Design

Participants. Participants for this study were recruited using the purposeful sampling method. According to Palinkas et al. (2015), "purposeful sampling is widely used in qualitative research for the identification and selection of information-rich cases related to the phenomenon of interest" (p. 2). This sampling method includes identifying and selecting individuals or groups of individuals that are willing and available but also knowledgeable about the experience of the phenomena (Palinkas et al., 2015). Sampling methods maximize efficiency and validity (Morse & Niehaus, 2009). Inclusion criteria involved persons who are HIV-positive and persons who identify as caregivers of an HIV-positive person who are 18 years of age and older.

Setting. Currently, the latest numbers from the CDC reveal that Memphis is eighth in the country regarding new HIV transmissions (Tennessee Department of Health [TDOH], 2019). Also, TDOH (2019) statistics show that per 100,000 people in Memphis and Shelby County, 690

are living with HIV. These figures are alarming compared to the nationwide statistic of 280 per 100,000. In 2017, most of those diagnosed were between the ages of 15-34, African American gay males (TDOH, 2019). Legislators, activists, and public health officials have vowed to reduce new infections through treatment and prevention to address this sobering public health issue. These stakeholders acknowledge that socio-political issues such as outdated policies and regulations, poor access to healthcare resources, and poorly supported programs are structural barriers that contribute to the high infection rates in the South (Reif et al., 2017).

Structural barriers undermine disease prevention and treatment success. Racism, homophobia, and HIV-related stigma are present barriers to treatment adherence among PLWHA (Garcia et al., 2016). Add to these structural barriers, other social determinants of health, such as poverty, low health literacy, and low educational attainment and people become more susceptible to diseases like HIV through their environment (Reif et al., 2017). Inequitable resources such as housing, employment, education, and healthcare among minorities make this population more vulnerable to infectious diseases. Public health officials must optimize treatment adherence among those infected to decrease new infections. In response to this challenge, the research facility provides supportive services to PLWHA. I will not disclose the name or address of the site to ensure that I protect the identity of the research participants.

All participants were recruited from downtown Memphis, Tn. The facility is one of the oldest and most comprehensive AIDS support organizations in the southern United States, servicing eight nearby counties in Tennessee, Arkansas, and Mississippi (Friends for Life, 2019). The FFLF (2019) focuses all its services on achieving four goals (1) helping people living with HIV/AIDS to become and remain medically adherent; (2) reducing and preventing homelessness among people living with HIV/AIDS; (3) reducing HIV/AIDS infections through a wide variety

of prevention tools; (4) and offering education about HIV to reduce HIV stigma in the Mid-South. These services are only available to people who have tested positive for HIV.

Many of these PLWH deal with social disadvantages such as homelessness, poverty, low educational attainment, poor health, and social stigma not only for having HIV but also for being black, gay, or transgender in an ultra-religious southern community such as Memphis, TN (Reif et al., 2017). These clients also deal with multiple health comorbidities (type 2 diabetes, heart disease, COPD, hypertension, mental illness, and substance abuse), which increase their disease burden. To give this population an equal opportunity for health, the facility offers holistic, supportive services to address the needs of patients and provides a safe zone for HIV-positive community members. The center offers social services to give this population access to resources they would otherwise not have. The center is open Monday through Friday from 8:30 am to 4:00 pm and offers everything from free coffee and donuts to movie viewings. For many patients, this center is a home that provides a space of belonging. Educational programming, medical case management, and in-house pharmacist and nutritionist are also available. The center facilitates many health-promoting workshops for clients daily. Topics such as clinical navigation, disclosure (regarding serostatus), self-protective behaviors, social stigma, family communication, and emotional coping provide clients with skills that support adherence to treatment.

Using an integrative healthcare model, the facility addresses a myriad of psychosocial issues. It provides psychotherapy through group therapy sessions and individual counseling to help patients cope with past traumas, abuse/neglect, substance abuse, and social stigma. The center employs peer mentors who are caseworkers who are also HIV-positive. Peer mentors have achieved the treatment objective of viral suppression through treatment adherence and show others how to navigate the experience of living with HIV successfully. These mentors

accompany new clients to medical visits and help them to set up social systems that support

medication adherence. These peer mentors understand the context of the HIV-real world

experience. They can speak (with nuanced, context-specific meaning) to those who are newly

diagnosed and grappling with the challenges of managing a chronic disease. The program's main

aim is to prevent the spread of HIV/AIDS by preventing new infections and helping those in

treatment achieve viral suppression.

Recruitment. I obtained a letter of support from the facility to submit to the Institutional

Review Board (IRB) application necessary to research human participants. Immediately after

IRB approval, I began recruitment. To establish a familiar face in the setting, I provided a health

literacy course to clients about medication management as a health communication doctoral

candidate and a licensed nurse. This workshop was conducted weekly over four weeks at the

center in October 2018. The workshop encouraged PLWH to participate in clinical

communication and treatment planning actively. Clients discussed medication beliefs, symptom

management, and stigma during the seminar. Flyers for the current study were distributed after

each workshop (see Appendix I). I used that flyer as a script for face-to-face discussions with

prospective participants (see Appendix J). Those interested added their name to a list so they

could be contacted later for participation.

Data Collection Procedures

Data was collected in the spring of 2019 for 12 weeks at the facility in Memphis, Tn. Due

to the threat of HIV-related stigma, I took measures to protect the participant's identity. Each

participant was interviewed individually in a small room at the facility with a closed door. I

requested a waiver of informed consent, as participant signatures would be their only linkage to

this study. Instead of written informed consent, I reviewed an informational study sheet (see

Appendix A) with each participant to be sure to answer participants' questions about the study. Participants understood and agreed to be audio-recorded. Following the study information sheet review, I completed the demographic sheet with participants (see Appendix B). I performed semi-structured interviews first (Appendix C [patients] and Appendix D [caregivers]). Then I collected the FCCT (see Appendix H) and the FCAT (see Appendix G) from patient/caregiver and caregiver participants. Some participants required that I read the options aloud to them. After completing the demographic sheet and survey items, I conducted semi-structured interviews with all participants. I labeled each participant's demographic worksheet, the interview guide, and the surveys with an anonymous matching number. All data were de-identified to protect the identity of the participants. I recorded interviews on my iPhone via the SuperNote application and later transcribed the data using temi.com. I made simple notations on the interview guide during the interview as well. I collected data alone, with only the participant present in a private room with the door closed.

I told participants they ended participation at any point and did not have to disclose information they did not wish to share. Data collection sessions ranged from 45-60 minutes. Transcriptions resulted in 222 single-spaced pages of data. At the end of each session, I gave each participant a $10.00 Kroger gift card and thanked them for contributing to the study.

Demographic Characteristics. The demographic questionnaire (see Appendix B) gathered information about treatment status, how many years the participant or loved one had been in treatment, viral suppression, age, gender identity, race/ethnicity, primary language, living situations, education, marital status, employment, income, and whether the patient/caregiver had a primary care doctor. For informal caregivers, the additional "relationship to the patient"

question was a part of the demographic survey. I read survey questions out loud for participants and checked for understanding before they selected answers for each item.

Semi-Structured Interview Protocols. Participants completed a semi-structured interview. I used interview protocols to collect narratives from the patient (see Appendix C). Because medication adherence is a direct problem of the patient, I used more additional probing in these interviews compared to the informal caregiver interviews.

Informal caregiver participants completed the informal caregiver semi-structured interview protocol (see Appendix D). This protocol was like the patient interview protocol, except the caregivers, answered questions about their loved ones' perceptions of illness and treatment. The interview guides, additional probing, and the interviewer were the instrumentation used to collect narrative data.

Survey Measures. For the brief survey portion of the study, I collected pen/paper surveys from caregiver participants to explore variables related to caregiving in HIV treatment. I used the Family Caregiver Communication Tool (FCCT). The Family Caregiver Activation in Transitions Tool (FCAT) surveys to explore activation in transitions (the process of being discharged from the hospital and taking over care management as a caregiver) and family communication patterns among HIV-positive patients' caregivers (a tool used to assess the communication needs of informal caregivers). Although these tools are validated, statistical power is not the focus of this study. Tools are exclusively used to identify caregiver communication needs and informal caregiver influence on treatment-related behaviors.

Data Analysis

I began the data analysis with the transcription of audio-recorded interviews. Basing my research on the Temi transcripts, I first cross-checked drafts for quality transcription with the

97

audio recordings, at which point I identified inaccuracies and adjusted text for accuracy. Once the transcribed audio files were cleaned using this process, I began the first phase of analysis.

Open Coding. In her seminal book *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*, Charmaz (2006) explains that coding in GT is used to identify concepts, ideas, and constructs in the data. In the initial coding phase of GT analysis, images or codes are assigned to every unit of study: word by word, line by line, and incident by incident. Coding in GT consists of picking up general terms from interviews, such as symptoms or knowledge, to examine the participants' nuanced meanings of action. Initially, I performed holistic coding as a "grand tour" overview. In the process of comprehensive coding, I employed In Vivo software to attune myself to participant language, perspectives, and worldviews (Saldana, 2011; Saldaña, 2015). I coded interviews to facilitate the iterative process for which GT is known before going into the second coding cycle.

Axial Coding. The second phase of analysis, axial coding, exists to relate categories and subcategories and subcategories (Strauss, 1987). According to Strauss (1987), axial coding builds a rich illustration of relationships around the "axis of a category." This level of analysis gives new meaning to the initial coding to add coherence to emerging codes (Charmaz, K., 2006). Glaser (1992) describes axial coding as the thread that "weaves the fractured story back together" as they are integrative in the function (Glaser, 1978). The following analysis phase moves the analytic results in a theoretical direction (Charmaz, K., 2006).

Selective Coding. In the third primary phase of coding, codes are more directed, selective, and conceptual than the first phase codes (Glaser, 1978). Focused coding requires the researcher to decide which initial codes make the most logical sense for categorizing the data (Charmaz, K., 2006). During this phase of coding, the most salient reoccurring themes in the data

become categories and subcategories. Constant comparative methods organized these meaning segments to highlight analytic distinctions from one incident to the next (Glaser & Strauss, 1967). I sorted reoccurring concepts into distinct classifications.

      Theoretical Coding. The final phase is the theoretical coding (Glaser, 1978). To Glaser (1978:72), theoretical codes conceptualize "how the substantive codes may integrate hypotheses into a theory." Glaser (1978) argued that hypothetical coding families such as structural units, for example, provide an analytical edge to an analysis by examining subcategories such as family, organizational, role, societal, status, etc. This kind of analysis offers an understanding beyond preconceptions and misconceptions to deliver objective and subjective insights into the phenomena under examination (Charmaz, 2009). This analytic technique provides a deeper understanding of action to the actors and the observers, which is needed to advance adherence knowledge to improve health outcomes for the chronically ill.

Trustworthiness

      The trustworthiness and validity of qualitative research depend on how the investigator conducts the research process. Qualitative researchers have widely used rigor criteria to establish reliability. The survey tools used in this project are validated, so the primary purpose of this section will be to discuss the trustworthiness of qualitative research. To establish scientific rigor in qualitative research, four dimensions of trustworthiness must be met: creditability, transferability, dependability, and confirmability (Lincoln & Guba, 1985).

      According to Merriam (1985), creditability is the qualitative equivalent concept of internal validity. Creditability ensures that constructs are consistent with participants' thoughts and ideas (Shenton, 2004). Lincoln & Guba (1988) argued that ensuring creditability is one of the most critical factors in achieving trustworthiness in qualitative research.

I addressed confirmability in the study. For instance, to evaluate whether or not the concepts and ideas of this research were explained and illustrated accurately, I involved the assistance of an HIV-positive case manager at the facility to ensure that operational measures, concepts, codes, and themes were correct and valid according to the everyday experience of those being investigated (Shenton, 2004). Also, I used In vivo coding for many of the codes and themes to keep operational terms grounded in the data. In vivo coding, also known as verbatim coding, is a form of qualitative data analysis in which the researcher emphasizes the actual spoken words of the participant's (Manning, 2017). For example, one concept was consistent across multiple interviews: "just take the medicine." This code became a category in the analysis process. These tasks ensured the internal validity, or confirmability, of this study.

Transferability is a means to establish external validity or generalizability in a qualitative study (Shenton, 2004). External validity concerns "the extent to which the finding of one study can be applied to another situation" (Merriam, 1998). While naturalistic researchers argue that conventional generalizability is never possible when comparing research that is subjective and context-specific (Erlandson et al., 1993), others suggest that it is the responsibility of the investigator to provide sufficient contextual information to allow readers to make their inferences (Shenton, 2004; Lincoln & Guba, 1985).

Transferability also pertains to how closely the findings correlate with other documented experiences of people across multiple settings. This representativeness illustrates how critical comparative analysis is in establishing rigor in the qualitative research (Nowell et al., 2017). I performed three tasks to meet the transferability criteria: I used constant comparative analysis within the research sample to compare experiences and concepts between participants; I met with peer mentors at the facility to fact-check and made sure that codes, themes, and categories were

credible, transferable, and dependable; and I provided a detailed section about the research setting and the research sample so that readers can determine whether or not findings from my research are transferable to other research settings and populations.

The following criteria for trustworthiness, and dependability, are met by ensuring that the research process is "logical, traceable, and documented" (Nowell et al., 2017). Koch (1994) states that audit trails provide readers with the rationale behind each decision regarding the research paradigm and design (Nowell et al., 2017). A study that meets the rigor criteria of dependability determines that a researcher with the same data, approach, and situation would arrive at a similar or comparable conclusion, not contradictory (Koch, 2006). To meet the dependability criteria, I outlined the research design and procedures.

Confirmability is the final criterion for trustworthiness in a qualitative research project. Confirmability checks that the investigator's interpretations are derived from the data. The researcher must demonstrate how conclusions were derived from the data (Tobin & Begley, 2004). Lincoln & Guba (1989) argue that confirmability is accomplished when the investigator achieves credibility, transferability, and dependability. This study is scientific as it is systematic and rigorous and meets the four criteria of trustworthiness.

Summary

The goal of this chapter was to outline the research method used to answer the research questions. A discussion of the method, procedure, study participants, data collection, and interview questions outlined how the study was conducted and who participated. Study participants contributed to this work by sharing their illness and treatment experiences in HIV care and their perspectives of what motivates them to adhere to treatment over time. Chapter IV aims to provide the study results and demonstrate the methodology applied from Chapter III.

Chapter IV: Analysis and Results

This chapter offers answers to this study's research questions. I collected 28 interviews (222 pages of transcribed interview data) and two sets of survey data from caregiver surveys which I evaluated, analyzed, and interpreted. While analyzing data, I used the grounded theory method of constant comparison to keep emerging themes rooted in the participants' narrative (Urquhart, 2012). As a part of the iterative analysis process, I worked and reworked concept models to conclude the coding process. I completed data analysis and coding in four steps 1) open coding, 2) axial coding, 3) selective coding, and 4) theoretical coding (Charmaz, 2014).

The study sample includes three participant cohorts: patients (20), caregivers (5), and patient-caregivers (3) who responded as both patients and caregivers. Overall, the participants were 90% African American/African descent, 100% English speaking, and between 41-60 years old. According to demographic survey responses, sixty-five percent of participants self-identified as male, 20% as a transgender female, 10% as female, and 5% as non-conforming gender or gender variant. Ninety-five percent of patients were in treatment, and 75% of the participants were virally suppressed and in medicine. Seventy percent of the population was single; 70% had at least a high school education, and 90% were unemployed. All participants reported having a primary care provider.

Profiles

I include participants' profiles to contextualize adherence experiences and demonstrate that they are full of meaning rooted in individual human experiences. Crowe et al. (2011) assert that the case study approach allows for "in-depth, multi-faceted explorations of complex issues in their real-life settings" (pp.1). This study is rooted in unique experiences that ultimately

illuminate the human struggle of achieving and sustaining medication adherence. To protect participant anonymity, I did not use names but used letters instead to denote whether the participant was a patient (P), a caregiver (CG), or a patient/caregiver (PCG).

P1. Diagnosed in 1993, P1 learned he was HIV-positive from a routine check-up. P1 is a black male who has been in treatment for 4-6 years. He is forty-one to fifty years old and has a college education. He reports that he is not virally suppressed. He lives alone, is single, and is employed, making more than ten thousand dollars a year. He says having a primary care doctor.

P2. P2 was diagnosed in Memphis, Tennessee, in 1995. He was donating blood at a local college. He reports receiving a certified letter stating that he tested positive for HIV. After receiving his diagnosis, he says he did not go to the doctor for six months. P2 is a black male who has been in treatment for 6-plus years. He is fifty-one to sixty years old and has a high school education. He reports that he is virally suppressed. He lives alone, is single, and makes more than ten thousand dollars a year.

P3. P3 is a black male who was diagnosed in 1993. He has been in treatment for six-plus years. He is forty-one to fifty years old and has a high school education. He reports that he is not virally suppressed. He lives alone, is single, and prefers not to reveal his income.

P4. P4 was diagnosed in 2004. He is a black male who has been in treatment for six years. He is fifty-one to sixty years old and has a high school education. He reports that he is virally suppressed. He lives alone, is single, and is employed, making more than ten thousand dollars a year.

P5. P5 was diagnosed in 2007. P5 is a black male who has been in treatment for 4-6 years. He is forty-one to fifty years old and has a high school education. He reports that he is virally suppressed. He lives with his spouse and makes ten thousand dollars or less a year.

P6. P6 was diagnosed in 2013. P6 is a white transgender English-speaking female who has been in treatment for 4-6 years. This participant prefers the feminine pronoun, she. She is forty-one to fifty years old and has a college education. She reports that she is virally suppressed. She lives alone, is single, and is unemployed.

P7. P7 was diagnosed in 2004. P7 is a black male who has been in treatment for six-plus years. He is forty-one to fifty years old and has a high school education. He reports that he is virally suppressed. He lives alone, is married or partnered, and is unemployed.

P8. P8 was diagnosed in 1999. P8 is a black male who has been in treatment for 1-3 years. He is sixty-one to seventy years old and has a high school education. He reports that he is not virally suppressed. He lives alone, is single, and is employed, making more than ten thousand dollars a year.

P9. Diagnosed in 1996. P9 is a black female in treatment for six-plus years. She is fifty-one to sixty years old and has a college education. She reports that he is virally suppressed. She lives alone, is married or partnered, and is unemployed, making ten thousand dollars or less a year.

P10. Diagnosed in 2013, P10 is a black female who has been in treatment for 4-6 years. She is sixty-one to seventy years old and has a high school education. She reports that she is not virally suppressed. She lives alone, is divorced, and is unemployed making ten thousand dollars or less a year.

P11. Diagnosed in 1991, P11 is a black transgender female who has been in treatment for six-plus years. She is fifty-one to sixty years old and has a college education. She reports that she is not virally suppressed. She lives with her partner, is married or partnered, and is unemployed, making ten thousand dollars or less a year.

P12. Diagnosed in 1997, P12 is a black male who has been in treatment for six-plus years. He is fifty-one to sixty years old and has a high school education. He reports that he is virally suppressed. He lives with his family, is single, and is unemployed, making ten thousand dollars or less a year.

P/CG13. Diagnosed in 1994, P13 is a black male in treatment for six-plus years. He is forty-one to fifty years old and has a college education. She reports that She is virally suppressed. She lives with her spouse but identifies as being single. P13 is unemployed, making ten thousand dollars or more a year.

P/CG14. CG 14 is a white male HIV-negative caregiver who cares for his life partner, a black male who is HIV-positive. CG14 takes Prep to protect himself from getting HIV from his life partner. His partner has been in treatment for 4-6 years. They are both forty-one to fifty years old and have a college education. The care receiver is virally suppressed. CG 14 lives alone, is single, and employs more than ten thousand dollars a year.

P15. Diagnosed in 2000, P15 is a black male who has been in treatment for six years. He is sixty-one to seventy years old and has a college education. He reports that he is virally suppressed. He lives alone, is single, and is unemployed, making ten thousand dollars or less a year. He writes says having a primary care doctor.

P16. Diagnosed in 2013, P16 is a black male who has been in treatment for 6six plus years. He is fifty-one to sixty years old and has a high school education. He reports that he is virally suppressed. He lives with his spouse, is married, or partnered, and is employed, making ten thousand dollars or less a year.

P17. Diagnosed in 2009, P17 is a black nonconforming, transgender female who has been in treatment for six-plus years. He is thirty-one to forty years old and has a high school

education. She reports that she is virally suppressed. She lives alone, is single, and is unemployed.

P18. Diagnosed in 1991, P18 is a black male who has been in treatment for six years. He is forty-one to fifty years old and has a college education. He reports that he is virally suppressed. He lives alone, is single, and is unemployed, making ten thousand dollars or less a year.

P19. Diagnosed in 2005, P19 is a black male who has been in treatment for 4-6 years. He is forty-one to fifty years old and has a college education. He reports that he is not virally suppressed. He lives alone, is single, and is employed, making more than ten thousand dollars a year.

P/CG20. Diagnosed in 2003, P/CG20 is a black male who has been in treatment for six years. He is forty-one to fifty years old and has a high school education. He reports that he is virally suppressed. He lives with his partner and makes more than ten thousand dollars a year. P/CG20 is also a caregiver to his partner, who has been in treatment for over six years and is unemployed.

P21. Diagnosed in 1995, P21 is a black male in treatment for six-plus years. He is fifty-one to sixty years old and has a high school education. He reports that he is virally suppressed. He lives alone, is single, and is unemployed, making over ten thousand dollars a year.

P22. Diagnosed in 1999, P22 is a black male in treatment for six-plus years. He is fifty-one to sixty years old and has a high school education. He reports that he is virally suppressed. He lives alone, is single, and is unemployed.

P23. Diagnosed in 1998, P23 is a black male in treatment for six-plus years. He is thirty-one to fifty years old and has a college education. He reports that he is not virally suppressed. He lives alone, is single, and is unemployed, making less than a thousand dollars a year.

CG24. CG24 is a black female family/friend caregiver caring for a friend in treatment for 4-6 years. She is forty-one to fifty years old and has a college education. She reports that her friend is not virally suppressed. The care receiver lives alone is single and employs more than ten thousand dollars a year annually.

CG25. CG25 is a black female whose care receiver is a black male who is her friend. This care receiver has been in HIV treatment for 4-6 years. CG 25 is sixty-one to seventy years old and has a college education. She reports that her care receiver is virally suppressed. She lives alone, is single, and is employed, making more than ten thousand dollars a year.

CG26. CG26 is a black female who cares for a son who is HIV-positive. The care receiver has been in treatment for less than one year and is not virally suppressed. CG 26 is fifty-one to sixty years old and has a high school education. She lives alone, is single, and is employed, making more than ten thousand dollars a year.

CG27. CG27 is a black male friend of his caregiver who has been in treatment for 4-6 years. He is forty-one to fifty years old and has a college education. He reports that his care receiver is not virally suppressed. CG27 lives alone, is single, and employed, making more than ten thousand dollars or more a year.

CG28. CG 28 is a black male who cares for his sibling, a black HIV-positive male who has been in treatment for 4-6 years. He is fifty-one to sixty years old and has a college education. He reports that his care receiver is virally suppressed. CG28 is single and employed alone, making more than ten thousand dollars a year. He says having a primary care doctor.

Coding and Theory Development

Open Coding Procedure and Categories. According to Corbin and Strauss (2015), each researcher should develop their analysis methods. I began the data analysis process by performing a line-by-line open coding analysis to identify concepts, ideas, and constructs concordant with Charmaz's (2006) recommendation for open coding. I reviewed each transcript multiple times with a different intent to glean as much rich meaning as possible from each interview response. The initial analysis was done using hand-written notes taken during the interview and notes made line-by-line throughout interview transcriptions.

First, I read interviews were read and compared them with the original audio recording to verify accuracy. Once transcripts were corrected and consistent with audio-recorded interviews, fifty-six open codes were identified during the initial analysis. I determined which themes were repeated across multiple interviews from the initial investigation to develop categories for the axial coding.

Axial Coding Procedure and Categories

Using the axial coding process, I organized concepts into categories by revealing linkages between codes. I used inductive and deductive reasoning to fit open codes into primary categories. I identified seven primary categories and one core category connected to the preceding categories. Participants discussed the seven primary categories most often. These categories appeared to have the most relevance to the phenomenon of medication adherence: 1) Illness Experience, 2) Medication, 3) Illness Adjustments, 4) Self-management, 5) Health Education Needs of HIV Caregivers, 6) Patient/Provider Communication Challenges for Patient/Caregiver Dyads, and 7) Communication Needs of HIV Caregiver Typologies. Axial

coding identified causal relationships, context, and confounding conditions that interconnected the data. Each of the categories influenced or predicted participants' adherence journeys.

During the selective coding stage, I understood the relationships between categories, which led to the final phase, theoretical coding—the final coding phase details insights into the action, the actors, and observers of medication adherence.

Primary Category 1: Illness Experiences. In medical anthropology and sociology, illness experience is a construct that details the social influences of experiencing illness. This process is integral to the interpretative aspect of meaning-making in condition. These experiences explain the somatic discomfort of disease and how it drives participants to either avoid or address medication adherence.

Illness experiences are a reoccurring theme in all participant narratives that provide critical insights into adherence behaviors. Illness Experience is a primary category that includes socially constructed subcategories such as (a) diagnosis narratives, (b) isolation, stigma, and disclosure, and (c) lifestyle changes, nonadherence, and consequences. These subcategories provide experiential context to individual suffering and outline how people respond to the stress of illness.

The first section of the semi-structured interview asked questions about the interviewees' conceptualizations of HIV. When participants answered this question in the discussion, it led to storytelling in which the person's answers were rooted in the Lifeworld reality of social complexities such as forbidden lifestyles in the south, poverty, trauma, and survival. Diagnosis narratives are the beginning of storytelling.

Secondary Category 1: Diagnosis Narratives. Diagnosis narratives are the stories of how people learned that they were infected with HIV. These narratives described the initial onset of

symptoms and provided a timeline for a person's illness experience. *Diagnosis narratives set the tone for participants' illness experiences.* The subjectivity of experiences provides insight into how people subscribe meanings to social circumstances. Some participants described the traumatic nature of their HIV diagnosis. Diagnosis narratives provided the context and timeline for how the HIV diagnosis impacted participants' existence.

> For instance, P21 compared his diagnosis to the death of his mother.
>
> I felt a very, very hard blow. I felt a loss; I felt something that I have never felt before…loneliness. I felt pain…with something like that because you've heard all your life, you know, how deadly it is. I thought that all relations with others were cut off. That's how I felt. (P21)

Narratives of loss revealed that in addition to coming to terms with the trauma of facing a life-threatening illness, participants were also dealing with the consequent social losses of being infected with a heavily stigmatized disease such as HIV. Many participants lost their families and became pariahs within their communities. P3, for instance, shared that he lost his wife and children due to his diagnosis. His "diagnosis and now" images were listed as sad: "sad to me…because I lost my wife behind it". He revealed that he married his wife without knowing his HIV serostatus.

> I carried it down there (Jackson, TN) with me. I didn't know myself. I didn't know. I got married and everything and didn't think nothing about it...I was just sad about it because I lost something that I could have had...the trust wasn't there…back in 1993, it was kind of like if you had HIV, you thought you were going to die. It was sad because you know, you thought people might look at you different or that it was gonna change your life. (P3)

The circumstances of loss disproportionately increase the psychosocial burden of living with HIV. These psychosocial burdens often overwhelm an HIV-positive person's ability to cope and respond to this health threat effectively. Participant 13 talked about stressors and anxiety:

> I experienced all these difficult stressors and anxieties and all that kind of stuff and this low self-esteem. I just felt worthless, all that made it hard for me to become medically adherent . . . at that particular time, I didn't care if I lived and as a result of that, I ended up getting pneumonia. (P13)

In conclusion, participants' diagnosis experiences detailed how it shook their sense of self. The trauma of social stigma and abandonment caused some participants to spiral into depression and self-loathing, which stifled their abilities to cope with stressors such as being ill and the challenges of learning how to master treatment recommendations to become or stay well. Consequently, many fell into maladaptive coping approaches while in a state of depression. Maladaptive coping strategies led to medical non-adherence.

Secondary Category 2: Stigma, social isolation, and disclosure. Many participants expressed that the most stressful aspect of HIV care is navigating social situations such as stigma, social isolation, disclosure, and consequent identity crisis. This is a contextual subcategory as it tells how people initially experienced all the dimensions of suffering from illness: socially, physiologically, psychologically, and emotionally. Every participant recounted what they described as painful experiences of stigma, rejection, and isolation. As participants disclosed their HIV status to family, friends, and their community, they learned that they had become pariahs among those whom they loved:

> I found out that you can't tell anybody else about that…It's something you can deal with long as you keep it a secret to yourself (P8)

112

…it always be a change on how you know how the next person gone feel about you after they know. Some turn off and some say let's get a condom…something like that. Some of them just don't want to mess with you at all. They make you go back and get in the pity mode (P10).

He saw one of my pills and…he googled it. He was like, man you are taking HIV meds. I was like naw those are my uncle's meds …after that, I started to put my pills in a big glass and discarded the bottles (P19).

I guess me telling (that he had HIV) her (mother), it just kind of you know, just messed her head up a little bit. I tested my siblings too. I asked them how do y'all feel if somebody you knew had HIV or AIDS? And they was like, I wouldn't want nobody around me like that…it really made me feel out of place because these are my own brothers and sisters (P19).

when I first found out, you know you, I was like separating from everybody. Like my family. My wife left me. My family put me out, and so I have been… just been living from one abandoned home to another (P7).

Other participants described the feeling of internalized stigma, which caused them to feel isolated because they were "different."

Yeah, I go to the store. You know everybody that hang out at the store. I just feel separated by me knowing I got this, and they don't (P7)

It make me feel bad, you know, this and that people hugging me. Especially when I be at church. So many people at church and I don't know half their names. Now, what if one person knew. Then everybody in there would know. Then how they gone treat me? (P7)

On the contrary, some participants reported that social connectedness became a buffer to the many negatives of being ill and socially stigmatized. For instance, P5 stated that his boyfriend and brother helped him to realize that an HIV diagnosis was not the end of his life:

> the people around me…gave me so much. Like my boyfriend and seeing my boyfriend and seeing my brother, it showed me like it's nothing. It was like, just do what you gotta do, but keep, enjoy your life. . . (P5)

> So, um, so HIV really is a big part of my life but not like in the way it is because in a way like, like people think it's like, uh, so bad, but in a way, you know, you have to the good and the bad. Actually, it helped me to understand more about my body and what's going on in my body. Because if I didn't have it ... I promise I was not going to be going to see no doctor; get my teeth checked. Things like that, I wouldn't be going. I know I wouldn't. But I know more about what's going on in my body now. … (P5)

Secondary Category 3: Lifestyle choices, non-adherence, and illness consequences.
While the possibility of being able to control HIV is promising to many, the challenges of self-regulation became a formidable barrier to treatment success. Common themes in the primary category of illness experience included lifestyle, nonadherence, and consequences. These themes are interconnected as many narratives illustrated a struggle between lifestyle preferences and healthy lifestyle choices such as regimen adherence. Lifestyle choices range from diet, exercise, substance use, sexual behavior, etc.— any behavior, thought, or action that impacts a person's health. Some participants reported that the choice to be nonadherent resulted in comorbidities

114

such as STDs, cancer, pneumonia, and lengthy hospital stays. For most participants, the decision to adhere was the beginning. Treatment adherence became a multi-faceted skill that participants learned over time. Healthy lifestyle choices could be deceptively simple as 'just taking the pill' but as complicated as addressing multiple layers of trauma, mental health issues, and maladaptive coping behaviors to perform practical self-management tasks such as medication adherence, abstinence from substance use, and high-risk sex. The inner turmoil between modifying lifestyle choices to become healthy is a genuine human struggle.

Participants described the struggle of incorporating medication adherence into their lifestyles. Taking medicines had to become a priority as other aspects of their lives, including drinking, doing drugs, working, living, and other preferred activities. P2 discussed how he had to prioritize taking his meds and drinking alcohol. He had bouts of nonadherence as "street life" seemed to compete with the priority of taking his medicine. Then one day, he realized he had to incorporate his medication-taking into his lifestyle, which included drinking alcohol — treatment adherence could not hinge on his sobriety but had to be incorporated into his alcohol use.

> They told me what I needed to do and this and that… and so I had to try to
> incorporate that in my life. I make it a point to, even when I'm drinking…If I feel
> I get too much alcohol in my system, then I'll hold off from taking the medicine
> for a couple more hours until some of the alcohol dun wore off… and if I am still
> up, I say damn let me take this pill. (P2)

Eventually, in his narrative, P2 decided to refrain from binge drinking.

> when I drink, it… it's just; it's just to quench that thirst. It's not…I don't go on a binge…
> I gotta respect what I got. As long as I am thinking about it, I'm going to respect it to the
> fullest." (P2)

After careful self-reflection and evaluation, he decided to incorporate healthier choices to optimize the efficacy of ART. He explained that people who only take medicine but don't incorporate behavior change don't reap the full benefit of ART. He communicated that initially, he was still living an unhealthy lifestyle, and initially- he looked terrible and felt bad even while adhering to his medication-taking. To look good and feel good, he had to get his rest, stop smoking crack, binge drinking, and stay out all night. Eventually, through personal experiences, he learned that adherence was his best choice.

> … the mixture that they're putting with their drug, and it's not doing what it's supposed to do. Taking it, you don't see nothing happen because usually you still smoking crack or smoking marijuana or drinking beer. You want to do this all night. You haven't made that commitment to take this medicine that you're supposed to take to keep your head . . . to keep you looking and feeling good. So, they feel bad, and they look bad and claim that the medicine isn't working . . . but their failure to change is why they having all of these up and down symptoms and situations. (P2)

Participant 19 reported that he did well taking his medications but struggled with behaviors such as high-risk sex. He recounted having unprotected oral sex with a married man. He contracted stage 2 syphilis. In the timeline of his illness experience, this event represented a pivotal moment of self-reflection. He described becoming sick immediately after the high-risk encounter.

> My first time when I got when I contracted it, I was giving this guy oral, and I didn't know that his wife had syphilis stage two and it was on his penis. . . And he had a bump there. It was really bad, and I didn't pay attention to it. And when I thought about it, I was like, wow, syphilis stage 2. . . it made me sick off the bat. I

116

like started to lose weight . . .having any type of STD in a second stage is more

crucial. Especially oral, or anal. . .see when stuff like that occurs, you start to

think like damn. And it was weird there was a thunderstorm. It was raining. I was

scared. The power went out. Like it was weird. It was like a real freak show (P19)

Remembering the consequence of this behavior helped Participant 19 contemplate

abstinence from high-risk sex. He contracted multiple sexually transmitted diseases before

coming to terms with the fact that HIV made him more susceptible to other infections. Although

he desired to avoid events like this, he had to develop self-control before he could become

abstinent. His decisions' consequences helped the participant pay attention to his behaviors while

taking his medicines.

In comparison, Participant 2 (who struggled with alcoholism) expressed confidence in

HIV treatment but ultimately went through a nonlinear process of adherence to therapy because

he had to gain the mindset and skillset to self-regulate his behaviors to become more adherent.

This evidence proves that adherence is a nonlinear process that happens over time due to

experiences. Adherence changes as individuals change and as life changes. Ultimately,

adherence is a process that is subjective to each participant due to their illness experiences,

personality, coping style, and their social environment (how much stress stimuli this environment

presents to the patient and the presence or absence of social support). In the case of these

participants, their illness experiences influenced the trajectory of their adherence journey; in

addition to illness experiences, medication-taking beliefs, and behaviors heavily influenced

participants' ability to adapt to treatment.

Primary Category 2: Medication Adherence. *Medication adherence*

encompasses a significant component of participants' narratives about self-

117

managing chronic illness. Subcategories under this primary category included medication knowledge/experience, medication beliefs, and medication attitudes. Medication adherence predicts a more excellent quality of life free from preventable hospital stays, comorbidities, and death.

Adherence, as well as non-adherence, is a combination of beliefs and behaviors. Nonadherence is a significant barrier to ideal health outcomes among those living with chronic illnesses. Participants reported that medication adherence was crucial for their survival once infected with HIV/AIDS. Healthcare professionals and healthcare researchers pose the question as to why patients decide not to take medicine that has the potential to protect their lives and health. Patient narratives reveal that adherence is a social phenomenon shaped by illness experiences, medication beliefs, and attitudes.

***Secondary Category 1: Medication Knowledge/Experience.** At the research site, ongoing classes about medication and treatment were readily available. These interventions, provided by the research site, address participants' beliefs about the disease and treatment. Narratives revealed that the knowledge they gained was a combination of professional and laypeople information. Physicians, pharmacists, and other practitioners educated participants about the evidence-based practices of HIV care. At the same time, people living with the disease provided vicarious learning as they shared their experiences with the participants. Peer knowledge, in addition to clinically provided information, helped translate knowledge into practice. Participant 9 shared that he had to put it all together:*

The people that teaches HIV, but they don't have it, but they try and tell you what you dealin' with but don't know. And that has a lot to do with it to … I put it together with common sense" (P9)

From experience, Participant 17 learned how to improve his schedule to improve his adherence routine:

Through experiences and listening to my doctor because they was saying like it's good, you know like when you take it like this, a set schedule will make more adherent, so I started doing this like that's my routine (P17)

Participant 11 learned from a culmination of different sources how the medicines worked. He applied knowledge from classes, his profession in the medical field, and his provider to put it all together:

So, between the doctor giving me information on it. And also, I go to classes and counseling at hope house, uh, and being in the medical field and I know about it. I know what my medicines do, and I know what medicines don't work on me. I've been on almost all of them. And so, uh, that's how I know about it, basically. (P11)

These narratives reveal that information and knowledge come from multiple sources. Adherent people learned to put it all together before they could successfully master self-management skills for adherence. There was no cookie-cutter approach because adherence plans had been customized over time with each participant as they took medicine in real-world settings and dealt with confounding barriers to treatment success. Due to individual physiologies, lifestyles, coping styles, and environments, adherence plans were personalized. Personal awareness of disease symptoms and medication side effects

119

helped participants determine if the medication or the way they were taking it worked. For instance, Participant 18 initially experienced drowsiness with the drug and decided she would adjust the time she took medicine so she could remain functional throughout her day:

"I've learned that my medication makes me a little drowsy. So, I learned to get up around three or four in the morning and take my medication that way. I eat something, take my medication, and lay back down and let it do what it does… And by morning time, about seven o'clock, I'm over the little feeling I have" (P18).

Participant 21 recognized disease symptoms as an indication that the drug was not suppressing their viral load:

Um, I could miss one or two days taking the pill and uh, my viral load will start increasing. (P21)

Participants expressed that they could tell when they were "off" to know if the medication was performing optimally. While providers ran tests to check the efficacy of the medicine, participants "knew" from how they felt whether the drug was working. Layperson's experiential knowledge about the disease and illness provided feedback to healthcare teams so they could adjust treatment plans to achieve success.

*   **Secondary Category 2: Medication Beliefs.** Participants described nonadherence as a rational decision. Participants explained different rationales behind the perceived benefits and disadvantages of treatment adherence. For instance, some participants believed that medication should not be taken without symptoms. They believed that drugs presented just as many or more risks than the*

illness itself. For some participants, it took hospital stays to make the connection that medication nonadherence could lead to disease or death. These beliefs formed attitudes based on cognitive, behavioral, and affective information that ultimately influenced how participants responded to treatment recommendations to prevent comorbidities and death.

In the case of this study, most participants were adherent. Their narratives were a testament to what ART adherence meant to them. ART adherence and the consequent experience shaped illness and treatment perceptions, ultimately impacting adherence outcomes. For instance, Participant 3 described ART adherence as a means of control: ...It can be maintained. I understand it. I can be maintained now that I have so much (P3). Some participants explained that the medication allowed them to be undetectable: *I take it it's doing its job. I don't feel infected. I go to my doctors . . . it's undetectable* (P8). Participant 9 explained that she thought that treatment adherence allowed her medicine to work optimally:

> Because I know how my body is, I feel like my body reacted to the medicines good because I did what I'm supposed to do, and I ate like we were supposed to eat. I tried to maintain health that I didn't miss doctor's appointment. If I couldn't make it, I would reschedule whatever. (P9)

For other participants, ART adherence was a source of hope, and this hope became a motivator for optimal adherence: ... Participant 4 explained *...HIV doesn't mean HIV to me. Because it's not a life-threatening disease anymore* (P4)*,* these **beliefs and expectations gave participants hope for an average life expectancy and a higher quality of life if they took their medicines.**

121

Participants also described hope for chronic disease management that is not complex or overly burdensome. Participants shared the belief that ART adherence promised reduced risks of developing drug resistance and having complicated drug regimens. ART adherence meant just taking one pill a day:

> … I've learned that I can get resistant … because it makes a person who, and especially in HIV, it makes the person who used to take one pill take a variety of pills, which complicates the matter greatly because one pill was worse enough to take. But when you get to taking two and three and four … it becomes overwhelming and can, cause, I mean, you know, no one wants to take medications, especially something that didn't taste good. Smell good, that they have to pay for, I mean, and it's no pleasure in, So the, um, as he's saying one pill, it would be a burden. Three or four is just a burden. (P18)
>
> Just one pill a day. … Um, I could miss one or two days taking the pill and uh, my viral load will start increasing. You know, it'll make it hard for me to fight off any other colds or anything. You know, infections like can get cut and it will be slow healing. So, the pill is very important to me. (P21)

While all participants reported that they were educated about disease and treatment by healthcare providers, their belief that this information was true or accurate determined their health-seeking behaviors. For instance, P18 revealed he lacked confidence in the efficacy of ART when he was initially diagnosed: "*I didn't feel that they were competent enough because it was new. Uh, people were afraid. You could see fear in the medical providers*" (P18). Participant 18 resisted treatment because he did not believe the medication was efficacious.

Treatment beliefs expanded into treatment attitudes. For instance, participants might believe that if they take their medicine, they will survive. This belief becomes an attitude, a mindset towards treatment efficacy. People who decide they want to stay make decisions to adhere to treatment recommendations.

Medication adherence or nonadherence is ultimately a way to cope with illness. Medication knowledge, beliefs, and attitudes determine if people avoid or approach treatment, thus medication adherence. Beliefs that treatment worked led to an approach coping in which patients engaged in treatment by taking their medicines. Attitudes of skepticism about the benefits of treatment led to negative attitudes about the treatment, which led to avoidance coping. Participants revealed that avoidance coping led to non-adherence. For instance, Participant 18 used a denial-avoidance coping approach to his treatment. He was diagnosed in 1991, but he reported he did not begin taking medicines until 2005. Consequently, he began presenting AIDS-related complications such as Kaposi's sarcoma, a relatively common opportunistic condition that occurs when HIV has progressed into full-blown AIDS. He tried to treat the skin cancer with Bactrim until he finally accepted that the only way to treat Kaposi's sarcoma was to take his HIV medication.

> I had already traveled everywhere and looked for cures in Chicago…New York.
> And it's like the stress level and stuff; it was making me more vulnerable. And so,
> I just say, at some point I had to sit myself down and say, I'm not, you know…I, I
> can't figure this out…I'm gonna just have to get what's available for me (P18)

Because he avoided treatment and allowed the disease to progress, he suffered from comorbidities and disability. From those consequences, he learned to have confidence in his HIV

medication. He began to connect his medication's efficacy and his body's ability to heal and maintain normal functioning.

Primary Category 3: Illness Adjustment. Illness adjustment is discussed in the literature as "a process that begins with the presentation of symptoms and continues throughout the course of illness and responds to the change in illness status" (Sharpe & Curran, 2006). Illness adjustment is a fore step to autonomous self-management that results in optimal medication adherence. For this reason, this construct is a primary category because it connects illness experiences to adherence outcomes which directly impacts medication-taking. This construct was also a recurrent theme among participants' narratives. It illustrates the dynamic experiences of people learning to reintegrate illness into their daily lives. Participants' narratives featured mental, emotional, and functional adjustments to overcome suboptimal adherence and nonadherence. This section will discuss constructs such as controllability, cognitive reappraisal, and accountability as narratives depict how vital these concepts play in achieving and sustaining medication adherence.

Secondary Category 1: Controllability. Controllability seemed to help people to fight through the many challenges of behavior change. Many of the participants of this study had HIV before it could be controlled— the only prognosis for them was a bad death**.** As HIV research presented the possibility of controllability— and the possibility of managing disease via ART therapy—, participants had to modify their illness beliefs about the disease and treatment before reorganizing their efforts to adhere to treatment goals. The most vital belief was that the disease could be controlled through intentional behaviors such as medication adherence, abstinence from high-risk sex, and substance use. Participants expressed that they believed that taking the medication properly could not only protect their health but also prevent them from spreading the

disease. In his own words, P18 explained that ART adherence allowed him to become *"untransmittable"*. Other participants expressed how they understood how the disease could be controlled with medicine.

It can be maintained by taking the medication properly (P3)

I understand this disease a deadly disease and it can take me out if I don't take

care of myself or take that one pill daily (P21).

In conclusion, participants went through a process of reframing their minds about the disease so they could move forward with behavior change. The concept of controllability helped participants to change their health prognosis using treatment adherence. Participants explained that while controllability put new possibilities back into reach, the heavy psychosocial burdens of living with HIV made cognitive reframing even more essential. To get their minds beyond this burden, participants described how they used cognitive reappraisal to move forward toward health.

Secondary Category 2: Cognitive Reappraisal. Recognizing that the disease could be controlled now meant that participants could be accountable for their health-seeking decisions and actions. Accountability included lifestyle choices such as treatment adherence and abstinence from high-risk behaviors such as substance abuse and unprotected sex. To overcome the complex challenges of behavior change, participants initially used cognitive reappraisal to achieve treatment adherence and then again to persist in long-term treatment adherence.

While conducting this study, I interviewed a social worker that discussed the necessity to "push through" to achieve and maintain medication adherence and viral suppression. Many participants described how they had to "push through" to take their medicine in the face of mood

changes and medication fatigue. For instance, to take HIV medication, some participants said

they had to tell themselves to "just take the pill":

> . . . when I take it's not like I go HIV . . . It's like I am taking a vitamin. No, it's
>
> like this is helping me. So, it's just that mindset that you get because at one time I
>
> hated it. (P5)

Participant 9 said, "it's the difference. I mean do I want to live…do I want my body to get

stronger?" Participant 5 talked about overthinking his medicine before he finally decided: "*I'm*

going to take that pill and I'm not going to spend any more energy on this…". Participant 4

shared that he learned to see the medicine as a vitamin: *"I take a vitamin every day. That's how I*

look at it…it makes me stronger". These narratives reveal participants' ability to cognitively

reappraise the burden of medication adherence. But becoming resolute about change was

constantly challenged by the complexity Lifeworld demands.

> **Secondary Category 3: Accountability**. Participants expressed the importance of

accountability in medication adherence. According to Participant 6, accountability is the most

helpful aspect of HIV care: *My accountability partners which include my healthcare provider, my*

*therapist, uh, people in my support groups (*P6*).* Participant 13 echoed this sentiment and

explained that accountability provided a "net" to help him get back on track:

> … But the help of my team of doctors and nurses, um, medical case workers,
>
> social worker, um, close friends who are in the same situation that I am . . . and
>
> they know these people all hold me accountable. And that's a good thing . . .Yeah.
>
> And they hold me very much so accountable. So, if there's anything that's going
>
> wrong and I, you know, we talk about it isn't anything more wrong than I know

that I have a net somewhere, I have a net. So, if I look like I'm going to fall they

say uh, huh we gone help get you back together. (P13)

Participant 13 described his relationships with his healthcare team as a vital factor in his

accountability. According to Participant 13, the healthcare team knew him as a person before

they were able to challenge him to be accountable. In the past, before he developed a personal

relationship with his healthcare team, he delivered false reports about his adherence behaviors.

Participant 13 said he "was just going through the motions" before he began providing honest

feedback about the challenges, he faced with his treatment plan. Eventually, he could see his

providers other than people "*just wearing that professional hat*" (Participant 13). He recalled

how his provider called him out when his report was inconsistent with his bloodwork by

commenting, "*well, we can tell whether you take your meds like you're supposed to or not by*

*your bloodwor*k" (P13). This account reveals that collaborative interpersonal communication

between patient and provider, by which the pair have established rapport and are equally

engaged, yielded the ideal treatment outcomes through collaborative communication as a team:

we can talk; I can talk about a-n-y-t-h-i-n-g. And it's, I love because it

makes me feel comfortable and I don't just automatic, I just don't just see

just the professional hat (P13)

In conclusion, participant narratives revealed that illness adjustments are an essential

aspect of medication-taking because participants identified them as one of the steps before

medication adherence. Overall, three primary categories emerged from the data to reveal three

umbrella or primary categories: illness experiences, medication adherence, and illness

adjustment. Further exploration into these constructs reveals an overarching theme of patient-

provider communication. Narratives illuminated that patient-provider communication is the

gateway to successful chronic disease management. I will discuss the core category of patient-provider communication.

Exploring the relationships between these categories revealed that patient-provider communication was the core category that connected the primary categories of illness experiences, medication adherence, and illness adjustment. Initially, participants discussed how patient-provider communication provided information during diagnosis. Then participants shared how disease and treatment information was presented at the beginning of treatment. Most participants described experiencing the illness until they learned to accept their diagnosis. Next, health promotion inspired participants to make healthier choices by introducing medication and self-management education. Narratives illuminated the presence of a patient-provider collaboration by which the provider would prescribe treatment, and the patient would try these recommendations in the context of their life. During the follow-up medical visit that is customarily done every 6 months in HIV care, participants' subjective experiences with the medication, and the illness, in conjunction with the results of their HIV blood work, determined whether the medication and the patients' management skills achieved therapeutic goals such as viral suppression. These illness experiences are primarily informed by provider support and communication. And finally, health communication helped participants to adjust to illness by strengthening coping mechanisms that result in optimal adherence (controllability, cognitive reappraisal, and accountability). Once participants developed a mindset for self-regulation or controlling the disease, they had to learn how to manage all the many facets of disease management through self-management mastery.

Primary Category 4: Self-management. Self-management is an exercise of agency. Agency is the ability to perform actions to yield a specific effect. In the case of self-management,

this included communication and self-regulation skills. Many participants discussed how HIV truly saved their lives because they were forced to take control over the circumstances of their lives to survive HIV. Participants discussed six required skills they used to become medically adherent. These skills are listed as the following subcategories: communicating needs, problem-solving, self-regulation, coping, disclosure communication, and social environment.

   Secondary Category 1: Communicating Needs. Collaborative decision-making demands openness, mutual information sharing, and clinical negotiation. An essential aspect of patient-provider partnerships is the patients' willingness and ability to communicate their needs during a medical visit. Bell and Associates (2001) said it best, "Given that physicians wield almost exclusive control over the order sheet and prescription pad, the primary means by which patients exert influence in the medical partnership is through requests for information and action" (pp. 1). The ability to request information and action is vital for the patient to exercise the agency necessary to negotiate a treatment plan to which they can adhere. It is a major task for patients who feel powerless and possibly disenfranchised to question and negotiate with credentialed healthcare professionals during treatment planning. In addition to asking questions, participants detailed how they could gain resources by making their desires known. Discussions with providers allowed participants to get referrals for needs outside of HIV medical care. For example, some participants got psychotherapy for depression or other cognitive/emotional needs. Some received housing and food, as many were in unsafe environments or homeless. Other participants discussed social services support for job training, getting GEDs, or therapeutic pursuits that helped managed stress. Creating a care plan to which participants could agree to adhere all started with their ability to communicate their needs and desires.

Well, it took a lot of; I had, like I said, I got linked to, um, my medical

case worker. They were outstanding at The MED. Melissa Wright was her

name. And at that particular point during it's that time, I was homeless for

a short period of time. I just lost my mom to cancer, and uh, I really felt

bad, and I didn't have nowhere to go. And for me, she got me hooked up

into a group home, Peabody house. And from that point on, um, part of the

requirements to stay there was that you had . . . stay medically adherent

(P13).

This example illustrates that, in chronic care, holistic care is paramount to improving

patient and caregiver health outcomes. This concept is consistent with Maslow's Hierarchy of

needs which asserts that people must meet their most basic needs for things such as food and

shelter before they can focus on higher goals like medication adherence.

Secondary Category 2: Problem-Solving. Communication was needed for problem-

solving. On several occasions, participants explained that pharmacists, physicians, social

workers, nutritionists, and psychiatrists helped them with challenges regarding adhering to

treatment recommendations. For instance, one participant talked about how his medications

made him feel lethargic. A conversation with the pharmacist helped this participant decide when

and how to take medicine.

Sometimes it makes me drowsy, or sometimes it makes me sick. Or when I was

taking that A triple, they had me taking four or five medicines a day, and I was

like a Zombie. So, I had to have somebody around me because I couldn't, I

couldn't even go to the store and get a drink. It had me like spaced out. . . so that

is why I take the medicine at nighttime. (P7)

130

Secondary Category 3: Self-regulation. In the context of self-management training, provider communication helped patients and caregivers cope with the reality of their health or illness. In this study, Participant 2 shared how his provider enabled him to achieve the goal of taking just one pill a day while struggling with alcoholism.

> But before, I was taking it twice a day. I was progressing with the disease . . .my doctor told me she made me promise to take my meds twice a day. She said, "no matter what you do outside of your meds, each dose needs to work eight hours for you. That's what she told me… So, I tried to, even when, even when I had a little alcohol in my system, I tried to wait till after some alcohol die down so the meds can have it's opportunity to work (P2)

Participant 2's provider relayed to him the importance of getting his medication in his system with some measure of frequency to increase his adherence. Her instructions were simple and directive. She expressed the expectation that this participant would take his medicine no matter what was happening with his behavior (in this example, drinking). The interpersonal communication between patient and provider reveals that the provider is aware of her patients' Lifeworld challenges. She took this insight and used it to formulate a message that captured this patient's attention and challenged him with the task of controlling his drinking as well as his medication-taking. The fact that the participant felt comfortable enough to discuss his real-life issues with his physician speaks to the rapport, trust, and respect that this patient-doctor dyad shared. The result appeared to be that he gained the capacity to self-regulate.

For this participant and many others, this small success gave him the confidence to gain control over his alcoholism and, eventually, other aspects of his life that needed improvement. He went on to repair relationships with his children and became concerned with eating healthy in

addition to taking his medicine. The provider delivered communication that helped this participant to save his own life—truly pivotal communication. This participant now only takes one daily pill and reports that he no longer abuses substances.

    Secondary Category 4: Self-actualization. Participants all described a process by which they had personal goals outside of HIV self-management that helped them to stay on track. Participant 23 discussed the importance of taking his medicine to be around those he loves. He understands that his adherence is not just for him but also for those impacted if he didn't live. This purpose added direction and motivation to his quest to adhere to ART.

> Okay. I got to stick around, not just for me. And you know, there's others beside
> me, you know the loved ones in there, like friends, real friends. Yes. Yeah. You
> know, your life doesn't consist of just you. Your life consists of all those. It's a
> network (P23).

Participant 17 described his initial reaction to his diagnosis to his current outlook on the illness.

> I would describe it as very gloomy … my outlook on life was the worst, but now
> it is not a death sentence…I have the power not to infect people, and I have the
> power to educate and inform others. (P17)

Participants diagnosed with HIV before ART was available viewed the medication as an opportunity for second chances— an opportunity to right past wrongs. While this could also be listed under the cognitive reappraisal section, I listed it here because it goes beyond self to self-empowerment to help or protect others. Participant 2 shared that he had to succeed in treatment because he had unfinished business with his children, "*I got some kids that didn't get to call nobody daddy at a young age. I was too busy being the man*" (P2).

Secondary Category 5: Psychosocial Coping. Participants reported being referred to mental health services, support groups, and group therapy to help them cope with HIV. Participants reported that these supportive services enabled them to adapt to the unique demands of being chronically ill with HIV. For instance, Participant 6 shared that her therapist helped her to identify a therapeutic outlet for her illness-related frustrations:

> My therapist helped me to realize that communication was for me. It's not something I'm wanting to be. I'm not gonna give it to you. Read and then it becomes a best seller. It's just for me. Once a week. It is very helpful for me… sometimes it's just a letter to God, and sometimes I'm saying I'm fed up with this shit. Please help me. (P6)

Secondary Category 6: Disclosure Communication. Participants expressed the importance of disclosure communication. Social and mental health workers helped them learn communication strategies for disclosing their HIV serostatus. Participant 6 shared that he considered disclosure communication a self-protective aspect of patient training: "*how to relate through other people, how to talk to people about the disease, uh, and when to be quiet about it.*" (P6). Teaching PLWHA communication strategies for disclosing HIV helped participants to understand with whom they should share their HIV-serostatus.

Although not directly related to healthcare management, participants described that this communication strategy was most helpful to exercising control over their social lives, contributing to their overall emotional well-being. They learned to disclose their status to people willing to offer support and not use this information to stigmatize the participant or present unnecessary emotional distress. Disclosure strategies also included negotiating safe sex and safe relationships. Disclosure communication strategies were also described as a means of

reintegrating the old self with the new self as participants worked to reconcile relationships with their children and loved ones. Participants shared that after many years of living with the disease, they still grappled with two disclosure situations, when or whether not to tell their children and when or whether to tell love interests at the beginning of relationships. Consequently, participants listed counseling with professionals and peers as a valued intervention that helped participants to navigate this complex social circumstance to create safe and healthy relationships.

  Secondary Category 7: Controlling Social Environment. Once their medical crisis is under control, participants described reintegrating new and old self-identities into their social environment. These participants described using different communication skills to navigate their social environments at home, work, and in society. To do this, they had to create new environments, new social networks, and new selves. *The social environment of a participant proved to be an essential determinant of medication adherence as it helped some to maintain sobriety and allowed others to reduce depressive symptoms. Participants spoke of how people's reactions to their HIV status impacted them emotionally. Stigmatizing comments or behavior could revert participants' behaviors. The additional stressor of other people's negativity became a distraction to treatment. Peer support groups were used by many to maintain social connectedness while staying on track to achieve treatment goals. Participants expressed the significance of being able to be around people who were also HIV positive.*

   It's also great support cause you're around others like you. You know, you're looking at people, and you looking at their similarities, and that's what makes you go on. That's why I came by here today. I told my friend that came on my apartment. I said, no, I'm going so I can visit the others that are like me, you know, and I feel good (P8)

Family/Friend Caregivers Categories. The HIV caregiver plays a significant role in treatment adherence and must be considered in interventions to improve medication adherence (Gichane et al., 2018) I have provided separate sections for patients and caregivers because I have derived from the data that caregiver perspectives, experiences, and needs are different and sometimes discordant with patients.

Caregivers offer emotional and functional support. For this study, I focused on the caregiver narratives that featured the stories of participants who were both patients and caregivers. These narratives provided unique perspectives of the experience of HIV management. Participants 13, 14, and 20 shared the unique challenges of performing the caregiver role while also being a patient.

Primary Category 5: The Health Education Needs of HIV Caregivers.
Patient/Caregiver 20 shared that the most valuable skills he learned from the medical facility were dosage related. He also discussed learning how to use tools such as calendars and pill boxes to track his and his partners' pill taking. Participant 14, a patient/caregiver, explained that he uses a calendar to track all other aspects of life because adherence is all about routine and a less chaotic lifestyle. He also uses the calendar to track doctor appointments. Following the calendar is an important aspect of self-management success for himself and his partner.

Primary Category 6: Patient/Provider Communication Challenges for Patient/Caregiver Dyads. *Narratives revealed the unique challenge of health communication for providers' care planning with patient/caregiver couples. Relationship dynamics can influence treatment adherence (Conroy et al., 2019). For instance, participant 13 discussed that even though he was undetectable, he still preferred to practice protected sex with his partner. He explained that his partner was not always adherent to his medication which caused his viral load*

135

to change, which introduced health risks to the couple. Participant 13 expressed that he and his

partner were at different stages of change in their adherence journeys. This is an essential issue,

as two HIV-positive people in a relationship can be at various stages of change. They may need

individualized health communication to help them prioritize adherence to protect themselves and

their partner from treatment failure.

   Another challenge for relationships in HIV care is the necessity for practical

communication skills. When I asked participant 13 if being in a relationship with an HIV-positive

person was less challenging than a relationship with an HIV-negative person, he expressed that

HIV-positive relationships require a lot of disclosure and communication between parties so that

each one is informed of risks and is therefore protected. When asked about his partner's

adherence, he shared, "he usually follows my lead." When asked what helps him to keep on track

with caregiving, he expressed, "what keeps me on track is caring for myself. . . That keeps me on

track to care for you" (P13). *Also, participant 13 presented the scenario in which an HIV-*

negative person can pose threats to an HIV-positive person who is undetectable in a relationship.

*In any case, e*ach person in the relationship must remain *"vigilant and self-protective" to remain*

safe. In addition to the support that they offer each other, this patient/caregiver dyad goes to

group therapy to get support from others who are living with HIV.

   Participant 14 is a caregiver who cares for his partner, who is HIV-positive and

undetectable. He shared that he takes Pre-exposure prophylaxis (PrEP) as a "safety net"

(P/CG14) for him and his partner. He explained that he and his partner's medication adherence

reflect their love and desire to protect each other. Participant 14 explained that he expects his

partner to take care of him but still explains.

He gets pretty sickly sometimes. I go to the doctor's office to make sure that he

would get the correct medications, or if they weren't working, then they could

switch them around (PCP14)

Like patient/caregiver 13, patient/caregiver 14 is vested in his partner's health. So, he

attended his doctor's visits to ensure his viral loads were undetectable and to discuss treatment

planning with providers. When his partner achieved undetectable status, he said that was good

news.

He gave me the good news that he was undetected now since he's been here and

all that stuff and that he thanks me for that. So that's a good thing (PCP14).

At that time in the interview, I asked him what he thought his partner was thanking him for, and

he replied,

Being there for him when we went to the doctors to talk to the doctors and stuff

like he has a problem sometimes talking with the doctors. Like the last doctor's

visit, I pretty much spoke to the doctor for him to get his x-rays, his chest, all his

different stuff. . . (PCP14)

Caregiver Surveys. I collected surveys from the caregiver and patient-caregiver

cohorts to further delve into caregiver concerns. Research has shown that medication

adherence and low self-efficacy increase caregiver burden. In these instances, caregivers

welcome tools for adherence communication and medication education (Gichane et al.,

2018)**. The Family Caregiver Communication Tool was used to identify communication**

typologies of HIV caregivers in this study. The Family Caregiver Activation Tool was used

to assess caregiver self-efficacy regarding HIV medication management for their loved

ones. The surveys evaluated caregiver typologies to provide insight into patient/caregiver

communication needs. The FCAT offers a look into caregiver perceptions about transitions of care.

The FCCT results. The Family Caregiver Communication Tool has been used to tailor health communication to cancer caregivers. For this study, the tool measured HIV caregiver typologies to tailor health communication messages to this population. According to the survey results from this study, there were three types of caregivers: lone (4), carrier (2), and partner (2).

The FCAT results. The Family Caregiver Activation in Transitions tool measured caregiver self-efficacy in caring for a chronically ill loved one. In this study, caregivers expressed self-efficacy in most areas. Caregivers felt ill-prepared, however, in listing questions before medical appointments and listing, checking, and knowing medications. This finding indicates that patient-provider communication should be tailored to increase caregivers' self-efficacy in communicating questions and managing their loved one's medications.

Primary Category7: The Communication Needs of Caregiver Typologies. The literature has established that HIV caregivers are an underutilized resource used by healthcare providers. Since family/friend caregivers play a significant role in medication adherence, I decided to delve further into the topic of caregiver-related concepts. Two surveys provided additional insight into the communication needs of caregivers. One survey tool explored caregiver communication typologies, while the other explored caregiver perceptions about care transitions after hospital discharges (these tools are discussed in greater detail in Chapter 3). Together data from these tools can inform health communication praxis and theory by illuminating the reality of caregiver communication concerns and needs.

Table 1: Family Caregiver Communication Tool Results for Caregiver Types

Participants	Conversation Score	Conformity Score	Caregiver Types
P/CG 13	Low	Low	Lone
P/CG 14	Low	Low	Lone
P/CG 20	Low	Low	Lone
CG 24	High	Low	Partner
CG 25	High	Low	Partner
CG 26	Low	Low	Lone
CG 27	Low	High	Carrier
CG 28	Low	High	Carrier

Secondary Category 1: Lone Caregivers. Of the eight caregiver participants, fifty percent were lone caregivers. Twenty-five percent were carrier caregivers, and twenty-five percent were partner caregivers. These typologies have diverse health communication needs and preferences.

According to Goldsmith et al. (2015), lone caregivers typically focus on one aspect of care: physical. The lone caregiver is focused on treatment objectives rather than the quality-of-life outcomes and performs caregiving without family support or communication. This caregiver benefits from health communication that uses plain language. They do not care for large healthcare team meetings. The lone caregiver is responsive to questions such as "What gives you hope?".

Secondary Category 2: Carrier Caregivers. Carrier caregivers avoid discussing caregiving with family but will typically discuss it with others. This typology relies on the patient to make care decisions and assumes all caregiving tasks for the family. Carriers avoid talking about death or other alternatives other than a cure. According to Goldsmith et al. (2015),

carrier caregivers prefer communication that offers caregiver support and advocation that address the caregiver burden. These caregivers respond well to questions such as "What have you done for yourself today?".

Secondary Category 3: Partner Caregivers. And finally, the partner caregiver, in contrast to the lone caregiver, initiates conversations about death, dying, and quality of life. The partner caregiver accepts caregiving assistance from other family members and, shares and discusses the burden of caregiving patient and family. This caregiver type appreciates communication focused on education, the use of medical words and the teach-back approach. According to Goldsmith et al. (2015), the partner caregiver values large family meetings and responds to questions such as "What do you need from the team?".

Results from the FCAT revealed that caregivers expressed the least amount of self-efficacy among issues that involved medication knowledge and management. Research has shown that caregiver beliefs can undermine adherence outcomes (Gichane et al., 2018).

Selective Coding Procedure: Relationships and links

Upon discussion with my dissertation chair and re-analysis, I identified from the data, the most salient issues discussed among participants. I analyzed the axial categories to discover which codes would emerge as the selective categories. From this reanalysis, seven primary categories emerged: Illness Experiences, Medication, Illness Adjustment, Self-management, Health Education Needs of HIV Caregivers, Patient/Provider Communication Challenges for Patient/Caregiver Dyads, and The Communication Needs of Caregiver Typologies.

Primary categories were all connected to patient-provider communication because it is a constant intervention that translates medical knowledge into self-management support to help patients and caregivers achieve ART adherence. Patient-provider communication helped

140

participants to manage their illness, prevent future complications, and cope with the impact of both the disease and the illness. Some participants confessed that HIV was one of the best things that happened to them because, in trying to survive, they were empowered to take control over substance addiction and other chaotic or unhealthy lifestyles. In the face of adversity, participants outlined multi-dimensional levels of personal growth that allowed them to negotiate meanings in the HIV illness experience — they were able to turn a curse that some initially that was a curse, into a blessing. Relationships between concepts revealed greater insight into the phenomenon of medication adherence. These relationships are listed below:

1. Relationship: Illness Experience and Disease Symptomology. Many participants shared that they did not have symptoms for years. For many, it made it hard for them to accept that they were ill and needed medicine to keep from being sick. After bouts of illness or hospital stays, patients could grasp that they could not heal or recover until they took their HIV medicine. Also, some people had comorbidities such as cancer, which taught them that adherence to HIV medication meant also prevented other illnesses.

2. Relationship: Illness Experience and Social Circumstances. Participants expressed having to overcome social circumstances to improve their medication adherence. For some, if they were in an environment that was negative, it could impact their mood and motivation to live. This was exacerbated by the fact that they were struggling with gender identities, and many came from backgrounds of trauma and abuse. This all contributed to how well participants could cope and adapt to stressors such as HIV, medication management, and stigma.

3. Relationship: Medication and Illness Perceptions. Patient's perception of the illness strongly influenced their adherence trajectory. Patients who experienced strong feelings of shame from being homosexual or from being a substance abuser tended to use an avoidance coping approach. Also, patients who believed that the disease was manageable seemed to be quicker to use an approach coping mechanism for medication-taking. For many, medication adherence became an approach coping mechanism for dealing with the fact that they had HIV.

4. Relationship: Medication Knowledge and Education. Providers had to effectively communicate the value of preventive medicine. Taking ART prevented disease progression, new infections, and comorbidities. This helped participants to understand the value of taking a medicine that, for some, does not present any symptoms unless the patient goes years without taking it. In this healthcare communication model, the doctor is not paternalistic and, therefore, does not attempt to hold medical education under the guise of the doctor who knows best. Participants consistently provided accounts of thorough education about the disease, the illness, the medication, and multiple confounding issues from healthcare professionals who hoped to help patients and caregivers to succeed in HIV self-management.

5. Relationship: Medication Knowledge and Experience. According to participants, providers in the HIV care model validated laymen's experience and incorporated that knowledge into care plans that worked for participants, which allowed them to succeed in self-management

6. Relationship: Medication Management and Collaborative Partnerships Between Patients/Caregivers and Providers. Patients who reported having good collaborative

relationships with their providers seemed to have less experience with comorbidities and preventable hospital stays.

7. Relationship: Illness Adjustment and Self-Management. To become effective with self-management, patients developed skills. They addressed issues that are indirectly related to their disease or medication-taking so that they could adjust to living with illness. Also, narratives revealed that participants had to keep moving toward multiple objectives to achieve the singular goal of viral suppression.

8. Relationship: Patient-Provider Communication- Illness Experience. When a patient is diagnosed with a new illness, they are often overcome with questions and uncertainties. Information-seeking is a part of the initial process of dealing with an illness. Participants described how other people's perception of the illness largely influenced their initial reaction to their diagnosis. A provider presented facts without emotion and judgment, which participants perceived helpful. Patients who received disease and treatment education from experts could perceive that a very scary disease such as HIV could be manageable.

9. Relationship: Patient-Provider Communication- Medication-Knowledge/Experience. Patient-provider communication was important for educating patients about their options so far as treatment. Challenges such as chaotic lifestyles and comorbidities made it paramount for the patient and providers to collaborate on treatment plans. Patients provided feedback about their medication experiences to the provider so that problems could be identified, and treatment modified. Providers were willing to consider Lifeworld's concerns while planning care to personalize care plans toward adherence success. The provider's willingness to meld the world of medicine with the

participant's lifeworld had a direct impact on the patient/caregiver's willingness to communicate openly about their medication-taking experiences. For one participant, his initial concern was whether he could continue to drink alcohol while taking HIV medicines. His provider listened to his concern and advised him on how to take the medicine while drinking alcohol. This fortified the patient's ability to trust his provider and continue in treatment.

10. Relationship: Patient-Provider Communication- Illness Adjustment. The literature has well established that adjusting to illness is a process. That adjustment does not happen in one day or with the accomplishment of one task. Providers are social actors for change because they are equipping and developing a patient to recognize symptoms, adjust behaviors, and communicate with experts about their needs and desires regarding their drug regimen and their lifestyle priorities.

11. Relationship: Supportive Provider Communication- Self-Management. Provider communication helps to develop self-efficacy in patients and caregivers. As patients/caregivers go in for their check-ups, their ability to self-manage is evident in treatment biomarkers such as viral loads, t-cell counts, and the status of other co-morbidities. The provider, according to narratives, affirms what the patient is doing, which builds their self-efficacy to the point that even if they do not reach treatment goals, their confidence in their ability to make changes is enhanced through affirming communication received during medical visits. The patient leaves that visit knowing that they have six months to further improve their self-management skills or their health.

12. Relationship: Collaborative Patient-Provider Communication- Troubleshooting In Medication Management. As established in previous chapters, many patients do not receive support for medication management as many providers do not follow up with the patient's medication-taking until there is an adverse event such as a hospitalization or unless the patient presents to the doctor's office with symptoms. In this study, participants shared that the provider listened to their experiences and adjusted treatment until the patient had minimum side effects and achieved viral suppression. Unlike other healthcare models I have witnessed as a nurse, providers are very engaged with medication-taking issues and utilize feedback to adjust treatment recommendations.

13. Relationship: Patient-Provider Communication and Caregiver/Patient Couples. This Study Had a Small Cohort of Patient-Caregiver Couples. Those narratives revealed how interwoven their clinical communication could be. When sexual relationships are involved, it was important to protect the other, and it was important for each partner to be informed of the other's health status. Providers had to use communication strategies to best manage multiple patient issues and to meet the unique communication needs of patient/caregiver couples and of uncoupled patient/caregiver teams.

14. Relationship: Patient-Provider Communication and Caregiver Typologies. Narratives reported that when dealing with patient/caregiver dyads, either the patient or the caregiver is the lead. The cohort for the study was too small to infer this to all patient/caregiver dyads. Still, in this instance, the provider needs to understand the

caregiver typology so that the expert can tailor health communication to the primary

decision maker, which may not always be the patient or the patient alone.

Patients and caregivers learned that with information and support, they could overcome

the challenges of disease, illness, and medication nonadherence. Providers were able to improve

the outcomes of patients and caregivers by using health communication as a medical

intervention. Throughout the illness experience, practitioners have a profound influence on

health outcomes through the process of health communication, education, and promotion.

Final Analysis Phase: Theory Development

Throughout the data analysis process, diagrams were drawn on notes and dry-erase

boards to explore connections that might lead to adherence theory. I worked and reworked causal

relationships and influencing factors to grasp a better understanding of medication-related issues

and, ultimately, medication adherence/nonadherence. I grounded my conclusions in participant

narratives to depict true and relevant findings.

After primary and axial coding, I suggest an initial model to identify relationships

between factors regarding the social phenomenon of treatment adherence. After the selective

coding phase, primary and secondary categories revealed different connections and links that

caused me to edit the initial model to a new model that reflected the emerging theory. The model

describes events during the adherence trajectory and their consequent effects on adherence

outcomes.

Theory of Adherence Communication Throughout the Chronic Illness Trajectory

Patient-provider communication in chronic disease management affects adherence

outcomes. Communication was an intricate part of the chronic disease experience, from

diagnosis to treatment adherence. I will discuss what critical elements of communication addressed medication nonadherence throughout the treatment experience.

Participants described how scary the HIV diagnosis was. Many contracted the disease in the early days of the pandemic when treatment was uncertain. After participants received an HIV diagnosis, they relied on their providers to share information about treatment and the disease. Also, because the HIV disease carries such heavy social consequences, providers linked participants to supportive social services which directly supported adherence tasks. The clinical communication participants received after their diagnosis enabled them to adjust to the illness until they eventually achieved ideal HIV health outcomes, such as taking just one pill and being virally suppressed.

Providers delivered information at diagnosis and elicited patient narratives to assess medical history and patient health literacy to identify barriers in treatment management. Then as patients began to take medicines, providers worked collaboratively with patients and caregivers to manage medication side effects and illness complications such as symptoms. Participant narratives illustrated the importance of the patient/caregiver-provider partnership. The partnership relied on open communication and feedback to achieve health outcomes such as viral suppression by addressing the person's overall well-being. According to participants, providers quickly referred them to healthcare personnel to address mental and social aspects of self-care, such as substance abuse and homelessness. Many participants shared that medication adherence became less complicated once they addressed psychosocial issues. But these interventions could only be provided because patient/caregiver/provider partnerships went beyond biomedical questioning about the disease to explore the patient's overall environment. As participants engaged in treatment and reported feedback to providers, the HIV care team adjusted treatment

to meet the needs of the participants. With this knowledge, health communication interventions through the chronic illness trajectory reduced struggles with nonadherence, preventable comorbidities, and deaths. While the literature acknowledges that provider communication is a key determinant of medication adherence, the development of adherence communication models is lagging. Further research into adherence communication theories could advance modern medicine, lower healthcare spending, and improve mediation adherence among those living with HIV.

Future research in adherence communication could use participatory research methods to examine the experiences of people taking medicine and identify communication interventions that could improve adherence outcomes during different times in treatment. The impact of communication interventions to support patient adherence has great potential to empower patients to live well with chronic conditions.

The news of being infected with HIV was often traumatic and disruptive to participants' lives. Providers used collaborative communication and shared decision-making to create trust and partnership with patients and their loved ones during what many described as a time of crisis. This trusting relationship helped patients recover from a devastating life event to achieve treatment adherence and high quality of life. Providers empowered patients to become actors in their fate by holding them accountable and challenging them to master self-management skills.

Conclusions

Participants illustrated that their adherence journeys had some similarities, were notably different, and were often nonlinear. Caregiver data revealed that HIV caregivers have different approaches to communicating with family and healthcare providers and report low self-efficacy in medication management when caring for loved ones. Overall, research results revealed

variabilities in how participants responded to illness over time, indicating that personalized communication is a necessary intervention for self-management support in chronic care for patients, caregivers, and patient-caregiver dyads. In this study, some participants' diagnosis narratives started in the backdrop of chaotic lifestyles such as drug abuse, high-risk sex, partner abuse, homelessness, and poverty. Many participants were poor black, gay, or transgender and living in the South. This demographic had a more challenging time establishing that they wanted to live and were worth saving. Many of these participants experienced shame and guilt from their diagnosis because their families attributed their illness to lifestyle choices such as homosexuality, drug use, or otherwise. These participants reported a more challenging time committing to behavior change. Therefore, the context of how the person got HIV sets the tone for how they seek health after the diagnosis. Knowing the circumstances of the diagnosis narrative may predict obstacles that the person may have to overcome. For instance, participants who had strong social support or had family members whom they could share the disease with adapted to the illness faster and with less denial coping, which led to fewer disease complications and preventable hospitalizations.

Constant comparison analysis was exercised to discover seven primary categories emerging from the open codes. This study summarizes the contributing factors that motivate participants to achieve viral suppression: (1) Illness Experiences, (2) Medication, (3) Illness Adjustment, (4) Self-management, (5) Health Education Needs of HIV Caregivers, (6) Patient/Provider Communication Challenges for Patient/Caregiver Dyads, and (7) Communication Needs of Caregiver Typologies. Health communication interventions provided pivotal communication between patients and caregivers that helped them to adaptively cope with

illness experiences and challenges with medication adherence. Chapter V includes the discussion and conclusion.

Summary

To better understand the phenomenon of medication adherence, I conducted a qualitative grounded theory study with the lens of social constructivism to explore the narratives of 28 HIV-positive patients, caregivers, and patient-caregiver dyads. I analyzed transcribed data, memos, and notes to follow the four steps grounded methodology: 1) primary open, 2) axial, 3) selective, and 4) theoretical coding to conceptualize categories to deliver insight into the phenomenon of medication adherence.

I began with open coding categories, which I further analyzed during axial coding and combined into seven primary categories among patient, caregiver, and patient/caregiver dyads: Illness Experience, Medication, Illness Adjustment, and Self-management. The first primary category, Illness Experience, had three subcategories: Diagnosis Narratives, Stigma/Social Isolation/Disclosure, and Lifestyle Choices/Nonadherence/Illness Consequences. The second primary category, Medication, had three subcategories: Medication Knowledge and Experience, Medication Beliefs, and Medication Attitudes. The third primary category, Illness Adjustment, had three subcategories: Controllability, Cognitive Reappraisal, and Accountability. And the fourth primary category, Self-management, had seven subcategories: Communicating Needs, Problem-Solving, Self-Regulation, Self-Actualization, Psychosocial Coping, Disclosure Communication, and Controlling Social Environment. The next categories began primary codes for caregiver themes. The fifth primary category, Health Education Needs of HIV Caregivers, had no subcategories. The sixth primary category, Patient/Provider Communication Challenges for Patient/Caregiver Dyads, had no subcategories. And finally, the seventh primary category,

The Communication Needs of Caregiver Typologies, had three subcategories: Lone Caregivers, Carrier Caregivers, and Partner Caregivers.

I understood the relationships between categories during the selective coding stage, which led to the theoretical coding analysis phase. The following core ideas can describe the theory:

1. Providers should assess social factors that contribute to participants' illnesses. Many participants told stories of trauma, poverty, and isolation. These circumstances often increase health risks and should be addressed to help the patient become well. Those basic needs from Maslow's Hierarchy should be met before providers expect patients to focus on higher-level functions such as medication adherence.

2. Patients with narratives of loss and trauma need social support as much as medical guidance. Providers must be vigilant in integrating psychosocial interventions with patients who may be traumatized or lack social support.

3. Patients and caregivers need supportive communication from providers when diagnosed with a chronic illness. Supportive communication includes active listening and information sharing — a non-paternalistic approach that facilitates patient empowerment is necessary to build the patients' and caregivers' capacity to self-manage.

4. Health education buffers patients and caregivers from the fear of the unknown and misinformation from family and the public. Patients and caregivers may have misperceptions about the disease and treatment, and this needs to assess in the initial medical consultation, so patients'/caregivers' health education needs can be addressed. Informed patients/caregivers can make informed decisions.

5. Patients'/caregivers' medical knowledge, life experiences, values, beliefs, coping skills, and past trauma affect their ability to receive, recall, and communicate information. Providers must engage patients in clinical discussions and decision-making. With each autonomous decision, the patient commits to treatment on some level until they become optimum self-managers.

6. HIV Patients and caregivers experience distress from the stigma of HIV, which influences health-seeking behaviors, including medication adherence. Providers must continue to educate patients/caregivers and socialize them with the disease by introducing multi-dimensional, interdisciplinary interventions to help integrate new ideas and decrease stress and anxiety (both of which are barriers to adherence)

7. The first step to fixing problems is identifying them. Providers must include this skill-building in medical consultations. Participants shared that they had follow-up visits to test viral loads and to determine if treatment planning was reaching therapeutic goals. Empowering patients to identify problems to address improves their overall coping skills. It facilitates adaptive coping behaviors, which sets them up to be effective self-managers as it builds autonomy, agency, and self-determination. Empowering patients to cope with illness includes helping and working with them to develop living plans.

8. Healthcare plans do not work unless the patient and caregiver agree. Participants must know that their adherence plan is feasible for their life. Adherence planning needs to incorporate the context of their life so that they can continue to be "them" and fulfill valued social roles such as mother, employee, friend, lover, etc. Some narratives reported that their provider had to plan around substance addiction or sexual promiscuity until the

participant could gain the skills necessary to regulate. Providers had to be patient and allow patients to develop the will and capacity to adhere.

9. Providers must actively listen to patients to assess them for their needs. Listening to the patient's story allows providers to provide social medicine interventions because they have some insight into the person's social life. This may mean stepping away from guided questioning toward narrative medicine, which allows the patient to tell their story. Asking questions from a biomedical perspective provides a small window into the factors participants face when attempting to adhere to treatment recommendations. Many challenges patients and caregivers need to overcome to become medically adherent are social, emotional, and psychological. Providers cannot learn this in a medical consultation that they lead and dominate through prompted questions. Listening to patient/caregiver narratives allows the provider to determine which intervention to use to promote increased social support, improved socioeconomic status, improved health literacy, greater access to resources, and considerations for coping and resiliency traits.

10. Providers must value laypeople's knowledge and experiences to remain open to complementary therapies outside conventional medicine when permitted. If the patient believes supplements or journaling can improve their health, the provider should affirm this belief and facilitate the action plan when possible.

The conclusions from this study can be applied to understand how health communication interventions support optimal adherence. The implication of the proposed theory includes contributions to the existing literature, contributions to nursing education/recommendations, study limitations, and recommendations for future research. These implications will be discussed in Chapter V: Discussion and Conclusions.

Chapter V: Discussion and Conclusions

Before this study, I understood that medication nonadherence presented health risks to HIV-positive patients. As a nurse and researcher, I studied this topic as a graduate student exploring providers' insights into medication nonadherence. That study project concluded that provider communication was a strong determinant of medication adherence. This led me to explore the topic as a Ph.D. student examining the emic perspectives of patients and caregivers. I explored a panoramic view of the phenomenon from many perspectives; I interviewed patients and caregivers to learn that nonadherence was a normal part of treatment management that should not cause providers to doubt their patients' desire or ability to be healthy. While each participant's struggle differed from the next, each narrative told stories of how collaborative planning between healthcare team members and participants addressed treatment challenges to preserve life. Also, from this study, I learned that what I understood as a nurse and researcher were very different from the lived experiences of HIV-positive people and their caregivers. Emic perspectives from patients and caregivers revealed how participants valued provider communication during treatment's highs, lows, and plateaus. While other studies have validated that patient-provider communication is a determinant of adherence, this study explains why. Participants described provider communication that activated, engaged, and supported them in their journey to live well with the disease.

This study explored the medication-taking experiences of patients and caregivers. Twenty-eight participants contributed to this study by sharing their narratives. Findings from this grounded theory research study can be applied to health communication praxis via the development of adherence communication theories and models. A discussion of the significant conclusions as it relates to future implications for the Health Communication praxis and research

155

is detailed in this chapter. This chapter concludes with a discussion of the limitations of the study, areas of future research, and a summary.

This study's concepts are the building blocks of the selective codes and core categories. The concepts are organized into selective codes, which are broader and more abstract. The core categories in this study are Illness Experiences, Medication, Illness Adjustment, Self-Management, Health Education Needs of HIV Caregivers, Patient/Provider Communication Challenges for Patient/Caregiver Dyads, and Communication Needs of HIV Caregiver Typologies. I used theoretical coding to examine relationships between the core categories.

After an extensive review of participant interviews, surveys, notes, and other materials and the completion of primary, selective, axial, and theoretical coding, it became apparent that providers used health education to activate patients, collaborative decision-making, and treatment planning to engage them into treatment recommendations to which they could agree, and finally, providers used communication for capacity building tasks such as problem-solving to empower patients to self-manage treatment. These communication strategies were a consistent theme among narratives and enhanced participants' illness and medication experiences.

This study revealed how providers ascertained social assessments when actively listening to unstructured patient dialogue and narratives. In the traditional medical conversation, the provider dominated the conversation, and patients or caregivers commonly provided the information requested through biomedically focused lines of questioning. This study revealed how unstructured narratives provided a complete view of the patient and their social world. These conversations revealed serious barriers to treatment such as psychological trauma, addiction, and other social issues that undermined treatment adherence which may have not been revealed through biomedical questions about the disease or body.

156

For example, one participant in this study spoke about the difficulty of becoming medically adherent while also dealing with multiple psychosocial stressors. This participant shared that as he was addressing these compounding issues, he could get on track with medication adherence because his provider assessed him for social support. This participant discussed how his provider helped him to address homelessness, poverty, and substance addiction while tackling medication non-adherence.

Another participant spoke about attempting medical adherence while struggling with alcoholism. He needed support from his provider to be cognizant of the medication having to be taken within "windows" to reach a therapeutic effect. As the participant saw the results of his "adherence," he went on to higher and more challenging tasks such as sobriety and, eventually, self-care.

One participant discussed his challenge with high-risk sex. Rapport with his provider allowed him to report lapses in his behavior. Trust and open communication allowed the provider to mitigate risks by prescribing the appropriate testing and medication to address sexually transmitted diseases that complicated the participants' ART treatment. Each time these lapses happened, the provider could reinforce health education and promotion until the patient internalized this information and manifested it into self-protective actions like using condoms or avoiding high-risk sex.

Another participant discussed how he spent several years avoiding HIV medication because he had doubts about its efficacy. A provider remained patient with the participant and respected his autonomy and self-determination not to take ART. The provider treated opportunistic infections and comorbidities with antibiotics and antifungal agents until the participant accepted that he needed ART to resolve all his immunity-related comorbidities, such

157

as Kaposi's and cancer. This experience allowed the patient to make the connection that ART made him healthy. Once the patient realized that HIV medication helped him to heal and resolve opportunistic infections, he became intrinsically motivated to take his medicines and eventually went from having AIDS-related complications to just taking one pill a day to manage his HIV.

Contributions to the Existing Literature

Results from this study are consistent with the literature on the value of trust relationships between patients, caregivers, and providers (Brown et al., 2016). Results also emphasized that patients preferred patient-centered communication and collaborative information sharing between patients/caregivers and providers regarding treatment planning and medication adherence (Molassiotis et al., 2007). The literature revealed, in addition, that these communication practices have been associated with treatment adherence (Schoenthaler et al., 2017).

Results from these study support findings from the literature that the major components of practical self-management training are managing psychosocial factors such as coping styles, decision-making, and stress management. Addressing impaired coping through patient-centered health communication enhances self-management success (Quinn, Toms, Anderson & Clare 2015). Effective communication behaviors such as patient/caregiver-centered communication, information sharing, and collaborative problem-solving from providers are essential to promoting medication adherence among patients and caregivers managing chronic conditions (Glenn et al., 2021)

Results from these study support findings from the literature that health literacy empowered patients and caregivers to participate in clinical communication. Many participants appreciated the providers' thorough education about the disease, medication, and the resources

available through social/supportive services. Health information can be complex, and challenges hamper individuals' self-efficacy to participate in shared decision-making. Patients with limited health literacy have poor recall of health information and perceived low self-efficacy in understanding and using prescribed medication, and are more likely to disengage in the treatment communication (Palumbo, 2015). Once informed and prepared, participants engaged in the challenges of living with a chronic condition such as HIV. Training patients to collaborate with providers prepared them to practice greater agency, allowing them to become actors in their narratives.

This study revealed that agency is a fundamental concept in the self-management process. Compared to more traditional healthcare delivery models in which the patient is acted upon and left out of conversations about their health, chronic disease demands that the patient/caregiver act with purpose and self-determination achieve an outcome. In this study, patients and caregivers practiced agency in their narratives once informed about the disease, illness, and treatment. Other aspects of agency included patients' ability to speak "their truth" to receive the needed care. These aspects of clinical communication should be encouraged and reinforced so that honest and transparent communication can occur in clinical settings. Provider communication, in this study, helped participants organize and mobilize ideas to modify behaviors and manage their illnesses. Healthcare providers must be prepared and equipped with health communication skills to improve adherence among those living with HIV.

Most research on medication adherence from the patients' and caregivers' perspectives does not emphasize theory-based patient/caregiver-centered communication models. Communication strategies to promote patient self-management have been suggested (Boxer & Snyder, 2009). The REDE Model of healthcare communication was created to train healthcare

professionals to optimize relationships between patients and providers (Windover et al. 2014). Still, no specific communication model for treatment adherence has been designed to guide health communication praxis for patients, caregivers, and providers managing chronic conditions. An evidenced-based communication model for palliative care called the COMFORT Model has been used to educate patients, caregivers, providers, families, and communities about cancer treatment and palliative care. It is a health communication model that approaches health education and interaction from all perspectives. Such a model in chronic care would have many implications that could enhance adherence outcomes, healthcare delivery, and health outcomes.

Contributions to Nursing Education/Recommendation

Based on the findings from this study, including participant accounts of what they perceived to be most helpful to their adherence journey, I formalized some ideas from what they communicated to be their most salient experiences and concerns in treatment. Pre-treatment included the patient's initial consultation and would be a practical intervention point for multiple healthcare professionals.

Pre-Treatment Period. The pre-treatment period covers the patient's initial consultation during or after the diagnosis. It is the visit where many participants said they received education about the disease and talked to the physician about proposed medications and treatment plans. Overall, all participants expressed the importance of the provider establishing rapport by talking to them as a person. The provider described this quality by asking questions about the person, their social circumstances, fears and concerns, and their needs. Participants expressed that this visit laid the foundation for rapport with their healthcare team so they could comfortably divulge personal information and ask questions. According to participants, providers did not dominate the conversations with interruptions and biomedical closed-ended questioning. Instead, providers

listened to assess patients and caregivers for social support systems, coping skills, mental health and resiliency, and health literacy.

Pre-treatment risk assessment is vital before prescribing regimens. Many participants described having immediate concerns such as homelessness, hunger, poverty, substance addiction, and abusive relationships that presented risks to their ability to cope with and address the issue of being infected with HIV. Through the provision of resources, providers met these needs and satisfied these concerns. It was a great way to link transient populations to care.

The risk assessment also allowed providers to assess coping skills. A patients'/caregiver's coping style presents barriers to treatment. If the patient has an avoidance coping style, they will need additional emotional support. They may need interventions for maladaptive coping behaviors such as binge drinking, substance abuse, or having high-risk sex. This assessment allowed healthcare teams to mitigate the risks of new transmissions and disease progression for the patient through psychosocial support, treatment, health education (information about drug resistance and other dangers), and health promotion (medication adherence, maintenance, medical visits, and self-care).

Providers established rapport to facilitate a relationship of trust. Patients/caregivers may be racked with fear and anxiety about the HIV diagnosis. Calming, reassuring communication between patients/caregivers and their nurse has great potential for eliciting the patient's concerns. Because the nurse spends more time with patients and caregivers in acute settings than most other clinicians, the nurse should build rapport with the patient regarding questions they may have about a new diagnosis, such as HIV or another chronic disease. Patients will sometimes discuss more with their nurse than their doctor. While the nurse should continue to encourage the patient to participate in creating care plans and communicating with other

161

clinicians, the nurse can certainly play a role in assessing the patient through conversations. The nurse can then communicate needs and concerns to the physician or implement nursing interventions to help patients provide truthful feedback about their medication experiences. In this study, open communication between patients, caregivers, and providers allowed the partnership to solve the inevitable problem of patients becoming new self-managers of an illness. Establishing rapport provided the best foundation for patient/caregiver/provider collaboration. Without establishing rapport, the patient has a high likelihood of treatment non-adherence. Patient-provider connection made space for cooperation, informed consent, engagement, and, ultimately, patient empowerment.

Nurses can also be informed in how to request social services for patients living with HIV. Participants described that linking patients/caregivers to peer mentors and support groups was perceived to be helpful by all participant groups. Peer mentors and HIV support groups helped socialize patients/caregivers to the HIV experience. It helped to normalize the disease, which reduced stress and improved coping. Through this aspect of treatment patients and caregivers were allowed to build networks for treatment success.

Course Content Recommendations

In nursing school, therapeutic communication was taught. Therapeutic communication principles teach the nursing student to talk to the patient without judgment. A communication model for adherence conversations would emphasize the importance of eliciting the patient's narrative, assessing the social determinants of the patient's illness, while also teaching the patient about their disease. Also, as a nurse, talking to the patient about their role in clinical communication in chronic disease management is essential. This aspect of chronic disease treatment should be emphasized in nursing school curriculums. In contrast, to traditional patient

roles, the patient's role in chronic disease management is to collaborate and co-create care plans by asking questions, voicing their concerns and needs, and self-determining health and life goals.

High-fidelity simulation training for nurses and other healthcare professionals could develop communication skills that effectively support self-management training with patients and caregivers. Communication tasks with patients or caregivers are not simulated in the current nursing school curriculum as simulations in nursing school tend to focus on critical care tasks such as clear clinical communication between healthcare professionals during acute healthcare situations. Hospitals require nurses to provide educational interventions every shift, but this does not always include training in medication management. Research reveals that nurses are poorly prepared to deliver effective patient-centered communication that can impact patients through health education.

The results from this study agree with the current literature that coping approaches predict adherence behaviors. Participants with denial coping tended to report more illness consequences from treatment noncompliance, whereas patients with approach coping tended to accept their diagnosis and engage in treatment recommendations. The considerations mentioned above, should be at the heart of self-management training in nurse training curriculums.

Contributions to Health Communication/Praxis

Findings from this study can be applied to an adherence communication model. As the leading causes of death come from chronic diseases, this model can help patients and providers to achieve excellent health. Under the guidance of my head committee advisor, who has done extensive work on evidenced-based communication models for the terminally ill, I propose a communication model for chronic care. A model for communicating about adherence has the

potential to impact and improve the current healthcare model by reducing preventable deaths, comorbidities, and hospitalizations.

A communication model that supports effective self-management and treatment adherence would need to be based on theoretical assumptions to design interventions; research could be performed and inferred to large populations. Creating a communication model for chronic disease management would highlight the vital role of health communication in the self-management training of patients and caregivers living with HIV and other chronic conditions.

A communication model designed for chronic conditions would be distinctive from other models of patient-provider communication because it emphasizes the partnership between patients, caregivers, and providers in collaborative treatment planning. Adherence training would require professionals to offer holistic care that satisfies the biomedical and biopsychosocial conditions and significantly activate, engage, and empower patients to self-manage chronic conditions. It would be novel to the acute care visit by which the doctor asks biomedical questions, performs diagnostics, prescribes medications, and then the patient is cured. "Adherence" communication requires far more involvement and skill because it is for the long haul and builds laypersons to become agents of their health and well-being.

Adherence communication emphasis could be addressed at an institutional level by teaching physicians, nurses, etc., to support medication adherence and self-management using health education and health promotion that encourages and reinforces lifesaving medication-taking behaviors among patients. I understand as a nurse that "adherence communication" does not happen in the hospital and remains a poorly understood phenomenon by healthcare professionals and patients alike. More research about this health communication domain could advance health communication practice and research.

Interpretation of the Findings

In summary, to answer the research questions, participants in this study consistently described HIV as a life-defining event. Many thought they would die and certainly experienced the social consequences of the stigmatizing disease. After struggling to accept and cope with the fact that they had HIV, participants generally described ART as a second chance at life.

Participants described patient-provider communication as the cornerstone of their treatment success. Health education informed participants of HIV controllability and empowered participants to change. Productive medical consultations assess the needs of patients and caregivers for referral services. A physician's willingness to make referrals to supportive services increased participants' capacity to manage the cognitive and emotional stressors of the HIV disease, which significantly improved participants' ability to adhere to treatment plans. Participants reported instances in which multidisciplinary healthcare teams (doctors, nurses, social workers, peer navigators, mental health providers, etc.) gave them the skills and tools necessary to become effective self-managers. Participants evolved to achieve viral suppression and expanded their self-management skills to actualize a new and better self. These processes were dynamic, nonlinear, and contextual.

This discussion remains committed to illuminating the experiences of those living with HIV with the sole intention of improving health outcomes for patient populations living with chronic illness. While this study is in the context of the HIV population, some findings will be relevant to different disease populations managing chronic conditions. The results of this study helped to answer the following research questions:

RQ1: How do HIV patients and FFCs define and understand the concept of adherence?

RQ2: How do patients and FFCs conceptualize the HIV disease process and treatment?

RQ3: What aspects of the medical world do HIV patients and FFCs identify as supportive and central to begin, adhere to, and persist in treatment?

RQ4: What elements of the lifeworld day-to-day lived experiences do HIV patients and FFCs identify as substantial determinants of the beginning, adhering, and persisting in treatment?

RQ5: How are FFCs describing their role in treatment?

RQ1: How do HIV patients and FFCs define and understand the concept of adherence? As a nurse, I assume that patients and caregivers automatically make the connection that illness experiences improve with medication adherence. But this assumption contradicts what participants shared in their narrative. On several occasions, I had to explain the definition of adherence to many participants. I took from this nuanced perspective that adherence is more of a clinical term widely used by providers. Participants speak more to have they live than how they handle their medicine. It's a nuanced perspective that could easily be the source of discordant beliefs and objectives between laypersons and healthcare professionals. Participants described what they accomplished from adherence, such as taking just one pill, living to be there for their loved ones, or avoiding other diseases and preventable hospitalizations. Participants rooted the word adherence into the context of being able to live and get on with their lives beyond the disease/illness. Adherence to ART was intermingled with quality of life and social issues. At least initially, until providers build the value of adherence to the patient, they should mirror the definitions of the patient so that they are speaking the patient's language until they begin to understand the value and meaning of adherence—this a fundamental principle of the communication accommodation theory.

FFCs, in comparison, appeared to focus more on adherence management and tasks than patient participants, who appeared to concentrate on illness experiences such as symptoms and

166

stress management. While their foci eventually merge because adherence is the vehicle capable of optimizing treatment management and decreasing the experiences of disease-related stress and symptom occurrence. Their goal was to prolong the life of their loved ones. Adherence seems that the patient participants may have felt the psychosocial and emotional burden of the disease more deeply than those who were caregiving. The objectivity of some caregivers appeared to help patient participants to lean more toward action-coping rather than emotionally based coping, which is most often associated with maladaptive coping.

RQ2: How do patients and FFCs conceptualize the HIV disease process and treatment? Patients and caregivers alike conceptualized the disease by illness experiences. Some of those experiences were physiological, psychological, and social. Depending on the subjective context of these experiences, participants had different coping responses to the disease. Coping responses varied between avoiding or addressing HIV stressors. Factors such as health literacy and social support played heavily in coping responses. Some people identified HIV as a restorative story in which they were forced to change destructive behaviors such as substance abuse or high-risk sex, while others still saw HIV as a detrimental aspect of their existence because they experienced abandonment and rejection and the loss of the valued self-identity of being wed to be a less complicated concept for them as it did not require the caregiver to change their behavior — the loved ones alone had to commit to behavior change.

In contrast to the caregiver's perspectives, their conceptualization of the disease and treatment most often reflected their loved one's perception of the illness. Caregivers have front-row seats to how the disease and its treatment impact their loved one's quality of life. The more that the healthcare team and family were able to make treatment fit into a person's identity and energy, the more likely the caregiver and participant were able the healthcare team and family

167

were able to make treatment fit into a person's identity and life, and the more likely the caregiver and participant were to have adaptive coping responses to the illness.

RQ3: What aspects of the medical world do HIV patients and FFCs identify as supportive and central to begin, adhere to, and persist in treatment? Participants and caregivers identified provider communication as the most supportive aspect of the medical world in the chronic care model. This communication, in the beginning, reduced the burden of information-seeking and buffered participants from the ill-informed information they would hear from society. Communication with providers gave participants actions and provided ways for the HIV-positive to protect other people from becoming infected. Providers, most importantly, empowered patients with information, supported participants with treatment planning and challenged participants with accountability.

Caregivers also identified provider communication as supportive of the HIV chronic care model. According to the survey responses, medication knowledge was a concern for most caregivers. The more the provider promoted open communication, the more confident the caregiver appeared to be in asking questions and asking for support to achieve treatment goals. For instance, one couple reported that their calendar and pill boxes (an intervention suggested by their provider) played a significant part in their adherence success. The couple said the provider helped them problem-solve and troubleshoot challenges with adherence.

RQ4: What elements of the lifeworld day-to-day lived experiences do HIV patients and FFCs identify as substantial determinants of the beginning, adhering, and persisting in treatment? Participants' narratives consistently reported many stressors involved with living with HIV. As a nurse and a researcher, I have witnessed that HIV can present an overwhelming psychosocial burden to patients and caregivers due to social stigma. It is a disease that shakes

168

people's worlds and identities. Participants in this study shared that they became equipped to control their thoughts and behaviors to stay on track with treatment, sobriety, and other issues that ultimately undermine treatment adherence. Managing the psychosocial burden of the disease became as detrimental as taking medicine.

Referral services were vital in supporting participants deal with challenges. Self-regulation skills helped participants break through barriers such as depression, substance abuse, and high-risk behaviors such as unprotected sex and intravenous drug use. These factors ultimately lead multiple narrators to not only reinvent themselves but also to reinvent their social environments and networks.

Regarding the lifeworld aspect of HIV caregivers, especially those who were lovers or life partners, they had to be involved and engaged in treatment to protect their health. Even for those couples who were HIV-positive, less than optimum adherence presented risks to the other partner's health. Patient/caregiver narratives revealed that communication skills were necessary to promote and maintain healthy and supportive relationships between patient/caregiver dyads.

RQ5: How are FFCs describing their role in treatment? Caregiver/patient-caregiver cohorts described their role as supportive? Communication between caregivers and participants influenced patient motivation to achieve viral suppression. Caregivers were instrumental in helping patients maintain their treatment focus on treatment. Caregiver and patient participants discussed how FFCs helped patients to remember to take their medicines, to keep medical visits, and notice changes in their medical status. Caregivers performed the vital role of objective observers of patient behaviors, catching potential medication management or self-care barriers. FFCs helped patient participants to regulate motivation and supported

functional tasks such as using a calendar to schedule medical visits and document how and when they are taking medicine.

Another aspect of FFC support is treatment planning. Caregivers can sometimes collaborate with providers and patients to create feasible treatment plans and answer questions the patient may not be able to answer. Then later, after the visit, many participants explained that the FFC helped with remembering information discussed during the medical visit.

Implications for Theory/Research and Praxis

Chapter II included descriptions of cognitive, behavioral, and communicative theoretical frameworks. Because nonadherence behaviors are multi-dimensional, these frameworks provide a lens by which to understand the phenomenon better. Theoretically, adherence, as well as non-adherence, is a coping behavior. In health communication, patient narratives genuinely have the power to illuminate the many novel concepts that support or undermine adherence.

The adherence literature sparsely discusses awareness about the necessity of adherence communication. There is a need for more exploratory research regarding dialogues between patients, providers, and caregivers about taking medicines so that providers can be prepared for challenges with non-adherence. Awareness of the communicative processes of adherence conversations is vital for improving HIV treatment outcomes and all chronic disease domains.

As praxis, chronic disease education must be emphasized as a clinical skill for practitioners treating people with chronic illnesses. I recall an incident with a patient who came to the acute care floor with a blood sugar of 1200. As I handed him his discharge papers, I asked if he had been referred to a specialist, and he said no. I asked him questions about insulin management, and his answers revealed that he did not understand how to monitor blood sugars or self-administer insulin properly. As his nurse, there was only so much I could do at discharge.

I worried that the patient would return to the emergency room with high blood sugar because the healthcare system had failed to provide educational support to this patient. This is a common practice among multiple chronic disease domains in acute care settings. The consequences are often fatal or debilitating. For the HIV patient, it could result in the spread of the infection, and for other patients, it could predict poor health outcomes and preventable deaths. A communication model for chronic disease management and adherence training for nurses and other practitioners could prevent poor health outcomes.

Limitations and Recommendations for Future Research

While the researcher agrees that qualitative research was the right choice for this study, a mixed methods approach could add greater credibility to this study. Also, based on the criteria of this study, all participants were in treatment and, therefore, mostly adherent. An analysis in which the requirements allowed a comparison or an exploration into the experiences of nonadherent patients might also be insightful.

Conclusion

The results of the study prove that health communication saves lives. Participants in this study reported complicated social circumstances that presented compounding barriers and stressors such as stigma, poverty, mental illness, addiction, social isolation, homelessness, and abandonment. Participants eventually could cope with HIV to manage the disease well enough to achieve wellness.

As a nurse and medical anthropologist, I have watched patients interact with providers, only to learn that communication is often subpar in clinical settings. I have witnessed physicians deliver a diagnosis without explaining what it means or without scheduling a follow-up visit to ensure the patient receives and engages in care. I have also seen patients and caregivers nodding

171

in agreement with the physician while talking, only for them to turn and look to me for understanding when the physician leaves the room. The patient does not understand, nor did they ask for understanding — in this reality how can patients and caregivers be expected to adhere to treatment? It is time to build an adherence communication model for chronic disease management. A theory-guided model for adherence communication could move healthcare forward in this era of chronic conditions. My objective in this research query was to suggest a communication model for adherence conversations between patients, caregivers, and providers. As a nurse, medical anthropologist, health communication scholar (Ph.D.), and an actor in this social phenomenon, I suggest an adherence communication model (ACM) that takes a patient-centric approach.

The patient-centric healthcare paradigm establishes partnerships between practitioners, patients, and their families by eliciting feedback from actual patients and their loved ones to make shared decisions about designs for treatment, research, and other health solutions. In the patient-centric ACM, providers would elicit patient/caregiver illness narratives to gather a holistic assessment of the patient they intend to care for as a person, not the disease. The provider would use information from the narrative to make referrals for supportive services and look for ways to decrease the everyday stresses and anxieties that accompany chronic disease diagnoses and often undermine adherence goals. Care providers would, in essence, be able to respond to patients and caregivers with a holistic plan of care that considers the patient's physiological, mental, emotional, financial, and social well-being. This would be a communication exchange in which the patient and provider are partners engaged in cocreating care plans to realize health goals most salient to the patient and their family. In addition, the patient-caregiver-provider partnership would enable the patient and their family to navigate the challenges that accompany

treatment in the context of life by adjusting care plans as needed to accomplish patient health goals. This mode of interaction stems from the UK NHS's school of thinking, "no decision about me, without me." To advance patient-provider communication to this collaborative model, some existing theoretical models could help providers, patients, and caregivers communicate more productively.

Informing this new adherence model would be the HCAT (Habermas' Communicative Action Theory), and the CAT (Communication Accommodation Theory) could inform curriculums to train providers, patients, and caregivers on collaborative interaction. The HCAT would clarify the new role of the provider to educate the patient about the disease and treatment options without the pressure to coerce the patient or caregiver to pursue a provider-centric ideal or goal. This communication strategy gives patients the information they need to make informed decisions that align with their values and goals. Also, the HCAT helps the interacting groups to keep in mind the other's worldviews (Lifeworld versus the Voice of Medicine) in the conversation. Understanding each other's perspectives allows for more transparent and translational communication that enables partners to negotiate adherence plans. The CAT is a framework that features the adjustment of nonverbal communication to accommodate each of their interlocutors. Accommodative strategies such as convergence can give patients, providers, and caregivers tools to adapt communicative behaviors such as accent, speech rate, smiling, gazing, pauses, and utterances to build rapport, respect, and trust. Paradigm shifts away from traditional notions of provider-driven and disease-focused health communication systems to a new culture of health communication that emphasizes patient and caregiver preferences, needs, and experiences could change the ethos of modern healthcare.

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APPENDICES

Appendix A: IRB Approval

Institutional Review Board
315 Administration Bldg.
Memphis, TN 38152-3370
Office: 901.678.2705
Fax: 901.678.2199
IRB #:
Expiration Date: Page **1** of **3**
Research Study Information Sheet

Medication-taking Narratives of People Self-managing Health

and Wellness in the Memphis Area

WHY ARE YOU BEING INVITED TO TAKE PART IN THIS RESEARCH?
You are being invited to take part in a research study because you have identified yourself as someone who self-manages
their health and wellness or the health and wellness of a loved one. This study is about the medication-taking
narratives of people who self-manage their health or the health of a loved one in the Memphis area. We
would like to examine the adherence experiences of participants. If you volunteer to take part in this study, you
will be one of about 11-20 people to do so.

WHO IS DOING THE STUDY?
The person in charge of this study is Lisa Dale, MA, BSN, RN who is a health communications doctoral student
(*Lead Investigator, LI*) at the University of Memphis Department of Communication. Dale can be reached at 901-
678-5458 or at lldale@memphis.edu. Her faculty advisor, Joy Goldsmith, Ph.D. (Co-Investigator, CI) from the
Department of Communication at the University of Memphis will work with Dale on this study.

WHAT IS THE PURPOSE OF THIS STUDY?
The purpose of this study is to examine the medication-taking experiences of participants who are actively taking
medicines or providing care for loved ones taking medicine. The goal of the study is to bring greater
understanding to the individual experiences of participants who actively strive to adhere to prescribed medicines.
The study goal is to contribute information that will develop adherence communication that is focused on
participant identified outcomes and health goals.

WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST?
Interview sessions will be held at ████████████████████████. Questionnaires will be passed out
after each audio-recorded interview to complete the session. You will fill out the questionnaires in a private room
with the lead investigator. The questionnaires and audio-recorded interviews will take approximately 60 minutes.

WHAT WILL YOU BE ASKED TO DO?
You will be asked to fill in a questionnaire about your demographics (age, gender, race) as well questions about
how you self-manage care for yourself or a loved one living. You will also be interviewed about your adherence
challenges and experiences. You will only share the information that you feel comfortable sharing. Shared
information will remain private and confidential.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?
To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience
in everyday life.

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No identifying information will be collected in the questionnaire. See the section below on "who will see the
information you provide?"

WILL YOU BENEFIT FROM TAKING PART IN THIS STUDY?
a) There is no guarantee that participants will receive any benefit from taking part in this study other than the $10.00 Kroger's gift card provided at the completion of the study. They will have the opportunity to reflect on their medication-taking experiences as well as the experiences of those around them.
b) Dissemination of these findings will contribute to future studies in health communication and literacy related to medication-taking tasks and the ways in which these concepts are studied, measured, understood, and discussed. Additionally, participant contributions may potentially inform interventions that play a role in supporting adherence to drug therapies among the Memphis population.

DO YOU HAVE TO TAKE PART IN THE STUDY?
If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you chose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering. You can also remove yourself from the study even if you initially participate in the interview collection.

IF YOU DON'T WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?
If you do not want to be in the study, there are no other choices except not to take part in the study.

WHAT WILL IT COST YOU TO PARTICIPATE?
There is no cost associated to take part in this study with the exception of 60 minutes of your time.

WILL YOU RECEIVE ANY REWARDS FOR TAKING PART IN THIS STUDY?
There will be a $10 Kroger's gift card rewarded to participants who complete participation in this study.

WHO WILL SEE THE INFORMATION THAT YOU PROVIDE?
We will make every effort to keep private all research records that identify you to the extent allowed by law.
No identifiable information will be collected in the questionnaire. If participants included identifiable information, the research team will de-identify the information before combining with information from other people taking part in the study.
When we write about the study to share it with other researchers, we will write about the combined information we have gathered. You will not be personally identified in these written materials. We may publish the results of this study; however, we will keep your name and other identifying information private.
We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. All the data will be stored in a password-protected computer within a locked room, and only the faculty researcher will have access to the room. We will keep private all research records that identify you to the extent allowed by law.
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CAN YOUR TAKING PART IN THE STUDY END EARLY?
If you decide to take part in the study, you still have the right to decide at any time that you no longer want to continue. You will not be treated differently if you decide to stop taking part in the study.
The individuals conducting the study may need to withdraw you from the study. This may occur if you are not able to follow the directions they give you, if they find that your being in the study is more risk than benefit to you, or if you become upset by talking about health issues. You would not be penalized for ending the study early.

WHAT IF YOU HAVE QUESTIONS, SUGGESTIONS, CONCERNS, OR COMPLAINTS?
Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions, suggestions, concerns, or complaints about the study, you can contact the lead investigator, Lisa Dale, at lldale@memphis.edu or at 901-678-5458. If you have any questions about your rights as a volunteer in this research, contact the Institutional Review Board staff at the University of Memphis at 901-678-2705 or irb@memphis.edu. We will give you a signed copy of this consent form to take with you.

WHAT ELSE DO YOU NEED TO KNOW?
While there is no risk to you beyond what you'd experience in everyday life, it is important for you to understand that the University of Memphis does not have funds set aside to pay for the cost of any care or treatment that might be necessary because you get hurt or sick while taking part in this study.

Appendix C: Patient/Caregiver Demographics

Demographics for Patient

1. Status of HIV treatment
In treatment
Not in treatment
2. Number of years living with HIV
<1 year
1-3 years
4-6 years
6+ years
3. Are you virally suppressed
Yes
No
4. Your age:
□ 20-30 years □ 31-40 years □ 41-50 years □ 51-60 years □ 61-70 years
5. To which gender do you identify most?
□ Female □ Male □ Transgender Female □ Transgender Male
□ Gender Variant/ Non-conforming □ other _____
6. Race/Ethnicity
Black
White
Other: _____
7. Primary Language
English
Spanish
Other: _____
2
8. Living Situation
Live Alone
With Family
With Spouse
Other _____
9. How much school did you complete?
Elementary School
High School or Secondary Education
College
More than College
10. Marital Status
Married or Partnered
Single
Other_____
11. Employment Status
Employed
Unemployed

12. Income
10,000 or less
10,000 or more
Prefer not to answer
13. Do you have a primary doctor?
Yes
No
3

Demographics for Family Caregiver

1- Relationship to Patient:
Parent
Child
Spouse/Partner
Sibling
Other: _____
2- Status of HIV participation
In treatment
Not in treatment
3- Number of years living with HIV
<1 year
1-3 years
4-6 years
6+ years
4- Is your loved one virally suppressed
Yes
No
6. Your age: _____
□ 20-30 years □ 31-40 years □ 41-50 years □ 51-60 years □ 61-70 years
7. To which gender do you identify most?
□ Female □ Male □ Transgender Female □ Transgender Male
□ Gender Variant/ Non-conforming □ other _____
5- Race/Ethnicity
Black
White
4
Other: _____
6- Primary Language
English
Spanish
Other
7- Living Situation
Live Alone
With Family
With Spouse
8- Education

Elementary School
High School or Secondary Education
College
More than College
9- Marital Status
Married or Partnered
Single
Other _____
10- Employment Status
Employed
Unemployed
Other _____
11- Income
10,000 or less
10,000 or more
12- Do you have a primary doctor?
Yes
No

Appendix D: Patient Semi-Structured Interview

Topic one: Conceptualization of disease and treatment

1. Please tell me how you understand HIV- the disease?

2. If you could describe your HIV when you were first diagnosed in the form of a picture or an image or a word, how would you describe or imagine it? How would you describe or imagine it now?

3. What does antiretroviral therapy mean to you?

4. What does adherence to antiretroviral therapy mean to you?

5. Where did you learn to manage HIV? What kinds of things did you learn?

6. What are some of your motivations for wanting to take ART?

Topic two: HIV self-management

1. What do you do to manage your HIV?

2. What were your symptoms at diagnosis? What were you feeling? What are your symptoms now?

3. Walk me through a typical day. What time do you wake up, exercise, eat, take your medications?

4. What do you do that helps you the most with your HIV?

5. How do you manage HIV symptoms? What are you thinking? What do you do?

6. What keeps you on track? What is your day-to-day plan

7. What happens when you get off track?

Topic three: Barriers and factors for success in HIV self-management

1. What's your biggest struggle you have with daily HIV self-management?

Appendix E: Caregiver Semi-Structured Interview

Topic one: Conceptualization of disease and treatment

1. Please tell me how you understand HIV- the disease?
2. What does antiretroviral therapy mean to your loved-one?
3. What does adherence to antiretroviral therapy mean to you and your loved-one?
4. Where did you learn to manage your loved-one's HIV? What kinds of things did you learn?
5. What are some of your motivations for wanting to support you loved-one's adherence to ART?

Topic two: HIV self-management

1. What do you do to support your loved-one's management of HIV?
2. What were your loved one's symptoms at diagnosis? What were they feeling? What are their symptoms now?
3. Walk me through a typical day. What time do time do and your loved-one wake up, exercise, eat, take your medications?
4. What do you do that helps your loved-one the most with HIV management?
5. How do you manage your loved-one's HIV symptoms? What are you thinking? What do you do?
6. What keeps you on track for caregiving? What is your day-to-day plan
7. What happens when your loved-one gets off track?

Topic three: Barriers and factors for success in HIV self-management

1. What's your biggest struggle you have supporting your loved-one with daily ART adherence?

Appendix F: The Family Caregiver Activation in Transitions Tool

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1. I am able to make sure my loved one goes to every scheduled medical appointment

DISAGREE STRONGLY	DISAGREE	DISAGREE SLIGHTLY	AGREE SLIGHTLY	AGREE	AGREE STRONGLY

2. I make sure a written list of questions is taken to each of my loved one's medical appointments

DISAGREE STRONGLY	DISAGREE	DISAGREE SLIGHTLY	AGREE SLIGHTLY	AGREE	AGREE STRONGLY

3. I know what things to watch for that would mean my loved one's condition is getting worse and how to respond

DISAGREE STRONGLY	DISAGREE	DISAGREE SLIGHTLY	AGREE SLIGHTLY	AGREE	AGREE STRONGLY

4. I maintain an accurate list of my loved one's medications

DISAGREE STRONGLY	DISAGREE	DISAGREE SLIGHTLY	AGREE SLIGHTLY	AGREE	AGREE STRONGLY

5. I have or will check with my loved one's doctor to make sure what medications my loved one should be taking (including how often and how much)

DISAGREE STRONGLY	DISAGREE	DISAGREE SLIGHTLY	AGREE SLIGHTLY	AGREE	AGREE STRONGLY

6. For every medication my loved one is to take I know when, how much, and how it is to be taken

DISAGREE STRONGLY	DISAGREE	DISAGREE SLIGHTLY	AGREE SLIGHTLY	AGREE	AGREE STRONGLY

7. I have a trusted pharmacist or pharmacy in my community that I can contact if I have medication questions

DISAGREE STRONGLY	DISAGREE	DISAGREE SLIGHTLY	AGREE SLIGHTLY	AGREE	AGREE STRONGLY

8. I keep a written record of my loved one's health conditions, allergies, medications, along with the names and phone numbers of treating health professionals

DISAGREE STRONGLY	DISAGREE	DISAGREE SLIGHTLY	AGREE SLIGHTLY	AGREE	AGREE STRONGLY

9. I understand which of the instructions in my loved one's care plan are most important and need to be completed first and which instructions are less urgent

DISAGREE STRONGLY	DISAGREE	DISAGREE SLIGHTLY	AGREE SLIGHTLY	AGREE	AGREE STRONGLY

10. If my loved one needs help from a healthcare professional, I am confident I can insist until I get what is needed

DISAGREE STRONGLY	DISAGREE	DISAGREE SLIGHTLY	AGREE SLIGHTLY	AGREE	AGREE STRONGLY

The FCAT tool was developed to foster more productive interactions between health care professionals and family caregivers.

Appendix G: Family Caregiver Communication Tool

Family Caregiver Communication Tool
Directions: Family can be your partner and/or children. Family can also be the family you were born into, like your parents/guardians and brothers and sisters. As primary caregiver for your loved one, think about the family that is connected to you and your loved one (patient). How many people are in this family? ____

1. I talk with my family, which can include online and text messages, about my loved one's illness.
Frequently (4) Occasionally (3) Rarely (2) Very rarely (1) Never (0)

2. After a medical appointment, I contact family members to share details of the visit.
Frequently (4) Occasionally (3) Rarely (2) Very rarely (1) Never (0)

3. Family members ask me about my loved one's illness.
Frequently (4) Occasionally (3) Rarely (2) Very rarely (1) Never (0)

4. My family talks about death and dying with our ill loved one.
Frequently (4) Occasionally (3) Rarely (2) Very rarely (1) Never (0)

5. My family talks about what might happen if treatment doesn't work.
Frequently (4) Occasionally (3) Rarely (2) Very rarely (1) Never (0)

6. My family lets me know that they expect me to take care of my loved one and that I am to do most of the caregiving.
Frequently (4) Occasionally (3) Rarely (2) Very rarely (1) Never (0)

7. When I am stressed from caregiving, I prefer to hide this from family members.
Frequently (4) Occasionally (3) Rarely (2) Very rarely (1) Never (0)

8. My family hides their opinion about the quality of my caregiving.
Frequently (4) Occasionally (3) Rarely (2) Very rarely (1) Never (0)

9. My family tries to act as though my loved one is not ill.
Frequently (4) Occasionally (3) Rarely (2) Very rarely (1) Never (0)

10. My ill loved one lets me know that he/she expects me to provide care and do most of the caregiving.
Frequently (4) Occasionally (3) Rarely (2) Very rarely (1) Never (0)

Instructions for scoring the Family Caregiver Communication Tool (FCCT)
Overview
The FCCT is a valid and reliable instrument for obtaining information about the frequency, range, and congruence of communication within the patient's family. It is composed of two subscales: conversation and conformity. The FCCT is a 10-item instrument completed by the primary family caregiver about their communication with family about the patient's illness and values and beliefs about caregiving. The purpose of FCCT is to conclude a specific caregiver type. Below are instructions for scoring the FCCT.

Scoring instructions for the FCCT
A family caregiver type is computed as follows:
1. Add items 1-5 to calculate the score for conversation.
2. Add items 6-10 to calculate the score for conformity.
The maximum range of scores for each subscale of the FCCT is from 0 to 20, with higher scores indicating a
stronger communication pattern.

Interpreting the FCCT score
To determine a caregiver type, use the median score as the cut-off point between the two subscales (0-11 low;12-20 is high) and interpret the score as follows:
Conversation low, Conformity low – Lone Caregiver
Conversation low, Conformity high – Carrier Caregiver
Conversation high, Conformity low – Partner Caregiver
Conversation high, Conformity high – Manager Caregiver