# Understanding the Interplay of Psychosocial Factors and Community Dynamics in a Mobile Health Intervention for People with Comorbid Substance Use Disorder (SUD) and Human Immunodeficiency Virus (HIV)

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## DEDICATION

I dedicate my dissertation to the memory of the countless lives we have lost and continue to lose due to Human Immunodeficiency Virus (HIV) and addiction.

## ACKNOWLEDGEMENTS

I owe my deepest gratitude to the grace of God that sustained me throughout this journey. As I consider the multitude of names for acknowledgment, I feel compelled to give special recognition to the individuals who directly and indispensably shaped my dissertation phase.

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In conclusion, I take a moment to acknowledge the effort and dedication I have invested in this journey. With humility and pride, I recognize the significance of my achievement. I offer myself heartfelt congratulations, saying, "Well done, Adati!"

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## ABSTRACT

Medication adherence poses a significant challenge for individuals living with both Human Immunodeficiency Virus (HIV) and substance use disorders (SUD). To gain insights into medication adherence behaviors, our study, guided by Self-Determination Theory, explored relevant constructs among users of the mobile health intervention Addiction Comprehensive Health Enhancement Support System (A-CHESS)-designed to enhance engagement in HIV care. Through logistic regression analysis of baseline surveys, we examined factors associated with medication adherence in these individuals. Additionally, we investigated how they form supportive virtual communities, fostering social relatedness to promote health behaviors, using a computer-mediated analysis.

Our findings revealed an association between stigma and medication adherence. The study also shed light on the messaging strategies employed within the virtual community. Research staff and case managers adapted their messages, incorporating HIV and SUD resources and incentivizing engagement to encourage active participation from the users. In contrast, participants tailored their messages to their unique needs, seeking advice and establishing in-person networks within the virtual community.

Furthermore, examining the message board content related to HIV and substance use uncovered themes highlighting their experiences, motivation, and treatment decisions related to HIV and SUD. Participants openly disclosed their substance use experiences and how it impacted their medication adherence behaviors. They also shared their motivations for staying sober, often reflecting on the history and severity of their substance use and identifying the impact of substance use on taking their medication.

These findings underscore the importance of creating stigma-free virtual communities and providing a safe space for participants to seek support and accountability in their substance use goals and HIV medication adherence. Understanding these factors is crucial in developing effective interventions that address the challenges faced by this vulnerable population, ultimately leading to improved health outcomes and a more supportive environment for individuals living with HIV and SUD.

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# CHAPTER 1

# INTRODUCTION

## Antiretroviral Therapy (ART) adherence

Medication adherence is described as the extent to which individuals take medications as prescribed by healthcare providers concerning the timing, dose, and frequency of medication-taking during the prescribed time (Osterberg & Blaschke, 2005). Medication adherence is crucial for individuals with the Human Immunodeficiency Virus (HIV) as it directly impacts their health outcomes. People with HIV who adhere to their medications experience lower healthcare utilization, fewer hospitalizations, and fewer opportunistic infections than patients with nonadherence (Gardner et al., 2008; Keiser et al., 2001). However, despite advances in HIV medication and treatment, a significant portion of the population remains non-adherent. For instance, in 2016, only 65% of people living with HIV in the United States were taking antiretroviral therapy (ART) and virally suppressed (Li et al., 2019). This highlights the need for effective strategies to improve ART adherence.

Among those diagnosed with HIV, approximately 1.2 million individuals live in the United States, with projections indicating nearly 400,000 more individuals will be diagnosed with HIV in the next 10 years(Office of Infectious Disease and HIV/AIDS Policy, 2021). Furthermore, 2018 statistics reported 38,000 new HIV-related diagnoses and 16,000 deaths (Segarra et al., 2021). Of concern is that approximately 69% of new infections were transmitted by individuals aware of their diagnosis but not receiving care. In comparison, 20% of transmissions occurred from persons receiving ART but not adhering to their regime, leading to

a lack of viral suppression (Fauci et al., 2019; Harris et al., 2019). Thus, highlighting the critical importance of addressing ART adherence among people with HIV.

## ART adherence and Substance Use Disorder (SUD)

Individuals with HIV and Substance Use Disorder (SUD) face additional challenges in maintaining medication adherence. Research indicates that disruptive life events, such as drug use relapse, changes in housing status, or incarceration, often trigger lapses in treatment for people with SUD (Westergaard et al., 2013; R. P. Westergaard et al., 2011). Additionally, patient-level factors such as depression, low self-efficacy, and inadequate social support have been consistently correlated with treatment interruption for people with HIV and SUD (Holloway et al., 2021; Illangasekare et al., 2013). The prevalence of SUD among people with HIV is significant, with over 81% of people with HIV reporting illicit drug use and one in four meeting the diagnostic criteria for an SUD (Claborn et al., 2017). The high prevalence of SUD among people with HIV and the evidence of poorer health outcomes related to medication-taking behaviors highlight the critical need to thoroughly understand the needs of this population and deliver targeted interventions (Dombrowski et al., 2015; Himelhoch et al., 2017; Holtzman et al., 2015).

## Mobile health interventions

In addition to interpersonal factors impacting their care, people with HIV who have SUD often receive inadequate medical care, partly due to the separation of traditional HIV care and substance use services (Andersen et al., 2003; Claborn et al., 2017; Cunningham et al., 2011). One potential solution to integrate HIV and SUD care is using mobile health interventions. Studies have shown that utilizing digital resources to remain engaged in care can benefit individuals with HIV (Kalichman et al., 2005; Kirk et al., 2013). However, the availability of

HIV-related mobile health applications for individuals with HIV and SUD is limited, presenting a significant gap in healthcare delivery. Over 200 HIV-related mobile health apps exist for people with HIV on Android and Apple platforms—about 30% focus on HIV prevention, with even fewer targeting both HIV and SUD (Claborn et al., 2017).

### Addiction Comprehensive Health Enhancement Support System (A-CHESS)

One application that integrates HIV and SUD care is the Addiction-Comprehensive Health Enhancement Support System (A-CHESS) (Gustafson et al., 2016; Hochstatter et al., 2021). Versions of A-CHESS have been used for hepatitis C care (Hochstatter et al., 2018), opioid use disorder treatment (Gustafson et al., 2016), and have proven efficacy in providing alcohol recovery support (Ford Ii et al., 2015; Gustafson, McTavish, Chih, Atwood, Johnson, Boyle, Levy, Driscoll, Chisholm, Dillenburg, et al., 2014). Our study adapted mobile health intervention to improve engagement in HIV care, including medication adherence among people with SUD and HIV.

A benefit of the A-CHESS app is its theory-informed design. The design of A-CHESS is grounded in Self Determination Theory which posits that providing individuals with resources to enhance their competence, autonomy in decision-making, and a sense of connectedness to others can motivate them to engage in health behaviors (Patrick & Williams, 2012; Williams et al., 2009). SDT has been used to study health behaviors, including medication adherence, among people living with HIV (Ntoumanis et al., 2021; Sheeran et al., 2020). SDT has also been applied to mobile health studies showing that extrinsic motivation, intrinsic motivation, and health beliefs positively impact people's behavioral intentions (Hsieh, 2023). In SUD research, SDT has been applied to understand treatment behaviors (Cornelius et al., 2017).

To enhance the use of mobile health technology in improving health behaviors among people with HIV and SUD, exploratory studies are essential to understand patient behaviors on mobile health platforms. Previous research has demonstrated the feasibility and acceptability of the A-CHESS app in delivering care to individuals with HIV and SUD (Westergaard et al., 2017).

## Study objectives

Building on this foundation, our study takes a step further by investigating two critical aspects:

1. Medication adherence within A-CHESS: Understanding the constructs related to medication adherence is pivotal, as it represents a significant behavioral gap among people with HIV. By exploring factors influencing medication adherence on the A-CHESS app, we aim to identify key determinants that can inform targeted interventions and enhance treatment outcomes.

2. Virtual community formation and HIV and SUD-specific support within A-CHESS: Besides medication adherence, we delve into how individuals form virtual communities to support one another on the A-CHESS platform. We also examine how the app users perceive the interplay of their HIV and SUD and how they seek or provide support for their HIV and SUD, including support related to medication adherence. Examining the dynamics of these supportive communities and how individuals discuss their HIV and SUD experiences offers valuable insights into their unique needs and ways to optimize the use of mobile health technologies to meet their requirements effectively.

To understand medication adherence and related support systems within A-CHESS, our study will pursue three specific objectives, and each objective will be presented as a separate

manuscript tailored to different audiences interested in SUD, HIV care, mobile health interventions, and research methodologies. Our overarching goal is to disseminate our findings widely to advance the use of theory-driven interventions and enhance the understanding of health behaviors to improve care for individuals with HIV and SUD, mainly focusing on improving medication adherence by enhancing engagement in care and addressing the community's specific needs. Our research objectives are as follows:

Objective 1: Identify Factors informed by SDT Impacting Medication Adherence

This objective aimed to investigate the factors informed by SDT that may be associated with medication adherence among users of the A-CHESS platform. According to SDT, individuals were more likely to adhere to their medication regimen when they felt a sense of autonomy, competence, and relatedness (Patrick & Williams, 2012). To achieve this objective, we used a baseline survey of participants on A-CHESS to gain insights into the factors associated with their medication adherence behaviors.

*Findings:* The findings of this objective are presented in Paper 1: "Associations Between Stigma, Social Isolation, Treatment Self-Regulation, And Positive and Negative Affect on Adherence Among Individuals with HIV And Substance Use Disorder."

The findings of this paper will be submitted to the Journal of Behavioral Medicine.

Objective 2: Explore the Formation of a Virtual Support Community

Our objective was to explore the formation of virtual communities on A-CHESS as a support system to enhance social relatedness, thereby influencing health behaviors such as

medication adherence. Through qualitative data analysis of interactions on the A-CHESS message board, we aimed to gain valuable insights into how this virtual support community was formed.

*Findings:* The findings of this objective are presented in Paper 2: "Computer-Mediated Discourse Analysis of a Virtual Community of People with HIV And Substance Use Disorder."

The findings of this paper will be submitted to AIDS and Behavior.

Objective 3: Exploring Experiences and Support-seeking in Discussions about Addiction and HIV within the A-CHESS Support Community.

Aligned with SDT construct of social-relatedness, this objective investigated how individuals with SUD and HIV communicated about their HIV and SUD as they related to their peers on the A-CHESS app. Content analysis of forum discussions offered valuable insights into the participants' experiences, perceptions of their HIV and SUD, and how they sought or received support concerning managing their HIV and SUD.

*Findings:* The findings of this objective are presented in Paper 3: " Utilizing The Common Sense Model To Explore Perceptions Of Hiv And Substance Use Disorder: Analysis From A Mobile App Virtual Community."

The findings of this paper will be submitted to Qualitative Health Research.

Significance: Enhanced Interventions and Healthcare Outcomes

Our study is primarily exploratory, as there is limited knowledge about the ongoing mechanisms of support and interactions among participants within mobile health interventions.

While previous research has mainly focused on outcomes, we aim to delve deeper into the A-CHESS support community's dynamic relationships and ongoing support mechanisms. Understanding these factors and their potential association with medication adherence can lead to valuable insights that can significantly enhance the effectiveness of mobile health interventions for individuals with SUD and HIV.

# CHAPTER 2

# LITERATURE REVIEW

This study investigates medication adherence among people living with HIV and SUD and the virtual communities they form to support healthy behaviors. The literature review summarizes findings from relevant literature in the following sections 1) The critical role of medication adherence in ending the HIV epidemic; 2) the impact of poor adherence to ART on clinical health outcomes; 3) Suboptimal ART adherence among individuals with substance use disorder, and 4) Digital health interventions to improve ART medication adherence.

## The critical role of ART and medication adherence in ending the HIV epidemic

Globally, as of 2019, approximately 38 million individuals were living with HIV, and 690,000 died due to HIV-related illness (Harris et al., 2019; Jani et al., 2021). Over the epidemic since the early 1980s, HIV-related illnesses have resulted in a staggering death toll of over 32.7 million individuals (Mollel et al., 2022). However, encouragingly, about 39% fewer deaths due to HIV in 2019 compared to 2010, indicating progress in combating the disease (Jani et al., 2021). For example, the US's average mortality rate was over 50,000 cases in 1995, compared to less than 20,000 cases in 2002 (Konopnicki et al., 2005; Mocroft et al., 2003). Approximately only 40% of deaths in people with HIV are HIV-related, with the following leading causes being liver-related, treatment complications, and suicide/drug overdose (Jani et al., 2021).

The decline in HIV-related mortality can be primarily attributed to significant improvements in HIV management, particularly the introduction of highly active antiretroviral combination therapies (Chesney, 2003; Chesney et al., 2000). Highly active antiretroviral therapy (HAART) is a treatment regimen typically comprised of a combination of three or more antiretroviral drugs. HAART is also considered ART (Chesney, 2003; May et al., 2007).

A fundamental cornerstone of HAART is the co-administration of different drugs that inhibit viral replication by several mechanisms so that the propagation of a virus with resistance to a single agent becomes inhibited by the action of the other two agents (Yeni, 2006). For the treatment of HIV, there are more than 25 medications in six different classes. The standard of care for most individuals that have been newly diagnosis and have never taken ART is a combination of two nucleoside reverse transcriptase inhibitors (typically tenofovir-emtricitabine) plus one non-nucleoside reverse transcriptase inhibitor or integrase strand transfer inhibitor (Siegfried et al., 2010). Alternative classes or drugs within each class may be recommended when patients have concurrent conditions or medication interactions (Chesney, 2003).

Previously, ART therapies had a high pill burden, drug-drug interactions, and frequent short- and long-term adverse effects, leading to decreased adherence to prescribed regimens (Chesney et al., 2000; Oh & Han, 2021). Over time ART has become a better-tolerated drug with low or no dietary restrictions and fewer drug interactions (Astuti & Maggiolo, 2014; Langebeek et al., 2014). Newer medications have become safer and easier to take.

The goal for prescribing HAART to patients is to reduce morbidity and mortality, improve the quality of life, reduce plasma viral RNA load, prevent transmission to others (sex partners, needle-sharing partners, mother to infant), prevent drug resistance, and improve immune function (Eggleton & Nagalli, 2020). With the use of HAART, a reduction of HIV-1 RNA levels has been shown to reduce the risk of sexual transmission to partners to nearly zero in some studies, even among couples that engaged in condomless sexual acts (Okoli et al., 2021). A combination of these drugs is also available for people who engage in high-risk behavior. Known as Pre-exposure Prophylaxis (PrEP), these combinations of HAART have been demonstrated to reduce the risk of acquiring HIV infection by more than 90% (Baeten et al., 2013). For pregnant

patients, the use of HAART is critical in the prevention of mother-to-child transmission (Chibwesha et al., 2011).

The timing of treatment initiation for HIV-1 infection has been a topic of much research and discussion among healthcare professionals. Current recommendations are that HAART should be initiated immediately after confirming an HIV diagnosis and detectable virology, regardless of CD4 count or clinical symptoms (Eggleton & Nagalli, 2020). Early HAART initiation, vs. waiting for CD4 counts to decline, as were the previous recommendations, has been shown to reduce the severe progression of HIV to Acquired Immune Deficiency Syndrome (AIDS) and AIDS-associated illnesses (Crum et al., 2006).

Many of these medications are administered orally, once a day, in a co-formulated combination tablet. However, some medications are not yet in combination with formulas, thus creating a significant pill burden for patients who require a regimen of three or four drugs twice daily (May et al., 2007). The increased number of pills can decrease patient adherence, particularly for patients in resource-limited settings, patients with dysphagia, or patients who struggle with the financial burden of a HAART regimen. There are liquid preparations or crushable tablets for patients with dysphagia or trouble swallowing, though dosages may need to be adjusted (Eggleton & Nagalli, 2020; Forough et al., 2018). Combination medications with once-daily dosing are preferred as these regimens have increased patient compliance up to three times over more complex dosing regimens (Ingersoll, 2004; Nachega et al., 2011). These medications require infrequent dosing also due to their long half-lives (Astuti & Maggiolo, 2014; Cutrell et al., 2020). With the advancement of HIV treatment, the focus of the epidemic has shifted from controlling or managing the epidemic to ending the epidemic.

Collaborative efforts by the World Health Organization (WHO) and the Joint United Nations Program on HIV/AIDS (UNAIDS) have also played a vital role in reducing the global burden of HIV-related morbidity and mortality through the formulation of policies and guidelines (Braitstein et al., 2006; Chesney, 2003). Various strategies implemented worldwide to address the needs of high-risk populations and raise awareness have further contributed to the overall decrease in HIV mortality worldwide. However, challenges remain in some regions (Braitstein et al., 2006).

In 2014, UNAIDS and its partners established the 90-90-90 targets, intending to diagnose 90% of all HIV-positive individuals, provide antiretroviral therapy (ART) to 90% of those diagnosed, and achieve viral suppression for 90% of treated individuals by 2020 (Dave et al., 2019; Grobler et al., 2017). This initiative led to a more widespread and early administration of ART, emphasizing the importance of rapid and effective treatment to achieve sustained viral suppression (Fauci et al., 2019; Giroir, 2019).

In early 2019, the United States Department of Health and Human Services launched an initiative to end the HIV epidemic in the United States by 2030 (Fauci et al., 2019). The department proposed strategic initiatives to reduce the number of incident infections by 75% within 5 years and by 90% within 10 years (2030), aiming to effectively "end the AIDS epidemic as a global health threat" (Girardi, 2020). Central to these efforts is the rapid and effective treatment of HIV infection to achieve sustained viral suppression, defined as having less than 200 copies of HIV per milliliter of blood (Bavinton et al., 2018; Crepaz et al., 2018a). However, a 2014 study found that only 48.8% of individuals living with HIV had sustained viral suppression, falling significantly short of the global target of achieving viral suppression in 95% of all people with HIV on ART (Crepaz et al., 2018b). Closing this gap will be crucial to

effectively combat the HIV epidemic and improve the health outcomes of those living with the virus.

In 2023, the National Institutes of Health's Office of AIDS Research released guidelines to effectively end the Epidemic, focusing on access to ART adherence. The goals of the guidelines (Table 1) were to ensure the following were assessed at each clinic visit for people with HIV that have been prescribed ART:

a. Monitor viral load as a vital biologic measure of adherence.
b. Use a simple behavioral rating scale or self-reported assessment.
c. Employ a structured format that normalizes or assumes less-than-perfect adherence and minimizes socially desirable or "white-coat adherence" responses.
d. Ensure that other health care team members also assess and support adherence.

**Table 1**

*2023 Guidelines from National Institutes of Health Office of AIDS Research on Adherence to ART*

| Guidelines for ART adherence |
| --- |
| 1. Linkage to care and adherence to both antiretroviral therapy (ART) and clinic appointments should be regularly assessed.<br>2. An individual's barriers to adherence to ART and appointments should be assessed before or shortly after the initiation of ART and regularly thereafter.<br>3. Rapid access to ART has become a pillar of the United States plan to end the HIV epidemic, and delays in access to ART should be addressed and treatment initiated as soon as possible.<br>4. People with HIV having ART adherence problems should be placed on regimens with high genetic barriers to resistance, such as dolutegravir, bictegravir, or boosted darunavir. Side effects, out-of-pocket costs, convenience, and patient preferences also need to be considered.<br>5. Adherence to ART should be regularly assessed by self-report at every clinic visit.<br>6. People with HIV having difficulties with adherence to appointments or ART should be provided additional adherence support using a constructive, collaborative, nonjudgmental, and problem-solving approach.<br>7. The approach taken to improve adherence should be tailored to each person's needs and barriers to care. Approaches could include, but are not limited to—<br>a. Changing ART to simplify dosing or to reduce side effects |

b. Allowing flexible appointment scheduling

c. Finding resources to assist with treatment costs to maintain uninterrupted access to both ART and appointments

d. Linking patients to resources to assist with unmet social and economic needs, such as transportation, food, housing, and support services

8. Linking patients to counseling to overcome stigma, substance use, or depression
9. Multidisciplinary approaches to finding solutions to problems of adherence to ART and appointments are often necessary, including collaborations with nursing, pharmacy, social work, and case management (to the extent available). The clinician's role is to help the patient understand the importance of adherence to the continuum of care, identify the barriers to adherence and address those that are within their purview, and link the patient to resources to overcome other barriers.
10. Single-tablet regimens are generally recommended when clinically appropriate, but high-quality evidence to definitively recommend them is lacking, and shared decision-making with patients is essential (BIII).
11. At this time, evidence does not support the use of financial incentives to engage patients in ongoing routine care.
12. Methods to estimate adherence based on drug levels measured in plasma, dried blood spots, urine, and hair samples are available. Measuring adherence with these methods has not been shown in randomized studies to improve outcomes. However, if these methods are used, it should be in a collaborative manner to avoid promoting an adversarial relationship between the provider and patient.

13. The Panel on Antiretroviral Guidelines for Adults and Adolescents recommends against the use of long-acting ART in people who have detectable viral load due to suboptimal adherence to ART and in people who have ongoing challenges with retention in HIV care, except in a clinical trial (AIII).
14. A summary of best practice interventions to improve linkage, retention, and adherence can be found at the Centers for Disease Control and Prevention's Compendium of Evidence-Based Interventions and Best Practices for HIV Prevention.

Rating of Recommendations: : A = Strong; B = Moderate; C = Weak
Rating of Evidence: I = Data from randomized controlled trials; II = Data from well-designed nonrandomized trials or observational cohort studies with long-term clinical outcomes; III = Expert opinion

The guidelines emphasize the importance of regular assessment of linkage to care and adherence to ART and clinic appointments for individuals with HIV. According to the guidelines, healthcare providers should assess an individual's barriers to adherence to ART and appointments, both before or shortly after initiating treatment and regularly thereafter, to tailor interventions and support as needed.

For individuals facing challenges with adherence, the guidelines recommend prescribing regimens with high genetic barriers to resistance and providing additional support that should be provided constructively and collaboratively. The guidelines also emphasized that regular adherence assessment through self-report at each clinic visit is essential to monitor patient adherence and optimize treatment outcomes. Recommended interventions to improve adherence were suggested to simplify dosing regimens, offer flexible appointment scheduling, address financial concerns, and link patients to social and economic support services.

According to the guidelines, a multidisciplinary approach involving collaboration among healthcare professionals may be necessary to address adherence challenges effectively. The guidelines highlight that shared decision-making with patients, including discussions about single-tablet regimens, can enhance treatment acceptance and adherence. One critical gap identified by the guidelines is the method for assessing adherence. Although methods to estimate adherence based on drug levels are available, their impact on outcomes remains uncertain. To understand how to ensure optimal adherence, we first explore the impact of poor adherence on clinical outcomes for people with HIV.

## Impact of poor adherence to ART on clinical health outcomes

Achieving HIV viral suppression is the most important means to improve the well-being of individuals with HIV. A suppressed or undetectable viral load in individuals with HIV yields

significant health benefits. Those aware of their HIV status, adhering to prescribed HIV medication, and maintaining an undetectable viral load can lead long, healthy lives (Chesney, 2003; Eggleton & Nagalli, 2020). Moreover, there is a crucial prevention advantage. By consistently taking HIV medicine and achieving an undetectable viral load, individuals with HIV cannot transmit the virus to others. This concept, often referred to as "treatment as prevention" or "undetectable = untransmittable" (U=U), has substantial implications for reducing new HIV infections (Marks et al., 2006). Beyond preventing sexual transmission, studies have shown that maintaining an undetectable viral load through HIV medication also offers additional prevention benefits:

Being virally suppressed significantly reduces the risk of transmitting HIV to a child during pregnancy, labor, and delivery. When a pregnant person follows a daily prescribed HIV medication regimen throughout pregnancy, labor, and delivery and provides HIV medicine to the baby for 2-6 weeks after birth, the risk of HIV transmission to the baby can be minimized to 1% or even lower (Nesheim et al., 2019).

Being virally suppressed may also reduce the risk of HIV transmission for people who inject drugs. While scientists have limited data on whether an undetectable viral load entirely prevents HIV transmission through needle-sharing during drug use, it is highly likely to reduce the risk (Booth Ph.D & Wiebel Ph.D, 1992).

However, viral suppression can only be attained if individuals take their HIV medication as prescribed. Due to HAART, individuals can achieve a very high level of virologic success and lower rates of virologic failure (Cutrell et al., 2020). Effective ART use results in a 96% decrease in the rate of new infections (Cohen et al., 2011). Yet, ART use is not optimized in current populations of people living with HIV. As such, inadequate ART medication adherence

continues to be considered the most critical barrier to successfully managing HIV infection (Gardner et al., 2009). Adherence to ART is defined as taking all antiretroviral medications at the appropriate time with the dosage prescribed by the physician (Yu et al., 2018). Suboptimal adherence may include missed or late doses, treatment interruptions, discontinuations, and subtherapeutic or partial dosing (Hawkins et al., 2016). Poor adherence results in subtherapeutic plasma antiretroviral drug concentrations, facilitating the development of resistance to a specific antiretroviral drug or cross-resistance to other drugs in the same class (Bangsberg, 2008; Ribeiro & Bonhoeffer, 2000; Wainberg & Friedland, 1998). Additionally, poor adherence is related to the progression of HIV to AIDS and death (Kim et al., 2018).

ART adherence has proven to be the most effective means of managing HIV. When the medication adherence rate is as high as 95%, the viral suppression rate approaches 78%. However, when the adherence rate is reduced to 80%, there is a dramatic reduction in the viral suppression rate, which can be as low as 20%. Medication adherence rates should be maintained at 95% or above to optimize antiviral outcomes and enhance viral suppression (Bezabhe et al., 2016). However, medication adherence remains a barrier to attaining viral suppression.

Medication adherence is a complex behavior influenced by a wide range of factors condition-related, treatment-related, and patient-related. Medication adherence, as defined by the World Health Organization, refers to the degree to which a person's behavior aligns with the agreed recommendations from a healthcare provider (Anghel et al., 2019). Various types of non-adherence exist, but categorization is not always clear-cut, and there can be overlaps.

The first type of non-adherence is primary non-adherence, where healthcare providers write prescriptions, but the patients never fill or initiate the medications. This situation is commonly called non-fulfillment adherence (Fischer et al., 2010).

A second type of non-adherence is called non-persistence, wherein patients decide to stop taking a medication after starting it without being advised by a health professional to do so (Mueller et al., 2017). Non-persistence is typically unintentional and may result from miscommunication between patients and providers regarding therapeutic plans. Unintentional non-adherence can also arise due to capacity and resource limitations hindering patients from following treatment recommendations, such as issues with prescription access, financial constraints, or competing demands (Gadkari & McHorney, 2012; Unni & Farris, 2011). Another type of non-adherence is intentional non-adherence (Mukhtar et al., 2014). This is where patients decide not to take their medication even after prescribed and made available. This type of nonadherence stems from patients' beliefs, attitudes, and expectations, influencing their motivation to start and persist with the treatment regimen (Atkins & Fallowfield, 2006; Clifford et al., 2008).

The third type of non-adherence is known as non-conforming, encompassing various ways medications are not taken as prescribed (Jimmy & Jose, 2011). This behavior can range from skipping doses to taking medications at incorrect times or incorrect doses or even taking more than prescribed (Bazargan et al., 2017).

The complexity of treatment regimens can pose challenges for inexperienced patients, potentially leading to unintentional non-adherence or ineffective use of HIV medications (27, 28). Mental health comorbidities may also compromise adherence to these intricate medication regimens, contributing to poor comprehension, forgetfulness, and functional disorganization (Cutrell et al., 2020). The presence of mental health comorbidities, combined with disparities in HIV access to care, places specific key populations of people with HIV at higher risk of non-adherence.

**Suboptimal ART adherence among individuals with substance use disorder**

In addition to the general population of people with HIV, significant disparities in viral suppression exist among those patients with poor adherence to treatment, such as younger patients, Black adults, and those with a SUD (P Giordano et al., 2009; Yehia et al., 2012). These target populations face challenges with the complexities associated with adherence to ART, such as selecting appropriate regimens and monitoring to identify medication issues.

Thus, providers should collaborate with a multidisciplinary team to support patients' complex medication-related needs. The National HIV/AIDS Strategy identified increasing access to quality HIV care and reducing HIV-related disparities as an effective means of decreasing new HIV infections to achieve the goal of sustained viral suppression among 95% of people with HIV (Holtgrave et al., 2012; Nachega et al., 2018). Our study specifically focuses on people with SUD due to the high prevalence of substance abuse and misuse among people with HIV leading to poor health outcomes.

For our study, SUD is described using the DSM-IV: Diagnostic and Statistical Manual of Mental Disorders (Bell, 1994). According to the DSM IV, SUD is a maladaptive pattern of substance use, resulting in significant impairment or distress, and is characterized by three (or more) of the following manifestations occurring within 12 months:

a. Tolerance is defined as either: (a) a need for markedly increased amounts of the substance to achieve intoxication or the desired effect or (b) a markedly diminished effect with continued use of the same substance.
b. Withdrawal is indicated by either: (a) experiencing the characteristic withdrawal syndrome specific to the substance or (b) using the same (or closely related) substance to alleviate or avoid withdrawal symptoms.

c. The substance is often consumed in larger quantities or over an extended period than initially intended.
d. A persistent desire or unsuccessful efforts exist to reduce or control substance use.
e. A significant amount of time is devoted to activities involving the acquisition, use, or recovery from the effects of the substance.
f. Important social, occupational, or recreational activities are given up or reduced due to substance use.
g. The substance use continues despite awareness of having a persistent physical or psychological problem likely caused or worsened by the substance (e.g., continuing cocaine use despite acknowledging cocaine-induced depression).

There is a high prevalence of SUD among people with HIV, including alcohol use disorder, opioid use disorder, injection drug use, and poly substance use. Global estimates suggest that 15.6 million people inject drugs, and almost one-fifth (18%) live with HIV (Wagman et al., 2020). Among people with HIV, cannabis use rates range from 25% to 38% compared to 18% in the general population. In comparison, stimulant use rates ranging from 5% to 15% have been reported compared to 2% in the general population (Przybyla et al., 2022). In a prior study among a cohort of people with HIV who inject drugs, participants who achieved viral suppression after initiating ART had a one-in-four risk of virologic failure during any 6-month interval (Kiweewa et al., 2019). Virologic failure was more common if participants reported recent incarceration, daily drug injecting, or homelessness (Ryan P. Westergaard et al., 2011). Several patient-level factors have consistently correlated with treatment interruption, specific disruptive behaviors, and life events. These include depression and anxiety, low self-efficacy, internalized HIV-related stigma, and inadequate social support (Chapman Lambert et al., 2020).

When followed longitudinally over time, the risk of lapses in HIV care appears widespread among people with substance use disorders. Among a cohort of people who inject drugs followed for a median of 8.7 years, 86% achieved viral suppression at the time of at least one study visit. Yet, only 12% were found to be virally suppressed at every study visit after ART initiation, meaning nearly 9 in 10 patients experienced virologic failure at some point throughout their treatment (R. P. Westergaard et al., 2011).

Similar to injection drug use, excessive consumption of alcohol is significantly associated with poor HIV viral suppression and ART nonadherence (Cook et al., 2017). Alcohol consumption often overlaps with several other health conditions or behaviors that could be linked to poor HIV viral suppression, including social determinants of health (Gordon et al., 2006; Kim et al., 2018), comorbid behavioral health conditions such as depression and anxiety,(Garey et al., 2015; Gordon et al., 2006), and other substance use.(Braithwaite et al., 2016; Green et al., 2010) There is an enormous potential health benefit to tailoring ART adherence strategies to the subgroup of people living with HIV and co-occurring substance misuse. To contribute to ongoing efforts to end the HIV epidemic, these target populations can benefit from integrating HIV/drug abuse treatment and leveraging technology to address disparities (Canan et al., 2020; Thompson et al., 2012).

Building upon the definition of SUD, as well as understanding the prevalence of SUD among people with HIV and its impact on medication adherence, we will now explore interventions designed to address medication and treatment adherence for individuals living with both HIV and SUD.

## Mobile health (mHealth) technological interventions for ART adherence

Mobile technologies offer promising opportunities to bridge systemic gaps and enhance access to health services, especially among underserved populations. mHealth, which refers to mobile and wireless technologies for health purposes, leverages the widespread adoption of information and communication technologies to enhance health system efficiency and improve health outcomes (Beratarrechea et al., 2013). In the last decade, there has been a rapid proliferation of mHealth solutions globally.

Due to their accessibility and acceptability, mHealth interventions play a crucial role in supporting individuals who are disproportionately affected by the HIV epidemic and are less likely to achieve viral suppression (Canan et al., 2020; Crepaz et al., 2018a). These technologies empower patients with direct delivery of individualized motivation, education, and support. To improve clinical health outcomes among people living with HIV, the World Health Organization recognizes text messaging in its current guidelines as an evidence-based intervention for encouraging ART adherence (Chiang et al., 2018). The Guidelines from the International Association of Physicians in AIDS Care Panel for improving adherence recommend using cellular technology as an evidence-based approach to improve medication adherence (Thompson et al., 2012).

Prior studies have demonstrated the feasibility and acceptance of mHealth support for medication-taking behavior (Muessig et al., 2013), and a growing literature supports the role of mHealth in resource-limited settings. There is also promising evidence that mHealth can directly improve mental health systems like stress, anxiety, and depression, which are associated with lapses in adherence. Among people with substance use disorder, to ensure maximal benefit,

social support and care coordination strategies are needed to address the specific barriers which can be part of mHealth technologies (Westergaard et al., 2017).

A study of an application that allowed a two-way messaging system to communicate with HIV-positive patients over an extended period showed that reminders are insufficient to improve adherence; instead, a system that allows people living with HIV to communicate with others improves adherence (Dunbar et al., 2003). Additional features are recommended in mHealth applications for people with HIV and substance use disorder, including community resources that support both comorbidities (Claborn et al., 2017).

The goal of mobile health intervention to enhance HIV care coordination for patients with substance use disorders can empower patients with direct delivery of individualized motivation, education, and support (Westergaard et al., 2017). Previous studies have shown that mobile health interventions improve engagement in HIV care and clinical outcomes for individuals with a history of substance use (Dillingham et al., 2018). Despite the potential benefits of digital health interventions, few mhealth interventions are focused on people with HIV and SUD. In a systemic review of mobile apps for people with HIV, only 8 interventions were specific to people with SUD (Maloney et al., 2020). Our study adapted an evidence-based mobile health intervention for people with SUD to improve medication adherence and treatment adherence for people with HIV and SUD. The following section describes the intervention and its guiding theoretical framework.

## Overview of the A-CHESS application

This section provides a brief overview of the history of A-CHESS and its distinctive features tailored specifically to people living with HIV and SUD.

### A-CHESS history and design

A-CHESS is the mobile application adaptation of The Center for Health Enhancement Systems (CHESS). CHESS was developed based on patient-needs assessments and has been validated through 30 years of design and testing to improve health behaviors, quality of life, and access to care (Mayer et al., 2010; Wise et al., 2007). CHESS use has been studied in different disease states, including cancer and HIV. In women living with cancer, compared to a control and an internet group, CHESS users showed improvements in quality of life and self-efficacy (DuBenske et al., 2008; Gustafson et al., 2001; Gustafson et al., 1993; McCarty et al., 2007). In a study of people living with HIV, CHESS improved the quality of life and care costs (Gustafson et al., 1999). Symptom distress and length of survival were improved in lung cancer patients using CHESS.(Gustafson et al., 2013) CHESS was used at home on personal computers and modems placed in patients' homes to provide information, social support, and decision-making assistance (Owens & Robbins, 1996). A-CHESS was developed in 2011 with the same core functionality as CHESS. However, it is more readily available due to its added benefit of being available on mobile phones and personal computers, making it more accessible and readily available. This study is the first to adapt A-CHESS use among people living with HIV diagnosed with a substance use disorder (opioids, stimulants, or alcohol).

### A-CHESS features

A-CHESS is a collaborative innovation between the Moore Clinic at the Johns Hopkins Hospital in Baltimore, MD, and the UW Health HIV clinic in Madison, WI. Both study sites

serve traditionally medically underserved populations with a high prevalence of substance use disorders. They also have robust programs for medical case management, Epic Systems-based electronic health records, and track records of conducting clinical research and innovative systems of care. The following app features are designed to integrate healthcare systems at Moore clinic and UW Health HIV clinic.

*Coach-monitored discussion groups* (Krishna et al., 2009) foster the exchange of emotional and instrumental support among patients. Discussions are monitored daily by research team members skilled in organization, interaction, persistence, and willingness to work unusual hours. The research team members increase and sustain A-CHESS by reviewing data weekly and following up to engage users with low engagement via private messaging.

*Panic button:* When a patient presses this, the system automatically notifies nearby pre-approved friends, family, and peers, who can respond to a request for support. The patient can also be linked to positive activities, such as selected games and audio/video-based relaxation recordings.

*Monitoring functionality* includes the location tracker self-assessment measures and a record of A-CHESS use. A weekly assessment of a patient's self-reported Brief Addiction Monitor (BAM)(Nelson et al., 2014) is recorded. A-CHESS sends patients with worrisome responses suggestions of coping skills, relaxation exercises, online peer support, healthy events, etc. With the patient's permission, a prediction of high risk is sent to their addiction counselor.

*Location tracker* uses Global Positioning System (GPS) to monitor patient movement with their permission. If a patient approaches a location they have previously identified as high risk for relapse, A-CHESS initiates a patient-defined recovery process. This might start with a

beep, a vibration, and then a call, followed by notifying selected members of the patient's support group.

*Triage and feedback functionality* is designed to derail the relapse process, giving the patient 'just in time' tailored coping support and monitoring information and data collected during set-up to link patients to relevant A-CHESS resources. For example, when a patient experiences a craving triggered by environmental cues, A-CHESS reminds her of relaxation exercises, connects her to online peer support and the healthy events calendar, and notifies a counselor, who may initiate contact.

*The Clinician Repo*rt, developed by addiction physicians and psychologists, gathers clinically relevant data from A-CHESS and presents it to counselors to help them quickly: (a) identify patients who may be at high risk for relapse and benefit from clinical intervention, (b) see a detailed analysis of a patient's recent history, e.g., trends in individual BAM items, A-CHESS use, and relapse data, (c) intervene with patients (e.g., through texting in A-CHESS). When a counselor logs into the Clinician Report, he sees a list of 'red pins' generated when A-CHESS (using counselor priorities) determines that a patient may be at high risk. The counselor can adjust the cutoffs for red pins so the ones he sees are the most useful.

*HepNet:* A-CHESS integrates components of HepNet,(Westergaard et al., 2016), the existing computerized risk reduction system that collects data on patient risk behaviors and delivers behavior change interventions tailored to the patient's self-reported readiness for change. At enrollment, participants in both conditions will be asked if they have been screened for HIV and Hepatitis C Virus (HCV). Patients will self-report results via A-CHESS - for those who test negative or do not self-report, A-CHESS will send reminders about future testing at a frequency based on reported risk behaviors. Patients discovered to be HIV or HCV-positive will be

provided health education content and location-specific referrals to clinical care and case management.

*Addiction recovery information:* Meetings to local Alcohol Anonymous and Narcotics Anonymous meetings, information to help with substance cravings, and games to help A-CHESS users relax during triggering events are readily available on the app.

A-CHESS encompasses these key features that cater to the multifaceted challenges individuals face with addiction. The call for help function provides immediate assistance and support during times of crisis or distress. Cognitive behavioral therapy boosters offer valuable tools and techniques to enhance coping skills and promote positive behavioral changes. The GPS location tracker helps individuals avoid high-risk areas and find nearby 12-step meetings, fostering a sense of community and support.

Recognizing the specific needs of individuals with HIV, A-CHESS has been tailored to promote medication adherence and facilitate regular evaluations with healthcare providers. This ensures that individuals can effectively manage their HIV care alongside their recovery journey. The Information tab within the app offers carefully curated content, reviewed by clinical experts, that explicitly addresses HIV and SUD self-management. This information is a valuable resource, providing daily guidance and support to individuals.

Additionally, users actively engage in a weekly survey, vital for monitoring recovery progress and assessing protective and risk factors within their social environment. This enables individuals to gain insights into their recovery journey and make informed decisions about their ongoing care and support needs.

Overall, A-CHESS is a comprehensive and adapted mobile app that provides individuals with HIV and SUD access to a wide range of supportive services and resources.

With a focus on promoting self-determination and overall well-being, A-CHESS embraces the principles of self-determination theory, recognizing the fundamental psychological needs of competence, autonomy, and relatedness. The app aims to enhance self-motivation and empower individuals to manage their recovery by addressing these needs.

## A-CHESS Framework – Self-Determination Theory

Self Determination Theory (SDT) is the theoretical framework that guided the design of A-CHESS. SDT postulates that meeting three needs improves a person's adaptive functioning: competence, social relatedness, and autonomous motivation (Ryan & Deci, 2000). Key A-CHESS services addressing these needs include a call for help function, cognitive behavioral therapy boosters, a GPS location tracker, tailored coping support, a counselor dashboard, coach-monitored discussion groups, and HIV services (Gustafson et al., 2016). These services foster a social, digital environment that supports the psychological needs that impact autonomous motivation. Alternatively, when these psychological needs are not well met or even thwarted through social interactions, the quality of our motivation is more controlled (Niemiec et al., 2006; Williams et al., 2009).

A unique function of the A-CHESS is the coach-monitored discussion forum. Participants support each other and share information related to their HIV medication, abstinence from substances, and other support tools they use. The forum was designed to foster relatedness, a construct of SDT. As supported by SDT, healthcare providers are known to play a central role in supporting adherence to ART (Bakken et al., 2000; Kennedy et al., 2004), and studies of people living with HIV showed that a patient's perception of their relationship with their provider is

directly related to medication adherence (Abel & Painter, 2003; Demmer, 2003; Russell et al., 2004). However, evidence from qualitative studies of people living with HIV suggests that adherence may be influenced by healthcare providers and members of the individual's social network who know patients' HIV-positive status. However, SDT does not capture these other meaningful interactions (Roberts & Mann, 2000). Thus, exploring relatedness in the context of the support people living with HIV receive from their peers on the application's discussion forum is imperative to understanding medication adherence in this subset of individuals living with HIV.

A limitation of using the SDT alone to explore A-CHESS use is that it does not consider the digital social environment in which these participants engage in various behaviors that impact their autonomy. These behaviors include information seeking to improve their competence, bonding, and provision of social support, which impacts their relatedness, and providing weekly updates on their motivations. Prior studies have shown that when social environments are supportive, the quality of an individual's motivation becomes more autonomous. Therefore, augmenting the SDT with a digital health framework to understand the digital environment in which the app users interact to build autonomous support is critical. A-CHESS, a mHealth app, health information technology, wearable devices, telehealth and telemedicine, and personalized medicine are all digital health approaches to care (Administration, 2020). During the COVID-19 pandemic, digital health has overlapped with health equity due to the need to adapt healthcare to be delivered digitally and issues with inaccessibility to care by under-resourced communities.

As much as digital health can promote equity through, for example, seamless technological adaptations (e.g., language, literacy, or cultural tailoring), bridging accessibility

barriers, or scaling treatment approaches, digital health can perpetuate inequities (Sun et al., 2018). Medication adherence, especially in people living with HIV, is an issue of health equity. It is well-established that the HIV epidemic disproportionately affects racial and ethnic minority groups, marginalized groups, and disenfranchised communities. Historically, ART adherence is typically poorer among African Americans and individuals with low income, low educational attainment, lack of medical insurance, and unstable or low-income housing (Mehta et al., 1997). Thus, SDT has limitations in exploring A-CHESS use in diverse communities. The demographics of A-CHESS users vary across platforms; for example, in a study of people with opioid use disorder targeting hepatitis C virus infection using A-CHESS was, 70% unemployed, and approximately 90% did not have a college education (Hochstatter et al., 2018). In a pilot study of the potential influences of the COVID-19 pandemic on A-CHESS users, 75% identified as Black or other races, and 66% were formally incarcerated (Hochstatter et al., 2018). Given the history of A-CHESS users, exploring their interaction through health equity lenses provides deeper meanings to their social relatedness. After all, social and cultural factors impact the acceptability of digital health tools across target groups (Kwasnicka et al., 2022). The ability to seek health care relates to the concepts of personal autonomy and capacity to choose to seek care, knowledge about health care options, and individual rights that would determine expressing the intention to obtain health care. This relates to ensuring that care meets the needs of different cultural, socioeconomically disadvantaged, and vulnerable populations.

Despite its limitation, SDT provides a framework for exploring factors associated with medication-taking behaviors and understanding how social support is formed as a source of autonomous motivation to engage in a behavior. According to SDT (Williams et al., 2000), autonomous motivation is predicted by autonomy support or perceived support from others for

making autonomous decisions concerning a particular health behavior (Williams et al., 1998). SDT also suggests that the relationship between autonomous motivation and the behavior of interest (e.g., medication adherence) is mediated by perceived competence for the behavior. Additionally, SDT posits that social relatedness, also known as social support, is important in motivating people to adhere to a behavior. This theory is in line with studies of people with HIV, where social support has been shown to improve health outcomes in those with SUD (Lehmann & Fingerhood, 2018; Muhrer, 2019). Social support is critical in avoiding treatment interruptions and addressing adverse health outcomes related to substance abuse and HIV (Hochstatter et al., 2021). Social support has been shown to improve the physical and mental health of people with HIV (Bekele et al., 2013). Research has demonstrated the significance of social support in digital spaces, such as mobile health interventions, where individuals living with HIV and SUD can find much-needed support. This is especially crucial considering the high stigma associated with these illnesses (Davison et al., 2000).

SDT guides the present research and consists of three papers that explore the relationships between SDT constructs and medication adherence, examine the formation of virtual communities as a means of social support, and analyze the content of messages shared by participants to understand their perceptions of HIV and SUD and the health-related behaviors they adopt. This study aims to offer a comprehensive understanding of the experiences of individuals living with HIV and SUD as they navigate their health, seek support, and engage in digital health interventions. The following three chapters present manuscripts of the three papers, utilizing logistic regression, computer-mediated discourse analysis, and directed content analysis of data obtained from A-CHESS study participants.

# CHAPTER 3

# PAPER 1

# ASSOCIATIONS BETWEEN STIGMA, SOCIAL ISOLATION, TREATMENT SELF-REGULATION, AND POSITIVE AND NEGATIVE AFFECT ON ADHERENCE AMONG INDIVIDUALS WITH HIV AND SUBSTANCE USE DISORDER

## Background

Antiretroviral therapy (ART) has transformed the health and quality of life of people living with HIV (PWH), enabling them to achieve life expectancies comparable to those without the virus (Dunne et al., 2019). However, the effectiveness of ART depends on appropriate medication adherence (Byrd et al., 2019), which entails following the prescribed timing, dosage, and frequency over the recommended treatment duration (Huang et al., 2020). Optimal adherence to ART decreases viral load (Gross et al., 2001), improves immune function (Barnes et al., 2020), reduces mortality rates (Boussari et al., 2015), and enhances the overall quality of life in PWH (Fumaz et al., 2002; Mannheimer et al., 2005; Oguntibeju, 2012).

According to HIV surveillance data from the Centers for Disease Control and Prevention (CDC), only 62.7% of PWH achieve viral suppression (Harris et al., 2019), indicating suboptimal medication adherence. Prior research indicates that ART adherence is impacted by several complex psychosocial factors, including substance use disorder (SUD) (Cherenack et al., 2022; Hendershot et al., 2009). The syndemic theory suggests that multiple co-occurring psychosocial comorbidities interact synergistically to contribute to poor health outcomes for PWH (Singer et al., 2017). Substance use has been identified as an independent risk factor for poor HIV outcomes within the syndemic context (Carrico, 2011; Meyer et al., 2013). For instance, a prospective study found that individuals using drugs, regardless of their usage pattern

(e.g., intermittent use, persistent use), had higher odds of having an unsuppressed viral load than non-users (Feldman et al., 2019). Moreover, increased alcohol consumption has been linked to lower odds of improving ART adherence (Azar et al., 2010; Barai et al., 2017). Therefore, it is imperative to investigate medication adherence within this subpopulation to understand the factors influencing adherence and develop targeted interventions.

Factors impacting care among PWH and SUD operate on multiple levels, including intrapersonal, interpersonal, community, societal, and structural (Cherenack et al., 2022; Singer et al., 2017). Multiple behavioral change theories explore the factors influencing adherence in chronic disease management (Liddelow et al., 2020; Lu et al., 2020). Specifically, psychological theories such as the Health Belief Model (Rosenstock, 1974), Social-Cognitive Theory (Bandura, 1991), and Theory of Reasoned Action (Fishbein, 1979) have challenged the passive role of patients in healthcare, emphasizing that adherence depends on individuals being informed, motivated, and convinced of treatment benefits (Abbas et al., 2023; Al-Noumani et al., 2023). Despite the promises of these theories in understanding medication adherence, they do not account for external factors, such as social relationships, that impact the individual's engagement in a behavior (Abbas et al., 2023).

Additionally, there are still limitations in applying theory-driven evidence-based models to develop effective interventions to understand and address medication adherence (Xu et al., 2020). A recent scoping review of qualitative studies exploring the complexity of medication adherence in patients with chronic disease found that only 17 studies had a behavior theory-based approach to understanding medication adherence (Kvarnström et al., 2021). A review of the utility of health behavior theories for developing interventions to promote long-term medication adherence identified that only one study employed an explicit theoretical framework

(Munro et al., 2007). Specifically, in HIV research, many ART adherence interventions have limited or no explicit theoretical basis (Galárraga et al., 2013).

Self-determination theory (SDT) is one prominent theory used extensively to promote health behavior change (Patrick & Williams, 2012; Ryan & Deci, 2000). Findings from a recent meta-analysis support the efficacy of SDT interventions in promoting health behavior change (Sheeran et al., 2020). SDT suggests that individuals achieve greater self-regulation by internalizing their behaviors, moving from external control to autonomous regulation, with motivation types and environmental factors playing a role in this process (Caruso et al., 2021). A qualitative study of PWH in New York integrated Critical Race Theory, Harm Reduction, and SDT to identify and understand the complex and multi-level factors that drive poor engagement in HIV care focused on the positive impact of the SDT construct of social-relatedness and engagement in care (Cluesman et al., 2023). Similarly, SDT was applied to address drug-related harm among PWH who use drugs (Gwadz et al., 2022). SDT provides valuable insights into the impact of social environments on addiction among individuals with unmet psychosocial needs, such as relatedness (Sun & Zhang, 2021).

Psychological theories and approaches are valuable in identifying modifiable factors associated with behaviors like medication adherence (Conn et al., 2016), and they hold particular promise for individuals with SUD who face unique challenges with adherence. Theory-based interventions can significantly improve health outcomes for people with SUD The proven efficacy of SDT in diverse health behaviors suggests its potential to effectively identify the complex factors that impact treatment adherence among PWH and SUD. Our study aims to apply Self Determination Theory to examine the association between SDT and ART adherence among

individuals with SUD, utilizing a secondary analysis of a larger mobile health study focused on identifying risky behaviors impacting treatment adherence in PWH and SUD.

## Methods

### Study design

This cross-sectional study assessed associations between medication adherence among PWH and SUD using survey data collected from March 2019 to June 2019.

This study is part of a larger project implementing the Addiction-Comprehensive Health Enhancement Support System (A-CHESS) from March 2019 to March 2020 to enhance support and engagement in care for individuals with HIV and SUD. A-CHESS, developed by the Center for Health Enhancement System Studies at the University of Wisconsin-Madison, offers a comprehensive range of services to address the multifaceted challenges faced by individuals seeking addiction treatment and prevention (Gustafson et al., 2016). These services include discussion forums, cognitive behavioral therapy boosters, games, relaxation activities, and educational resources on hepatitis C, HIV, and SUD. Aligned with the components of self-determination theory, A-CHESS aims to enhance self-motivation and well-being by catering to the psychological needs of competence, autonomy, and relatedness (Hochstatter et al., 2021). Our study uses a baseline survey completed by A-CHESS participants (Appendix A).

### Participant recruitment

PWH and SUD were identified by research coordinators at HIV clinics in Wisconsin through provider referrals. To be eligible for participation, individuals had to be 18 years or older, have clinical documentation of HIV infection, and have a history of substance use disorder. SUD history was defined by meeting one or more of the following criteria: a positive result on substance-use screening tests, evidence of substance use within the past year, current

involvement in a substance-abuse treatment program, regular participation in a substance-use disorder-oriented support group (at least monthly), or a lifetime history of problematic drug or alcohol use with recent incarceration.

Data collection and measures

The baseline survey for A-CHESS study participants was administered by trained research staff, who conducted the surveys over the phone or in person. The estimated completion time for the survey was 20 to 30 minutes, and all data collected by the research staff were securely stored in a Research Electronic Data Capture (REDCap) database (Harris et al., 2009). Participants received $50 for completing the baseline survey.

The baseline survey administered to the A-CHESS study participants included various items assessing aspects such as health service utilization, withdrawal symptoms, and risky sexual behaviors (Appendix D). However, only theory-informed relevant measures were utilized for this study. The selection of specific baseline survey measures was guided by the principles of SDT as outlined in the existing literature.

According to SDT, intrinsic motivation is the satisfaction of the three innate basic psychological needs of autonomy, competence, and relatedness (Ryan & Deci, 2000). When these needs are satisfied, it is assumed that self-determined forms of motivational regulation guide behavior such as medication adherence (Ryan & Deci, 2000). Autonomy involves having a sense of volition in determining one's behavior (Ryan & Deci, 2008). Competence consists of the experience of feeling capable and effective when interacting with one's environment (Church et al., Stanley et al. 2 2013; Ryan & Deci, 2000). Relatedness involves feeling a sense of support and connection with others (Ryan & Deci, 2002). Guided by these constructs, we selected

positive/negative affect, loneliness scale, internalized AIDS-related stigma, and treatment self-regulation as independent measures.

## Dependent Variable

Our dependent variable of interest is ART adherence, measured using the Four-item Morisky Medication Adherence Scale (MMAS-4)(Morisky et al., 1986). The MMAS-4 is widely used to capture self-reported medication-taking behavior (Fayet et al., 2020). It consists of four items, including questions such as "How often do you forget to take your HIV medications?" and "If you feel worse from taking your HIV medications, how likely are you to stop taking it?" with response options ranging from 1 (indicating a higher frequency or likelihood) to 5 (indicating a lower frequency or likelihood). Each question was assigned one point, resulting in a total score of 20. Adherence was defined as achieving the maximum score of 20 points, while nonadherence scored as any total points below 20 (Guerra et al., 2022). Previous research has shown that the MMAS-4 effectively evaluates ART adherence (Walsh et al., 2002). MMAS-4 has also demonstrated a moderate to high concordance with electronic medication monitoring devices (Shi et al., 2010). The sensitivity and specificity of the MMAS were reported as 81% and 44%, respectively. Cronbach's alpha reliability coefficient is 0.6 (Tan et al., 2014).

## Independent Variables

### *Positive Affect Negative Affect Schedule (PANAS)*

To measure individuals' feelings of self and engagement in personally meaningful activities and their sense of constraint and frustration, we utilized the Positive and Negative Affect Schedule (PANAS) (Watson et al., 1988). The PANAS has strong reported validity with such measures as general distress and dysfunction, identified as feelings that undermine

autonomy (Crawford & Henry, 2004). Negative affect, on the other hand, involves experiencing the world more negatively (Merz et al., 2013). Participants were asked to respond to the 20 items of the PANAS. The reliability and validity of the PANAS scale are moderately good (Crawford & Henry, 2004; Watson et al., 1988). The Cronbach alpha coefficient for the Positive Affect Scale is 0.86 to 0.90; for the Negative Affect Scale 0.84 to 0.87 (Magyar-Moe, 2009). We measured negative and positive affect as two distinct measures.

*Internalized AIDS-Related Stigma Scale*

Internalized stigma refers to the process whereby individuals living with HIV internalize negative societal attitudes and develop self-deprecating beliefs about themselves. We utilized the Internalized AIDS-Related Stigma Scale to measure internalized AIDS-related stigma on a six-item scale (Kalichman et al., 2009). Each item offers a binary (yes/no) response, and the total scale score is computed as the sum of the items. The internalized stigma scale is internally consistent, as suggested by its Cronbach's alpha of 0.73 [9 % confidence interval (CI), 0.69–0.78] (Tsai et al., 2013).

*The University of California-Los Angeles 3-item Loneliness Scale*

We utilized the 3-item Loneliness Scale developed by the University of California-Los Angeles (UCLA) to measure social relatedness (Perissinotto et al., 2012). Loneliness encompasses isolation, disconnection, and a lack of belongingness (Hughes et al., 2004). The scale assesses three aspects of loneliness: feeling left out, isolated, and lacking companionship. Participants are asked to indicate the frequency with which they experience each of these feelings, ranging from hardly ever (or never) to some of the time or often. We calculated a continuous scale score for the loneliness measure, with scores falling within the range of 3 to 12

(Rosenberg et al., 2020). The loneliness scale has undergone validation and exhibits favorable psychometric properties, including good internal consistency with a Cronbach's α of 0.72 (Rosenberg et al., 2020).

*Treatment Self-regulation Questionnaire (TSRQ)*

Competence refers to an individual's experience of feeling capable and effective when interacting with their environment. In the context of SDT, competence is one of the three basic psychological needs that, when satisfied, contribute to intrinsic motivation and well-being.

We assessed competence using the Treatment Self-regulation Questionnaire (TSRQ) (Brown et al., 1999). Treatment self-regulation involves regulating and managing one's own behaviors, thoughts, and emotions related to adhering to a treatment regimen (Hagger, 2010). It reflects an individual's perceived competence in effectively engaging in self-directed actions to adhere to a behavior. Our scale asked questions regarding their substance use and self-regulation regarding their treatment. By assessing treatment self-regulation, researchers can gain insights into an individual's perceived competence in managing their health-related behaviors and the extent to which they feel capable of adhering to the treatment requirements.

On a 5-point Likert scale, participants were asked to rate the self-regulation questions from "Not True" to "Very True." Each score on the scale is worth one point, and the total points are 30. Previous tests of the TSRQ found good reliability (Cronbach's $\alpha = .88$) and predicted change in health-related behavior ($p<.001$) (Mayer et al., 2018).

*Sociodemographic Information*

We asked participants to provide information regarding their gender. We collected age as a continuous variable, allowing participants to enter their exact age. We inquired about the

highest level of education completed by each participant and categorized it as either having completed college or not. For participant race, we presented options including White, Black or African American, Asian, Native Hawaiian or other Pacific Islander, and American Indian or Alaskan Native. We also allowed participants to enter a different race through an open text field.

Data analysis

Frequency distributions and descriptive statistics were used to summarize the characteristics of A-CHESS participants. All categorical variables are described as numbers and percentages. A two-sided $p < 0.05$ was considered statistically significant. All the statistical analyses will be carried out using SPSS version 28.

Multivariable logistic regression was used to examine the association between the dependent variable, medication adherence, and the primary independent variables of interest (AIDS-related stigma, loneliness, positive/negative affect, treatment self-regulation). Other covariates were selected based on their hypothesized association with the primary covariates of interest and medication adherence. These variables are self-reported and include participants' sociodemographic characteristics. Demographic characteristics reported included age, gender ("male," "female," and "transgender"), educational level, and employment status.

## Results

A total of 208 individuals with HIV and SUD were enrolled in the study and completed the baseline survey. Most participants were male (75%) with a mean age of 46.34( SD ± 11.26). Among the participants, 65.90% identified as Black/African American. Additionally, 57.20% reported being single, and approximately 66.80% were unemployed (Table I).

**Table 2 (Table 1 – Paper 1)**

*Sociodemographic characteristics of A-CHESS participants at baseline*

| Variable name | | No. of participants n= 208 | Percentage(%) | Mean ± SD |
|---|---|---|---|---|
| **Gender** | | | | |
| | Male | 156 | 75.00 | |
| | Female | 48 | 23.10 | |
| | Other | 4 | 1.90 | |
| **Age** (years) | | | | 46.34 (11.26) |
| | 50–59 | 74 | 35.58 | |
| | 40–49 | 49 | 23.56 | |
| | 30–39 | 38 | 18.27 | |
| | 18–29 | 23 | 11.06 | |
| | 60+ | 23 | 11.06 | |
| **Race** | | | | |
| | Black/African American | 137 | 65.90 | |
| | White | 64 | 30.77 | |
| | Other | 8 | 3.85 | |
| | American Indian/Alaskan Native | 5 | 2.40 | |
| **Relationship status** | | | | |
| | Single | 119 | 57.21 | |
| | Partnered | 89 | 42.79 | |
| **Education** | | | | |
| | High school graduate or GED | 72 | 34.60 | |
| | Some college or 2-year degree | 67 | 32.20 | |
| | Some high school but did not graduate | 49 | 23.60 | |
| | More than a 4-year college degree | 9 | 4.30 | |
| | 4-year college graduate | 7 | 3.40 | |
| | 8th grade or less | 4 | 1.90 | |
| **Employment status** | | | | |
| | Unemployed | 139 | 66.80 | |
| | Employed | 69 | 33.20 | |

SD = Standard Deviation

The logistic regression analysis examined the associations between SDT constructs and medication adherence among individuals with HIV and SUD. The results revealed that stigma was significantly associated with medication adherence (adjusted odds ratio = 0.83, 95% CI [0.70, 0.99], p = 0.04). Higher levels of stigma were associated with reduced odds of medication adherence. Education level was also significantly associated with medication adherence (adjusted odds ratio = 0.41, 95% CI [0.22, 0.76], p = 0.005). Participants who had completed college were less likely to exhibit medication nonadherence than those with less than a college education. However, the analysis did not reveal significant associations between medication adherence and several other variables, including age, gender, loneliness, negative affect, Treatment Self-Regulation (TSR), and positive affect.

The overall model, including all variables, was statistically significant ($\chi 2$ (df = 8, N = 208) = 17.19, p = 0.03), indicating that the model can distinguish between adherent respondents and those not adherent to ART. The model explained between 8.2% (Cox and Snell R square) and 10.9% (Nagelkerke R squared) of the variance in adherence and correctly classified 62.9% of cases.

**Table 3 (Table 2 – Paper 1)**

*Associations between positive and negative affect, treatment self-regulation, stigma, loneliness, and with medication adherence*

| Variable | Unadjusted OR (95% CI) | *p*-value[b] | Adjusted[b] OR (95% CI) | *p*-value[b] |
|---|---|---|---|---|
| **Age** | | | 1.00 (0.97 – 1.02) | 0.76 |
| **Education** | | | | |
| Less than college | | | | - |
| College | | | 0.41 (0.22 – 0.76) | 0.005 |
| **Gender** | | | | |
| Male | | | - | - |
| Female | | | 1.38 (0.69 – 2.77) | 0.37 |
| **Loneliness** | 0.95 (0.85 – 1.06) | 0.37 | 0.96 (0.86 – 1.08) | 0.53 |
| **Stigma** | 0.86 (0.73 – 1.00) | 0.06 | 0.83 (0.70 – 0.99) | 0.04 |
| **Treatment Self-Regulation** | 0.97 (0.53 – 1.79) | 0.93 | 0.91 (0.49 – 1.71) | 0.77 |
| **Negative Affect** | 1.00 (0.97 – 1.03) | 0.94 | 0.99 (0.96 – 1.02) | 0.51 |
| **Positive Affect** | 1.00 (0.97 – 1.05) | 0.62 | 1.00 (0.97 – 1.04) | 0.82 |

Hosmer and Lemeshow Test showed an acceptable model fit ($\chi 2 = 3.52$, P= 0.91)
[a]n = 208
[b]p-value significant at $\leq 0.05$ level
CI = confidence interval
OR = odds ratio

## Discussion

In the logistic regression analysis conducted based on self-determination theory, stigma, positive affect, negative affect, treatment self-regulation, and loneliness were examined in relation to medication adherence among individuals with HIV and SUD. While affect, treatment self-regulation, and loneliness were not significantly associated with medication adherence, stigma was found to be significantly associated with medication adherence. This finding underscores the negative impact of stigma surrounding HIV and substance use on treatment adherence, emphasizing the need for targeted interventions to address and reduce stigma-related barriers. Education level also demonstrated a significant association with medication adherence. Individuals who had completed college exhibited higher levels of medication adherence than those with less than a college education.

The differential findings between stigma and loneliness highlight the importance of considering the unique contributions of different factors related to self-determination theory in understanding medication adherence. While both stigma and loneliness are measures of social relatedness, only stigma showed a significant association with medication adherence. These findings suggest that stigma may have a more noticeable impact on medication adherence than feelings of loneliness or lack of social connectedness. Addressing and reducing stigma should be a central focus in interventions to improve medication adherence among individuals with HIV and substance use disorders.

The results of our study align with the existing literature that has consistently linked stigma to poor adherence to ART among individuals with HIV (Green et al., 2010; Vanable et al., 2006; Zeng et al., 2020). However, it is worth noting that few studies have reported the psychosocial mechanisms through which stigma operates. For example, a study that reviewed 38

studies reporting either cross-sectional or prospective analyses of the association of HIV-related stigma to medication adherence found substantial empirical evidence linking stigma to adherence. However, these studies and ours did not explore the multiple domains of stigma (Sweeney & Vanable, 2016). This calls for further research to explore the underlying processes through which stigma influences medication adherence, allowing for more targeted interventions to address stigma-related barriers.

Our study focused solely on internalized AIDS-related stigma and did not investigate the impact of intersectional stigmas. Individuals with HIV and substance use disorders may face multiple stigmatized identities (related to their HIV and SUD diagnosis) that can impact their health-seeking behaviors (Yang et al., 2023). Future studies should examine the effects of various stigmas, such as HIV-related stigma and substance use disorder-related stigma, to understand their influence on medication adherence.

Our findings shed light on the role of autonomy in medication adherence. Although autonomy measures, such as affect, were included in our study, they did not show a significant association with medication adherence. Our findings contrast with previous studies that have reported associations between negative affect and medication adherence (Grenard et al., 2011; Kardas et al., 2013; Sin & DiMatteo, 2014). It is vital to differentiate negative affect from depression and consider the conceptual and theoretical differences between these constructs. (Geisser et al., 2000). Our findings differ from studies showing unique positive associations between positive affect and health-related outcomes, including viral load suppression in those living with HIV (Wilson et al., 2017). One study showed that increased positive states of mind mediated the association between perceived social support and improved ART adherence

(Gonzalez et al., 2004). In a study of PWH who abuse methamphetamine, positive affect was independently associated with ART adherence (Carrico, 2011).

Studies examining competence in medication adherence within the framework of self-determination have been relatively limited. Our study aimed to address this gap by investigating competence in the context of treatment self-regulation related to substance use. While previous research has highlighted the importance of perceived competence as a strong predictor of adherence, these studies have primarily focused on competence in general without explicitly considering its relationship with substance use (Kennedy et al., 2004). Our findings showed that competence in managing SUD is not significantly associated with ART adherence.

Although theoretical frameworks, such as self-determination theory, provide a systematic approach to organizing psychosocial factors and developing tailored intervention messages and strategies for promoting behavioral changes (Dai & Calabrese, 2022), it is important to acknowledge that medication adherence is a complex behavior influenced by various factors beyond a single theory. External factors can significantly impact medication adherence, highlighting the need to consider multiple behavioral theories in understanding this phenomenon (Munro et al., 2007).

While our study focused on self-determination theory as a framework for examining autonomy, competence, and relatedness in relation to medication adherence, other behavioral theories may offer additional insights. Exploring the contributions of alternative theories that account for HIV and SUD, such as Capability, Opportunity, and Motivation–Behavior (Easthall & Barnett, 2017), could provide a more comprehensive understanding of medication adherence in individuals with HIV and substance use disorders. However, to facilitate meaningful

comparisons and enhance the overall evidence base, it is crucial to ensure consistency in the operationalization of theories across studies (Moore & Evans, 2017).

### Limitations

Our study has certain limitations that need to be acknowledged. First, the cross-sectional nature of the survey prevents us from establishing causality between socio-behavioral factors and medication adherence. While the Morisky Four-item medication adherence scale provides reasonable estimates of medication-taking behavior, it may not serve as an adequate explanatory tool for understanding why patients are not adherent, potentially leading to a weak relationship between the Morisky scale and objective clinical outcome measures (Tan et al., 2014). Additionally, reliance on self-report recall for measuring adherence, while validated in previous research (Blumenthal et al., 2019), is susceptible to recall bias. Although patient self-report is one of the critical indirect methods of measuring medication adherence (Tan et al., 2014), our study could benefit from improved data collection methods, such as integrating innovative technologies like smart pill bottles or medication event monitoring systems, to gather more frequent and objective data on medication adherence.

## Conclusion

Our study highlights the significant role of stigma in predicting medication adherence among individuals with HIV and substance use disorders. The findings suggest that interventions to improve medication adherence should prioritize addressing and reducing stigma. Future research should delve deeper into how stigma influences medication adherence and explore the impact of intersectional stigmas. Addressing medication adherence challenges requires a multifaceted and interdisciplinary approach considering the complex interplay of individual, social, and systemic factors.

# CHAPTER 4

# PAPER 2

# COMPUTER-MEDIATED DISCOURSE ANALYSIS OF A VIRTUAL COMMUNITY OF PEOPLE WITH HIV AND SUBSTANCE USE DISORDER

## Introduction

Despite the stable rate of new Human Immunodeficiency Virus (HIV) infections in the United States, which recorded approximately 34,800 infections in 2019 (Linley et al., 2021), there is an urgent need for advancements in managing the care of individuals living with HIV. Specifically, those with a substance use disorder (SUD) face more significant challenges resulting in higher mortality rates compared with people with HIV who do not abuse or misuse drugs (DeLorenze et al., 2011; Deren et al., 2019; Spinelli et al., 2019). SUDs are characterized by impaired control, social and functional impairment, and persistent substance use despite negative consequences (Muhrer, 2019).

The intersection between SUD and HIV is evident, as substance use is highly prevalent among individuals with HIV. For instance, an estimated 8.9 to 22.4 million people inject drugs, of which approximately 0.9 to 4.8 million are HIV positive (Des Jarlais et al., 2016). Additionally, alcohol abuse or dependence history is found in 40 to 50% of individuals living with HIV, and rates of cannabis and stimulant use are also higher compared to the general population (Duko et al., 2019; Przybyla et al., 2022). These high prevalence rates emphasize the significant co-occurrence of substance use and HIV, underscoring the need for comprehensive approaches that address both conditions to improve health outcomes.

The presence of co-occurring SUD and HIV leads to significantly worse health outcomes, including clinic inconsistency, delayed initiation of antiretroviral medication, poor adherence, and increased mortality (Crane et al., 2017; Croxford et al., 2017; Ridgway et al., 2021). This population also experiences a lower quality of life, with higher rates of comorbidities, psychological distress, and social stigma than those with HIV alone (Dolengevich-Segal et al., 2019; Johnson Shen et al., 2019; Rice et al., 2019). Individuals with SUD often face additional challenges, such as psychiatric illnesses and social isolation, hindering their engagement in care (Muhrer, 2019).

Research efforts have been made to improve the health outcomes for individuals with HIV and SUD using social support interventions (Des Jarlais et al., 2016; Hochstatter et al., 2021; Mi et al., 2020). Social support is critical in avoiding treatment interruptions (Rozanova et al., 2020) and addressing negative health outcomes related to substance abuse and HIV (Illangasekare et al., 2013). Additionally, people with HIV are more likely to achieve optimal health outcomes when they perceive the availability of social support promoting positive well-being (Brener et al., 2020).

Historically, individuals with HIV have actively participated in online support groups to form virtual communities, engage in discussions and receive social support (Ferguson, 1997). Online communities are formed by interacting socially around a shared purpose, such as health support, on a digital platform (Preece et al., 2003). Establishing connections within these communities relies on the willingness of participants to engage in social support groups (Moser et al., 2013; Ren et al., 2007).

With the widespread availability of mobile phones, individuals with SUD and HIV can access social support through mobile health applications (Westergaard et al., 2017), enabling

them to form online communities through digital message exchanges. Message boards within these mobile health interventions are recognized as crucial sources of social support for people with HIV, facilitating communication and support among community members (Flickinger et al., 2017).

Despite recognizing message boards' importance and widespread usage, only a few studies have explored the dynamics within these boards to optimize participant engagement and enhance social support. Previous studies have mainly focused on the feasibility (Waselewski et al., 2021), frequency (Canan et al., 2020), and types of messages posted on the message boards (Coursaris & Liu, 2009; Flickinger et al., 2020) as well as the characteristics of individuals posting (Flickinger et al., 2022; Flickinger et al., 2016). While understanding these aspects is crucial, further examination is needed to explore how a supportive community is formed within these apps, especially for the key population of individuals with HIV and substance abuse who have unique needs that are communicated and shared through message boards.

To address the research gap, our study utilized discourse analysis to examine the formation of virtual communities that offer social support for people with HIV and SUD. Discourse analysis rigorously studies natural talk and texts, revealing how language patterns and practices shape society and individuals (Traynor, 2006). Previous studies have utilized discourse analysis in HIV research to explore communication on HIV informative posters regarding treatment adherence and the prevention of stigmatization (Oyebode & Unuabonah, 2013) as well as to understand the behaviors of men who use drugs concerning viral load and reliance on antiretroviral therapy during sexual encounters through interviews (Souleymanov et al., 2019). However, discourse analysis has not yet been applied to investigate the communication of individuals with HIV and SUD in the context of social communities.

Our study used computer-mediated discourse analysis (Herring, 2019) to comprehensively explore the community message board feature of the Addiction Comprehensive Health Enhancement Support System (A-CHESS), a mobile health application designed to provide social support and improve engagement in HIV care for individuals with HIV and SUD (Yang et al., 2023). Through rigorous analysis of the messages posted on the message board, we aim to comprehensively understand the dynamics and interactions within the message board feature of the ACHESS mobile health intervention.

## Methods

### A-CHESS App Overview

A-CHESS is a modified version of the evidence-based CHESS (Comprehensive Health Enhancement Support System), which has proven efficacy in preventing relapse among individuals with alcohol use disorder (Gustafson, McTavish, Chih, Atwood, Johnson, Boyle, Levy, Driscoll, Chisholm, & Dillenburg, 2014). A-CHESS was adapted for use among people with SUD and HIV by expanding additional features aimed at promoting medication adherence, facilitating regular treatment evaluations, providing access to a community message board, offering case management services, and conducting weekly surveys to monitor recovery progress and evaluating protective and risk factors in the social environment (Yang et al., 2023). The A-CHESS app was based on self-determination theory, emphasizing competence, autonomy, and social relatedness to motivate participants to engage in healthy behaviors (Hochstatter et al., 2021).

### Setting and participant recruitment

Participants in the ACHESS study were recruited through the distribution of recruitment flyers at HIV clinics and collaboration with case managers and physicians for referrals. Inclusion

criteria required participants to be 18 or older, have a documented HIV infection, be able to speak and write in English and have a history of SUD. SUD was determined based on positive screening results, current engagement in substance abuse treatment, a lifetime history of problematic drug or alcohol use, or recent substance use-related incarceration. Enrollment took place on a rolling basis starting from January until April 2019.

The A-CHESS study obtained ethical approval from the Institutional Review Board (IRB) at the University of Wisconsin-Madison. Eligible participants were instructed to download the A-CHESS app onto their smartphones. Case managers provided tutorials to guide participants through the process of using the app, including creating a deidentified username to protect their offline identities and ensure anonymity. Participants were then familiarized with the app's various features, receiving step-by-step instructions on navigating and utilizing its functionalities.

Data source

The primary data source for our study was the A-CHESS message board, a public forum within the A-CHESS app where participants could engage with case managers, research staff, and peers. Our analysis included all messages posted by the participants and messages from the research staff and case managers, recognizing their membership in the virtual community and their contributions to community formation (Coulson & Buchanan, 2022). Participants were provided detailed guidelines on appropriate message board use and respectful dialogue. Participants were instructed not to share personally identifying information on the message board, and their posts were immediately visible to other users. The study team actively monitored the message board content, and personal contact through phone or text was available. In addition to the message board data, we collected baseline survey information to describe

participants' demographics, history of HIV, history of substance use disorder, and substance use patterns. This information was collected either in person during enrollment or over the phone by a research staff member.

Data sampling

To conduct a comprehensive longitudinal examination of virtual community formation, we analyzed all the messages posted on the message board throughout the 26-month study period s. Research staff extracted the information from the message board, including the posted messages, usernames, and time of posting for the analysis. Each message board posting or comment was placed into separate cells within an Excel workbook. The unit of analysis was an individual message posted. When examining data in a virtual community, various approaches can be used, such as *random* selection of messages, analyzing messages by *theme* (e.g., all messages in a particular thread), focusing on specific *time* frames (e.g., messages from a particular week), studying specific *phenomena* (e.g., messages related to jokes or conflict negotiation), or analyzing messages by *group* (e.g., messages posted by women or individuals who identified a particular substance as their drug of choice) (Herring, 2004a, 2019)—our sampling strategy combined sampling based on *time* and *theme*. Initially, we organized all the messages posted on the message board based on their respective time stamps, arranging them chronologically from the first to the last post on the message board. This time-based organization allowed us to capture the contextual richness of the longitudinal data. We refined our data management approach by reorganizing the messages based on the threads they belonged to, considering the corresponding time. For example, if a thread had an initiation message posted in May and a response message posted in December, we analyzed the May and December messages

together as they formed part of the same thread. This approach ensured that we maintained topical coherence within threads.

Data analysis

We used a computer-mediated discourse analysis (CMDA) approach to understand how a virtual community is being formed on the A-CHESS message board (Herring, 2004a). According to Herring, virtual communities are formed when individuals utilize computer-mediated platforms, such as A-CHESS, by establishing structure, deriving meaning in their communication, interacting, and engaging in social behaviors within these virtual communities (Herring, 2004a). CMDA analyzes language use in online communication, including forums, social media, chat rooms, and email, examining linguistic features, communication strategies, interaction patterns, social dynamics, structure, meaning-making, and social behaviors (Herring, 2004a, 2004b, 2019).

*Quantitative analysis: structure and interaction of A-CHESS virtual community formation*

To explore the structure and interaction patterns of the virtual community, we conducted a quantitative analysis of user interactions on the A-CHESS message board. This involved quantifying message types, examining discourse structure, and describing the participants' demographics in virtual community formation. Through this analysis, we identified patterns in language use, key participants, reciprocity of engagement, and the occurrence of extended conversations, providing valuable insights into the formation and dynamics of the virtual community. Descriptive statistics were performed using SPSS (specific version) to describe the study participants' characteristics.

*Qualitative analysis: meaning, social behaviors, and engagement patterns of the discourses in the message board*

In the qualitative analysis, we delved into the meaning exchanged on the A-CHESS message board, which explored how participants construct meaning in their interaction and the languages used to indicate their social behavior. This included examining participants' responses to messages, the types of messaging they initiated, and the level of participation exhibited by community members. By focusing on these aspects, we gained valuable insights into the evolving nature of the discourse within the app. We explored the range of topics discussed and how participants engaged with, responded to, and shaped the overall patterns of interaction, thereby creating a unique virtual community.

Within the discourse analysis, we paid close attention to several crucial aspects within each phase of the messaging structures. Our objective was to understand the purpose and function of each message as part of the broader discourse in the virtual community. By delving into these dimensions, we could extract valuable insights into the dynamics of the app's discourse, the topics being discussed, and how the interaction patterns evolved, providing a deeper understanding of this distinct virtual community.

*Coding process and framework*

The coding framework used in this study was developed by the researchers (A.T. and K.P.) to capture the various aspects of the messages, including their structure, meaning, interaction, and social behaviors. The first author, who has received training in qualitative research methods, thoroughly reviewed the messages over two months. Following an inductive approach, the researchers examined the patterns of interaction on the message board. Initially, a

quarter of the data was coded sequentially, with extensive discussions held for each message to reach a consensus on the assigned codes. These codes were then applied to the remaining data. Each message was assigned one or more codes to capture specific actions and behaviors. The researchers categorized these behaviors based on the structure of the messages, identifying common themes and patterns. Furthermore, the messages were grouped according to the key participants involved, focusing on understanding the actors within the interactions.

By combining quantitative and qualitative methodologies, we adopted a mixed-mode approach to comprehensively examine the virtual community formation on the A-CHESS message board. Our analysis provided valuable insights into the structural elements, interactional patterns, meaning-making processes, and social behaviors exhibited within the virtual community.

## Results

Between March 13, 2019, and April 30, 2021 (two years and one month), a total of 2071 messages were shared on the A-CHESS message board by research staff (including case managers) and study participants. Blank and duplicate posts were excluded from the analysis, resulting in 1834 posts being included in the discourse analysis. Our results are in two sections. First, we present quantitative findings of the participants contributing to the message board and the structure of engagement contributing to virtual community formation. Secondly, we present qualitative findings of the messaging types and social behaviors contributing to community formation. We also include quantitative findings of the engagement patterns and interactions within specific message types.

### Structure and interaction of A-CHESS virtual community formation

All 208 study participants were provided access to the A-CHESS message board and information on how to post to the message board. Approximately 41% (87 individuals) of all study participants posted on the message board at least once. The distribution of age, race, sex, employment, and education was similar for A-CHESS study participants who actively engaged with the message board (n=88), and those who did not post at all on the message board (n=120) are shown in Table 1.

**Table 4 (Table 1 – Paper 2)**

*Demographic characteristics of participants who posted on the message board vs. non-users*

| Variable | Message board users (n=88) | Message board non-users (n=120) |
|---|---|---|
| **Mean age (years)** | 45.88 (Range: 24 - 73) | 46.69 (Range: 24 - 60) |
| **Sex** | | |
| Male | 65 (74.7%) | 91 (75.8%) |
| Female | 22 (25.3%) | 26 (21.7%) |
| Other | 1 (1.1%) | |
| **Race** | | |
| Black | 57 (64.8%) | 80 (66.7%) |
| **Education** | | |
| Four-year college | 31 (35.2%) | 45 (37.5%) |
| **Employment** | | |
| Yes | 54 (62.1%) | 85 (70.8%) |
| No | 34 (39.0%) | 35 (29.2%) |

Out of the 1834 messages posted on the message board, the majority (70%) were contributed by study participants, while the remaining 30% were posted by research staff members, including two case managers. A small subset of participants played a significant role

in contributing to the engagement on the message board. Specifically, five participants were responsible for 40% of all the posts, with one alone accounting for 12% of the messages. A significant portion (70%) of the participants posted between 1 to 10 messages. Less than 22% of the posts were single posts without further engagement.

*Meaning, social behaviors, and engagement patterns of the discourses in the message board*

The discourse analysis on the app usage identified three coexisting message structures: premeditated and adlib messaging (both driven by case managers and research staff) and participant-driven messaging. Initially, research staff and case managers implemented a planned and structured approach to communication by posting premeditated messaging, utilizing predetermined topics, scheduled posts, and automated motivational messages within the app. Adlib messaging emerged approximately one month into the study, with research staff leading the communication. Compared to the premeditated messaging, the staff began incentivizing participant engagement and shared personalized stories to encourage active participation. In the participant-driven phase of messaging, participants actively shaped the app's interaction patterns, taking ownership and initiating discussions, fostering autonomy and creativity within the community by sharing unique messages alongside and inspired by the premeditated messages of the research staff. Although the premeditated phase occurred at the start of the app use and dominated through the 14 months of app usage, the messaging had transitions between phases, with elements of each phase coexisting or overlapping with others (Figure 1).

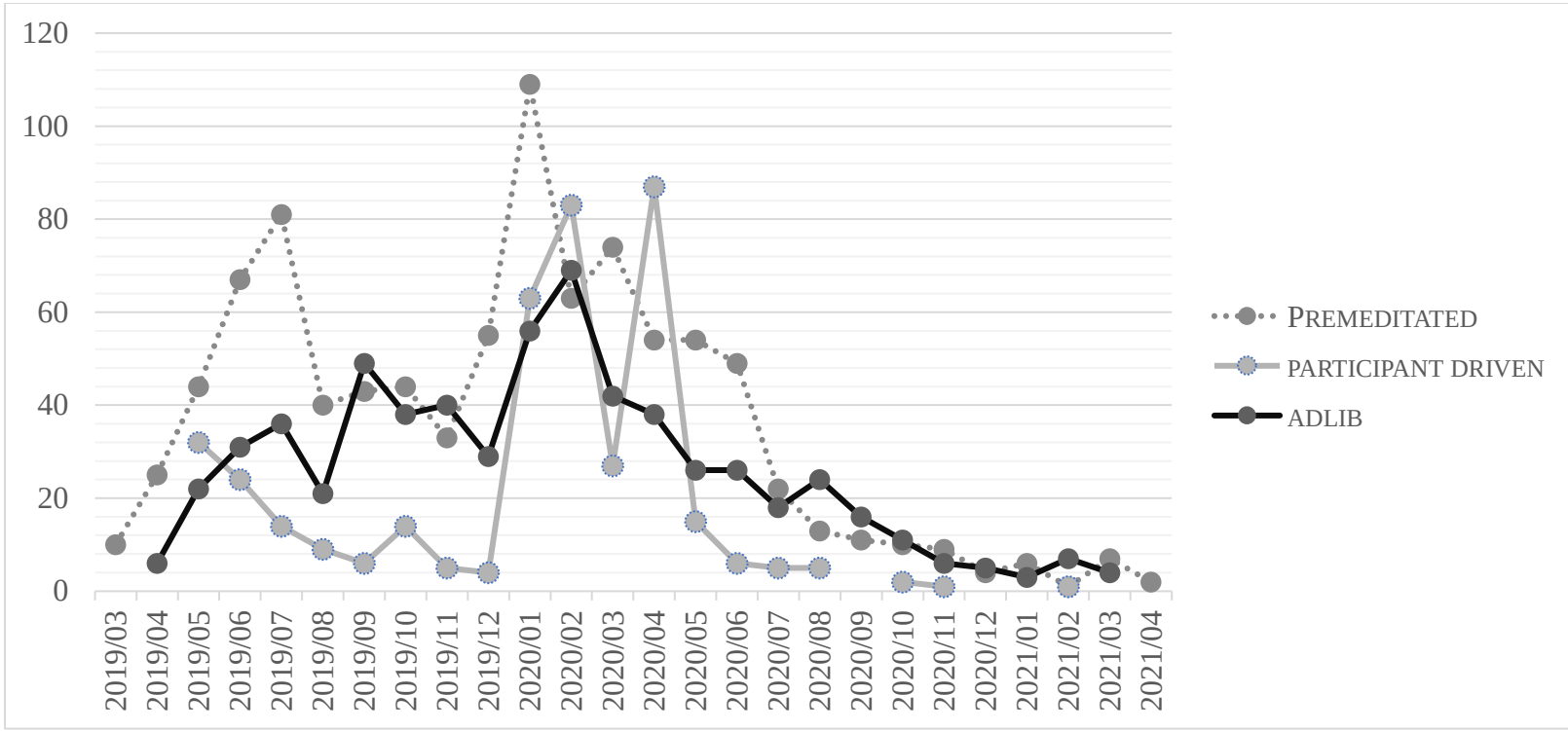


**Figure 1 (Paper 2)**
**Distribution of messaging type on the A-CHESS message board**

Note that verbatim quotes were used, preserving participants' non-standard spelling and grammar to accurately represent their voices and expressions in the analysis. Furthermore, the usernames presented are pseudonyms; new usernames were crafted to closely mirror the original ones, ensuring the anonymity of participants.

**Premeditated messaging**

The research staff followed a structured approach by planning and scheduling their posts in advance. They created a weekly schedule to outline the topics they intended to cover on the app, encompassing various subjects such as raising awareness about current issues, providing news resources, and sharing health-related information (Table 2). The study team was given access to this schedule, which confirmed that these posts were planned and not responsive to the day-to-day interactions on the message board. In addition to these planned posts, the ACHESS system generated daily posts known as "Thought of the Day" (TOTD), further contributing to the premeditated messaging strategy employed by the staff.

**Table 5 (Table 2 – Paper 2)**

*Description of premeditated message types, sample posts, and responses on the A-CHESS Message Board*

| Message types | Description | Sample initial and response messages | Engagement with messages |
|---|---|---|---|
| **Thought of the day messages** | The ACHESS app distributed automated messages. These were motivational messages that often included a short message and the author. Messages were randomly generated daily, and participants responded by aligning, applying, or interpreting the messages to themselves and other participants on the app. | **[Initiation post]**<br>**A-CHESS App\| March 12, 2019, 04:00 pm**<br>Thought of the Day – "A wise man gets more use from his enemies than a fool does from his friends. "<br><br>**[Response posts]**<br>**JAXSTORM\| March 13, 2020, 07:14 am**<br>>That is true all day.<br>**LunaSmiles\| March 13, 2020, 08:34am**<br>>To me it means sometimes you need everyone help getting thought the day<br>**greensquirrel4551\| March 13, 2020, 10:26 am**<br>>To me the thought of the day means choice your friends wisely<br>**MoonlitWander\| March 13, 2020, 02:06pm**<br>>My mom use to say that to me with I was younger.<br>**AsherTwilight18 \| March 13, 2020, 1:28p**<br>>A fool and his freind will be just that fools | Most of the messages in the app were responses to TOTD posts. Participants intuitively decided to follow one participant's engagement with the TOTD without explicit instructions on whether or how to respond, highlighting the development of community norms within the online space. |
| **News messages** | Case managers shared the HIV and SUD news with participants. Other news topics included from<br>current affairs, such as elections, and later included COVID-19. | [**Initiation post]**<br>**Case Manager\| April 09, 2019 11:32 am**<br>> Hi All-The first kidney transplant from a person living with HIV was given to another person who is living with HIV. I think this is awesome and I am happy to hear of this new milestone happening! What are your thoughts on this? [ Link] Happy Tuesday, [Name]<br>**[No responses]** | Approximately 150 messages posted on the app were news contents. Case managers posted news messages. However, participants did not interact or engage with news. |

| | | | |
|---|---|---|---|
| **Awareness messages** | Research staff and case managers also raised awareness on important topics such as | [**Initiation post]**<br>**Case manager**| **April 16, 2019, 09:52 am**<br>>Hey everyone,<br>Have you heard of the U=U campaign? Undetectable Equals Untransmittable. U=U signifies that individuals with HIV who receive antiretroviral therapy (ART) and have achieved and maintained an undetectable viral load cannot sexually transmit the virus to others.<br>**[No responses]** | Approximately 148 posted on the board were related to raising awareness. Similarly, participants did not engage with messages that were raising awareness and often only acknowledged the messages. |

1.1 Premeditated messaging: Thought of the Day (TOTD)

The A-CHESS app includes automated "Thought of the Day" (TOTD) posts shared with participants daily at 4:00 pm, featuring short motivational quotes attributed to their authors. One participant started responding to these TOTD messages in the first month of the study by stating their agreement with the TOTD message. A month later, other participants started to engage in the same behavior and provided interpretations of the TOTD. This collective decision to respond in similar approaches indicates the formation of a virtual community characterized by mirrored social behavior and a tacit agreement on the significance of the messages. Participants responded to these TOTD messages without explicit instructions from the research team on whether they should respond or how they should respond, highlighting the development of community norms.

*1.1.1 Aligning with TOTD*

When participants responded to the TOTD posts, some showed alignment with the posts by expressing an agreement or endorsement using words such as "yes" or "I agree" to the posts. In the example below, JAXSTORM responded to the TOTD post by simply agreeing that the TOTD is true. JAXSTORM's response demonstrates a brief affirmation of the TOTD without further elaboration or explanation.

> **A-CHESS App| April 17, 2020, 04:00 pm**
> Thought of the Day – "The sleeper gets nothing but the dream."
> **JAXSTORM | April 17, 2020, 06:19 pm**
> > Yes that is true.

The TOTD uses the metaphor of sleep and dreams to represent a state of inaction or passivity in pursuing one's goals. JAXSTORM's response did not provide a response that sheds

light on the meaning of the thought or how the thought can be applied to their lives or the lives of others in the A-CHESS app; instead, they use the word "true" to not only agree but signal that the message holds truth. Similar alignments to TOTD show participants agreeing with the messages, usually using "yes" and rarely questioning, disagreeing, or offering further detail to align with the TOTD posts. Other response types of interpreting and applying TOTD posts provided additional insights and showed how most participants engaged with the posts.

### *1.1.2 Interpreting TOTD*

Participants interpret the TOTD messages by sharing a personalized interpretation of what they mean and what the message tries to communicate to them or others. These interpretations showed the diverse perspectives and how participants make meaning of community messages. An example is described below.

**A-CHESS App| May 05, 2020, 04:00 pm**
>Thought of the Day – Today I have the courage to look without fear at what needs to be changed in my life.
**AsherTwilight18 | May 05, 2020, 07:51 pm**
> Don't be afraid to change what ever is holding u back

AsherTwilight18 shares an interpretation encouraging others to embrace change and not fear what might hold them back, interpreting the TOTD message as a call for courage to make changes people fear. While the TOTD included a personal message using an "I" statement, the participant's interpretation uses "u," which frames the interpretation as a message to others than oneself. AsherTwilight18 changes the message from an "I" statement (with" have the courage") to a more directive statement ("don't' be afraid"). AsherTwilight18 also interprets what needs to

be changed as "whatever holds a person back—"— going further than the initial quote by suggesting that a change is needed because something is holding people back.

### *1.1.3 Applying TOTD to self*

When participants apply TOTD posts to themselves, they often connect the message and personal experiences to their addiction and sobriety. This personal application of TOTD posts allows participants to find meaning and relevance in the TOTD messages based on their experiences. The TOTD example below shows a participant responding to a message about a behavior change.

**A-CHESS App| March 05, 2020, 04:00 pm**
> Thought of the Day – The change of one simple behavior can affect other behaviors and thus change many things. Jean Baer
**Allen18 | March 03, 2020, 08:05 pm**
> I don't drug today. Instead I get good sleep and can achieve more positive outcomes.

Allen18 identified their "change of one simple behavior" as not doing drugs. They used "I" statements to apply the message of the TOTD to themselves in their present day. While the TOTD is about change, the participant uses "instead" to show their behavior change—getting good sleep instead of doing drugs. Marking that sleep is "good" also shows the effect of not doing drugs on another behavior (sleep), as the change of one behavior affecting another is suggested in the original quote. Furthermore, the potential of "can achieve more positive outcomes" aligns with the quote's suggestion of "change many things," with the additional marking of these changes being "positive." Participants' responses to the TOTD show their connections with each message to their recovery, despite the many other behaviors to which the TOTD can be applied.

Most TOTD posts generally received individual participant responses, indicating personalized reactions to the messages. However, some TOTD posts received multiple responses; although these responses were not interconnected or linked, the messages followed established response types of aligning, applying, or interpreting the messages.

*Responses combining aligning, applying, and interpreting TOTD*

In posts with several responses, one participant may apply the message within the post by connecting it to their personal experiences, behaviors, or challenges. At the same time, other participants may interpret the TOTD by offering their insights, perspectives, or alternative ways of understanding the message. These multiple functions within a single response demonstrate the richness and complexity of participant engagement with the TOTD. Participants bring their own experiences, interpretations, and reflections to the message, resulting in multifaceted interactions. Here is an example of these occurring responses to the same TOTD post.

> **A-CHESS App| April 29, 2020, 04:00 pm**
> Thought of the Day – God Listens to Knee Mail
> **PsycheLark | April 30, 2020, 12:00 pm**
> >Simply to pray everyday.
> **Luna12 | April 30, 2020, 12:39 pm**
> >He Sure Does
> **AsherTwilight18 | May 1, 2020, 12:26 am**
> >Bend your knees
> **JAXSTORM | May 1, 2020, 2:55 pm**
> >God listens to all his children's

In this thread, four participants responded uniquely to the TOTD post about God listening to "knee mail," a metaphor for prayer, an example of using recovery language. PsycheLark interpreted the TOTD by explaining that it encourages praying every day. Their response focused

on understanding the message conveyed by the TOTD. Luna12, on the other hand, aligned with the TOTD by agreeing that God, "He," does indeed listen. Their response showed support for the sentiment expressed in the TOTD. AsherTwilight18's response was brief but still connected to the TOTD by suggesting to "bend your knees," reinforcing the concept of prayer. Finally, JAXSTORM also interpreted the TOTD by stating that God listens to "all his children." Their response aligned with the idea of God's attentiveness to prayers. These participants, without directly interacting with one another, demonstrated different ways of engaging with the TOTD, including interpretation, alignment, and brief expressions related to the message of the TOTD.

This observation suggests that when participants engage with coordinated posts like the TOTD, they establish their unique ways of interacting with the content rather than following a collective pattern or thread of discussion. Overall, the participants' engagement with the TOTD demonstrates their active engagement with the messages and ability to connect them within the broader context of their recovery journeys. They also followed the same example of how they saw one participant responding. The TOTD messages garnered the most response of all premeditated messages.

These participants in the virtual community exhibited various responses to the TOTD, including aligning with the messages, interpreting the messages, or applying the messages to their own lives. In addition to TOTD, research staff and case managers shared news messages as part of the preplanned messaging.

### 1.2 Premeditated messaging: News

The research staff shared the news to disseminate information about what was happening in the study setting or noteworthy happenings relevant to the study group participants. Usually,

the news posts were approximately a paragraph (longer than TOTD) and had external links providing the news source and more information about the news (Table 2). The news posts focused on recovery, healthcare topics, or recovery news. In contrast to the active engagement observed with TOTD posts, the news shared in the message thread did not elicit any responses from the participants.

In addition to news reports, case managers and research staff raised awareness on issues similar to news but corresponded to months dedicated to these efforts, such as stress awareness month.

### 1.3 Premeditated messaging: Raising awareness

The research staff intentionally posted messages to raise awareness on relevant topics for the study participants. These posts focused on stress awareness, sexual assault awareness, important historical days related to HIV/AIDS, and other health-related subjects. Additionally, awareness included appreciation for healthcare professionals, DEA drug-take-back days, mental health awareness days, overdose awareness days, and significant events like World AIDS Day on December 1. These topics were selected to share pertinent news and actively engage participants in discussing their SUD or HIV status.

Participants responded more frequently to the awareness topics compared to the news posts. The research staff's efforts to tailor the information to the participant's experiences and interests likely contributed to their engagement and willingness to participate in discussions on these topics. Table 2 shows an example of an awareness message shared by a case manager about the HIV "U=U campaign" sharing an external link to an American Medical Association message about HIV transmissibility and viral load suppression.

An essential process in virtual community formation is interaction. Most of the premeditated messages did not attract engagement from participants. To address the low engagement in the message board, the research staff and case managers posted more adlib messages that followed a similar framework as the premeditated messages but included overt incentives and direct questions to engage participants actively. By incorporating incentives and asking specific questions, the staff encouraged participants to actively participate in discussions about the awareness topics and increase engagement with the posts.

**2.0 Adlib Messaging**

The research staff and case managers introduced adlib messages to increase participant engagement. Some incorporated incentives and encouraged active participation. They started incentivizing engagement by offering rewards or benefits to participants who actively participated in discussions. Additionally, the staff utilized various techniques to encourage participation, such as sharing polls on different topics of interest.

Table 3 describes messages in the spontaneous phase of the study, characterized by research staff and case managers sharing entertaining messages, destigmatizing struggles, and incentivizing participant engagement.

Table 6 (Table 3 – Paper 2)

*Description of adlib message types, sample posts, and responses on the A-CHESS Message Board*

| Message types | Description | Sample initiating and responses to premeditated messages | Engagement with messages |
|---|---|---|---|
| Sharing entertainment | Research staff and case managers shared entertaining content, such as funny anecdotes, jokes, memes, or interesting articles, to add a light-hearted and entertaining aspect to the discussions. | **[Initiation post]**<br>**Research Staff\| December 11, 2019, 01:51 pm**<br>"How do you make an octopus laugh?<br>With ten-tickles!"<br><br>**[Response posts]**<br>**Luna12\| January 08, 2019, 03:58 pm**<br>Hahahaha<br>**OrionAdventures\| January 31, 2019, 10:46 am**<br>Thanks for the laugh<br>**WildSoul\| February 01, 2019, 04:25 pm**<br>💔 I thought by Tenkling...lol 💔<br><br>**[Initiation post]**<br>**Research Staff\| April 08, 2020, 01:47pm**<br>What's your favorite non-alcoholic beverage? Describe it or tell us why in the comments.<br>A) Coffee B) Black tea, hot or iced C) Juice D) Water E) Pop or soda F) Herbal infusions G) Other?<br>Coffee is my morning regular. It's more of a habit than a favorite.<br><br>**[Response posts]**<br>**Luna12\| April 08, 2020, 11:59pm** | Participants engaged with the entertainment by laughing, using emojis, or sharing their jokes. Unlike TOTD posts, the responses were not immediate and sometimes occurred after several weeks. Additionally, various participants responded to the entertainment posts, even those not engaging with the message board. |

| | | | |
|---|---|---|---|
| | | I love black tea. Now that's my favorite. I can drink it iced with sugar or hot .<br>**NovaBliss\| April 10, 2020, 08:36 am**<br>I love sprite its my favorite and it has no caffeine in it. | |
| Normalizing struggles | Before sharing resources with the group, the research staff and case managers openly discussed and shared their struggles or challenges related to different health-related topics. These differed from the news or awareness in the premeditated phase as staff started the posts by sharing their personal life before sharing the health information and resources. | [**Initiation post]**<br>**Case Manager\| April 09, 2019, 11:32 am**<br><br>Back in April of this year I started experiencing lower back pain. I wasn't sure what the cause of it was, but for over a week I rested my back thinking that was the only thing that would help it heal. After that week, it felt worse! I started working out again and to my surprise, it started to feel better. I was not sure what to make of all of it, until I saw this article on NPR about how you can establish pain relief by exercising. What exercise works for one, might not work for another person. Click [link] read more. What do you all think about this? Has it worked or not worked for any of you?<br>Happy Friday ✨<br><br>**[No responses]** | Participants did not engage with posts that destigmatize struggles. The few participants that frequently engage with messages on the board acknowledged some of the posts. However, participants did not engage with part of the posts where staff shared their personal lives. |
| Incentivizing participant engagement | The research team actively encouraged and motivated others to participate in discussions, surveys, or other activities within the study. They offered rewards, incentives, or recognition to promote engagement and | **[Initiating post]**<br>**Case manager\| June 09, 2020, 11:56 am**<br>"What does the "E" stand for in the name of the American restaurant chain Chuck E. Cheese?<br>Please message Research or I with your answer! The winner will be picked on<br>**[Response post]**<br>**StarJR\| June 10, 2020, 01:42 pm** | Posts that incentivize participant engagement received the most responses to the adlib messages. Participants responded to posts asking riddles and |

| | | | |
|---|---|---|---|
| | ensure active participation from other participants. | Entertainment | offering incentives for their engagement. |

### 2.1 Adlib Messaging: Sharing entertainment

Research staff and case managers began sharing entertainment posts to engage participants. These entertainment posts ranged from jokes to memes and riddles. While some of the adlib entertainment received engagement, the research staff further simplified the means of engagement with these messages by creating polls where participants could select an answer option. These polls were introduced six months into the study, coinciding with when engagement on the app saw a decline, as seen in August in Figure 1. The polls were well received, and the research staff incentivized responses to these polls to drive engagement. An example of the incentivized polls is in Table 3.

Other entertainment posts followed similar message patterns as the premeditated message where case managers raised awareness about fun topics such as "National Chocolate Covered Anything Day!". They provided external links to resources about chocolate, similar to when they raised awareness about HIV and SUD topics when posting premeditated messages.

In addition to entertaining messages, case managers approached adlib messaging by including more personalized stories about their everyday struggles to normalize difficult life experiences.

### 2.2 Adlib Messaging: Normalizing struggles

Case managers openly shared various topics, including their weaknesses and challenges. This shift in messaging type showed case managers revealing more about themselves, sharing personal stories about pet loss, lack of motivation, living with pain, and other relatable experiences. These personal messages were also followed by external resources or directed questions to engage participants about their experiences that may be similar to those of the case

managers. An example in Table 3 shows a case manager sharing their pain experiences and providing resources for pain relief.

These adlib entertainment and personalized posts allowed others to engage with the staff's posts. However, only participants that typically respond to posts engage with those posts. However, posts that incentivized participant engagement received responses from participants who had never responded to a message on the board.

2.3 Adlib Messaging: Incentivizing participant engagement

The research staff members occasionally introduced incentives such as challenges or contests to encourage further participation. These incentives could include gift cards, recognition, or tangible or symbolic appreciation. Incorporating these incentives motivated participants to engage with the app actively. The competitive nature of the challenges also brought about disputes atypical of the current interactions in the app. In the example below, a user disagrees with the crowned winner of a weekly challenge.

**Case Manager February 17, 2020, 12:55 pm**

"Big round of applause for the weekly challenge winner, WILLOWSERENADE!

[link https://commentpicker.com/random-name-picker.php?id=rnp_5e4ae18164d21840] February Weekly Challenge Winner [/link]

Thank you to EVERYONE who participated, and stay tuned for the next challenge in March.

Please let us know if you have any feedback on what you like/dislike about the challenges."

**NovaBliss| February 18, 2020, 08:56 am**

I'm but I'm confused who is WillowSerenade and does the challenge for the other group to or just are group?

**NovaBliss|February 18, 2020, 08:59 am**

I didn't even see a WillowSerenade in the discussion. I'm sorry I'm just confused how this works?

**NovaBliss|February 18, 2020, 09:04 am**

I feel Luna12 should of won.

**Case Manager| February 18, 2020, 09:16 am**

Hi NovaBliss! WillowSerenade made a comment and also completed the weekly survey and gained 6 entries into the drawing. We put all the entries into an online generator (click the February Weekly Challenge Winner to see the website we use) and that randomly picks a winner! The more entries you have, the better chance you have to win.

**NovaBliss|February 18, 2020, 09:23 am**

But I did the same thing. I guess. But I looked and I didn't see his stuff..

**Luna12|February 18, 2020, 02:11 pm**

Aww Nova thank you for the acknowledgment. It's appreciated much.

Case Manager named a winner and invited feedback as commonplace with the adlib messaging. NovaBliss challenges the announcement of the winner in several ways. First, by asking who the participant is (displaying their perceived lack of participation in the app); second, by asking about eligibility; third, by more overtly disputing that the winner had engaged in discussion with sensory evidence ("I didn't even see"); fourth, by asking about how the winner is selected; and fifth, by sharing their feelings about who should have won. This shows the participant's comfort in confronting the staff and standing up for other group members. Case Manager also uses exclamation marks in their explanation, which suggests a friendlier tone that may be used to resolve the conflict (Dickinson, 2017). Although NovaBliss was not satisfied by the response to their question, Luna12 stepped in and shared their appreciation, starting with "aww" as a description of how they felt about NovaBliss's gesture.

Although this post first declared the winner of a contest incentivizing participant engagement, the responses work through conflict negotiation, which often demonstrates togetherness and allyship in communities. This interaction also signals participants' knowledge of their peers' contributions, especially the key contributors. Key contributors like Luna12 often responded to the adlib and premeditated messages. However, they also adapted those messaging styles to create posts relatable to their experiences and other participants. These messaging types are described as participant-driven messaging.

### 3.0 Participant-Driven Messaging

During this phase, participants mirrored messaging styles the research staff and case managers created while tailoring them to their sobriety/HIV needs. As described in Table 3, participants adopted the TOTD posts as a model and provided similar messaging that pertained to their journey toward sobriety. Participants also applied the adlib messaging approach by crafting their own polls and sharing their own entertainment content. Lastly, participants used the message board beyond modeling the type of messages posted by the research staff/case managers to seek advice, share their substance use experiences, and address psychosocial needs, including dating and local activities. These messaging types signify the emergence of an autonomous and engaged community where participants take ownership of the app, fostering a supportive network and sharing valuable resources.

**Table 7 (Table 4 – Paper 2)**

*Description of participant-driven message types, sample posts, and responses on the A-CHESS Message Board*

| **Message types** | **Description** | **Sample initiating and responses to participant-driven messages** | **Engagement with messages** |
|---|---|---|---|
| Model following | Participants followed the model by research staff and case managers by sharing entertainment messages, creating their poll, and TOTD messages. | [**Initiation post]**<br>**WildSoul1\|February 13, 2020 01:14 pm**<br>Supebowl Poll Questions and Ratings<br>"What was your favorite Super Bowl commerical? Did you watch the Superbowl for the commercials or the halftime show?<br>I rate the Doritos commerical with the horses and Lil Nas and the dancing mastache a 5<br>I have no ratings for the halftime show. It was very entertaining as usual"<br>**[ Six responses omitted from this thread]** | Participants engaged with posts that modeled the research and case managers message types. Research staff also contributed to the messages, further encouraging engagement. |
| Seeking tailored support | Participants asked for information about issues concerning their lives, such as sobriety and legal advice, and sought updates about current issues, such as COVID-19 updates. | [**Initiation post]**<br>**NovaBliss\|April 10, 2020 08:41 am**<br>So my daughter is 19 and she is having a baby. I'm a little upset about it, but I'm excited to see my grandbaby. I guess I wish you would have waited a little till she's a little older. At 19 you don't really know how to be a mom I know because I was a mom I got pregnant when I was 19 I had her at 20 and now she's going to be 22. Thank you for listening can anybody give me some advice on how to just accept it because right now I'm a little upset | Like the modeled posts, research staff engaged with the messages seeking advice. Participants also contributed and asked insightful questions, often requiring someone seeking advice to share more |

| | | | |
|---|---|---|---|
| | | [**Response posts]**<br>**Case Manager\|April 10, 2020, 02:02 pm**<br>Wow, that is a lot to process! Thank you for sharing with us. I hear your concerns about your<br><br>daughter getting pregnant so young, but I'm glad you're excited to meet you grandchild. There are a few resources out there for expecting women so make sure to take care of yourself first and be there for your daughter as much as you can.<br>**Luna12\|April 11, 2020 08:44am**<br>You're not alone and your story sounds better than mine. | information about their issues. |
| Adapting the app use | Participants started trends in the app to add additional services or features that they perceived benefits, such as sharing their profiles for dating and conducting medication check-ins. | **SpiritSeeker \|January 24, 2020, 03:56 pm**<br>Im A single white male Looking for Love Im single 59 years old,did 28 years in prison been out for a year have my life pretty much together want to share it with someone special,lonely,<br><br>**London57\|July 04, 2020 07:37 am**<br><br>Legal help: I recently discovered I may be needing legal assistance or representation in the near future. I know that Vivent Health offers some assistance but I don't know how much they are capable of handling. I don't have the funds to hire an attorney. Does anyone have any suggestions or know of anyone that might offer help at a lower cost?<br>**Research Staff\|July 06, 2020, 04:26 pm**<br><br>>Here is the [link https://lasmilwaukee.com/]link[/link] to the Legal | Adapting the app was driven by a few participants. The research staff and other participants were receptive and encouraged others to participate. |

| | | | |
|---|---|---|---|
| | | Aid Society of Milwaukee. Their phone number is (414) 727-5300. Hope they can help you or refer you to a place who can assist you.<br><br>**[Initiating Post]**<br>**SpiritSeeker\|January 24, 2020, 03:56 pm**<br>Im single 59 years old,did 28 years in prison been out for a year have my life pretty much together want to share it with someone special,lonely,<br>**Luna12 \|January 25, 2020, 12:00 pm**<br>What were you in prison for<br>**SpiritSeeker\|January 25, 2020 03:56 pm**<br>Negligent homicide and Burglary<br>**Titan82 \|January 26, 2020 09:39 am**<br>Nice<br>**Titan82 \|January 26, 2020 09:39 am**<br>What happened<br>**WildSoul\|February 6, 2020 09:39 am**<br>💕Hello SpiritSeeker...nice to acquaintance you...thank you for being honest and fair to yourself...you are in the right place for support and gaining knowledge...you can Pvt/D.M. if you would like to or message here and I will gladly respond... 💕 | |
| Community-building beyond the app | Participants started sharing their phone numbers and creating events to meet outside of the app. | **TrayTon \|February 23, 2020, 08:06 pm**<br>Whats good to do in Milwaukee<br>**NovaBliss\|February 24, 2020, 10:58 am**<br>Bowling, sky zone, round 1, boat cruse<br>**Luna12\|February 24, 2020 01:31 pm** | Participants were receptive of finding time to meet outside the app and shared the information with other |

| | | | |
|---|---|---|---|
| | | We're planning a bowling trip if you would like to come | users who engaged with the messages. |

### 3.1 Participant-Driven Messaging: Model following

Participants followed the model created by research staff similar to the premeditated and adlib messages that involved sharing TOTD, sharing entertainment, and creating polls to drive engagement. However, when participants created their initial contributions, they tailored them to things specific to their experiences and recovery. For example, one participant started sharing messages similar to the TOTD. However, their messages were daily using Alcohol Anonymous (A.A.) literature.

### 3.2 Participant-Driven Messaging: Seeking tailored support

Participants who had limited engagement on the app began seeking personalized support. They reached out through messages to ask specific questions, seeking guidance on various topics such as dating, substance use, COVID-19 protocols, or legal assistance. In these instances, both case managers and peers played a role in responding to these inquiries.

Table 3 shows a contrast between how research staff interacted with participants when they sought advice, which differs from when participants interacted with one another.

London57 discusses their potential need for legal assistance soon but expresses uncertainty about the exact circumstances. Research Staff shares a link to a legal aid service without further inquiring about London57's situation.

Table 3 shows an engagement between SpiritSeeker and other participants. Their engagement showed that when participants engage with one another, they tend to ask more questions before offering support. This approach may serve multiple purposes, such as a better understanding of how they can provide assistance or getting to know the individual better to

establish camaraderie. Additionally, participants started sharing a desire to include additional features to the app, which differs from advice where they are asking for support.

### 3.3 Participant-Driven Messaging: Adapting the app use

Adapting the use of the app involved a few participants who took the initiative to create message types specific to their recovery and medication use. Some participants shared their profiles for dating, using the app as a platform to meet someone, similar to a dating app potentially. In the example below, Luna12 starts medication check-in, adding that checking on one another is what the group is for.

> **Luna12|April 05, 2020 05:54pm**
>
> 2020-04-05 17:54:33 UTC
>
> Check in: Hi everyone. Let's start doing a I took my meds today check in. Starting tomorrow. How about it?
>
> **Case Manager|April 06, 2020 07:19 am**
>
> This is an awesome idea!! Thank you for organizing this.
>
> **Luna12|April 06, 2020 11:49am**
>
> That's what this group is about. We need to check on each other

In this example, Luna12 introduces an idea centered on a daily behavior check-in. Similar to posts that focus on "today." They also seek direct feedback from other participants. The case manager uses exclamation marks to signal their enthusiasm for and support Luna12's idea. However, after several attempts to start medication check-in, there was a lack of engagement and follow-up; thus, Luna12 discontinued the medication check-in.

Including new features shows participants focus on doing something daily on the app and how they perceive the group's use. As such, participants also perceived the group as a place they could plan to meet and interact with others with whom they shared similar lived experiences.

### 3.4 Participant-Driven Messaging: Community-building beyond the app

Participants wanted to connect outside the app, indicating a need for an in-person community. They took the initiative to plan meetups and events, sharing their phone numbers and discussing potential activities in their local areas. This demonstrated their eagerness to foster real-life connections and engage in social interactions beyond the digital realm of the app. In the example below, SpiritSeeker shares their number to ask participants to connect with them.

**SpiritSeeker|January 20, 2020 01:36 pm**

Need a ear,That's Me. You you need a ear,some one to listen,I here,M/ number is [ phone number] call any time,I care.

**Luna12|January 20, 2020 03:45 pm**

Thank you

SpiritSeeker identifies themselves as a caring person. Although they do not contribute frequently with other participants, they asked to be reached anytime outside the app. Luna12 and Case Manager's gratitude shows an appreciation for SpiritSeeker's gesture. Other participants also offered to contact them and connect outside the app, showing community building moving from the mobile application to in-person meetings.

## Discussion

Our study used computer-mediated discourse analysis to investigate the formation of a virtual community among individuals with HIV and SUD on the A-CHESS mobile health application. While there is no universally agreed-upon definition of an online community, it is often characterized as individuals engaging in virtual interactions, guided by established norms and policies, and supported by technology (Porter, 2004; Preece et al., 2003). Notably, the formation of the A-CHESS virtual community was characterized by the active involvement of case managers and staff in driving participant engagement through adapted messaging styles, aligning with previous research emphasizing the role of community moderators in facilitating interaction (Hansen et al., 2010). Additionally, participants tended to mirror the behaviors of staff and their peers, indicating a shared understanding of the established norms of message response, consistent with the influence of social dynamics within online communities (Ren et al., 2007). Participants also demonstrated agency by shaping the app to meet their individual support needs, showcasing a sense of empowerment and ownership within the community.

While our study focused on the A-CHESS virtual community, it is worth noting that messaging app usage has often been associated with younger, white individuals of higher socioeconomic status (Goldzweig et al., 2013). However, participants contributing to the A-CHESS message board were predominantly older, Black, and unemployed. This demographic disparity highlights the importance of exploring the specific types of social support individuals from different racial backgrounds seek within mobile health apps. Future research could investigate the preferences and needs of diverse populations, informing the development of tailored apps that enhance engagement and user experience for individuals from various racial backgrounds.

Active engagement and interaction among members are vital to fostering online community relationships (McKenna et al., 2002). Our 26-month study revealed interesting trends in participant engagement and interaction. Active app participation peaked between months 10 and 14 but experienced a decline from month 18, which was 9 months before the study's conclusion. It is worth noting that the COVID-19 lockdown started during month 14, which could explain the increase in participant-driven messages during March 2020. Nonetheless, our study's pattern of engagement differed from findings in a study on an HIV message board, where post numbers peaked in the first six months, decreased between months 6-12, and then increased again between months 18-24 (Canan et al., 2020). Furthermore, our study identified a gradual increase in participant-driven interaction during the first year, indicating a shift towards seeking tailored support and taking ownership of the conversations within the app. These findings shed light on the evolving dynamics and focal content of participant interaction (Porter, 2004), underscoring the importance of fostering participant-driven interactions for meaningful and sustained online support in the context of HIV and substance use disorders.

The premeditated motivational messages in our study received the highest level of interaction from all study participants compared to all other messaging types, underscoring the significance of motivational messages within the virtual community. This finding is consistent with a study focused on improving engagement in HIV care, where participants expressed enthusiasm for receiving motivational messages (Dworkin et al., 2018). Our study participants also demonstrated a unique way of responding by applying, aligning, or interpreting the messages. The alignment observed in virtual community formation is often seen in agreement or shared perspectives among group members (Watson, 1997), but in this case, participants aligned themselves with automated messages. Mobile health applications can continue integrating

motivational messages to enhance user engagement and encourage users to actively interact with and respond to such messages.

It is worth noting that premeditated news and awareness messages in the A-CHESS virtual community did not generate significant interaction from participants. This lack of engagement can be attributed to the primary focus of participants in recovery groups on addressing feelings of loneliness and uncertainty, as observed in previous studies on support-seeking behaviors in individuals with substance use disorders (Liu et al., 2020). This finding aligns with results from an HIV online support group where messages providing jokes and pleasantries were posted as often as messages providing emotional support (Mo & Coulson, 2008). The discrepancy in engagement underscores the significance of incorporating varied message types that cater to community members' diverse needs and preferences. Despite different feelings/emotions, our study shows that attending to these emotions is beneficial compared to sharing news or raising awareness.

The adlib messages from case managers played a significant role in fostering virtual community formation within the A-CHESS app. Research studies have highlighted that members of online communities are more likely to form relationships when they have opportunities for self-disclosure and learning about each other (Ren et al., 2007). By personalizing their messages, case managers allowed participants to gain insights into the staff and case managers.

In the participant-driven message types observed in our study, key participants played a crucial role in initiating and maintaining interactions among participants, including responding to questions. These findings align with previous research on message board usage among people with HIV, which also identified the influential role of a few individuals in driving engagement (Flickinger et al., 2022). Moreover, our study highlighted the unique utilization of the message

board by participants seeking support and guidance regarding dating, reflecting the ongoing relevance of discussions about intimacy and relationships within online communities for individuals living with HIV (Guo & Goh, 2014). Additionally, our findings revealed that initial online connections often developed into offline meetups, reflecting the establishment of deeper relationships within the community.

We also observed differences in how staff and case managers interacted with participants compared to how participants interacted with each other within the virtual community. Participants were more likely to ask follow-up questions, while research staff primarily provided informational support. The act of asking questions is valued in online communication as it promotes efficiency, purposefulness, and clear understanding (Tidwell & Walther, 2002), fostering interaction within these communities. Furthermore, studies have indicated that responses to questions and requests for advice from participants are often met with emotional support in online environments (Suhr et al., 2004; Suler, 2004). These findings highlight the role of question-asking and supportive interactions in promoting engagement and creating a supportive atmosphere within the virtual community.

It is important to emphasize that online communities rely on their members' voluntary commitment, participation, and contributions. These communities thrive when members actively interact with one another, maintaining the community infrastructure, sharing new and updated information, and providing social and emotional support to fellow members (Loh & Kretschmer, 2023; Ren et al., 2007). In the context of the A-CHESS app, the collaborative efforts of case managers, research staff, and engaged participants collectively contribute to forming and sustaining the virtual community for the study duration.

Limitations

Our study has several limitations that should be acknowledged. Firstly, while discourse analysis provides valuable insights into participants' expressed intentions and behaviors, it does not provide direct access to their thoughts and motivations, limiting our ability to determine the intended behaviors behind each message posted. Secondly, the generalizability of our findings may be limited due to the specific population under study. The A-CHESS app was distributed to individuals living with HIV and SUD in a midwestern state, and the unique characteristics and context of this population may influence their engagement and interactions within the virtual community. Caution should be exercised when generalizing these findings to other populations. Lastly, the study was conducted during the COVID-19 lockdown, which may have impacted participants' interactions on the app. The restrictions and challenges imposed by the pandemic could have influenced the dynamics of the virtual community and the level of engagement observed. Future studies in different contexts and timeframes will provide a more comprehensive understanding of community formation and engagement patterns in diverse circumstances.

## Conclusion

In conclusion, our study examined the formation of a virtual community on the A-CHESS mobile health application for individuals with HIV and substance use. We identified the interaction dynamics, messaging strategies, and social behaviors within the community. Our findings revealed that research staff and case managers significantly drove participant engagement through premeditated and adlib messaging. Participants contributed tailored messages, demonstrating their interest in engaging and connecting with peers. Overall, our research sheds light on the complexities of virtual community formation in the context of HIV and substance use. It underscores the significance of messaging strategies, interaction dynamics,

and social behaviors in facilitating community engagement. The insights gained from this study can inform the development of effective interventions and support systems within mobile health applications to enhance virtual community formation and improve the overall well-being of individuals in similar populations.

Further research is warranted to explore the specific social support needs of individuals from different backgrounds and to delve deeper into the factors influencing long-term engagement and the role of participant-driven interactions in virtual communities. By addressing these gaps, we can continue to enhance the effectiveness of mobile health interventions and strengthen the sense of community among individuals facing similar health challenges.

# CHAPTER 5
# PAPER 3

# UTILIZING THE COMMON SENSE MODEL TO EXPLORE PERCEPTIONS OF HIV AND SUBSTANCE USE DISORDER: ANALYSIS FROM A MOBILE APP VIRTUAL COMMUNITY

## Introduction

Substance Use Disorder (SUD) is defined by the World Health Organization (WHO) as the harmful or hazardous use of psychoactive substances, including alcohol and illicit drugs (Duko et al., 2019). These disorders are characterized by adverse physiological and behavioral consequences such as tolerance, withdrawal, intense craving, and unsuccessful attempts to quit (Hartzler et al., 2017). Individuals with Human Immunodeficiency Virus (HIV) have significantly higher SUD rates than those without HIV. An HIV cohort study involving 10,652 individuals found a prevalence rate of 48% for SUD (Hartzler et al., 2017). This rate is higher than the prevalence of SUD in the general US population, which is 7.7% (Ridgway et al., 2021).

The coexistence of HIV and SUD poses significant challenges in the continuum of care. People with HIV who use substances are more likely to experience disparities, including lower retention in care, delayed initiation of Antiretroviral Therapy (ART), and poorer HIV treatment outcomes (Deren et al., 2019; Tarfa et al., 2023). Substance use has been identified as a barrier to engagement in HIV care, adherence to ART, and achieving viral suppression (Giordano et al., 2007; Ryan P. Westergaard et al., 2011). Additionally, when individuals return to substance use, it leads to delayed engagement in HIV care (Sprague & Simon, 2014).

To address the challenges posed by the coexistence of HIV and SUD, it is crucial to understand how individuals perceive their health conditions and navigate their treatment experiences, as guided by the Common-Sense Model (CSM) of Self-Regulation (Diefenbach &

Leventhal, 1996; Hagger, 2010). The CSM emphasizes the significance of individuals' cognitive representations (beliefs and understanding) and emotional reactions to their illnesses, further enhancing or determining their health behaviors (Hale et al., 2007). Understanding their perceptions of the severity, implications, and controllability of their illnesses can shed light on the factors that influence their treatment-seeking behaviors and adherence to care for their HIV and SUD treatment (Hale et al., 2007; Leventhal & Nerenz, 1985; Murray & Williams, 2020).

While quantitative studies have provided valuable insights into the prevalence of substance use and predictors of poor health outcomes among people with HIV (Benotsch et al., 1999; Pence et al., 2006; Westergaard et al., 2013; Ryan P. Westergaard et al., 2011), qualitative research has been indispensable in understanding the socio-behavioral complexities of HIV and substance abuse (Kotarba, 1990). Qualitative studies have shed light on lifestyle and contextual factors associated with risk-taking behaviors among various groups, such as people who use drugs (O'Reilly, 1995). However, despite using both quantitative and qualitative methodologies, engaging people with SUD in HIV care to explore how to optimize their health outcomes remains a challenge.

Although studies have separately examined substance use and HIV, their coexistence and impact on overall health outcomes warrant a comprehensive approach that considers the interconnectedness from the patient's perspectives. Previous research has shown that an individual's perception and comprehension of their illnesses significantly influence treatment responses(Mo et al., 2015; Reynolds et al., 2009; Spirig et al., 2005). However, there remains a lack of understanding regarding how individuals perceive these interconnected conditions, particularly concerning their HIV status.

While qualitative studies can offer valuable insights into individuals' understanding and responses to HIV and SUD, it is essential to acknowledge that they have certain limitations, primarily when relying on interviews and focus groups. These limitations include the potential for social desirability bias, where participants may provide responses they perceive as socially acceptable rather than their authentic experiences or beliefs (Flinton, 2020). Additionally, participant non-disclosure of substance use can impact the accuracy and completeness of the collected data(Nunn et al., 2010). Furthermore, interviews in qualitative studies may be influenced by the immediate health concerns of participants during the interview, potentially overshadowing other essential concerns in their HIV care journey (Sprague & Simon, 2014). Participants may also deny or provide partial or vague answers, particularly in sensitive or controversial research involving widely accepted attitudes, behaviors, or norms. This leads to complexities in interpreting findings (Bergen & Labonté, 2019). Moreover, individuals with SUD are often considered a "hard-to-reach" population, making it challenging to capture their behaviors in real time and rely on retrospective data when they re-engage in care (Bauman et al., 2013).

To overcome the limitations of traditional qualitative research and gain more nuanced insights, the collection of real-time data through mobile phones has been proposed as a helpful approach (Davis et al., 2019; Hyers, 2018). Mobile phones offer the advantage of capturing in-the-moment data and events in their natural setting, reducing reliance on retrospective recall and providing a private environment that minimizes potential biases (Davis et al., 2019). This approach enables the collection of real-time experiences, thoughts, and interactions, providing a more comprehensive understanding of the lived experiences of individuals with HIV and SUD (Takano et al., 2023).

In this context, our study analyzes messages shared on a study-wide message board within the Addiction Comprehensive Health Enhancement Support System (A-CHESS) mobile app. Through this message board, participants using the A-CHESS app connect with others facing HIV and SUD, forming social relationships and seeking support. Analyzing real-time conversations and discussions in a naturalistic setting allows us to grasp better how individuals with HIV and SUD communicate, relate to one another, and navigate their health and sobriety journeys within the online support group.

Our study's research questions are twofold:

1. How do individuals with HIV and SUD discuss the interconnectedness of HIV and SUD?
2. How do they describe the impact of substance use on their HIV care and vice versa, based on their shared experiences and reflections within the message board?

By exploring these questions, we aim to gain valuable insights into the perceptions of individuals living with both HIV and SUD. Through their shared experiences and reflections on the message board, we seek to understand better how they perceive the relationship between their HIV and substance use conditions.

## Methods

### Theoretical Framework

We have adopted the Common Sense Model (CSM) as our theoretical framework (Diefenbach & Leventhal, 1996). The model describes the dynamic parallel cognitive processing through which individuals regulate their responses to both the 'illness danger' (i.e., "What is this health threat, and what can I objectively do about it?") and their 'emotional control' (i.e., "How

do I feel about it, and what can I do to make myself feel better about it?") (Hale et al., 2007; Leventhal & Nerenz, 1985).

At the core of this theory is the proposition that patients' illness beliefs and representations profoundly influence their coping responses, which subsequently impact their evaluation of outcomes (Hagger & Orbell, 2022). The combination of illness beliefs and representations and individuals' prior ideas about illness allows them to comprehend their symptoms and guide their coping actions. By employing the CSM, we aim to gain deeper insights into how individuals perceive and respond to HIV and SUD within A-CHESS.

CSM centers on illness representations, reflecting individuals' 'lay' beliefs about illness, guiding their symptom interpretation and coping actions (Hale et al., 2007).

Leventhal and colleagues identify five components that constitute these illness representations:

1. Identity: This component involves the label or name given to the condition and its associated symptoms. A label for their symptoms can give individuals a sense of legitimization (Diefenbach & Leventhal, 1996; Meyer et al., 1985).
2. Cause: This component pertains to individualistic ideas about the perceived cause of the condition, which may not always align with biomedical accuracy. The representations are shaped by personal experiences, opinions of significant others, health professionals, and media sources, reflecting factors such as stress, environmental pollution, and other pathogens.
3. Timeline: This component relates to the predictive belief about the duration of the condition, determining whether it is perceived as acute or chronic (Diefenbach & Leventhal, 1996; Meyer et al., 1985).

4. Consequences: This component encompasses individual beliefs about the consequences of the condition and how it will impact them physically and socially (Diefenbach & Leventhal, 1996; Meyer et al., 1985).
5. Curability/Controllability: This component focuses on whether the condition can be cured or kept under control and how much the individual plays a role in achieving this outcome (Diefenbach & Leventhal, 1996; Meyer et al., 1985).

Data source:

This study is part of a larger research project that involved 208 participants with access to the A-CHESS mobile health application. Participants with HIV and SUD were recruited from clinics and through provider referrals. In addition to the message board, participants engaged in other study procedures, which included completing weekly surveys as momentary ecological assessments of substance use, medication adherence and quarterly surveys of their engagement in HIV care and psychosocial factors. Additionally, participants had access to various app features, including a personal journal, communication with research staff, games, and connections to Alcoholics Anonymous and Narcotics Anonymous resources (Yang et al., 2023).

The message board featured posts from three research staff, two case managers, and 208 study participants. Messages were not limited to predefined templates, allowing participants to openly discuss their experiences related to HIV, sobriety, or other health-related topics. An introductory message by a case manager provided context for the forum's introduction on March 14, 2019.

*UW Moderator:*

*"Hi, Everyone -*

*We are now starting to enroll people from Wisconsin in a new study phase. As a reminder, everyone in this group is living with HIV, so you are able to use this as a safe place to discuss anything that is on your mind. Everyone who is using the A-CHESS app also has access to the public use, so not everyone will be HIV positive. Some will be taking some type of*

*medication-assisted treatment, while some will not. Please feel free to share and support each other on both groups - that is what these discussions are for! Welcome to all the new users! I am new here myself. A little bit of information about me is that I have recently started here at UW Madison as an HIV Research Coordinator. Before my role here, I was a Case Manager at the AIDS Resource Center of Wisconsin (ARCW), where I worked with people who were newly diagnosed with HIV… Happy Thursday".*

Out of the 208 study participants, only 88 actively posted on the message board at least once. These participants were predominantly Black/African American men aged between 24 and 73. At baseline, the 88 participants lived with HIV for an average of 15.4 years, ranging from 1 year to 39 years.

Within the last 6 months, 34.09% of the participants attended SUD meetings, such as Alcoholics Anonymous, Narcotics or Cocaine Anonymous, or any 12-step or Smart Recovery meetings. Additionally, 31.18% had participated in an outpatient program for alcohol or drugs, which included counseling sessions, meetings, or group therapy. Only 6.81% of the participants had attended an alcohol or drug residential treatment center, where they stayed overnight.

Data analysis:

To address the research questions, we employed a directed content analysis approach (Hsieh & Shannon, 2005). From the pool of 1834 messages posted on the A-CHESS message board during the study period, we selected messages that fell under themes like "sharing sobriety journey," "health information," and "introducing self." We included only messages shared by the participants and excluded those posted by research staff or case managers, as well as messages unrelated to HIV and substance use.

Our research team fully immersed themselves in the data, reviewing each message on the A-CHESS message board. To structure our analysis, AT employed a coding framework based on predefined categories of illness representation according to CMS. These categories included

identity, cause, timeline, consequences, and controllability/curability. We systematically applied these predefined codes to the data, highlighting segments of text or entire posts that aligned with the specific illness representation constructs.

Throughout the analysis, we paid close attention to details in the data. This led us to develop subthemes that provided additional insights beyond the initial predefined codes, allowing us to understand the participants' experiences and perspectives regarding HIV and substance use more deeply. Any coding conflicts were resolved through open discussion and considering the context and frequency of responses, ensuring a reliable analysis.

## Results

In our analysis of the participants' posts related to HIV and substance use, we explored their illness representations within the predefined categories of Identity, Cause, Timeline, Consequences, and Curability/Controllability. Within the Identity category, we identified one subtheme: Self-Identification and Distinctions of Substance Use. Within the Cause category we identified one subthemes: Craving to Use Substances. Under the Timeline category, we identified the subtheme: Celebrating HIV and Substance Use Milestones. In the Consequences category, we further distinguished three subthemes: Loss and Death Associated with HIV and SUD, Contrasting Emotions and Perceived Positive Effects of Substance Use, and Withdrawal Symptoms and Impact on Physical and Mental Health. Lastly, within the Curability/Controllability category, we identified four subthemes: Embracing Motivation for Sobriety, Individual Strategies for Health and Well-being, Sharing Accountability for Sobriety and HIV Medication Adherence, and Negotiating Healthy Relationships and Their Impact on HIV and Substance Use. These subthemes provided valuable insights into the participants'

diverse perspectives and experiences, shedding light on the complexities of managing HIV and substance use.

To illustrate these categories, we share relevant text excerpts from the message board, including the time they were posted and information about the participants' gender, age, and years of living with HIV.

**Category 1: Identity**

Within this category, participants self-identified with their substance use and distinguished between being "sober" and "clean".

Subtheme 1: Self-Identification and Distinctions of Substance Use

Participants self-identified with their substance use, using specific terms to describe their state of being. In the example below, Participant 5 distinguishes between being "clean" and "sober," signifying that each term represents different phases or aspects of their recovery process.

> Example text entry from the message board:
> Date and Time: **June 5th, 2019, 10:23 am**
> **Participant 5: 48-year-old female living with HIV for 26 years**
>
> > Good morning everyone. My name is (name) pronounced as (pronunciation). I'm a 48 year young woman who is usually optimistic. I have been clean since 2009 and sober since 2011.

Associating different timeframes with each term suggests that being sober or clean holds unique meanings or significance for the participant.

**Category 2: Cause**

Participants shared messages that provided insights into the origins of their substance use and their experiences living with HIV. These narratives encompassed a wide range of perspectives, from recounting the initial instances of substance use to introspecting their

identities as individuals dealing with addiction and the emotional impact of their first drug encounters.

For example, one participant expressed how receiving the news of being HIV-positive devastated them, making them feel incapable of coping without substances.

> Sample Message Board Post
> Date and Time: June 06, 2019, 04:16 pm
> **Participant 14: 35-year-old male living with HIV for 4 years**
>
> > I got the news and it devastated me. I looked to my girlfriend at the time, and all I could muster after everything that had happened and getting the news was, 'I can't do this sober…

Participant 3 candidly shared their first experience with a substance, describing the intense emotions they felt during that moment and how this feeling increased their inclination to return to using crystal (meth).

> Sample Message Board Post
> Date and Time: May 28, 2019, 04:45 pm
> **Participant 3: 41-year-old male living with HIV for 21 years**
>
> > The first times I shot up it was intense I breathed deep and roared in a visceral animalistic passion. That anger makes me more likey to go back to using crystal.

These posts from Participants 14 and 3 highlight how the onset of substance use and living with HIV significantly influence their coping mechanisms and emotional responses.

Subtheme 1: Craving to Use Substances

Participants described their substance use as caused by a response to external environmental circumstances. These descriptions shed light on how participants turn to substance use as a coping mechanism in reaction to various challenges. In the text entry below, Participant 3 describes how environmental stressors, such as harassment and threats at the shelter, trigger their substance use cravings.

Example text entry from the message board:
Date and Time: **May 28th, 2019, 4:45 pm**
**Participant 3: 41-year-old male living with HIV for 21 years**

> I live in a shelter. I work 3rd shift, I have an employee who is harassing and threateningbme with (exiting) meaning you are kicked out the house. That's enough to give you a case of the fuck it's. I vaped some oil. This guy makes me want to use. Cyrstal could make it all so focused and logical. Unless you go in hard. The first times I shot up it was intense I breathed deep and roared in a visceral animalistic passion. That anger makes me more likey to go back to using crystal. I am so tired of this distaste this man has for me. God I wish I was high.

**Category 3: Timeline**

Participants displayed their perception of HIV and SUD as ongoing and continuous conditions that they actively monitor and celebrate milestones associated with them.

Subtheme: Celebrating HIV and Substance Use Milestones

In addition to sharing their struggles with cravings, active substance use, and medication adherence challenges, participants posted about their accomplishments in maintaining sobriety and achieving their desired HIV viral load. The following examples demonstrate participants' enthusiasm in celebrating these milestones:

Sample Message Board Post
Date and Time: May 31, 2019, 10:32 am
**Participant 8: 35-year-old male living with HIV for 10 years**

> Today marks 2 occasions ..1. 4 months and 2. 7 days clean from tina ..and today moving out of my shelter into my own apartment ..no government assistance required.

Participant 8 joyfully shared their achievements, celebrating 4 months and 7 days of being clean from "tina" (methamphetamine) and the milestone of moving into their own apartment without requiring government assistance. Participants also expressed their milestones related to HIV management and viral suppression:

Sample Message Board Post
Date and Time: April 19, 2020, 09:23 am

**Participant 5: 48-year-old female living with HIV for 26 years**

> Good morning. I looked at my test results from February and hadn't noticed until now that it shows the target is not detected, no copies of HIV. The test before that one showed 33 copies. I'm so grateful. I'm grateful for this program (A-CHESS).

In this example, Participant 5 shared their joy at achieving viral suppression in managing their HIV. They expressed gratitude for the A-CHESS study that contributed to their successful HIV management, underscoring the significance of this milestone in their health journey.

These examples highlight how participants actively perceive the timeline of their illness as something they monitor, manage, and celebrate as they strive for better health and well-being.

## Category 4: Consequences

Participants shared messages detailing the consequences of their substance use and how it impacted various aspects of their lives. These narratives shed light on the physical and social implications they experienced due to their SUD. Participants also shared how using substances makes them feel and the symptoms they experience when using or withdrawing from substance use.

### Subtheme 1: Loss and Death Associated with HIV and SUD

One recurring experience shared among participants was the loss they experienced due to their substance use. For example, Participant 14 (Table 1) vividly describes the extent of their losses while actively using substances, including relationships, employment, and inner peace. They also express perpetual fear due to their SUD, showcasing its profound impact on their lives.

Regarding HIV, Participant 2 shared about the loss of lives during the height of the acquired immunodeficiency syndrome (AIDS) epidemic. They recall how lack of knowledge and minimal care led to the loss of people they knew. However, they also express optimism about the

current situation, with improved knowledge and care leading to significant progress for people living with HIV.

> Sample Message Board Post
> Date and Time: July 07, 2019, 12:24 pm
> **Participant 2: 43-year-old male living with HIV for 14 years**
>
> > I can remember when the Aids epidemic affected many and in reality the ones I knew are no longer with us due to lack of knowledge and minimal care. Things are 300% better now

In contrast to the perpetual fear associated with SUD, as described by Participant 14, Participant 2 shares a different perspective on HIV. They reminisce about the AIDS epidemic's devastating impact on their community and the loss of lives due to a lack of knowledge and minimal care. However, Participant 2 expresses optimism and hope for the future, noting that things have improved significantly. They attribute this positive change to increased knowledge and advancements in HIV care, resulting in better outcomes and improved well-being for people with HIV.

Participants also shared contrasting emotional experiences related to their substance use.

Subtheme 2: Contrasting Emotions and Perceived Positive Effects of Substance Use

Some participants felt hopeful and heavenly when sober, while alcohol use made them despair. On the other hand, a few participants acknowledged perceived positive effects of substance use, such as increased confidence, relaxation, or insights into certain aspects of their life. However, these perceived benefits were often juxtaposed with the negative consequences they faced.

Participant 1 provides insight into how substance use affected their emotional state and decision-making process (Table 1). They draw a stark contrast between the two states: attending meetings and being sober, which they associate with hope and heavenly feelings, and using

alcohol, which they liken to a life akin to eternal death. This comparison underscores the significant difference in their emotional experiences during moments of sobriety and alcohol use.

However, Participant 7 shares a different perspective, acknowledging the complexities of their relationship with alcohol (Table 1). They express that alcohol helps them gain insights into certain aspects of their life, suggesting that they perceive some positive effects from their substance use. This highlights the diverse range of experiences individuals may have with substance use, with some perceiving it as beneficial in specific contexts.

Subtheme 3: Withdrawal Symptoms and Impact on Physical and Mental Health

Some participants shared in-depth experiences related to the consequences of their substance use, particularly how it exacerbated other mental health illnesses and physical sickness.

Participants openly discussed their encounters with withdrawal symptoms and the emotional impact of substance use. They delved into the psychological effects, such as depression and anxiety, associated with their drug use. For instance, Participant 14 candidly narrated the cyclical nature of withdrawal symptoms that trigger the desire to use the drug again (Table 1). Another participant (Participant 2) shared an episode of using substances as a depressing and unsatisfying experience. Below, they highlighted that they no longer experience cravings for the drug, which is a significant symptom of their substance use.

Sample Message Board Post
Date and Time: March 08, 2019, 01:22 am
**Participant 2: 50-year-old male living with HIV for 28 years**

> …This last cycle of using with him was very depressing and not fun. I've been clean since the weekend I threw my tools out over spit. I have no cravings to use. When I've quit before I wanted to use badly. Now I'm not craving anything.

These participants' posts provide valuable insights into the withdrawal symptoms and emotional experiences linked to substance use, highlighting individuals' complex challenges while attempting to overcome dependence. Their narratives suggest that substance use can be associated with feelings of depression, and withdrawal from these substances may also trigger similar emotional responses.

**Table 8 (Table 1 – Paper 3)**

*Illness Representation of Consequences of Substance Use and HIV*

| Subthemes | Sample posts |
|---|---|
| Subtheme 1: Loss and Death Associated with HIV and SUD | Sample Message Board Post<br>Date and Time: June 06, 2019, 04:16 pm<br>**Participant 14: 35-year-old male living with HIV for 4 years**<br>*I lost everything to this life, this horrid life, my friends, my love, my daughter, my job, my mind, and worst of all my peace. I'm resolved to work through this; I fear for what comes next*. |
| Subtheme 2: Contrasting Emotions and Perceived Positive Effects of Substance Use | Sample Message Board Post<br>Date and Time: May 14th, 2020, 4:03pm<br>**Participant 1: 54-year-old male living with HIV for 24 years**<br>*When I didn't go to meetings, I drank; if I drank, I didn't want to go to meetings. The former scenario gave me hope... almost heaven. The second option quickly created a life comparable to eternal death.*<br><br>Sample Message Board Post<br>Date and Time: June 02, 2019, 01:59 pm<br>**Participant 7: 37-year-old male living with HIV for 12 years**<br>*I enjoy imagery and music by none of that makes me not want to drink. If anything drinking helps me understand it better*. |
| Subtheme 3: Withdrawal Symptoms and Impact on Physical and Mental Health | Sample Message Board Post<br>Date and Time: June 06, 2019, 04:16 pm<br>**Participant 14: 35-year-old male living with HIV for 4 years**<br>*Thus, who are you familiar with the withdrawal from this drug, it's very light physically. You have little energy for a couple of weeks and just want to sleep the first five days, the next 9ish you exhaust* |

| | |
|---|---|
| | *easily, yet insomnia kicks in. Most of the issue, however, is depression, anxiety, and the overwhelming onslaught of everything you have been numbing out with the drug* |

**Category 5: Curability/Controllability**

Participants' posts revealed distinct variations in focus regarding treatment for HIV and SUD. They shared what they can do to manage their substance use, what helps or harms their recovery, and what motivates them to stay sober.

The Discussions about HIV primarily centered around medical treatment and the desire for a cure, emphasizing the impact of the epidemic and the need for improved access to care and information. For example, Participant 16 shares below their desire for a cure for HIV.

> Sample Message Board Post
> Date and Time: January 17, 2020, 10:36 am
> **Participant 16: 59-year-old male living with HIV for 24 years**
>> I Have a Dream A cure of HIV…

Participants discussed their HIV treatment, including behaviors like taking medication and checking their viral loads. They considered taking HIV medication as essential for maintaining good health.

Regarding substance use, participants did not mention specific treatment methods. Instead, they shared their personal self-improvement strategies, such as meditation and prayer, as part of their journey toward recovery. For example, Participant 6 shares God is what is helping them with their drinking.

> Sample Message Board Post
> Date and Time: October 22, 2019, 3:41 pm
> **Participant 6: 40-year-old female living with HIV for 19 years**
>> That drink does not take any oain away or a rememberance. you pray the process of healing begins.Cast your cares on God.Let it go.Watch God work in your favor

While Participant 2 below shares how spirituality helps with addiction.

Sample Message Board Post
Date and Time: February 02, 2020, 3:30 pm
**Participant 2: 43-year-old male living with HIV for 14 years**

> …Being newly introduced and influenced by bigger and better things other than our addiction helps create and enforce the new influences which we are taught. We also are taught to be spiritually intuned with our higher power

In addition to faith and other resources they have used to help their substance use, participants sometimes narrated their experiences with substance use and how they stayed sober when they wanted to use.

Subtheme 1: Embracing Motivation for Sobriety

Participants posted on the message board about the triggers that can lead to their substance use and, conversely, the motivations that inspire them to resist such urges and maintain sobriety. In the example below, Participant 3 shared their reasoning for not relapsing on crystal meth and identified death as motivating them not to use it.

Sample Message Board Post
Date and Time: June 6th, 2019, 4:27 am
**Participant 3: 41-year-old male living with HIV for 21 years**

> I have a million reasons why I might relapse on crystal meth, but I remember the reason I stopped, and that has kept me clean for 5 months now. It's not easy, and I was even having the 'can I or can't I' debate on my long walk home from work this morning. One reason rings loudest in my head, and it's what keeps me clean. I don't want to die today!

Participant 13 also shared their motivation for sobriety, which includes having housing, money, their kids, and not losing everything (Table 2).

Subtheme 2: Individual Strategies for Health and Well-being

Participants shared messages reflecting on their self-care practices, health goals, and the importance of medication adherence. Participants openly discuss their efforts to maintain sobriety and manage their HIV health. In the example below, Participant 5 shared how journaling had become a valuable tool for developing a relationship themselves and how it supports them to stay sober.

Sample Message Board Post
Date and Time: June 12, 2019, 10:17 pm
**Participant 5: 48-year-old female living with HIV for 26 years**

> I learned to journal. It helps me to have a relationship with myself, and little by little, this helps me stay clean and sober.

In a second example below, Participant 2 emphasized the significance of medication adherence and achieving an undetectable viral load as the goal in HIV care. They highlighted that medical adherence is crucial in reaching medication goals.

Sample Message Board Post
Date and Time: August 18, 2019, 05:37 pm
**Participant 2: 43-year-old male living with HIV for 14 years**

> 💟To me, taking medications and being undetectable should always be the ultimate goal. Medical adherence is necessary when obtaining your medication goals. It should not be how much you take but how your body accepts the medication being taken.💟

In the third example, Participant 12 reflected on their challenges, including feelings of loneliness and depression (Table 2). They shared their coping strategies: prayer, meditation, and gratitude for physical health. They also acknowledged the importance of not taking their struggles out on others.

The common thread in these statements is the participants' focus on self-care, well-being, and health goals. They highlight the significance of personal efforts and adherence to medication regimens in their journey toward sobriety and managing HIV.

Subtheme 3: Sharing Accountability for Sobriety and HIV Medication Adherence

Participants openly discussed their journey towards sobriety, sharing experiences, strategies, and coping mechanisms to sustain their recovery. They acknowledged the link between their drinking habits and missing HIV medication. Participants also offered mutual support, exchanged valuable tips and resources, and encouraged each other in navigating the complexities of managing sobriety and HIV medication adherence.

In this sample post, Participant 7 recognized a potential correlation between their disengagement with the online support group and lapses in medication adherence and increased alcohol consumption. Acknowledging the need for improvement, this participant shared their commitment to improving.

Sample Message Board Post
Date and Time: August 28, 2019, 08:35 pm
**Participant 7: 37-year-old male living with HIV for 12 years**

> I noticed while I wasn't posting or reading, I had an uptick in drinking and not taking my medication. I will do better

In Table 2, Participant 5 celebrated a successful week by diligently adhering to their HIV medication, engaging in physical activity, and prioritizing their overall well-being. They mentioned how participating in the study has been a valuable resource in helping them stay on track with their HIV medicines.

Subtheme 4: Negotiating Healthy Relationships and Their Impact on HIV and Substance Use

Participants discussed their relationships with partners, highlighting the importance of supportive partners in their journey with HIV. One participant shared gratitude for having a partner that is HIV-negative and is supportive.

Sample Message Board Post
Date and Time: July 07, 2019, 12:35 pm
**Participant 10: 51-year-old male living with HIV for 20 years**

> God woke me up this morning, staying strong, positive, and I'm very grateful for my girlfriend, who is HIV negative. She is very supportive.

In contrast, other participants shared their struggles in maintaining sobriety while in a relationship with someone who uses substances.

In Table 2, Participant 5 shared their journey of overcoming substance use in a relationship with a partner who also used substances. They emphasized the importance of self-love and valuing oneself in overcoming challenges related to substance use.

**Table 9 (Table 2 – Paper 3)**

*Illness Representation of Controllability/Curability of Substance Use and HIV*

| Subthemes | Sample posts |
|---|---|
| Subtheme 1: Embracing Motivation for Sobriety | Sample Message Board Post<br>Date and Time: February 18th, 2020, 9:21 am<br>**Participant 13: 42-year-old female living with HIV for 11 years**<br>*What does recovery mean to me..*<br>*It means not in the streets, no more wondering where in going to sleep.*<br>*It means not wondering where I'm going to get my next bag..*<br>*It means not storied about where I'm going to get money from..*<br>*It means keeping my kids..*<br>*I know that if I go back to my old ways I will lose everything I worked for. It's been a long road but with God's help I have grown up.* |
| Subtheme 2: Individual Strategies for Health and Well-being | Sample Message Board Post<br>Date and Time: March 08, 2020, 01:22 am<br>**Participant 12: 50-year-old male living with HIV for 28 years**<br>*I am alone & I get depressed sometimes. It's difficult. I pray a lot; I sleep a lot. I thank YAHWEH every day for my physical health. Mental health is a roller coaster. I don't take things out on others. I pray & meditate.* |

| | |
|---|---|
| Subtheme 3: Sharing Accountability for Sobriety and HIV Medication Adherence | Sample Message Board Post<br>Date and Time: April 16, 2020, 02:02 am<br>**Participant 5: 48-year-old female living with HIV for 26 years**<br>*I'm in this program (A-CHESS Study) for more than one reason. It started for the change but really that was an incentive. I needed to be guided some way to regularly take my meds. I have had the behavior of taking care of everyone else but me only to find out that nobody that I would expect, takes care of me the way I do them. Those dog on expectations. I need to learn how to do things first off for myself. I did that really good for 4 days straight this week. Took my meds, drunk extra water, walked 7 miles 2 times this week so far, and cleansed my inner being of some things. I did that plus worked.* |
| Subtheme 4: Negotiating Healthy Relationships and Their Impact on HIV and Substance Use | Sample Message Board Post<br>Date and Time: March 07, 2020, 04:51 pm<br>**Participant 5: 48-year-old female living with HIV for 26 years**<br>*…It took years to get clean while in a relationship with someone using. I detached myself after getting clean enough to realize that he was playing head games. Who wants to live that kind of lifestyle? I was with him since 2006. I met him at the drug house. I left his ass after realizing I could have a wonderful relationship with myself and allowed myself to have a relationship with me. After he saw that I wasn't playing with him or myself, he got clean. He wants me back. I'm taking it slow. I'm not giving him the best me for him to break my heart. I love me today. It took a while to get to this place, and I'm not going to throw it away for someone that has shown me that their value of themselves hasn't been much, so how could he possibly add value to me?* |

## Discussion

In our directed content analysis, we explored how individuals with HIV and SUD communicate about their health conditions and discussed the intricate relationship between HIV and substance use within the message board of a mobile health application. Our findings revealed significant subthemes that offer valuable insights into their experiences and perspectives, particularly regarding substance use and sobriety. Participants openly shared their experiences with triggers and cravings for substance use and their continuous monitoring of both HIV and substance use, marked by celebrated milestones. Additionally, they expressed fear

concerning substance use while remaining optimistic about their HIV care. The motivations for sobriety and reflections on relationships' impact on HIV care and substance use were also evident.

Our study explored how participants perceived a relationship between HIV and substance use. We found that some individuals turned to substances as a coping mechanism after an HIV diagnosis, revealing the complex interplay between the two conditions (Regenauer et al., 2020). While existing research has mainly focused on substance use as a risk factor for acquiring HIV(Aceijas et al., 2004; Chawla & Sarkar, 2019; Madhivanan et al., 2005), our study shed light on how individuals with HIV may use alcohol and drugs to navigate life with the virus.

Our participants candidly discussed the impact of active substance use on their medication adherence, which aligns with existing literature findings (Kalichman et al., 2017; Kuchinad et al., 2016). However, our study revealed an interesting perspective: participants discussed how staying sober and adhering to their HIV medications are interconnected goals. Some viewed taking HIV medication as their ultimate goal, while others saw sobriety as a means to better adherence. This highlights the need to consider sobriety integral to HIV care.

In our investigation of the curability/controllability of HIV and SUD, participants expressed distinct perceptions regarding treating these conditions. For HIV, they emphasized the importance of medication use and a desire for a cure. In contrast, when it came to substance use, their approach centered around spiritual practices, with many alluding to a Higher Power, God, or Yahweh as instrumental in managing their substance use and achieving sobriety. Notably, a significant portion of our participants identified as Black/African American, and existing research has highlighted the importance of spirituality for African Americans in managing illnesses (Shiyanbola et al., 2018). Previous studies on African Americans living with HIV have

also demonstrated their reliance on spirituality for their well-being (Dalmida et al., 2012; Himelhoch & Njie-Carr, 2016). Interestingly, while spirituality was not explicitly mentioned concerning HIV management in our study, approximately 34% of our participants had attended a 12-Step program, where addiction is often viewed as a manageable disease with spiritual growth (Donovan et al., 2013). This disparity in treatment perceptions presents an opportunity to explore and integrate models incorporating both the pharmaceutical benefits of HIV management and the religious/spiritual dimensions of substance use treatment.

In our study, participants demonstrated both optimism for HIV treatment and concerns about their substance use and the risk of relapse. Despite perceiving the severity of their illnesses, they continuously monitored HIV and substance use conditions and celebrated milestones, such as achieving an undetectable viral load and maintaining sobriety for significant periods. While traditional substance abuse treatment often focuses on tracking abstinence from substance use (Bae et al., 2017), previous research has shown that individuals are interested in tracking other activities that support their recovery, such as treatment participation, self-care practices, and attendance at 12-step meetings (Jones et al., 2021). Additionally, participants in our study shared how not engaging with the message board was associated with an uptake in their substance use and neglecting their HIV medication. This highlights their interest in tracking their progress and treatment-related milestones. Given these findings, there is a potential opportunity to integrate HIV care treatment into their recovery processes using mobile health technologies, allowing them to monitor and celebrate milestones related to both HIV and substance use management.

Our study makes a valuable contribution to the growing body of literature on the implementation of mobile health applications for substance abuse management (Aschbrenner et

al., 2016; Goldfine et al., 2020; Liang et al., 2018), with a specific focus on those that also integrate HIV care (Cordova et al., 2020; Quanbeck et al., 2014; Westergaard et al., 2017). Existing mobile health applications often gather information on trigger thoughts, places, and situations through text inputs or predefined lists (Larimer et al., 2004; Liang et al., 2018) and explore the social context of substance use, including whether individuals use substances with a romantic partner or alone (Liang et al., 2018). Previous feasibility and acceptability findings have shown that participants may prefer answering substance use-related questions on a cell phone, even though they can understand and respond to these queries during interviews(Kelly et al., 2014; Liang et al., 2018). However, our study uniquely demonstrated how participants utilize the message board to freely share their triggers, substance use patterns, and social contexts related to their substance use. This insight highlights the untapped potential of optimizing message board usage for a deeper understanding of substance use behaviors not adequately captured by surveys or interviews.

In addition to openly sharing messages such as triggers in our study, participants demonstrated a surprising level of openness by discussing their experiences with substance use. While individuals with substance use disorders have shown reluctance to attend in-person support groups due to the fear of connecting with people at different stages of recovery, which can lead to relapse (Russell et al., 2021), the A-CHESS app offered a safe space for them to openly share their goals, decisions, and struggles related to substance use. This transparent and candid discussion about active substance use and varying levels of sobriety aligns with harm reduction frameworks, which recognize that individuals may continue to use substances and emphasize personalized approaches to support their decision to continue to use or abstain from substances (McNeil et al., 2014).

Our study findings support the existing literature that advocates for the integration of substance use treatment and HIV care (Andersen et al., 2003; Azar et al., 2010; Haldane et al., 2017; Martin & Wang, 2013; Mathers et al., 2008). Integrating these services can improve health outcomes and overall care for individuals with HIV and substance use disorders. However, as noted in previous research (Edsall et al., 2021), successful integration faces various challenges.

One of the main barriers to effective integration is the limited expertise and knowledge among healthcare providers, particularly those with minimal exposure to clients with substance use disorders (Haldane et al., 2017; Pinto et al., 2019). Integrating substance use treatment into HIV care may require a multidisciplinary approach involving professionals from different disciplines, including addiction specialists, mental health professionals, and HIV care providers. Collaborative efforts can ensure a holistic and patient-centered approach to treatment, addressing both the medical and psychosocial needs of individuals with co-occurring HIV and substance use disorders.

Our study has limitations that should be acknowledged. One limitation is relying on data from a single mobile app's message board, with participants referred from HIV clinics, might not fully represent the diverse experiences of all individuals with HIV and SUD. Another limitation is the use of qualitative content analysis, which has its limitations while it is valuable in identifying categories for text data (Elo & Kyngäs, 2008). It may not capture all underlying themes comprehensively, leaving room for more in-depth analysis.

## Conclusion

In conclusion, our study sheds light on the intricate relationships between participants' illness representations regarding their HIV and substance use disorders (SUD) and how they perceive the connections between their HIV care and SUD treatment. We observed that

participants' perspectives on one illness often influenced their approach to managing the other. For instance, some participants viewed their HIV care as a motivation for sobriety, recognizing the importance of staying sober to adhere to their HIV medication effectively. Similarly, better management of their substance use was perceived as beneficial for their overall HIV care. These findings underscore the interconnectedness of HIV and SUD management, highlighting the significance of considering both aspects in treatment planning.

Furthermore, our study reveals the potential of mobile health technologies in facilitating the integration of HIV care and substance use treatment. By leveraging mobile health apps and digital platforms, individuals can conveniently track their treatment progress, celebrate milestones in their recovery journey, and access supportive resources. These technologies serve as valuable tools to enhance self-management and engagement in care, ultimately leading to improved adherence to both HIV medications and substance use treatment plans. Incorporating such innovative approaches into healthcare delivery can empower individuals to take a proactive role in their health and well-being, fostering better outcomes for those with co-occurring HIV and substance use disorders.

# CHAPTER 6

# DISCUSSION

The primary goal of our research was to explore medication adherence among individuals with HIV and SUD within the context of a mobile health intervention, specifically the A-CHESS app. Additionally, we aimed to understand the formation and dynamics of the virtual community aspect of A-CHESS and how it relates to medication adherence and support-seeking behaviors concerning HIV and SUD. We presented these findings in a three-paper format, with the first paper exploring associations between constructs of SDT and medication adherence, the second paper describing how the virtual community is formed, and the third paper specifically focusing on how individuals with SDT are using the virtual community to discuss their substance use and HIV. This discussion section will summarize the three-paper findings and their combined findings, future research directions, and study limitations.

Summary of the three-paper findings and the interpreting of combined findings:

Objective 1: Identifying factors informed by SDT impacting medication adherence

Paper 1 explored factors influencing medication adherence among A-CHESS app users using SDT as the framework. The study utilized baseline survey data from 208 participants living with HIV and SUD and applied logistic regression to analyze the associations. The results revealed that education and stigma were associated with medication adherence. However, loneliness, treatment self-regulation, positive affect, and negative affect did not show a significant association with medication adherence. The observed link between stigma and medication adherence underscores the detrimental effects of stigmatization on treatment adherence, emphasizing the importance of targeted interventions to address and reduce stigma-

related barriers in individuals with HIV and substance use disorders. The relationship between education level and medication adherence highlights the role of health-seeking behaviors in adherence behaviors. These findings provide valuable insights into how SDT constructs influence medication adherence behaviors among this population, offering potential avenues for tailored interventions and support strategies.

Objective 2: Exploring the formation of a virtual support community

Paper 2 delved into the formation of the virtual community within the A-CHESS app, analyzing all messages posted on the message board by research staff, case managers, and participants during the study. Utilizing computer-mediated discourse analysis, the study identified three messaging types within the message board: premeditated and adlib messaging driven by staff and participant-driven messaging.

In premeditated messaging, research staff and case managers shared pre-planned news about HIV and substance use and messages raising awareness about current health affairs. The A-CHESS app also provided premeditated motivational messages to participants, who engaged with these messages by aligning, interpreting, or applying them to their recovery journey. While premeditated messages received responses, news, and awareness messages did not elicit much engagement. Consequently, case managers and research staff adapted their messaging approach, sharing more entertaining posts, asking directed questions, and using incentives to engage participants. Adlib messaging saw better engagement compared to premeditated messaging. Participants also actively created their own messages, known as participant-driven messages, where they shared entertainment, sought advice, and shared their motivation.

The active involvement of case managers and staff in driving participant engagement highlights the importance of supportive moderators in fostering interactions within the community. Participants mirroring the behaviors of staff and peers demonstrates the influence of established norms and social dynamics within the online community, contributing to a sense of belonging and connectedness among app users. Moreover, participants' agency in shaping the app to meet their individual support needs emphasizes the empowerment and ownership they experience within the virtual community. These insights shed light on the dynamics of the A-CHESS virtual community and its role in supporting individuals with HIV and substance use disorders.

Objective 3: Examining discussions about SUD and HIV within the A-CHESS virtual community

In Paper 3, we conducted a directed content analysis of messages from the A-CHESS virtual community to explore the perceptions of individuals with HIV and SUD using the CSM. The analysis revealed categories related to illness representation and subthemes where participants discussed cravings for substances, strategies to navigate triggers, and motivations for remaining substance-free. Participants candidly disclosed their substance use experiences and missed doses of HIV medication. They also shared accountability for sobriety and HIV medication adherence, celebrated milestones, and discussed overall health and well-being strategies. These findings provide a comprehensive understanding of how individuals in the virtual community communicate about their struggles with substance use and HIV, illuminating the complexities of their experiences.

Participants openly shared their substance use experiences, especially when facing cravings or triggers. Motivation played a significant role in their commitment to sobriety, driven

by the perceived consequences of their substance use. They relied on coping mechanisms, such as drawing strength from their motivations, practicing self-care, and finding solace in religious beliefs, to support their journey toward sustained sobriety.

Exploration of the causes, consequences, and controllability of their illnesses revealed discussions about the origins or triggers of substance use. Some participants identified their HIV diagnosis as a pivotal moment that initiated their substance use as a coping mechanism, underscoring the powerful influence of living with HIV on the development of SUD. Interestingly, the cause of substance use was intertwined with subthemes of controllability, where participants related their relationships to triggers for substance use, highlighting the intricate interplay between SUD and social interactions.

## Integration of findings from Paper 1, Paper 2, and Paper 3

### *Stigma and its impact on medication adherence and virtual community formation*

The findings from these three papers contribute to our understanding of medication adherence, virtual community formation, and support-seeking behaviors within the A-CHESS mobile health application. We focus on stigma as a relevant finding in our study. In Paper 1, our logistic regression reveals that stigma is associated with medication adherence. The groundwork for the literature on HIV-related stigma stems from Erving Goffman's early work (1963), where stigma is defined as "the discrediting of individuals based on an undesirable attribute." (Goffman, 1963). Our study corroborates earlier research findings (Levi-Minzi & Surratt, 2014; Turan et al., 2017; Wolitski et al., 2009), indicating that stigma significantly affects medication adherence among individuals living with HIV. Stigma may also explain messaging types shared by participants in Paper 2 and how participants described their experiences with HIV and SUD in Paper 3.

HIV-related stigma encompasses two primary forms: public stigma and self-stigma (internalized stigma). Public stigma involves negative societal beliefs about HIV, resulting in emotional reactions like anger, disgust and negative behaviors such as avoidance or mistreatment of individuals with HIV (van der Kooij et al., 2021). Public stigma could also have other forms, such as perceived stigma, enacted/experienced stigma, and discrimination (Feigin et al., 2013). On the other hand, internalized stigma occurs when individuals with HIV internalize negative societal beliefs. Previous studies have demonstrated that internalized stigma manifests in various ways, including feelings of shame, dirtiness, guilt, and fear (Nobre et al., 2018). Internalized stigma can profoundly impact the mental well-being and overall health of people with HIV, influencing their willingness to seek support, disclose their HIV status, and engage in effective health behaviors (Turan et al., 2017). Our study assessed stigma using the 6-item Internalized AIDS-related Stigma scale. This scale assesses difficulties in disclosing HIV status and feelings of guilt, dirtiness, shame, and guilt (Kalichman et al., 2009).

Analysis of the responses to the internalized AIDS-related stigma revealed that our participants were particularly concerned about disclosing their HIV status. Approximately half of the study participants (56.73%) reported experiencing difficulties in revealing their HIV infection to others, and 57.21% admitted to concealing their HIV status from others. Interestingly, while some studies have found no direct association between HIV disclosure and ART adherence (George & McGrath, 2019), it remains evident that HIV disclosure profoundly impacts individuals living with HIV. Disclosing one's HIV status introduces uncertainty about potential responses, leading individuals to conceal their status deliberately (Madiba et al., 2021).

Studies have revealed that stigma-associated disclosure can lead to "silencing," where individuals with HIV avoid discussing anything related to their HIV (including their status) due

to anticipated discrimination (Florom-Smith & De Santis, 2012). This may elucidate the notable absence of mentions of HIV status and experiences in Paper 2 and Paper 3. In Paper 3 specifically, we saw that when participants engaged in health-related discussions, most of the messages they posted were related to their substance use rather than HIV. Our participants may consider their substance use to be less stigmatizing, or they had been conditioned not to talk about their HIV due to experienced or internalized HIV-related stigma. Additionally, stigma may explain Paper 2, why participants showed limited engagement with HIV news, opting for more entertainment-focused content. Engaging with HIV news or information may inadvertently reinforce their self-stigmatizing beliefs, leading them to prioritize entertainment as a coping mechanism.

In addition to discussing their HIV experiences, stigma profoundly influences people with HIV's ability to form romantic relationships. The prospect of beginning a relationship creates a need for disclosure and triggers a fear of potential negative reactions or backlash (Florom-Smith & De Santis, 2012; Madiba et al., 2021). The barriers to relationships posed by disclosure of HIV status likely account for why, in Paper 2, some participants openly expressed their desire to find a life partner when seeking support within the group. They provided their age, gender, and race, stating their desire to find a companion. The fact that everyone in the group had HIV may have diminished the fear of disclosure typically associated with seeking a partnership. The topic of romantic relationships has been a focal point of discussion within the virtual community. One participant shared their experiences with a supportive partner who is HIV-negative. On the other hand, some participants discussed how their romantic partners either played a positive role in their recovery journey or contributed to relapses and substance use.

Therefore, examining the impact of stigma on forming romantic relationships holds significant importance for individuals with HIV and SUD.

Besides its influence on forming romantic relationships, stigma also significantly affects social connectedness. Stigma plays a defining role in shaping social interactions by conveying the devalued status of certain identities relative to others, leading to isolation or forming communities with similar individuals (Steward et al., 2008). As a result, stigma may impact the formation of virtual communities. The findings from our study in Paper 2 indicated that participants actively planned and met in person, establishing a community that extended beyond the virtual realm. This preference for face-to-face interactions could be attributed to their fear of disclosure and potential stigmatization in personal encounters with people who may not be aware of their HIV status. Seeking to connect with others who share similar experiences with HIV, individuals may initially connect in a virtual space and eventually build meaningful relationships through in-person meetings.

*Social support and medication adherence in the A-CHESS virtual community*

Stigma significantly impacts the social support received by individuals with HIV, consequently affecting their treatment adherence. When people with HIV are hesitant to disclose their HIV status, they often rely on their personal motivation rather than seeking support from others (Kennedy et al., 2004). However, in our study, where all participants were aware of each other's HIV-positive status, the virtual community's supportive environment likely played a crucial role in motivating them to collectively adhere to their health behavior. Participants disclosed when they had missed taking their medication, creating a sense of accountability and commitment to their ART regimen. These observations align with SDT, emphasizing the

importance of social relatedness and motivation as factors contributing to ART adherence (Figure 1).

Numerous studies have shown that greater social support is linked to improved health outcomes and healthier behaviors (Scheurer et al., 2012; Wang et al., 2003). There are different types of social support, and studies of online communities have identified two types of social support: emotional and practical. Practical support encompasses tangible assistance that helps individuals with specific tasks related to their health or well-being. This may include aid with medication management, prescription pick-up, transportation to medical appointments, and other practical tasks that facilitate adherence to treatment and overall health (Damulira et al., 2019; Scheurer et al., 2012). On the other hand, emotional support involves various forms of psychological and emotional assistance. This type of support includes encouragement, active listening, reassurance, and the sharing of relevant information that can positively impact an individual's emotional well-being and motivation to adhere to their health regimen. (Oliveira et al., 2020; Scheurer et al., 2012)

There is inconsistency regarding the type of social support most strongly associated with adherence. In one study, practical support was consistently linked to greater adherence to medication, while other studies indicated that emotional support, including informational support, was associated with improved adherence to ART (Damulira et al., 2019). Nevertheless, it is widely acknowledged that social support contributes to better ART adherence (Mi et al., 2020).

Although our study did not specifically examine the types of social support, the discourses in Paper 2 and categories/subthemes in Paper 3 are closely aligned with emotional support as the prominent type of support provided through the A-CHESS app. It may be possible

that when participants met or communicated through private messaging on the A-CHESS app, they received practical social support. However, we did not observe evidence of this type of support on the message board. Instead, the premeditated messages from case managers and research staff provided information support by sharing information relevant to participants, such as news or awareness about topics like the U=U campaign on medication adherence and viral suppression. While participants in our study provided and received various forms of emotional support, including spiritual support, where they described God or a Higher Power as a significant reason for their sobriety, participants also provided emotional support to each other when describing their motivations for sobriety.

*Autonomous motivation and medication adherence reminders*

According to SDT, motivation is a key factor influencing health behaviors, including medication adherence (Sheeran et al., 2020). SDT emphasizes the significance of autonomous motivation, wherein individuals make decisions based on personal importance rather than external pressure or medical authority (Kennedy et al., 2004; Sheeran et al., 2021). While our study did not directly measure motivation, interesting insights from Paper 2 and Paper 3 indicated that participants exhibited autonomous motivation in managing their health. They actively engaged in discussions about their medication-taking behavior without specific prompts from case managers or researchers, which shows that the research staff did not prompt this behavior to remember to take their medication. The use of the A-CHESS app as a medication reminder for participants reinforces findings from previous studies, where forgetting to take HIV medication was identified as a significant factor contributing to nonadherence, particularly among individuals with SUD (Cook et al., 2001; Freeman et al., 2021). Utilizing the virtual community to remind each other to take their medication aligns with a model tested in HIV

medication adherence studies, demonstrating that daily text reminders positively impacted adherence(Cook et al., 2018). Therefore, employing the virtual community as a means of mutual medication reminders holds great potential to impact adherence positively. Moreover, additional studies have shown that people with HIV who have support through medication reminders or assistance with refills exhibit higher adherence to ART (Damulira et al., 2019; Kelly et al., 2014). This highlights the importance of social support in enhancing medication adherence outcomes among individuals with HIV.

*Health information seeking in the A-CHESS virtual community*

Social support has a significant impact on health information seeking. Health information-seeking behavior refers to individuals seeking information about their health, risks, illnesses, and health-protective behaviors (Jacobs et al., 2017; Mills & Todorova, 2016). Based on SDT, studies show that the motivation to seek information online is driven by extrinsic needs, such as getting information to manage health conditions, and intrinsic motivations, including social support (Lee & Lin, 2016; Zhao et al., 2022). Paper 1 found an association between medication adherence and having a college education. Studies show that while education may not directly influence medication adherence, education is associated with increased engagement in online health-seeking behavior which is associated with medication adherence (Dutta-Bergman, 2004; Jacobs et al., 2017). The education level of our participants may have motivated their active engagement on the message board for health-related purposes.

In Paper 3, we found that participants used the A-CHESS message board to seek information about their substance use, in alignment with CMS, which suggests that people make sense of their illness based on the available information (Llewellyn et al., 2007). Studies have shown that people are more likely to seek information online based on the perceived severity of

their illness (Armitage & Conner, 2000; Zhao et al., 2022). This may explain why many conversations on the message board in Paper 3 were centered around substance abuse, with participants describing the experiences of their substance as being comparable to death. They actively sought information and motivational messages concerning their SUD, possibly perceiving it as more severe and detrimental than their HIV.

Online communities such as the one on A-CHESS provide valuable information about medical conditions and treatments, fostering emotional support and a sense of connection among individuals with shared concerns (Lee & Lin, 2020). However, our study differs in that our discourse analysis revealed participants were not engaging as much with premeditated information related to HIV or SUD; instead, they interacted more with participant-driven messages, adapting app use for their own benefits.

However, Paper 3 delves deeper into the messages shared by participants revealing they share information about their substance use and seek related information. For example, one participant asked the group if they were an alcoholic. Other participants shared their cravings to use substances but provided information on what motivates them to stay sober. This type of information, where participants share the consequences of their illness in alignment with illness representation, is known as experiential information (Snyder & Pearse, 2010; Wang et al., 2018). In our studies, participants actively sought and exchanged experiential information about their substance use and sought support from one another. Within this virtual community, they also freely shared valuable resources related to their treatments, offering their lived experiences as health information to benefit others.

Limitations

Our study is subject to several limitations that should be acknowledged. Firstly, our participants were recruited from a Midwestern state with a low burden of HIV. As a result, our sample size and demographics may not fully represent the diversity of individuals with HIV and substance use disorders, potentially limiting the generalizability of our results to other settings. Additionally, because our study was conducted using a mobile health application, individuals without access to smartphones or digital literacy may have been excluded, introducing selection bias and limiting the representation of certain key populations.

Secondly, our study relied on self-reported data, including medication adherence and substance use behaviors. Self-reporting can be susceptible to recall bias and social desirability bias, leading to potential inaccuracies in the reported information. The messages posted on the message board could also be susceptible to social desirability bias, where individuals only post messages that will be socially acceptable. In addition to surveys and message board data, our study could have benefited from other forms of data, such as focus groups and interviews, where we could learn more about the support-seeking behaviors within the app.

Thirdly, the message board data analysis primarily focused on interactions within the A-CHESS app. While insightful, participants' discussions may differ from interactions in other virtual communities, and the findings may not fully capture the nuances of support-seeking behaviors in alternative online platforms. Furthermore, the study's findings are based on the interactions and data available during the study period, and virtual communities are dynamic environments that may evolve, potentially impacting their impact on medication adherence and support-seeking behaviors.

Despite these limitations, addressing them in future research and app development will enhance our understanding of medication adherence, virtual community dynamics, and support-seeking behaviors within the A-CHESS app. This knowledge can lead to the development of more effective interventions and support systems for individuals living with HIV and SUD.

### Future directions

Based on our study's results and some of its limitations, we identified several areas for future research and intervention design and adaptation.

While our study provided valuable insights into medication adherence, future research should focus on understanding the circumstances under which individuals are nonadherent to their HIV medication. Participants in our study disclosed being nonadherent during periods of active drinking and other situations, but the reasons behind their nonadherence were not fully explored. Encouraging participants to share the specific circumstances when they are nonadherent through the message board could offer valuable information to develop tailored interventions. By understanding the barriers and facilitators of adherence behavior in real-time, personalized approaches can be implemented to support individuals navigating different situations that impact their medication adherence.

Previous studies of HIV medication adherence have shown a positive impact on text message reminders to medication adherence. Participants in the study also started medication check-ins on the message board. Research staff moderating message boards can incorporate medication check-ins as part of automated messages in the message board. Alternatively, given the positive response from participants to motivational messages, there is an opportunity to harness the power of these messages to encourage not only medication adherence but HIV and SUD treatment adherence. Integrating motivational messages targeting treatment adherence

could be a powerful tool to reinforce positive health behaviors and promote adherence to HIV medication.

Building on the findings from Paper 2 and Paper 3, A-CHESS can further develop personalized interventions and support features that cater to the unique needs of its users. By tailoring the content and resources provided within the virtual community to address both HIV and substance use-related challenges, the app can foster a stronger sense of connection and support among participants. Additionally, A-CHESS can utilize its messaging system to encourage open discussions about medication adherence and provide real-time feedback and encouragement to users facing adherence challenges. Personalized interventions can be pivotal in empowering individuals to actively manage their health and well-being actively, ultimately leading to improved medication adherence outcomes.

As technology and healthcare needs continue to evolve, evaluating and improving A-CHESS is imperative to ensure its ongoing effectiveness continuously. Regular feedback from participants can provide valuable insights that inform updates to the app, enabling it to effectively address emerging needs and preferences within the virtual community. Furthermore, with the increasing prevalence of digital health platforms, it becomes essential to understand the impact of online interactions on stigma experiences. Exploring how virtual communities such as A-CHESS influence stigma perceptions and interactions can help develop strategies to create supportive and less stigmatizing environments, fostering the well-being of individuals living with HIV and SUD.

# CHAPTER 7

# CONCLUSION

In conclusion, the three papers in this study provide valuable insights into medication adherence among individuals with HIV and substance use disorders and the dynamics of virtual support communities within the A-CHESS app. These findings contribute to understanding the complex factors influencing medication adherence and the role of social support in the lives of those facing HIV and SUD challenges.

Paper 1 highlights the importance of addressing socioeconomic factors and stigma-related barriers in HIV care, as evidenced by the significant associations between education, stigma, and medication adherence. Future interventions can use Self-Determination Theory principles to empower individuals and promote effective adherence to medication regimens.

In Paper 2, the analysis of virtual community interactions emphasizes the role of supportive moderators and established norms in fostering a sense of belonging and connection. Virtual support communities offer the potential for enhancing social relatedness and empowerment for individuals facing HIV and SUD challenges.

Paper 3 provides a comprehensive understanding of illness representation within the A-CHESS virtual community, focusing on addiction and HIV experiences. These insights can inform the development of tailored interventions that address the unique needs of individuals living with HIV and SUD, promoting better engagement and adherence to treatment regimens.

The papers highlight the significance of social support, the impact of stigma, and the role of empowerment in medication adherence and virtual community engagement. Healthcare professionals and app developers can use these insights to design more effective interventions for

individuals with HIV and SUD. Ongoing evaluation and improvement of such interventions will be essential to ensure their continued effectiveness and positive impact on those living with HIV and substance use disorders. By addressing these challenges and building upon these research findings, we can enhance support and care for this vulnerable population, leading to improved health outcomes and a better quality of life for individuals with HIV and SUD.

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# APPENDIX A

## STUDY INVITATION LETTER

Hello,

ARCW and UW Health are teaming up on a research study! You were sent this letter because you are receiving health care or services at ARCW. You might qualify for this research study. It is called A-CHESS and is led by Dr. Ryan Westergaard and his study team.

Eligible patients and clients will receive support through the use of a new smartphone app or web page. The goal of the study is to help people stay connected to their medical care. The program will give people health information, news about local events, and offers the chance to communicate anonymously with other patients and clients. This study is voluntary and any information you enter will be kept private.

Participants will meet with a study team member to enroll. This will take about 60 minutes and you will receive $50 for your time. Participants also will be invited to take two follow up surveys over the course of a year for another $50.

If you are curious about the study, or would not like to receive future mail about this study, please contact Sarah Liebert at (414) 840-9738. For any medical issues or emergencies, please call 911.

Thank you,

Ryan Westergaard, MD, PhD, MPH
Site Investigator
UW Health

# APPENDIX B

## STUDY OVERVIEW FOR PATIENTS

**Overview of A-CHESS study steps**

**Learn About the Study:** Potential study participants are invited by an ARCW staff member to participate in this study. A member of the research team will screen the potential participant by administering a brief questionnaire. If the participant is eligible, the participant sets up an in-person appointment with a member of the research team. (5-15 minutes)

**Eligibility and Consent:** The participant and researcher meet in-person to review the study rules, and confidentiality protections. If agreed, participants will sign a consent document and are reminded that their responses are **private** and **confidential** and are protected by a **Certificate of Confidentiality**. (15-30 minutes)

**A-CHESS Account Set Up:** A researcher will guide the participant on how to set up their A-CHESS account on their phone or access via web browser. Participants will select an **anonymous** username and password for their personal account. The participant and researcher will review the features of the app and answer any questions. (20-30 minutes)

**Baseline Survey:** Participants are asked to complete a 25 minute survey with a member of the research team. Responses are protected by a **Certificate of Confidentiality**. (25-30 minutes)

**Cash Payment:** Participants receive $50 for their time after completing all the above steps. This will either be mailed to a participant-approved address, or handed in person by a member of the research team.
(5 minutes)

**You Involvement**: Participants will have access to A-CHESS for 1 year. At 6 and 12-months participants will be asked to complete follow-up surveys with a member of the research team. Participants will receive $25 for each.

# APPENDIX C

# A-CHESS USER GUIDE

## APP FEATURES

MY Motivation

**MY MOTIVATION:** A place for you to keep track of your personal motivators: reasons to stay clean my gratitude and favorites.

**DISCUSSIONS:** Public messages for everyone to read and write.

**PRIVATE MESSAGES:** Send messages to one or more people that you choose.

**INFORMATION:** Recovery information including personal stories and A-CHESS help.

GAMES and Relaxation

**GAMES and RELAXATION:** Play games, watch TV, or listen to relaxation and mindful meditation audios.

**HELP WITH CRAVINGS:** Connect with others, distract yourself, or relax when you are struggling.

**PROFILES:** Share information about yourself and learn about others.

MEETINGS and Events

**MEETINGS and EVENTS:** View local events, such as AA/NA meetings and sober events.

**SETTINGS:** A Customize A-CHESS to help you get the support

Reminder that you always have the option to access the online version of the App by going to :

**https://chess.wisc.edu/OC**

# A-CHESS USER GUIDE

THANK YOU FOR PARTICIPATING IN THE A-CHESS STUDY. THIS GUIDE WILL WALK YOU THROUGH THE BASICS OF USING A-CHESS.

# APPENDIX D

## A-CHESS APP INSTALLATION INSTRUCTIONS

How to install the app
To allow installation:

-From Home screen, go to Settings -> Applications.

-Check "Allow installation of non-market applications."

To download A-CHESS:

-From Home screen, open browser app (e.g. "Browser," "Chrome," "Internet").

-
Enter **https://chess.wisc.edu/OC/** into the browser window address bar.

-On A-CHESS screen, click "Android App" to download.

To install A-CHESS:

-Click Home button, and drag down notification bar at top of screen.

-Download will start.

-When progress bar shows download is complete, click on A-CHESS to install app.

Open the app:

-Open A-CHESS when install is complete, or click A-CHESS from list of apps on Home screen.

-Enter user name and password you were given.

-If you have a choice of servers, click the server you were given.

Open browser (Safari) from Home screen.

Enter https://chess.wisc.edu/OC/ into the browser window, and click Go.

On A-CHESS screen, click "iOS App" to download.

Click Install.

Click Home. Find A-CHESS in list of apps, and click to open. If you get an alert for "Untrusted Enterprise Developer":

-Click Cancel.

-Open Settings.

-Navigate to General -> Device Management -> University of Wisconsin - Madison ->

Trust "University of Wisconsin - Madison". Click Trust.

-Click Home. Find A-CHESS in list of apps, and click on it to open.

-On A-CHESS screen, enter user name and password you were given. If you have a choice of servers, click the server you were given.

Getting started
Once the App is downloaded, tap the A-CHESS icon to go to the home screen. From the home screen, you can access any A-CHESS service.

**APPENDIX E:**

**BASELINE SURVEY FOR A-CHESS STUDY PARTICIPANTS**

**Recruitment ID#:**
**_____**

**Study ID#:**
**_____**

**Today's Date:**
**_____**

**ART-CHESS**

**Participant Baseline Survey**

If you have any questions please contact:

Klaren Pe-Romashko

University of Wisconsin – Madison

Center for Health Enhancement Systems Studies

1513 University Avenue

Madison, WI 53706

1-800-361-5481

1-608-263-3332

Thank you for taking part in this study. Any information you share on this survey is confidential. Your survey is labeled with a study code number to protect you. The code number is linked to your name, but only the Project Director and Project Assistant will have access to your name and code number.

This survey will help us better understand how you, as a person with substance abuse disorder, are dealing with the situation.

There are no right or wrong answers to the questions. If you feel uncomfortable with any question, you can skip it. Also, you are free to stop filling out the survey at any time. Please note that you will be asked some survey questions several times during the course of the study. This will help us look at changes over time.

If you have any questions about the survey or the study please contact Klaren Pe-Romashko, Project Director, at 1-800-361-5481 or (608) 263-3322.

**Demographics:**

1. Gender: Male Female

2. What is your age? _____

3. What is the highest grade or level of school that you have completed?

○1 8th grade or less

○2 Some high school, but did not graduate

○3 High school graduate or GED

○4 Some college or 2 year degree

○5 4-year College graduate

○6 More than 4-year college degree

4. Are you of Hispanic or Latino origin or descent?

○1 Yes, Hispanic or Latino

○2 No

5. What is your race? (Mark all that apply)

○1 White

○2 Black or African American

○3 Asian

○4 Native Hawaiian or other Pacific Islander

○5 American Indian or Alaskan Native

○6 Other, please specify _____

6. Where do you access the Internet? (Mark all that apply)

○1 No access to the Internet

○2 At home

○3 On mobile device/phone

○4 At work

○5 At family or friends' homes

○6 At public sites (e.g. library, clinic, church, club)

○7 Other: please specify _____

**Tech Competence:**

| **7. How comfortable are you (on a scale from 1-5)…** | Not at all Comfortable | A little bit | Some-what | Quite Comfortable | Very Comfortable | N/A |
|---|---|---|---|---|---|---|
| a) Using a smart phone | 1 | 2 | 3 | 4 | 5 | |
| b) Using Facebook or other social media | 1 | 2 | 3 | 4 | 5 | |
| c) Using email or online instant messaging | 1 | 2 | 3 | 4 | 5 | |

8. In the past 30 days, have you posted information (that is, you wrote something or shared a picture that others could see on the Internet) on any of the following sites?

□1 Facebook

□2 Twitter

□3 Instagram

□4 YouTube

□5 SnapChat

□6 Tumblr

□7 Grindr

□8 Tinder

9. For each site that you have used, how many different times have you posted something in the past week?

a. Facebook _____

b. Twitter _____

c. Instagram _____

d. YouTube _____

e. SnapChat _____

f. Tumblr _____

g. Grindr _____

h. Tinder _____

**Status of Current Housing:**

10. Who do you currently live with? (Mark all that apply)

□1 I live by myself

□2 I live with my partner (spouse, lover)

□3 I live with one or more dependent children

□4 I live with one or both of my parents

□5 I live with other family members

□6 I live with a friend or friends

□7 Sober house

□8 Other, please specify _____

11. Do you currently have a spouse/partner/significant other? [ ] Yes [ ] No

12. Are you currently employed (for wages)? [ ] Yes [ ] No

**If Yes:** Approximately how many hours do you work per week?

_____

**If No:** If not employed for wages, are you: (Mark all that apply)

□1 A homemaker

□2 Retired

□3 On disability

□4 Looking for work

□5 Other: _____

13. Have you been diagnosed with any mental health concerns other than substance use disorder (such as depression, anxiety, bi-polar, ADHD…)

[ ] Yes [ ] No

a. If yes, what is your diagnosis:

○1 ADHD

○2 Anxiety/Social Anxiety

○3 Bipolar/Manic Depression

○4 Borderline Personality Disorder

○5 Depression

○6 Obsessive Compulsive Disorder (OCD)

○7 Panic Disorder

○8 PTSD

○9 Other: _____

14. Do you have a history of treatment for chronic pain? [ ] Yes [ ] No

If yes, please describe:

_____

_____

_____

**Pain Severity Scale (NRS 11)**

| In general… | No pain | | | | | | | | | Worst imaginable pain |
|---|---|---|---|---|---|---|---|---|---|---|
| 1. "Please rate your pain from 0 to 10 with 0 indicating no pain and 10 representing the worst possible pain." | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

**Opioid Use History**

1. How old were you when you first used opioids and what did you use (e.g., Heroin, Morphine, Dilaudid, Demerol, Oxycontin, Oxy, Codeine, Tylenol 2,3,4, Percocet, Vicodin, Fentanyl, etc.)? _____

2. How old were you when you started to regularly use opioids? _____

3. Did your regular use of opioids begin through a doctor prescribing them to you?

[ ] Yes [ ] No

4. How many times have you been in treatment to stop using opioids? _____

5. When did you last use opioids (date)? _____

**Rating Scale for Withdrawal**

1. When did you last experience withdrawal? _____

a. If yes, what were you withdrawing from? _____

b. How severe were your withdrawal symptoms (e.g. muscle cramps, painful joints, etc) on a scale from 1 (not at all) to 10 (very severe) _____

**Morisky Medication Adherence Scales: MMAS-4**

**Are you currently taking:**
**[ ] Vivitrol [ ] Suboxone [ ] Methadone [ ] None [ ] Other:**
**_____**

1. How often do you forget to take your [MAT drug]? _____
(1 almost always forget, 5 never forget.)

2. Are you careless at times about taking your [MAT drug]? _____
(1 very careless, 5 not at all careless.)

3. If you feel worse from taking your [MAT drug] (e.g. side effects), how likely are you to stop taking it? _____
(1 very likely to stop taking it, 5 not at all likely to stop taking it.)

4. If you feel good (e.g. like you have your recovery under control), how likely are you to stop taking your [MAT drug]? _____
(1 very likely to stop taking it, 5 not at all likely to stop taking it.)

**If no longer taking [MAT], why not?**
**_____**

**_____**
**_____**

**Time Line Follow Back/ Risky Behavior:**

1. In the past 30 days, did you consume any alcohol? [ ] Yes [ ] No

If yes, date of last drink: _____

- If yes: How many of the past 30 days did you have at least…

**Men:** 4 standard drinks in a 2 hour period _____
**Women:** 3 standard drinks at any one time? _____

- If yes: How many of the past 30 days did you have at least…

**Men:** 5 drinks _____
**Women:** 4 drinks _____

**One drink = one shot of hard liquor (1.5 oz.), a 12- ounce can/bottle of beer, or a 5 ounce glass of wine*

2. In the past 30 days, did you use any illegal/street drugs (including marijuana) or abuse any prescription medications? [ ] Yes [ ] No

**If No skip to #5**

3. Did you use a needle/syringe to inject any drugs in the past month**?** [ ] Yes [ ] No

**If No skip to #4**

a. How many times in the last month have you used a needle after someone else had already used it? _____

b. How many times in the last month has someone used a needle after you used it? _____

4. Drug Use:

A. In the past 30 days, how many days did you use **Opioids** (e.g., Heroin, Morphine, Dilaudid, Demerol, Oxycontin, Oxy, Codeine, Tylenol 2,3,4, Percocet, Vicodin, Fentanyl, etc.): _____ days

Which type of opioids did you use?
- Heroin
- Morphine
- Dilaudid
- Demerol
- Oxycontin
- Oxy

□ Codeine
□ Tylenol 2, 3, 4
□Percocet
□ Vicodin
□ Fentanyl
□ Other _____

Date of last use of any opioid: _____

- Do you want to quit using? [ ] Yes [ ] No
- On a scale of 1 (not at all confident) to 10 (extremely confident), how confident are you in your ability to be completely abstinent (clean) from **Opioids** in the next 30 days? _____

B. In the past 30 days, how many days did you use **Marijuana** (cannabis, pot, weed): _____ days

Date of last use: _____

- Do you want to quit using? [ ] Yes [ ] No
- On a scale of 1 (not at all confident) to 10 (extremely confident), how confident are you in your ability to be completely abstinent (clean) from **Marijuana** in the next 30 days? _____

C. In the past 30 days, how many days did you use **Sedative/Tranquilizers** (e.g. "benzos", Valium, Xanax, Ativan, Ambien, "barbs", Phenobarbital, downers, etc. : _____ days

Date of last use: _____

- Do you want to quit using? [ ] Yes [ ] No
- On a scale of 1 (not at all confident) to 10 (extremely confident), how confident are you in your ability to be completely abstinent (clean) from **Sedatives/Tranquilizers** in the next 30 days? _____

D. In the past 30 days, how many days did you use **Stimulants** (e.g. Cocaine, amphetamine, methamphetamine, Desedrine, Ritalin, Adderall, "speed", "crystal meth", "ice", etc.): _____ days

Date of last use: _____

- Do you want to quit using? [ ] Yes [ ] No
- On a scale of 1 (not at all confident) to 10 (extremely confident), how confident are you in your ability to be completely abstinent (clean) from **Other Stimulants** in the next 30 days? _____

5. How many people, including casual partners have you had sex with in the last month? _____

**IF None, skip the next question**

In the last month, how many times did you have sex with a *casual* partner (paid or otherwise) without the use of a condom? _____

**Brief Addiction Monitor:**

| **In the Past 7 Days…** | **Not at all** | **Slightly** | **Moderately** | **Considerably** | **Extremely** |
|---|---|---|---|---|---|
| 1. In the past 7 days, how much were you bothered by cravings or urges to drink alcohol or use drugs? | 1 | 2 | 3 | 4 | 5 |
| 2. Does your religion or spirituality help support your recovery? | 1 | 2 | 3 | 4 | 5 |
| 3. In the past 7 days, how much have you been bothered by arguments or problems getting along with any family members or friends? | 1 | 2 | 3 | 4 | 5 |
| 4. In the past 7 days, how many days did you attend self-help meetings like AA or NA or Smart Recovery to support your recovery? _____ | | | | | |
| 5. In the past 7 days, how many days were you in any situations or with any people that might put you at an increased risk for using alcohol or drugs (i.e. around risky | | | | | |

| |
|---|
| "people, places or things") _____ |
| 6. In the past 7 days, how many days did you spend much of the time at work, school, or doing volunteer work? _____ |
| 7. In the past 7 days, how many days were you in contact with or spent time with any family members or friends who are supportive of your recovery? _____ |
| 8. In the past 7 days, how many nights did you have trouble falling asleep or staying asleep? _____ |
| 9. In the past 7 days, how many days have you felt depressed, anxious, angry or very upset? _____ |

**HIV/HCV Screening Status**

When did you first test positive for HIV (give the approximate date)? _____

How long after you found out that you had HIV first did you see an HIV care provider?

O1 Less than one month

O2 Between 1 and 6 months

O3 Between 6 and 12 months

O4 More than 1 year

How long after you found out that you had HIV did you start taking antiretroviral medications?

O1 Less than one month

O2 Between 1 month and 1 year

O3 Between 1 and 2 years

O4 More than 2 years

O5 I have never started HIV treatment

Are you currently taking antiretroviral medications? [ ] Yes [ ] No

- How often do you forget to take your HIV medications? _____
  (1 almost always forget, 5 never forget.)

- Are you careless at times about taking your HIV medications? _____
  (1 very careless, 5 not at all careless.)

- If you feel worse from taking your HIV medications, how likely are you to stop taking it? _____
  (1 very likely to stop taking it, 5 not at all likely to stop taking it.)

- If you feel good, how likely are you to stop taking your HIV medications? _____
  (1 very likely to stop taking it, 5 not at all likely to stop taking it.)

Have you ever been tested for Hepatitis C virus? [ ] Yes [ ] No [ ] Don't know

**If Yes**, what was the approximate date of the test? _____

**If Yes**, what was the result of your Hepatitis C test? [ ] Positive [ ] Negative [ ] Don't Know

**If Positive or Reactive**, did you see a medical provider? [ ] Yes [ ] No

**If Yes**, did you have a blood test to determine whether you are still infected with the virus? [ ] Yes (still infected) [ ] Yes (cleared/not infected) [ ] No [ ] Don't know

**If Yes/still infected**, have you ever received medications to treat Hepatitis C? [ ] Yes [ ] No

**If Yes/still infected**, are you currently taking medications to treat Hepatitis C? [ ] Yes [ ] No

- How often do you forget to take your Hep C medicine? _____
  (1 almost always forget, 5 means never forget.)

- Are you careless at times about taking your Hep C medicine? _____

(1 very careless, 5 not at all careless.)

- If you feel worse from taking your Hep C medicine, how likely are you to stop taking it? _____

(1 very likely to stop taking it, 5 not at all likely to stop taking it.)

- If you feel good, how likely are you to stop taking your Hep C medicine? _____

(1 very likely to stop taking it, 5 not at all likely to stop taking it.)

**If Yes,** were you told that you were cured of the infection? [ ] Yes [ ] No

**Treatment Self-Regulation Questionnaire**

On a scale of 1 to 5, where 1 is not true and 5 is very true, please tell me how true each of the following statements is:

| **I WILL NOT USE DRUGS BECAUSE…** | **Not true** | | | **Very True** | |
|---|---|---|---|---|---|
| 1. I want to take responsibility for my own health. | 1 | 2 | 3 | 4 | 5 |
| 2. I believe it is the best thing for my health. | 1 | 2 | 3 | 4 | 5 |
| 3. Others would be upset with me if I did. | 1 | 2 | 3 | 4 | 5 |
| 4. I believe that not using is very important for many aspects of my life. | 1 | 2 | 3 | 4 | 5 |
| 5. It is an important choice I really want to make. | 1 | 2 | 3 | 4 | 5 |
| 6. It is consistent with my life goals. | 1 | 2 | 3 | 4 | 5 |

**Drug Taking Confidence Questionnaire: DTCQ (8-items)**

| **I would be able to resist the urge to use Opioids …** | Not at all | | | | Very confident |
|---|---|---|---|---|---|
| 1. If I were angry at the way things turned out. | 1 | 2 | 3 | 4 | 5 |
| 2. If I had trouble sleeping. | 1 | 2 | 3 | 4 | 5 |
| 3. If I had remembered something good that had happened. | 1 | 2 | 3 | 4 | 5 |
| 4. If I wanted to find out whether I could use opioids occasionally without getting hooked. | 1 | 2 | 3 | 4 | 5 |
| 5. If I unexpectedly found some opioids or happened to see something that reminded me of opioids. | 1 | 2 | 3 | 4 | 5 |
| 6. If other people treated me unfairly or interfered with my plans. | 1 | 2 | 3 | 4 | 5 |
| 7. If I were out with friends and they kept suggesting we go somewhere and use. | 1 | 2 | 3 | 4 | 5 |
| 8. If I wanted to celebrate with a friend. | 1 | 2 | 3 | 4 | 5 |

**Positive and Negative Affect (PANAS):**

On a scale of 1-5, with 1 being Almost Never and 5 being Almost Always, please give me the answer that comes closest to how you have been feeling **during the past month**.

**Almost Never** **Almost Always**

| | | | | | |
|---|---|---|---|---|---|
| 1. Interested | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 2. Distressed | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |

| | | | | | |
|---|---|---|---|---|---|
| 3. Excited | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 4. Upset | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 5. Strong | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 6. Guilty | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 7. Scared | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 8. Hostile | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 9. Enthusiastic | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 10. Proud | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 11. Irritable | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 12. Alert | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 13. Ashamed | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 14. Inspired | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 15. Nervous | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 16. Determined | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 17. Attentive | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 18. Jittery | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 19. Active | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |
| 20. Afraid | ○ 1 | ○ 2 | ○ 3 | ○ 4 | ○ 5 |

**Loneliness Scale**

The next questions are about how you feel about different aspects of your life.

| **How often do you feel…** | Never | Rarely | Sometimes | Always |
|---|---|---|---|---|
| 1. that you lack companionship? | | | | |
| 2. left out? | | | | |
| 3. isolated from others? | | | | |

**Internalized AIDS-Related Stigma Scale**

1. It is difficult to tell people about my HIV infection [ ] No [ ] Yes

2. Being HIV positive makes me feel dirty [ ] No [ ] Yes

3. I feel guilty that I am HIV positive [ ] No [ ] Yes

4. I am ashamed that I am HIV positive [ ] No [ ] Yes

5. I sometimes feel worthless because I am HIV positive [ ] No [ ] Yes

6. I hide my HIV status from others [ ] No [ ] Yes

**Use of Health Services**

In the last 6 months, have you gone to any of the following?

1. Alcoholics Anonymous, Narcotics or Cocaine Anonymous meeting, or any 12 step or Smart Recovery meetings?
[ ] Yes [ ] No

2. An outpatient program for alcohol or drugs where you have counseling sessions, meetings, or group therapy but do not spend the night (could be intensive outpatient, multiple meetings/hours per week)?
[ ] Yes [ ] No

3. An alcohol or drug residential treatment center (where you spend nights there)?
[ ] Yes [ ] No

4. Any other agency or professional for substance use disorder (therapy, counseling…)?
[ ] Yes [ ] No

If yes, pls. specify: _____

5. How many times were you admitted to the hospital in the past 6 months (being admitted to the hospital means spending at least one night there)?
[ ] None _____ times

Approximate date: _____

Length of Stay: _____

Reason for hospital admission(s):
_____

6. How many times did you visit an emergency room or urgent care clinic in the past 6 months?
[ ] None _____ times
Approximate date: _____
Reason for each visit:
_____

7. Did you see any other doctors or health care providers in the last 6 months?
[ ] Yes [ ] No

General Practitioner:
How many times: _____
Reason for
visits:_____
_____

_____
_____

_____
_____

Dentist:
How many times: _____
Reason for visits:_____
_____

_____
_____

_____
_____

Other (e.g. chiropractor, naturopath, physiotherapist, optometrist, podiatrist):
How many times: _____
Reason for visits: _____

**Self-Stigma Scale (self-devaluation subscale)**

**In the past week,** how often did you feel the following?

| | **Never** | **Rarely** | **Some-times** | **Quite frequently** | **Nearly Always** |
|---|---|---|---|---|---|
| 1. A major reason for my problems with substances is my own poor character. | ○1 | ○2 | ○3 | ○4 | ○5 |
| 2. I deserve the bad things that have happened to me. | ○1 | ○2 | ○3 | ○4 | ○5 |
| 3. I can be trusted. | ○1 | ○2 | ○3 | ○4 | ○5 |
| 4. I feel inferior to people who have never had a problem with substances. | ○1 | ○2 | ○3 | ○4 | ○5 |

| | | | | | |
|---|---|---|---|---|---|
| 5. I feel out of place in the world because of my problems with substances. | ○1 | ○2 | ○3 | ○4 | ○5 |
| 6. I've permanently screwed up my life by using drugs. | ○1 | ○2 | ○3 | ○4 | ○5 |
| 7. I feel ashamed of myself. | ○1 | ○2 | ○3 | ○4 | ○5 |

**Bonding Scale**

Please indicate how frequently each of the following statements is true for you.

| | **Never** | **Rarely** | **Some-times** | **Quite frequently** | **Nearly Always** |
|---|---|---|---|---|---|
| 1. I can get information from others dealing with substance abuse. | ○1 | ○2 | ○3 | ○4 | ○5 |
| 2. I am building a bond with others dealing with substance abuse. | ○1 | ○2 | ○3 | ○4 | ○5 |
| 3. I feel stronger knowing that there are others in my situation. | ○1 | ○2 | ○3 | ○4 | ○5 |
| 4. I've been getting emotional support from others dealing with substance abuse. | ○1 | ○2 | ○3 | ○4 | ○5 |
| 5. It helps me to be able to share my feelings and fears with others dealing with substance abuse. | ○1 | ○2 | ○3 | ○4 | ○5 |

**Satisfaction with Life Scale**

Using a 1 - 5 scale, with 1 being strongly disagree and 5 being strongly agree, please tell me how much you disagree or agree with the following statements:

| In general… | **Strongly Disagree** | | | | **Strongly Agree** |
|---|---|---|---|---|---|
| 1. I have a lot of energy. | 1 | 2 | 3 | 4 | 5 |
| 2. I feel calm and peaceful. | 1 | 2 | 3 | 4 | 5 |
| 3. My worries overwhelm me. | 1 | 2 | 3 | 4 | 5 |
| 4. I worry about dying. | 1 | 2 | 3 | 4 | 5 |
| 5. I have difficulty sleeping. | 1 | 2 | 3 | 4 | 5 |
| 6. I am able to perform my daily routines. | 1 | 2 | 3 | 4 | 5 |
| 7. I am able to keep up with my commitments. | 1 | 2 | 3 | 4 | 5 |
| 8. I am limited in what I can do physically. | 1 | 2 | 3 | 4 | 5 |