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**I, Joseph D Perazzo , hereby submit this original work as part of the requirements for the degree of Doctor of Philosophy in Nursing Research.**

It is entitled:

**Translating the News: A Grounded Theory of Care Initiation by Individuals Living with HIV**

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Translating the News: A Grounded Theory Study of Care Initiation by Individuals

Living with HIV

A dissertation submitted to the

Graduate School

of the University of Cincinnati

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by

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## Abstract

**Background:** Despite tremendous advances in HIV treatment, less than 30% of the more than 1 million people living with HIV in the US are achieving optimal treatment outcomes. Researchers have recognized that there is an urgent need to understand factors and processes that influence individuals with HIV to initiate HIV care.

**Purpose:** The specific aims of the study were to develop a theoretical framework to explain the psychosocial process of care initiation in individuals living with HIV to identify the critical junctures, defined as pivotal events reported by study participants, that influence individuals living with HIV in their decision to initiate HIV care

**Methods:** Grounded theory was the method used to analyze in-depth interviews with individuals living with HIV. A team of IRB-approved researchers analyzed the data using three levels of coding: Open coding, selective coding, and theoretical coding. Analysis was conducted with an aim of identifying the psychosocial process of care initiation by individuals living with HIV.

**Results:** 30 individuals living with HIV (28 men, 2 women) participated in the study. Participants shared their stories about how they went from learning that they had HIV to the point of HIV care initiation. The core category discovered in the data was concept of HIV as news. News, by definition, is impactful information that was not previously known that is delivered by one party and received by another. Participants described a process in which they progressed through five distinct stages: a) receiving the news, b) interpreting the news, c) incorporating the news, d) acting on the news, and e) moving beyond the news. Each stage was moderated by influential factors including perceived susceptibility to HIV infection, symptoms, HIV information, and feedback from others. The initial receipt of the news was typically interpreted as ‘bad news’. However, through reflection, interaction with others, and information seeking, participants learned that HIV was not a death sentence and that there are treatment options available to them. In effect, the participants were able to translate the news, often beginning as something bad, but changing into something good. The constructed framework is known as “Translating the News: A Grounded Theory of HIV Care Initiation”

**Conclusion:** Individuals who are diagnosed with HIV often encounter a myriad of challenges at the point of diagnosis. Individuals are able to move through the care initiation process with fewer complications when they are provided with encouragement and information, particularly about their treatment options. The key to successful care initiation is helping individuals with HIV to realize that while the diagnosis may seem like bad news, there is also good news: HIV is not a death sentence.

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### **Dedication:**

This work is dedicated to my wonderful husband, family, and dear friends who have provided me with the strength and wisdom to pursue my dream of becoming a scientist. Jeff West, you enrich my life beyond measure and I want to thank you so much for always supporting me- this is for you! Dad, I would be nowhere without your help and I will be forever grateful for the hard work and sacrifices you have made to be sure that I was able to become anything I wanted to be. Mom, I know that you are always with me because I take you everywhere- thank you for giving me wings. Grandma, I am beyond grateful that I am able to share this work with you. Thank you for always being my friend and my cheerleader. To my siblings, thank you for cheering me on and sharing in my excitement as we have grown up, set goals, and reached them.

There are not enough pages to name everyone to whom I am grateful. To all of my family and friends: Thank you so much for believing in me- you are truly a gift. Your love, support, and influence has made every page of my work possible.

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Joe Perazzo, PhD, RN

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## CHAPTER 1: BACKGROUND AND SIGNIFICANCE

Infection with the Human Immunodeficiency Virus (HIV) has the potential to lead to the fatal occurrence of ‘Acquired Immunodeficiency Syndrome’ (AIDS). The term AIDS was coined in 1982 shortly after the first cases of a rare condition known as *pneumocystis carinii pneumonia* (PCP) were reported (Centers for Disease Control and Prevention [CDC], 2013a). Over the last three decades, global health authorities have worked tirelessly in an effort to understand, control, prevent, and treat HIV. Collectively, the progress in the fight against HIV/AIDS has been astonishing. Scientists have been able to educate the public on the modes of HIV transmission, helping to introduce a new level of understanding to a disease that was once a subject of mass hysteria (Henry J. Keiser Foundation [KFF], 2013).

National and international organizations have dedicated immense effort to the development of strategies to prevent, treat, and ultimately eradicate the disease. Among these are the World Health Organization (WHO), UNAIDS, The United Children’s Fund (UNICEF) and the Global AIDS Program (CDC,2010; CDC, 2013b).The result of this global effort is a significant decrease in HIV-related deaths from 2.3 million deaths in 2005 to 1.7 million deaths in 2011 (CDC, 2010; CDC, 2013b; WHO, 2013b; WHO, 2013c).Despite this notable progress, HIV continues to be a major global health concern, with approximately 6,300 new cases being diagnosed every day (WHO, 2013b; WHO, 2013c).

At present, the highest global burden of HIV infection rests in the geographic region of Sub-Saharan Africa, with approximately 80% of all individuals living with HIV residing in this region (KFF, 2013; WHO2013b; WHO, 2013c). The majority of new infections globally are transmitted through heterosexual contact (KFF, 2013), with population-specific transmission statistics varying in different geographic regions. In the United States, over one million people are living with HIV, and approximately 14% are unaware that they have HIV (CDC, 2010; CDC,

2013b; Gardner, McLees, Steiner, del Rio, & Burman, 2011). Racial and ethnic minority populations and men who have sex with men (MSM) have been identified as the US populations at highest risk for HIV infection (CDC, 2010; CDC, 2013b; CDC, 2013c). As such, research efforts on population-based prevention and treatment have become a priority in the US. The fight against HIV/AIDS has resulted in a significant economic impact; with an estimated \$28 billion US healthcare dollars spent on domestic and global research efforts (KFF, 2013).

HIV is transmitted from person to person through exchange of bodily fluids including blood, semen, pre-seminal fluid, vaginal secretions, rectal mucous and breast milk. Theoretically, HIV can also be transmitted through amniotic fluid, synovial fluid, and cerebrospinal fluid. Infection can be spread through sexual contact, IV drug use, mother-to-baby transmission, and occupational exposure (United States Department of Health and Human Services [DHHS], 2013d; Stine, 2012). HIV infection results in a complex disease process and equally complex treatment regimens are required to prevent replication of HIV in the body (DHHS, 2013b; DHHS, 2013e; DHHS, 2013g; Stine, 2012).

Advances in medicine led to the discovery of anti-retroviral therapy (ART), which has increased the number of medical treatment options from one generally accepted pharmaceutical agent to more than 30 different medications that can be used in various combinations to treat HIV (DHHS, 2013e; Stine, 2012). ART is the most effective method of treating HIV, and has demonstrated the ability to decrease mortality, increase the lifespan, and increase quality of life in infected individuals (DHHS, 2013a; Gardner et al., 2011; Little et al., 2002; WHO, 2013a).

Despite the promise that ART has demonstrated, estimates are that as many as 50% of people living with HIV are not engaged in HIV care. Engagement in HIV care occurs when individuals living with HIV receive consistent and continuous medical care throughout the

trajectory of the HIV illness (Gardner et al., 2011). The demonstrated benefits of ART coupled with the risks associated with lack of or inconsistent treatment has prompted the need for researchers to examine psychosocial factors that influence HIV treatment. The current body of knowledge regarding psychosocial factors that influence HIV care has included theoretically-framed studies examining HIV-related health behaviors, and examination of psychosocial phenomena such as treatment readiness and adherence.

Researchers have used the Health Belief Model (Rosenstock, 1974), the Theory of Reasoned Action (Fishbein & Ajzen, 1975), the Theory of Planned Behavior (Ajzen, 1991), and the Transtheoretical Model of Behavior Change (McConaughy, Prochaska, & Velicer, 1983) to investigate psychosocial factors related to HIV. However, few of these studies based on these models have focused on factors related to HIV care initiation. Most have primarily focused on treatment adherence in individuals who have already initiated care (Aspeling & van Wyk, 2008; Saal & Kagee, 2012; Wringe et al., 2009). The results of these studies have indicated that successful treatment adherence is associated with knowledge of the HIV illness, perceived vulnerability to the consequences of HIV, and encounters with individuals close to the individual that prompt treatment-related behaviors.

Readiness for HIV treatment has also been investigated and determined to be an important psychosocial factor related to HIV treatment (Aspeling & van Wyk, 2008; Nordqvist, Södergård, Tully, Sönnnerborg, & Lindblad, 2006). Similar to the theoretically-framed studies, the majority of HIV readiness studies have examined readiness for adherence to HIV regimens (Aspeling & van Wyk, 2008; Balfour et al., 2006; Bloch et al., 2010; Chesney, 2003; Enriquez, Lackey, O'Connor, & McKinsey, 2004; Enriquez & McKinsey, 2004; Kennedy IV, 2000; Kip, Ehlers, & van der Wal, 2009; Roberts, 2000; Sabatâe, 2003; Södergård et al., 2007; Tuldrà &

Wu, 2002), specifically in situations where previous treatment attempts have been abandoned or have failed (Enriquez et al., 2004; Enriquez & McKinsey, 2004). The results of these studies indicate that assessment of readiness is crucial to treatment success, as higher levels of readiness have been found to predict greater levels of adherence to HIV medication (Nordqvist et al., 2006; Södergård et al., 2007).

The present body of knowledge regarding psychosocial factors influencing HIV treatment provides valuable insight into factors that influence adherence to HIV treatment regimens. However, a noticeable gap exists in the literature related to HIV care. Nearly all studies examining psychosocial factors related to HIV care have focused on the phenomenon of *treatment adherence* in individuals linked with HIV care. Researchers have recently emphasized the benefit of *test-and-treat* strategies, which are aimed at preventing delays between receiving a positive HIV test result and initiating HIV treatment (Gardner et al., 2011). These researchers have provided results that clearly demonstrate the benefit of early initiation of HIV treatment. Gardner et al. (2011) concluded that in the US, 75% of individuals who test positive for HIV initiate care within three to six months, and 80-90% initiate care within three to five years following diagnosis. The optimal time point for care initiation following HIV diagnosis has been debated among HIV experts, but an increasing body of evidence suggests that early initiation of HIV treatment (defined as initiation of care with CD4+ cell count  $\leq 500$  cells/mm<sup>3</sup>) is beneficial to individuals with HIV.

Regardless of biomedical indicators for treatment, investigators have discovered that psychosocial factors, especially readiness for HIV treatment, are predictive of HIV treatment adherence. Less is known, however, about the process individuals go through when initiating HIV care following an HIV diagnosis. No prior studies have examined the psychosocial

processes that individuals who have received a positive HIV test undergo in order to initiate HIV care. Therefore, the purpose of this study was to explore the psychosocial process of care initiation by individuals living with HIV.

### **The Study**

#### **Specific Aims:**

The primary aims of the study were:

- 1) to develop a theoretical framework to explain the psychosocial process of care initiation by individuals living with HIV
- 2) to identify the critical junctures, defined as pivotal events reported by study participants, that influence individuals living with HIV in their decision to initiate HIV care

#### **Assumptions and Definitions:**

**Assumptions:** The investigator conducted the study with the following assumptions:

- 1) The initiation of care is beneficial and has the potential to improve quality of life and increase life sustainability in individuals living with HIV;
- 2) The use of in-depth interviews and procedures prescribed in the grounded theory research method will successfully elicit data that can be used to explain the psychosocial process of care initiation by people living with HIV; and
- 3) Participants respond to questions honestly and will provide accurate accounts of their own life experiences;

**Definitions:** The following definitions were applied throughout the investigation:

- 1) *HIV-positive*: The investigator defines positive serostatus as the receipt of a positive antibody response to a preliminary enzyme immunoassay (EIA) and/or a confirmatory Western Blot HIV test

2) *Care Initiation*: The investigator defines care initiation as the action taken by individuals to start HIV care within a healthcare facility by connecting with an HIV care provider following a positive HIV test result.

## CHAPTER 2: REVIEW OF THE LITERATURE

The aim of the study is to examine the psychosocial factors that influence care initiation in individuals diagnosed with Human Immunodeficiency Virus (HIV). A thorough understanding of the current state of the science is crucial to providing a foundation and justification to the study.

### Overview of the Literature Review

An extensive review of current literature was conducted using the University of Cincinnati Health Sciences Library database. The author used a variety of electronic databases to obtain relevant literature including but not limited to: CINHAL, ERIC, PsycInfo, The Cochrane Collaborative, and PubMed. The author also used a literature search engine through the Health Sciences Library that pulled articles from over 1,000 peer-reviewed scientific publications from various disciplines. Finally, the author used resources published by global, national, and local health authorities to obtain the most recent HIV data presently available. Key words and Boolean phrases used in the literature search included: *Human Immunodeficiency Virus, HIV, HIV treatment guidelines, HIV treatment readiness, HIV treatment-seeking, HIV treatment Qualitative, HIV treatment Quantitative, HIV grounded theory, HIV psychosocial factors, HIV care initiation, HIV treatment adherence, HIV Care, HIV Care Initiation, HIV Care Behavior, and HIV treatment theory*. Key words and Boolean phrases were used in various combinations to ensure that a thorough search of the literature was conducted. Finally, the author reviewed the reference lists within obtained resources to ensure that all relevant literature was acquired.

The present literature review was inclusive of articles written in the English language. No parameter on publication date was set to ensure rigor in the literature search. However, all reports from health authorities were verified to be the most recent available data from each

resource. A total of 173 resources were reviewed including 20 reports from health authorities and 153 peer-reviewed publications.

The review of the literature will provide:

- 1) An overview of the HIV illness, including discussion of the HIV microorganism, HIV transmission, the HIV lifecycle, and the HIV pathophysiology and disease process;
- 2) A current epidemiological profile of HIV, including global, national, state, and local statistics (United States, Ohio, and Hamilton County respectively), as well as a description of population-specific characteristics at each level, and finally, a discussion of social determinants of health using HIV as a model case;
- 3) An overview of biomedical HIV treatments, including a historical sketch of the evolution of HIV treatment, currently used medications for the treatment of HIV, current HIV treatment recommendations from the World Health Organization (WHO), and a report of current global treatment goals and progress
- 4) A description of the HIV Care Continuum from Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA), current US treatment statistics, and recommendations for treatment-related research in HIV
- 5) A thorough discussion of psychosocial inquiry related to HIV treatment, including theoretical frameworks that have been used in HIV research, and peer-reviewed research on psychosocial factors related to HIV treatment, a brief discussion of grounded theory studies examining HIV-specific psychosocial processes, and a discussion of the current state of the science using the HIV Care Continuum as a framework
- 6) A conclusion and discussion of how the study addresses the gap in current knowledge



## HIV: An Overview

This section will provide a parsimonious overview of the HIV illness, including brief descriptions of the HIV microorganism, HIV Transmission, the HIV lifecycle, and HIV pathophysiology and disease process.

### **The HIV Microorganism:**

HIV is a virulent microorganism that specifically targets the cells of the human immune system. HIV is a spherical-shaped virus only 1/10,000<sup>th</sup> of a millimeter in diameter, and is a member of the family *Retroviridae* (Retrovirus) (DHHS, 2013g; Stine, 2012). The defining features of retroviruses are the single-stranded ribonucleic acid (RNA) genetic material and the subsequent viral replication through the process of reverse transcription. The anatomical structure of HIV includes a *viral envelope* which is a protective shell surrounding the virus that is composed of two layers of lipid molecules. Embedded within the viral envelope are approximately 72 copies of a complex HIV protein called the *Env protein*. These complex proteins protrude from the viral envelope and are often referred to as *spikes*. The spikes are comprised of two glycoproteins, specifically *gp41* and *gp120* (Stine, 2012).

Inside the viral envelope is a bullet-shaped viral core known as the viral *capsid*. The capsid houses two single-stranded RNA molecules that carry the genetic material of HIV. Also housed within the capsid are two molecules of *reverse transcriptase*, an enzyme that facilitates the conversion of the single stranded RNA molecules to double stranded deoxyribonucleic acid (DNA) molecules. It is the resultant HIV DNA that becomes integrated into a host cell's genetic information(DHHS, 2013g; Stine, 2012).

## HIV Transmission

HIV is transmitted from person to person through the exchange of specific body fluids from which HIV is able to infiltrate host immune cells. HIV can be spread through the exchange of blood, semen, pre-seminal fluid, breast milk, vaginal fluid, and rectal mucous (DHHS, 2013g; Stine, 2012). Table 1 provides an overview of the various modes of HIV transmission, the potential body fluid exposures associated with each mode of transmission, and the mechanism of transmission associated with each mode of transmission.

Table 1: Modes of HIV Transmission (DHHS, 2013d)

Mode of Transmission	Body Fluid Exposure	Mechanism of Transmission
Sexual Contact	Semen Pre-seminal Fluid Vaginal Fluid Rectal Mucous	Microscopic tearing in the lining of the vagina, vulva, penis, rectum, or mouth during sex permit the exchange of fluid
Pregnancy, Childbirth, and Breastfeeding	Blood Amniotic Fluid Breast Milk	During pregnancy/childbirth process and during breastfeeding after pregnancy permit the exchange of infected fluid from mother to child
Intravenous (injection) drug use	Blood	Sharing of needles containing infected blood permits the exchange of infected blood from one person to another
Blood Transfusion and Organ Transplant	Blood	Very rare due to screening requirements, but can permit the exchange of virus
Occupational Exposure	Blood Amniotic Fluid Cerebrospinal Fluid Synovial Fluid	Needle sticks, open cuts/sores, and splashing into mucosa allow viral transmission from infected patients to healthcare workers

## HIV Lifecycle

This section will present a basic overview of the HIV lifecycle. A basic understanding of the HIV lifecycle will provide a foundation for understanding the goals and functions of medical treatments prescribed to persons living with HIV.

HIV targets human immune cells, specifically lymphocytes carrying the *Cluster Differentiating Protein or Antigen Number 4* (CD4, hereafter abbreviated as CD4+). Once the virus has been transmitted and has gained access to a human host, the HIV lifecycle begins. The HIV lifecycle consists of seven stages: *Binding, Fusion, Reverse Transcription, Integration, Transcription and Translation, Assembly*, and Budding (Stine, 2012).

- 1) **Binding:** The virus makes contact with the human immune cell and forms an attachment when the spikes on the surface of the viral envelope meet CD4+ receptors on the surface of the CD4+ cell (Stine, 2012)
- 2) **Fusion:** Once binding is complete, the viral envelope of HIV and the cell membrane on the CD4+ cell fuse together, allowing HIV to enter the CD4+ cell (Stine, 2012)
- 3) **Reverse Transcription:** Once HIV has gained access to the inside of the CD4+ cell, the *reverse transcriptase* molecule is activated, and converts the single stranded viral RNA contained within HIV capsid into a double stranded viral DNA molecule (HIV RNA → HIV DNA) (Stine, 2012)
- 4) **Integration:** HIV produces another enzyme called *Integrase*, which allows the HIV to enter the nucleus of the CD4+ cell, and integrate the HIV DNA into the host cell's DNA (Stine, 2012)
- 5) **Transcription and Translation:** At this point in the lifecycle, the HIV DNA completely integrated into the human host's DNA, and uses the normal human cellular mechanism of

*transcription and translation* to continue replication and build new proteins. However, unlike the normal human cellular mechanism, these proteins form the building blocks for more HIV rather than healthy new immune cells. (Stine, 2012)

- 6) **Assembly:** Another HIV enzyme, called *Protease*, cuts the long protein chains into smaller HIV proteins. The small HIV proteins combine with HIV RNA to form a new virus within the intracellular space of the CD4+ cell (Stine, 2012)
- 7) **Budding:** The final step in the HIV lifecycle occurs when the newly formed HIV leaves the CD4+ cell by pushing out (budding) from the CD4+ cell (Stine, 2012)

The newly formed HIV leaves the CD4+ cell, and the process repeats as the newly formed HIV makes contact with another CD4+ cell.

### **HIV Pathophysiology and Disease Process:**

The completion of the HIV lifecycle immediately begins a process of rapid viral replication in the human body. Once the HIV DNA has infiltrated the host cell's DNA, the infection becomes irreversible, as replication will occur whenever the host cell replicates (Stine, 2012). HIV directly influences cell-mediated immunity (cells that attack invaders) and the production of antibodies (specific proteins that target specific invaders). CD4+ cells are crucial to the human immune system's ability to produce immune cells to kill or neutralize the invading pathogen. Over time, as the virus replicates, the number of healthy, functional CD4+ cells in the human body decreases. It is for this reason that CD4+ cell counts are used to evaluate HIV disease progression and treatment efficacy (DHHS, 2013g; Stine, 2012).

Following the initial exposure to HIV, the immune system reacts to the invader by producing HIV antibodies. At first, the antibodies are not numerous enough to be detected in the serum. However, within several weeks of infection, the number of HIV antibodies produced by

the host cells increases to a detectable number. The process of moving from a non-detectable to detectable number of HIV antibodies following initial infection is known as *seroconversion* (DHHS, 2013g; Stine, 2012). Scientists will often refer to *serostatus* in discussion of HIV infection, with *sero-positivity* indicating that an individual is infected with HIV, or more commonly, is *HIV-positive*.

Many individuals who become infected with HIV remain asymptomatic, with no clinical indicators of infection. However, estimates of up to 50% of newly infected individuals experience an acute illness known as *Primary HIV Infection*, also known as *Acute Retroviral Syndrome (ARS)* (Stine, 2012). ARS can occur as early as 2-4 weeks following exposure to HIV, and the result is severe flu-like symptoms including fever, chills, night sweats, rash, sore throat, muscle pain, fatigue, mouth ulcers, and swollen lymph nodes. ARS is an indicator of high serum virus level (aka '*viral load*'), and during this time, there is a high risk of person-to-person transmission (DHHS, 2013g; Stine, 2012).

Following the initial infection and seroconversion, HIV becomes less active in the body and the infected individual enters the *clinical latency* phase of the HIV disease process. The latency phase of the HIV disease process is quite lengthy, and can last up to 10 years (possibly longer). The delayed onset of symptoms caused by HIV has resulted in the classification of HIV as a *lentivirus* or a virus that has a long incubation period prior to significant symptoms. During the latency phase of the HIV disease process, a person may be completely unaware of their infection due to lack of symptoms, which greatly contributes to the transmission of HIV (DHHS, 2013g; Stine, 2012).

Left untreated, HIV continues to replicate over this long period of time, destroying immune system cells and diminishing the efficacy of the immune system. Healthy human beings

typically have a CD4+ cell count between 500-1,000 cells/mm<sup>3</sup>. Once the CD4+ cell count of the individual infected with HIV drops to or below 200 cells/mm<sup>3</sup>, an individual's immune system is considered in a state of compromise. No longer able to fight off invaders, the body becomes susceptible to potentially fatal opportunistic infections (CDC, 2008; DHHS, 2013g; Stine, 2012). This state of immune compromise is known as Acquired Immunodeficiency Syndrome, or AIDS (DHHS, 2013g; Stine, 2012). AIDS is officially diagnosed upon discovery of a CD4+ cell count less than 200 cells/mm<sup>3</sup> and/or the presence of an AIDS-defining opportunistic infection or malignancy (CDC, 2008). Untreated AIDS diagnoses often have poor prognoses, but even individuals with AIDS-defining criteria have been found to benefit from interventions. However, death from AIDS demonstrates the potentially fatal nature of infection with HIV. Table 2 lists current conditions that are considered AIDS-defining conditions (CDC, 2008).

Table 2: AIDS-defining Conditions; Center for Disease Control and Prevention (CDC); MMWR Recommendations and Reports, December 5, 2008: Available in Public Domain

AIDS-Defining Conditions
<ul style="list-style-type: none"> <li>• Bacterial infections, multiple or recurrent <sup>(1)</sup></li> <li>• Candidiasis of bronchi, trachea, or lungs</li> <li>• Candidiasis of esophagus<sup>(2)</sup></li> <li>• Cervical cancer, invasive<sup>(3)</sup></li> <li>• Coccidioidomycosis, disseminated or extrapulmonary</li> <li>• Cryptococcosis, extrapulmonary</li> <li>• Cryptosporidiosis, chronic intestinal (&gt;1 month's duration)</li> <li>• Cytomegalovirus disease (other than liver, spleen, or nodes), onset at age &gt;1 month</li> <li>• Cytomegalovirus retinitis (with loss of vision)<sup>(2)</sup></li> <li>• Encephalopathy, HIV related</li> <li>• Herpes simplex: chronic ulcers (&gt;1 month's duration) or bronchitis, pneumonitis, or esophagitis (onset at age &gt;1 month)</li> <li>• Histoplasmosis, disseminated or extrapulmonary</li> <li>• Isosporiasis, chronic intestinal (&gt;1 month's duration)</li> <li>• Kaposi sarcoma <sup>(2)</sup></li> <li>• Lymphoid interstitial pneumonia or pulmonary lymphoid hyperplasia complex <sup>(1)(2)</sup></li> <li>• Lymphoma, Burkitt (or equivalent term)</li> <li>• Lymphoma, immunoblastic (or equivalent term)</li> <li>• Lymphoma, primary, of brain</li> <li>• <i>Mycobacterium avium</i> complex or <i>Mycobacterium kansasii</i>, disseminated or extrapulmonary<sup>†</sup></li> <li>• <i>Mycobacterium tuberculosis</i> of any site, pulmonary, <sup>†§</sup> disseminated,<sup>†</sup> or extrapulmonary<sup>†</sup></li> <li>• <i>Mycobacterium</i>, other species or unidentified species, disseminated<sup>†</sup> or extrapulmonary<sup>†</sup></li> <li>• <i>Pneumocystis jirovecii</i> pneumonia<sup>†</sup></li> <li>• Pneumonia, recurrent<sup>†§</sup></li> <li>• Progressive multifocal leukoencephalopathy</li> <li>• <i>Salmonella</i> septicemia, recurrent</li> <li>• Toxoplasmosis of brain, onset at age &gt;1 month<sup>†</sup></li> <li>• Wasting syndrome attributed to HIV</li> </ul> <p>(1) Only among children &lt; 13 years of age            (2) Condition that might be diagnosed presumptively            (3) Only among adults and adolescents ≥ 13 years of age</p>

This section has provided an overview of the HIV illness, including discussions of the HIV microorganism, HIV transmission, the HIV lifecycle, and finally, HIV pathophysiology and the HIV disease process. Section II will provide an epidemiological profile of HIV disease.

### **Epidemiology of HIV**

The purpose of this section is to present current epidemiological statistics on HIV at the global, national, state, and local levels. Data were taken from four reports by four health

authorities (WHO, CDC, Ohio Department of Health [ODH], and The Henry J. Kaiser Foundation [KFF]). Each report represented the most recent data presently available from each resource.

### **Global HIV Statistics**

According to data from the WHO (2013), an estimated 35 million people are infected with HIV worldwide, a 5.6 million increase since 2001. The increase can be attributed to multiple factors, including population growth, increases in lifespan in people living with HIV, and continuing new infections (KFF, 2013). In 2012, there were 2.3 million new HIV infections (approximately 6,300 new infections per day) globally, a 33% decrease in annual new infections since 2001 (WHO, 2013c). Sub-Saharan Africa carries the overwhelming majority of the global HIV burden, with 71% of all infected individuals currently living in this region. South Africa is the country with the highest number of individuals living with HIV (4.3 million) in the world currently (WHO, 2013c). Table 3 depicts current global HIV incidence and prevalence by geographic region.

The majority of new infections globally were transmitted through heterosexual contact. However, modes of transmission vary in different geographic regions. Approximately one half of all people living the HIV are women (52%), which is attributed to sociocultural inequalities between men and women as well as the increased biological susceptibility to HIV infection in women (KFF, 2013; WHO, 2013c). Among adolescent and adult populations, 39% of new infections occurred in young people (defined as ages 15-24), and statistics indicate that young women are twice as likely to become infected than young men (KFF, 2013). Over 3 million children are living with HIV as of 2012 (WHO, 2013c), and 210,000 children died from AIDS in 2011 (KFF, 2013). In 2012, 260,000 new infections were diagnosed in children, 88% of which



occurred in Sub-Saharan Africa (KFF, 2013; WHO, 2013c). Table 3 provides a compilation of global incidence and prevalence by geographic region.

**Table 3: HIV Incidence and Prevalence by Geographic Region (KFF, 2013)**

<b>Region</b>	<b>Total Number of people Living with HIV (2012)</b>	<b>Total Number of New HIV Infections (2012)</b>	<b>Prevalence of HIV (Adult Data Only; 2012)</b>
<b>Sub-Saharan Africa</b>	25.0 Million (71%)	1.6 million	4.7%
<b>South/South-East Asia</b>	4 Million (11%)	270,000	0.3%
<b>Latin America</b>	1.5 Million (4%)	86,000	0.4%
<b>Eastern Europe/Central Asia</b>	1.3 Million (4%)	130,000	0.7%
<b>North America</b>	1.3 Million (4%)	48,000	0.5%
<b>Western/Central Europe</b>	860,000 (2%)	29,000	0.2%
<b>East Asia</b>	880,000 (2%)	81,000	<0.1%
<b>Middle East/North Africa</b>	260,000 (0.7%)	32,000	0.1%
<b>Caribbean</b>	250,000 (0.7%)	12,000	1.0%
<b>Oceania</b>	51,000 (0.1%)	2,100	0.2%
<b>Global Total</b>	<b>35.3 Million (100%)</b>	<b>2.3 million</b>	<b>0.8%</b>

### **United States of America HIV Statistics**

In the United States (US), approximately 1.1 million people are living with HIV, and approximately 208,000 (21%) of those individuals are unaware of their HIV status (DHHS, 2013c; Gardner et al., 2011; Stine, 2012). An estimated 49,273 new infections were reported in 2012, and 32,052 people died from AIDS in 2012 (CDC, 2013b; DHHS, 2013c; Stine, 2012).

According to 2010 CDC data on HIV risk factors, gay, bisexual, and other men who have sex with men (MSM) carry the highest HIV burden in the US. An increase from 26,700 to 29,800 new infections occurred between 2008 and 2010 (CDC, 2010) among MSM. MSM represent 4% of the male population in the US, but represent nearly 80% of the new diagnoses in

the US (CDC, 2010). Heterosexuals accounted for 25% of new infections in the US, and account for over 80% of infections among US women (CDC, 2010). According to the 2010 report, 8% of new infections were transmitted through intravenous (IV) drug use, and an estimated 182,000 IV drug users have died of AIDS since the onset of the HIV/AIDS epidemic (CDC, 2010).

African Americans carry the highest number of new diagnoses (46%) representing the largest HIV burden of any US racial/ethnic group (CDC, 2010; CDC, 2013b; CDC, 2013c; Stine, 2012). Hispanic/Latino populations represent 20% of new infections according to the most recent data, a rate that is 2.5-4.5 times that of Caucasian Americans for men and women respectively (CDC, 2010).

### **State of Ohio and Hamilton County HIV Statistics**

Ohio is ranked fourteenth in the total number of cumulative AIDS cases in the United States (CDC, 2011). In 2012, 17,087 people in Ohio were living with HIV. There were a total of 1,101 new HIV infections reported in 2012, and a total of 85 diagnoses of AIDS (Ohio Department of Health [ODH], 2013b). Hamilton County had the third highest number of HIV diagnoses of any county in Ohio in 2012, with approximately 155 new diagnoses between January and December. In addition, approximately 47 individuals were diagnosed with late-stage HIV or AIDS (ODH, 2013b).

Between 2007 and 2011, African Americans carried the highest burden of new HIV diagnoses at 51% (ODH, 2013a; ODH, 2013b). Caucasians represented 42% of new diagnoses and, in significant contrast to national statistics, Hispanics/Latinos only accounted for 4% of new infections (ODH, 2013a; ODH, 2013b). Young African American males represent the group with the greatest increases in diagnoses both in the state of Ohio and in Hamilton County (ODH, 2013a).

Half of all new diagnoses in Ohio were the result of MSM (ODH, 2013b). Thirty-five percent of new diagnoses had an exposure category of “unknown” according to the most recent Ohio data, making it difficult to accurately assess the transmission-specific statistics in the state of Ohio as a whole, as well as Hamilton County (ODH, 2013b). However, Ohio/Hamilton County data closely reflect US statistics, with MSM and African American males comprising the highest number of new infections (CDC, 2010; CDC, 2013b; CDC, 2013c; DHHS, 2013c; ODH, 2013b).

### **Background of Social Determinants of Health and HIV**

Epidemiological data provide invaluable evidence in identifying geographic and population-based characteristics of health. However, the epidemiological data alone are not sufficient to understanding causes and conditions associated with health problems. Research on social determinants of health has indicated that health disparities are often related to race/ethnicity and socioeconomic status (SES) (Adler & Ostrove, 1999; Barr, 2008; Braveman et al., 2005; Kreps, 2006; Smith, 2004; Williams, 1999; Williams, Mohammed, Leavell, & Collins, 2010). The epidemiological data on HIV presented in this work clearly illustrate the relationship between disease, race/ethnicity, and SES. The purpose of this section is to provide a brief discussion of the social determinants of health, specifically to describe the cyclical relationship between race, socioeconomic status, and health, followed by an illustration of social determinants of health using HIV as a model case.

Health disparities can be defined as inherent differences in rank, amount, or quality of health in one or more specific groups of people when compared to another/other group(s) of people (Fink, 2009). SES, which is comprised of income, employment status, and education attainment level, has been identified as a strong predictor of health disparities (Adler & Ostrove,

1999; Braveman et al., 2005; Smith, 2004; Winkleby, Jatulis, Frank, & Fortmann, 1992). Mortality and disease-specific statistics have consistently indicated that low SES is related to increased likelihood of disease, decreased lifespan and decreased quality of life (Adler & Ostrove, 1999; Braveman et al., 2005; CDC, 2013c; Smith, 2004; Winkleby et al., 1992). In contrast, individuals of high SES often enjoy greater care access, longer lifespans, and generally less likelihood of chronic disease and co-morbidity (Barr, 2008).

The relationship of SES to health has been hypothesized to be a product of low resource availability secondary to low income. The low level of resource seen in lower income communities is compounded by the decreased availability of educational opportunity in these areas (i.e. poor schools/no schools). Low levels of educational attainment lead to increased difficulty in obtaining gainful employment, resulting in individuals remaining in low-income/low-resource areas and perpetuating the cycle (Adler & Ostrove, 1999; Barr, 2008; Braveman et al., 2005; Smith, 2004; Winkleby et al., 1992). As such, individuals born into low SES families are considered to be at an inherent disadvantage in comparison to others born into high SES families, thus defining the health disparity.

Health disparities related to race/ethnicity are often closely connected to SES. In fact, there has been research to suggest that it is very difficult to separate the two (Williams, 1999; Williams et al., 2010). Individuals belonging to racial and ethnic minorities, regardless of global geographic region, often have low SES due to social oppression, discrimination and segregation (Williams, 1999). Statistics on the health of racial and ethnic minorities in the US provides a clear illustration of the increased risk for disease and mortality experienced by individuals of minority groups. African Americans, for example are at higher risk for heart disease, stroke, obesity, infant death, and HIV (CDC, 2013c) Additionally, Williams et al. (2010) discussed that

sociocultural differences related to race/ethnicity were related to decreased trust of healthcare providers, decreased sleep quality, PTSD symptoms, and increased levels of anxiety. The result is a clear health disparity in which individuals of racial and ethnic minorities have inherent health-related disadvantages when compared to those in a racial/ethnic majority.

The relationship between race/ethnicity, SES, and health is cyclical. Beginning with sociocultural factors that result in segregation of individuals (often racial/ethnic minorities) to low-income/low-resource areas, individuals get caught in a cycle of increased risk of disease and mortality and a simultaneous decrease in ability to attain higher SES (Adler & Ostrove, 1999; Barr, 2008; Braveman et al., 2005; Fink, 2009; Kreps, 2006; Smith, 2004; Wight et al., 2008; Williams, 1999; Williams et al., 2010; Winkleby et al., 1992). The low SES persists, and therefore the health disparity is able to continue.

The HIV epidemic is a model case to illustrate the cyclical relationship between race/ethnicity, SES, and health status (in the present work, *health status* is defined as the presence of HIV infection). The global epidemiological data indicate that 97% of people living with HIV are living in low to middle income countries (KFF, 2013; Stine, 2012; WHO, 2013c). Inadequate resources (a consequence of low SES) have contributed to decreases in the ability to identify, treat, and prevent HIV in these areas. Health education and health literacy in highly affected areas is lacking, leading to decreased ability to obtain and comprehend important self-care information afforded to individuals in higher SES countries. The response to the disparity has been increased efforts by global health authorities to provide education on prevention and to increase treatment and health resource availability to low and middle-income countries (Bendavid & Bhattacharya, 2009; Padian et al., 2011). The US epidemiological data presented above demonstrate that racial and ethnic minorities comprise the highest number of new

infections and have very disproportionate rates of annual infection compared to Caucasians (CDC, 2010; CDC, 2013b; CDC, 2013c).

The previous sections have provided an overview of the HIV illness and the present epidemiological profile of HIV at the global, national state, and local levels. A discussion of the social determinants of health has provided insight and explanation to the epidemiological data regarding highly affected populations. The next section will explore the solutions that are currently in place to address the extensive HIV problems previously described.

### **Biomedical Treatments for HIV**

The purpose of this section is to provide the following: a historical sketch of the evolution of HIV treatment since the beginning of the HIV epidemic, a discussion of currently used medications in the treatment of HIV and their relationship to the HIV lifecycle, a discussion of the current HIV treatment recommendations from the WHO, and a report of current global and national treatment goals.

#### **The History of HIV Treatment**

A tremendous amount of progress has been made in the development of medical treatment options for HIV since its discovery in 1981 (DHHS, 2013f). Even after scientists had discovered HIV and made the connection of HIV to AIDS, clinicians struggled to provide effective treatment to those afflicted. The result was many thousands of deaths in a short period of time, prior to the initial use of AZT in the treatment of HIV in 1986 (DHHS, 2013f; Stine, 2012). AZT was a nucleoside analog once evaluated for the treatment of cancer. AZT was found to slow the replication of HIV and became a standard treatment in HIV patients (Stine, 2012). The realization that nucleoside analogs were effective in slowing HIV replication guided medical research efforts, resulting in the creation and approval of a second antiretroviral drug, *didanosine*

(DDI) in 1991 (Stine, 2012). A further four years passed and the first protease inhibitor, *saquinavir*, was introduced in 1995. Scientists took immediate notice of the promise demonstrated by combination therapies (Stine, 2012) The year 1996 marked the birth of a strategy using three-drug combinations of agents for HIV treatment known as Highly Active Antiretroviral Therapy, hereafter referred to as ART (DHHS, 2013c; DHHS, 2013e; Stine, 2012).

### **Currently Used Medications for the Treatment of HIV**

Despite a slow start, medical advances have resulted in treatments for HIV burgeoning from a single treatment to over thirty different medications that are used in various combinations to treat HIV (Stine, 2012). The current treatments include *nucleoside reverse transcriptase inhibitors*, *non-nucleoside reverse transcriptase inhibitors*, *protease inhibitors*, *fusion inhibitors*, *entry inhibitors*, and *integrase inhibitors*. Table 4 lists each drug class, discusses each drug class's mode of action, and identifies the stage in the HIV lifecycle that the drug affects. Table 5 gives a list of currently used medications in each drug class.

ART remains the gold standard of HIV treatment and is considered the most effective weapon in the fight against the HIV disease process (Bendavid & Bhattacharya, 2009; Gardner et al., 2011; Little et al., 2002; Louie & Markowitz, 2002; Palella et al., 2003; Thorner & Rosenberg, 2003; WHO, 2013c). ART has made it possible for individuals living with HIV to maintain active, functional, healthy lives, and has been the most crucial contributor to the reclassification of HIV from a fatal malady to a chronic and manageable disease (DHHS, 2013e; Palella et al., 2003).

<b>Medication Class</b>	<b>Mode of Action</b>	Stage of HIV Lifecycle Affected
Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NTRIs)	Block the action of the Reverse Transcriptase Enzyme, thereby not allowing the conversion of HIV RNA to HIV DNA	<b>Stage 3:</b> Reverse Transcription
Non-Nucleoside Reverse Transcriptase Inhibitors	Block the action of the Reverse Transcriptase Enzyme, thereby not allowing the conversion of HIV RNA to HIV DNA	<b>Stage 3:</b> Reverse Transcription
Protease Inhibitors	Blocks the action of the HIV enzyme protease, thereby not allowing HIV to cut strands of genetic material into smaller strands, resulting in an inability to make viral copies	<b>Stage 6:</b> Assembly
Entry/Fusion Inhibitors	Block the CD4 receptor sites, thereby not allowing HIV to enter immune cells at the beginning of the HIV lifecycle	<b>Stages 1 &amp; 2:</b> Binding and Fusion
Integrase Inhibitors	Block the action of the integrase enzyme, thereby not allowing HIV DNA to integrate into human DNA within immune cells	<b>Stage 4:</b> Integration

Table 4: HIV Medication Class, Mode of Action, Stage of HIV Lifecycle Affected (DHHS, 2013e; Stine, 2012)



Table 5: Currently Available Antiretroviral Medications

<b>Medication Class</b>	<b>Currently Available Medications</b>
Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NTRIs)	Combivir, Emtriva, Epivir, Epizcom, Retrovir, Trizivir, Truvada, Videx EC, Videx, Viread, Zerit, Ziagen
Non-Nucleoside Reverse Transcriptase Inhibitors	Atripla, Edurant, Intelence, Rescriptor, Sustiva, Viramune, Viramune XR
Protease Inhibitors	Agenerase, Aptivus, Crixivan, Invirase, Kaletra, Lexiva, Norvir, Prezista, Reyataz, Viracept
Entry/Fusion Inhibitors	Selzentry, Fuzeon
Integrase Inhibitors	Isentress, Tivicay, Striblid

(DHHS, 2013e; Stine, 2012)

## **Viral Resistance to HIV Medications**

Viral resistance to HIV medication is an omnipresent concern in the discussion of HIV treatment (Little et al., 2002; Palella et al., 2003; Thorner & Rosenberg, 2003). An understanding of factors related to viral resistance to HIV medication is important to the present work because treatment guidelines and decisions are often influenced by the risk of, prevention of, or presence of viral resistance to specific drugs.

HIV replicates billions of times once it gains access to a human host (DHHS, 2013b; Stine, 2012). During step three of the HIV lifecycle, *Reverse Transcription*, the reverse transcriptase enzyme transcribes the HIV RNA to a molecule of HIV DNA (DHHS, 2013b; Stine, 2012). However, the process of HIV reverse transcription is highly imperfect, and no mechanism exists within HIV's lifecycle to correct transcription errors in genetic information (Stine, 2012). The result is the development and replication of a multitude of HIV copies with varying genetic properties (or genetic *mutations*). While currently prescribed HIV treatments are able to fight many variations of HIV, there are some genetic variations that are unaffected by HIV medication (resistant), rendering certain medications/combinations useless in those individuals (Stine, 2012).

In addition to resistance caused by the natural mutations of HIV, resistance can also occur as a result of inconsistent use of HIV medication (Little et al., 2002; Palella et al., 2003; Thorner & Rosenberg, 2003). In the event that the level of medication in the body drops (from a person not taking the medication appropriately), naturally occurring mutations (as described above) may include a virus that is resistant to the medication, allowing the virus to continue to replicate even in the presence of medication (Stine, 2012). Research has demonstrated that an estimated 95% adherence to non-boosted protease-inhibitor based regimens is necessary to

prevent resistance and maximize the efficacy of medications (Chesney, 2003). Other regimens that include drugs with long half-lives may require approximately 80% adherence to maximize efficacy and prevent resistance. Regimens to which patients can be adherent have been strongly recommended by clinicians to decrease the likelihood of resistance, such as single-tablet regimens (combinations of medication in one tablet) and once-daily dosing.

Resistance creates potentially devastating complications to medical treatment efforts, and is therefore one of many factors considered when clinicians develop treatment plans for individuals living with HIV. The following section will provide an overview of the current recommendations for medical care initiation in people living with HIV.

### **WHO Treatment Recommendations**

Since the inception of ART, the dramatic increase in treatment options that are available to individuals living with HIV has inspired widespread continued efforts to establish treatment guidelines that will best serve the diverse populations affected by HIV. Specific clinical treatment plans (i.e. specific drug combinations) are outside the scope of the present work. However, in June 2013, the WHO released a report that contained general recommendations for the initiation of ART that will be discussed in this work.

Prior to discussing specific WHO guidelines it is important to understand a current debate among scientists regarding the appropriate clinical indicators for the initiation of HIV treatment. The recommendations have gone through multiple revisions over time. Historically, the gold standard for the initiation of ART in individuals living with HIV was to initiate medical intervention when the patient's CD4+ cell count was  $<500$  cells/mm<sup>3</sup>, then  $\leq 350$  cells/mm<sup>3</sup> (DHHS, 2013a; Siegfried et al., 2010; WHO, 2013a) However, recent research has demonstrated that there are both individual and public health benefits to early initiation of ART. The benefits

of early initiation of ART include decreased likelihood of HIV transmission and decreased mortality in individuals living with HIV (DHHS, 2013a; Palella et al., 2003; Siegfried et al., 2010; Thorner & Rosenberg, 2003; WHO, 2013a).

The current guidelines for adults and adolescents  $\geq 10$  years of age are:

- Initiate ART in individuals with CD4+ cell counts  $\leq 500$  cells/mm<sup>3</sup> with priority initiation in individuals with severe or advanced HIV disease or a CD4+ cell count  $\leq 350$  cells/mm<sup>3</sup>

The guidelines also specify specific situations in which ART should be initiated *regardless of CD4+ cell count or clinical presentation*:

- If the patient has active tuberculosis
- If the patient has a hepatitis-B and requires treatment
- If the patient is pregnant and/or breastfeeding
- If the patient is the HIV-positive partner in a serodiscordant partnership, as ART has been found to decrease the risk of transmission to an uninfected partner (WHO, 2013a)

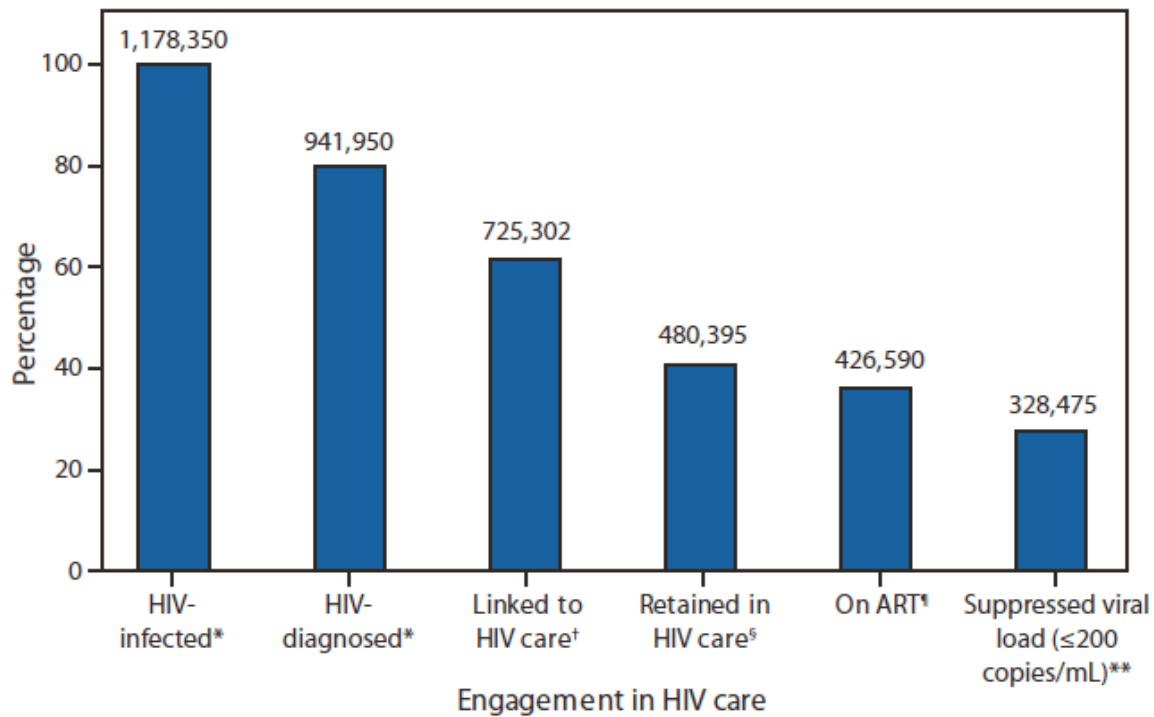
Sections I through III of the present review have provided an overview of the HIV illness, current HIV statistics, current HIV treatment options, and global HIV treatment goals. The following section will discuss the current state of HIV treatment in the US, including an introduction to the HIV Care Continuum, provide current US treatment statistics specific to treatment linkage and adherence, and will discuss treatment-related recommendations for future research.

## HIV Treatment in the United States

### The HIV Care Continuum

The HIV Care Continuum (See figure 1) is a framework that describes the various stages of HIV treatment, and is inclusive of treatment statuses ranging from complete unawareness of HIV-positive status to full engagement in HIV primary medical care (CDC, 2011; DHHS, 2011).

Figure 1: The HIV Care Continuum (CDC, 2011) Available in Public Domain



The following six stages comprise the HIV Care Continuum:

#### STAGE 1: HIV Infected

- An estimated 20% of individuals living with HIV are unaware of their HIV status, and therefore does not access care services or move through the rest of the stages of the continuum

#### STAGE 2: HIV-Diagnosed

- This stage includes individuals who have learned their HIV status by getting an HIV test and learning that they have HIV. Individuals in this stage may or may not be referred to an HIV

care provider, and if referred, may or may not keep the referral. Individuals in this stage of the continuum may be receiving other medical care but NOT HIV care.

**STAGE 3: Linked to HIV Care**

- HIV Care is initiated during this stage, and individuals may or may not remain in care. This stage includes individuals who enter care but drop out and are lost to follow-up, as well as individuals who are in and out of HIV care or are infrequent users of care.

**STAGE 4: Retained in HIV Care:**

- This stage includes individuals who attend required visits with HIV care providers to monitor disease progression and receive necessary treatments to sustain health while living with HIV.

**STAGE 5: On Antiretroviral Therapy (ART)**

- This stage includes all individuals linked with and retained in HIV care who are receiving ART, three drug combinations from at least two different medication classes to treat HIV.

**STAGE 6: Suppressed Viral Load**

- This stage includes individuals who have achieved an undetectable viral load (<200 copies/mL) through consistent retention in HIV primary care and adherence to ART regimens.

The HIV Care Continuum provides a map of the HIV healthcare process, including such milestones as diagnosis, the initial linkage with treatment, the retention in HIV care, and the accomplishment of viral suppression through successful engagement in HIV treatment (DHHS, 2011; Gardner et al., 2011). Individuals living with HIV encounter some or all of the stages in the continuum, and may move both backwards and forwards through specific stages throughout their lifetime (DHHS, 2011). The continuum is invaluable to scientists and clinicians examining HIV treatment needs and in the identification of areas in need of HIV research. The HIV Care

Continuum will be used as a framework in the present discussion of the current state of HIV treatment in the US, and in the discussion of current psychosocial care-related HIV research efforts.

### **The State of HIV Treatment in the US**

Gardner et al. (2011) used the HIV Care Continuum as a guideline to evaluate the engagement of HIV-positive Americans in primary HIV medical care. The authors completed a thorough review of multiple cohort studies and used a meta-analytic technique to compile the results of these studies to provide up-to-date statistics on the current state of HIV treatment in the US. Gardner et al. (2011) conducted an investigation in which they concluded that an astonishing 21% of HIV-infections are undiagnosed in the US. Individuals are unaware of their HIV status and therefore are often not compelled to be tested for HIV, or to seek out medical care.

Among those individuals in the US who test positive for HIV, a failure to initiate care in a timely manner is common. Approximately 75% of individuals who test positive for HIV initiate care within three to six months following diagnosis, and 80-90% seek treatment within three to five years (Gardner et al., 2011). Failure to initiate care in a timely manner can have devastating consequences if the HIV disease has significantly progressed during the delay (Little et al., 2002; Palella et al., 2003; Siegfried et al., 2010; Thorner & Rosenberg, 2003).

Among individuals in the US who initiate care, approximately 45-55% fail to remain linked with HIV care. HIV treatment requires a lifelong commitment with strict adherence to treatment regimens to achieve and maintain viral suppression, but approximately one third of all individuals in the US living with HIV adequately complete three consecutive years of treatment. Although many will make an initial link with healthcare providers, approximately 25-44% of individuals living with HIV in the US become lost to follow-up (Gardner et al., 2011).

Estimates of care engagement indicate that the majority of individuals living with HIV in the US are aware of their HIV status (79%), but of those individuals, 50% are not engaged in HIV care. Estimates as high as 67% of HIV-individuals in the US are eligible to receive ART, but 21% of eligible individuals are not engaged in care and therefore are not receiving ART (Gardner et al., 2011).

Viral suppression, defined as the presence of such low levels of HIV in the blood in response to treatment that the number is below the level of detection (currently <20 copies/mL), is the ultimate goal of ART (CDC, 2012; Stine, 2012). Suppressing HIV has been found to increase the lifespan and reduce HIV transmission. According to the DHHS (2013), of the more than one million people living with HIV in the US, only 25% are virally suppressed (CDC, 2012).

Using the HIV Care Continuum as a guide, scientists have been able to identify gaps in current knowledge and service delivery, leading to recommendations for future research and care efforts. A consistent recommendation asserted by multiple health authorities and HIV research scientists is the pronounced need to understand psychosocial factors that influence HIV treatment. The following section will discuss psychosocial research efforts related to HIV treatment, providing the current state of the science and identifying gaps in current scientific knowledge.

### **Psychosocial Research of HIV Care and Treatment Factors**

This section will provide an overview of psychosocial research efforts related to HIV. The review will include discussion of psychosocial theoretical frameworks that have been used in HIV investigations, a discussion of research on psychosocial factors associated with HIV treatment, and a brief discussion of HIV-specific psychosocial processes discovered using the



grounded theory method. The author will then use the HIV Care Continuum to frame the current state of the science and identify the gap in current knowledge.

### **General Theoretical Frameworks Related to Health Behavior**

Several health behavior theories have been used as frameworks in psychosocial research related to HIV, including the Health Belief Model [HBM] (Rosenstock, 1974), the Transtheoretical Model of Behavior Change [TTM] (McConaughy et al., 1983), the Theory of Reasoned Action [TRA] (Fishbein & Ajzen, 1975) and the Theory of Planned Behavior [TPB] (Ajzen, 1991). Each theory contains constructs that seek to describe, explain, and predict health behaviors, specifically factors that influence individual readiness to take a health-related action.

**The Health Belief Model:** The HBM is a theory that has been used in health research as a framework to explain human motivation toward health-related behaviors. The theory posits that human engagement in a health behavior is dependent on multiple dimensions of cognitive process. These dimensions are described in the six primary constructs that form the theoretical framework:

***Perceived Susceptibility:*** personal feelings regarding one's own vulnerability to a condition. High perceived susceptibility would theoretically increase the likelihood of an individual engaging in a health behavior

***Perceived Severity:*** personal feelings regarding the seriousness of a condition. High perceived severity would theoretically increase the likelihood of an individual engaging in a health behavior.

***Perceived Benefits:*** personal feelings regarding the effectiveness of a health behavior. High perceived benefit would theoretically increase the likelihood of an individual engaging in a health behavior.

***Perceived Barriers***: personal feelings regarding negative aspects and impediments associated with a health behavior. High perceived barriers would theoretically decrease the likelihood of an individual engaging in a health behavior.

***Cues to Action***: internal or external stimuli that influence the decision engage in a health behavior. Exposure to cues to action would theoretically increase the likelihood of an individual engaging in a health behavior.

***Self-Efficacy***: personal belief in one's own ability to engage in a health behavior. High perceived self-efficacy would theoretically increase the likelihood of an individual engaging in a health behavior.

(Janz & Becker, 1984; Rosenstock, 1974)

Since the 1960s, the HBM has been used as a framework by countless investigators who seek to understand the human health behaviors in relation to a wide variety of conditions, and have included research on preventative health measures, screening behaviors, sick role behaviors, and treatment behaviors (Janz & Becker, 1984). A review of 20 articles in which the HBM was used as a theoretical framework in HIV investigations was conducted for the present review.

The majority of the studies (n=10) were conducted to examine psychosocial factors related to risk reduction in HIV transmission, including condom use (Anrudh et al., 2011; Brooks, Lee, Stover, & Barkley, 2009; Coleman & Ball, 2009), HIV Education Programs, (Baghianimoghadam, Forghani, Zolghadr, Rahaei, & Khani, 2012; Orel, Stelle, Watson, & Bunner, 2010), and safe sex practices (Asare, Sharma, Bernard, Rojas-Guyler, & Wang, 2013; Baghianimoghaddam, Hossein, Razie, Zohre, & Parisa, 2010; Kabiru, Beguy, Crichton, & Zulu, 2011; Oyekale & Oyekale, 2011; Tenkorang, Rajulton, & Maticka-Tyndale, 2009). Three

investigators examined health beliefs in relation to HIV testing and counseling (Bradley, Tsui, Kidanu, & Gillespie, 2011; Shi, Kanouse, Baldwin, & Kim, 2012; Vermeer, Bos, Mbwambo, Kaaya, & Schaalma, 2009). General community-specific attitudes and knowledge about HIV were also examined (Chen & Han, 2010; Cianelli, Villegas, Gonzalez-Guarda, Kaelber, & Peragallo, 2010). Only three of the 20 studies examined HIV treatment. Two (Aspeling & van Wyk, 2008; Kip et al., 2009) examined health beliefs about adherence to medication regimens in the post-treatment-initiation time frame and the third examined health beliefs related to consistency of clinic attendance in a Tanzanian sample (Wringe et al., 2009).

**The Transtheoretical Model of Health Behavior Change:** The TTM is a theory that posits that changes in health behavior follow a six-stage process:

**Precontemplation:** No intention of change, possibly uninformed about the consequences of a present behavior

**Contemplation:** Intention to change is fostered, often measured as intention to change within the next six months; balancing of costs and benefits to change

**Preparation:** Behavior change intention more immediate, often measured as intention to change within the next month; significant development toward change taken by this point

**Action:** Changes have been made that can be seen overtly

**Maintenance:** Behavior has been changed, individual efforts to prevent relapse applied

**Termination:** Change complete, 100% self-efficacy in changed state, no doubt or temptation for relapse despite emotional changes (McConaughy et al., 1983).

In addition to the theoretical tenets, investigators using the TTM as a framework have also explored a wide variety of emotions, temptations, states of relief, and crises that occur as an individual progresses through change (Bouis et al., 2007; Gasiorowicz et al., 2005; Gazabon,

Morokoff, Harlow, Ward, & Quina, 2007; Grossman et al., 2008; Hacker, Brown, Cabral, & Dodds, 2005; Huber et al., 2012; Kafaar, Kagee, Lesch, & Swartz, 2007; Ko et al., 2010; Leonard, Markham, Bui, Shegog, & Paul, 2010; Longmire-Avital, Golub, & Parsons, 2010; MacNair-Semands, Cody, & Simono, 1997; McConnaughy et al., 1983; Naar-King, Kolmodin, Parsons, Murphy, & Atn 004 Protocol Team, 2010; S. Naar-King et al., 2008; Naar-King et al., 2006; Naar-King et al., 2006; Patten, Vollman, & Thurston, 2000; Riley, Toth, & Fava, 2000; Stevens, 1996). The theory has been used in the health sciences primarily to describe psychosocial factors that influence efforts to engage in healthy behaviors (McConnaughy et al., 1983).

A total of 18 HIV-specific articles in which the TTM was used as a theoretical framework were reviewed. The literature included investigations related to sexual transmission risk reduction (Gasiorowicz et al., 2005; Gazabon et al., 2007; Grossman et al., 2008; Hacker et al., 2005; Ko et al., 2010; Leonard et al., 2010; MacNair-Semands et al., 1997; Naar-King et al., 2010; Naar-King et al., 2008; Naar-King et al., 2006; Naar-King et al., 2006; Patten et al., 2000; Stevens, 1996). One group of investigators examined participation in HIV vaccine trials as a health behavior (Kafaar et al., 2007) and one group of investigators examined smoking cessation efforts among people living with HIV (Huber et al., 2012). Only two studies were focused on psychosocial factors related to HIV treatment. Bouis et al. (2007) used the TMM in an investigation of a treatment program catered to individuals with HIV, substance abuse, and mental illness. Longmire-Avital, Golub, and Parsons (2010) used the TMM to investigate the effect of self-reevaluation on medication adherence in HIV-positive alcoholics.

**Theory of Reasoned Action and Theory of Planned Behavior:** The TRA and TPB are theoretical frameworks that are closely related, as the TPB became an extension of the TRA

(Ajzen, 1991). The TRA posits that behavior changes (including health behaviors) are a function of human intention. The theory suggests that intention to perform a specific behavior is a direct product of attitude toward a behavior. As such, intention and attitude form the level of readiness to perform a behavior. In addition to attitude, subjective norms (i.e. perception of how loved ones feel about a behavior) influence the likelihood for engagement in a behavior (Fishbein & Ajzen, 1975). The TPB was developed as an extension of the TRA because the TRA assumed that behaviors could be manifested by one's own volition in all cases. The addition of perceived levels of control (by the TPB) allowed the theory to then be inclusive of behaviors requiring specific skills, circumstances, and the cooperation of others for successful execution. Ultimately, behavioral, normative, and control beliefs influence intention which then leads to the performance of a behavior (Ajzen, 1991).

A total of 38 HIV-specific investigations using the TRA and/or the TPB as a theoretical framework were reviewed. The overwhelming majority of the studies (n=28) focused on HIV prevention and risk reduction behaviors (Abraham & Sheeran, 1994; Albarracín, Johnson, Fishbein, & Muellerleile, 2001; Blank & Hennessy, 2012; Bryan, Ruiz, & O'Neill, 2003; Fishbein & Ajzen, 1975; William A. Fisher, 1997; W. A. Fisher, Fisher, & Rye, 1995; Gebreyesus Hadera, Boer, & Kuiper, 2007; Gredig, Nideroest, & Parpan-Blaser, 2006; Gu et al., 2009; Hogben, Lawrence, Hennessy, & Eldridge, 2003; Jemmott, 2012; Jemmott et al., 2007; Martín, Martínez, & Rojas, 2011; Matthew & Manoj, 2010; Mausbach, Semple, Strathdee, & Patterson, 2009; Ortega, Huang, & Prado, 2012; Paula, Matthew, Nina, Carlos del, & Mark, 2007; Rye, Fisher, & Fisher, 2001; Schultz, Butler, McKernan, & Boelsen, 2001; Serovich & Greene, 1997; Sheeran & Taylor, 1999; Wise, Goggin, Gerkovich, Metcalf, & Kennedy, 2006; Wood, 2010). Six studies focused on factors related to HIV testing (Abamecha, Godesso, &

Girma, 2013; Fogg & Mawn, 2010; Gredig et al., 2006; Kakoko, Åstrøm, Lugoe, & Lie, 2006; Mirkuzie, Sisay, Moland, & Astrøm, 2011; Shemsedin & Jemal, 2010). Two studies focused on factors associated with living with the HIV illness including one study on employment seeking among people living with HIV (Kenneth, Scott, & Glenn, 2004) and one study examining HIV status disclosure (Ben Natan, Zeltzer, & Melnikov, 2011).

### **Synthesis of the Theoretically-Framed Literature**

The results of the literature review of studies that used the aforementioned theoretical frameworks indicate that the majority of current research has been conducted with focus on psychosocial factors that influence HIV prevention and risk reduction, HIV counseling and screening efforts, and HIV treatment adherence.

**HIV Prevention and Risk Reduction:** The majority of the theoretically-framed investigations reviewed (n=42) were conducted to explore psychosocial factors influencing HIV prevention and risk reduction. The results of these investigations indicate that engagement in preventative and risk-reducing behaviors is influenced by several psychosocial factors. Individuals are more likely to engage in preventative and risk-reducing behaviors when they are knowledgeable about the HIV disease process, specifically how HIV is transmitted (Baghianimoghaddam et al., 2010; Coleman & Ball, 2009; Jemmott, 2012; MacNair-Semands et al., 1997; Orel et al., 2010; Oyekale & Oyekale, 2011).

In addition to knowledge of the HIV illness, engagement in preventative and risk-reducing behaviors is influenced by individual perception. People are more likely to engage in preventative behaviors when they believe HIV is an illness that they are vulnerable to and that having HIV will lead to serious health consequences (Anrudh et al., 2011; Asare et al., 2013; Brooks et al., 2009; Grossman et al., 2008; Shemsedin & Jemal, 2010; Stevens, 1996).

The results also provide evidence that individuals are highly influenced to engage in preventative and risk-reducing behaviors by people in their lives. Individuals are more likely to engage in health behaviors, such as preventative health behaviors, when clinicians, friends, family members, and other peers encourage them to do so (Blank & Hennessy, 2012; Fogg & Mawn, 2010; Fogg, Mawn, & Porell, 2011; Gasiorowicz et al., 2005; Hacker et al., 2005; Hogben et al., 2003; J. B. Jemmott, 2012; Matthew & Manoj, 2010; Mausbach et al., 2009; Mirkuzie et al., 2011; Ortega et al., 2012; Rye et al., 2001; Sheeran & Taylor, 1999; Tenkorang et al., 2009).

Finally, the likelihood of individual engagement in preventative and risk-reducing behavior increases when individuals believe that they are able to engage in these behaviors and that engagement will benefit their health (Abraham & Sheeran, 1994; Bryan et al., 2003; Eshrati et al., 2008; W. A. Fisher et al., 1995; Fogg & Mawn, 2010; Fogg et al., 2011; Gazabon et al., 2007; Gredig et al., 2006; Grossman et al., 2008; Gu et al., 2009; J. B. Jemmott, 2012; r. J. B. Jemmott et al., 2007; Judith et al., 1998; Leonard et al., 2010; Longmire-Avital et al., 2010; Matthew & Manoj, 2010; Mausbach et al., 2009; Mirkuzie et al., 2011; Sylvie Naar-King et al., 2006; Rye et al., 2001; Serovich & Greene, 1997; Sheeran & Taylor, 1999; Uhrig, Davis, Rupert, & Frazee, 2012; Wise et al., 2006).

**HIV Education and Screening:** Participation in HIV education and screening behaviors was another topic that researchers have investigated using the aforementioned theoretical frameworks. The results of these studies indicate that individuals are more likely to participate in HIV education and screening when they have knowledge of the HIV disease process and believe that they are at risk for HIV transmission (Baghianimoghadam et al., 2012). Kakoko, Astrom, Lugoe, and Lie (2006) conducted an investigation and discovered that in addition to perceived

risk of HIV transmission, positive attitudes toward HIV screening and perceived increased control over one's health increased the likelihood of engaging in HIV testing behaviors. The perception that one is at risk for HIV has also been found to increase the likelihood of participation in HIV testing behaviors (Bradley et al., 2011; Kabiru et al., 2011; Shi et al., 2012; Vermeer et al., 2009).

Finally, peer influences also influence participation in HIV education and screening. Individuals are more likely to seek counseling and get tested for HIV when friends and peers encourage participation in education and screening behaviors and/or engage in education and screening behaviors themselves (Abamecha et al., 2013; Baghianimoghadam et al., 2012; Gebreyesus Hadera et al., 2007). Baghianimoghadam et al. (2012) conducted an investigation exploring the use of peer education among high school students, producing results that indicated that peer education was more effective than professional counseling in increasing the perceived benefit of screening behaviors.

**HIV Treatment Adherence:** Relatively few studies in the review of theoretically-framed investigations examined HIV treatment. Those researchers who investigated psychosocial factors influencing HIV treatment primarily focused on the phenomenon of treatment adherence.

Education on the HIV disease and higher levels of knowledge increase the likelihood that individuals will adhere to treatment regimens (Aspeling & van Wyk, 2008; Bouis et al., 2007; Kip et al., 2009; Wringe et al., 2009). Bouis et al. (2007) conducted an investigation in which a theoretically-framed educational intervention was presented to a sample of individuals addicted to drugs who were HIV-positive. The results of the study indicated that educational interventions designed to increase knowledge result in positive psychobehavioral changes including an increased readiness to cooperate with the treatment process (Bouis et al., 2007).



As seen in multiple studies, peer and family encouragement has been found to increase the likelihood of individuals with HIV adhering to treatment regimens. Vissman et al. (2011) conducted an investigation to determine factors that influence HIV treatment adherence. The results of their investigation indicate that family members, partners, and spouses were influential in treatment adherence through expressions of constant encouragement and support (Vissman et al., 2011).

Finally, Wringe et al. (2009) conducted an investigation aimed at determining factors that influence treatment adherence. The results of the investigation demonstrated that individual perceptions of disease severity influenced treatment adherence. These results suggest that individuals who perceive the HIV disease as serious and consider themselves vulnerable to symptoms are likely to adhere to their treatment regimens when compared with individuals who do not perceive the HIV disease as serious.

The theoretically-framed investigations provide invaluable evidence to the current state of the science of HIV-specific psychosocial research. However, few investigations focused on psychosocial factors related to initiation of HIV care. Investigations framed by the aforementioned theoretical frameworks are insufficient in providing evidence about the psychosocial factors that influence HIV care initiation. As such, a continued search of the literature was conducted to obtain non-theoretically-framed studies that specifically examined psychosocial factors related to HIV treatment.

### **Psychosocial Factors Associated with HIV Treatment**

Despite medical advances in HIV treatment, health authorities and researchers agree that understanding of psychosocial factors that influence HIV treatment is crucial to the provision of HIV care and for successful outcomes in HIV treatment (WHO, 2013). The present review of the

literature included studies in which researchers examined psychosocial factors such as personal perceptions of HIV treatment, and readiness to pursue HIV treatment.

Research on perceptions of HIV treatment included two studies, both examining the perceptions of patients linked with care providers and on ART. Meystre-Agustoni et al. (2000) conducted a qualitative inquiry to explore patient perceptions about antiretroviral therapies. Based on the findings, the researchers were able to provide strong insight into the complexities of ART. The interviewed participants reported struggles with the day-to-day practicalities of their treatments, concerns about the way their treatments would affect their future opportunities, worry about long-term effects of their medications, and concern and confusion about the constant changes made to their regimens.

Morgenstern, Grimes, and Grimes (2002) conducted an investigation that demonstrated the influence of negative emotions on care initiation timing in people living with HIV. The results indicate that strong negative emotions (i.e. anxiety, anger, depression) are associated with HIV diagnoses, and that higher levels of these emotions were strongly correlated with delayed entry into HIV care (Morgenstern, Grimes, & Grimes, 2002).

Enriquez, Lackey, O'Connor and McKinsey (2004) conducted a phenomenological inquiry to examine the experiences of individuals who had difficulty consistently engaging in HIV treatment. The study revealed that attitudes toward medication and toward HIV care were strong influences on the decisions of participants to become more consistent in their treatment (Enriquez et al., 2004; Enriquez & McKinsey, 2004). The results of the study coupled with the aforementioned benefits of ART provide evidence that patient perceptions and attitudes toward treatment options are as crucial to health in people living with HIV as the medication itself.

A very important psychosocial concept discussed in the literature related to HIV treatment is the concept of readiness. Fowler (1998) completed a concept analysis to explore readiness, using HIV as a model case. The analysis provides an in-depth definition of the concept of readiness as a psychological phenomenon in which an individual is prepared to undergo a major life change. Readiness is psychologically achieved when an individual is aware of benefits and barriers to a decision or change and has accepted the responsibility of taking the action necessary to execute the change. The result is a psychological state of personal control, resulting in the execution of actions toward a life change (Fowler, 1998).

Readiness has been examined in various ways in the literature. Significant delays and complete refusal to seek treatment have been strongly associated with a lack of treatment readiness (Balfour et al., 2006; Gebrekristos, Mlisana, & Karim, 2005; McCusker et al., 1994; Nordqvist et al., 2006; Raveis, Siegel, & Gorey, 1998). The results of several studies indicate that lack of readiness is influenced by negative emotions upon receipt of HIV diagnosis, fear of adverse medication side effects, and feelings of not being prepared for strict HIV medication regimens (Balfour et al., 2006; Gebrekristos et al., 2005; McCusker et al., 1994; Nordqvist et al., 2006; Raveis et al., 1998).

Consistent with many of the investigations in the present review, the majority of the literature on treatment readiness focused on readiness in relation to *medication adherence* in populations of people linked with care and on ART. Multiple studies conducted with an aim of quantifying and measuring readiness using instruments concluded that readiness was predictive of greater adherence to ART and that low readiness scores were related to increased likelihood for resistance and medical complications in HIV treatment (Balfour et al., 2007; Fleury, 1994; Södergård et al., 2007). Researchers in one study investigated the readiness of patients to adhere

to medication following periods of inconsistent treatment (Enriquez et al., 2004), and another discussed readiness to undertake rescue therapy in patients that experienced treatment failure (Alfonso, Toulson, Bermbach, Erskine, & Montaner, 2009). Finally, researchers in another study provided a mathematical model using readiness and adherence as latent concepts in a secondary analysis of cross-sectional data provided by 828 people living with HIV. The results provide quantitative evidence that it is crucial to examine readiness as a predictor of treatment success rather than placing complete focus on adherence (Södergård et al., 2007).

Investigators in two studies examined readiness in relation to starting HIV medication regimens. Balfour et al. (2006) developed and tested a psychosocial educational intervention for newly diagnosed individuals living with HIV who had not yet started ART. The result was an increase in reported preparedness for HIV medication when compared with individuals who did not receive the educational intervention (Balfour et al., 2006). Gebrekristos, Mlisana, and Karim (2005) provide valuable insight into treatment readiness as a psychological factor that begins prior to any treatment action (i.e. following a positive test result), and define treatment as the start of drug therapy. Readiness prior to care initiation includes obtaining basic knowledge of HIV disease, gaining an understanding of treatment, and the fostering of support systems to cope with HIV-related life changes (Gebrekristos et al., 2005).

The literature examining psychosocial factors associated with HIV treatment has demonstrated both a valuable body of evidence and a notable gap in current knowledge. The review included studies that demonstrated the importance of psychosocial factors to the success of treatment, particularly the significant impact of the emotional experiences of individuals who are diagnosed with HIV, and the concept of treatment readiness. However, very few studies have examined the psychosocial factors that influence care initiation, and those that have addressed

care initiation provide limited detail on specific events, experiences, and processes that influence the initiation of care. The study described in this dissertation filled this gap by examining the processes that influence care initiation using the grounded theory method, which will provide rich detail and a theoretical framework.

### **HIV-Specific Grounded Theories**

The method of investigation employed in this study was the grounded theory method (see Chapter 3: Methodology). This section of the current review will provide a brief overview of how the grounded theory method has been used to investigate psychosocial processes in HIV research studies.

A total of 29 grounded theory studies were reviewed. Many studies addressed psychosocial processes that individuals living with HIV go through when adjusting to life after HIV diagnosis, including status disclosure (Relf et al., 2009; Rutledge, 2007), stigma (Ingram, 1999), disease manifestations (Gagnon & Holmes, 2012; Wilson, Hutchinson, & Holzemer, 2002), partner selection and sexual behaviors (Brooks et al., 2011; Hailemariam, Kassie, & Sisay, 2012; Mallory & Stern, 2000; Relf et al., 2009), and reproductive behaviors (Barnes & Murphy, 2009). Grounded theory has also been used to describe psychosocial processes such as reliance and hope following HIV diagnosis (De Santis, Florom-Smith, Vermeesch, Barroso, & DeLeon, 2013; Kylmä, Vehviläinen - J., & Lähdevirta, 2001), adaptation (Perrett & Biley, 2012), and HIV screening attitudes (Crozier, Chotiga, & Pfeil, 2012).

Psychosocial processes related to HIV treatment included studies focusing on patient-provider interactions (Barfod, Hecht, Rubow, & Gerstoft, 2006; Carr, 2001; Mallinson, Rajabiun, & Coleman, 2007), movement from inconsistent to consistent treatment attendance (Mallinson et al., 2005), living with side effects (De Santis & Barroso, 2011; Gagnon & Holmes, 2012; Wilson

et al., 2002), and adherence to medication (Barfod et al., 2006; Wendorf & Mosack, 2013; Wilson et al., 2002).

The psychosocial processes investigated in the HIV-specific grounded theory studies can be placed into three primary categories: screening and transmission prevention, transition into HIV-positive status, and living life HIV-positive.

**Screening and Transmission Prevention:** Several studies were conducted with focus on HIV screening and transmission prevention (Brooks et al., 2011; Crozier et al., 2012; Lotfi, Tehrani, Yaghmaei, & Hajizadeh, 2012). The results of these studies demonstrate that both HIV-negative and people living with HIV undergo a process of self-risk evaluation when making decisions related to getting screened for or preventing the transmission of HIV. Decisions to engage in screening and transmission prevention behaviors are motivated by self-protection, decreased levels of anxiety, and perceptions of benefit to self and others (Brooks et al., 2011; Crozier et al., 2012; Lotfi et al., 2012). Brooks et al. (2011), for example, conducted semi-structured interviews with 25 gay and bisexual sero-discordant couples with an aim of identifying factors that facilitate or impede the adoption or pre-exposure prophylaxis. The results of the investigation indicated that screening and transmission-prevention measures are motivated by self-protection, and the benefit of having unprotected sex with their partner without fear of viral transmission.

**Transition into HIV-positive Status:** Several studies were conducted with focus on psychosocial processes that individuals living with HIV undergo when transitioning from HIV-negative to HIV-positive status. The results of these studies demonstrate that the adjustment to HIV-positive status can be a turbulent and complex experience, with confrontation of mortality, changes in interpersonal relationships, redefining normalcy, encountering hatred and stigma, and

mastering new skills to maintain health (De Santis & Barroso, 2011; De Santis et al., 2013; Klunklin & Greenwood, 2005; Kylmä et al., 2001; Mallinson et al., 2005; Perrett & Biley, 2012; Poteat, German, & Kerrigan, 2013). The results indicate that transitioning from HIV-negative to HIV-positive status often requires the progression through a host of challenges, and those who successfully progress through the challenges have higher quality of life. Perrett and Biley (2012) conducted semi-structured interviews with eight men living with HIV from a clinic to explore the process of adaptation that individuals go through after receiving an HIV diagnosis. The conclusion indicated that individuals diagnosed with HIV encounter uncertainty about the changes that are ahead of them when they learn their diagnosis. Participants successfully adapted as they developed a sense of hope for their futures and began to live life as they did prior to their diagnosis (living 'as-was'; Perrett & Biley, 2012).

**Living Life HIV-Positive:** The majority of the grounded theory investigations were conducted to explore a wide variety of psychosocial processes that individuals living with HIV go through in their lives following their HIV diagnosis. These processes include facing difficulties associated with a changing state of health such as bodily changes, and coping with illness symptoms and harsh medication side-effects (Barfod et al., 2006; Barnes & Murphy, 2009; del Rosario Valdez, 2001; Gagnon & Holmes, 2012; Gaskins & Brown, 1997; Hailemariam et al., 2012; Madiba, 2012; Madiba & Mokwena, 2012; Mallinson et al., 2007; Oturu, 2011; Relf et al., 2009; Rutledge, 2007; Sauka & Lie, 2000; Wendorf & Mosack, 2013; Wilson et al., 2002).

The results of these studies provide evidence that individuals with HIV encounter progressive and often difficult changes to their bodies, and are often confused by the sources of new symptoms (i.e. disease-related or medication-related), and must learn to cope and adapt with

undesired consequences of the HIV illness and HIV treatment. The results of unexpected and undesirable changes, particularly those caused by new medication regimens, lead some individuals living with HIV to a place of confusion about the benefit of medications intended to treat their disease. The confusion is compounded when an individual is asymptomatic without medication, but biomarkers such as CD4+ cell count suggest a need for medication. Individuals who can successfully adapt to adverse health events related to HIV and its treatment are better able to persevere and continue treatment. Wilson et al. (2002) conducted in-depth interviews with 66 individuals living with HIV. The participants reported difficulty ascertaining whether symptoms they were having were the result of medication side-effects or the advancement of their disease. In addition, when asymptomatic, participants reported lack of understanding of biomarkers of disease that did not match the way they felt (Wilson et al., 2002).

The grounded theory studies examined in the present review provide an in-depth perspective of the many challenges faced by individuals diagnosed with HIV. In the following section, the author will examine the placement of the psychosocial investigations in the present review on the HIV Care Continuum.

### **Psychosocial HIV Research and the HIV Care Continuum**

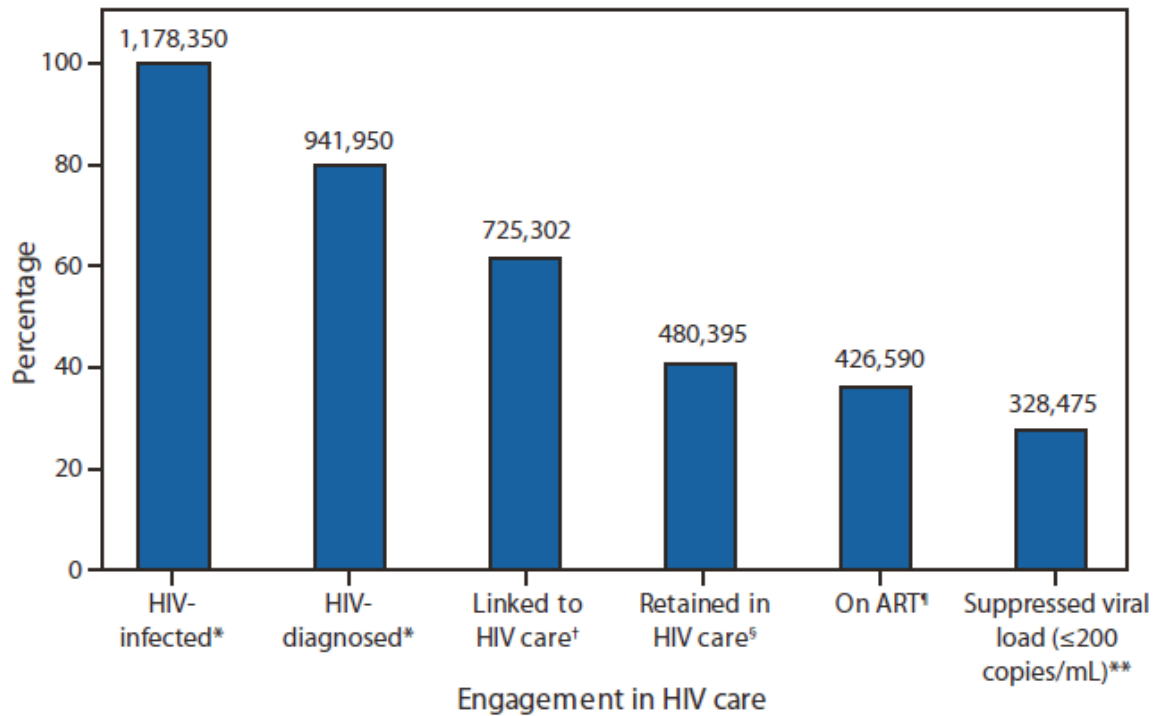
The HIV Care Continuum provides an ideal framework for describing the current state of HIV-specific psychosocial research. In this section the author will categorically summarize the psychosocial research in the present review and identify gaps in current knowledge based on the HIV Care Continuum.

Prior to the discussion of psychosocial research and the HIV Care Continuum, it is important to first reiterate the purpose of the HIV Care Continuum and the populations to which the continuum is applicable. The HIV Care Continuum was developed as a model for the



identification of HIV treatment status in people living with HIV (DHHS, 2011). Individuals with HIV fall into one of six stages on the continuum, ranging from the receipt of positive sero-status but unaware of status to achievement of undetectable viral load through full engagement in HIV primary care (CDC, 2011; DHHS, 2011).

Figure 2: The HIV Care Continuum (CDC, 2011) Available in Public Domain



Many of the psychosocial investigations reviewed by the author were completed with samples of individuals who are not living with HIV, specifically the investigations of HIV prevention, HIV education, and HIV risk reduction (Abraham & Sheeran, 1994; Bryan et al., 2003; Eshrati et al., 2008; W. A. Fisher et al., 1995; Fogg & Mawn, 2010; Fogg et al., 2011; Gazabon et al., 2007; Gredig et al., 2006; Grossman et al., 2008; Gu et al., 2009; Jemmott, 2012; Jemmott et al., 2007; Judith et al., 1998; Leonard et al., 2010; Longmire-Avital et al., 2010; Matthew & Manoj, 2010; Mausbach et al., 2009; Mirkuzie et al., 2011; Naar-King et al., 2006; Rye et al., 2001; Serovich & Greene, 1997; Sheeran & Taylor, 1999; Uhrig et al., 2012; Wise et al., 2006). For the purpose of this section, these investigations are considered “pre-continuum”,

as the investigations included content relevant to participants that would not fit into any stage of the HIV Care Continuum. The studies discussed in this section will only include psychosocial studies conducted with individuals living with HIV.

The psychosocial investigations with participants with HIV included the following categories:

- theoretically-framed studies on HIV treatment adherence
- investigations about readiness to adhere to medications after various treatment attempts or treatment failure
- general readiness to adhere to HIV medication regimens following care initiation
- HIV-specific provider-patient interaction studies
- pre-care initiation psychological factors influencing treatment readiness
- grounded theory investigations about psychosocial processes experienced by people living with HIV

The majority of the studies reviewed were conducted with samples of individuals living with HIV who had initiated care and were moderately to completely engaged in HIV treatment, corresponding to Stages 4 through 6 of the HIV Care Continuum (CDC, 2011; DHHS, 2011).

Other studies included participants who had discussions about initiating HIV treatment but had not started on medication (Bloch et al., 2010; Gebrekristos et al., 2005) and/or exhibited delays in treatment entry after making contact with a healthcare provider (Gold, Hinchey, & Batrouney, 2000), corresponding to Stages 4 and 5 of the HIV Care Continuum (CDC, 2011; DHHS, 2011). Finally, the remaining studies were conducted to investigate phenomena unrelated to HIV treatment among persons living with HIV (Otoru, 2011; Relf et

al., 2009; Rutledge, 2007; Sauka & Lie, 2000), making it difficult to assess placement on the HIV care continuum.

The cumulative results indicate that the majority of psychosocial research has been conducted with an aim of investigating phenomena related to Stages 4 through 6 of the HIV Care Continuum. These studies investigate phenomena related to HIV treatment following initial contact with a healthcare provider, including adherence, medication experience, and provider-patient dynamics.

The scant amount of research pertaining to Stages 1 through 3 of the HIV Care Continuum presents a notable knowledge gap in the current state of the science. While researchers have investigated psychosocial factors that influence HIV care initiation (see manuscript 1), no studies have investigated the psychosocial process of HIV care initiation. The study was conducted to address this gap in knowledge by completing a grounded theory investigation about the process of HIV care initiation.

### **Conclusion**

HIV is a virulent retrovirus that is transmitted from person to person through a variety of transmission routes, including sexual contact, during pregnancy/childbirth, IV drug use, blood transfusion/organ transplant, and through occupational exposure (DHHS, 2013d, 2013g). Left untreated, HIV replication depletes the CD4+ component of the immune system, which can eventually result in a state of profound immune system compromise known as AIDS (DHHS, 2013d, 2013g; Stine, 2012).

HIV affects approximately 35 million people worldwide, with the majority of the global burden affecting resource-poor countries, specifically those in regions of Sub-Saharan Africa (CDC, 2013b; Henry J. Keiser Foundation (KFF), 2013; WHO, 2013c). In the United States, an

estimated 1.1 million people are infected with HIV, and an estimated 208,000 individuals are unaware that they have HIV (Bendavid & Bhattacharya, 2009; CDC, 2010; DHHS, 2013c; Gardner et al., 2011). MSM carry the highest burden of infection in the US, and recent data indicate that African Americans are the group with the largest rate of new infections annually, which is highly disproportionate to the number of African Americans in the US (CDC, 2010, 2013b, 2013c; DHHS, 2013c; Gardner et al., 2011; Hall, Frazier, Rhodes, & et al., 2013; Stine, 2012). The state of Ohio ranks fourteenth in the number of cumulative AIDS cases in the US, and Hamilton County has the third highest rate of new HIV diagnoses in the state. Demographic characteristics in Ohio and Hamilton County closely mirror US statistics, with MSM and African Americans disproportionately affected by HIV (CDC, 2010; ODH, 2013a, 2013b).

Treatments for HIV have burgeoned in the last 30 years, from one pharmaceutical agent to over 30 medications designed to treat HIV infection throughout the lifespan (DHHS, 2013e; Stine, 2012). ART, defined as combination antiretroviral treatment targeting HIV at multiple lifecycle stages, is the gold standard for HIV treatment and is considered the most effective means of combatting HIV infection (CDC, 2012; DHHS, 2011; Gardner et al., 2011; Louie & Markowitz, 2002; Siegfried et al., 2010). However, individuals on ART must strictly adhere to their regimens to avoid the development of viral resistance to HIV medications, a circumstance that can render even the most effective therapies futile (Palella et al., 2003). Although there is controversy over the optimal start time for HIV medication (DHHS, 2013a; Gardner et al., 2011; Little et al., 2002; Louie & Markowitz, 2002; Palella et al., 2003; Siegfried et al., 2010; Thorner & Rosenberg, 2003), health authorities currently recommend that people living with HIV immediately link with a care provider and begin ART when their CD4+ cell count is  $\leq 500$

cells/mm<sup>3</sup> (DHHS, 2013a; WHO, 2013a). The guidelines have presented the opportunity for larger numbers of people living with HIV to initiate medical treatment (WHO, 2013a).

In the United States, an estimated 20% of individuals living with HIV are unaware of their HIV status (Gardner et al., 2011), and of those that are aware, 50% are not fully engaged in HIV care. Failure to initiate HIV treatment in a timely manner is common, and can result in profound disease progression depending on the length of treatment delay (Gardner et al., 2011). These data present a need to understand human factors related to HIV and its treatment.

Psychosocial HIV research has included a wide variety of investigations largely framed by human behavioral theories. The majority of these studies have been conducted to investigate HIV prevention, risk reduction and HIV education and screening (Abraham & Sheeran, 1994; Bryan et al., 2003; Eshrati et al., 2008; Fisher et al., 1995; Fogg & Mawn, 2010; Fogg et al., 2011; Gazabon et al., 2007; Gredig et al., 2006; Grossman et al., 2008; Gu et al., 2009; Jemmott, 2012; Jemmott et al., 2007; Leonard et al., 2010; Longmire-Avital et al., 2010; Matthew & Manoj, 2010; Mausbach et al., 2009; Mirkuzie et al., 2011; Sylvie Naar-King et al., 2006; Rye et al., 2001; Serovich & Greene, 1997; Sheeran & Taylor, 1999; Uhrig, Davis, Rupert, & Frazee, 2012; Wise et al., 2006). Far fewer investigators have conducted studies in which they examine psychosocial factors related to HIV treatment. The majority of investigations conducted with a focus on HIV treatment have primarily focused on HIV treatment adherence, specifically factors that predict or increase the likelihood of HIV treatment adherence in populations of individuals that have linked with HIV care providers (Aspeling & van Wyk, 2008; Bouis et al., 2007; Kip et al., 2009; Wringe et al., 2009).

Grounded theory is an ideal method in the investigation of complex psychosocial processes (Glaser & Strauss, 1967). A group of HIV-specific grounded theory studies was

discussed in this review. The results indicate that many of the studies were conducted to examine phenomena that are unrelated to HIV treatment (Brooks et al., 2011; Crozier et al., 2012; De Santis & Barroso, 2011; del Rosario Valdez, 2001; Gagnon & Holmes, 2012; Hailemariam et al., 2012; Ingram, 1999; Klunklin & Greenwood, 2005; Lotfi et al., 2012; Madiba, 2012; Mallory & Stern, 2000; Oturu, 2011; Perrett & Biley, 2012; Relf et al., 2009; Rutledge, 2007; Sauka & Lie, 2000). Those grounded theory studies that did focus on HIV treatment were primarily concerned with treatment adherence and the psychosocial processes that individuals living with HIV go through while on treatment (Barfod et al., 2006; Carr, 2001; De Santis et al., 2013; Mallinson et al., 2007; Poteat et al., 2013; Wendorf & Mosack, 2013; Wilson et al., 2002).

The HIV Care Continuum was used as a framework to identify gaps in current knowledge on psychosocial research on HIV, specifically, studies focused on HIV treatment in samples of people living with HIV. The framework was used to categorize each of the studies examined in the present review. Theoretically-framed psychosocial studies on HIV and treatment-specific psychosocial HIV research have primarily focused on individuals that have linked with care providers and are receiving HIV treatment, corresponding to Stages 5-6 on the Care Continuum (CDC, 2011; DHHS, 2011).

A notable gap in current knowledge has been presented through this review of literature. No studies have been conducted that focus on exploring the psychosocial factors that influence the initiation of care by persons living with HIV. The study addressed this gap in the literature. The investigator used the grounded theory method to explore the psychosocial factors that influence the initiation of HIV treatment in a group of people living with HIV. Chapter 3 provides an overview of the methods that were used to conduct the study.

## CHAPTER 3: METHODOLOGY

The purpose of this study was to investigate the psychosocial process of care initiation by individuals living with HIV. This chapter will detail the research methods and design that were employed in the investigation and will include:

- A definition and description of the grounded theory method, including the philosophical underpinnings and history of grounded theory
- An overview of the study methods, including discussion of the sample recruited for the study, inclusion/exclusion criteria, sample size, and protection of human subjects
- Finally, the data collection, data management, and data analysis procedures employed in the study

### **Grounded Theory**

Grounded theory is a qualitative research method used to develop theory through inductive investigation of a phenomenon (Glaser & Strauss, 1967). Grounded theory is differentiated from other qualitative research methods (i.e. phenomenology, ethnography) in aim and procedure. The aim of grounded theory research is to generate a theory that provides an explanatory framework for human social processes (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1990), in contrast to other qualitative methods that aim to provide descriptive and thematic outcomes (Denzin & Lincoln, 2011).

Grounded theory is also defined by a set of unique procedures that differentiate the method from other forms of qualitative and quantitative inquiry. Grounded theory involves the simultaneous collection and analysis of data (Glaser & Strauss, 1967), in contrast to the majority of research methods that prescribe that collection and analysis of data in divided, independent phases (Denzin & Lincoln, 2011). Another defining feature of grounded theory research is the

employment of theoretical sampling. Theoretical sampling involves the selection of participants based on their ability to provide relevant data for the emerging theory as opposed to a predetermined set of participant characteristics (Draucker, Martsof, Ross, & Rusk, 2007; Glaser & Strauss, 1967).

Research providing descriptive and interpretative data on human experiences is invaluable. However, descriptive data are not sufficient in the explanation of human psychosocial processes. Grounded theory research provides a unique contribution to science by helping scientists to explore complex psychosocial processes, in particular processes in which humans encounter psychosocial problems and progress through a period of adaptation and change.

### **Philosophical Underpinning**

Grounded theory is philosophically rooted in the sociological tradition of symbolic interactionism (Glaser & Strauss, 1967). Symbolic interactionism is a theoretical perspective of human behavior comprised of three primary tenets:

- *Human beings act toward things on the basis of the meanings that the things have for them*
- *The meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows*
- *Meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters (Blumer, 1969, p.2)*

Symbolic interactionism assumes that human beings are active agents who create meaning based on interpretation of social events and environment. Human behaviors are the actions taken by individuals that are driven by interpretative meanings of events and the contexts within which



they occur (Blumer, 1969). As such, symbolic interactionism provides a strong framework for grounded theory investigations because a primary goal of grounded theory is to understand and explain how individual human perceptions and meanings influence actions taken in specific psychosocial contexts (Aldiabat & Le Navenec, 2011; Glaser & Strauss, 1967). In the case of the present study, the author aimed to explain the psychosocial processes that influence care initiation in people living with HIV.

### **Grounded Theory: A History**

#### **Origins of Grounded Theory:**

Grounded theory was developed in the 1960's by American sociologists Barney Glaser and Anselm Strauss (Glaser & Strauss, 1967). The majority of scientific inquiry at the time followed the positivist tradition (Charmaz, 2006; Denzin & Lincoln, 2011; Glaser & Strauss, 1967; Strauss & Corbin, 1990), with axiological emphasis placed on verification of theoretical constructs (Denzin & Lincoln, 2011; Glaser & Strauss, 1967). Glaser and Strauss proposed a new way of approaching sociologic investigations; by inductively investigating social phenomena and developing theories that are *grounded* in the investigated data (Glaser & Strauss, 1967). The resultant theory would, therefore, be intimately connected to the data, increasing its value and applicability in the investigated contexts. Together, Glaser and Strauss published *Discovering Grounded Theory* in 1967 to provide a description of and directions to the grounded theory research method.

#### **Classic 'Glaserian' Grounded Theory:**

Grounded theory has evolved since Glaser and Strauss's original 1967 publication. A division between Glaser and Strauss occurred in the 1980's due to disagreements on grounded theory procedures and applicability (Charmaz, 2006). Glaser's later work more closely

resembled the classic description of the grounded theory method than other subsequent publications on grounded theory (Charmaz, 2006). Glaser emphasized the need for strict inductive reasoning, abandonment of preconception including literature review, and the development of theories that were considered emergent from the data (Glaser & Strauss, 1967).

### **Strauss and Corbin:**

Strauss joined Juliet Corbin in the creation of systematic guidelines for conducting grounded theory investigations. Strauss and Corbin emphasized that researchers approach investigations with a phenomenon of interest, and data analysis should include the placement of data into preconceived categories (Strauss & Corbin, 1990). Additionally, deductive reasoning and verification in the data analysis process were added, including the development and investigation of hypotheses, in direct contrast to the idea of pure induction and categorical emergence asserted in classic grounded theory (Strauss & Corbin, 1990). Strauss and Corbin's description of grounded theory and classic grounded theory differ both in approach and procedure, but both versions of grounded theory aim to generate theory intimately connected to data (Glaser & Strauss, 1967; Strauss & Corbin, 1990).

### **Constructivist Grounded Theory:**

Most recently, an alternative approach to grounded theory research in the tradition of constructivism has been developed, acting as the middle ground between positivist and post-modernist research perspectives (Charmaz, 2006). Constructivism is a paradigmatic perspective asserting that reality is not an objective entity to be discovered, but rather, is constructed through social interaction (Denzin & Lincoln, 2011). According to Charmaz (2006), grounded theory is developed through the co-construction of knowledge between researchers and participants under investigation (Charmaz, 2006). Constructivist grounded theory and classic grounded theory

differ primarily in paradigmatic approach, with constructivist grounded theory following the tenets of constructivism, and classic grounded theory holding with the post-positivist paradigm. However, both constructivist and classic grounded theory employ similar procedural actions in the generation of grounded theories (Charmaz, 2006; Glaser & Strauss, 1967). Constructivist grounded theory procedures more closely align with classic grounded theory than with the grounded theory approach proposed by Strauss and Corbin (Charmaz, 2006).

In summary, multiple approaches have been proposed for the generation of grounded theory (Charmaz, 2006; Denzin & Lincoln, 2011; Glaser & Strauss, 1967; Strauss & Corbin, 1990). The differences between the aforementioned perspectives on grounded theory research are procedural and paradigmatic in nature, but each approach shares a goal of generating theory that is grounded in the data of the investigation. A classic grounded theory approach was employed in the present investigation to generate a theory to explain the psychosocial processes that influence care initiation in people living with HIV (see Data Analysis section).

## **Methods**

The purpose of this section is to describe the methods that the investigator used to conduct the study, and will include discussion of the study sample, study setting, recruitment procedures, protection of human subjects, data collection and management procedures, and finally data analysis procedures.

### **Sampling Plan:**

The investigator aimed to uncover the psychosocial process of care initiation by individuals living with HIV. Grounded theory investigations require participants who are theoretically relevant to the phenomenon under investigation (Glaser & Strauss, 1967). As such, adult individuals living with HIV who had initiated HIV care were considered for inclusion in

the study. Care initiation was defined as the action taken by individuals to start HIV care within a healthcare facility, and was operationalized in this study through the recruitment of study participants at the University of Cincinnati Infectious Disease Center who had confirmed HIV serostatus and who were beginning or in care at the facility at the time of the study.

**Inclusion and Exclusion Criteria:**

The following inclusion/exclusion criteria were used as a guide in the recruitment of participants:

**Inclusion Criteria:**

- 18 years of age or older
- Confirmed HIV-positive serostatus
- Initiating or receiving care through the University of Cincinnati Infectious Disease Center

**Exclusion Criteria:**

- Inability to speak, and understand English
- History of multiple treatment attempts
- Health status requiring immediate medical interventions in addition to routine HIV care

**Sample Size and Characteristics:**

Selection of participants was based on theoretical relevance as opposed to a pre-determined sample size, in line with the tradition of grounded theory (Glaser & Strauss, 1967). The investigator recruited 30 participants, including 28 men and 2 women. Table 6 provides an overview of sample characteristics.

Table 6: Sample Characteristics

<b>Category</b>	<b>Type</b>	<b>Sample n (%)</b>
<b>Gender</b>	Men	28 (93%)
	Women	2 (7%)
<b>Age</b>	18-24	8 (27%)
	25-34	11 (37%)
	35-44	3 (10%)
	45-54	6 (20%)
	55-64	2 (7%)
<b>Race/Ethnicity</b>	African American	6 (20%)
	Caucasian	20 (67%)
	Native American	1 (3%)
	Hispanic/Latino	2 (7%)
	More than one Race	1 (3%)
<b>HIV Exposure Category</b>	MSM	26 (87%)
	Hetero. Contact	3 (10%)
	IDU	1 (3%)
	Other	
<b>Timeframe from Diagnosis to HIV Care Initiation</b>	< 1 Month	6 (20%)
	1-3 Months	20 (67%)
	3-6 Months	1 (3%)
	6-12 Months	2(7%)
	>12 Months	1 (3%)
<b>HIV Treatment Status</b>	Started HIV Medication	13 (43%)
	Not Started HIV Medication	17 (57%)

**Study Site:**

The University of Cincinnati Holmes Hospital Infectious Disease Center (IDC) provides HIV-specific healthcare to approximately 200 individuals with new HIV diagnoses. The site is a Ryan White funded HIV treatment center and includes services from nine infectious disease physicians, four infectious disease fellows, one internist, two psychiatrists, one mental health counselor, one pharmacist, one advanced practice nurse, three registered nurses, two licensed practical nurses, two medical assistants (front desk/phlebotomy), and three administrative staff members. Individuals newly diagnosed with HIV initiate care through the HIV New Intake

Program. Participants were recruited for the study through the New Intake Center (n=26) and from the established pool of patients (n=4). The research team partnered with the New Intake Coordinator to gain access to study participants.

### **Protection of Human Subjects**

Prior to the initiation of study procedures, the investigator obtained permission to conduct the study from the University of Cincinnati Institutional Review Board (IRB). Additionally, a meeting with personnel working at the HIV clinic was conducted to gain support for the conduct of the study and to address any questions or concerns.

All study participants received an informed consent document outlining the purpose of the study and describing study procedures. The investigator thoroughly reviewed the consent document with all participants prior to the initiation of study procedures. Participants were informed that their participation was strictly voluntary, that they were free of any and all obligation, and that the decision to not participate would not affect their treatment in any way.

The study involved participants providing retrospective accounts of their experiences moving from the receipt of a positive HIV test result to their decision to initiate care. Participant confidentiality was maintained through the assignment of a participant number. The risks associated with the study included distress related to HIV-specific stigma and unintentional disclosure of participant HIV status during study procedures.

Every effort was made to avoid unintentional disclosure of participant HIV status and protect participant confidentiality. All study data was placed on an encrypted research drive within the University of Cincinnati College of Nursing mainframe and hard copies were destroyed immediately. Records will be retained on the encrypted research drive for three years following the completion of the study in accordance with federal regulations and the University

of Cincinnati College of Nursing's Standard Operating Procedures (*CON-SOP-4-2; Section 4-2 V*).

### **Recruitment Procedures:**

Participants were recruited in person at the University of Cincinnati Infectious Disease Center in partnership with the New Intake Coordinator. New intake appointments took place on Mondays, Tuesdays, and Thursdays in the Infectious Disease Center. No patients were approached about the study until the *end* of their intake appointment to avoid any interference with care procedures. Prior to any investigator contact, the New Intake Coordinator asked patients whether they were interested in meeting the investigator using a scripted approach. If a patient agreed to meet the investigator, the investigator approached them, also adhering to an approved script. If a participant expressed interest in participating in the study, an interview was scheduled. In the event that an individual was *not* interested in participating in the study, they were thanked for their time and reminded that their choice would have no impact on their treatment.

### **Data Collection and Analysis:**

**Data Collection:** In the interest of human subjects protection, interviews were conducted in a private room within the Infectious Disease Center. Prior to the collection of any data, the investigator thoroughly reviewed the informed consent document with each participant. The investigator conducted in-depth interviews with 30 participants in a private room within the Infectious Disease Center. Prior to beginning the interview, the investigator established rapport with participants through general conversation and reminded the participant that the interview would be audio recorded.

An interview guide was used and participants were asked questions designed to elicit retrospective accounts of their experiences from the time they were diagnosed up to and including HIV care initiation. The in-depth interviews began with a universal question for each participant (see manuscript 3; Table 1), and follow-up questions were used to obtain additional detail regarding significant statements made by participants. Interview duration ranged from 40 minutes to two hours.

**Theoretical Sampling:** A crucial defining component of grounded theory research is *theoretical sampling* (Draucker et al., 2007; Glaser & Strauss, 1967). Grounded theory data analysis was immediately initiated following the first interview. As theoretical constructs of interest emerged from the data, those constructs guided the direction of data collection. As such, the aforementioned interview guide evolved as the study commenced to include theoretically sensitive questions in addition to the universal question and questions to elicit detail.

**Data Management:** Two sources of audio recording were used during each interview to prevent loss of data through technical complication. The interviews were recorded using a Sony<sup>®</sup> handheld digital recording device and an Apple<sup>®</sup> i-Phone. Once the interviews were completed, the audio files were uploaded to the encrypted research drive within the University of Cincinnati College of Nursing mainframe and deleted from all external devices. Each interview was transcribed, and hard copies of documents were uploaded to the encrypted research drive and destroyed.

**Data Analysis:** A team of IRB-approved researchers, including the principal investigator, the principal investigator's dissertation chairperson, and two research associates worked together to analyze the transcribed data collected in the study. The study followed guidelines outlined by Glaser and Strauss (1967) to analyze the collected data. Data analysis followed a constant



comparison method, with transcripts reviewed multiple times and constantly compared with other transcripts to identify theoretical comparisons among data sources (Glaser & Strauss, 1967). The analysis process included three levels of coding: open coding, selective coding, and theoretical coding.

***Open Coding:*** The transcribed interviews were reviewed line-by-line, with each and every line examined and coded based on the content of the text contained within each individual line. Open coding forms a foundation for data analysis through the identification of similar phenomena within and between transcripts (Glaser & Strauss, 1967; Jones & Alony, 2011). Patterns among the codes formed the basis for categorization of data, which is used to guide the direction of subsequent data collection and analysis efforts.

***Selective Coding:*** Selective coding occurred as the open coding process began to reveal categories that consistently emerged from collected data. These emergent concepts guided subsequent analysis efforts (Glaser & Strauss, 1967; Jones & Alony, 2011). The categories pointed the research team in a direction to seek relevant data from new transcripts and to review previous transcripts to verify that all data relevant to the emergent categories had been identified.

***Theoretical Coding:*** The final step in the coding process was theoretical coding, occurred when the emergent categories became saturated. Theoretical saturation is defined when the research team, through rigorous analysis and discussion, concluded that no further theoretical concepts emerge to guide the investigation (Charmaz, 2006; Glaser & Strauss, 1967; Jones & Alony, 2011). As such, no new categories develop during the aforementioned open and selective coding procedures.

***Memo Writing:*** Throughout the process of data analysis, the research team recorded research memos, which are personal reflections on their interpretation of the data (Charmaz,

2006). The creation and collective review of research memos are crucial steps in theory development, as memos assist the research team members in presenting a variety of ideas regarding the emerging theory (Jones & Alony, 2011).

**Theory Generation:** Once the research team agreed that theoretical categories have reached theoretical saturation, extensive discussion of the data was conducted to identify a basic social process. The basic social process was identified through the creation of explanatory models that demonstrate the relationship between concepts. The final step in data analysis occurred when the research team reached consensus regarding the basic social process that had emerged from the data, and the final product is written: a grounded theory (Charmaz, 2006). The resultant theory in the present study is “Translating the News: A Grounded Theory of Care Initiation by Individuals Living with HIV”.

#### **Data Trustworthiness:**

The research team followed Guba (1981)’s criteria for trustworthiness in qualitative inquiry. Trustworthiness is evaluated based on four primary characteristics: *credibility*, *dependability*, *confirmability*, and *transferability* (Guba, 1981).

*Credibility* refers to the extent to which study data and subsequent interpretation of the data are accurate reflections of the participants’ stories, and is accomplished through prolonged engagement with a study site, persistent observation, triangulation of data sources, and member checks (Guba, 1981).

*Dependability and confirmability* refer to the stability of the data and congruence of data interpretation between two or more people respectively (Guba, 1981). Guba (1981) recommends the use of inquiry audit trails, which include to enhance the dependability and confirmability of an investigation.

Finally, *transferability* refers to the extent to which the findings of an investigation can be applied (transferred) to different groups of people or different settings (Guba, 1981). Guba (1981) recommends the use of theoretical or purposive sampling techniques and rich description of the data (i.e. context, unique attributes of participants) to enhance the transferability of an investigation.

**Credibility:** The researcher established credibility in the study by developing a relationship with the study site and establishing rapport with study participants. The data collection included in-depth interviews, detailed notes on verbal and nonverbal cues from study participants, and investigator field notes. The researcher also reviewed interview notes with each participant at the end of the interview to establish that interpretation of participant reports were accurate. The research team worked together to review interview transcripts, memos, and field notes individually and as a group. Interpretation and meaning of study data were decided based on consensus of research team members.

**Dependability and Confirmability:** To establish dependable and confirmable data, the research team established an inquiry audit trail that outlined the movement of raw data to abstract theoretical categories. The audit trail was established beginning with the analysis of the first transcribed interview and continued through the completion of the theory. The audit trail made it possible for external sources to review the analysis process used by the research team in the creation of the resultant theory.

**Transferability:** To increase the likelihood of transferability of the study, the researcher implemented theoretical sampling as recommended by Glaser and Strauss (1967). In addition, a thorough description of the characteristics of the study site and study participants was provided to establish the context with which the study was undertaken.

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## **Manuscript 1**

### **Psychosocial factors that influence HIV care initiation: An integrative review**

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#### **Abstract:**

HIV care initiation is a crucial time point on the HIV care continuum in which individuals living with HIV enter HIV-specific healthcare following diagnosis. Psychosocial factors have been shown to influence HIV care initiation. The purpose of this literature review is to synthesize findings of current research on psychosocial factors that influence HIV care initiation. A variety of databases were searched, yielding 27 articles that met the inclusion criteria for the review. Overall, six psychosocial factors that influence HIV care initiation were identified in the literature, including HIV stigma, social support, psychological reaction to diagnosis, HIV status disclosure, perception of HIV disease and treatment, and vulnerable predisposing factors. The majority of these factors increased the likelihood of HIV care initiation delays following diagnosis. This review provides both clinical implications related to each identified factor as well as direction for future inquiry.

**Key Words:** care initiation, HIV treatment, psychosocial factors, HIV treatment initiation

Approximately 70% of individuals living with Human Immunodeficiency Virus (HIV) in the United States (US) are eligible for treatment, but half of these individuals are not engaged in HIV care (Gardner, McLees, Steiner, del Rio, & Burman, 2011). Timely entry into HIV care facilitates optimal HIV treatment outcomes, specifically the achievement of an undetectable viral load (Ulett et al., 2009). HIV care initiation is defined as the action taken by individuals living with HIV to enter HIV care following diagnosis. HIV care initiation corresponds to the beginning of the “linkage with care” stage of the HIV care continuum (United States Department of Health and Human Services, 2014). It is important to note that care initiation may or may not correspond with the initiation of antiretroviral therapy (ART) treatments. This review will focus on factors that influence individuals with HIV to make their initial contact in the care environment rather than on factors that influence their decisions to initiate ART.

Psychosocial factors have been shown to influence the decisions of individuals diagnosed with HIV to initiate care. Psychosocial factors involve the interrelation of social influence with individual thoughts, feelings, and perceptions that affect behavior (Martin & McFerran, 2014).

Initiation of HIV care is crucial for optimal patient outcomes because current treatments, specifically ART, are highly effective in promoting health in individuals living with HIV (DHHS, 2013). ART decreases the likelihood of progression to acquired immunodeficiency syndrome (AIDS) and HIV transmission, resulting in individual and public health benefits (DHHS, 2013; Palella et al., 2003; World Health Organization [WHO], 2013). At present, however, challenges remain in providing timely, effective, and sustained treatment to individuals living with HIV.

Despite well-documented evidence of ART efficacy, delayed entry into HIV care is common (Gardner, McLees, Steiner, del Rio, & Burman, 2011), and as many as one half of

individuals living with HIV do not receive treatment until late in the trajectory of the HIV illness (Cheever, 2007). Care initiation is the time point at which an individual enters HIV care following the receipt of a positive HIV diagnosis. United States data indicate that 25% of individuals who test positive for HIV will fail to ever initiate care, and another 28% will delay HIV care initiation (Marks, Gardner, Craw, & Crepaz, 2010).

Researchers have defined timely initiation of care in multiple ways in the literature including: 1) specific time periods between diagnosis and care initiation such as three, six, and twelve months (Anthony et al., 2007; Giordano et al., 2005; Marcellin et al., 2009; Raveis, Siegel, & Gorey, 1998; Reed et al., 2009; Samet et al., 1998; Turner et al., 2000), 2) clinical indicators of disease progression such as CD4+ T-lymphocyte count and viral load (Giordano et al., 2005), and 3) psychological factors such as readiness for care (Gold, Hinchy, & Batrouney, 2000; Morgenstern, Grimes, & Grimes, 2002; Nordqvist, Södergård, Tully, Sönnnerborg, & Lindblad, 2006). In this review, multiple definitions were accepted based on how each of the authors reviewed operationalized timely HIV care initiation.

Less than 30% of individuals living with HIV in the US are achieving viral suppression (CDC, 2011), creating an urgent need to understand factors that influence the decisions of individuals living with HIV to initiate care following diagnosis. The majority of HIV care initiation research has focused on population-based (demographic, economic, geographic) factors that influence the initiation of HIV care. However, individual factors such as psychosocial factors also influence HIV care initiation. At present, there is no published synthesis of investigations about psychosocial factors that influence HIV care initiation. Therefore the purpose of this article is to synthesize current research on psychosocial factors that influence care initiation by individuals living with HIV.

## The Review

### **Aim**

The aim of this integrative review is to identify and analyze psychosocial factors that influence HIV care initiation. The review will include a brief background of the problem, a discussion of the findings of the literature review, and recommendations for practice and future inquiry.

### **Design**

The integrative review method involves critical examination of quantitative, qualitative, mixed method, and theoretical research to gain holistic understanding of phenomena. (Whittemore & Knafl, 2005).

### **Search Methods:**

CINHAL, ERIC, PsycInfo, Cochrane Collaboration, and PubMed databases were used to conduct an exhaustive literature search. The author also used a university library search engine designed to pull articles from over 1,000 peer-reviewed scientific publications from various disciplines. Search terms included: *Human Immunodeficiency Virus, HIV, HIV care initiation, psychosocial factors, and HIV care linkage*. Search terms and Boolean phrases were used in various combinations to ensure that a thorough search of the literature was conducted. Finally, a review of the reference lists of retrieved articles was conducted to ensure that all relevant literature was acquired.

The review of the literature was completed in December of 2014, and articles were included in the review if: a) the findings of the quantitative, qualitative and mixed methods studies included psychosocial factors related to HIV care initiation; b) the article was published between 2004 and 2014, and c) the article was published in the English language. Studies related

to HIV without findings related to HIV care initiation were excluded from this review. HIV care initiation studies that did not include investigation of psychosocial factors were also excluded.

### **Search Outcome**

The authors used a modified PRISMA flow chart to illustrate the process of the literature review (Moher, Liberati, Tetzlaff, & Altman, 2009; see figure 1). The initial search yielded 4,210 results. The results of the initial search were filtered to only include articles published within 10 years, articles published in the English language, and articles with a specific focus on HIV care initiation, which eliminated 4,051 articles, resulting in 159 potential articles from peer-reviewed publications. The author screened the abstracts of the articles, and 112 articles were excluded due to content focus on HIV-related subject matter outside of care initiation. After thorough review of the remaining articles, 20 more studies were excluded because, although they were investigations about factors that influenced HIV care initiation, psychosocial factors were not investigated. A total of 27 articles were included in the review (see Table 1).

### **Quality Appraisal**

The integrative review method requires the evaluation of a diverse range of methods (Whittemore and Knafl, 2005). The authors assessed quality of individual studies using two, eight-point rating scales for both quantitative and qualitative studies as outlined by Jinks, Cotton, and Rylance (2011). Table 2 outlines the specific criteria that were assessed for each article included in the review. Articles were scored based on the presence or absence of eight crucial quality criteria, with *0* indicating the criterion was absent, and *1* indicating that the criterion was present. The author planned to exclude any article with a quality score of 4 or less, as those articles would theoretically lack scientific rigor, but all articles included in this review met nearly

all crucial quality criteria assessed. Quality scores for the obtained literature ranged from 6-8, and no articles were eliminated due to poor quality.

### **Characteristics of the Literature**

Quantitative (n=21), qualitative (n=5), and mixed methods (n=1) research methods were employed in the investigations. Quantitative inquiries included cross-sectional designs, surveys and questionnaires, medical record reviews, and computer-assisted interviews. Sample sizes ranged from 160 to 5,881 participants. Researchers conducting qualitative studies used a variety of methods including grounded theory, focus groups, and semi-structured interviews analyzed using general qualitative data analysis methods. Sample sizes ranged from 11 to 130 participants.

The authors reviewed each study and identified specific findings that were defined by an interrelation of social influences with individual thoughts, feelings, or behaviors. Following methods described by Miles, Huberman, and Saldaña (2014), the authors developed a concept clustering matrix which involves the collection of individual data units from various source to identify common themes. Each psychosocial finding (i.e. statistical results or narrative data) was entered into the matrix, and narrative explanations of the influence the factor had on HIV care initiation were developed. The findings were then categorized within the matrix, ultimately resulting in six specific psychosocial factors that were found to influence HIV care initiation. All of the psychosocial factors identified in the analysis appeared in two or more of the included studies and were selected based on consensus between the authors (see Table 1).

The six factors included: (a) HIV stigma, (b) social support, (c) psychological reaction to diagnosis, (d) HIV status disclosure, (e) perception of the HIV disease and HIV treatment, and (f) vulnerable predisposing factors. The following discussion of the findings related to

psychosocial factors related to HIV care initiation will be organized around each of the six factors.

### **HIV Stigma**

Stigma related to HIV infection still exists, and has been found to affect the decisions of individuals diagnosed with HIV to initiate care (Burns, Imrie, Nazroo, Johnson, & Fenton, 2007; Fortenberry, Martinez, Rudy, & Monte, 2012; Kinsler, Wong, Sayles, Davis, & Cunningham, 2007; Sayles, Wong, Kinsler, Martins, & Cunningham, 2009; Sprague & Simon, 2014). Stigma is a phenomenon in which individual or group differences are given negative connotation due to a perceived deviation from social norms (Nyblade, Stangl, Weiss, & Ashburn, 2009; Sayles et al., 2009). Individuals with HIV can experience stigma through encounters of prejudicial behavior, or through internalization, also known as self-stigma (Sayles et al., 2009). Regardless of its source, stigma has been found to contribute to delays in HIV care initiation.

In quantitative studies, stigma was measured in self-report questionnaires (Kinsler et al., 2007; Sayles et al., 2009). Kinsler et al. (2007) determined that stigma may completely disrupt individuals' attempts at seeking healthcare services. In their study, individuals who reported that they perceived stigma related to their HIV diagnosis from healthcare providers were statistically less likely to access HIV care services than those who did not report perceptions of stigma from their provider.

Sayles et al. (2009) examined the relationship between internalized stigma and multiple components of HIV care, including the presence of a regular care provider. The study included 202 individuals living with HIV who completed quantitative measures of HIV-specific stigma (Sayles et al., 2008;  $\alpha = 0.93$ ) as well as HIV care-related questions. Participants reporting high levels of self-stigma were more likely to report that they had no regular source of HIV



health care than those individuals, increasing their risk of delayed HIV care initiation (Sayles et al., 2009). The results of the study suggest that providers are uniquely positioned to combat HIV stigma, as they become a source of understanding for those with internalized stigma. While not all clinicians provide HIV-specific care, all providers have the ability to provide support and education to individuals diagnosed with HIV.

Qualitative studies were conducted by several investigators and provided insight into specific causes and conditions of HIV-specific stigma. Beer, Fagan, Valverde, and Bertolli (2009) conducted a qualitative inquiry in which 37 participants took part in focus groups designed to identify specific barriers to HIV care initiation. Individuals with HIV sometimes perceived that physicians treated them differently, in a negative way, after finding out they have HIV. In addition, the participants reported feeling as though their physicians no longer wanted to be associated with them when they were referred to another physician for care (Beer et al., 2009).

Similarly, Sprague and Simon (2014) conducted a qualitative study examining the experiences of people with HIV in Alabama, and found that stigma and negative healthcare encounters can lead to individuals making the choice to not pursue care at all. Furthermore, individuals with HIV may choose to discontinue healthcare following an encounter in which they feel they are being judged (Sayles et al., 2009).

Two qualitative studies provided insight into experiences and perceptions of healthcare professionals who work with people living with HIV. Burns et al. (2007) and Fortenberry et al. (2012) conducted interviews with HIV healthcare workers. The results indicate that stigma often results from the attachment of character judgments to HIV diagnoses (Burns et al., 2007; Fortenberry et al., 2012). Judgment is often related to assumptions made about HIV

transmission, especially sexual transmission (Burns et al., 2007). Assumptions and overt discriminatory behaviors result in the experience of stigma, which decreases the readiness of newly diagnosed individuals to initiate HIV care (Fortenberry et al., 2012).

The results of the studies reinforce that stigma is a major psychosocial factor that impacts the decision of individuals living with HIV to initiate care following diagnosis. Across the studies, experiences of stigma invariably resulted in increased delay and distress in the HIV care initiation process.

### **Social Support**

Social support was another factor that was found to influence the initiation of HIV care. (Aidala, Lee, Abramson, Messeri, & Siegler, 2007; Brewer et al., 2007; Craw et al., 2008; Cunningham et al., 2007; Fortenberry et al., 2012; L. I. Gardner et al., 2007; Hatcher et al., 2012; Hightow-Weidman, Jones, et al., 2011; Hightow-Weidman, Smith, Valera, Matthews, & Lyons, 2011; Konkle-Parker, 2010; Molitor et al., 2006; Pollini, Blanco, Crump, & Zúñiga, 2011; Ramirez-Avila et al., 2012; Sprague & Simon, 2014; Tobias et al., 2007; Torian, Wiewel, Liu, Sackoff, & Frieden, 2008; Zetola et al., 2009). Social support, in this context, is defined as the availability of people and resources that will promote HIV care initiation (Pollini et al., 2011; Sayles et al., 2009; Sprague & Simon, 2014). Individuals diagnosed with HIV often must navigate an increasingly complex health care system in order to initiate and establish HIV care. The likelihood of successful linkage with HIV care increased when two primary forms of social support were present: tangible support and informational support.

Tangible support is a form of social support that assists individuals through the provision of material aid such as housing assistance, transportation, food, and relief from healthcare navigation activities (McCoy et al., 2009; Sherbourne & Stewart, 1991; Sprague & Simon,

2014). In the reviewed studies, tangible support efforts increased likelihood of timely HIV care initiation (Aidala et al., 2007), while the absence of such services often resulted in delayed care initiation (Aidala et al., 2007; Cunningham et al., 2007; Hightow-Weidman, Smith, et al., 2011; Konkle-Parker, 2010). Provision of stable housing was predictive of HIV care initiation among clients in need (Aidala et al., 2007; Sprague & Simon, 2014). Even the simple act of healthcare workers making the initial appointment for HIV care following diagnosis significantly increased the likelihood of HIV care initiation (Pollini et al., 2011). Participants in Sprague and Simon's (2014) study described the receipt of housing and transportation support as being instrumental to their ability to receive HIV care and to their overall health.

Informational support is a form of social support involving the provision of advice and guidance (McCoy et al., 2009; Sherbourne & Stewart, 1991). Individuals who test positive for HIV are often provided with a large amount of information about the HIV disease, treatment options, and referrals to HIV treatment specialists (Anthony et al., 2007; Marcellin et al., 2009). Studies indicated that individuals were more likely to initiate care when provided with honest and detailed information about HIV at diagnosis as opposed to only receiving a passive referral (Anthony et al., 2007). Perceived support from healthcare providers was also influenced by the way health-related information was delivered to patients. Individuals in one study (Beer et al., 2009) reported feeling overwhelmed by technical information, and that they did not receive adequate emotional support from providers.

Case managers provide assistance in navigating the healthcare system and obtaining care-related resources. Case manager assistance was found to be a major determinant of success in the HIV care initiation among newly diagnosed individuals when compared to individuals passively referred into care (Craw et al., 2008; Pollini et al., 2011). Pollini et al. (2011) examined factors

associated with individuals never linking with HIV care. Individuals who never initiated care reported receiving less direction following diagnosis compared to individuals receiving case management services, who were more likely to initiate care within three months of diagnosis (Pollini et al., 2011).

Social support was consistently associated with successful and timely initiation of HIV care. Conversely, when individuals were not provided social support, they were at increased risk of delays and refusals to initiate HIV care (Pollini et al., 2011). Social support, which is inclusive of tangible and informational support, is crucial to successful initiation of care by individuals diagnosed with HIV.

### **Psychological Reaction to Diagnosis**

Psychological reaction to HIV diagnosis was a factor that influenced HIV care initiation (Beckerman & Fontana, 2009; Beer et al., 2009; Konkle-Parker, 2010; Sprague & Simon, 2014). Upon receiving a positive diagnosis, individuals may experience intensely negative emotions such as anger, fear, and shame (Beckerman & Fontana, 2009). While these emotions may be an understandable or even expected response to diagnosis, psychological reaction to diagnosis and subsequent coping behaviors can significantly impact the initiation of HIV care.

Denial of serostatus was a psychological reaction that impeded timely initiation of HIV care following diagnosis, and has been examined in both quantitative and qualitative inquiries (Beckerman & Fontana, 2009; Beer et al., 2009; Konkle-Parker, 2010; Pollini et al., 2011). Denial resulted in care initiation delays when individuals avoided healthcare interactions in an attempt to not think about having HIV. Pollini et al. (2011) administered surveys to participants to identify factors related to delayed HIV care seeking. The results of the study indicated that individuals who reported not wanting to think about the fact that they have HIV were likely to

delay initiation of HIV care following diagnosis. Beer et al. (2009) provided specific insight into the experiences of individuals following HIV diagnosis. Participants shared that while they knew they had HIV, they did not want to think about it or focus on it, resulting in behaviors aimed at avoiding the initiation of HIV care. Conversely, results of Konkle-Parker's (2010) study suggest that disease acceptance can potentially *facilitate* timely HIV care initiation. Konkle-Parker (2010) conducted semi-structured interviews with 130 individuals living with HIV, 23% who delayed entry into HIV care. Eleven percent of participants reported that acceptance of their HIV status was a prelude to the decision to initiate HIV care (Konkle-Parker, 2010).

The psychological reactions of individuals with HIV following their initial diagnoses are influential in the decision to initiate HIV care. The results provide evidence that denial of serostatus following diagnosis results in delayed initiation of HIV care while acceptance of serostatus can facilitate the initiation of HIV care.

### **Individual Perceptions of Health and HIV Treatment**

HIV has a deceptive dormant period in which individuals are infected but are asymptomatic for up to a decade following diagnosis. While asymptomatic, individuals diagnosed with HIV are often faced with a baffling incongruence between their perceptions of their physical wellness and clinical indicators of disease progression, which can influence their care decisions (Beer et al., 2009; Marcellin et al., 2009; Pollini et al., 2011). Research has indicated that perceptions of being in good health due to a lack of symptoms can result in delayed care initiation and even care refusal among individuals newly diagnosed with HIV. In addition, the perceptions these individuals hold about HIV treatment options also influence the decision to initiate care following HIV diagnosis (Beer et al., 2009; Marcellin et al., 2009; Pollini et al., 2011; Sprague & Simon, 2014)

Pollini et al. (2011), surveyed 100 individuals who were not in care and found that nearly half of these individuals reported that they were not in care because they did not feel ill. Participants Beer et al.'s (2009) articulated that the purpose of initiating care becomes questionable when one does not feel ill. Despite the potential benefit of prompt HIV care initiation, the reviewed investigations provide valuable insight into the reason why long delays between diagnosis and care initiation occur. Individuals newly diagnosed with HIV may have considerable difficulty reconciling clinical recommendations that do not match their own perceptions of their physical health (Sprague & Simon, 2014).

Individuals with HIV are more likely to delay care when they believe that HIV treatment will be more detrimental than helpful to their health. Pollini's et al. (2011) study on care initiation barriers indicated that participants did not initiate care when they: a) believed that HIV medications would do more harm than good, b) they viewed current HIV treatment regimens as untrustworthy and lacking definitive evidence of effectiveness, and c) believed that it was best to wait to take medication until they were symptomatic. Other negative perceptions about HIV medications in the literature included the idea that medications are prescribed primarily for the financial benefit of providers as opposed to the benefit of the patient, that initiation of medication regimens would be a constant painful reminder of HIV status (Beer et al., 2009), and that taking HIV medications lead to negative side effects (Marcellin et al., 2009).

Beliefs that care was only necessary when symptomatic or that treatment would cause more harm than good consistently led to delays in care. Participants in both Beer's et al. (2009) and Sprague and Simon's (2014) demonstrated that some care delays from such perceptions can result in serious but preventable illness. The experiences of participants in these studies establish

the crucial connection between the perceptions and beliefs of individuals, and the timing of HIV care initiation.

### **HIV Status-Disclosure**

Disclosure of HIV status occurs when an individual takes the action of informing others about being infected with HIV (Eustace & Ilagan, 2010), and is a psychosocial factor that was found to influence HIV care initiation in the reviewed studies (Beer et al., 2009; Burns et al., 2007; Hatcher et al., 2012; Kigozi et al., 2009; Pollini et al., 2011). Individuals in these studies often chose not to disclose their status due to their inability to control where the information goes once disclosed (Beer et al., 2009; Burns et al., 2007). Often, fear associated with encountering stigma motivates individuals to not disclose their HIV status. Choosing to not disclose HIV status can potentially result in an increase in psychological vulnerability due to a lack of social support while living with HIV (Burns et al., 2007; Chesney & Smith, 1999; Kigozi et al., 2009; Pollini et al., 2011).

In addition to general societal stigma, concerns about confidentiality within the healthcare system motivate non-disclosure of HIV status among newly diagnosed individuals. Burns et al. (2007) discussed the challenges faced by African-born citizens in Great Britain. HIV care delays and care refusal were the result of clients' efforts to keep their HIV status private and avoid situations (i.e. healthcare visits) that could result in disclosure. Participants expressed fear of social isolation and rejection, and a concern that HIV status disclosure could adversely affect others such as family and friends (Burns et al., 2007). Beer et al. (2009) had similar findings. Participants reported being anxious about revealing their HIV status due to a concern that others would disclose their status. In these studies, individuals attributed care initiation delays to their anxieties about HIV status disclosure.

Findings from several quantitative studies supported the qualitative study results in which specific reasons why individuals chose to not disclose their HIV status were illuminated.

Individuals who chose not to disclose their HIV status were statistically less likely to initiate care in a timely manner and even refused HIV care following diagnosis (Pollini et al., 2011). HIV status disclosure is a psychosocial factor that can potentially govern the decision to initiate HIV care. Across the reviewed studies, the choice to not disclose HIV status was directly associated with delay of the initiation of HIV care, and was, therefore, a contributor to preventable disease progression.

### **Vulnerable Predisposing Factors**

Researchers in multiple studies determined that vulnerable predisposing factors, such as mental health diagnoses and substance misuse, resulted in psychosocial sequelae that profoundly influenced HIV care initiation (Anthony et al., 2007; Bhatia, Hartman, Kallen, Graham, & Giordano, 2011; Craw et al., 2008; Fortenberry et al., 2012; Giordano et al., 2005; Konkle-Parker, 2010; Molitor et al., 2006; Ramirez-Avila et al., 2012; Sprague & Simon, 2014; Tobias et al., 2007; Torian et al., 2008). These vulnerable predisposing factors were the psychosocial factors most frequently discussed in the literature that affect HIV care initiation. Statistically significant relationships between vulnerable predisposing factors and delayed or refused initiation of HIV care were identified, and narrative data from qualitative studies provided insight to causes and conditions of care initiation delays.

Individuals with mental health diagnoses were at increased risk for delays in care initiation compared to individuals without mental health conditions (Bhatia et al., 2011; Ramirez-Avila et al., 2012). Bhatia et al. (2011) and Ramirez-Avila et al. (2012) conducted studies that measured the relationship between depressive symptoms and the initiation of care



following HIV diagnosis. The results indicate that depression was a significant correlate to care initiation delays when compared to participants who initiated care promptly following diagnosis. In these studies, depression screening occurred in the pre-diagnostic time frame (Bhatia et al., 2011; Ramirez-Avila et al., 2012), and was associated with delays upwards of three months following diagnosis, and with refusal to initiate care.

Even more prevalent than depression in the literature were findings explicating the relationship between the psychosocial sequelae from substance misuse and delays in HIV care initiation (Anthony et al., 2007; Craw et al., 2008; Fortenberry et al., 2012; Giordano et al., 2005; Konkle-Parker, 2010; Molitor et al., 2006; Sprague & Simon, 2014; Tobias et al., 2007; Torian et al., 2008). Substance misuse is defined as the use of substances in a manner that is not consistent with legal guidelines or medical recommendations, resulting in negative impacts on health and functioning (WHO, 2014). Substance misuse is strongly related to delayed initiation of HIV care and HIV care refusal. The most frequently discussed form of substance misuse was injection drug use (Anthony et al., 2007; Craw et al., 2008; Fortenberry et al., 2012; Giordano et al., 2005; Konkle-Parker, 2010; Molitor et al., 2006; Pollini et al., 2011; Tobias et al., 2007; Torian et al., 2008). People who inject drugs have been identified as a group not only at risk for HIV transmission, but also for care initiation delays. The majority of the studies provided statistically significant evidence of a relationship between injection drug use history and an increased likelihood of delayed HIV care initiation. The relationship was exemplified in a study conducted by Anthony et al. (2007), in which data from 270 HIV-infected individuals indicated that individuals with were one fourth as likely as people who do not inject drugs to see a care provider following their HIV diagnosis.

Substances that did not fall into the category of injection drugs were often placed under an umbrella of “drug use” or “illicit drug use”. Two authors discussed the impact of crack cocaine use on care initiation by individuals with HIV (Bell et al., 2010; Brewer et al., 2007). They reported statistical relationships between crack cocaine use and failure to initiate HIV care when controlling for other variables. Regardless of the substance, there was strong agreement across the quantitative investigations that substance misuse, particularly recent to the time of diagnosis, was related to delayed and even failed HIV care initiation (Anthony et al., 2007; Bell et al., 2010; Brewer et al., 2007; Craw et al., 2008; Fortenberry et al., 2012; Giordano et al., 2005; Konkle-Parker, 2010; Molitor et al., 2006; Pollini et al., 2011; Tobias et al., 2007; Torian et al., 2008).

Qualitative studies provided insight into specific reasons for delayed or refused care. Participants in Sprague and Simon (2014)’s study described substance misuse as a way to blunt the impact of emotional distress associated with receiving an HIV diagnosis. Participants reported engaging in heavy drug use to avoid thinking about the fact that they had HIV (Sprague & Simon, 2014). Substance misuse, particularly persistent use following diagnosis, diminished the ability of individuals living with HIV to perceive the significance of their diagnosis, resulting in a lack of motivation to seek care (Sprague & Simon, 2014).

Individuals who use illicit drugs sometimes perceive that healthcare providers do not want to treat them because they use drugs, resulting in avoidance of contact with healthcare providers (Anthony et al., 2007). Konkle-Parker (2010) provides a different but complementary perspective of the relationship between substance misuse and care initiation, reporting that cessation of drugs and alcohol actually facilitated the initiation of HIV care, reinforcing the link between substance misuse and failure or delay in HIV care initiation (Konkle-Parker, 2010).

Individuals with mental health diagnoses and those who engage in substance misuse are at a particularly high risk of delaying HIV care initiation, and in some cases, failing to ever initiate HIV care. In addition, promoting cessation of substance misuse was found to increase the likelihood of HIV care initiation.

### **Discussion:**

The initiation of HIV care is multifaceted, complex, and influenced by a multitude of psychosocial factors. Six psychosocial factors were identified in this review that affect HIV care initiation: HIV stigma, social support, psychological reaction to diagnosis, individual perceptions of health status and HIV treatment, HIV status disclosure, and vulnerable predisposing factors. The majority of the factors identified as barriers to HIV care initiation, with fewer factors discussed as facilitators to HIV care initiation.

Although each of the factors was presented individually and exclusive of one another in this paper, they were often found to be closely related to one another in the literature. For example, close relationships between HIV stigma and the choice to disclose HIV status were found throughout the literature (Anthony et al., 2007; Beer et al., 2009; Burns et al., 2007). Fear of stigma by individuals with HIV has been associated with a decision to not disclose one's HIV status, resulting in an increased likelihood of delays in HIV care initiation (Beer et al., 2009; Pollini et al., 2011; Sprague & Simon, 2014). Disclosure, in turn, was found to be associated with linkage with care providers and the subsequent tangible social support services (Burns et al., 2007).

Vulnerable predisposing factors and the psychological reaction to HIV diagnosis were also shown to be related. Individuals with HIV may not be able to grasp the reality of their diagnosis due to substance misuse or mental health problems (Anthony et al., 2007; Bhatia et al.,

2011; Pollini et al., 2011; Ramirez-Avila et al., 2012). Many intricate connections between these psychosocial factors exist, and can ultimately impact the success of timely HIV care initiation following HIV diagnosis. The following sections provide both clinical implications for healthcare professionals who work with individuals who have been diagnosed with HIV and direction for future research.

### **Clinical Implications**

The literature indicated that HIV stigma is multifaceted, and that patients sometimes even perceive stigma from the healthcare providers who diagnose and treat them (Burns et al., 2007; Fortenberry et al., 2012; Kinsler et al., 2007; Sayles et al., 2009). The data demonstrate that providers should be cautious during the referral process with newly diagnosed HIV patients. While a referral may be routine, newly diagnosed individuals may perceive the transition as the provider's desire to discontinue interaction with them because of their diagnosis. The data suggest that provider-patient interactions are crucial because individuals may choose not to link with an HIV care provider due to negative experiences with providers at the time of diagnosis. Fear of judgment from healthcare providers can potentially lead individuals with HIV to delay care until the onset of acute illness rather than early in the disease trajectory, adding unnecessary complications to their HIV treatment (Kinsler et al., 2007). Clinicians should be diligent in creating a supportive environment and providing encouraging follow-up to individuals diagnosed with HIV.

Provision of social support by clinicians and loved ones facilitated HIV care initiation. The evidence suggests that clinicians can make a monumental difference when providing tangible support such as assisting clients with telephone calls for appointments and services (Pollini et al., 2011), resulting in the prevention of unnecessary care delays (Konkle-Parker,

2010; Pollini et al., 2011). Informational support was also identified as crucial to successful HIV care initiation. Guidance from clinicians and case managers is invaluable to individuals diagnosed with HIV. Clinicians and case managers should provide advice and guidance about treatment and provide health support services to increase the rate of successful HIV care initiation.

Diagnosis is arguably the most important time points in the HIV care continuum. An individual's reaction to the receipt of an HIV diagnosis may determine the success or failure of timely HIV care initiation. Some individuals deny the reality of their HIV diagnosis, which complicates their ability to recognize the need for care and to initiate care (Konkle-Parker, 2010; Pollini et al., 2011). The literature indicated that when individuals accepted the realities of their diagnosis, they were more likely to initiate care (Konkle-Parker, 2010). While the process of coming to accept one's HIV diagnosis is unique to each individual, clinicians can be proactive by providing newly diagnosed clients with education and social support. Participants in some studies reported that they did not want to think about having HIV. For some, initiating HIV care would result in constantly having to think about their HIV status (Beer et al., 2009; Pollini et al., 2011), and thus, care was avoided. Individuals diagnosed with HIV should be given detailed, comprehensive information about their diagnosis in a supportive manner with respect to initial misgivings about initiating care.

Delays in the initiation of HIV care are sometimes the result of asymptomatic individuals with HIV not believing they are sick (Beer et al., 2009; Marcellin et al., 2009; Pollini et al., 2011). The absence of symptoms may prompt individuals with HIV to delay care until symptomatic, at which point the individuals may be suffering from advanced HIV disease (Sprague & Simon, 2014). Clinicians should recognize and be understanding about the

dissonance between patients' perceptions of their own health and clinical indicators of disease. Clinicians can facilitate initiation of HIV care by thoroughly educating patients on both clinical indicators and physiological manifestations of HIV, thereby helping patients understand the need for HIV treatment.

Concerns about disclosing HIV status were found to be a contributing factor to the decision to initiate HIV care (Beer et al., 2009; Burns et al., 2007; Hatcher et al., 2012; Kigozi et al., 2009). Individuals newly diagnosed with HIV may choose not to disclose their HIV status out of fear that disclosure could lead to inappropriate sharing of status information (Beer et al., 2009; Sprague & Simon, 2014). However, disclosure, at least in the clinical setting, is necessary to take the first steps into HIV care. Clinicians must recognize patient privacy concerns, and be diligent in building a trusting provider-patient relationship. Clinicians can also provide support and direction regarding status disclosure, and empower individuals with HIV as they make decisions about disclosure.

Finally, the reviewed studies indicated that psychosocial sequelae resulting from vulnerable predisposing factors such as mental health diagnoses and substance misuse increase the risk of HIV care delays. Clinicians must be ready to address the needs of such individuals. Substance misuse and mental health problems can profoundly impact the ability of individuals newly diagnosed with HIV to grasp the reality of their diagnosis (Sprague & Simon, 2014), and can therefore, be detrimental to timely HIV care initiation. Clinicians must thoroughly assess clients with mental health problems, and provide appropriate treatment and follow-up to those at high risk for care delays (Bhatia et al., 2011; Ramirez-Avila et al., 2012).

Individuals who engage in substance misuse may feel uncomfortable approaching clinicians, assuming that they will be judged based on their substance use rather than on their

HIV healthcare needs. Clinicians can assist individuals diagnosed with HIV by openly discussing the issue of substance misuse, recognizing and addressing it in a judgment-free manner, especially during initial encounters following diagnosis. Healthcare providers should assess client motivation for substance misuse, and be aware of the potential for increased substance misuse as a means of dealing with emotional stress following diagnosis. Providing a judgment-free environment in which the individual can receive support, particularly in efforts to stop drinking or using substances, will facilitate a supportive provider-patient relationship and increase the likelihood of timely HIV care initiation.

### **Implications for Future Research**

There is a need for further research on each of the six psychosocial factors in order to develop strategies to promote timely initiation of HIV care. To address the factor of HIV stigma, future research should focus on the identification of specific behaviors within the healthcare setting that promote stigma or result in perceived stigma by individuals living with HIV. Social support can be more closely examined by investigating the impact of family involvement in the HIV care initiation process. Additionally, there is a need to investigate what actions can be taken by providers and community leaders to foster a supportive environment for individuals with HIV in order to promote timely initiation of HIV care.

To address psychological reactions to being diagnosed with HIV, researchers can formulate studies aimed at understanding psychological factors that promote disease acceptance. In-depth exploration of the concept of acceptance as it relates to HIV diagnosis will allow researchers and clinicians to better understand how to provide optimal emotional support to newly diagnosed patients. Due to the dissonance that can occur between patient perceptions of health and clinical indicators of disease, researchers should also focus on development and

testing of interventions aimed at assisting individuals with HIV who are asymptomatic to enter into treatment prior to onset of significant symptoms.

Furthermore, scientists should specifically examine the relationship between HIV status disclosure and timeliness of HIV care initiation. In-depth qualitative inquiry will help researchers and clinicians to better understand the process that individuals with HIV go through when informing other people about their HIV status and will identify interventions to help these individuals through the process of disclosure. To address predisposing factors, future research should examine care initiation trajectories among individuals with various mental health disorders and those who engage in misuse of specific substances. Such inquiry will help researchers to identify specific barriers that individuals with these disorders encounter when initiating care. Studies should focus on the best way to remove psychosocial barriers to care initiation in these individuals and promote timely initiation of HIV care.

Across the reviewed studies, the majority of the investigations focused on barriers to timely initiation of HIV care. Equally as important are those factors that promote or facilitate HIV care initiation. A study should be designed in which individuals who have successfully initiated HIV care are interviewed in order to develop a theory about the process by which HIV-positive individuals initiate care. Future research efforts should include development and testing of psychosocial interventions that clinicians can adopt to promote timely initiation of HIV care following diagnosis.

**Limitations:**

This review was inherently limited by the inclusion and exclusion criteria used to identify the literature of interest. Most of the investigations were conducted using quantitative research methods. While these methods provided invaluable statistical evidence of crucial relationships



between the examined psychosocial factors and HIV care initiation, qualitative studies are necessary to provide detailed description and contextual understanding of these relationships. Investigators will benefit from employing mixed methods designs in future inquiry, combining the strengths of both quantitative and qualitative methods.

**Conclusion:**

HIV care initiation is extremely important to ensure optimal treatment outcomes for individuals diagnosed with HIV. However, delays in care initiation are common. Psychosocial factors, including HIV stigma, social support, individual perception of health status, psychological reaction to diagnosis, HIV disclosure, and vulnerable predisposing factors have been found in a number of studies to be related to HIV care initiation. These findings provide insight for clinicians who work with individuals living with HIV and provide direction for future scientific inquiry.

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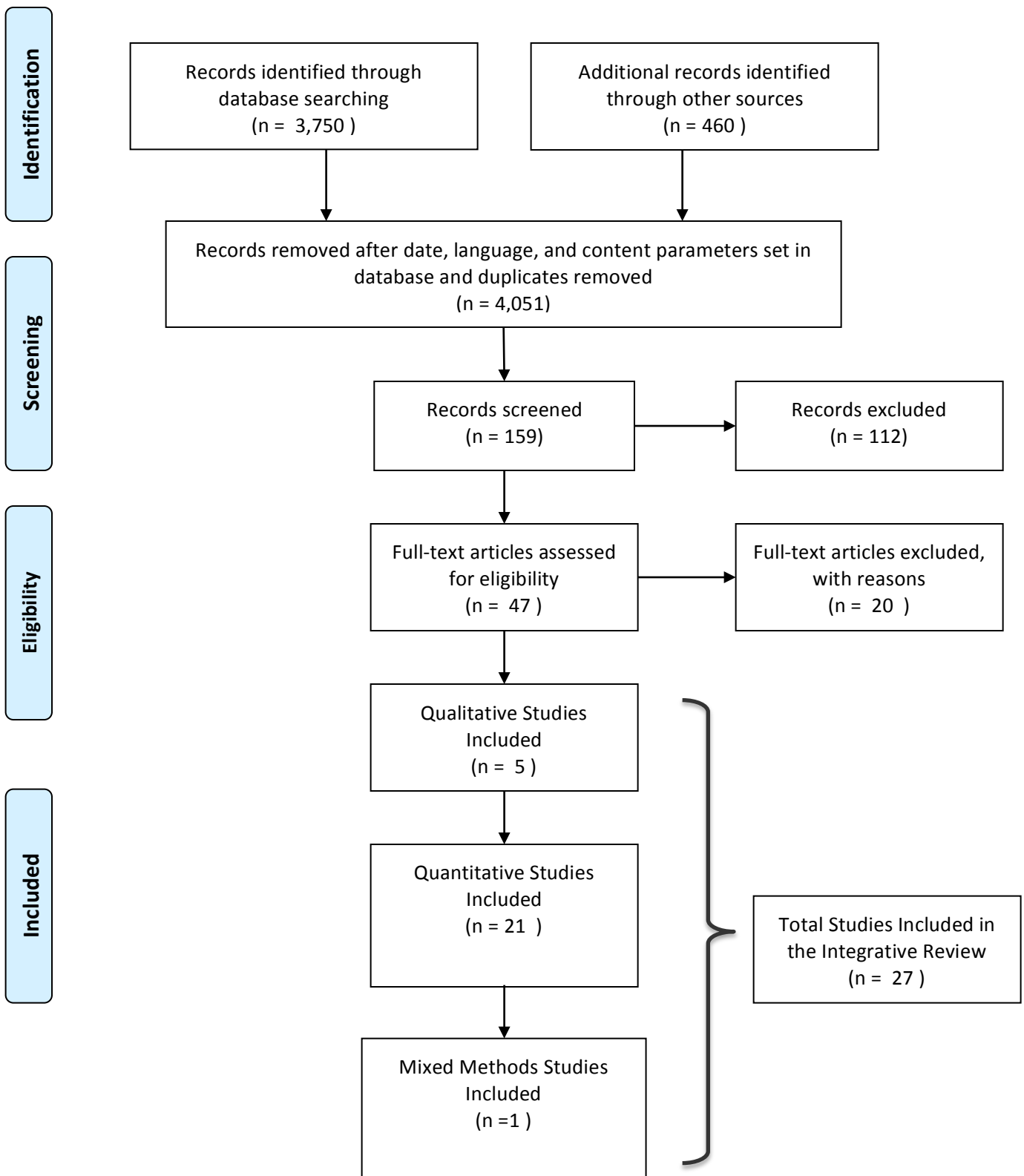
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Figure 1: The Literature Search



Author	Purpose	Sample/Methods	Psychosocial Variables Investigated	Implication for Timely Care Initiation	
				Increased Likelihood	Decreased Likelihood
<b>Quantitative Methods</b>					
Aidala et al. (2007)	Investigates housing status as a contextual factor affecting access and maintenance in appropriate HIV medical care.	Sample: Pooled data from 5,881 adults living with HIV <b>Quantitative:</b> Coded interview data	Social Support	X	
Anthony et al. (2007)	Examine psychosocial variables on care initiation	270 HIV-positive individuals participating in the Antiretroviral Treatment Access Study <b>Quantitative:</b> Self-report survey	Vulnerable Predisposing Factors (Illicit Drug Use)		X
Bell et al. (2010)	Examine the factors that influence HIV-infected crack cocaine users who have never entered care	355 adults living with HIV who are addicted to crack cocaine <b>Quantitative:</b> Structured interview data	Vulnerable Predisposing Factors (Substance misuse) Social Support	X	X
Bhatia et al. (2011)	To examine the prevalence and correlates of depression at the time of HIV diagnosis, focusing on factors known to predict poor linkage and retention in HIV care.	180 Adults living with HIV <b>Quantitative:</b> Survey, Medical Record Review	Vulnerable Predisposing Factors (Mental Health)		X
Brewer et al. (2007)	Examine the role of crack cocaine as a potential barrier to initiating care among persons living with HIV	286 adults living with HIV <b>Quantitative:</b> Audio Computer Assisted Self-Interview	Vulnerable Predisposing Factors (Illicit Drug Use)		X
Craw et al. (2008)	Evaluate a brief case management intervention delivered in health departments and community-based organizations to link recently diagnosed HIV-infected persons to medical care rapidly	626 adults living with HIV <b>Quantitative:</b> Medical record and case management summary report review following case management intervention	Social Support Vulnerable Predisposing Factors (Illicit Drug Use)	X	X

Cunningham et al. (2007)	Examine factors associated with health care utilization in hard-to-reach marginalized HIV-infected individuals	610 adults living with HIV <b>Quantitative:</b> Face-to-face interview, correlates of specific variables to health care utilization	Social Support	X	
L. I. Gardner et al. (2007)	Examine psychological and behavioral variables as predictors of attending an HGIV medical care provider among persons recently diagnosed with HIV	273 Adults living with HIV (136 case-managed participants; 137 Standard of Care (SOC) participants) <b>Quantitative:</b> Multivariate analysis of successful linkage to care following case management intervention	Social Support Vulnerable Predisposing Factors (Illicit Drug Use)	X	X
Giordano et al. (2005)	Describe the incidence of failing to establish outpatient care in the HAART era	404 HIV+ patients establishing care <b>Quantitative:</b> Retrospective chart review	Vulnerable Predisposing Factors (Illicit Drug Use)		X
Hatcher et al. (2012)	Explore interpersonal and institutional factors that determine linkage to care	483 adults living with HIV <b>Quantitative:</b> Cross sectional design	Social Support Disclosure	X X	
Hightow-Weidman, Jones, et al. (2011)	Examine the characteristics of participants and program delivery that were associated with early linkage and retention in HIV care	334 Young men who have sex with men (YMSM) of racial and ethnic minority groups diagnosed with HIV <b>Quantitative:</b> Questionnaire	Social Support	X	
Kigozi et al. (2009)	Investigate factors associated with late presentation to care	2,311 people living with HIV <b>Quantitative:</b> Cross sectional analysis of initial care visits at a university clinic	Non-Disclosure		X
Marcellin et al. (2009)	Study individual factors on delayed first consultation after HIV diagnosis	3,151 HIV-infected adults <b>Quantitative:</b> Cross sectional survey	Negative Perception of Treatment		X

Molitor et al. (2006)	To exclude persons with some history of HIV medical care and examine correlates of time without HIV care and linkage to medical care among clients who had never received any prior HIV-related medical care	323 Adults living with HIV <b>Quantitative:</b> Linkage documentation analysis	Vulnerable Predisposing Factors (Illicit Drug Use)		X
Pollini et al. (2011)	Identify barriers to care among persons who were diagnosed with HIV but never initiated care	100 individuals living with HIV but not receiving care <b>Quantitative:</b> Cross sectional; questionnaire	Social Support (Lack) Disclosure (Non-disclosed) Denial of status		X X X
Ramirez-Avila et al. (2012)	Examined the prevalence and correlates of depressive symptoms in adults who were surveyed before HIV testing and subsequently diagnosed with HIV in two out-patient clinics	1,545 individuals screened for HIV with subsequent positive diagnosis <b>Quantitative:</b> Questionnaire and record review	Vulnerable Predisposing Factors (Mental Health)		X
Sayles et al. (2009)	Estimate the association between HIV stigma and: self-reported access to care	202 people living with HIV <b>Quantitative:</b> Cross-sectional survey	Stigma		X
Tobias et al. (2007)	Examine factors associated with the receipt of HIV medical care among people who know their HIV status and are not newly diagnosed with HIV	1133 Adults living with HIV (n=121: No care received) <b>Quantitative:</b> Face to Face Interview, Medical Record Review (Quantitized interview response data)	Vulnerable Predisposing Factors (Illicit Drug Use) Social Support (Lack of support in healthcare setting)		X X
Torian et al. (2008)	To measure time to initiation of care in New York City residents diagnosed as having HIV by positive Western Blot test in 2003	1928 Adults living with HIV <b>Quantitative:</b> Medical Record Review	Vulnerable Predisposing Factors (Illicit Drug Use)		X

Zetola et al. (2009)	Describe the characteristics of patients having a newly diagnosed HIV infection who entered into HIV medical care; show the effect of having had a public health investigator interview after a first positive HIV test on the likelihood of entering medical care within three months of the initial HIV diagnosis.	160 Adults living with HIV <b>Quantitative:</b> Medical Record Review	Social Support (within the healthcare setting)	X	
Kinsler et al. (2007)	Evaluate the relationship between perceived stigma from a health care provider and access to care among HIV-infected individuals in Los Angeles County	223 low-income adults living with HIV	Stigma		X
<b>Qualitative Methods</b>					
Beer et al. (2009)	Explore reasons individuals living with HIV were not receiving care	37 adults living with HIV <b>Qualitative:</b> Focus Group	Psychological Reaction to Diagnosis (Denial)		X
Burns et al. (2007)	Identify the current key issues influencing service uptake by HIV+ Africans	11 Key Informants (health care workers) <b>Qualitative:</b> Semi-structured interviews	Stigma Fear of Disclosure		X X
Fortenberry et al. (2012)	To understand linkage to care practices at sites providing clinical services to newly-diagnosed HIV-positive adolescents	28 Personnel involved in linkage to care at 15 sites providing specialty care to HIV-positive adolescents <b>Qualitative:</b> In-depth Interviews	Stigma		X

Konkle-Parker (2010)	Explore factors that influence care entry and dropout	130 individuals living with HIV (23% who delayed initiation of care) <b>Qualitative:</b> Semi-structured interviews	Psychological Reaction (Denial) Disclosure (Anxiety) Vulnerable Predisposing Factors (Illicit Drug Use) Psychological Reaction (Acceptance)	X	X X X
Sprague and Simon (2014)	Understand experiences of low-income people living with HIV	25 people living with HIV <b>Qualitative:</b> grounded theory	Psychological Reaction/Perception of health status (fear/distress)  Social Support (Perceived Lack: Healthcare)  Social Support in healthcare setting  Vulnerable Predisposing Factors (Illicit Drug Use)	X	X X X
Mixed Methods					
Beckerman and Fontana (2009)	To identify individual and service system characteristics that impact access, retention, and adherence to an HIV/AIDS medical treatment regimen	100 Adult men who have sex with men (MSM) living with HIV <b>Mixed Methods:</b> Interviews, focus groups, questionnaire	Psychological Reaction to Diagnosis (Fear/Anger) Negative Perceptions of HIV treatment Stigma Social Support	X	X X X

Table 1: Investigations of care initiation with implications for timely initiation of HIV ca

Assessment of Quantitative Studies*	Score 0 = Absent 1 = Present/Not Applicable	Assessment of Qualitative Studies*	Score 0 = Absent 1 = Present/Not Applicable
Research questions/objectives/hypotheses are clear and appropriate		Research aims are clear and appropriate	
Clear overview of intervention is given with use of appropriate outcome measures		Clear overview of method/intervention is given	
Sample size is given		Number of participants is given	
Recruitment procedure is discussed and Randomization method is used in sample selection		Recruitment of participants is adequately described	
Attrition rate from the intervention is recorded		Attrition rate from the study is recorded	
Data Analysis is adequately described and rigorous		Data analysis is adequately described and rigorous	
Outcomes of the analysis are clearly described		Outcomes of the analysis are clearly described	
Ethical issues are suitably addressed		Ethical issues are suitably addressed	
Total Score (0-8)		Total Score (0-8)	

Table 2: Literature Quality Assessment

\*Modified from quality assessment outlined by Jinks, Cotton, & Rylance (2011)



## Manuscript 2

### Translating the news: A grounded theory of care initiation by individuals living with HIV

Perazzo, J., Martsof, D., Pritchard, T., & Tehan, R.

#### Abstract

Despite tremendous advances in HIV treatment, less than 30% of the more than 1 million people living with HIV in the US are achieving optimal treatment outcomes. Researchers have recognized that there is an urgent need to understand factors and processes that influence individuals with HIV to initiate HIV care.

**Purpose:** The specific aims of the study were to a.) develop a theoretical framework to explain the psychosocial process of care initiation in individuals living with HIV, and b.) to identify the critical junctures, defined as pivotal events reported by study participants, that influence individuals living with HIV in their decision to initiate HIV care

**Methods:** Grounded theory was the method used to analyze in-depth interviews with individuals living with HIV. A team of IRB-approved researchers analyzed the data using three levels of coding: Open coding, selective coding, and theoretical coding. Analysis was conducted with an aim of identifying the psychosocial process of care initiation by individuals living with HIV.

**Results:** 30 individuals living with HIV (28 men, 2 women) participated in the study. Participants shared their stories about how they went from learning that they had HIV to the point of HIV care initiation. The core category discovered in the data was the concept of HIV as news. News, by definition, is impactful information that was not previously known that is delivered by one party and received by another. Participants described a process in which they progressed through five distinct stages: a) receiving the news, b) interpreting the news, c) incorporating the news, d) acting on the news, and e) moving beyond the news. Each stage was moderated by influential factors including perceived susceptibility to HIV infection, symptoms, HIV information, and feedback from others. The initial receipt of the news was typically interpreted as ‘bad news’. However, through reflection, interaction with others, and information seeking, participants learned that HIV was not a death sentence and that there are treatment options available to them. In effect, the participants were able to translate the news, often beginning as something bad, but changing into something good. The constructed framework is known as “Translating the News: A Grounded Theory of HIV Care Initiation”

**Conclusion:** Individuals who are diagnosed with HIV often encounter a myriad of challenges at the point of diagnosis. Individuals are able to move through the care initiation process with fewer complications when they are provided with encouragement and information, particularly about their treatment options. The key to successful care initiation is helping individuals with HIV to realize that while the diagnosis may seem like bad news, there is also good news: HIV is not a death sentence.

## INTRODUCTION

Over the last three decades, global health authorities have worked tirelessly to understand, control, prevent, and treat Human Immunodeficiency Virus (HIV). Research indicates that antiretroviral therapy (ART) has the potential to increase lifespan, promote viral suppression, and decrease the likelihood of advancement to acquired immunodeficiency syndrome (1, 2). In addition to the individual patient benefits, HIV treatment decreases the likelihood of HIV transmission from infected individuals, producing a notable public health benefit (1-4). US data indicate that less than half of people living with HIV are achieving optimal treatment outcomes (5), specifically viral suppression, and less than half of individuals diagnosed with HIV are even engaged in care (5-8). As such, there is an urgent need for scientists to investigate factors that influence individuals with HIV to seek out and initiate care following diagnosis.

The *HIV care continuum*, also known as the *HIV treatment cascade* is a framework that allows clinicians and health authorities to evaluate engagement in HIV care and treatment (8, 9). The continuum is inclusive of all individuals living with HIV, ranging from those who are living with HIV but are unaware of their diagnosis to those who have achieved viral suppression in which the individual's viral load has become undetectable (9). The continuum also provides researchers with a model to assess the state of current research, including psychosocial research, related to HIV care and treatment. Care initiation occurs at the crucial time point on the HIV care continuum when an individual living with HIV takes the action to enter HIV care (6, 8). A greater understanding of factors that influence HIV care initiation will help researchers and clinicians provide optimal transition from HIV diagnosis to treatment, resulting in a greater number of individuals living with HIV who experience the benefits of HIV treatment.

A review of the literature revealed that psychosocial factors are among the many factors that influence individuals newly diagnosed with HIV to pursue HIV care. Factors such as psychological response to diagnosis, stigma, and lack of social support, as well as predisposing risk factors such as mental illness and substance misuse have been found to cause delayed initiation of HIV care (10-17). Conversely, psychosocial factors such as disease acceptance and tangible and informational support have been found to promote HIV care initiation (18-21). These studies provide invaluable evidence of the impact of psychosocial factors on HIV care initiation. However, no studies have been conducted that examine the psychosocial process of HIV care initiation used by individuals diagnosed with HIV. The present work will address this gap in knowledge by presenting the results of a grounded theory study conducted with an aim of exploring the psychosocial process care initiation by individuals living with HIV.

## **METHODS**

### **Ethical Considerations:**

The research team received approval from the university's Institutional Review Board prior to the initiation of study procedures. All study documentation was kept on an encrypted mainframe within the university that was accessible only by the research team.

### **Participants**

Participants were recruited in person at new intake visits within the infectious disease center at a Midwestern university medical center. The research team partnered with the site's New Intake Coordinator, who acted as a gatekeeper for the identification of potential participants. If an individual expressed interest in the study, a research team member reviewed the informed consent document and scheduled an interview. Participants were eligible to

participate if they were at least 18 years of age, had received a confirmed seropositive HIV test result, had not previously initiated HIV care, and were able to speak and understand English. Participants were not eligible to participate if they were experiencing acute illness requiring inpatient hospitalization at the time of intake. Recruitment of participants with specific characteristics occurred as the study progressed in accordance with the grounded theory principle of theoretical sampling. Characteristics of the final study sample are summarized in Table 1.

### **Design**

Grounded theory (22) is a qualitative inquiry method that is ideal in the investigation of psychosocial problems, particularly problems to which individuals must adapt over a period of time. Grounded theory involves the technique of constant comparison in which study data are collected and analyzed simultaneously (22-24). Another defining feature of grounded theory is the employment of theoretical sampling, in which data collection efforts evolve based on the developing theory rather than a pre-determined algorithm protocol (25).

### **Data Collection and Analysis:**

Data were collected between April 2014 and December 2014. Participants met with a study team member (first author) in a private room within the medical center. In-depth, individual interviews were conducted and tape-recorded and lasted between 45 minutes and two hours. The same team member conducted all interviews. The researcher asked a universal open-ended question that elicited participants' experiences with the initiation of HIV care:

*“I understand that you learned that you have HIV [Insert Timeframe: i.e. two months ago] and you have come here to receive healthcare for HIV. Tell me*

*your story about how you went from learning that you have HIV to making the decision to come here to get care.”*

The researcher also included follow-up questions designed to obtain additional detail about significant statements made by participants. For example, when participants said they had a particularly ‘good’ or ‘bad’ experience with a healthcare worker during the process:

*“Can you tell me more about your interaction with [healthcare worker]? What did they do, specifically, that made the interaction [good/bad]?”*

Interview questions evolved throughout the study to explore theoretical concepts that were discovered during data analysis. In addition to interview data, the research team collected data in the form of field notes, participant education material, and information collected from HIV-specific websites discussed by participants.

#### **Data Analysis:**

Transcribed interviews were analyzed by a team of IRB-approved researchers trained in the analysis of grounded theory data by the second author, a methodological expert in grounded theory. Data analysis followed constant comparison method in which transcripts were reviewed multiple times and were compared within each transcript and across other transcripts to identify theoretical comparisons among data sources (22). The analysis process included three specific levels of coding: open coding, selective coding, and theoretical coding.

During open coding, transcribed interviews were reviewed and coded line-by-line, forming a foundation for subsequent data analysis (22, 26). Patterns among the open codes resulted in the tentative categorization of data, which then guided the direction of data collection and analysis efforts. As open coding revealed data categories, the research team moved on to selective coding. The categories discovered pointed the research team to seek

relevant data from new interviews and previous transcripts. The final step in the coding process was theoretical coding, which occurred once the categories became saturated. Theoretical saturation occurred when the research team, through rigorous analysis and discussion, concluded that no further investigation into a theoretical category was necessary (22, 24, 26).

### **Results:**

The study sample consisted of 30 participants, including 28 men and 2 women living with HIV who initiated care through the infectious disease center at a Midwestern urban teaching hospital. Table 1 illustrates the characteristics of the sample based on gender, race/ethnicity, age, HIV exposure category, timeframe from diagnosis to HIV care initiation, and HIV treatment status at the time of the study interview.

Participants included a) individuals diagnosed with HIV and initiating care for the first time (n=26), and b) individuals established in care who reflected on their experiences with HIV care initiation (n=4). Participants were interviewed to gain their perspective on the phenomenon of HIV care initiation. Results from these interviews are shared within the context of the theoretical framework developed from participant responses.

### **The Theory: Translating the News**

As participants shared their stories, they and other people mentioned within their stories often used the term “the news” to describe learning that they tested positive for HIV (see Table 2). The word *news* is defined as *previously unknown information, and something that has a specified influence or effect* (27). News in the context of the present study is used to describe the way that participants acquired and worked through the new and impactful information that they have HIV. News has typically been discussed in the field of

communication and has been described as *information presented via a variety of media* (i.e. written documents, face-to-face communication, television, telephone, artwork etc.) *between a sender and a receiver* (Severin & Tankard, 2010). The response of a receiver of news is determined by intrinsic characteristics and perceptions of the receiver as well as extrinsic feedback, cues and events encountered by the receiver (Severin & Tankard, 2010; Kreitner & Kinicki, 2011). In their stories, participants described the news of their HIV diagnosis as the catalyst that set subsequent thoughts, feelings, and actions in motion, ultimately resulting in a decision to initiate care for HIV.

### **Bad News and Good News**

The participants described the news of their HIV diagnosis as a transformative phenomenon that evolved over time from bad news to good news. The concept of translation was used to describe the movement from bad news to good news described by participants. The term *translate* is defined as *changing from one place, state, form, or appearance to another* (28). The initial diagnosis was commonly interpreted as bad news, often related to the participant's thoughts about their prognosis. One participant shared about learning his HIV status:

*"I couldn't even talk... I was like I don't know what I'm going to do, and I don't know how this happened. And I just thought I was going to die. I did. I thought it was a death sentence."*

Once participants were in possession of the news, they commenced into an often rapid process of reflection and information seeking to determine how HIV would impact their current and future lives. The participants grappled with psychological, social, and pragmatic realities of having HIV. In each case, participants shared that as they reflected and gathered

information, their perspective of their condition changed. Participants learned about treatment options for HIV that many expressed they did not know existed. The result in each case was the realization that HIV was not a death sentence, and that they would be able to move forward with their lives while living with HIV. Participants often described learning this monumental information as ‘good news’. One participant said that he did not know about the medications that were available for HIV and shared about the conversations with his provider and other healthcare workers in which he learned about treatment options:

*“They’ve said that they’ve got new drugs that will keep you alive... and you can live almost a normal life expectancy... that’s where all the reassurance comes from.. people saying, ‘it’s fine! We’ve got great drugs now that keep people alive! We can get your T-cells back up’...I mean it’s... it’s good news. When can I start? ... I was hoping to immediately start on drugs.”*

In the process, participants translated the news from a situation they felt was hopeless, to a situation for which they believed there was a solution. The process includes five distinct stages: Receiving the News, Interpreting the News, Incorporating the News, Acting on the News, and Moving Beyond the News (see Figure 1). The theory will be presented in the following way: each stage of the theory will be defined and illustrated using theoretical exemplars from the data. Following the description of each stage, four specific factors will be discussed that influenced participants during the process.

**Receiving the News:** To *receive* is defined as *to come into possession of or to acquire* (29). Participants shared their stories of how they initially were given the news that they had HIV. With the exception of the five individuals who bought home HIV tests, all of the participants described receiving the news from another person. The majority of the



participants received the news from physicians. Others received the news from public health workers, volunteers, and through written directions for interpreting home test results.

Regarding home testing, three of the five participants who received a home test chose to take the test in the presence of at least one other individual, while the remaining two shared that they took the test alone.

The majority of the participants described receiving the news in the form of face-to-face conversations with healthcare professionals who informed the participants that they had tested positive for HIV, either on a rapid test or in laboratory analyses.

*“[The Physician] said, ‘It’s not good news and I wanted to be the one to tell you.’ And he told me that I was HIV positive.”*

Some participants did not receive the news in person. For example, one individual received the news when his test result was inadvertently released to an online medical record system prior to his follow up with his provider. Another participant described learning about his HIV status during a telephone call with his provider:

*“She called to tell me that my HIV test came back positive. I had a typical reaction that you might expect upon hearing that news. Just flushed, my heart felt like it – my stomach felt like it dropped out. I nearly dropped the phone.”*

Although individuals are not officially diagnosed with HIV until they have received a confirmatory lab test, participants typically discussed receiving the news when they received their first positive indicator, regardless of whether the result was confirmed.

**Interpreting the News:** Once participants had received the news, they immediately proceeded to interpret what was happening to them. The term interpret is defined as *to explain the meaning of* and *to conceive in the light of individual belief, judgment, [and]/or*

*circumstance* (30). Participants articulated their interpretations of the news by reflecting on their thoughts, feelings, and beliefs at the time of their HIV diagnosis.

Participants interpreted the news through reflection about their past and present beliefs about the HIV illness: through speculation about how HIV would affect them physically, mentally, socially, and sexually, and how their lives would have to change now that they have HIV. Across the study sample, each participant's interpretation was unique and grounded in his or her own personal experiences. Participants often discussed feelings of shock, sadness, disbelief and uncertainty upon finding out that they had HIV. One participant shared his thoughts after being told he had HIV:

*“After I heard the, ‘You’re HIV positive,’ it was just sort of like – I was in a state of shock and disbelief. It was hard for me to concentrate on the rest of the conversation. That’s pretty much exactly how it went, as I recall.”*

At some point, all participants shared about coming to a realization that regardless of their initial thoughts, feelings, and beliefs about their diagnosis, that treatment was available to them and that their lives were not over. As one participant shared:

*“I accepted that....if I don’t get treatment I’m going to die. It is a death sentence if you don’t have treatment.”*

**Incorporating the News:** To incorporate means *to merge, to unite one thing with something that already exists, and to embody* (31). As participants interpreted and found meaning in their diagnosis, they shared that they were also faced with the challenge of incorporating this new phenomenon into their lives. Incorporation of the news occurred in two primary ways: a) psychologically in the form of a new identity, and b) practically in the form of learning how to live everyday life with HIV.

**Psychological Incorporation:** Many participants grappled with how their identity was shaped with regard to HIV. One participant described his thought

*“I have to say that word [HIV] over and over again, and I have to say that word pertaining to me, not pertaining to this person or that person that I know. It's now pertaining to me.”*

Some participants shared that their previous beliefs about HIV and the people who have it were challenged as they incorporated the news. One participant described how his identity initially did not match his perceptions of people who have HIV:

*“I'm not that type of person. I'm not out there whoring around, not promiscuous, none of that kind of stuff.”*

Participants varied in their adoption of HIV as part of their identity. Some participants shared that they viewed HIV as a minimal component of who they are, while others believed that HIV was now a fundamental part of their identity. However, all described their thoughts about the permanency of HIV infection. One participant shared:

*“Now if it's like a cold or a headache or something like that- that's not something that I typically seek treatment for. But with something like this I know that there are steps to take...knowing that it's going to be something that I have for the rest of my life is probably one of the factors that [made me realize] I need to do something about it.”*

**Practical Incorporation:** Participants shared a multitude of concerns that they had about living with HIV. Such concerns included: their general health, obtaining healthcare and its financial impact, disclosure, and the pragmatic realities of having a daily medication regimen.

As participants were incorporating the news of their HIV diagnosis, concerns about what their diagnosis meant for their general health were discussed. Some participants discussed that they did not feel any differently and did not believe that HIV was going to hold them back from living their normal lives. Conversely, other participants expressed that they were plagued by uncertainty about their own health and wondered whether they would be able to continue to lead their normal lives.

*“I just knew in some way that for the rest of my life, I’m going to have to be very cautious and aware of what I do. I’m going to have to really start taking care of myself and just really watching my health.”*

Practical incorporation also included the information seeking and actions taken by participants as they grappled with how to make HIV treatment a reality in their lives. Common among many participants were concerns about where to go for HIV care and the financial implications of HIV treatment. One participant described his concerns about finances after researching the cost of HIV treatment:

*“It was kind of like how am I going to pay for this? I worked so hard to get through school and I still can’t afford any of this. And I can’t get any assistance from anybody else because I make over \$30,000.00 a year.....the drug companies denied the assistance for me because I made too much money. And at that point when I had realized that I couldn’t get any assistance to help me out.”*

Another common concern was whether or not they were obligated to tell people that they have HIV. One participant described his concerns about how having HIV would affect his employment:

*“Who do I have to tell? Like am I not going to be able to go to work? Like for my job’s sake....what I have to tell my job [?]...Is it going to affect my career in any way shape or form.... things like that.”*

Participants discussed their realization that part of their ability to live with HIV included the reality that they had to take medicine every single day. Some participants stated that the idea of taking medication every day caused them great anxiety

*“I have to constantly worry about that. What if I forget, what's that gonna do to me? Or, I mean, what if I forget them at home and I'm an hour away from home? What am I supposed to do?”*

Other participants expressed that the medication regimen would likely not disrupt their lives at all. As one participant shared:

*“I feel like it is just a chronic medical issue.... Like diabetes, people use that one a lot. Like I [will] take my pill every day and I am fine as long as I am in control of it.”*

**Acting on the News:** Once participants had incorporated the news, they commenced to take action. In sharing their stories about linking with healthcare providers and initiating HIV care, participants described the different ways they navigated through the healthcare system moving from the point of diagnosis to their first entry into the healthcare arena. Some participants were entirely self-directed through the referral process. As one participant shared:

*[The hospital] basically referred me to the [HIV treatment center]. And so I pretty much called and – well, I didn’t call right away, but I called that day and set up an appointment to come in.*

However, many participants shared that employees of local public health agencies were crucial in assisting them in linking with HIV care providers. One participant shared his feelings about the caseworker who helped drive him to set up his appointments:

*“We really have some great resources and without them I wouldn't be here. I think everyone plays a part. I probably would have panicked, and reclused, and not done anything. And everyone helps to get me further along. It's like droplets of water in a puddle – wouldn't be as big without each droplet.”*

Across the study sample, participants discussed attending their first appointment for HIV care and about the relationships they began to develop with care providers. Participants described their initial interactions with HIV care providers as profoundly influential in calming their anxieties about the HIV illness, equipping them with knowledge about HIV, and motivating them to begin HIV treatment. One participant shared the impact that his intake appointment had on his perspective about HIV:

*“The appointment went really well. A lot of my questions were answered. [New Intake Nurse] was very warm and totally non-judgmental as I would expect her to be...just wanting to make sure that she got the information that she needed to give me appropriate care while also answering my questions and making sure that I left with the information that I wanted.”*

**Moving Beyond the News:** All study interviews were conducted at a time point that followed the participants' completion of the intake process. Although not all participants had started taking medication at the time of the study interview, all participants discussed that medical treatment for HIV is providing, or will provide them with the ability to move forward in their lives. Participants discussed moving beyond the news through projections and

speculations about their future life with HIV, specifically through discussion of their life goals in the context of their HIV infection. Some participants described their primary goal as initiating care and starting HIV treatment so that their life could return to the way it was prior to their diagnosis. As one participant shared:

*“I want to get care and I want to get treated. I want to live a normal life like I always have ...knowing that I’m sick but you know being healthy...work[ing]....having somebody you’re in love with. Having a job...Have a life...Having HIV. I know medications will help you live longer... all those plans that you had you want to keep having them.”*

Other participants shared that they wanted their diagnosis to be the catalyst that led to a better life than they were living previously. One participant reflected on his life prior to diagnosis and discussed how he planned to change:

*“I don’t feel like [HIV] was put here to bring me down or to stop me...I just feel like it was kind of like a wakeup call, because I was living a very destructive lifestyle. It’s a disease.... And I can’t say that it’s going to kill me, eventually it’s going to take over my body.... But maybe I was put in this position to where I could get my life together, and then maybe I can help somebody else who’s going through the same situation.”*

In each case, participants described HIV care and treatment as the tool that would make it possible for them to accomplish their goals and to move forward with their lives. One participant offered insight into the realization that many participants described, that HIV care providers gave them the tools to move forward but the choice to pursue treatment was ultimately in their hands:

*“The medication is obviously a huge factor in it not being a death sentence....I mean being on medications is one of the huge things that’s preventing people from dying at an early age. So I think that knowing that has really helped me come to this point and being like, okay, I need to get on medicines, and I need medicines soon...I can’t wait to be able to feel almost like normal again....I’m just ready to...be able to get up and just feel normal and feel like myself again...I mean it’s pretty much like in my hands. You know? I can do whatever I want with it.”*

### **Influential Factors in Translating the News:**

The aforementioned description provides an overview of the theoretical framework and the progression through the process of HIV care initiation. The data revealed that participants’ experiences at each stage in the process were uniquely influenced by four factors: their perceived susceptibility to HIV, the presence of symptoms, HIV information, and feedback from others.

**Perceived Susceptibility to HIV:** Perceived susceptibility is defined as the personal belief that participants had about their risk of becoming infected with HIV. Participants’ stories revealed that perceived susceptibility was particularly influential in their experiences with receiving and interpreting the news.

*Receiving the News:* Perceived susceptibility was influential to participants receiving the news, as it often motivated HIV testing behavior. Some participants knew they were at risk. One participant described his decision to get tested was based on the fact that he had an unprotected sexual encounter with someone who was living with HIV:



*“There was a situation that I thought that I probably was at risk and when I went to get tested the results were positive.... When I went to get tested it was just because I actually wanted to get tested because I needed to know”*

Other participants were unaware that they were at risk for HIV, and they were tested as part of a diagnostic workup. One participant shared his experience with why he was tested for HIV:

*“I was at the hospital. My [Doctor] ran a battery of tests. He had no idea that I would even be considered for an HIV candidate because, you know, I’m not that type of person.”*

*Interpreting the News:* Perceived susceptibility was also very influential in the way that the participants interpreted the news they had received. The majority of the participants described receiving the news as a shocking experience. However, the level of distress experienced by the participants differed based on their perceived susceptibility. One participant described learning that he had HIV after being called back to his provider’s office following an HIV test:

*“I was sad for a moment... and in a very odd way I felt like I had to fake some sadness... I don’t know why... because I wasn’t shocked by it.... through my life I have kind of mentally prepared myself... but in that moment I remember I felt like I had to kind of fake a little bit of sadness...but I was prepared.”*

Reasons for low perceived susceptibility included: heterosexuality, not being an intravenous drug user, and being in a monogamous relationship. Some participants described the devastation they felt after receiving the news because they never believed that HIV

infection would happen to them. One participant shared her thoughts after learning that she had HIV during a hospitalization for a back injury:

*“I got really like emotional. I was like I never ever imagined that would happen to me... .... the first thing on my mind was oh, my God. I’m going to die. I’m going to be dead within five years.”*

Generally, it was not uncommon for participants to have feelings of shock and sadness upon receiving the news. However, perceived susceptibility was found to influence both the reasons for HIV testing (and subsequent receiving of the news), and the interpretation of the news they received, particularly the level of distress the news caused the participant.

**Symptoms:** The presence of symptoms was a factor that primarily influenced how participants received and interpreted the news. Participants who experienced symptoms described the development and persistence of illness that eventually led them to seek medical attention, sometimes even resulting in a hospital admission. Participants who did not experience symptoms sometimes expressed confusion about their diagnosis.

*Receiving the News:* Participants shared that their symptoms prompted them to take an HIV test, or led to their providers’ decisions to test them for HIV. One participant described knowing he needed to get tested after persistent flu-like symptoms:

*“I was tested again..probably right around three [months later] ...it was just time. I’d had a feeling that something wasn’t right. That flu was really bad. I knew that that was it.”*

Another participant described learning about his HIV status after being admitted to the hospital for pneumonia:

*“At [the hospital] they did a battery of tests, they did two bone marrow biopsies, they*

*went as far as that, and everything kept turning up negative- negative –negative- negative- negative..... everything was negative, and I guess he finally went to the HIV test*

*and it came up positive, because he had no reason to believe I would [have HIV], because I'm not a street drug person, I go to work and I go home and that type of stuff. And then, I don't know what led him to believe to do an HIV test.....And I was shocked when it did, and he was shocked too."*

*Interpreting the News:* Several participants described their difficulty with interpreting the news due to their lack of symptoms and not feeling ill. One participant shared his experience with getting tested:

*"So I never thought that I would have had anything, I never showed any symptoms, I never recall feeling - I know it's common when someone first gets infected to have that really bad cold or flu- I don't recall ever being sick like that. So I didn't feel like I was ill or had anything. So it was surprising to hear that too, without having any symptoms that I was – had a virus in me....I never thought that I would have HIV, not once."*

Finally, some participants experienced symptoms but described their confusion about the incongruence between the symptoms that led to their hospital admission and their HIV diagnosis. One participant in the study was admitted to the hospital with leg pain, and was tested for HIV as part of a hospital-based screening program. The participant described his feelings of shock, and trying to reconcile his admission to the hospital for leg pain, and his discharge with HIV:

*“Been in shock ever since [I tested positive]. Go in for one thing, and come out with this other. Life-changing news. At least my numbers were good, and everything else with it. It's been a rough diagnosis.”*

Like perceived susceptibility, symptoms primarily influenced the beginning of the process, as participants received and interpreted the news. Symptoms prompted participants and/or their providers to test for HIV, which led to the participant receiving the news of their HIV diagnosis. It was not uncommon for positive tests to lead to confusion for participants, particularly when they did not suspect HIV as the source of their symptoms. Additionally, some participants shared about a similar confusion that resulted from a lack of symptoms at the time of diagnosis.

**HIV Information:** HIV information was influential throughout the entire process. At each stage, participants' experiences varied based on the amount of HIV-specific information they possessed or sought out. Some participants discussed already having knowledge prior to being diagnosed. Typically, prior knowledge was obtained through acquaintance with individuals living with HIV, and reflections on HIV-related information acquired via media and social interaction. Following diagnosis, knowledge was sought out in a variety of ways, including discussions with individuals living with HIV, discussions with healthcare providers, the internet, and printed materials.

*Receiving the News:* Participants described HIV information as influential in receiving the news, particularly in the choice to be screened for HIV. In addition to individuals who were self-directed in their actions to be screened for HIV, and others who were screened by providers in the inpatient clinical setting, some participants were screened for HIV because

they were prompted to do so by a source of HIV information. Participants described the influence of obtaining HIV information in their decision to get tested for HIV.

One participant described information presented in a television commercial that influenced him to get tested with HIV, and to subsequently learn that he had HIV:

*“I seen this commercial.... and it was saying ‘know your status’..... the first time the commercial came on, I paid attention to it but it kind of like passed by me. Then when it came on again about 25 minutes later, I’m like, ‘I gotta go get tested’.... ‘I gotta go get tested’.”*

Several participants discussed having feelings of disbelief when receiving the news, and seeking out information on the possibility that their HIV test was wrong. Information sources included the internet and conversations with healthcare workers. One participant described the conversation he had with a clinic nurse during a discussion about his positive HIV test result, and the internet research he did to confirm what she said:

*“[The nurse] said, ‘Your results came back that you have HIV.’.... I said, ‘Are you sure?’... and she said, ‘yes, you’re producing antibodies on both tests.’... [I said] ‘Is there any chance that the test might be wrong?’...[she said] ‘most likely not.’ I tried to search online... the main search that I was looking online for was a false-positive...on a test... that there is a very slim chance.”*

*Interpreting the News:* Perhaps more than any other stage in the process, HIV information influenced the way that individuals interpreted the news of their HIV diagnosis. The majority of participants reflected on the conceptions they held prior to diagnosis about HIV as a disease and the people who get it. Often, participants admitted to having negative

opinions and limited education about HIV. One participant described his feelings toward people with HIV prior to his own diagnosis:

*“When I first started hearing about HIV and finding out that some people have it and things like that, I mean I was freaked out myself. I was like, ‘Oh, you have HIV? Like, I don’t want to hang out with you at all. Like, I don’t want to be around you. Like, I don’t want to get it’.”*

After receiving the news, participants shared about the HIV knowledge they had at the time of diagnosis and their efforts to obtain information about HIV to gain a greater level of understanding. Sources of information included: various forms of media, conversations with healthcare providers, interactions with acquaintances living with HIV and the internet.

The media was found to profoundly impact the HIV-related information that the participants discussed. Participants described knowing about HIV through television show characters, cast members, celebrities, commercials, and HIV-related initiatives aimed at increasing HIV awareness. Individuals varied in whether the information obtained from the media was positive or negative in their eyes. Some individuals discussed only knowing about HIV through high profile individuals whom they knew had HIV and died from AIDS. One participant described his fear of HIV based on what he had seen on TV:

*“They [Robert Reid and Rock Hudson] were nice leading men on TV, and then in their dying years, they showed pictures of them after they had passed. I don’t know if you’ve seen the images or not or whatever, but they were just, like, frail.”*

Other individuals discussed knowing about HIV from seeing high profile individuals who are healthy and living with HIV:

*“[Magic Johnson] has been going good for years since he's been diagnosed, and real healthy”.*

Participants described the influence of the media as something they reflected upon after receiving the news, and often these reflections elicited strong emotional responses, particularly when the media were related to death from HIV. In many cases, individuals were not able to define specific media from which they knew about HIV. Rather, media was often discussed as a general term to describe HIV as something that one living in this day and age hears about.

One of the most common ways in which individuals found meaning in their diagnosis after receiving the news was through efforts to find information about HIV on the internet. Participants described the specific ways they used the internet to learn more about HIV so they could understand what was happening to them. Participants described the use of smart phones and computers to visit a multitude of websites to gain insight into the news they had received. The directions participants took when using the internet was often governed by whether they were provided with internet-specific resources. For example, some participants were given specific websites that clinicians recommended they visit to get more information about HIV. Participants who used the OraQuick home testing kit were provided with internet resources in a booklet that comes with the product.

The majority of participants described using search engines, specifically Google, to search out information on HIV. Participants thoroughly described the searches they performed. One participant described using the internet to find out more about HIV:

*“I need[ed] to look more up on the HIV. So I spent hours and hours on the computer just*

*looking things up. And I think more importantly reading different blogs more than anything else.....I started off at Google and just typed in... 'new HIV infection' .... And everything pops up.”*

Across the sample, innumerable websites were described that provided participants with information about the HIV disease process, medications that are available to treat HIV, images of individuals living with HIV, HIV-related statistics, personal stories and experiences of individuals living with HIV, and local HIV-specific groups, events, and venues. Participants described their use of the internet as crucial to obtaining information that taught them about HIV, influenced their feelings about the disease and the news they had received, and influencing the decisions they made about their next steps. In nearly all cases, individuals described their use of the internet as helpful as they interpreted the news of their HIV diagnosis.

As participants were interpreting the news, one of the most influential sources of HIV information were other individuals living with HIV who shared their personal experiences with the participants. Individuals living with HIV were particularly influential in helping participants to realize that their HIV diagnosis was not a death sentence. One participant shared that he immediately sought support from a friend with HIV after receiving the news:

*“I just knew that I wanted to go and talk to him because he um... he’s... he’s a really good friend and I knew that he would give me good information like... where I go from here. I went and I talked to him and he said, ‘this is what’s going to happen... you’re going to go get blood work done, you’re going to go get medicine, you’re going to start medicine.... And...all these things are going to happen.... And then you can just go on living your life’.”*



*Incorporating the News:* HIV information also influenced the way that participants incorporated the news, both psychologically and practically after being diagnosed. Many participants described how other people living with HIV helped to give them insight into living life with HIV. One participant described realizing the reality of living with HIV after an interaction with a friend who was living with HIV:

*“The day before he approached me I didn't expect to be [monitoring my health]. And then just suddenly it happens. This is – that's my reality now...there won't be a day in my life that I don't have to take a pill now or I'll be going – I'll be getting blood drawn constantly, because that's my life. I'll be on vitamins for the rest of my life.”*

Participants also shared about the use of HIV information to help prepare them for the practical realities of living with HIV on a daily basis. One participant described doing research about changes he would need to make in everyday situations:

*“I have a knowledge is power mentality. I wasn't afraid of learning about...what it meant for me and how it was going to change my lifestyle. I even worried about telling my dental hygienist and just visualizing her having to put a face mask on that she didn't used to wear before and coming to terms with feeling like my semen and my blood were toxic to my partner.”*

*Acting on the News:* After participants made the decision to pursue care, participants described using HIV information when acting on the news. Participants described using conversations with healthcare professionals, internet resources, and interactions with individuals living with HIV to learn what steps to take to practically incorporate HIV care and treatment into their lives. Participants sought out information about local HIV care facilities and the providers that work there. Acquaintances living with HIV were able to provide insight

into how the process of getting started in care would work. Participants were also able to learn about local HIV resources using the internet. One participant described visiting the website of a local HIV treatment center which influenced his decision to approach them for care:

*“I don’t remember exactly what it said... but it gave me the feeling that they knew what they were doing. They have been around and they have very experienced and qualified people that can help me. Because I didn’t want to go to some guy who for all intents and purposes, has a private practice.”*

Multiple participants described using materials they received while being tested for HIV and web-based resources to become more educated about HIV and its treatment prior to approaching their HIV care providers for the first time. One participant described reading HIV literature from his primary care provider and from the internet prior to his first appointment with an HIV provider:

*“I was thirsty for knowledge I needed to control the situation... I needed to take in as much knowledge as possible so that I’m educated about the subject... I know what to expect when my appointment happens... I don’t know what questions I should ask... I want to know what route to take next... I need to be able to look at a doctor and say are you going to be adequate for my needs?”*

Another participant discussed using web-based resources to investigate medical treatment options prior to his appointment with his HIV provider:

*“I was very concerned about the side effects. I already have pretty high cholesterol and I knew some increased cholesterol. I have a history with depression and anxiety and night terrors. Those class of drugs that increase – have the potential to increase anxiety and*

*depression and vivid dreams, I was very concerned about. I went into my first appointment with those – with that knowledge and those questions to ask.”*

In addition to HIV information obtained prior to care initiation, nearly all participants described the information they received during their new-intake consultation as profoundly helpful and influential in their decision to pursue HIV treatment. One participant shared about the profound impact that the new intake visit had on him:

*“I get back there with [New Intake Nurse], and it was the tip of the iceberg for the phrase knowledge is power because when it comes to HIV, it's absolutely what it is because I feel so much more ready to deal with this because I know more.”*

*Moving Beyond the News:* Participants described how the information they had received, particularly from their initial appointments with HIV providers was going to influence their future paths. Participants often described feeling very hopeful for their futures after meeting with HIV care providers, and described their care and treatment efforts as the necessary tool to help them achieve their goals. One participant described a takeaway message from the information provided at his intake visit:

*“I think that I will be okay....today's medicine is improved so much...the way [New Intake Nurse] explained it to me, you can also take a pill a day and it will take your T cells up and try to make your viral load very low....stuff like that to make you feel very you're going to live a healthy life..... everything is going to be okay as long as I get treated”*

### **Feedback from Others:**

Another factor found to be influential throughout the entire process was feedback from others. Feedback from others included personal interactions, conversations with other people,

and even their perceptions about others' beliefs. At each stage in the process, participants described their interactions with people in their lives, including healthcare providers, family members, friends, and even people they did not know.

*Receiving the News:* Feedback from others was very influential to how individuals with HIV experienced receiving the news. Participants often discussed their feelings about the way they were told about their HIV diagnosis. Some participants described an optimal experience in which they were provided both informational and emotional support, while others believed that they did not receive adequate support. One participant described his appreciation for the way a public health worker delivered the news:

*“It was a wonderful experience because she was just totally compassionate and totally understanding with the situation that was gonna occur. When she was gonna report the findings to me, she done it in a way that I didn't feel no harm is gonna come to me.”*

Other participants described feeling as though their provider did not offer them adequate support. One participant described his interactions with his provider the day that he was diagnosed:

*“There was no information given about where to go, what to do. Do you need counseling? Do you need help? There was no assessment taken of anything about me. ‘You're HIV positive. Here's a doctor that you might want to call to make an appointment. Have a nice day.’ Simple as that.”*

Some individuals did not receive the news in a clinical environment, but instead, chose to take the test at home. Several individuals shared that they wanted to have someone else with them when they took the test at home. Such people included siblings, partners, and

friends. One participant described learning about his HIV status with a friend while taking a home test:

*“He said that mine was positive. And then like I said, I just started crying. And they both held me, and as I’m bawling my eyes out and getting snot and tears everywhere, all over their shirts and just whatever. They just – they were there for me when I was having a low point. And we were close before, but we’ve been closer since.”*

*Interpreting the News:* Participants also described the effect that feedback from others had as they interpreted the news. Often, individuals speculated on what other people were going to think about them now that they had HIV. One participant described his concerns about the opinions of others while at a social gathering with loved ones who did not know he had HIV:

*“I am HIV-positive. None of these people know I’m HIV-positive... but I’m HIV-positive. And I thought what is [friend’s] family going to think when I tell them... They are like my second family even more than my first family. I mean, they are so close to me. What are they going to think? When am I going to tell them? Will I ever tell them?”*

Other participants shared their fears about having HIV based on what they believe society generally thinks about people with HIV. As one participant stated:

*“A whole bunch of things that go through your head... but it’s always fear of judgment some people attribute it to being a gay disease. Some people attribute it to just being flat out nasty... not having protected sex....I felt fear of judgment...[when ]you [are] dealing with a complete stranger, you have nothing to fear. But when you’re dealing*

*with somebody that know your status, you don't know their opinion or their beliefs on HIV."*

Another participant shared:

*"I thought people were just going to reject me just because of the diagnosis and not actually get to understand me as a person... more like a presumption like, 'oh you're HIV positive... you're ... you're a slut, you're like.... you're dangerous... you don't take care of yourself'. Things like that."*

Participants also shared about the impact that positive feedback from others had on their ability to interpret the news. One participant discussed his healthcare provider talking to him about HIV stigma:

*"What I was most afraid of in that moment was the stigma part of it because I was thinking about that... And she was very quick to reply with 'the only stigma that it has is the stigma that you give it. So it doesn't matter what other people are thinking... You need to be empowered'."*

Several participants described interactions with friends and family after receiving the news that helped them as they interpreted what their diagnosis meant in their lives. One participant described that he felt guilty about getting HIV, and his sister helped him to get perspective:

*"[She said] 'Don't walk around moping and mad and feeling like it's your fault... it can happen to anybody.' .... A weight was lifted off my shoulder when she told me that... because...somebody was already in my corner... I was already... I was already took under somebody's wing... somebody actually cares about me."*

*Incorporating the News:* Feedback from others was also very influential in the incorporating stage of the process. Participants shared that healthcare workers, friends, family members, and acquaintances living with HIV helped them to realize that HIV was not a death sentence and gave them insight into their reality of living with HIV. One participant shared that his sibling encouraged him to realize that his HIV status did not change him as a person, but rather added a component to his life:

*“[She said] ‘don’t let you having this virus affect your life.’ She said, ‘the only thing that’s going to be different about you having this is you’re going to be taking medicine’.”*

Participants also described the impact of receiving feedback from individuals living with HIV, in particular, observing their ability to lead normal lives. Often, it was the feedback from these individuals that truly defined that HIV was not a death sentence for participants. One participant shared about observing his friends with HIV leading healthy lives.

*“I’m amazed at how many people that I know that are HIV positive...that has turned into a really good thing for me...they’re like living a functional healthy lifestyle, and that has become very helpful.”*

*Acting on the News:* Feedback from others was often crucial to participants as they took action to initiate their care. One of the greatest challenges for many of the participants was taking their first steps into HIV-specific healthcare. Often, participants were fearful about having to discuss their HIV status for the first time since being diagnosed. One participant described his anxiety about calling the HIV treatment center for the first time:

*“I felt nervous because I made the phone call and I got a secretary... A general person.... And I remember I was going to have to say the words ‘I was diagnosed HIV-*

*positive can you connect me to someone who can help me?’... it made me feel bad that this person is going to know that I’m HIV-positive and they are going to judge me now.”*

Similarly, multiple participants experienced anxiety upon entering the HIV treatment center for the first time. As one participant shared:

*“I’m thinking, ‘Is this doctor going to like me? Am I going to like this doctor? Is the nurse going to look at me this kind of ways?’ You understand? Is other people in the lobby looking at me wondering why I’m [here]?”*

Some participants described being championed by people in their lives as they prepared to go into care. One participant shared about his mom helping him overcome his fear of talking to HIV healthcare workers for the first time about his HIV status:

*“My mom is like my cheerleader. We were on the way there and she’s like I can’t tell. I cannot fathom walking up to a stranger and telling them this. She says, ‘no you’re gonna walk up and you’re gonna tell them, and we’re gonna start this. This all starts today’.”*

Participants discussed interactions with healthcare workers that helped them in the care initiation process. Such individuals included public health workers, clinicians, and office workers. One participant shared about the nurses and office workers at the HIV treatment center and the impact they had during the care initiation process:

*“She talked to me like I was a normal person... she asked me what I do... why I was there... She just made me feel at ease... She made conversation with me... it wasn’t about you’re here for the first time as an HIV-positive person... It was... let’s have a conversation and that’s what made me feel really good.”*



*Moving Beyond the News:* Participants shared that feedback from others was instrumental in helping them to move beyond the news. In addition to their own thoughts and feelings about their life goals, participants shared that friends, family members, clinicians, and acquaintances provided them with encouragement and helped them to feel hopeful as they moved forward. One participant shared the encouraging words he received from his friends:

*“ [My friends] have been telling me... ‘Get on medicine. Just go to the doctor...get help... do that as quickly as you possibly can, and you’ll be fine. You can do whatever you want to do.’ ”*

Finally, another participant shared advice given to him by his family regarding his future life with HIV:

*“‘Be strong... you’ve still got a full life ahead of you...do what you need to do to get what you want... having HIV does not stop you... does not stop the show. All it does is make you look at life more carefully’.”*

## **DISCUSSION:**

The data in the study revealed the process of translating the news. Following diagnosis, participants progressed through a series of stages from the time they were diagnosed with HIV to the time that they initiated HIV care. These stages included: receiving the news, interpreting the news, incorporating the news, acting on the news, and moving beyond the news. As they progressed through the process, participants’ experiences were influenced by their perceived susceptibility to HIV, the presence of symptoms, HIV information, and feedback from others.

The findings in this study are in line with the findings of current research on psychosocial factors that influence the initiation of care by individuals living with HIV. The

results of the present study suggest that the psychosocial process is defined by the movement from negative beliefs (bad news) to hopeful, positive beliefs (good news). Perret and Biley (32) yielded similar results in the *Negotiating Uncertainty Theory*, in which eight participants described their transition into life with HIV. Similar to the present study, the investigators uncovered a process in which individuals move from hopelessness to optimism following HIV diagnosis (32).

Participants' stories about incorporation complements findings by Mallison et al. (33) whose Maintaining Normalcy Theory. Participants in the study (n=27) demonstrated that successful engagement in HIV care is influenced by contending with obstacles and assimilating HIV care and treatment into their everyday lives (33). Similarly, incorporation allowed participants to begin the process of moving forward after being diagnosed with HIV.

As evidenced at each stage of the theory, participants' experiences about initiating care were often shaped by feedback from people in their lives, including family, friends, significant others, and healthcare workers. This finding is closely aligned with current literature that suggests that the presence of social support increases the likelihood that individuals will successfully engage in HIV care with minimal distress (17, 18, 34, 35). When describing the experience of receiving the news, some participants described the experience as negative when they did not feel the provider was supportive or understanding about the diagnosis. This finding is also well-supported in current literature on provider-patient dynamics that suggests that negative interactions with healthcare workers has the potential for clients to lose trust in providers and can deter the care initiation process (14, 21, 36-38). Finally, participants expressed the importance of their first HIV care visit to their ability to obtain HIV knowledge and to move beyond the news. This finding is similar to findings by

McCoy et al.'s (39) investigation in which individuals diagnosed with HIV cited their first HIV care visit as critical to their coping process following HIV diagnosis.

The present study contributes to the current state of the science in several ways. First, while investigations to identify specific psychosocial factors that influence HIV care initiation have been conducted, no study to date has explored the specific psychosocial process of HIV care initiation. Second, while the impact of patient-provider dynamics on medication adherence has been investigated, this study contributes insight into the impact of patient-provider dynamics during diagnosis and referral. Finally, the present study established that a crucial component of the HIV care initiation process was each participant receiving not only the news of their HIV infection at diagnosis, but also the importance of in-depth discussion about HIV not being a death sentence. This was a critical juncture that often prompted participants to begin searching for HIV-specific healthcare.

The present study has several limitations. Although the majority of participants were interviewed within two months of their diagnosis, the retrospective design allows for error in recall of events and details shared by participants. The majority of the study sample were Caucasian men who have sex with men. Although the study team did not identify significant differences based on gender or race/ethnicity, the study is limited by underrepresentation of women and racial/ethnic minorities. Finally, the findings of the study are not generalizable to the general population, but rather, are transferrable to similar samples.

The results of this study provide a framework for clinicians who are working with newly-diagnosed HIV patients. Participants often felt emotionally distressed upon receiving the news, but reported feeling much better about their situation when they learned that a) HIV was not a death sentence, and b) there are many options for treatment despite any

preconceptions. As such, clinicians should be diligent in providing both emotional and informational support to people newly diagnosed with HIV. Finally, participants in the study consistently sought out information using various media in order to learn more about HIV. Clinicians should provide newly diagnosed individuals with reliable, literacy-appropriate resources, and encourage patients to become actively involved in the initiation of their care and treatment.

Participants consistently cited acquaintances living with HIV as an invaluable source of support. Future research should examine the impact of developing and implementing HIV support interventions leveraging participation from individuals living with HIV. Partnership between clinicians and individuals living with HIV will help to provide optimal informational, emotional, and social support following HIV diagnosis. Since so many of the participants discussed using the internet as a source of information following diagnosis, future research should determine the impact of web-based interventions that are aimed at promoting transition into HIV care for individuals newly diagnosed with HIV. Finally, the results of the study provide evidence that micro-system level interventions should be developed to transition individuals diagnosed in the primary care setting into HIV care.

## **CONCLUSION:**

HIV treatment presents both individual and community-level health benefits. Gaining a greater level of understanding of the process of HIV care initiation will result in a greater number of individuals being linked with care, and by extension, provide a strong contribution to stopping the spread of HIV.

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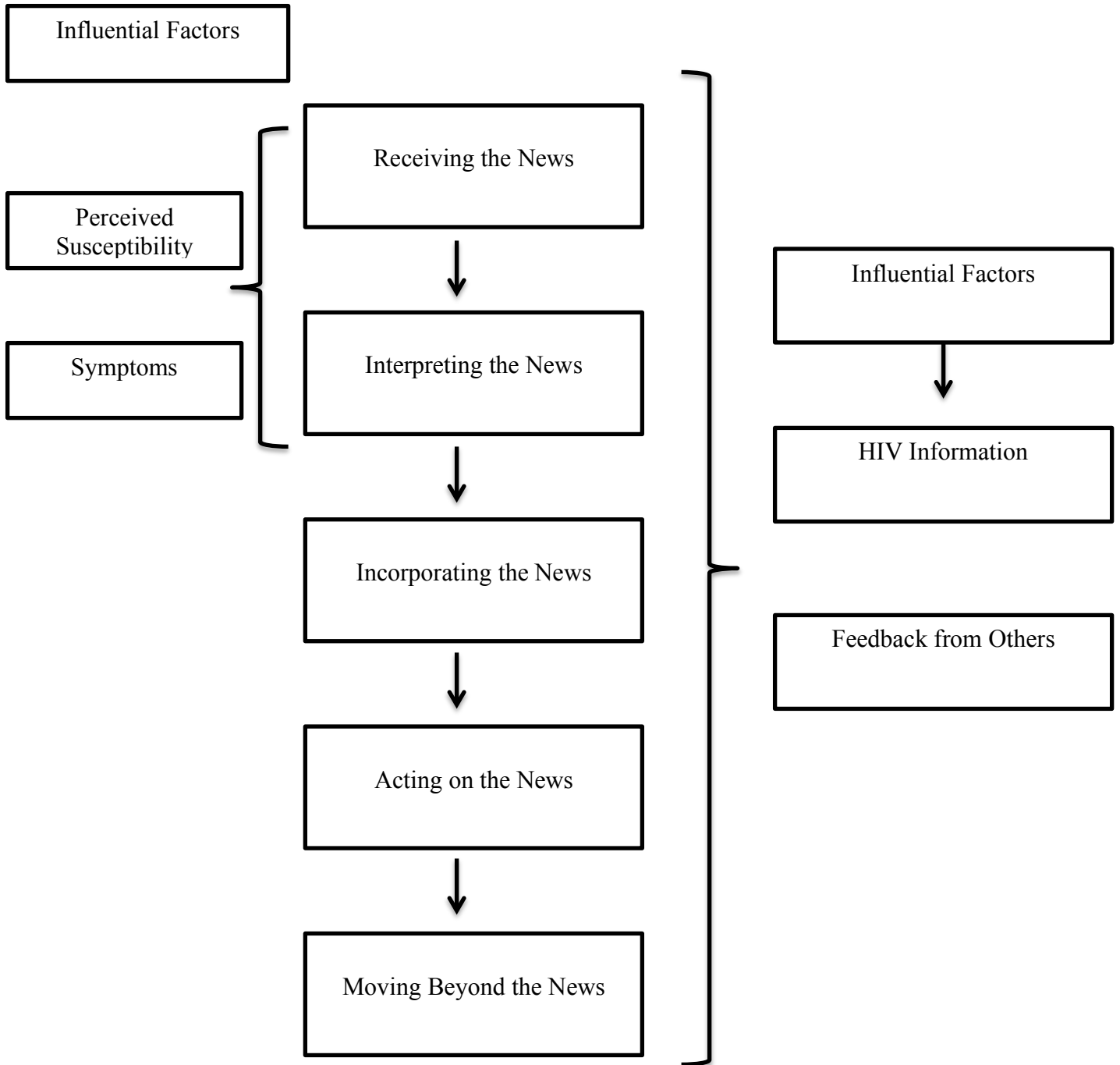


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Table 1: Sample Characteristics

<b>Category</b>	<b>Type</b>	<b>Sample n (%)</b>
<b>Gender</b>	Men	28 (93%)
	Women	2 (7%)
<b>Age</b>	18-24	8 (27%)
	25-34	11 (37%)
	35-44	3 (10%)
	45-54	6 (20%)
	55-64	2 (7%)
<b>Race/Ethnicity</b>	African American	6 (20%)
	Caucasian	20 (67%)
	Native American	1 (3%)
	Hispanic/Latino	2 (7%)
	More than one Race	1 (3%)
<b>HIV Exposure Category</b>	MSM	26 (87%)
	Hetero. Contact	3 (10%)
	IDU	1 (3%)
	Other	
<b>Timeframe from Diagnosis to HIV Care Initiation</b>	< 1 Month	6 (20%)
	1-3 Months	20 (67%)
	3-6 Months	1 (3%)
	6-12 Months	2(7%)
	>12 Months	1 (3%)
<b>HIV Treatment Status</b>	Started HIV Medication	13 (43%)
	Not Started HIV Medication	17 (57%)

Figure 1: Translating the News



### **Manuscript 3**

## **Use of internet and social media in care and treatment decisions by individuals diagnosed with HIV**

Perazzo, J.

### **Abstract**

Individuals living with HIV have more treatment options than ever before, and engagement in HIV treatment provides benefits to both the individual patient and the community. Presently, there are still a significant number of individuals diagnosed with HIV who are not engaged in HIV care. Today, the internet and social media (ISM) are commonly used by individuals living with HIV for multiple reasons, including information-seeking and social support. However, no studies have examined the specific ways individuals newly diagnosed with HIV use ISM in their care and treatment decisions. The purpose of this study was to analyze interviews with 23 individuals newly diagnosed with HIV and determine how they used ISM in their care and treatment decisions. Qualitative content analysis was conducted and revealed that individuals used ISM in five primary ways: to establish the need for care, to seek out care, to interpret health information, to prepare for treatment, and for motivation for future care and treatment. The results suggest that individuals diagnosed with HIV may use ISM for a wide variety of reasons, many of which may influence their care and treatment decisions. Clinicians should leverage ISM resources as a tool for educating and empowering individuals with HIV as they cope with their diagnosis and start HIV care and treatment.

## **Introduction:**

The Centers for Disease Control and Prevention (CDC) report that new cases of HIV continue to occur at a rate of approximately 50,000 new diagnoses each year (1). In the nearly 35 years since HIV was discovered, there has been a tremendous evolution in the way society obtains, interprets, and uses health-related information. A major facet of the evolution is the use of the Internet and Social Media (ISM) as tools for obtaining health information and connecting with other people for health-related purposes (2). Researchers have established that people living with HIV often use ISM, but little data is available to inform scientists and clinicians about specific ways that ISM influences their care and treatment decisions. The purpose of this article is to present findings from a study in which the research team interviewed individuals recently diagnosed with HIV, and determined how they used ISM during the process of care initiation.

More than one million people living in the United States have been diagnosed with HIV (1). The extraordinary medical advancements that have occurred since the beginning of the epidemic have revolutionized HIV care and treatment. The advent of antiretroviral therapy (ART) marked the transition of HIV from a fatal disease to a chronic and manageable condition (3, 4). ART thwarts the progression of HIV disease and decreases the likelihood of infected individuals advancing to acquired immunodeficiency syndrome (AIDS; 5). More than ever before, individuals with HIV are achieving full life expectancy and reporting improvements in quality of life thanks to medical intervention, making ART the gold standard of HIV treatment (6-8).

Unfortunately, recent data suggest that many individuals diagnosed with HIV will fail to link with a healthcare provider following diagnosis (9, 10). Despite the promise offered by

ART, US health authorities indicated that in 2012, nearly 28,000 individuals were diagnosed with AIDS (1), and only 28% of Americans living with HIV were achieving viral suppression (11, 12). Viral suppression, also known as an undetectable HIV status, is an indicator of optimal treatment outcomes that are achieved through consistent ART engagement (11). These data identify the crucial need for scientists to investigate phenomena that influence health-specific actions taken by people living with HIV.

Approximately 87% of individuals in the United States use ISM, and an estimated 72% use ISM as a source of health-related information (2). Online, individuals are able to access a seemingly endless array of resources, including descriptions of diseases and their risk factors, treatment recommendations, personal experiences and testimonials of individuals living with diseases, and social/emotional support (2). People living with HIV are no exception in their use of ISM. Using a variety of methods, researchers have discovered that many individuals who are diagnosed with HIV use ISM as a source of information and social support (13-17). The results of these investigations have indicated that ISM has the potential to be an invaluable resource for people living with HIV.

For example, a thematic analysis of online forum entries by Coursaris and Liu (18) provided rich insight into ISM as a tool for individuals to meet other people living with HIV from whom they can get support. The results of the investigation indicated that these individuals most often use web-based resources for information and emotional support. Courtenay-Quirk et al. (19) conducted a mixed methods investigation into the perceptions of HIV-related websites by a sample of individuals recently diagnosed with HIV. Participants in the investigation were able to provide insight into specific types of websites and content that are important to people living with HIV following diagnosis. Among the most important to

participants were websites that provided information about medical treatments (19). The results also demonstrated that ISM can be consistently used as a source of health-specific information over time.

These and other investigators have established that ISM has often been a beneficial source of information for people living with HIV, particularly with regard to treatment options (14, 18-20). In addition, ISM presents a forum within which individuals can gain social and emotional support from other people living with HIV (14, 15, 18). While the benefit of ISM to gaining information and social support has been established, a gap in current knowledge is evidence about specifically how people living with HIV use ISM in their care and treatment decision-making. The current study will contribute to the state of the science by providing insightful qualitative data about how a group of individuals diagnosed with HIV used ISM in their care and treatment decisions.

## **Methods**

### *Setting and Participants:*

Men and women (n=30) diagnosed with HIV were recruited from April to December 2014 from an urban, Ryan White funded HIV treatment center in a Midwestern city. Participants were recruited following new intake and research visit appointments at the treatment center with the assistance of nursing staff members who acted as gatekeepers for the research team. Individuals were included in the study if they were at least 18 years of age, had a confirmed positive HIV serostatus, and were seeking care for the first time. As the study progressed, theoretical sampling was used to obtain four participants who had been diagnosed for more than five years. The study team determined that individuals with longer experience could reflect back on the care initiation experience and provide insights about the process that

would clarify information provided by recently diagnosed participants. All study activities were approved by the University of Cincinnati Institutional Review Board (IRB).

*Procedures:*

Following approved consenting procedures, in-depth, audiotaped interviews with participants took place in a private room within the HIV treatment center. Individuals were asked a universal question regarding their personal experiences during the time between receiving their HIV diagnosis and their initiation of HIV care (see Table 1). During the interview, when the participant mentioned use of ISM, the researcher would pursue a line of questioning to gain greater insight into the participant's use of ISM. The interviews lasted between 45 minutes to two hours. Following the completion of interviews, participants were compensated for their time, and the interviews were transcribed for data analysis.

*Analysis:*

Qualitative content analysis of the transcribed interviews was completed to identify data to describe how participants used ISM when making care and treatment decisions. Content analysis involves a process of data unitizing, in which specific coding units are identified for analysis (21). Interview content related to the use of ISM in care and treatment decision-making was identified and isolated for analysis. Twenty-three (76%) of the 30 participants discussed ISM in care and treatment decision-making. Specific excerpts, or coding units (n=91), in which ISM was discussed, were placed into a table and reviewed for categorical distinctions, which is a process of separating the coding units into various 'families' of data based on their specific content (21; see figure 1). Once categories had been identified, specific coding units were selected as exemplars for each category.



### *Results:*

The final analysis included interview data from 23 participants. Table 2 provides an overview of the sample characteristics. Participants varied in the timeframe that elapsed between the time they were diagnosed and the time they initiated HIV care. Four participants initiated care less than one month following diagnosis, sixteen participants initiated care between 1-3 months following diagnosis, two participants initiated care between 6-12 months following diagnosis, and one participant initiated care three years following diagnosis. The analysis revealed that ISM influenced individuals in five common ways with regard to their care and treatment decisions: a.) establishing the need for care, b.) seeking out care, c.) interpreting health information, d.) preparing for treatment, and e.) providing motivation for future care and treatment. Each of these ways in which ISM was used by individuals recently diagnosed with HIV will be discussed and illustrative study participant quotations will be included.

#### **Establishing the Need for Care:**

Some participants discussed that they used ISM from the very beginning of their experience with HIV. In several cases, decisions to get an HIV test were made following a series of searches online to explain symptoms that they were having. One participant reflected on using search engines to research his symptoms:

*[I] read on the internet saying that you get these kind of symptoms or stuff like that when you get infected but I only got like a flu kind of thing which that made me think about it [having HIV].*

Participants shared that at some point they identified HIV as a potential source of symptoms, which led them to decide to seek HIV care. One participant described his decision to get tested being influenced by information he read about having persistent canker sores:

*I just put in the word canker sore ..... I looked up online what causes them, and HIV was one of the symptoms that causes them. So I said let me just make sure because it's been a while since I've been tested.*

Upon receiving a positive HIV result, it was common for participants to investigate the likelihood that the test they took was wrong. One participant described his search for alternative explanations for his positive HIV test result.

*I tried to search online... the main search that I was looking online for was a false-positive...on a test... that there is a very slim chance.*

ISM, specifically an electronic medical record portal, was the medium through which two of the 30 participants described learning about their HIV status for the first time after being tested by primary care providers unaffiliated with the HIV treatment center. As one participant shared:

*I was like I'm just gonna check [Online Medical Record System]. So I get online and it said like 'HIV-1: positive' ....when I looked at it, I was like, Oh....I probably shouldn't have found out this way so I kind of just laid there in bed for like an hour and a half*

It was often during the immediate post-diagnosis time period that individuals used ISM to gain a better understanding of HIV and what was happening to them, a finding consistent with multiple other ISM investigations. Participants shared about coming to the conclusion that based on the information in front of them, it was best for them to take action.

*I just started searching ‘what do I do when I’m HIV-positive?’ Or ‘I’m HIV- positive what happens now?’. I’m typing these things into the Google search bar... and I’m sifting through the websites*

### **Seeking Out Care:**

Participants shared that they used ISM to seek out care in two primary ways: locating a facility, and choosing a provider. While many participants discussed that they were referred to specific locations for HIV care, many discussed using ISM to locate and establish contact with specific facilities. ISM provided information about specific facilities, which influenced the decisions of some participants as they sought out care. Participants also shared that they used ISM to learn about specific providers. Participants were able to learn about various providers by using search engines to read about the backgrounds of clinicians. One participant shared that information learned through ISM about care providers increased his confidence in their abilities, and ultimately led to his decision to seek care from them.

*I searched for [Physician’s Name].... And then the name of the facility.....I did a little [search] on them also and just read the little blurb about them on the main page..... I just said ‘I’m going to go with them hopefully I’m making the right choice’.... So that’s why I ended up calling them the next day.*

In participants’ efforts to seek out care, ISM was a source of information that could answer a variety of questions about HIV treatment facilities and the people who work there. Some participants described feeling that they were making more informed decisions regarding their care after doing their own research. As one participant shared:

*I needed to take in as much knowledge as possible so that I’m educated about the subject... I know what to expect when my appointment happens... I don’t know what*

*questions I should ask... I want to know what route to take next*

### **Interpreting Health Information**

Multiple participants in the study described their first encounters with health care professionals. In many cases, participants were not immediately started on HIV treatments, but rather, had laboratory analyses completed for genotyping and the assessment of disease progression. Participants shared about their experiences with learning ‘their numbers’, and using ISM to help them interpret the results. Individuals described their thought processes as they compared their lab values to those discussed by various sources of ISM.

Although it is questionable whether many of the participants conceptually understood biomarkers such as CD4+ count and viral load, many participants described comparing their own lab results to information they read online.

*I checked a bunch of different stuff, I checked symptoms, helplines, um... where you are at with the disease... that's how I figured I had AIDS because I had thrush... and that's typically between 200 and 100 or lower.*

One participant shared about his decision to delay care for one year because his CD4+ count was higher than the treatment threshold he read online:

*The U.S. Guidelines. So that was basically it. And they said they don't want you to really start until you hit the 500 mark and I knew I wasn't anywhere near that yet so it wasn't that big of a priority right now.*

### **Preparing for Treatment:**

Another use of ISM widely discussed by participants was their research about medication options. In many cases, participants discussed that they used ISM to gain information so they could actively participate in discussions regarding their care. Participants

shared about specific pieces of information that they found online that influenced their perceptions of different medications. One participant describes how a pre-populated search about a specific medication altered his perspective of the usefulness of the medication.

*I start to type something and it finishes, so I typed [medication name] and it finishes, [medication] not good for HIV.’ So I’m like oh, no... and then I pull it up and it says [medication] not the best option for HIV*

In addition to information obtained from HIV-specific websites, participants described learning about medication options through the personal experiences shared by people living with HIV who used social media. Participants shared that the stories they read about other people taking certain medications often influenced their decision about whether they would choose to take those medications. One participant discussed how he searched for personal experiences from people who took medications from a list he was given at his intake appointment:

*I’ve sat at my computer for hours looking up [specific medication]....I want to know long-term side effects. I wanted to know less about the side effects from the drug study and more about personal experiences from people. How has it affected you? What were your side effects? I don’t want to read ‘you could have diarrhea, you could have headaches, you could have jaundice’...I want to know from the real people what did you deal with on this medication? I did that on every medication that was on that list.*

All of the participants stated that they were going to ultimately place the decision about medication in the hands of the provider. However, in nearly all cases, participants

described ISM as providing them with information that made them feel empowered as they approached healthcare professionals for discussions about their treatment.

### **Providing Motivation for Future Care and Treatment**

While the information obtained through ISM varied across the study sample, almost all participants indicated that the information obtained through ISM motivated them to stay in care and adhere to treatment. Both informative websites and personal support through social media played a role in demonstrating the benefits of HIV care and treatment. Participants described others' stories about the positive impact that care and treatments had on their lives, and how it motivated their efforts to initiate and engage in their care. One participant shared about reading about someone his age online, and making the decision to pursue care.

*It just felt a lot like this similar story of what I had and that's what really was the turning point of this is – I need to do this now otherwise who knows down the road if I wait too long if I'm going to have my immune system be compromised.... I felt like I needed to take control of this virus and keep it under control if I wanted to live my life like I wanted to.*

### **Discussion**

The results of the study provide valuable insight into specific ways in which individuals with HIV use ISM in their care and treatment-related decision making. Consistent with recent literature, individuals in the study reported using ISM for health-related information and social support. Participants described ISM to search information on symptoms they were experiencing, which led in time to their decision to get tested for HIV, and to establish their need for care. ISM was also used to help participants locate a facility and provider for care. As participants told their stories about initiating HIV care, they described using ISM to learn more about HIV and interpret health information (i.e. biomarkers). The

information they learned was described as a prelude to discussions with providers about their questions, concerns, and decisions regarding specific treatment. Finally, participants used ISM to learn more about other people living with HIV, and in all cases, drew hope and motivation from the information they obtained.

While previous studies have demonstrated the profound impact that online resources have on the ability for people living with HIV to obtain information (19, 20) and receive emotional support (15-18), much less is known about specifically how ISM impacts care and treatment decisions. The evidence generated in this study carries both clinical implications and directions for future inquiry.

### **Clinical Implications:**

It is important for clinicians to be aware of and understand the clinical implications of the use of ISM in the treatment decisions of people living with HIV. In some cases, individuals used ISM with an aim of determining whether their HIV test was a false positive. These data exemplify the importance of post-diagnosis counseling, and the importance of appropriate clinical follow up after HIV testing occurs. If the test is completed outside of the clinical setting, individuals who doubt their test results should be encouraged to seek clinical consultation to ensure confirmatory testing is completed. Failure to address doubts or distrust of test results could lead to decisions to forego the decision to pursue care. Web-based information resources should make sure they address false-positives, as it may be one of the primary ways individuals newly diagnosed with HIV may receive the information (19).

Healthcare systems should maximize ISM leverage to provide up-to-date and accurate information about their facilities and providers. The data from this study suggest that some individuals make care decisions based on information they are able to obtain online.

Participants shared that when they learned information online about the HIV disease, particularly biomarkers, that they would often compare their own baseline results to information they read. Regardless of the authenticity of their interpretations, individuals who observe that they have biomarkers that are discordant to normal range values based on their online research can experience acute distress. Conversely, participants who see that their biomarkers are within the normal range may lack a sense of urgency regarding when they should link with a healthcare provider. Clinicians should provide crucial patient education regarding the HIV illness, but should also not hesitate to leverage web-based resources that they deem reliable, safe, and understandable. While it is certainly possible that an individual will encounter misinformation online, there are reliable resources that clinicians can direct patients to in the event that the patient wants to research on their own.

Another common finding in the data was the influence that ISM had on treatment-specific decisions. Recent literature has indicated that web-based resources geared toward medical treatment options are considered both important and useful to people living with HIV (14-16, 18, 19). Participants in the present study reported using both informative websites and social media to learn technical information about medicines (i.e. side effects), and to read about other peoples' personal experiences with specific treatments. Clinicians should actively seek out opportunities to answer patient questions about specific treatments. Clinicians can likewise provide patients with direction toward reliable web-based resources (13).

### **Directions for Future Inquiry:**

The data reported in this study open up many avenues for future research. Some individuals in the study chose to search for help online because they were able to obtain information without breaking their anonymity. In some cases, individuals began searching



online for explanations for symptoms. In many cases, this was a repeated process in which they eliminated a variety of other potential causes for their symptoms before determining that HIV may be the cause. Researchers should partner with people living with HIV to explore the processes by which individuals seek out symptom-specific information online prior to diagnosis, and determine what factors ultimately lead to the decision to get tested.

Participants shared that ISM was often used to collect information about HIV treatment locations and about HIV providers. Future research should examine specific attributes about the facility-specific web resources are most useful to newly diagnosed individuals, and determine what information about providers is important to individuals preparing to seek care. Future research should evaluate the quality of web-based resources regarding medication, and develop web-based interventions aimed at educating newly diagnosed patients about their treatment options.

Finally, participants reported that they felt encouraged when reading the experiences of individuals who were successfully engaged in treatment. Such individuals shared about their experiences initiating care and starting treatment, and included honest and valuable feedback that participants expressed a desire to know. Researchers can partner with clinicians in the creative development of evidence-based, patient-centered web resources at the microsystem level (i.e. a treatment center's website). People living with HIV should be instrumental in the development of such resources in order to gain crucial insight and to reach the target population.

**Limitations:**

The present study is not without limitations. While qualitative methods are unmatched in facilitating the collection of detailed and insightful detail, the generalizability of the

findings is limited. The study sample primarily included a demographically high-risk group (MSM), but had limited representation of women and racial/ethnic minorities. While other studies examining ISM use have focused on such populations (16, 18), future research into ISM use in care decision-making should focus on obtaining a greater level of insight from underrepresented groups.

**Conclusion:**

People living with HIV encounter a myriad of challenges following diagnosis. ISM has become a means of gaining both information and social support. In addition, care and treatment-related decisions made by individuals following diagnosis have been influenced by information discovered online. Clinicians and researchers should seize every opportunity to use this powerful resource to provide crucial education, direction, and support to individuals diagnosed with HIV.

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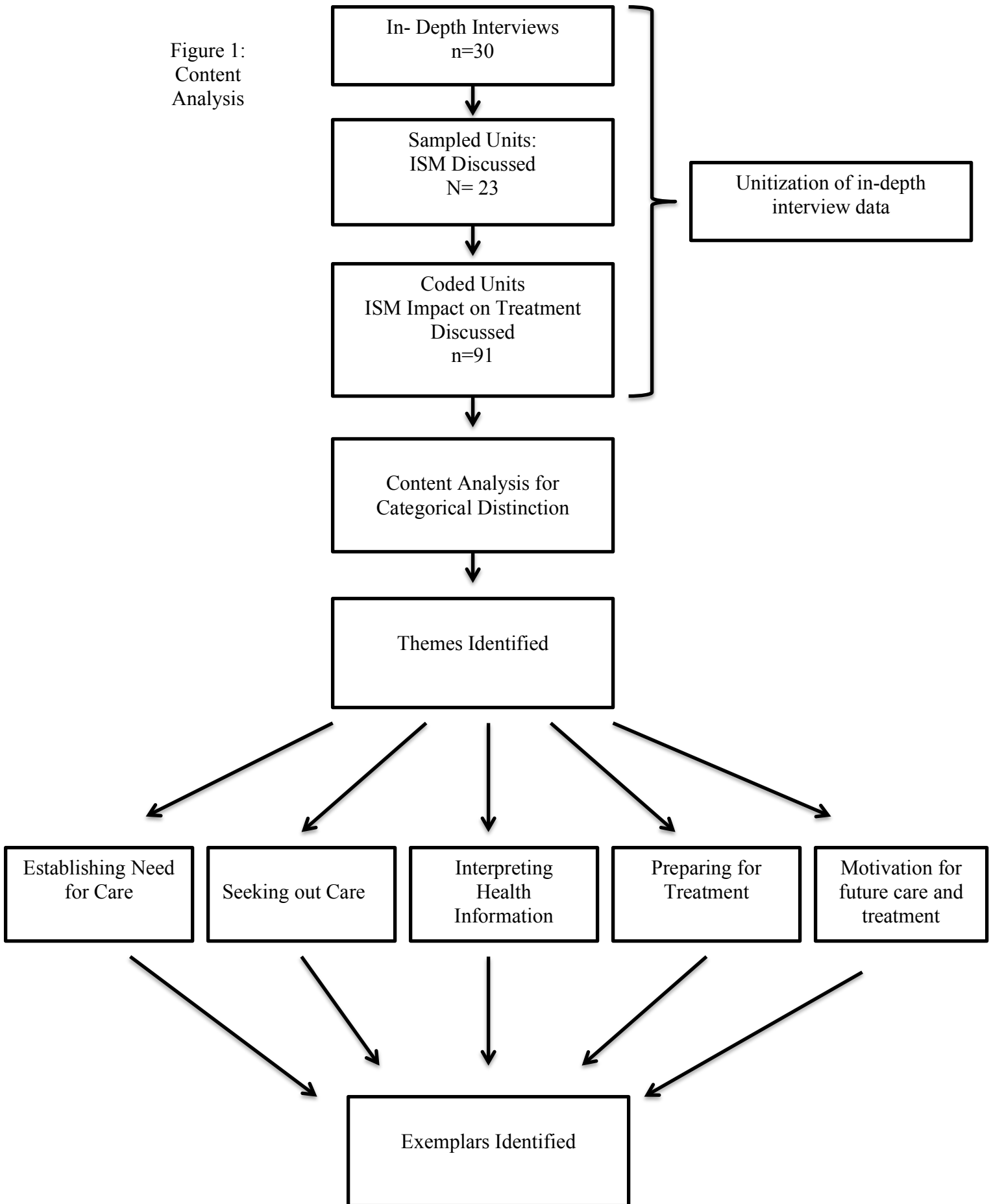
Table 1: Interview

Universal Question: You were diagnosed with HIV on [Date]. Tell me your story about how you went from learning that you had HIV to coming here to receive care.	
ISM-Specific Statement	Secondary Question
Statement about searching for information online	Walk me through your search online. What terms did you use? What kind of results did you find?
Statement about reading information online	Tell me about the information you read online. Did anything particular stick out to you from the reading?
Statement about corresponding with someone or writing in a blog online	Tell me about the responses you received from [person/people]

Table 2: Sample Characteristics

Characteristic	Sample: n (%)
Sample Size	N = 23
Gender	Male 22 (96%) Female 1 (4%)
Race/Ethnicity	African American: 5 (22%) Caucasian: 15 (65 %) Hispanic/Latino: 2 (9%) Native American: 1 (4%)
Exposure Category	MSM: 20 (87%) Heterosexual Contact: 3 (13%)

Figure 1:  
Content  
Analysis





## **CHAPTER 7: MANUSCRIPT 4**

### **The patient with HIV: Guidelines for primary care providers**

Perazzo, J.

#### **Abstract**

More than one million people in the US are living with HIV. While astonishing progress in HIV treatment has been made in the last 30 years, less than 30% of people living with HIV are receiving the full benefit of treatment. As primary healthcare becomes more available to individuals at risk for HIV, primary care providers will continue to play a pivotal role in screening and identifying individuals living with HIV, and helping to create an optimal pipeline into HIV care. This article provides recommendations and insights that can be used by primary care providers when providing care to people who are at risk or who test positive for HIV. The recommendations are based on current literature and a study in which 30 individuals living with HIV shared their stories about being diagnosed with HIV and initiating HIV care.

## **HIV: A Snapshot**

There are currently more than one million people living with HIV in the United States <sup>1</sup>. Since the dawn of the HIV epidemic in the early 1980s, monumental advances in HIV treatment have been made, resulting in the transformation of HIV from an invariably fatal infection to a manageable chronic disease <sup>2</sup>. Unfortunately, new HIV infections continue to occur at a rate of approximately 50,000 new cases annually in the U.S. <sup>1</sup>, and disproportionately impact African Americans, Latinos, men who have sex with men (MSM), and individuals of low socioeconomic status <sup>1,3</sup>. Members of these groups have historically contended with varying access to healthcare services, resulting in an inability for some to benefit from recent advances in HIV treatment <sup>3</sup>. However, recent changes in American healthcare policy, specifically the passage of the Affordable Care Act (ACA), have provided the opportunity for individuals to receive healthcare services who were previously ineligible <sup>4</sup>.

While HIV has had a profound impact on society as a whole, specific groups have been particularly affected by the problem (see Figure 1). Men who have sex with men (MSM) are the group at highest risk for HIV infection, accounting for approximately 64% of new infections, and nearly 80% of new infections among all men. More than one half of all people with HIV currently living in the United States are MSM. Heterosexuals comprise approximately 26% of new infections, with woman comprising more than 80% of infections through heterosexual contact, and 20% of new infections. Finally, injection drug users (IDUs) are at risk for HIV, accounting for an estimated 8% of new HIV infections and an overall total of 15% of all people living with HIV <sup>1</sup>.

When examined from a racial/ethnic perspective, HIV impacts African Americans more than any other group in the United States <sup>1,3</sup>. African Americans comprise less than 15% of the

total US population, but account for nearly half of all new infections, and approximately 40% of all Americans living with HIV. Young African American MSM are a group that is, perhaps, most profoundly impacted by HIV, as they account for the largest increase in new diagnoses of any specific subgroup<sup>1</sup>. Disparities also exist within the Latino community. Individuals in the Latinos account for approximately 16% of the US population, but more than 20% of new HIV infections<sup>1</sup>.

The increased access to primary care services by at-risk populations presents opportunities for primary care providers to identify individuals with HIV and facilitate entry into HIV care<sup>4</sup>. In addition to obtaining up-to-date knowledge on current testing guidelines, it is crucial that primary care clinicians are also knowledgeable about factors that facilitate or impede the ability of newly diagnosed individuals to optimally transition into HIV care. The purpose of this article is to provide primary care clinicians with an evidence-based resource that can be used to facilitate that transition.

The author conducted a study in which in-depth interviews with 30 people living with HIV were conducted to learn about their experiences with the process of initiating HIV care. The majority of the individuals in the study (n=26) were newly diagnosed, while the remaining four had been on HIV treatment between four and 24 years and were able to reflect back on their experiences with initiating HIV care. Many of the individuals shared that they learned about their HIV status from their primary care provider, and described the impact that the interaction with their provider had on their decision to pursue care following diagnosis. The author also examined current literature on psychosocial factors that influence HIV care initiation to inform the recommendations in this article. The information presented in this article will include five recommendations based on the interview data and current literature. The five recommendations

are: a) becoming informed about HIV testing guidelines, b) identifying patients at risk for HIV, c) taking action on a positive HIV test result, d) delivering the news to a newly diagnosed patient, and e) providing referral and follow-up to the newly diagnosed patient.

### **Becoming Informed:**

Interviews with individuals diagnosed with HIV provided insight into the importance of providers being able to give direction to patients diagnosed with HIV. Participants shared that they experienced distress when they felt that their provider was not able to provide them with adequate information to find help for HIV. One participant spoke of the appointment with his provider in which he was told that he had HIV:

*“He came in and sat down, and he told me that they had done some additional research and found out that I was HIV positive...He had not prepared any type of document to give me, any type of information about being HIV positive, what it meant, and what options might be available to me for treatment.”*

Conversely, some participants shared that their providers were very instrumental in helping them to transition into HIV care. One participant shared that he did not believe his primary care provider was an HIV expert, but did a very good job referring him to people who could help him:

*“This [conversation] is really good...she gave me this paperwork and she said, ‘here’s some general information about HIV. It might answer some common questions... And then I’m going to give you the names of some people that you need to call back.... They are going to be infectious disease specialists.’”*

Research has consistently suggested that clinicians will best serve the patient with HIV by making the transition into HIV care as seamless as possible<sup>5</sup>. Receiving an HIV diagnosis

can be an overwhelming and even traumatic experience <sup>6</sup>, and attempting to navigate the healthcare system without help can increase the likelihood that a newly diagnosed patient will not link with care. Clinicians can avoid unnecessary complications by being well informed and prepared to provide newly diagnosed patients with direction into HIV care.

HIV treatment today is incomparable to HIV treatment in the early years of the HIV epidemic. Antiretroviral therapy (ART) options now include more than 30 medications that can be administered to slow HIV disease progression <sup>7-10</sup>. Accompanying this progress has been the evolution of national and international guidelines on HIV treatment <sup>9,11</sup>. Clinicians in the primary care setting can leverage online resources published by health authorities (see Table 1).

Clinicians should also become acquainted with local sources of HIV care and support such as local case management and emotional support services. Clinicians should make contact to gain information on how to best offer patients with HIV a pathway to receive services.

### **Identifying Patients who are At Risk:**

Some participants shared that they made the decision to get tested for HIV because someone suggested it. These suggestions were made by friends, co-workers, and healthcare workers. One participant shared about his personal physician screening him for HIV risk factors and recommending a test:

*“He did ask me... do I have same-sex or different-sex partners or both... then he asked me... ‘how many partners do you normally have?’ ....and from my answers he said.. ‘I think you’d be fine with going ahead and getting just an HIV test.’”*

Historically, research has demonstrated that one of the many reasons people choose to engage in a health-related behavior, such as HIV testing, is because they are prompted to do so

<sup>12,13</sup>. Clinicians in the primary care setting are uniquely positioned to identify patients who are at risk for HIV, and to proactively approach such patients for screening.

The CDC (2006) recommends a universal opt-out approach to HIV screening, making HIV testing a routine assessment in healthcare settings. Research has suggested that opportunities in the primary care setting have been missed when discussions about HIV are only limited to specific groups rather than being part of routine assessment. Normalization of HIV-related assessments, in a similar vein as those assessments for heart disease and diabetes, will not only keep the dialogue about HIV open, but will also promote early identification of HIV in patients who may not have been tested otherwise <sup>15</sup>.

Screening should only be withheld if a patient specifically declines the test. In addition to testing, HIV-specific counseling should also be part of routine care and not only provided as part of HIV diagnoses. Clinicians should be able to identify high-risk individuals and encourage them to be tested at least annually in accordance with CDC recommendations, and should promote early identification of HIV infection.

### **Taking Action on a Positive HIV Test Result:**

Clinicians are often charged with the complex task of delivering difficult news to patients. Clinicians will best serve patients by positioning themselves for success when preparing to deliver the news. Interviews with participants revealed several factors that may impact the success of the delivery of an HIV diagnosis. These factors include: cautious use of technology, strategic timing of notification, and ensuring protected time with the patient.

**Cautious Use of Technology.** Electronic medical records are becoming increasingly common, and many patients are able to access their medical information online. However, clinicians must be careful that delivery of sensitive information is done in-person. Data from the

study indicate that even when home testing kits are used, people often prefer to have a source of social support present when they receive their result. One participant shared that he about his HIV status on his care provider's electronic medical record system prior to any contact from a clinician:

*"I get online and [the lab result on the system] said like 'HIV1 positive' ... When I looked at it. I was like 'oh, I probably should not have found out this way' so I kind of just laid there in bed for like an hour and a half and I was like.....this is the day. I didn't have a doctor tell me....My doctor was upset I found out that way, too. She's like 'I'm so sorry- You should not have found out that way.'"*

Receiving an HIV diagnosis in this way carries multiple clinical implications. HIV diagnoses can result in feelings of acute distress, anxiety, and anger<sup>6</sup>. As such, clinicians should exercise caution with regard to releasing records before talking to a patient to prevent patients from learning about their HIV status without support. Clinicians can ensure that appropriate social support is provided by ensuring that HIV results are not released to patients, and preferably having them come into the clinical setting for appropriate consultation.

**Timing is Everything:** Participants in the study often discussed that they 'had a feeling' that they were being called back in because they had tested positive for HIV. They discussed that their assumption was grounded in the fact that they knew they had been screened for HIV, and that they had never been asked to come back in before. Participants in the study discussed the significant distress that occurs when they believe something is wrong, but they cannot be provided with the information. One participant shared about being called while at work:

*"I asked what was wrong and could she [the receptionist] tell me over the phone...they refused to tell me. I was thinking maybe cancer.... I knew it wasn't good... and actually*

*they were leaving and they didn't think I would make it in time. They wanted me there in 20 minutes and the doctor would wait, and I told them I would be there in 15.. so I left work immediately to go meet with her and then that's when she told me."*

In many cases, such as when HIV tests are sent out to a laboratory (as opposed to on-site rapid testing), patients are not informed about their HIV result for several days following the collection of the blood sample. When HIV tests come back positive, clinicians usually will call individuals back to the office to discuss the results in person. Clinicians should exercise vigilance about the timing of contact with the patient whose HIV result has come back positive.

Clinicians must exercise a strategic approach to the notification of patients that they need to come in to receive a positive HIV test result. While there is no algorithmic timeframe that is best for notifying patients about their status, participants in the study indicated that being permitted to come in as soon as possible (often the same day) was crucial, because after receiving the phone call they expressed that it was something that they felt could not wait.

**Protected Clinician Time:** Several participants in the study shared that their difficulty in receiving their HIV diagnosis was compounded by what they perceived to be a hurried encounter with their provider. One participant discussed his interpretation of his provider's behavior at his first consultation after testing positive:

*"[The provider said] 'Well then, we'll start you on a [HIV Medication] Here's your script. Here's a script for the sleeping pill. And we'll see you in three months'. And that was the extent. He didn't ask if I had any questions or anything. And it was very quick. I kind of felt like 'I have other patients I need to see... I'm behind' because I had to wait like 45 minutes to an hour...so I just felt like I was very rushed."*



The results of recent research have indicated that one of the main barriers to implementation of HIV-related counseling in the primary care setting is time constraint<sup>15</sup>. However, interaction with providers at the point of HIV diagnosis has a profound impact on people living with HIV as they link with providers for HIV care. Results of multiple studies have suggested that when providers are unable to provide patients with an adequate amount of time to discuss the diagnosis, patients may perceive them as rushed, careless, or even discriminatory<sup>6,16</sup>. One study participant stated that he received no counseling or direction upon receiving his diagnosis, describing the encounter as *'five minutes and a pamphlet'*. When preparing to deliver the news of an HIV diagnosis, providers should make every effort to dedicate an adequate amount of time to thoroughly discuss the situation with the patient.

#### **Delivering the News to a Newly-Diagnosed Patient:**

Delivering the news of HIV-positive serostatus is very difficult. Reactions to an HIV diagnoses are as diverse as the individuals being diagnosed. As with any other healthcare interaction, assessment is crucial to the success of the encounter. The conversation should be tailored to the patient's individual circumstances, but should always be supportive. Clinicians will be most successful if they deliver the news in a calm, direct, and supportive manner with caution to avoid being apathetic or defeatist. Clinicians should use the conversation to address the following: assessing current HIV knowledge level, assessing perceived risk for HIV and expectation of HIV diagnosis, dispelling myths, empowering patient regarding disclosure, and championing the patient's next steps.

**Assessing Current HIV Knowledge:** During the study interviews, participants shared their knowledge about HIV. In multiple cases, participants expressed that upon learning their

HIV status, they believed that death was imminent. One participant who was diagnosed in 2008 shared about her initial thoughts after she was told that she had HIV:

*“At the time [of my diagnosis] the first thing on my mind was ‘oh, my God. I’m going to die. I’m going to be dead within five years because back in the day the only thing I knew about AIDS was when you get it, you know you die in five years.’”*

Another participant shared his thoughts about his family’s risk of catching HIV from him when he came home after finding out he had HIV:

*“I won’t share a glass with my family now....I don’t want to take a chance on them getting it....So I was like, ‘This is my glass. Don’t pick it up by accident and drink out of it.’”*

It is not uncommon for individuals to have little to no knowledge about HIV, or to have knowledge that is inaccurate or outdated. HIV has been more than a microorganism or a disease process. It has been a rapidly-evolving sociocultural phenomenon <sup>2</sup>. Individuals hold knowledge from a variety of sources ranging from personal acquaintance with healthy people living with HIV to outdated portrayals of people dying from HIV in television or movies. Assessment of a patient’s knowledge and understanding of HIV should be a top priority once the news has been delivered, as it is the patient’s level of knowledge that will allow the clinician to tailor the rest of their approach. Once the clinician has established the patient’s knowledge level, proceeding with basic education about HIV should commence. Clinicians can make use of education materials made available from national health authorities, but should always tailor language and illustrative discussion to the patient’s preferred learning style.

#### **Assessment of Perceived Risk for HIV and Expectation of a Positive HIV Test**

**Result:** Participants varied from one another in their perceived risk for HIV infection, and their

expectation of a positive HIV test result. Some participants expressed that they did not believe they were at risk for HIV. One participant discussed his shock when he learned that he had HIV:

*“He had no idea that I would even be considered for an HIV candidate because, you know, I’m not that type of person. I’m not out there whoring around, not promiscuous, none of that kind of stuff.”*

Other participants expressed that they knew they had engaged in behaviors that put them at risk for HIV infection. One participant shared that when he became ill, he immediately thought of his HIV risk:

*“It was always in the back of my mind, as a gay man. It’s one of those things that you always know there’s a risk out there. And I was with somebody for nine months, and we had unprotected sex, so it was kind of on the forefront of my mind. And that was just the first thing that my mind jumped to it could be [HIV].”*

Patients may differ significantly in their reactions to an HIV diagnosis based on their perceived risk for HIV and their expectation that they would receive a positive HIV test result. Some patients may have been self-directed in their request for an HIV test while others were only tested because they were prompted to do so. These differences are crucial when delivering the news of a patient’s HIV status. Some individuals may be completely unaware that they were ever at risk for HIV. Their inability to perceive risk may come from a lack of knowledge about HIV transmission or because they were unaware of a partner’s HIV status. Clinicians must be prepared to provide both education about HIV transmission as well as emotional support to these individuals, as there is a high likelihood of distress upon receiving the news.

Other individuals, particularly those individuals in high-risk groups (see Table 1), may express a more thorough understanding of their risk. The patient’s knowledge may be grounded

in higher levels of HIV knowledge, acquaintance with people living with HIV, or acknowledgement that at some point they engaged in a transmission-risk behavior. In some cases, individuals may even expect their HIV test to come back positive if they know that they have been exposed. However, even in such cases, it is important that the clinician be ready to approach the patient in an emotionally supportive and informative way.

Clinicians should tailor their approach to each patient based on their assessment of the patients' needs. Some individuals may require less emotional support in favor of a more informative approach from the clinician, while others may not be able to process more informative counseling due to emotional distress. In either case, the ultimate goal of the interaction should be to foster trust and support so the patient will be able to take their next steps in the care process.

**Dispelling Myths:** Many of the participants in the study shared about misconceptions they previously thought or heard about HIV and the people who have it. One participant shared:

*“I think [people] still believe that it’s this giant epidemic from the 80s where everyone’s going to die....I think people think [if you have HIV] you’re promiscuous or you’re a drug user... dirty or slutty.... Or unsafe or you don’t have a high moral character... you don’t care about your body.”*

As medical treatments have evolved and advanced, so has the societal perspective of HIV<sup>2</sup>. Today, in 2015, there are many people who have witnessed the epidemic from its infancy up to and including the present day. Patients who test positive for HIV may hold preconceptions that are not accurate in light of today’s HIV treatment options. It is crucial that the clinician provide education on the reality of HIV today, and to actively dispel common myths about HIV (see Table 2). One of the greatest myths of all is that individuals with HIV are unable to live a

‘normal’ life. If no other myth is addressed, it is crucial that clinicians emphasize that the patients have options available to them. While they may have significant anxieties regarding their future living with HIV, helping patients to realize that HIV is not a death sentence is invaluable in the care initiation process.

**Empowering the Patient Regarding Disclosure and Stigma:** One of the greatest concerns expressed by participants in the study was disclosure of their HIV status to others. Many participants expressed that when they initially learned that they had HIV they did not want anyone to know. In multiple cases, participants shared that they chose to only discuss their status with their healthcare provider, and wondered whether there were other people they were required to tell. One participant expressed his concern about telling his employer:

*“How could this happen to me?... Who do I have to tell? Like am I not going to be able to go to work? A whole bunch of things that concern... like.... living... like my normal day-to-day life.”*

The concerns they expressed were primarily related to their vulnerability to HIV stigma. Participants discussed their concerns about what others thought, including society, friends, family members, and even healthcare workers. One participant shared about his concerns about entering the HIV treatment center for the first time:

*“I was very nervous coming here. I was walking in feeling like everyone was staring like, ‘What are you here for?’. I just felt like that stigma.... I just didn’t want to be in the waiting room anymore”*

The HIV illness, since its discovery, has always been accompanied by social controversy. While societal views on HIV have evolved tremendously, and individuals with HIV have more resources than ever before, stigma related to HIV still exists<sup>17,18</sup>. People living with HIV unfortunately continue to face challenges related to their HIV-status, including social isolation, depression, anxiety, self-stigma, and overtly bigoted and discriminatory behavior<sup>17</sup>. HIV-related stigma often stems from fear and misinformation about HIV and the people who have it. Fear of negative feedback from other people regarding their HIV status may cause newly diagnosed individuals a significant amount of distress, and they may express that they are afraid to tell the people in their lives about the diagnosis<sup>17,18</sup>.

Clinicians must take the lead in providing the patient with the facts about HIV status disclosure. The only imperatives with regard to disclosure of HIV status are the patient's current and past sexual partners, and those with whom they share(d) needles. These individuals must be notified that they have potentially been exposed to HIV. The clinician can best serve the patient by explaining this fact honestly, and if the patient is reluctant about notifying these individuals, the clinician should help the patient to get in touch with local health department personnel who can help with the disclosure process. It is also strongly recommended (but not required) that individuals with HIV discuss their status with primary care providers and dentists, as both may be instrumental in the identification of HIV disease progression over time.

Regarding disclosure to any other person or entity, it is not uncommon for individuals to refrain from general disclosure, or to be very selective about with whom they share their status. The clinician, who can empower the patient to use their discretion about HIV-status disclosure, should support this trusting relationship, and continually provide emotional support to the patient in the event that they experience stigma or struggle with status disclosure.

**Championing the Patient’s Next Steps:** Participants shared about the influence their healthcare providers had regarding their perspective of HIV and what it meant for their future. Several participants regarded the encouragement by their healthcare providers as invaluable in helping them to realize that HIV is not a death sentence and that they can still accomplish their goals. One participant shared about the advice given to him after his provider told him he had HIV:

*“[My doctor] said ‘it’s not a death sentence and I want you to know that everything is going to be fine.’ And I did tear up a little bit at that point... It wasn’t a cold professional relationship”*

Research has established that receiving an HIV diagnosis can be an incredibly challenging experience<sup>19</sup>. The time period directly following an HIV diagnosis can be overwhelming for a patient. Patients may believe that their diagnosis is a barrier to their life goals. The clinician should be open to hearing about the patient’s concerns, and where appropriate, reinforce ways in which individuals can continue to lead the lives they want to live with HIV. Research has repeatedly demonstrated that support, including support from within the healthcare system, is a vital component of successful HIV care and treatment efforts. Clinicians should be diligent in the development of a supportive relationship with the patient as they take action to address their HIV diagnosis.

**Providing Referral and Follow-up:**

Although some participants shared that they were self-directed through the entire care initiation process after diagnosis, many participants stated that they received assistance from within the healthcare system. Some participants credited the help of social workers and case managers for their fundamental ability to seek out care. One participant shared

*“I’m so truly thankful and blessed... without them [case managers] I wouldn’t be here. I think everyone plays a part. Had urgent-care not called the [case managers] – I probably wouldn’t have. I probably would have panicked, and reclused [SIC], and not done anything...everyone helps to get me further along.”*

Conversely, some participants expressed that they felt they were not provided with any assistance or information, which led to distress and confusion during the care initiation process. One participant shared about his confusion following a brief encounter with his primary care provider:

*“There was no information given about where to go, what to do. Do you need counseling? Do you need help?...No assessment taken of anything about me. ‘You’re HIV positive. Here’s a doctor that you might want to call to make an appointment,. Have a nice day.’ Simple as that.”*

In many cases, patients diagnosed with HIV are referred to specialists for the management of their HIV-specific care. In addition to the psychological processing and adjustment that patients experience after diagnosis, they then have to navigate an often complex healthcare system in order to link with a new provider and begin treatment<sup>15,20,21</sup>. Patients often experience anxiety and uncertainty related to unfamiliar locations, new and unfamiliar clinicians, and obtaining healthcare coverage. These anxieties are often compounded by the aforementioned concerns about discussing their HIV with others. A robust body of research has developed that has conclusively demonstrated that patients provided social work and case management services are more likely to achieve successful outcomes when initiating HIV care and engaging in HIV treatment<sup>20,22,23</sup>. Such services provide an ongoing source of support following diagnosis.



Clinicians can drastically increase the likelihood that their patient will successfully link with an HIV care provider by providing the patient with access to tangible support, such as transportation. Clinicians play a crucial role in helping patients to link with case management. In addition to helping patients link with social work and case management efforts, clinicians should also follow up with the patient to ensure that they are established in HIV care and that their needs are met.

**Conclusion:**

The aim of this article was to provide guidance to primary care providers who play an invaluable role in the identification of individuals living with HIV, and the subsequent transitioning of those individuals into HIV-specific care. The recent expansion of healthcare service eligibility will afford large numbers of individuals, including many who are at risk for HIV, to develop relationships with primary care providers. Primary care clinicians are well positioned to identify individuals with HIV, thoroughly assess their needs, arm them with support and the resources for their next steps, and facilitate an optimal transition into HIV-specific care and treatment. The efforts of primary care clinicians will continue to play a pivotal role in the fight against HIV. Helping individuals in their transition into HIV care will result in both individual and public health benefits: the individual achieves optimal treatment outcomes, and the community benefits because of the decreased likelihood of HIV transmission by individuals engaged in HIV care and treatment.

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Table 1: HIV Web Resources

Resource	Website
U.S. Department of Health and Human Services	<a href="http://www.aids.gov">www.aids.gov</a>
Centers for Disease Control and Prevention	<a href="http://www.cdc.gov/hiv/">www.cdc.gov/hiv/</a>
National Institutes of Health HIV Treatment Guidelines	<a href="http://aidsinfo.nih.gov/guidelines">aidsinfo.nih.gov/guidelines</a>
Joint United Nations Programme on HIV/AIDS	<a href="http://www.unaids.org">www.unaids.org</a>
World Health Organization (WHO) HIV/AIDS Site	<a href="http://www.who.int/hiv/en/">www.who.int/hiv/en/</a>
The Henry J. Kaiser Family Foundation HIV/AIDS Site	<a href="http://kff.org/hivaids">kff.org/hivaids</a>
The Body: Complete HIV/AIDS Resource	<a href="http://www.thebody.com">www.thebody.com</a>
AIDS Education and Training Centers National Resource Center	<a href="http://www.aids-etc.org">www.aids-etc.org</a>
American Academy of HIV Medicine (AAHIVM)	<a href="http://www.aahivm.org">www.aahivm.org</a>
John's Hopkins AIDS Service	<a href="http://www.hopkins-aids.edu">www.hopkins-aids.edu</a>
U.S. Department of Health and Human Services Health Resources and Services Administration (HRSA) HIV/AIDS Bureau	<a href="http://hab.hrsa.gov">hab.hrsa.gov</a>

Table 2: HIV Myths and Truths

Myth	Truth
HIV and AIDS are the same thing	HIV is the virus that, when left untreated, can result in a diagnosis of AIDS, in which the immune system is profoundly damaged
HIV is a third-world problem	More than one million people that are living with HIV live in the United States
HIV is a death sentence	Treatments for HIV have made it possible for people to live normal lifespans with HIV.
HIV only affects gay people, drug users, prostitutes, or people who are promiscuous	HIV can affect any group
HIV is no big deal, they have medications for that now	While tremendous advances in HIV treatment have been made, HIV is not curable, and people with HIV are on lifelong treatment.
I would know if I had HIV, I don't feel sick	Many people do not have symptoms for years after they are infected with HIV. That is why it is very important to be tested
I would be able to tell if my partner had HIV	The only way to know HIV status is to get tested.
I can get HIV from kissing, causal contact, and mosquitoes	HIV is primarily spread through unprotected sex and sharing of needles containing HIV-infected blood
I can't catch HIV from oral sex	While oral sex is less risky, it is still important to use protection, as HIV can be spread from men or women during oral sex
If I have unprotected sex with someone who has HIV and takes medicine, I won't catch HIV	Even though treatment reduces the chance that HIV will be transmitted during sex, there is still the possibility that an individual can become infected. Therefore, it is always best to use protection.

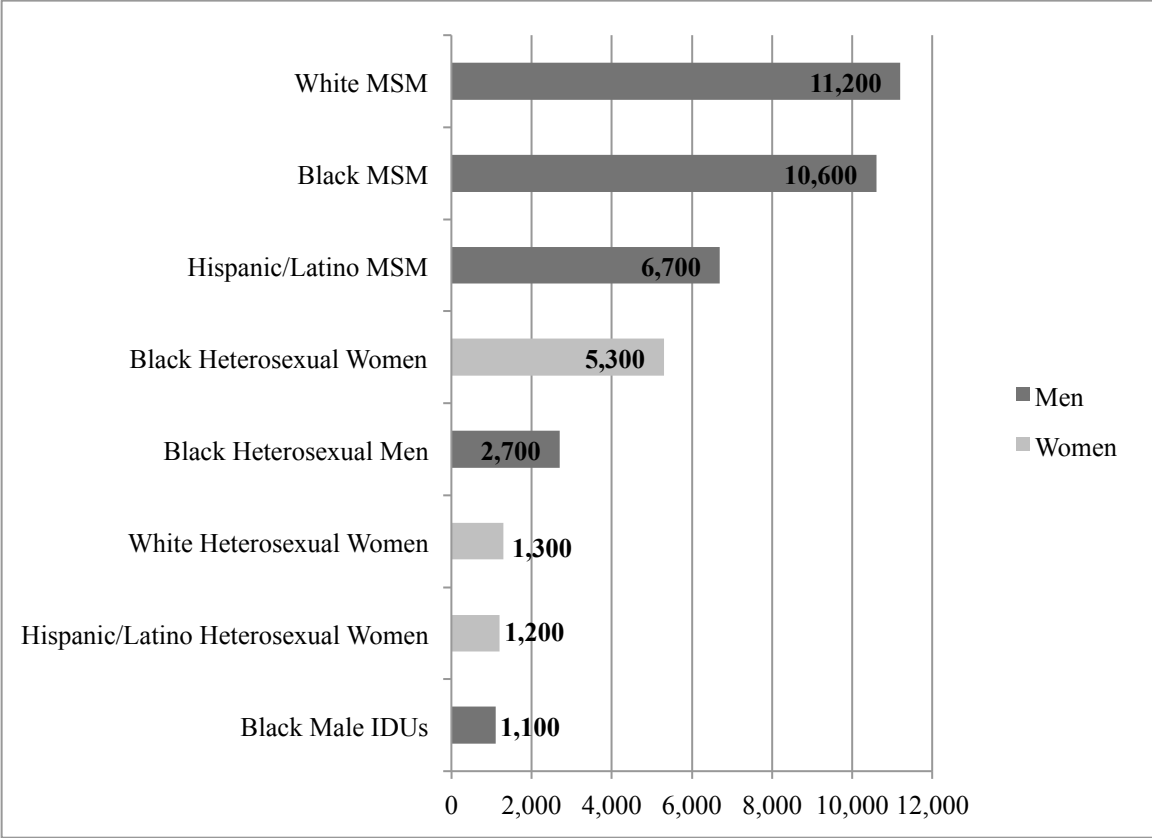


Figure 1: Groups Affected by HIV by Risk Group; Available through Public Domain<sup>1</sup>