Addressing Barriers to Care in HIV-Positive African-American Women through an

Interdisciplinary Comprehensive Care Worksheet

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Abstract

HIV care requires patients to be diagnosed, linked to care, retained in care, prescribed antiretroviral treatment, and reach viral suppression. Progressively more patients fall off the cascade at each step, and in doing so struggle to reach positive outcomes. African-American HIV-positive (black HIV+) women bear a significant burden of HIV morbidity, mortality, incidence, and prevalence. This is due to multiple barriers to care this population faces that prevent them from staying engaged in the cascade. A review of the literature was completed to understand the barrier categories stigma, trauma, social, and medical. These are significant in both prevalence and severity in black HIV+ women. Comprehensive care is healthcare that utilizes providers and communication to ensure every member of the HIV care team understands every barrier a patient faces. This is the best method of care delivery for black HIV+ women because of their many barriers. To facilitate comprehensive care, an Interdisciplinary Comprehensive Care Worksheet (ICCW) was developed to promote provider communication. The ICCW uses information gathered from the literature review of barriers, and was validated by two HIV care experts. By creating a better method of communication between providers, barriers to care in black HIV+ women can be identified and addressed more easily, increasing the likelihood of positive care outcomes.

Introduction

Human Immunodeficiency Virus (HIV) is a sexually transmitted incurable disease that compromises a person's immune system. HIV's origins in oppressed groups and stigma continue to affect the lives of HIV patients, complicating disease trajectory and healthcare adherence (Alonzo & Reynolds, 1995). Marilyn Frye (1983) famously compared oppression to a birdcage in an essay, serving as a metaphor for how complicated HIV treatment can be for some patients:

> Consider a birdcage. If you look very closely at just one wire in the cage, you cannot see the other wires. If your conception of what is before you is determined by this myopic focus, you could look at that one wire, up and down the length of it, and be unable to see why a bird would not just fly around the wire… It is only when you step back, stop looking at the wires one by one, microscopically, and take a macroscopic view of the whole cage, that you can see why the bird does not go anywhere. (p.4-5)

This is exemplary of how African-American HIV-positive (black HIV+) women are trapped in their own cages, surrounded by the wires of barriers that prevent them from reaching HIV-related health goals. Their unique, complex barriers include increased risk for financial problems, potential pregnancy, and HIV stigma, all of which affect one another in ways both seen and unseen by healthcare providers. Attempting to help black HIV+ women live with HIV by addressing barriers separately and not recognizing the individual patient's cage is to ignore the essence of who they are and what they need.

Positive health outcomes only occur when every barrier is acknowledged and treated as part of a larger problem. Comprehensive care is based in this and addresses the patient as a whole, understanding that fixing one problem will not necessarily lead to desired outcomes. Coordinated efforts with macroscopic vision are necessary for comprehensive care. Many

healthcare providers are on the same HIV care team for the patient, making communication necessary for care to be comprehensive. Black HIV+ women face many barriers to care that are significant in both prevalence and severity. To facilitate comprehensive care as the method of care delivery, an interdisciplinary communication tool was created to increase provider awareness of individual patient barriers to care. HIV barriers to care exist around the world, but for the purposes of this project, only black HIV+ women in the United States and their relationship with comprehensive care will be studied.

HIV Treatment

HIV infection starts with entrance into the bloodstream through contact with sexual fluids or blood. The most common method of transmission for women is heterosexual contact, while homosexual contact is the most common method for men (Division of HIV/AIDS Prevention [DHAP], 2015a). The virus then enters CD4 lymphocytes and multiplies throughout the body while destroying CD4 cells, eventually leading to immunosuppression and acquired immunodeficiency syndrome (AIDS) when the number of CD4 cells drops below 200. AIDS makes the body very prone to certain types of opportunistic infections (OI) that a healthy immune system would be able to eradicate. Without treatment, HIV would deplete the immune system; the patient would likely contract an OI, and eventually die. HIV is currently an incurable disease because of rapid viral mutations and memory lymphocytes; therefore, curative treatment is not the goal for patients.

According to the Panel on Antiretroviral Guidelines for Adults and Adolescents (PAGAA), the goals for HIV treatment are to suppress viral load, restore immune function by increasing CD4 count, reduce HIV morbidity, improve quality of life, and prevent transmission. (2016, p.D-1). The first step in HIV treatment is being diagnosed with HIV, followed by finding

a HIV healthcare team, staying with that team, receiving antiretroviral (ART) prescription, and reaching viral suppression (DHAP, 2014). These steps make up the HIV Care Continuum, a treatment cascade used to deliver HIV care and identify gaps in treatment. The continuum outlines steps necessary for viral suppression, which allows the body to recover enough and create CD4 cells faster than HIV destroys them. While there are many ways to measure treatment outcomes, viral load and CD4 count are the most objective measurements available that reflect medication adherence and immune system function.

ART is considered the gold standard of HIV treatment, and has been shown to significantly reduce viral load in patients, thus decreasing HIV morbidity and mortality (PAGAA, 2016, p.E-1). Current guidelines recommend starting patients on ART regardless of CD4 count (PAGAA, 2016, p.E-2). ART prescription is arguably the most important step in the continuum because it directly reduces a patient's viral load. The identified treatment goals are therefore direct outcomes of ART adherence. However, focusing on lab values alone makes it difficult for providers to connect with their patients and see the best overall treatment. Approaching all patients with ART adherence as the only priority may alienate patients who have different treatment priorities for themselves. ART is an integral aspect of every patient's HIV care, but limiting patient-provider interactions to discussions surrounding ART adherence is not an effective strategy. Priorities must be shared between the patient and their HIV care team, and they must include an ART regimen.

In order for patients to receive the best care possible, they must progress through every step in the continuum; simply prescribing medications is not a guarantee of viral suppression. Progressively fewer persons living with HIV/AIDS (PLWHA) are engaged in each step of the continuum, with the largest gap occurring at retention in care (DHAP, 2014). The National HIV

Surveillance System defines retention in care as having at least two provider appointments at least three months apart in the last year (DHAP, 2014, p. 4). In 2011, 86% of all PLWHA had been diagnosed with HIV, 80% of those diagnosed in 2011 were linked to care, 40% were retained in care, 37% were prescribed ART, and 30% were virally suppressed (DHAP, 2014). Less than half of those who were diagnosed stayed in care, and 75% of those who stayed in care reached treatment goals. These statistics show that the problem does not lie in the medication adherence step, but rather in the care retention step. Despite having great significance for treatment success, present HIV care does not need significant changes to ART interventions, but rather care retention interventions.

African-American Women Disparities

When addressing the PLWHA population, healthcare providers must take into account black women as a focus of interventions. Black women have the fourth highest incidence of HIV among the most-affected subpopulations in the United States, preceded by white, black, and Latino men who have sex with men (DHAP, 2015b). According to the 2014 HIV Surveillance Report, black women had an HIV incidence rate (out of 100,000) of 30.0 compared to 6.1 for all women, an HIV prevalence rate of 813.8 compared to 167.7 for all women, and a PLWHA ever diagnosed with AIDS rate of 435.3 compared to 90.4 for all women (DHAP, 2015a). Additionally, the CDC Office of Women's Health found HIV was the fourth leading cause of death for black women ages 35-44 in 2013, but did not rank in the top ten causes of death for white or Hispanic women (2015a; 2015b; 2015c). Compared to the general female population, black women are more likely to be diagnosed with HIV, live with HIV, develop AIDS, and die from HIV/AIDS. These four measurements of disease demonstrate the current gap in healthcare for black women; the system is failing them.

When analyzing the HIV care continuum steps, black women had only slightly lower rates of care linkage, retention, and viral suppression than all HIV diagnosed women (Whiteside et al., 2014). Though the undiagnosed population was not taken into account, 2010 reports showed 81.3% of newly diagnosed black women were linked to care, 50.9% of previously diagnosed black women were retained in care, and 39.8% of previously diagnosed black women achieved viral suppression (Whiteside et al., 2014). These statistics are slightly higher than the overall rates along the continuum for the entire PLWHA population, though there is obvious room for improvement. When comparing the significant disparities in incidence, prevalence, morbidity, and mortality, the lack of disparity in the continuum does not seem to add up. If black women get to care, stay in care, and receive ART as much as the rest of the HIV population, why are they more likely to contract HIV, develop AIDS, and die from HIV than other women? Why are they less likely to reach HIV treatment goals?

Dropping out along the continuum affects black women more than other races due to personal and systemic barriers black women face. They face complex barriers involving multiple areas of their lives, making them difficult to understand and address. In order to better understand this paradox and the barriers black women face, I sought to research barriers against retention in care in this population. Retention is as important as ART in managing HIV, and is associated with better health outcomes and reduced community viral burden (Thompson et al., 2012, p.818). However, only half of all diagnosed black women are retained in care. Missing appointments, even if their ART prescription stands, means patients miss vital health services that make a big difference for black women. Even though black women could fall off the care continuum at any step, I have chosen to focus my research on retention because most of those who fall do so at this step.

Barriers to Care in HIV+ African-American Women

When identifying barriers to retention in the black HIV+ female community, the intersections between race, gender, and diagnosis must be taken into consideration. Even though HIV+ black women fall into each category separately, experiences and barriers felt by the black community, female community, and HIV+ community do not necessarily apply to HIV+ black women. Identified barriers in each of these communities must be placed into the context of this population in order to understand their implications for care. By being sensitive to the most common barriers black women face, healthcare providers can step back and visualize the "cage" around each patient, then make an individualized plan with the right interventions, connections, and people. While there is a lack of systematic reviews on barriers that affect black HIV+ women, a review of the literature revealed four significant categories of barriers: stigma, trauma, social, and medical (Peltzer, Domian, & Teel, 2016; Grodensky et al., 2015; Lanier, & DeMarco, 2015; Messer et al., 2013). Barriers were chosen based on high prevalence and severity in black HIV+ women. One notable facilitator of care specific to this population is spirituality, which has been found to promote care engagement (Dalmida, Holstad, DiIorio, & Laderman, 2012). Even though spirituality will be addressed differently than barriers, recognizing that spiritual care is an important part of many black women's lives will lead to more holistic and comprehensive care.

Stigma

Due to the method of transmission and the original AIDS epidemic in the United States in the 1980's, HIV often gets classified as a "gay" disease with negative connotations related to homophobia in America. Homophobia helped perpetuate stigma initially, but the discrimination persists through all sexual orientations and genders. For example, one study quoted a young black woman describing a time she overheard a nurse saying, "They really need to just ship [HIV

patients] all off to an island so they can keep breathing and infecting each other," showing how stigma and discrimination is alive and well within our own healthcare system (Peltzer, Domian, & Teel, 2015, p.114). This is experienced by all patients, but must be placed in the context of the black female experience. In another study of the same participants, the common ground found between young black women was the idea that HIV invaded every part of their lives, from the obvious medical side to the less expected emotional, spiritual, and social lives (Peltzer et al., 2016, p.6). Many older black women report strict nondisclosure after seeing friends treat others with a known HIV diagnosis differently, afraid of being shunned by those closest to them (Grodensky et al., 2015). Societal HIV stigma creates a strong barrier to care retention because it manifests primarily in fear of disclosure consequences. Women limit themselves socially, medically, and emotionally because of their fear of experiencing discrimination due to HIV stigma.

This limitation is termed the Theory of Self-Silencing, in which black women will repress feelings and not disclose their HIV status for fear of actual and perceived stigma (Lanier, & DeMarco, 2015). HIV stigma directly isolates women because of discriminatory acts of others, and indirectly because of self-induced isolation. Positive social and provider relationships are key to staying in care and therefore must be facilitated in black women (Messer et al., 2013). The stigma black HIV+ women face is not just subtle manifestations in casual conversation, although it certainly includes that as well. Stigma and discrimination infiltrate every aspect of their lives to the point they are unable to maintain relationships, be true to themselves, and live their lives as they did before diagnosis. HIV's history in America cultivated stigma because minorities were the most affected, methods of transmission were unknown, and patients died horrible deaths. Though HIV has become a chronic illness and transmission is well documented, the stigma

persists. The HIV care team must present a united front against stigma to allow black women the chance for a normal life after diagnosis.

Trauma

The American Psychological Association defines trauma as the emotional response to a terrible event, meaning that the true meaning of the event relies on how the person reacts (2016). A 1997 study documented this response in women newly diagnosed with HIV, using each woman's own words to show how the diagnosis affected them; over half described a traumatic response (Stevens, & Doerr). Sometimes the response is severe enough to result in permanent neurotransmitter changes in the brain, leading to post-traumatic stress disorder (PTSD). Trauma can also be the result of physical force on the body resulting in injury: a car accident or fist fight, for example. Injury producing trauma can come from a person close to the patient in small doses over time, eventually leading to submission, depression, injury, and, in some cases, death. This is known as intimate partner violence (IPV), which includes physical, emotional, sexual, and psychological trauma. Black HIV positive women are at a higher risk of developing PTSD due to their race, have a higher chance of experiencing IPV due to their gender, and must endure the trauma of receiving an HIV diagnosis and the accompanying stigma (Roberts, Gilman, Breslau, Breslau, & Koenen, 2011; Breiding et al., 2014). Trauma is a significant barrier for black HIV+ women because of its severity and prevalence in this population.

PTSD develops after a person goes through something extremely dangerous, unsettling, or scary, and is typically associated with veterans of active combat (National Institute of Mental Health [NIMH], 2016a). Symptoms of PTSD include nightmares, avoiding reminders of the trauma, difficulty sleeping, and loss of interest in activities (NIMH, 2016a). Because trauma is determined by the response to an event, PTSD can come from a variety of places, including IPV

and HIV diagnosis. If left untreated PTSD can interact with HIV to exacerbate both conditions, leading to distorted thoughts about oneself and avoidance of reminders; for example, avoiding the doctor or not taking medication because it is a reminder of HIV (Neigh, Rhodes, Valdez, & Jovanovic, 2015). This can be a significant problem when typical HIV care includes numerous doctor visits, at least daily medication, and uncomfortable disease symptoms. Women are more likely to experience childhood sexual abuse and rape than men, therefore putting them in situations that could cause later PTSD (Aaron, Criniti, Bonacquisti, & Geller, 2013). Depression is often cited as the primary mental health comorbidity to HIV, though more evidence shows higher PTSD prevalence in black HIV+ women seeking mental health services (36%) than previously thought (Brownley, Fallot, Berley, & Himelhoch, 2015). Confiding in others can be difficult because of HIV stigma, and if a patient with PTSD finds herself dealing with HIV alone, good outcomes are not likely. Providers must be aware of existing and potential PTSD in order to plan the patient's care correctly and connect them to necessary resources such as a social worker or case manager.

IPV is physical, sexual, or psychological harm caused by a partner or spouse (Division of Violence Prevention, 2015). Because this type of trauma can take place over time and result in unstable living conditions, the chance for HIV care interference is high. In 2014, the Centers for Disease Control and Prevention (CDC) reported that women experienced all types of IPV (sexual violence, physical abuse, psychological aggression) significantly more than men in 2011 (Breiding et al., 2014). If a woman is in a relationship with an HIV positive man who rapes her, her chances of being infected grow exponentially. Depending on the level of control he exerts, she may never be diagnosed and enter the HIV care continuum. If she is diagnosed, disclosure to her partner may put her life in danger, limiting her ability to stay in care and take ART as

prescribed. Fear of her partner may result in complete nondisclosure to friends and family, resulting in social isolation and risk of treatment failure. Increased stress levels over time can deplete the immune system and increase the severity of her HIV infection. 55% of HIV positive women experience IPV, meaning that approximately half of all the women a HIV healthcare provider sees could be dealing with any of these issues (CDC, 2014). IPV and HIV intersections are subtle and complex because they each affect many aspects of a woman's life in extreme ways; the full effects of both may never be known. IPV adds to the barrier of trauma and compounds the impact of HIV on a woman.

Social

Social issues have plagued HIV+ people, women, and African-Americans in the United States for decades, if not centuries. When assessing black women with HIV, providers must remember the birdcage: wires symbolizing race, gender, and diagnosis are already present, significantly increasing the likelihood of more social issues affecting HIV care. For example, in 2014, the average income of a black woman was 63% of the average income for a white man (American Association of University Women, 2016, p.11, Fig. 4). A positive HIV status decreases this even more because patients must find a job accommodating to their HIV needs. According to Maslow (1943), a person must address basic needs—food, safety—before concerning themselves with higher needs—non-emergent medical care, gas, medication. If a black HIV+ woman only has enough disposable income for either food or a bus pass to her appointment, she is more likely to spend it on food because it is a basic need. The list of social inequalities like income disparity is very long for black HIV+ women, so research was focused on the major problems that prevent optimal HIV care in many ways.

In order to be engaged in HIV care and reap all of the benefits, patients must come to appointments. Because personal, well-maintained cars are expensive and are considered a higher need, black HIV+ women with a lower disposable income may need to rely on public transportation, trustworthy friends, or questionable cars. While other factors affect the motivation to come to appointments, limited methods of transportation affect the physical ability to attend. In rural areas where public transportation is unavailable, systemic barriers such as fewer educational opportunities and poorer healthcare access prevent black women from having the means to attend appointments (National Rural Health Association, 2014). Lack of transportation is enough to keep women from attending their appointments, and was cited as an important barrier by women in multiple studies (McDoom, Bokhour, Sullivan, & Drainoni, 2015; Kempf et al., 2010; Messer et al., 2013). Inflated gas prices affect this population significantly because the income percentage spent on fuel increases dramatically, making it more difficult to travel long distances to clinics without support (Kempf et al., 2010). Patients are sometimes forced to choose between being seen at a community clinic where they could be "outed" as HIV+, and finding risky transportation to far-away clinics (Kempf et al., 2010). Not having reliable transportation is related to other barriers as well, such as food insecurity, poverty, and unemployment (Kalichman et al., 2014). Providers may not think about the patient beyond clinic walls, yet patients often highlight their travel to and from clinic as a major concern.

Unstable housing and homelessness are key social barriers that disproportionately affect black HIV+ women in prevalence and severity. Without a reliable place to keep medications and use as an address for important documents, keeping up with HIV care becomes nearly impossible, thus increasing morbidity and mortality (Audain et al., 2013, p.2). Stable housing is positively associated with good HIV-related outcomes, and should be regarded as imperative to a

patient's health (Leaver, Bargh, Dunn, & Hwang, 2007). Unstable housing increases severity of

disease as well; Khanijow et al. (2015) found that homeless HIV+ people had lower five-year

survival than those who were HIV+ and not homeless. While statistically more men than women

are homeless, African-Americans share a larger burden of homelessness than Caucasians, with

40% of the unstably housed being black (Henry, Shivji, de Sousa, & Cohen, 2015, p.9). Black

HIV+ women's higher risk for lower disposable income also contributes to unstable housing.

This population experiences a higher prevalence of homelessness due to their black race, and a

higher severity of HIV when they are unstably housed. Therefore, homelessness is a significant

barrier to retention in care, and should be systematically addressed in black HIV+ women due to

their increased risk.

Medical and OB-GYN

Because HIV is an immune disorder, every system of the body is affected by the patient's

weakened ability to fight infection. Symptoms and diseases can also interfere with a patient's

HIV medication, disease process, and motivation to stay in care. Providers should be aware of

any medical issues outside HIV their patients are experiencing, but should particularly watch for

OB/GYN issues and depression in black HIV+ women. Other medical barriers are highly

individualized for each patient, and therefore will not be studied for this project.

With some exceptions, almost every black woman being seen for HIV will have ovaries

and a uterus. Half of all women with HIV are under 35 years old, meaning many of them will

become pregnant or want to become pregnant while HIV+ (Kaiser Family Foundation, 2014).

HIV transmission during pregnancy, birth, and postpartum can be all but eliminated if a woman

is diagnosed early in pregnancy via a screening, takes ART as prescribed to reduce her viral load,

and does not breastfeed (DHAP, 2015c). Diagnosis during pregnancy screening is an important

step for many young women who may not otherwise have contact with the formal healthcare system; their prenatal care would automatically include HIV care (DHAP, 2015c). The process can be quite different for previously diagnosed women who face misconceptions regarding HIV and pregnancy. For example, small but significant percentages of HIV+ women desiring to have children reported perceived provider stigma that affected how they spoke about having children, perceived provider disapproval regarding pregnancy, and certain misconceptions regarding HIV and pregnancy (Haddad et al., 2015). Poor perinatal HIV care is exacerbated by social and economic factors like transportation and stigma, barriers that already exist for black HIV+ women (hIarlaithe, Grede, de Pee, & Bloem, 2014). If providers continuously ask and educate HIV+ women on their pregnancies, not only will more women be engaged in care, but also fewer children will be born HIV+.

While there are barriers to care during pregnancy, postpartum women tend to have lower HIV care engagement than pregnant women (Mellins et al., 2008). This is partially because the motivation to protect their unborn child no longer exists as a perceived benefit of HIV care (Rosenstock, 1966, p.100). Engagement in HIV care postpartum improves the chances of mother and child survival because of the widespread benefits of HIV care, especially because HIV+ pregnant and postpartum women have a higher level of immunosuppression (Rollins et al., 2014). All of the barriers in place for non-perinatal black HIV+ women are still in place for postpartum women, except the postpartum women now also have a newborn baby to care for. Finances become more limited than before, reducing the amount of disposable income available for healthcare. These exacerbated barriers are slightly offset by new facilitators to care based around a woman's maternal instincts and links to her baby; even though her actions no longer physiologically affect her child, women express motivation to stay healthy and increase their life

expectancy in order to "be there" for their children (Boehme et al., 2013). Every woman's life changes after a birth, but for HIV+ women the changes could mean lower care retention, higher viral load, and a higher risk of developing AIDS (Boehme et al., 2013). Retaining HIV+ black women in HIV care during and after pregnancy is an opportunity all healthcare providers should be aware of, as it can be the moment women are entered into lifesaving care.

Physical ailments are easier to recognize because of their clinical, objective symptoms, but mental illness, especially depression, can affect every aspect of a person's life without being diagnosed. Patients and providers miss diagnoses because depressive symptoms are attributed to medication side effects or the shock of a new diagnosis, yet 31% of female HIV patients reported any kind of depression in 2009 (Do et al., 2014, Table 2). This is because chronic illnesses like HIV are a risk factor for developing depression, though depression can also exacerbate HIV (NIMH, 2016b). Depression is also more common among women and non-Hispanic blacks compared to men and other races, placing black HIV+ women at an increased risk for developing depression (CDC, 2013). Depression significantly affects retention in HIV care and ART adherence, and is therefore imperative for HIV providers to address (Zuniga, Yoo-Jeong, Dai, Guo, & Waldrop-Valverde, 2016). Women may be more vulnerable to depression, and the black community contains a higher level of depression-related stigma than the white community (Saadat, Behboodi, & Saadat, 2015; Conner et al., 2010). The complicated relationship between HIV, women, the black community, and depression shows the far-reaching consequences of oversight and the necessity of understanding each individual patient's case.

Spirituality as a Facilitator of Care

One notable care facilitator for black HIV+ women is spirituality—feeling a connection to the universe or a higher power to find meaning in life—and support from religious institutions.

Black heterosexual women with HIV reported the most positive effects from spirituality when compared to other demographic groups in one study, and every woman out of 15 interviewees brought up spirituality as a care facilitator without being asked in another study (Kremer, & Ironson, 2014; Grodensky et al., 2015). Women reported relying on God for coping with an initial HIV diagnosis, feeling closer to God because of their diagnosis, finding a support system within their churches, and seeking solace in religion when they had no where else to go (Grodensky et al., 2015). Though some have experienced stigma within their religious institutions, finding a connection to a higher being can be a powerful link to life. Some of the studied benefits of spirituality include healing, greater access to a support system, improved mental health, finding a purpose in life, and finding motivation to "keep going" (Dalmida et al., 2012). This means greater engagement in HIV care across the continuum and partial offset of some potential barriers to care. In order to help black HIV+ women reach their full HIV care potentials, providers must be aware of how many people in this population use spirituality to cope and how powerful of a coping mechanism it can be. A wealth of care opportunities open when a patient's supportive spiritual life and committed HIV care team work together to find the best solutions for her needs.

Addressing Barriers with Comprehensive Care

It is easy to visualize a cage around each black HIV+ woman with these barriers in place. Attempting to individually dismantle every force working to keep a patient out of care can be futile and exhausting. Every member of the HIV care team must therefore practice comprehensive care, the type of care that treats a patient's body, mind, and spirit together in order to identify and address barriers. Every interaction with a healthcare provider is centered on the provider's specialty and viewed in terms of the patient's entire health. Instead of basing care

around ART adherence, viremia, and immunologic status, care should be based around individual patient priorities that are the biggest barriers to health for the person. Certain parts of a patient—her HIV and depression—should not be treated more than other parts—unstable housing and IPV—because her providers look at her issues microscopically. Comprehensive care has two important aspects: multidisciplinary care, and interdisciplinary knowledge. That is, expert providers in every area of care, and knowledge across disciplines to preserve continuity of care. This allows every member of the care team to see what the most pertinent problems are for patients and how these problems could affect the outcomes in their own discipline. Comprehensive care allows a woman's cage to be visualized, understood, and unlocked.

Aspects of comprehensive HIV care

One of the most defining characteristics of comprehensive HIV care is the coordinating of people and resources. An HIV care team needs expertise in every area of need for a patient, and must make this expertise readily available to patients. Just as the barriers for black HIV+ women are complicated, so too must be their care. This directly contrasts with segmented care when either not enough specialties are represented in a care team or when team members do not communicate. The discussed barriers are key points that must be included or anticipated in every black HIV+ woman's care; therefore, interdisciplinary coordination around these topics must be facilitated.

The Health Resources and Services Administration (HRSA) identified three structures for ideal comprehensive HIV care delivery: coordinated services in different locations, co-located services, and integrated services that are co-located without administrative barriers (2014). Some "factors for success" in care delivery models include co-located services, diverse teams of providers, stigma-reducing culture, comprehensive service availability, effective communication,

and high-quality care (HRSA, 2014, p.5-6). Women have also reported personal preference of comprehensive care clinics where multiple services are available during one appointment due to transportation and employment barriers (Kempf et al., 2010). Important members of a comprehensive HIV care team include specialists from each area of need, HIV expertise from each provider, and a care coordinator—typically a case manager—to ensure seamless transitions (Gallant et al., 2011).

The Ryan White Care Act, a federal funding program specifically for HIV/AIDS, supports comprehensive care by providing insurance to patients who do not have the means to afford the HIV care they need (HRSA, 2016a). It funds all types of comprehensive services, including mental health services, transportation to appointments, and child care services in the Part D program targeted specifically towards women (HRSA, 2016b). Ryan White also funds comprehensive care programs that have shown positive outcomes in short-term studies, and funds clinics that offer a variety of services to patients in house (Irvine et al., 2015). Comprehensive care is at the forefront of tertiary prevention for HIV patients as evidenced by the HRSA recommendations, the Ryan White support, and the effectiveness of the care.

Because black HIV+ women have so many barriers, it is difficult to effectively treat them with a few primary care interactions a year, especially when retention is low. Clinics with many services and highly integrated comprehensive care teams are advantageous for women who have barriers to care because they have fewer appointments they are obligated to keep. The HIV stigma patients face negatively impacts mental health; mental illness negatively impacts healthcare retention; low retention negatively impacts health education; and inadequate education leads to poor medication adherence and misconceptions regarding HIV and pregnancy. In a comprehensive care setting not only would each of these issues be more easily treated,

providers will be able to anticipate problems across disciplines and work with each other to fully address barriers to care and improve retention.

Communication in comprehensive HIV care

As barriers grow, so too does the patient's healthcare team, adding experts in every area of need. Communication in interdisciplinary teams is essential for positive patient outcomes (Nancarrow et al., 2013). Because comprehensive HIV care naturally involves many disciplines working together, communication plays an important role in maintaining a flow of current patient information. Barriers faced by black HIV+ women often affect multiple disciplines; by identifying a barrier in one healthcare visit, HIV care team members can communicate the problem to the rest of the team to address the barrier and prevent future problems. This aligns with both aspects of comprehensive HIV care: each team member must communicate in some way with every other member in order to understand the implications for their specialty's treatment of the patient.

The Ryan White Care Act recognizes the importance of communication, and provides software called CAREWare specifically designed for patients with HIV/AIDS. Any HIV care provider has access to this database where patient information is updated and communicated between all disciplines (HRSA, 2016c). Clinics noted communication via electronic health records (EHR) as a facilitator of care, which is especially important when services are not co-located (Ojikutu et al., 2014). For example, rural areas with HIV patients over a large geographical area rely on EHR to communicate between providers when co-located clinics are not possible (Messer, Parnell, Huffaker, Wooldredge, & Wilkin, 2012). CAREWare and software like it provide communication opportunities that make patient care more accessible and comprehensive, regardless of location.

Because healthcare communication is often via EHR's, CAREWare and other tools have great significance in comprehensive care communication. Standard healthcare tools such as checklists to prevent central line infections and surgical errors have greatly improved patient outcomes in recent years (Pronovost et al., 2006). Afsar-manesh, Perkins, Breger, & Zadunayski (2015) developed another checklist communication tool to prevent common hospital problems that proved effective in reducing negative outcomes. Though these checklists took place in acute care settings, they also involved interdisciplinary teamwork and communication to reach the best outcomes. A similar checklist tool for black HIV+ women would offer a simple, streamlined method of communication where all disciplines could contribute and learn from each other.

Proposal for Interdisciplinary Communication Tool

To facilitate interdisciplinary communication and achieve comprehensive care for black HIV+ women, I propose an Interdisciplinary Comprehensive Care Worksheet (ICCW). This is a one-page document with text boxes of common barriers faced by black HIV+ women and personalized descriptions for each. The ICCW is meant to coordinate and link patients to preexisting interventions by making important information available to every necessary healthcare provider. Because every patient is different, every ICCW will be different; text box organization is based on importance, placing the most pertinent information at the top where it is seen first. While the template in Appendix A places the boxes in a certain order, arrangement will vary based on the patient's principle barriers. The most important aspect of the ICCW is its customizability, making it transferable to any charting system and any patient. The researched barriers will be the titles of text boxes, with guidelines for type of information to be placed in each box below. This is not meant to be an in-depth look at the patient, but rather a concise snapshot of the most important barriers and facilitators to care. The ICCW gives every HIV care

team member the macroscopic view they need to address barriers, strengthen facilitators, and appropriately treat each patient.

At the top of the ICCW (Appendix A) is a heading with patient name, age, medical record number, contact information including an emergency contact number, latest CD4 count and viral load with date, last and next HIV appointment date, if the patient has a history of missing appointments, age at diagnosis, and method of transmission. The rest of the document will start out as boxes with the headings Stigma, Trauma, Social, Medical, OB-GYN, Facilitators of Care, and Other. Healthcare providers can write pertinent information in these boxes for each section. Each box will have expansion options for different categories within the major headings with the exception of the Stigma heading. Stigma will be a place for patient impressions and quotes about their experiences to help providers understand the patient's perspective in her own words. This is also where providers can enter whom the patient has disclosed their status to in order to offer insight about how stigma affects their support system. Trauma will have sections for history of IPV, childhood abuse, sexual abuse, how they reacted after diagnosis, and if they have or had PTSD. Social will have housing situation, transportation needs, financial status, employment status, history of or current substance abuse, and significant negative but non-traumatic relationships with a partner, family, or friends. Medical will have a place for comorbidities, including other important medical diagnoses and psychiatric illnesses, along with ongoing or past interventions. Pertinent dental history will be here. OB-GYN will have gravidity and parity status with HIV outcomes if they were pregnant while HIV+, if they are pre or post menopausal, any education providers have given about pregnancy and HIV, if the woman would like to have more children, her next cervical cancer screening, comments about her libido, and if she has pain during sex. This is separate from medical because it applies to every female patient

with a uterus and ovaries, and is not an illness. Facilitators of Care is for spirituality support and any other significant support systems in a patient's life. Other will be a place for any notes about a patient that do not fall into a listed category, or pertinent notes from provider interactions.

Because this is just a snapshot, each heading will be a hyperlink to take providers to the specific section of the chart with more information. Boxes can be non-permanently removed if they are not currently a problem for the patient, though still available from a dropdown menu. In order to fit onto one page for ease of reading, the boxes will automatically shorten themselves and create a "click here for more" on each box that does not have everything fit. Even if a patient has barriers in every listed area, the provider should be able to look at this document and quickly discern a direction of their care. An example completed ICCW is in Appendix B.

In order to establish content validity of the ICCW, I consulted two HIV/AIDS experts: Jonah Pierce, ACRN, and Lynda Bell, MSN, FNP. Both Pierce and Bell work at the University of North Carolina Infectious Disease Clinic, and have devoted their careers to treating HIV/AIDS patients. Pierce, who serves as the charge nurse of the clinic and a case manager, believes the ICCW would fit with the patients seen at the clinic, noting the social aspects of the categories as strengths of the tool (personal communication, March 10, 2016). He also agreed with the possible transferability to UNC's computer system, though is not an expert in software (J. Pierce, personal communication, March 10, 2016). Bell believes this is a "comprehensive evaluation" for black HIV+ women, and offered suggestions for assessing a woman's romantic/sexual relationships. Her recommendations for what to place in different sections of the tool were incorporated into the development of the tool (personal communication, March 11, 2016).

Suggestions for Use

Because all places of care have different charting systems, the ICCW is a prototype to be developed by each institution to fit their system and language. It is also only available electronically to fit the need of most charting systems, though can be printed when needed. Ideally it will be the first thing every healthcare provider sees when opening the chart for each patient and will give them the information they need to adequately plan care. It is essential to update this document at every healthcare appointment to be sure coordination of care occurs. A case manager would ideally be the point person for this document, and is who other providers will report suggestions and questions. The case manager will decide where boxes will be placed on the document based on patient interactions and reports from other providers; no one else should change the layout of the ICCW. While similar prototypes could work for other populations, the ICCW is specifically designed for black HIV+ women to anticipate and treat their barriers to care, and should only be used with this population. The goal is to create a customized document that can identify trends and offer insight to types of interventions that would be most beneficial. Many interventions already exist to take down one barrier to care at a time, but the ICCW will help these interventions work together to take down both barriers and barrier interactions.

Providers should ask open-ended questions when filling out the ICCW, and avoid quoting the document to patients. For example, instead of asking for negative and supportive relationships in a woman's life, a provider could ask "Tell me about the important people in your life. What do they bring to the relationship? What do you bring to the relationship?" (L. Bell, personal communication, March 11, 2016). This will create space for information not otherwise offered under specific questions.

The ICCW was developed with outpatient care and tertiary prevention as the main method of care delivery, and thus the implications and direction for use in an acute care setting were not studied. However, the ICCW should be accessible to members of the care team in a hospital if there is a progression to AIDS in order to personalize discharge plans and prevent further hospitalizations. During interdisciplinary meetings this document should be referred to and updated, potentially printed as a hard copy for ease of reference. If a case manager is not available to be the administrator of the ICCW, the HIV provider or other designated team member should fill this role. The ICCW will work in conjunction with the three identified methods of comprehensive care delivery—coordinated services in different locations, co-located services, and integrated services that are co-located without administrative barriers. It will be especially meaningful for systems that are not co-located because it helps eliminate the disconnected communication that can occur when physical proximity is not possible.

Summary

The goal of HIV care is to live the healthiest life possible with a low viral load and high CD4 count. This healthy life is achieved through steps in the care continuum: diagnosis, linkage to care, retention in care, ART prescription, and viral suppression. These steps are much more difficult for black HIV+ women due to existing barriers that prevent good outcomes, leading to this population carrying a significant burden of disease. Just as barriers are complex and nuanced, so too must be the care black HIV+ women receive. Comprehensive care looks at the entire patient and treats the person within a body; this is challenging without interdisciplinary communication between the many providers on a woman's HIV care team. In order to facilitate this communication, the ICCW was created to serve as a snapshot of vital patient information so all providers are aware of the patient's situation. The best way to treat black HIV+ women is not

to lean in closer to examine each microscopic reason treatment is failing them, but to step back

and see the larger picture with a macroscopic view. Only then will the patient be strong enough

to fly out of her cage.

References

Aaron, E., Criniti, S., Bonacquisti, A., & Geller, P. A. (2013). Providing sensitive care for adult HIV-infected women with a history of childhood sexual abuse. *JANAC: Journal Of The Association Of Nurses In AIDS Care*, *24*(4), 355-367. doi: 10.1016/j.jana.2013.03.004

Afsar-manesh, N., Perkins, C.E., Breger, K.S., & Zadunayski, M.M. (2015). ABCs of hospitalized patients: a simple before-after study of a communication tool to improve quality of inpatient care. *Journal of Patient Safety,* published ahead of print. doi: 10.1097/PTS.0000000000000212

Alonzo, A.A., & Reynolds, N.R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science & Medicine, 41*(3), 303-315. doi: 10.1016/0277-9536(94)00384-6

American Association of University Women (2016). The simple truth about the gender pay gap: Spring 2016 Edition. Retrieved from http://www.aauw.org/files/2016/02/SimpleTruth_Spring2016.pdf

American Psychological Association (2016). *Trauma*. Accessed 3/2/16. Retrieved from http://www.apa.org/topics/trauma/

Audain, G., Bookhardt-Murray, L.J., Fogg, C.J., Gregerson, P., Haley, C.A., Luther, P....& Knopf-Amelung, S. (Editor) (2013). *Adapting your practice: Treatment and recommendations for unstably housed patients with HIV/AIDS, Third Edition*. Nashville, TN: Health Care for the Homeless Clinicians' Network, National Health Care for the Homeless Council, Inc.

Boehme, A.K., Davies, S.L., Moneyham, L., Shrestha, S., Schumacher, J., & Kempf, M.C. (2013). A qualitative study on factors impacting HIV care adherence among postpartum

HIV-infected women in the rural southeastern USA. *AIDS Care, 26*(5), 574-581. doi: 10.1080/09540121.2013.844759

Breiding, M.J., Smith, S.G., Basile, K.C., Walters, M.L., Chen, J., & Merrick, M.T. (2014, September 5). Prevalence and characteristics of sexual violence, stalking, and intimate partner violence victimization — national intimate partner and sexual violence survey, United States, 2011. *Morbidity and Mortality Weekly Report Surveillance Summaries, 63*(SS08), 1-18. Retrieved from

http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6308a1.htm?s_cid=ss6308a1_e

Brownley, J.R., Fallot, R.D., Berley, R.W., & Himelhoch, S.S. (2015). Trauma history in African-American women living with HIV: effects on psychiatric symptom severity and religious coping. *AIDS Care, 27*(8), 964-971. doi: 10.1080/09540121.2015.1017441

CDC Office of Women's Health; Centers for Disease Control and Prevention (2015a). *Leading Causes of Death by Age Group, White Females-United States, 2013*. Retrieved from http://www.cdc.gov/women/lcod/2013/womenwhite_2013.pdf

CDC Office for Women's Health; Centers for Disease Control and Prevention (2015b). *Leading Causes of Death by Age Group, Black Females-United States, 2013*. Retrieved from http://www.cdc.gov/women/lcod/2013/womenblack_2013.pdf

CDC Office for Women's Health; Centers for Disease Control and Prevention (2015c). *Leading Causes of Death by Age Group, Hispanic Females-United States, 2013*. Retrieved from http://www.cdc.gov/women/lcod/2013/womenhispanic_2013.pdf

Centers for Disease Control and Prevention (2013). *Depression Statistics*. Accessed 3/7/16. Retrieved from http://www.cdc.gov/mentalhealth/data_stats/depression.htm

Centers for Disease Control and Prevention (2014). *Intersection of Intimate Partner Violence and HIV in women*. Accessed 3/5/16. Retrieved from

http://www.cdc.gov/violenceprevention/pdf/ipv/13_243567_green_aag-a.pdf

Conner, K.O., Copeland, V.C., Grote, N.K., Koeske, G., Rosen, D., Reynolds III, C.F., & Brown, B. (2010). Mental health treatment seeking among older adults with depression: the impact of stigma and race. *The American Journal of Geriatric Psychiatry, 18*(6), 531-543. doi: 10.1097/JGP.0b013e3181cc0366

Dalmida, S.G., Holstad, M.M., DiIorio, C., & Laderman, G. (2012). The meaning and use of spirituality among African American women living with HIV/AIDS. *Western Journal of Nursing Research, 34*(6), 736–765. doi: 10.1177/0193945912443740

Division of HIV/AIDS Prevention; Centers for Disease Control and Prevention (2014). *Understanding the HIV Care Continuum*. Retrieved from

http://www.cdc.gov/hiv/pdf/DHAP_Continuum.pdf

Division of HIV/AIDS Prevention; Centers for Disease Control and Prevention (2015a). *HIV Surveillance Report, 2014, 26*. Retrieved from

http://www.cdc.gov/hiv/statistics/overview/index.html

Division of HIV/AIDS Prevention; Centers for Disease Control and Prevention (2015b). *HIV Among Women*. Accessed 2/29/2016. Retrieved from

http://www.cdc.gov/hiv/group/gender/women/#refb

Division of HIV/AIDS Prevention; Centers for Disease Control and Prevention (2015c, June 23). *HIV Among Pregnant Women, Infants, and Children*. Accessed 3/7/16. Retrieved from

http://www.cdc.gov/hiv/group/gender/pregnantwomen/

Division of Violence Prevention; National Center for Injury Prevention and Control (2015).

      Intimate Partner Violence. Accessed 3/5/16. Retrieved from

      http://www.cdc.gov/violenceprevention/intimatepartnerviolence/

Do, A.N., Rosenberg, E.S., Sullivan, P.S., Beer, L., Strine, T.W., Schulden. J.D.,…Skarbinski, J.

      (2014). Excess burden of depression among HIV-infected persons receiving medical care

      in the United States: data from the Medical Monitoring Project and the Behavioral Risk

      Factor Surveillance System. *PLoS ONE, 9*(3), 1-10 (e92842). doi:

      10.1371/journal.pone.0092842

Frye, M. (1983). *The politics of reality: Essays in feminist theory*. Trumansburg, NY: The

      Crossing Press.

Gallant, J.E., Adimora, A.A, Carmichael, J.K., Horberg, M., Kitahata, M., Quinlivan, E.B.,…&

      Williams, S.B. (2011). Essential components of effective HIV care: a policy paper of the

      HIV Medicine Association of the Infectious Diseases Society of America and the Ryan

      White Medical Providers Coalition. *Clinical Infectious Diseases, 53*(11), 1043-1050. doi:

      10.1093/cid/cir689

Grodensky, C.A., Golin, C.E., Jones, C., Mamo, M., Dennis, A.C., Abernethy, M.G., &

      Patterson, K.B. (2015). ''I Should Know Better'': The roles of relationships, spirituality,

      disclosure, stigma, and shame for older women living with HIV seeking support in the

      South. *Journal of the Association of Nurses in AIDS Care, 26*(1), 12-23. doi:

      10.1016/j.jana.2014.01.005

Haddad, L.B., Machen, L.K., Cordes, S., Huylebroeck, B., Delaney, A., Ofotokun, I.,…&

      Jamieson, D.J. (2015). Future desire for children among women living with HIV in

      Atlanta, Georgia. *AIDS Care*. doi: 10.1080/09540121.2015.1114996

Health Resources and Services Administration; U.S. Department of Health and Human Services

> (2014). Interdisciplinary care teams: a lifeline for people with HIV/AIDS. *HRSA Care
>
> Action, Janurary 2014*. Retrieved from
>
> http://hab.hrsa.gov/deliverhivaidscare/interdisciplinarycareteamsnewsletter.pdf

Health Resources and Services Administration; HIV/AIDS Programs (2016a). *Legislation*.

> Accessed 3/8/16. Retrieved from http://hab.hrsa.gov/abouthab/legislation.html

Health Resources and Services Administration; HIV/AIDS Programs (2016b). *Part D - services

> for women, infants, children, youth & their families*. Accessed 3/8/16. Retrieved from
>
> http://hab.hrsa.gov/abouthab/partd.html

Health Resources and Services Administration; HIV/AIDS Programs (2016c). *Ryan White

> CAREWare*. Accessed 3/8/16. Retrieved from
>
> http://hab.hrsa.gov/manageyourgrant/careware.html

Henry, M., Shivji, A., de Sousa, T., & Cohen, R. (2015, November). *The 2015 Annual Homeless

> Assessment Report (AHAR) to Congress, Part 1: point in time estimates of homelessness*.
>
> Washington, DC: Office of Community Planning and Development; US Department of
>
> Housing and Urban Development.

hIarlaithe, M.O., Grede, N., de Pee, S., & Bloem, M. (2014). Economic and social factors are

> some of the most common barriers preventing women from accessing maternal and
>
> newborn child health (MNCH) and prevention of mother-to-child transmission (PMTCT)
>
> services: a literature review. *AIDS And Behavior, 18*(5), 516-530. doi: 10.1007/s10461-
>
> 014-0756-5

Irvine M.K., Chamberlin, S.A., Robbins, R.S., Myers, J.E., Braunstein, S.L., Mitts, B.J.,...&

> Nash, D. (2015). Improvements in HIV care engagement and viral load suppression

following enrollment in a comprehensive HIV care coordination program. *Clinical Infectious Diseases, 60*(2), 298-310. doi: 10.1093/cid/ciu783

Kaiser Family Foundation (2014, March 6). *Women and HIV/AIDS in the United States*. Accessed 3/7/16. Retrieved from http://kff.org/hivaids/fact-sheet/women-and-hivaids-in-the-united-states/

Kalichman, S.C., Hernandez, D., Cherry, C., Kalichman, M.O., Washington, C., & Grebler, T. (2014). Food insecurity and other poverty indicators among people living with HIV/AIDS: effects on treatment and health outcomes. *Journal of Community Health, 39*(6), p.1133-1139. doi: 10.1007/s10900-014-9868-0

Kempf, M., McLeod, J., Boehme, A.K., Walcott, M.W., Wright, L., Seal, P.,…& Moneyham, L. (2010). A qualitative study of the barriers and facilitators to retention-in-care among HIV-positive women in the rural southeastern United States: implications for targeted interventions. *AIDS Patient Care and STDs, 24*(8), 515-520. doi: 10.1089/apc.2010.0065

Khanijow, K., Hirozawa, A., Ancock, B., Hsu, L.C., Bamberger, J., & Schwarcz, S.K. (2015). Difference in survival between housed and homeless individuals with HIV, San Francisco, 2002-2011. (2015). *Journal of Health Care for the Poor & Underserved*, *26*(3), 1005-1018. doi: 10.1353/hpu.2015.0071

Kremer, H., & Ironson, G. (2014). Longitudinal spiritual coping with trauma in people with HIV: implications for health care. *AIDS Patient Care and STDs, 28*(3), 144-154. doi: 10.1089/apc.2013.0280

Lanier, L., & DeMarco, R. (2015). A synthesis of the Theory of Silencing the Self and the Social Ecological Model: understanding gender, race, and depression in African American

women living with HIV infection. *AIDS Patient Care and STDs, 29*(3), 142-149. doi: 10.1089/apc.2014.0116

Leaver, C.A., Bargh, G., Dunn, J.R., & Hwang, S.W. (2007). The effects of housing status on health-related outcomes in people living with HIV: a systematic review of the literature. *AIDS and Behavior, 11*(supplement 2), 85-100. doi: 10.1007/s10461-007-9246-3

Maslow, A. H. (1943). A theory of human motivation. *Psychological Review*, *50*(4), 370-396. doi: 10.1037/h0054346

McDoom, M.M., Bokhour, B., Sullivan, M., & Drainoni, M. (2015). How older black women perceive the effects of stigma and social support on engagement in HIV care. *AIDS Patient Care and STDs, 29*(2), p.95-101. doi: 10.1089/apc.2014.0184

Mellins, C.A., Chu, C., Malee, K., Allison, S., Smith, R., Harris, L.…& Larussa, P. (2008). Adherence to antiretroviral treatment among pregnant and postpartum HIV-infected women. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV, 20*(8), 958-968. doi: 10.1080/09540120701767208

Messer, L.C., Parnell, H., Huffaker, R., Wooldredge, R., & Wilkin, A. (2012). The development of a health information exchange to enhance care and improve patient outcomes among HIV+ individuals in rural North Carolina. *International Journal of Medical Informatics*, *81*(10), 46-55. doi: 10.1016/j.ijmedinf.2012.07.009

Messer, L.C., Quinlivan, E.B., Parnell, H., Roytburd, K., Adimora, A.A., Bowditch, N., & DeSousa, N. (2013). Barriers and facilitators to testing, treatment entry, and engagement in care by HIV-positive women of color. *AIDS Patient Care and STDs*, *27*(7), 398-407. doi: 10.1089/apc.2012.0435

Nancarrow, S.A., Booth, A., Ariss, S., Smith, T., Enderby, P., & Roots, A. (2013). Ten

   principles of good interdisciplinary team work. *Human Resources for Health, 11*(19). doi:

   10.1186/1478-4491-11-19

National Institute of Mental Health; National Institutes of Health (2016a). *Post-Traumatic Stress

   Disorder*. Accessed 3/5/16. Retrieved from http://www.nimh.nih.gov/health/topics/post-

   traumatic-stress-disorder-ptsd/index.shtml#part_145372

National Institute of Mental Health; National Institutes of Health (2016b). *Chronic Illness and

   Mental Health*. Accessed 3/7/16. Retrieved from

   http://www.nimh.nih.gov/health/publications/chronic-illness-mental-health-

   2015/index.shtml

National Rural Health Association (2014). HIV/AIDS in rural America: disproportionate impact

   on minority and multicultural populations. *National Rural Health Association Policy

   Brief, April 2014*.

Neigh, G.N., Rhodes, S.T., Valdez, A., & Jovanovic, T. (2015). PTSD co-morbid with HIV:

   separate but equal, or two parts of a whole? *Neurobiology of Disease*. doi:

   10.1016/j.nbd.2015.11.012

Ojikutu, B., Holman, J., Kunches, L., Landers, S., Perlmutter, D., Ward, M.,…& Hirschhorn, L.

   (2014). Interdisciplinary HIV care in a changing healthcare environment in the USA.

   AIDS Care, 26(6), 731-735. doi: 10.1080/09540121.2013.855299

Panel on Antiretroviral Guidelines for Adults and Adolescents; Department of Health and

   Human Services (2016). *Guidelines for the use of antiretroviral agents in HIV-1-infected

   adults and adolescents*. Accessed 2/28/2016. Retrieved from

   https://aidsinfo.nih.gov/contentfiles/lvguidelines/adultandadolescentgl.pdf

Peltzer, J., Domian, E., & Teel, C. (2015). Living in the everydayness of HIV infection: experiences of young African-American women. *Medsurg Nursing, 24*(2), 111-118.

Peltzer, J., Domian, E., & Teel, C. (2016). Infected lives: lived experiences of young African American HIV positive women. *Western Journal of Nursing Research, 38*(2), 216-230. doi: 10.1177/0193945914552167

Pronovost, P., Needham, D., Berenholtz, S., Sinopoli, D., Chu, H., Cosgrove, S.,…& Goeschel, C. (2006). An intervention to decrease catheter-related bloodstream infections in the ICU. *The New England Journal of Medicine, 355*(26), 2725-2732. doi: 10.1056/NEJMoa061115

Roberts, A. L., Gilman, S. E., Breslau, J., Breslau, N., & Koenen, K. C. (2011). Race/ethnic differences in exposure to traumatic events, development of post-traumatic stress disorder, and treatment-seeking for post-traumatic stress disorder in the united states [Abstract]. *Psychological Medicine, 41*(1), 71-83. doi: 10.1017/S0033291710000401

Rollins, N.C., Becquet, R., Orne-Gliemann, J., Phiri, S., Hayashi, C., Baller, A. & Shaffer, N. (2014). Defining and analyzing retention-in-care among pregnant and breastfeeding HIV-infected women: unpacking the data to interpret and improve PMTCT outcomes. *Journal of Acquired Immunodeficiency Syndrome, 67*(2), 150-156. doi: 10.1097/QAI.0000000000000355

Rosenstock, I.M. (1966). Why people use health services. *The Milbank Memorial Fund Quarterly, 44*(3), part 2, 94-127. doi: 10.2307/3348967

Saadat, M., Behboodi, Z. M., & Saadat, E. (2015). Comparison of depression, anxiety, stress, and related factors among women and men with human immunodeficiency virus

infection. *Journal of Human Reproductive Sciences*, *8*(1), 48–51. doi: 10.4103/0974-1208.153128

Stevens, P., & Doerr, B. (1997). Trauma of Discovery: women's narratives of being informed they are HIV-infected. *AIDS Care, 9*(5), 523-538.

Thompson, M.A., Mugavero, M.J., Amico, K.R., Cargill, V.A., Chang, L.W., Gross, R.,…Nachega, J.B. (2012). Guidelines for improving entry into and retention in care and antiretroviral adherence for persons with HIV: evidence-based recommendations from an International Association of Physicians in AIDS Care panel. *Annals of Internal Medicine, 156*(11), p.817-W294. doi: 10.7326/0003-4819-156-11-201206050-00419

Whiteside, Y.O, Cohen, S.M., Bradley, H., Skarbinski, J., Hall, H.I., & Lansky, A. (2014, February 7). Progress Along the Continuum of HIV Care Among Blacks with Diagnosed HIV— United States, 2010. *Morbidity and Mortality Weekly Report, 63*(5), p.85-89.

Zuniga, J.A., Yoo-Jeong, M., Dai, T., Guo, Y., & Waldrop-Valverde, D. (2016). The role of depression in retention in care for persons living with HIV. *AIDS Patient Care and STDs, 30*(1), 34-38. doi: 10.1089/apc.2015.0214

Appendix A

Patient:_____	**Age:**_____	**MRN:**_____	**Contact #:**_____	**Emergency#:**_____

Viral Load (date):_____   **CD4 Count (date):**_____

Last HIV Care Appointment:_____   **Next HIV Care Appointment:**_____

Hx of Missed Appointments (yes/no):_____ **Age at diagnosis (method of transmission):**_____

STIGMA
- Patient impressions on stigma in their lives using direct quotes
- Provider impressions based on what patient reported
- Only update if the information here is no longer accurate to prevent clutter
- Who knows she is HIV+

TRAUMA
- IPV
- Childhood abuse
- Sexual abuse
- Reaction after HIV diagnosis
- PTSD

SOCIAL
- Transportation
- Housing situation
- Financial status (insurance)
- Employment
- Substance abuse
- Negative relationships
- Sexual relationships
- Romantic relationships

MEDICAL
- Comorbidities
- Psychiatric illness
- Ongoing/past interventions for comorbidities
- Dental History (if pertinent)

OB-GYN
- Gravity and parity
- HIV status during pregnancy & outcome for baby
- Menopausal status, libido, pain during sex
- Education given about pregnancy and HIV, safe sex, contraception
- Desire to have children
- Next cervical cancer screening

FACILITATORS OF CARE
- Support from spirituality
- Other significant care facilitators and support systems

OTHER
- This box can be deleted, but is a place where boxes can be added or notes that do not fit in another place but are pertinent to patient care

Appendix B

Patient: Jane Doe	**Age:** 26	**MRN:** 12345	**Contact/Emergency #:** 012-345-6789

Viral Load (date): 250   **CD4 Count (date):** 375

Last HIV Care Appointment: 01/02/16   **Next HIV Care Appointment:** 03/10/16

Hx of Missed Appointments (yes/no): yes   **Age at diagnosis:** 23 (heterosexual contact)

STIGMA
- "I feel like I can't tell my friends because they think only gay people get HIV, and I'm not gay"
- Jane lives far away, feels she must travel to avoid friends at the clinic; has affected retention in the past
- Close family and friends know she is positive

MEDICAL
- Type 2 Diabetes Mellitus
- Diabetic foot ulcer R foot
- Hx of depression w/o SI
- Metformin (no insulin), SSRI

SOCIAL
- Transportation: Jane lives far away and relies on bus routes
- Ryan White member
- Current smoker (2ppd)
- Works at her local post office
- Estranged from brother after diagnosis

TRAUMA
- Was in abusive relationship (physical, verbal) when diagnosed, no longer in relationship
- Dx with depression after HIV diagnosis, responded well to medication

OB-GYN
- G2 P1; child lives with her
- Father of children is current boyfriend
- HIV+ during both pregnancies, retained in HIV care during pregnancy
- Would like to have more children
- Regular condom use with boyfriend, conceived in the past via home insemination (received education)

FACILITATORS
- Reports regular attendance at church, pastor and some congregants are aware of status and are supportive (drive to appointments sometimes)
- Cites children and boyfriend as support system in her life

OTHER
- Patient seemed more depressed than usual 1/2/16 but did not elaborate on cause, will follow up with phone call before next appointment