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Picturing Life: Using Photo Journals to Explore Challenges and Supports for Women  
Living with HIV (WL-HIV)

Toshua Willingham Kennedy

A dissertation submitted to the faculty of Medical University of South Carolina in partial  
fulfillment of the requirements for the degree of Doctor of Philosophy in the College of  
Nursing

April 2015

**Approved by:**

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Ida Spruill, Ph.D., RN, LISW, FAAN  
Chairman, Advisory Committee

---

Elaine J. Amella., Ph.D., RN, FAAN

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Susan D. Newman, PhD., RN, CRRN

---

Michelle Teti, DrPH

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## Abstract

Toshua Willingham Kennedy. Picturing Life: Using Photo Journals to Explore Challenges and Supports for Females Living with HIV

Human immunodeficiency virus (HIV) is a health-related stigmatizing condition that progresses to acquired immune deficiency syndrome (AIDS), characterized by a weakened immune system and opportunistic diseases. South Carolina ranks eighth for AIDS prevalence in the United States, and for socioeconomic reasons, women, specifically minority women, in the southern region of the country experience the worst clinical outcomes after receiving an HIV diagnosis. Research that focuses on strategies to improve clinical outcomes for women living with HIV (WL-HIV) has great value in promoting empowerment and health equity especially among minority women. The current study used a participatory research design to collaborate with WL-HIV to create photo journals to identify personal challenges and supports. Data source included (discussions, photographs, and one-on-one interviews). The investigator used a grounded theory approach to analyze the data and identified major themes and subthemes. Major themes for supports included spirituality and empowerment; and subthemes were, reinventing self and positive relationships. The investigator identified stigma as the major theme for challenges, and public silence on HIV and missed opportunities were subthemes. The author provided specific recommendations for future research and clinical practice.

**Manuscript 1:** Defining Hope among HIV-Positive African American Females. This article was a concept analysis of hope among African American females living with HIV and was accepted for publication by *The Journal of Christian Nurses*, (Kennedy, 2015).

**Manuscript 2:** Ethical Considerations Regarding Barriers and Facilitators to Research Participation for Patients Affected by Health-related Stigmatizing Conditions. This integrative review focused on the ethical implications of omitting persons living with health-related stigmatizing conditions, such as human immunodeficiency virus, substance use disorders, and intimate partner violence. The author formatted this manuscript for *The American Journal of Nursing*.

**Manuscript 3:** Picturing Life: Using Photo Journals to Explore Challenges and Supports for Women Living with HIV. This manuscript explored the challenges and supports experienced by women with HIV in South Carolina. This qualitative study employed a participatory research design with Photovoice as the method of data collection.

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## Introduction

Acquired immune deficiency syndrome (AIDS) is a chronic life-threatening condition caused by the human immunodeficiency virus (HIV) (Mayo Clinic, 2014). Because HIV damages the immune system, there is interference in the ability to fight infectious agents that cause diseases. This virus is a communicable disease transmitted from infected blood and body fluid through sharing needles, sexual contact, childbirth, and breastfeeding. Conversion of HIV to AIDS typically takes years as the immune system weakens. Despite the fact that there is no cure for HIV and AIDS, there are medications designed to slow disease progression.

In 2011, it was estimated that 34 million people worldwide have HIV (World Health Organization, 2013), and according to the National Institutes of Health (NIH) global prevalence for HIV and AIDS in women has continued to increase (National Institutes of Health, 2010). In 2011, the incidence of HIV among women in the United States was estimated to be 10,257, accounting for 20% of all new cases (Centers for Disease Control and Prevention, 2012), with AIDS as a leading cause of death for WL-HIV (Quinn & Overbaugh, 2005; Vogler, 2002). In 2012, the highest HIV/AIDS prevalence for females in South Carolina was among childbearing ages (15 – 45 years) totaling 2,231 (South Carolina Department of Health and Environmental Control, 2012a). In 2010, the percentages of WL-HIV by race in the United States were 64% African American, 18% White, 15% Hispanic (Centers for Disease Control and Prevention, 2012), and 3% other. Further, in 2011, South Carolina's percentages by race for women were 80% African American, 15% White, 3% Hispanic (South Carolina Department of Health and Environmental Control, 2012b), and 2% other.

## **Significance of Treatment**

The Centers for Disease Control and Prevention (CDC) determined that treating HIV with antiretroviral therapy (ART) improves the patients' health and is the priority for reducing the transmission of HIV to others (Centers for Disease Control and Prevention, 2013b). However, the CDC estimated that only half of the women diagnosed with HIV are in care, and only four out of ten WL-HIV have the virus under control as indicated by blood monitoring of CD4 cells and viral load. The CD4 cells are the four differentiation white blood cells that protect the body's immune system; viral load is the amount of HIV inside the person's body.

Consistent treatment with ART improves health outcomes, reduces viral load, and increases CD4 counts, thus slowing the conversion from HIV to AIDS. However, research identifies women as being slow to start ART for HIV, with 53% of women diagnosed remaining in care one year after diagnosis and only 42% having adequate viral suppression (Centers for Disease Control and Prevention, 2014). Such finding indicated inconsistent treatment adherence and support research to examine influences for positive outcomes among WL-HIV.

## **Population of Interest**

The three manuscripts in this dissertation targeted people with HIV especially WL-HIV because of the level of vulnerability and inequities for those affected. The principal investigator (PI) spent time with WL-HIV (n = 10) and observed the level of joy and hope displayed among and within the group. Manuscript 1 used a concept analysis approach to explore sources of hope among African American females living with HIV.

Research that targets interventions for WL-HIV can be effective if results are suitable for the specific population. For example, essential studies that target treatment adherence and compliance for WL-HIV may be futile without the perspective of those affected with HIV. Manuscript 2, an integrative review sought to identify barriers to participating in research studies especially among targeted individuals with stigmatizing conditions such as HIV, substance use disorders, and intimate partner violence. This study also reviewed the ethical and social justice implications for excluding participants with these conditions from research.

Community-engaged research allows participants to partner and have a sense of ownership, improves community engagement, and helps to achieve the study's aim (Udoh et al., 2013). A participatory research study, a type of community-engaged research, explored the challenges and supports encountered by WL-HIV. The PI described this study in Manuscript 3. Previous research studies have successfully applied a participatory research design to highlight the perceptions for living with HIV, and findings from those studies have contributed to advances in translational medicine and improvements (Michener et al., 2012). In addition, this study collected data using Photovoice, photographs to describe a phenomenon and a method used previously among WL-HIV to learn about their lived experiences (Hergenrather, Rhodes, & Clark, 2006). Clinical research for behavioral and educational interventions may result from reducing the challenges and increasing supports. Specifically, these interventions may target ART adherence and other behavioral interventions for positive outcomes among WL-HIV.

## Manuscript 1

Concept Analysis: Hope, HIV, and African American Females

Toshua W. Kennedy MSN, MPH, PHCNS-BC

Medical University of South Carolina

### Author Note

Toshua W. Kennedy, MSN, MPH, PHCNS-BC, is a Community Health Clinical Nurse Specialist, Senior Nursing Instructor at the University of South Carolina Upstate, and a PhD Student at the Medical University of South Carolina. She is a believer in Christ and grateful for the hope that Christ gives. The Journal of Christian Nurses accepted this manuscript for publication (Kennedy, 2015).

## **Abstract**

Human immunodeficiency virus (HIV) affects heterosexual African American females (AAFs) with morbidity and mortality rates higher than females of any other race, accounting for the fourth largest number of HIV infections in the United States. Defining hope is important for understanding and therapeutic use of the concept in AAFs with HIV. A literature review exploring uses for the concept among HIV-positive AAFs, and a dimensional analysis, revealed positive and negative influences for hope. Truthful and positive messages need to be developed for this population.

*Keywords: African American, AIDS, dimensional analysis, females, HIV, hope, nursing, Snyder's Hope Theory*

## Hope, HIV, and African American Females

Human immunodeficiency virus (HIV) is an epidemic affecting heterosexual African American females (AAFs) with morbidity and mortality rates higher than females of any other race, and account for the fourth largest number of HIV infections in the United States (Centers for Disease Control and Prevention [CDC], 2014). Defining hope and exploring its assumptions are important for convergence and the development of unity in nursing care, and for the therapeutic use for the concept of hope in AAFs with HIV. Given that HIV is an incurable disease characterized by negative connotations such as stigma and death, instilling hope may lead to a more positive life with encouraging health outcomes.

Hope is an important component connected to better health outcomes and increased value for life, as well as improved survival when facing life-threatening diseases (Phillips & Sowell, 2000). The CDC reports that African Americans are burdened with HIV more than any other racial group in the United States (CDC, 2013). Furthermore, African Americans have difficulty seeking HIV diagnosis and with treatment compliance, which are exacerbated by factors such as fear and apathy (Harzke et al., 2004). Although hope is an important concept to consider in any population with or without a chronic disease, AAFs are the focus for this article because of the disparate influence HIV has among this population. In 2010, AAFs accounted for 13% of all new HIV infections in the United States and 64% of all new infections among women (CDC, 2012). It is estimated that unless the AIDS epidemic changes, 1 in 32 AAFs will be diagnosed with HIV over their lifetime (CDC, 2013). This literature review examines the understanding and uses for the concept hope among HIV-positive AAFs.

The analysis sought to answer: Which dimensions and sub-dimensions of the concept hope exist in the literature among HIV-positive AAFs? How can these findings guide future research about behavioral and educational best practices to improve screening rates and medication compliance in this population? What improvements to health and quality of life in this population result from understanding the effects of hope?

### **Defining Hope**

Hope has been defined as “a combination of expectation and desire... to mentally look with expectation and to entertain expectation of something desired, to trust and have confidence, and to look forward to something desired” (Oxford Dictionary, n.d.). The Merriam-Webster Dictionary (n.d.) defines hope as “cherishing a desire with anticipation, to expect with confidence, and trust or desire with expectation and belief in its fulfillment.” The ancient King Solomon, known for his great wisdom, wrote, “Hope deferred makes the heart sick: but when the desire comes, it is a tree of life” (Proverbs 13:12, NKJV). In 1861, Poet Emily Dickinson defined hope as “...the thing with feathers that perches in the soul and sings the tune without words and never stops at all” (Johnson, 1960, p. 116). Hope transcends borders and cultures and is part of the very essence of human beings (Cutcliffe, 2004). Hopefulness accompanies the belief that life is worth living presently and futuristically, and characteristics of hope include the belief that life will be good, worth the effort, and adds power to a person’s life (Kylmä et al., 2001).

Hope Theory, created by Charles Snyder (1994), suggests that hope is a positive motivational state based on an interactively derived sense of success (Snyder et al., 1991). Hope also is defined as the progression of thinking about desired goals where



the person has the perceived knowledge to produce: (a) ways to reach goals (pathway thinking) and (b) the essential motivation to use those routes (agency thinking) (Snyder, Lopez, Shorey, Rand, & Feldman, 2003).

Hope Theory is composed of three key constructs: Goals, Pathway Thinking, and Agency Thinking. There are two types of Goals in Hope Theory: positive and negative outcome goals (Snyder, 2002). These goals are defined as: a cognitive element; the anchor for Hope Theory (Snyder, 1995); the target of structured mental actions; and may even be visual images (Snyder, 2002) or verbal descriptions (Pylyshyn, 1973). Goals can vary from short term to long term and occur in varying degrees. For instance, goals that are vague are considered less likely; they have little motivation for pursuit (Pylyshyn, 1973), and thus are characterized by lower levels of hope. Alternately, goals are more likely to occur when accompanied by thoughts of high hope.

Goals are unanswered calls if there are no means for achieving them; therefore, people approach goal pursuits with thoughts of creating the necessary routes to reach their goals. For persons with specific goals, Pathway Thinking involves the production of one plausible route, with a sense of confidence in the planned route. As such, persons with high hope or hopefulness ought to be more decisive as compared to low-hope persons (Snyder, 2002).

Agency thinking is the perceived capacity to use personal pathways to reach desired goals, and is the motivational part of Hope Theory. These thoughts involve the mental energy to start and continue on a pathway through the steps toward pursuing the determined goal (Snyder, 2002).

According to Hope Theory, when people are guided by genuine efforts, the result is goal attainment (Chang & Banks, 2007; Gallagher & Lopez, 2009). An example is consistent adherence to medical treatment among HIV-positive AAFs. An absence of goals is indicative of low levels of hope. Researchers Chang and Banks (2007) suggest there is a lack of knowledge about the expression of hope among different racial and ethnic groups. Researchers assert that there is little information about hope in minorities and it is unknown whether or not hope is expressed the same among various ethnicities. Exploring hope among HIV-infected AAFs is needed. Hope Theory provides a framework for this exploration of how hope manifests in HIV-positive AAFs.

### **Dimensional Analysis**

Dimensional analysis is useful for placing concepts in social context. Dimensional analyses help nurse researchers understand social concepts by facilitating the examination of processes involved in constructing the concept (Rodgers & Knafl, 2000). Dimensional analysis helps to express authenticity when using the concept hope. In a dimensional analysis, the researcher identifies and explores dimensions and sub-dimensions of a concept to show obvious meanings, portrayals, and uses (Davidson & Knafl, 2006). Dimensional analysis is an evolutionary method of concept analysis and emphasizes the temporal and interactive nature of concepts (Caron & Bowers, 2000). Dimensional analysis focuses on illustrating how a concept comprises varying perspectives. According to Caron and Bowers, a dimensional analysis is useful for understanding the conceptual environment that shapes the evolution of concepts, as well as the changeability of the concept across varying perspectives and contexts. This dimensional analysis examined how the concept hope has been socially constructed

from multiple standpoints (Davidson & Knafl, 2006), and determines an understanding of uses for the concept of hope by HIV positive AAFs. The following question guided the dimensional analysis: What are the dimensions and sub-dimensions of the socially constructed concept, hope, in published studies of HIV positive AAFs. The analysis identified social, environmental, and individual influences dimensions and sub-dimensions for the concept of hope.

### **Exploring Hope in African American Females**

Literature was examined for publications that focused on the concept of hope in HIV-positive AAFs. Keywords HIV, AAFs, and hope were used to search EBSCOhost and PubMed at the National Library of Medicine. A search yielded a total of eight studies in EBSCOhost and eight in PubMed. Articles published prior to 2005 as well as studies with only male research participants were then excluded from the review. From the 16 publications, 8 met the defined criteria. Studies included in this review were from inside and outside the United States with adult participants. Tables 1 and 2 provide the citations and summary information for the eight articles.

The initial plan for this exploration was to extract positive influences for hope, but among the eight publications, negative factors also were identified. Influences for the concept hope shown for the individual, social, and environmental dimensions are in Table 3, along with corresponding sub-dimensions. Included below are comparisons between the uses for hope in the eight publications, and definitions for hope from Hope Theory.

Table 1: EBSCOhost- Results With Combined Concepts Hope, HIV African American Females

<p><b>Citations:</b></p>	<p>Phillips, I. (2005). Religious and Spiritual Supports of the Christian African-American HIV-Affected Grandparent Caregiver. <i>Journal of HIV/AIDS &amp; Social Services</i>, 4(4), 65-80. doi:10.1300/J187v04n04_05</p>	<p>Davis-Carroll, H. (2011). An ethic of resistance: Choosing life in health messages for African American women. <i>Journal of Religion And Health</i>, 50(2), 219-231. doi:10.1007/s10943-010-9434-8</p>	<p>Jones, R., &amp; Oliver, M. (2007). Young urban women's patterns of unprotected sex with men engaging in HIV risk behaviors. <i>AIDS Behavior</i>, 11(6), 812-821. doi: 10.1007/s10461-006-9194-3</p>	<p>Fair, C. &amp; Albright, J. (2012). "Don't tell him you have HIV unless he's 'the one'": Romantic relationships among adolescents and young adults with perinatal HIV infection. 26(12), 746-754. doi: 10.1089/apc.2012.0290</p>
<p><b>Purpose</b> <b>Aim</b></p>	<p>Phenomenological qualitative study designed to learn the live experience of grandparents dealing with HIV</p>	<p>Critiques of health messages that focus on high mortality and morbidity rates, yet have not reduced health disparities, but have reduced Black women's bodies to carriers of disease</p>	<p>Qualitative study: to determine why females engage in sex with men they distrust relative to HIV prevention</p>	<p>Qualitative study: Learn the lived experience related to romantic relationships</p>

Table 1: EBSCOhost- Results With Combined Concepts Hope, HIV African American Females				
<b><u>Findings</u></b>	HIV-affected grandparents believe caring for HIV-infected loved ones would be easier if the African American churches were more educated about the disease to reduce the stigma surrounding it	AAFs need a more active role in creating positive messages of health in the AA community	Unprotected Sex is used to maintain hope, sensuality, intimacy, strategic gain, and stability with a male partner	Researchers learned that more education to HIV-infected females on how to maintain support relationships
<b><u>Concepts Explored</u></b>	Quality of life, experience of roles support systems religion & spirituality African American church	Spirituality, health promotion,  stereotyping faith-health	Power, risk-taking, sexual behaviors	Relationships, HIV, support
<b><u>Sample Description</u></b>	6 AAF custodial grandparents caring for HIV-infected family member.	N/A	43 AAFs and Latinas engaged in 7 focus groups in public housing & neighborhood centers	HIV-infected individuals who contracted HIV perinatally discuss their experience  Participants were mostly AA and 65% female

Table 2: Pubmed Articles: Results With Combined Concepts Hope, HIV, African American Females

<b><u>Purpose</u></b> <b><u>Aim</u></b>	Study the prevalence of AIDS denialism beliefs and association to health-related outcomes among people living with HIV/AIDS	Exploring the relationships between social, cultural and individual factors and midlife AAFs' risk taking and protective practices related to HIV/AIDS	Faith-based HIV prevention designed to increase HIV awareness and knowledge and reduce HIV risk behaviors among African American congregations	This study examines a possible success story in coping with the epidemic as found in the dramatic decrease of the HIV/ AIDS death rates for the city of Chicago, Illinois
<b><u>Findings</u></b>	Denial may be common among people living with HIV/AIDS and such beliefs are associated with poor health outcomes	Stereotypical views of midlife African-American women must be overcome to ensure that they are treated appropriately in the clinical setting	findings demonstrate that faith leaders who participate in specific and ongoing HIV prevention education training can be useful sexual health resources for youth in faith-based settings	The impact of HIV/AIDS regarding black females was as hypothesized and statistically significant
<b><u>Concept(s) Explored</u></b>	Knowledge attitude, denial, AIDS	Decision-making, HIV, risk-factors	Religion, HIV, African American, health promotion	Epidemic, AIDS, AAFs, healthcare access
<b><u>Sample Description</u></b>	266 men and 77 women with HIV/AIDS middle-aged and African American	36 HIV-negative AAF were interviewed	adolescents between the ages of 13 and 19, 20 FBOs provided HIV education to 212 adolescents	77 community areas participate in cross-sectional study
<b><u>Citations:</u></b>	Sherer, R. D., Fath, M. J., Da Silva, B. A. Nicolau, A.M., & Miller, N. L. (2005). The importance of potency and durability in HIV patient antiretroviral therapy preferences: A telephone survey. <i>AIDS Patient Care STDS</i> , 19 (12), 794 – 802. 10.1089/apc.2005.19.794			

Table 2: Pubmed Articles: Results With Combined Concepts Hope, HIV, African American Females

<b><u>Purpose</u></b>	45-minute telephone interviews to evaluate the importance of major treatment attributes			
<b><u>Aim</u></b>				
<b><u>Findings</u></b>	Efficacy attributes (lowering viral load, raising CD4, durability) "most important" or "very important" by more patients than other attributes (resistance profile, appearance side effects, gastrointestinal side effects, dosing frequency, pill burden, cholesterol side effects)			
<b><u>Concept(s) Explored</u></b>	Viral load, healthcare models			
<b><u>Sample Description</u></b>	total of 387 patients were surveyed (72% male; 44% African American, 41% Hispanic; 28% with no high school diploma, 29% high school graduate, 25% college with no degree; 46% infected through men who have sex with men 19% infected through injection drug use			

**Social Influences.** Phillips (2005) focused on examining religious and spiritual support toward the family of HIV-positive individuals from the African American church. Fair and Albright (2012) investigated supportive relationships that HIV-positive individuals possessed. Williams et al. (2011) explored connections for social, cultural, and individual factors for AAFs related to risk taking and protective practices for HIV/AIDS. The research indicated that families of HIV-positive AAFs hoped the church would play a more active role in reducing stigma by educating parishioners (Phillips, 2005), and increasing HIV prevention among African American youth (Williams et al., 2011). Fair and Albright (2012) concluded that individuals who contracted HIV in the perinatal period should receive education about how to maintain supportive intimate relationships. The studies correspond to Hope Theory, in part, by addressing the possibility for a lack of HIV knowledge among church members and other social supports. However, the studies cited above do not define hope in the context of a positive outcome.

**Environmental Influences.** Davis-Carroll (2011) demonstrated that an environment with low levels of hope led to poor health outcomes, and thus, low goal attainment. Although that study did not limit its discussion to HIV or involve HIV positive AAFs, the findings suggest how health messages can affect the experience of hope in populations living in low-hope environments. Other researchers have discussed the desire to improve health outcomes by changing negative messages presented on morbidity and mortality to this population (Davis, Bolding, Hart, Sherr, & Elford, 2004), and to reduce stereotypical views in the clinical setting toward AAFs (Mallory, Harris, & Stampley, 2009). Davis-Carroll (2011) stressed that focusing on the concept of



wholeness instead of disease helped to create an ethic of resistance that benefitted AAFs and their spiritual health. The author urged that patients avoid the passive reception of negative messages and, instead, actively resist such messages. Despite being religious, many AAFs perceived the church as being silent on messages of health that could encourage life and hope (Davis- Carroll, 2011; Fair & Albright, 2012). Such findings confirm that the environment affects the experience of hope in AAFs. Of particular concern are the fearful messages of health to this population. Research has shown that fear reduces participation in screenings, thus increasing health disparities (Davis-Carroll, 2011).

**Individual Influences.** Studies involving mostly female HIV-positive participants had similar designs: One explored the lived experience relative to engagement in romantic relationships (Fair & Albright, 2012), and the other sought to determine why females ages 15 to 24 engage in sex with untrustworthy partners (Jones & Oliver, 2007). According to Jones and Oliver, study participants indicated that unprotected sex was useful for maintaining hope, sensuality, and intimacy; thus conflicting with or demonstrating unawareness of epidemiological knowledge about role of unprotected sex in disease transmission. Fair and Albright's participants offered encouragement that stressed the importance for HIV-positive young the adults to remain hopeful with an expectation of finding a supportive partner, while being patient in the process. The use of hope in this study indicated an expectation of both positive and negative outcomes.

Alternately, in a study designed to explore denial of diagnosis, Kalichman, Eaton, and Cherry (2010) demonstrated that hope based on false information (false hope) was dangerous and resulted in negative health outcomes. In that study, participants who

were African American male and female HIV-positive individuals, evidenced false hope and asserted that denial may be common among this population, as reflected in beliefs that HIV was harmless and AIDS is curable with natural remedies. The avoidance of medication was often the result of such beliefs, thus harmful outcomes resulted from false hope. In another study, treatment efficacy was investigated and researchers determined from 45-minute telephone interviews that controlling side effects and preventing medication resistance were important to HIV-positive persons, but not as important as increasing CD4 counts or reducing viral load (Sherer, Fath, Da Silva, Nicolau, & Miller, 2005).

Hope is a condition of agency, and a critical factor in HIV-positive AAFs where motivation affects goal attainment. It is possible to learn agency thinking and to reinforce motivation toward goals or, alternately, obstruct and discourage motivation. Snyder's Hope Theory offers a useful theoretical basis for exploring new behavioral approaches in HIV treatment that focus on building hope in order to improve coping and resilience among HIV-positive AAFs.

<b>Dimension</b>	<b>Sub-dimension</b>
<b>Individually</b>	<b>Risk-taking</b> <b>Power</b> <b>Support Relationships</b> <b>Denial</b>
<b>Socially</b>	<b>African American Churches</b> <b>Spirituality</b> <b>Support Systems</b>
<b>Environmentally</b>	<b>Health Promotion</b> <b>Health Access</b> <b>Education</b> <b>Health Messages</b> <b>Stereotyping</b>

**Table 3: Dimensions and Sub-dimensions Affecting Hope in HIV-positive AAFs**

## **Discussion**

This study examined the concept of hope in published research involving HIV-positive AAFs in order to determine if common themes exist in the literature regarding hope in this population. Levels of hope determine an individual's ability to believe that the future will include positive outcomes (Chang, Bendel, Koopman, McGarvey, & Canterbury, 2003). Table 3 offers dimensions and sub-dimensions of the concept hope found in literature about HIV-positive AAFs. This review supports early research that there are positive relationships in AAFs with HIV relative to hope and coping, hope and illness management, and hope and spirituality (Phillips & Sowell, 2000). Additionally, this analysis correlates with other research findings not included in this review that

suggest social support shields suffering, helps with coping, and reduces depression (Stutterheim et al., 2011). These factors correlate to hope in HIV-infected individuals.

The current analysis points to the importance of honesty in health messages to HIV-positive AAFs, as well as the need for positive messages in addition to negative/avoidance messages. Considering the asserted effect of negative messages in public service announcements, future studies need to show resilience and empowerment among HIV-positive AAFs and how they affect screening and early treatment. Equally important are truthful messages among this population to remove hope based on falsehoods.

Based on findings from this exploration, positive and negative influences for hope exist. These results beckon an exploration from the participants' perspective, to identify items that influence hopefulness as a means to inform future studies with interventions. Future research should explore factors that contribute to or obstruct hopeful agency thinking and resilience in HIV positive AAFs, with the goal of improving screening rates and treatment compliance. Identifying factors for hopeful agency can lead to behavioral and clinical interventions that may increase hope levels, thus contributing to goal attainment, improved quality of life and, possibly, reduced morbidity and mortality for HIV positive AAFs.

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Manuscript 2

Ethical Considerations Regarding Barriers and Facilitators to Research Participation for  
Patients Affected by Health Related Stigmatizing Conditions

Toshua W. Kennedy MSN, MPH, PHCNS-BC: Medical University of South  
Carolina

Ida Spruill Ph.D., RN, LISW, FAAN: Medical University of South Carolina

Susan Newman D., Ph.D., RN, CRRN: Medical University of South Carolina

Michelle Teti, DrPH: University of Missouri

Corresponding Author: Toshua W. Kennedy MSN, MPH, PHCNS-BC  
99 Jonathan Lucas Street  
Charleston, SC 29425  
864-877-0823 (phone and fax)  
[kennedtw@musc.edu](mailto:kennedtw@musc.edu)

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## ABSTRACT

Health related stigmatizing conditions (H-RSC) such as human immunodeficiency virus (HIV), substance use disorders (SUD), and intimate partner violence (IPV) pose ethical and social justice implications that may affect research participation. This integrative review sought barriers and facilitators to participating in condition-specific research among individuals with the H-RSC of HIV, SUD, and IPV. Whittemore and Knafll's framework for integrative reviews guided the exploration from the following databases: PubMed, CINAHL, and PsycINFO for the years 2002-2014. Twenty-eight studies met the search criteria and of the factors revealed the primary connection for barriers and facilitators to be recruitment strategies. Among other barriers were time constraints, feeling like a guinea pig, and cultural insensitivity; and, facilitators included altruism and collaborative research efforts. Authors concluded researchers need flexible, culturally sensitive, and inclusive recruiting practices to ensure inclusion of subgroups, such as African American and Latino to avoid violating the principles of social distributive justice.

**Keywords:** *Research recruitment, participation, stigmatized conditions, social distributive justice, human immunodeficiency virus, substance abuse disorder, intimate partner violence*

## INTRODUCTION

Individuals with health-related stigmatizing conditions (H-RSC), such as human immunodeficiency virus (HIV), substance use disorders (SUD), and intimate partner violence (IPV), are targeted for blame, shame, and loss resulting from having certain a disease or condition (Deacon, 2006; Scambler, 2009). An H-RSC adds a very significant and preventable burden to chronic debilitating diseases (Luoma et al., 2007; Steward et al., 2008) that can compromise and negatively affect the individual's ability to be open with others, seek medical treatment, utilize resources, and maintain access to family and other supports. Research indicates that individuals with an H-RSC may be less likely to participate in studies, even if taking part could improve interventions and treatment (Luoma et al., 2007).

This article describes an integrative review in which authors sought to capture and summarize barriers and facilitators for participating in condition-specific biomedical and behavioral research among individuals with the H-RSC of HIV, SUD, and IPV. Authors apply evidence for barriers and facilitators to a social ecological model and discuss implications for social justice.

Social justice means societies have freedom from social afflictions such as war, poverty, marginalization, exploitation, colonization, and structural violence (Fu, Exeter, & Anderson, 2014). The Belmont report describes social justice according to the following components: (1) fairness; (2) equity in the allocation of power (i.e. social distributive justice); (3) just institutions, systems, structures, policies, and processes; (4) equity in human development; and (5) sufficiency of well-being (Belmont Report, 1979). The Belmont Report describes the importance of and criteria for ethical selection of

research participants. In 1974, the National Research Act became a law and created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (Belmont Report, 1979). The Commission's charge was to develop ethical guidelines and principles for research among human participants. Specifically, in this four-day discussion principles were designed to (1) set boundaries between research and routine medical practice, (2) determine risk-benefit criteria for study participants, (3) identify appropriate selection process for choosing study participants, and (4) define the nature of informed consent in different research settings. In these discussions, justice or fairness emerged as one of the basic principles for ethical research. Examples of historical injustice identified in the Belmont Report included research among poor, confined, and disadvantaged individuals who did not receive treatment or benefits from interventions that that research developed, such as the Tuskegee study of syphilis, in which rural African American males were not administered effective treatment. Research participants need careful scrutiny to determine reasons for their inclusion to avoid manipulating individuals in compromised positions such as individuals who are financially disadvantage, minority, and marginalized. Moreover, when financial support for research is from the government, the ability to pay should not affect access to its interventions and treatments, and study participants in such studies should not disproportionately involve individuals unlikely to benefit (Belmont Report, 1979).

## **METHODS**

This integrative review sought the most recent evidence describing barriers and facilitators experienced by individuals with HIV, SUD, and IPV for engaging in condition-

specific research. Updated integrative review methods by Whitemore and Knafl (2005) guided this analysis. Expanding on the work of Ganong (1987), researchers Whitemore and Knafl (2005) approached summarizing and analyzing literature from diverse databases and provided a more comprehensive understanding of a phenomenon, and the same is applied in this review. During the analytic phase, researchers applied a systematic and iterative approach to extract, categorize, and reduce the data to draw conclusions and verify results. Applying the same methodology, in this review, the investigators used consistently employed search terms and databases to obtain data for a comprehensive review (Whitemore & Knafl, 2005).

Authors conducted the initial literature search to locate evidence regarding participation in condition-specific biomedical and behavioral research for individuals with an H-RSC of HIV, SUD, or IPV. The authors searched PubMed, PsychInfo, and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) using the following search terms *research recruitment, participation, and HIV, SUD, or IPV*. Filters included free full text, reference list available, abstracts, studies reported in English for the years 2002 – 2014. The initial search yielded 71 from PubMed – 17 from CINAHL – and 15 from PsycINFO.

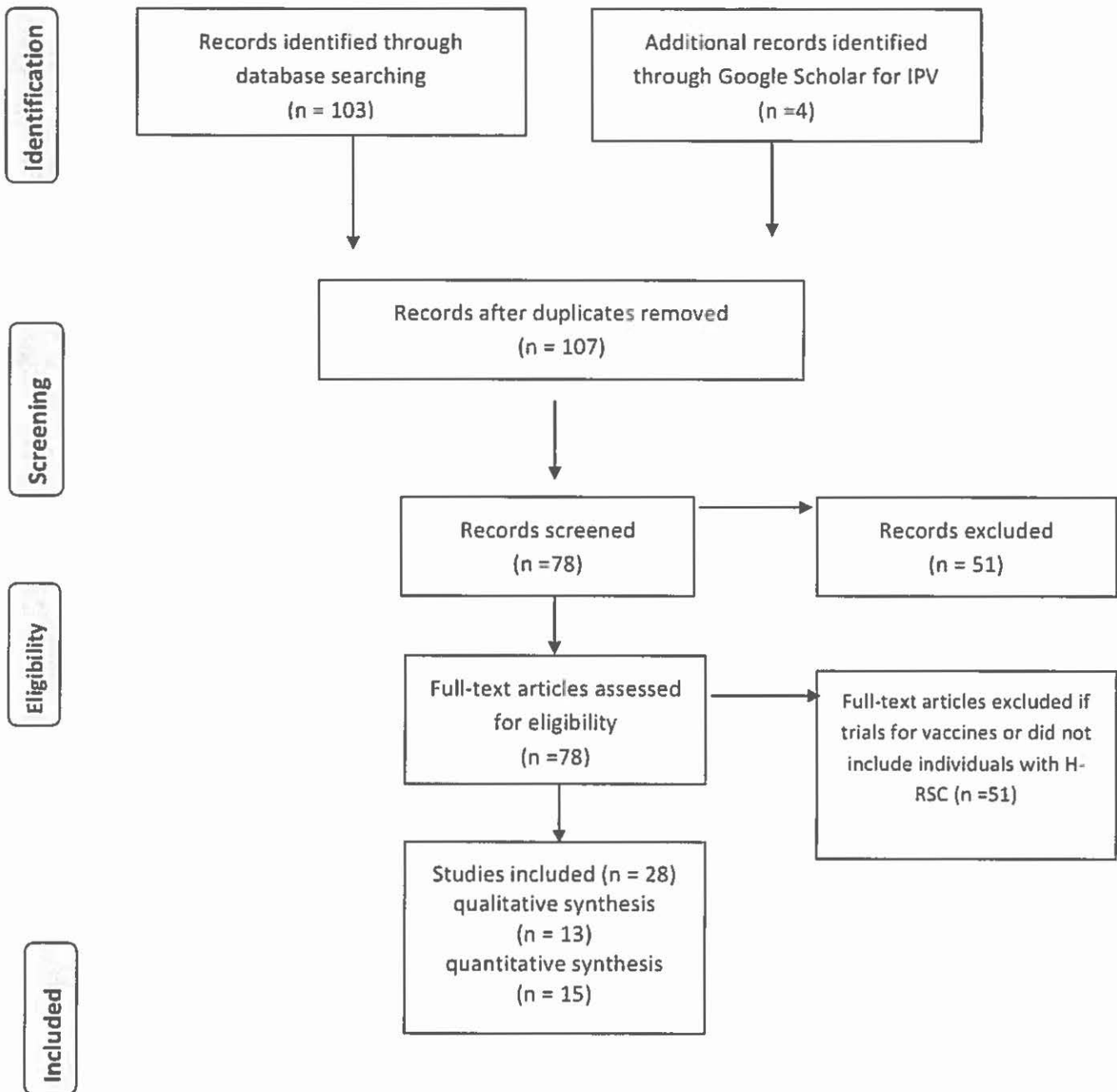
### **Inclusion/Exclusion Criteria**

Researchers included articles if they met the following criteria: Peer reviewed articles about research studies written in the English language, and had adult participants. Exclusion criteria were articles or studies in which participants did not have HIV, SUD, or IPV and vaccine trials. The final number of publications included in this review was twenty-eight. In Table 2, (see Appendix) the researchers organized the

selected articles in descending order by publication date for each H-RSC and with columns that include H-RSC, purpose, study method/type, underrepresented group, findings, social justice implications, and references. See Figure 1 below for description of article selection.



Figure 1: Description of Article Selection



## RESULTS

Ecological approaches help to describe complex relationships for individuals within the context of their physical, social and cultural environments (Kahan, 2014).

Social ecological models (SEM) assert that multi-level reciprocal relationships exist for

health behavior, decisions, and the social environment (McLeroy, Bibeau, Steckler, & Glanz, 1988). Since multiple factors likely influence participation decisions, we choose to use the SEM model to present results for barriers and facilitators among individuals with H-RSC. These levels are intrapersonal (e.g. race, attitudes, perceptions of the person with the H-RSC), interpersonal (e.g. friends, family), institutional (e.g. agencies conducting or recruiting for studies, institutional review board (IRB)), community (e.g. churches, social media), and policy (e.g. local, state, federal legislature).

### **Participation Barriers**

This integrative review sought barriers and facilitators for condition-specific research participation among individuals with HIV, SUD, and IPV and yielded twenty-eight articles. Below are the social ecological barriers to research participation for people with HIV, IPV, or SUD.

**Intrapersonal influences.** Intrapersonal barriers were perceived or actual stigma, fear, and shame (Zúñig et al., 2007). Safety concerns were identified as barriers among HIV populations connected to confidentiality (Rodriguez et al., 2013), and IPV participants had misgivings about researchers' intentions being career-focused instead of helpful for study members (M. B. Mechanic & Pole, 2013; Menezes et al., 2011; Sutherland & Fantasia, 2012). Further, some participants commented that feeling like a guinea pig was another barrier to taking part in research (Rivera-Goba et al., 2011; Rodriguez et al., 2013; Sullivan, McNaghten, Begley, Hutchinson, & Cargill, 2007). Contradicting notions of trust and fear being barriers to research participation because of past unethical studies, some minority IPV recruits asserted that disinterest was the hindrance to taking part in studies (El-Khorazaty et al., 2007). Additional

intrapersonal barriers to research were race and ethnicity. African Americans and Latinos stated that HIV research studies were not friendly to their race, because of perceptions that researchers held prejudices and biases against them and identified language barriers as an issue (Castillo-Mancilla et al., 2014; Zúñig et al., 2007).

**Institutional Influences.** According to Garber and colleagues, African Americans with HIV perceived White researchers to be uncomfortable talking to them and that they incorrectly assumed that recruiting from this subgroup would result in anger and distrust based on unethical research practices of the past (Garber, Hanusa, Switzer, Mellors, & Arnold, 2007). Our review revealed that across studies clinicians and recruiters were reluctant to refer individuals with HIV, SUD, and IPV to research investigations because of doubts regarding follow through by participants, suggesting a selection bias among practitioners (Greenfield et al., 2014; Gwadz et al., 2010; Zúñig et al., 2007). Clinicians and recruiters discriminated against minorities with HIV and SUD by omitting them from the referrals process altogether (Alvarez, Vasquez, Mayorga, Feaster, & Mitrani, 2006; Gwadz et al., 2010; Loutfy et al., 2014; Robinson et al., 2006; Wakim, Rosa, Kothari, & Michel, 2011). Specifically, rural clinic staff did not have a sufficient level of buy-in for some research studies, which influenced recruitment practices (Alvarez et al., 2006; M. B. Mechanic & Pole, 2013; Sutherland & Fantasia, 2012). In addition, clinicians' perceptions of barriers did not include stigma, transportation, and language appropriate information, although participants did highlight these as significant barriers (Zúñig et al., 2007).

**Community Influences.** Groups with HIV and SUD identified the following barriers to participating in studies as insufficient information, governmental distrust,

and system barriers such as the lack of public transportation and the lack of language appropriate services (Alvarez et al., 2006; Corbie-Smith, Isler, Miles, & Banks, 2012; Gwadz et al., 2010; M. B. Mechanic & Pole, 2013; Zúñig et al., 2007).

**Public Policy.** Public policy describes rules and regulations governing federal, state, and local levels that affect decisions about research involving individuals affected by HIV, SUD, and IPV (McLeroy et al., 1988). Specifically, IRBs are often hesitant to approve research on IPV because of the vulnerability and possible emotional distress of participants (Shorey, Cornelius, & Bell, 2011) and the same applies to individuals with HIV and SUD.

### **Participation Facilitators**

The following were facilitators for research participation among individuals with the H-RSC of HIV, SUD, and IPV from the twenty-eight articles. Below are the social ecological facilitators for research participation for people with HIV, SUD, or IPV.

**Intrapersonal Influences.** Our review revealed that Spanish-speaking individuals with HIV and IPV who participated in research studies believed doing so made them healthier (Castillo-Mancilla et al., 2014), and felt safer when researchers belonged to racial and ethnic minority groups who spoke their language (M. B. Mechanic & Pole, 2013; Rivera-Goba et al., 2011). Participants expressed the importance of being active partners, which entailed taking part in creating, recruiting, and implementing the research study. Being active partners in the research process led to respectful treatment, built trust, fostered value, and (those with HIV) hoped their participation would result in a cure (Garber et al., 2007; Rivera-Goba et al., 2011; Shorey et al., 2011; Zúñig et al., 2007). Males who participated in IPV research

perceived personal gains about themselves and relationships; male and female participants who were victims and perpetrators believed taking part in dating violence research outweighed potential risks (Shorey et al., 2011).

**Interpersonal Influences.** Researchers identified peer-driven interventions as culturally sensitive, effective, and low-costing interpersonal influence that targets behavior changes among individual with HIV (Gwadz et al., 2010). In the same study, peer support assisted with adherence to research protocols and help with retention.

**Community Influences.** Among rural and minority communities, the research process was effective when various groups took part, to include faith-based organizations and the individuals with the H-RSC (Alvarez et al., 2006; Corbie-Smith et al., 2012; Sutherland & Fantasia, 2012). Our review revealed that developing relationships with case management staff might generate referrals for better recruitment among individuals with SUD and HIV (Alvarez et al., 2006; Greenfield et al., 2014; Mariani et al., 2011). Further, individuals with SUD who were recruited from a community setting had better follow-up to care because of the linkage to care (Macleod et al., 2010).

**Institutional Influences.** Integrating HIV clinical trials with existing services and collaborating with entities that provide outreach services facilitated a more comprehensive view of the values held by individuals with HIV in rural minority areas (Corbie-Smith et al., 2012; Rivera-Goba et al., 2011; Shiramizu et al., 2012). Encouraging engagement that goes beyond the research study was another facilitator for participating according to individuals with HIV to include psychological training for researchers and recruiters about the experiences of people living with HIV (Corbie-

Smith et al., 2012). Culturally sensitive information from recruiters facilitated participation and included transportation, referrals and home visits as needed to ensure adherence to the research plan (Gwadz et al., 2010; M. B. Mechanic & Pole, 2013). Recruiters were encouraged to have tailored, mixed-methods, and flexible research protocols along with the freedom to revise as needed, to facilitate participation (Alvarez et al., 2006; Greenfield et al., 2014; Hessol et al., 2009; M. B. Mechanic & Pole, 2013; Sutherland & Fantasia, 2012). To make adequate revisions, evaluations of current methods were essential; research assistants evaluated tools used in data collection and determined paper and pencil methods to be easiest to administer and computer-based tools were fastest but the most complicated to create (A. Graham, Goss, Xu, Magid, & DiGuseppi, 2007; A. L. Graham, Bock, Cobb, Niaura, & Abrams, 2006).

In Table 1: below are the presentation of barriers and facilitators for research participation among individuals with HIV, SUD, and IPV. Bold print indicates similar themes for each condition.

Table 1. Barriers and Facilitators for Research Participation

H-RSC	Barriers to Participation	Facilitators to Participation
HIV	<p>Less likely to know about study, <b>language barriers</b>, limited healthcare utilization, and an unstable immigration status (Castillo-Mancilla et al., 2014)</p> <p><b>Time constraints, language barriers</b>, HIV disclosure/stigma issues, <b>lack of trust</b> of research personnel, fear of research, inaccessibility to child care and <b>transportation</b> (Loutfy et al., 2014)</p> <p><b>Guinea pig feeling, safety and privacy</b>, criminalization, lack of anonymity, partner disclosure, and <b>study fatigue</b> (Rodriguez et al., 2013)</p> <p>Health benefits limit their need to participate in clinical trials, <b>distrust in medical research</b>, lack of confidence in providers, the belief that <b>informed consent process provides little protection</b> (Menezes et al., 2011)</p> <p><b>Guinea pig” perceptions</b>, and obstacles to connection (Rivera-Goba et al., 2011)</p> <p>Less likely to be recruited or referred compared to their whites, concerns about patients’ abilities to adhere to protocols, <b>access and transportation</b>, historical distrust, substance use, study setting difficult to navigate (Gwadz et al., 2010)</p> <p><b>Guinea pig”, Lack of information</b> about the study, <b>not offered enrollment was more common among blacks, informed consent process is primarily to protect physicians and hospitals</b> (Sullivan et al., 2007)</p> <p><b>African Americans seemed very willing to participate in a trial but never been asked</b>, White researchers may be uneasy talking to African Americans about research assuming (incorrectly) that patients will react with anger or distrust given past abuses , unwillingness and uncertainty because of adverse effects of medications (Garber et al., 2007)</p> <p><b>Poor dissemination of information effect on the lack of Latina participation, shame, stigma, lack of transportation or language-appropriate services</b> (Zúñig et al., 2007)</p>	<p>Hispanics and Spanish speakers believed that participating in a study had made them healthier (Castillo-Mancilla et al., 2014)</p> <p>Rapport, empathy, acknowledging the sensitive nature of the research topic, financial compensation, <b>unique recruitment strategies</b>, respectful, flexible (Loutfy et al., 2014)</p> <p><b>Collaborating, integrating, working with other entities</b>, psychological training (Corbie-Smith et al., 2012)</p> <p><b>Building alliances with key community partners</b> (Shiramizu et al., 2012)</p> <p><b>Representation, building relationships, establishing connections, and participant partnership</b>, wanted people who “looked liked them” and Hispanics wanted people who spoke their language, believed in finding the cure for HIV (Rivera-Goba et al., 2011)</p> <p><b>Peer support groups</b> to assist patients with adherence to study protocols, culturally sensitive informational (Gwadz et al., 2010)</p> <p><b>Tailoring recruitment</b>, be willing to modify research protocols (Hessol et al., 2009)</p> <p>Find a cure for AIDS, to help the HIV community, and to obtain new and effective experimental HIV medication (Garber et al., 2007)</p>

<u>H-RSC</u>	<u>Barriers to Participation</u>	<u>Facilitators to Participation</u>
SUD	<p>Uncomfortable in group settings, lack of communication (Alvarez et al., 2006)</p> <p>Trial design characteristics, retention influenced by the empathy of the counselors, the severity of the participants' addiction, the criminal justice system (Wakim et al., 2011)</p>	
IPV	<p><b>mistrust the intentions of researchers, detection and deportation</b></p> <p>Believe that researchers will only exploit to satisfy their own careers (D. Mechanic &amp; Tanner, 2007)</p> <p><b>Mistrust of rural communities to outsiders, populations not actively involved with the clinics or recruitment sites have less buy-in (Sutherland &amp; Fantasia, 2012)</b></p>	<p>Involving members of the target group in recruitment, In person recruitment (M. B. Mechanic &amp; Pole, 2013)</p> <p>I was curious, to help others, to help myself, for the money, thought it might (Hebenstreit &amp; DePrince, 2012)</p> <p><b>Engaging the participants</b> in the study was critically important to recruitment and retention, continual reevaluation necessary to identify potential barriers and solutions to successful recruitment (Sutherland &amp; Fantasia, 2012).</p> <p>Female participants disclose their dating violence experiences is often perceived as valuable, men, dating violence research has benefit of providing participants with insight (Shorey et al., 2011)</p> <p>Targeted recruitment and retention strategies, minority women will participate at high rates in behavioral clinical trials (El-Khorazaty et al., 2007)</p>

## DISCUSSION

This integrative review sought barriers and facilitators for condition-specific research participation among individuals with the H-RSC of HIV, SUD, and IPV. Most studies in this review highlighted recruitment as essential for decision-making with the potential for being a barrier when information was not shared or appropriate referrals were withheld (Greenfield et al., 2014; Gwadz et al., 2010; Zúñig et al., 2007) (Loutfy et al., 2014) Alvarez, Vasquez, Mayorga, Feaster, & Mitrani, 2006; Robinson et al., 2006; Wakim, Rosa, Kothari, & Michel, 2011). On the other hand, recruitment facilitated participation when practices included flexible targeted procedures such as collaborating with participants and various agencies (Corbie-Smith et al., 2012;



Rivera-Goba et al., 2011; Shiramizu et al., 2012) (Alvarez et al., 2006; Greenfield et al., 2014; Hessol et al., 2009; M. B. Mechanic & Pole, 2013; Sutherland & Fantasia, 2012). However, there were instances when recruitment was a barrier because the proposed study was not of interest; therefore, recommendations included recruitment and targeted retention strategies to combat the lack of interest (El-Khorazaty et al., 2007). In addition, when participants were active partners their contributions to research helped to build trust and facilitate respect (Rivera-Goba et al., 2011).

Enrollment in condition-specific research for each H-RSC reflected demographics that are overwhelmingly White, from higher socioeconomic communities, and from larger urban areas (Corbie-Smith et al., 2012); however, individuals with racial and ethnic minority backgrounds need culturally appropriate practices in recruitment and research protocols to encourage their participation (Alvarez et al., 2006; Corbie-Smith et al., 2012; El-Khorazaty et al., 2007; Gwadz et al., 2010; Hebenstreit & DePrince, 2012; Hessol et al., 2009; Mariani et al., 2011; M. B. Mechanic & Pole, 2013; Rivera-Goba et al., 2011; Shiramizu et al., 2012; Sutherland & Fantasia, 2012; Tun et al., 2013; Uuskula et al., 2010; Zúñig et al., 2007). Without minority representation in research, generalization of findings would not be possible (Hessol et al., 2009), and research practices would continue to be unequal in the allocation of societal benefits and burdens (i.e. social distributive justice).

In some instances, there were disconnects for researchers and participants, meaning perceptions were not the same (Corbie-Smith et al., 2012). For example, a review that examined health care professionals' perspectives, showed how clinicians

did not list stigma as a barrier for participating in research studies among people living with HIV (Zúñig et al., 2007). In direct contrast, in the same study, sixty-three percent of the participants identified stigma as a barrier. Although distrust and fear still existed for some individuals because of historic unethical exploitations in research; ignoring, omitting, and excluding minority populations in the name of protection left the most vulnerable populations defenseless. Further, researchers were encouraged to move beyond creating trust to developing collaborative relationships to improve research engagement (Alvarez et al., 2006; Corbie-Smith et al., 2012). Supporting this notion, the Revitalization Act of 1993 encouraged the inclusion of minorities and females in research, (U. S. Department of Health Human Services, 1993); therefore flexible, non-threatening, welcoming and inclusive recruitment strategies were in order (Robinson et al., 2006; Sutherland & Fantasia, 2012; Tun et al., 2013) with community involvement for recruitment of underrepresented groups in research (Corbie-Smith et al., 2012).

Moreover, the benefits and risks of research should belong to all members of society (Belmont Report, 1979), and some participants believe that the benefit of participating outweighs the risk of experiencing negative emotions (Hebenstreit & DePrince, 2012). The Belmont Report (1979) stresses the protection of research participants and the need to consider risk-benefit criteria when determining the appropriateness of research and the selection process for study participants. For the attribute of social distributive justice and equity in the distribution of power, resources and processes for research must generally address equal distribution of society's benefits and burdens, while remedying protocols that marginalize subgroups or increase the risks for health inequities (Hessol et al., 2009). Thus, it is important to be diligent

and proactive in planning research recruitment and protocols to create a balance that helps to avoid unequal representation and exclusion of individuals with H-RSC (Gwadz et al., 2010; Hessol et al., 2009).

A participatory approach to research supports building partnerships with participants and stakeholders from the community of interest from the beginning at the planning phase to the study's completion (Corbie-Smith et al., 2012). Identified stakeholders were representatives from the stigmatized populations, family members of the stigmatized individuals, governmental agency representatives, and professionals that cared for them (Corbie-Smith et al., 2012). This approach to research, where relevant stakeholders are engaged in the process, shows promise as an approach for creating a collaborative effort that included populations with H-RSC (M. B. Mechanic & Pole, 2013; Rivera-Goba et al., 2011; Shiramizu et al., 2012). Further, to eliminate barriers and facilitate the recruitment of minority participants, researchers suggested that the research team consist of qualified individuals from various nationalities, language preferences, generations, acculturation levels, and populations with varying experiences with discrimination, social economic status, and gender to highlight and capitalize on variations in the target population (M. B. Mechanic & Pole, 2013). In other words, study participants prefer to have researchers who can identify with their experiences with discrimination. In addition, researchers are encouraged to consider the development and implementation of safety plans to reduce the risks that may result from study participation. Additional considerations include careful and compassionate interview protocols, as well as calls for better training of research investigators who work with HIV, SUD, and IPV populations, including students, healthcare

professionals, and IRB members (Corbie-Smith et al., 2012; Hebenstreit & DePrince, 2012).

## CONCLUSION

The goal of research is to improve patient outcomes by advancing healthcare delivery, access, and patient education. In the end, studies that include diverse representatives of the condition-specific population are more likely to reach the overall goal for research and to create interventions that lead to positive health outcomes. Barriers such as compromised recruitment result in underrepresentation and the continuance of health inequities among those excluded; however, participatory research among populations with H-RSC shares ownership and empowerment to participants who have a personal stake in a study's success.

Barriers encountered by subgroups reduce the likelihood of participation in research and increases their vulnerability. In other words, if there is underrepresentation for groups in research studies, scientists cannot determine whether those underrepresented groups will receive equal benefits from the treatment and interventions that result from that research. Therefore, researchers have a duty to employ flexible targeted recruitment to help ensure inclusion for all subgroups to avoid violating the principles of social distributive justice.

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**Table 2: Twenty-eight Articles Included in Integrative Review**

H-RSC	Study Type and Methods	Study Purpose	Underrepresented Research Groups Identified	Study Findings and Social Justice Implications	Reference
HIV	Quantitative Self-administered survey An anonymous, bilingual, self-administered survey on study participation was given to HIV-infected adults attending AIDS Clinical Trials Group-affiliated clinics in the US and Puerto Rico. Chi-square tests were used to evaluate differences by race/first language/level of education.	We aimed to evaluate the knowledge, experience, and factors that influence minority participation in HIV/AIDS studies in the United States.	African American and Latino	Minorities continue to face barriers for HIV/AIDS trial participation, even when clinical research is available. Enrollment strategies should better target minorities to improve recruitment in HIV/AIDS research. An anonymous, bilingual, self-administered survey on study participation was given to HIV-infected adults attending AIDS Clinical Trials Group-affiliated clinics. Hispanics were less likely to know about studies compared to Whites and AAs. Hispanics were less likely to know about studies compared to Whites and AAs. AAs and Hispanics were more likely to state that studies were not friendly to their race	Castillo-Mancilla, J. R., John, S. E., Krishnan, S., Cespedes, M., Floris-Moore, M., Schulte, G., . . . Acting Underrepresented Populations Survey, G. (2014). Minorities remain underrepresented in HIV/AIDS research despite access to clinical trials. <i>HIV Clinical Trials</i> , 15(1), 14-26. doi: 10.1310/hct1501-14
HIV	Mixed-methods: The survey consisted of questions regarding the important recruitment barriers and successes. Quantitative data were then contextualized within extensive knowledge from research personnel and team members.	To improve the existing understanding of recruitment for HIV-positive women	Women with HIV This rapport is facilitated by having study personnel who are respectful, trustworthy, empathetic, and flexible.	The highest ranked recruitment barriers identified were: sensitivity of the research topic (59%), time/availability constraints (59%), language barriers (53%), HIV disclosure/stigma issues (47%), lack of trust of research personnel (41%), fear of research (41%) and inaccessibility to child care and transportation (41%). The respondents felt that the most important personal attributes for recruitment were research personnel who were respectful (97%), skilled (91%), flexible (88%) and empathetic (88%) and had good communication skills (88%). The most successful recruitment strategies identified were: developing a strong rapport (88%) that was facilitated by an empathetic relationship (100%), acknowledging the sensitive nature	Loutfy, M. R., Logan Kennedy, V., Mohammed, S., Wu, W., Muchenje, M., Masinde, K., . . . Tharao, W. (2014). Recruitment of HIV-Positive Women in Research: Discussing Barriers, Facilitators, and Research Personnel's Knowledge. <i>The open AIDS journal</i> , 8, 58. doi: 10.2174/1874613601408010058

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				of the research topic (94%), providing cash financial compensation (88%), and developing recruitment strategies unique to women (88%).	
HIV	Qualitative Using focus groups, we sought to understand the perceptions related to participating in biomedical research of acute/recent HIV-1 infection (AHI) using complex sampling and data collection methods to reach this hidden group at highest risk of acquiring and transmitting HIV	Sought to understand the perceptions related to participating in biomedical research of acute/recent HIV-1 infection (AHI) using complex sampling and data collection methods to reach this hidden group at highest risk of acquiring and transmitting HIV.	To understand how recruitment and data collection methods affect AHI research participation willingness particularly among MSM of color.	Findings suggest that major barriers to research participation with complex sampling to identify AHI and intensive risk behavior collection. Barriers were diary methods are lack of anonymity, partner disclosure, and study fatigue.	Rodriguez, K., Castor, D., Mah, T. L., Cook, S. H., Auguiste, L. M., Halkitis, P. N., & Markowitz, M. (2013). Participation in research involving novel sampling and study designs to identify acute HIV-1 infection among minority men who have sex with men. <i>AIDS Care</i> , 25(7), 828-834. doi: 10.1080/09540121.2012.748164
HIV	Qualitative through use of focus groups.	Eleven focus groups and 35 interviews were conducted with people living with HIV/AIDS (PLWHA) to explore the perspectives of rural community leaders, service providers, and PLWHA about bringing HIV-related research, including clinical trials, into rural communities.	Eleven focus groups and 35 interviews were conducted with people living with HIV/AIDS	Respondents want an integrated approach to HIV research that builds trust, meets community needs, and respects their values. They conceptualize HIV research as part of a broader spectrum of HIV testing, prevention, and care, and suggest integrating HIV trials with existing community services, organizations, and structures, engaging various segments of the community, and conducting research using a personal approach.	Corbie-Smith G, Isler MR, Miles MS, Banks B. (2012). Community-based HIV clinical trials: an integrated approach in underserved, rural, minority communities. <i>Program Community Health Partnership</i> , 6(2):121-9. doi: 10.1353/cpr.2012.0023

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HIV	Qualitative: community-based participatory research (CBPR) Self- and health care provider (HCP)-obtained anal cancer screening specimens were reviewed for cytology and tested for human papillomavirus DNA. A follow-up evaluation elicited feedback on attitudes and experiences.	To increase anal cancer screening among Hawaii's underserved/minority populations.	Minorities and females	Community discussion sessions identified key messages about anal cancer, anal cancer screening, and HPV infection for materials and were used, that successfully recruited 46 individuals (38 males/8 females; 9 Native Hawaiians/Pacific Islanders/Asians, 2 Blacks, 6 Hispanics, 6 American Indian/Alaskan Natives, 23 Whites). Concordance in cytology results between self- and HCP-obtained specimens was moderated ( $\kappa=0.37$ ) with the perception that the self-obtained specimen procedure was private (93%), safe (100%), and easy to manage (100%); and a majority (92%) willing to use the self-obtained method again. CONCLUSIONS: CBPR was a practical approach in engaging Hawaii's HIV-infected minority participation in anal cancer screening research	Shiramizu, B., Milne, C., Terada, K., Cassel, K., Matsuno, R. K., Killeen, J., . . . Goodman, M. T. (2012). A community-based approach to enhancing anal cancer screening in Hawaii's HIV-infected ethnic minorities. <i>Journal of AIDS Clinical Research</i> , 3(6). doi: 10.4172/2155-6113.1000162
HIV	Quantitative We conducted a cross-sectional study of baseline demographic and behavioral, access-to-care, and clinical characteristics for trial and non-trial participants using the UNC CFAR HIV/AIDS clinical cohort. This cohort, comprising HIV-positive persons ( $\geq 18$ years old) who receive health care at the UNC Hospital Infectious Disease (ID) clinic	In the USA, women, racial/ethnic minorities and persons who acquire HIV infection through heterosexual intercourse represent an increasing proportion of HIV-infected persons, and yet are frequently underrepresented in clinical trials. We assessed the demographic predictors of trial participation in antiretroviral-naïve patients.	Gender did not appear to impact participation in HIV treatment trials, but Black patients were slightly less likely to participate in these trials. Considering the substantial proportion of HIV-infected patients who are Black, future trials need to consider strategies to incorporate such underrepresented population	Between 1996 and 2006, 30% of 738 treatment-naïve patients initiated HAART in a clinical trial. Trial participation rates for men who have sex with men (MSM), heterosexual men, and women were respectively 36.5, 29.6 and 24.3%. After adjustment for other factors, heterosexual men appeared less likely to participate in trials compared with MSM [PR 0.79, 95% confidence interval (CI) 0.57, 1.11], while women were as likely to participate as MSM (PR 0.97, 95% CI 0.68, 1.39). The participation rate in Black patients (25.9%) was lower compared with non-Black patients (37.5%) (adjusted PR 0.80, 95% CI 0.60, 1.06).	Menezes, P., Eron, J. J., Jr., Leone, P. A., Adimora, A., Wohl, D. A., & Miller, W. C. (2011). Recruitment of HIV/AIDS treatment-naïve patients to clinical trials in the highly active antiretroviral therapy era: influence of gender, sexual orientation and race. <i>HIV Medicine</i> , 12(3), 183-191. doi: 10.1111/j.1468-1293.2010.00867.x

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HIV	Qualitative A total of 35 HIV-infected Hispanic and African American patients enrolled clinical research protocols at the National Institutes of Health were recruited to participate in focus groups and in-depth interviews	Examined an expanded range of predictors of HIV research participation (clinic contact, clinical, and personal characteristics) to investigate observed ethno cultural differences in HIV research participation.	Results thus suggest that much of the variation in research participation associated with ethno cultural group or race is accounted for by clinic contact variables. This in turn suggests that it is the different patterns of clinical interactions and service use shown by these groups that may influence research participation. To attract under researched populations, attention should shift from the "who" research participation to the "how" of clinical interactions	Four major themes related to the decisions of participants to enroll in clinical trials emerged, which are as follows: enhancers, barriers, beliefs, and psychosocial context.	Rivera-Goba, M. V., Dominguez, D. C., Stoll, P., Grady, C., Ramos, C., & Mican, J. M. (2011). Exploring decision-making of HIV-infected Hispanics and African Americans participating in clinical trials. <i>JANAC: Journal of the Association of Nurses in AIDS Care</i> , 22(4), 295-306. doi: 10.1016/j.jana.2010.10.007
HIV	Quantitative Experimental potential participant screening for Aids clinical trial (ACT)	Test intervention to increase study involvement	African American and Latino populations	Successful behavioral and structural interventions to increase the participation of PLHA of color in screening for and enrollment into ACTs. HIV care settings, clinical trials sites, and trial sponsors are uniquely positioned to develop procedures, supports, and trials to increase the proportion of PLHA of color in ACTs.	Gwadz, M. V., Colon, P., Ritchie, A. S., Leonard, N. R., Cleland, C. M., Riedel, M., . . . Mildvan, D. (2010). Increasing and supporting the participation of persons of color living with HIV/AIDS in AIDS clinical trials. <i>Current HIV/AIDS Reports</i> , 7(4), 194-200. doi: 10.1007/s11904-010-0055-3
HIV	The WIHS, a prospective study at six clinical centers in	To assess study retention and attendance for two recruitment waves of	Preventing early loss to follow-up resulted in better study retention early, but late loss to	Factors associated with nonattendance at later visits (7-10) among HIV-infected participants were younger age, white race, not having a primary care provider, not	Hessol, N. A., Weber, K. M., Holman, S., Robison, E., Goparaju, L., Alden, C. B., . . . Ameli, N.

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	the United States, has experienced two phases of participant recruitment. In phase one, women were screened and enrolled at the same time, and in phase two, women were screened and enrolled at separate visits. Compliance with study follow-up was evaluated by examining semiannual study retention and visit attendance.	participants in the Women's Interagency HIV Study (WIHS).	follow-up may require different retention strategies.	having health insurance, WIHS site of enrollment, higher viral load, and nonattendance at a previous visit. In HIV-uninfected participants, younger age, white race, WIHS site of enrollment, and nonattendance at a previous visit were significantly associated with nonattendance at later visits.	(2009). Retention and attendance of women enrolled in a large prospective study of HIV-1 in the United States <i>Journal Womens Health (Larchmt)</i> , 18(10), 1627-1637. doi: 10.1089/jwh.2008.1337
HIV	Data were from 6,892 persons living with HIV infection, recruited in facilities in seven U.S. states and using population-based methods in eight other states, between 2000-2004. We calculated self-reported participation in a clinical research study of HIV medicines, factors associated with self-reported study	To describe participation in clinical research of HIV medicines among women and racial/ethnic minorities, and associated factors, we used data from a cross-sectional behavioral surveillance interview project conducted in 15 U.S. states	African American males	Among persons with HIV interviewed in these 15 states, self-reported participation in clinical research studies was higher among women than men, but racial/ethnic minority men were less likely to report study participation. Our data suggest that clinicians and researchers should make increased efforts to offer study participation to racial and ethnic minority men.	Sullivan, P. S., McNaghten, A. D., Begley, E., Hutchinson, A., & Cargill, V. A. (2007). Enrollment of racial/ethnic minorities and women with HIV in clinical research studies of HIV medicines. <i>Journal of the National Medical Association</i> , 99(3), 242-250. Retrieved from <a href="http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2569620/pdf/jnma00202-0062.pdf">http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2569620/pdf/jnma00202-0062.pdf</a>



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	participation among men and women, and reasons for not participating in a study among nonparticipants.				
HIV	Qualitative Questionnaire development and cross-sectional survey. Setting, Participants, and Measurements: In a sample of 200 HIV-infected African-American adults receiving medical care at the Pittsburgh AIDS Center for Treatment (a university-based ambulatory clinic), we assessed research participation rates and willingness to participate in future HIV treatment trials, trust in the medical profession, sociodemographic characteristics, attitudes, and concerns about HIV treatment trials.	(1) To develop a questionnaire that measures attitudes and concerns about HIV treatment trials among HIV-infected African Americans at a university-based clinic. (2) To determine actual participation rates and willingness to participate in future HIV treatment trials among HIV-infected African Americans at a university-based clinic.	Having never been asked to participate in research is a major barrier to the participation of HIV-infected African Americans in HIV treatment trials. African Americans who seek medical care for HIV infection should be asked to participate in HIV treatment trials.	Only 57% of survey respondents had ever been asked to participate in an HIV treatment trial but 86% of those asked said yes. Contrary to previous studies, neither trust/distrust in the medical profession nor beliefs about the dishonesty of researchers was associated with research participation rates or willingness to participate in future HIV treatment trials.	Garber, M., Hanusa, B. H., Switzer, G. E., Mellors, J., & Arnold, R. M. (2007). HIV-infected African Americans are willing to participate in HIV treatment trials. <i>Journal of General Internal Medicine</i> , 22(1), 17-42. doi: 10.1007/s11606-007-0121-8
HIV	Quantitative through use of interviewer administered	To identify barriers and facilitators to research	Forty HIV-positive Latina women, 10 HIV/AIDS service providers, and 4	Sixty-three percent of Latinas perceived individual-level barriers (e.g., fear, shame, and stigma), and 10% mentioned system-level barriers (e.g., lack of transportation or	Zúñiga ML, Blanco E, Martínez P, Strathdee SA, Gifford AL.(2007). Perceptions of barriers

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	structured surveys	participation	HIV/AIDS trial recruiters in the US-Mexico border region.	language-appropriate services); 70% of providers mentioned system barriers. HIV stigma was not reported as a barrier by providers.	and facilitators to participation in clinical trials in HIV-positive Latinas: a pilot study. Journal of Women's Health (Larchmt), 16(9), 1322-30. 10.1089/jwh.2006.0234
HIV and SUD	<p>Mixed Methods Study</p> <p>This article presents qualitative and basic quantitative measures of efficacy of our recruitment process. Quantitative measures included logging each time a contact was made with an organization and categorizing the type of contact, for example, a phone call, personal visit, or other contact. Qualitative data recorded in the Contact Log included who was spoken to, what was discussed, what suggestions were</p>	<p>Minorities with HIV presents a recruitment process model that has facilitated our recruitment efforts and has helped the authors to organize, document, and evaluate their community outreach strategies</p>	46 HIV + women with recent substance abuse	<p>For this study population of women who were HIV+ and recovering from substance abuse disorder, the authors found that establishing trust with community organizations that serve these women allows for a productive referral relationship. Although the majority of women in this study are African American, the authors were challenged in recruiting Hispanic women.</p>	<p>Alvarez RA, Vasquez E, Mayorga CC, Feaster DJ, Mitrani VB. (2006). Increasing minority research participation through community organization outreach. Western Journal of Nursing Research. 28(5):541-60. Doi: 10.1177/0193945906287215</p>

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	made by the contact, and what plans were made for future contact.				
HIV and SUD	Qualitative  Each site assessed the feasibility of recruiting at least 100 eligible intravenous drug users (IDUs) utilizing respondent driven sampling (RDS) and targeted sampling (TS) methods over an 8-week period in late 2004.	The current study sampled injection drug users in three U.S. cities using RDS and targeted sampling (TS) methods and compared their effectiveness in terms of recruitment efficiency, logistics, and sample demographics. Both methods performed satisfactorily.	IV drug users – difficulty in identifying individuals with SUD: “It also led to some bias in recruitment in Houston, where interviewers made the decision to recruit only individuals who <i>looked</i> like injection drug users on one particularly unsuccessful recruitment day.”	The targeted method required more staff time per-recruited respondent and had a lower proportion of screened respondents who were eligible than RDS, while RDS respondents were offered higher incentives for participation.	Robinson, W. T., Risser, J. M., McGoy, S., Becker, A. B., Rehman, H., Jefferson, M., . . . Tortu, S. (2006). Recruiting injection drug users: A three-site comparison of results and experiences with respondent-driven and targeted sampling procedures. <i>Journal of Urban Health, 83</i> (6 Suppl), i29-38. doi: 10.1007/s11524-006-9100-3
SUD	Effectiveness Study Quantitative control-trial with Women Recovery Group and Group Drug Counseling	present successful strategies to overcome the following barriers during the Women's Recovery Group (WRG) two-site clinical trial (N = 158): maintenance of sample size and balanced gender randomization during continuous enrollment,	Women with substance use disorders	94.3% were White, and 4.4% African American. Therapists were trained in two teams allowing for coverage and uninterrupted treatment over 24 months. Results: At both sites recruitment and enrollment increased with each successive quarter. Sample size and end date targets were met without disruptions in treatment. Group therapists reported high satisfaction with their training and treatment experiences	Greenfield, S. F., Crisafulli, M. A., Kaufman, J. S., Freid, C. M., Bailey, G. L., Connery, H. S., . . . Rodolico, J. (2014). Implementing substance abuse group therapy clinical trials in real-world settings: Challenges and strategies for participant recruitment and therapist training in the Women's Recovery Group Study. <i>The American Journal on Addictions, 23</i> (3), 197-

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		maintenance of group attendance, and training and retention of therapists over the 24-month continuous group enrollment.			204.
SUD	Quantitative A longitudinal cohort study to examine HIV incidence and behavior change pre- and post introduction of comprehensive HIV prevention services.	We utilized multiple recruitment approaches to recruit IDUs in a longitudinal cohort study to examine HIV incidence and behavior change pre- and post-introduction of comprehensive HIV prevention services.	When recruiting a large number of IDUs, using multiple recruitment modes is ideal with regard to diversification of IDU characteristics and risk profile. Although it was the most costly, ORW recruitment was more effective than the other two methods. Lack of monetary compensation for successful recruitment of peers may have hampered peer-referral.	Peer-referred IDUs were more likely to be living with family or relatives (50.7% versus ORW: 40.1% and walk-in: 39.8%; $p < 0.001$ ) rather than on the street or shared housings compared to the other two recruitment modes. Walk-ins were more likely than peer-referred and ORW-referred IDUs to be HIV-positive (walk-ins: 26.1%; peer-referred: 19.1%; ORW: 19.9%; $p < 0.01$ ) and have risky injection practices (walk-ins: 62.2%; ORW: 57.0%; peer-referred: 58.6%; $p < 0.05$ ). The cost per IDU recruited through ORW referral method was the most costly at USD 16.30, followed by peer-referral at USD 8.40 and walk-in at USD 7.50.	Tun, W., Sebastian, M. P., Sharma, V., Madan, I., Souidi, S., Lewis, D., . . . Sarna, A. (2013). Strategies for recruiting injection drug users for HIV prevention services in Delhi, India. <i>Harm Reduction Journal</i> , 10, 16. doi: 10.1186/1477-7517-10-16
SUD	Individuals completed a survey designed to evaluate factors associated with clinical trial participation in substance use disorders. Recruitment methods for all trials were similar and consisted primarily of paid	Examined the treatment history and intention to seek treatment among 489 individuals interested in substance use disorder clinical trial participation.	Free cost was the aspect of clinical trial participation that most influenced the decision to make an intake evaluation appointment for opioid-dependent patients as compared with cocaine- and cannabis-dependent participants, and the availability of individual psychotherapy most	Cannabis-dependent individuals evaluated for clinical trial participation reported that recruitment advertising was an important factor in leading them to seek treatment. These results have implications for clinical trial recruitment and public health efforts directed at encouraging cannabis-dependent individuals to seek treatment.	Mariani, J. J., Cheng, W. Y., Bisaga, A., Sullivan, M., Carpenter, K., Nunes, E. V., & Levin, F. R. (2011). Comparison of clinical trial recruitment populations: treatment-seeking characteristics of opioid-, cocaine-, and cannabis-using participants. <i>Journal of Substance Abuse Treatment</i> , 40(4), 426-

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	advertisements, Internet sources, and clinical referrals. Potential participants for all studies were initially screened over the telephone to determine general eligibility.		influenced those who were cannabis dependent.		430. doi: 10.1016/j.jsat.2011.01.005
SUD	Quantitative Recruitment and retention data from 24 Clinical Trials Network (CTN) trials conducted and completed between 2001 and 2010 were analyzed using single-factor analysis of variance and single-predictor regression methods to test their association with trial design characteristics	To test whether any of the following factors are associated with recruitment or retention: type of intervention, type of therapy, duration of treatment, total duration of trial, number of treatment sessions, number of follow-up visits, number of primary assessments, timing of primary assessments, number of case report form (CRF) pages at baseline, and number of CRF pages for the entire trial.	Almost all of the analyses performed did not show statistically significant patterns between recruitment and retention rates and the trial design characteristics considered.	In CTN trials, the relationship between assessment burden on participants and length of trial, on the one hand, and recruitment and retention, on the other, is not as strong and direct as expected. Other factors must impinge on the conduct of the trial to influence trial participation. Researchers may deem slightly more justifiable to permit inclusion of some of the design features that previously were assumed to have a strong, negative influence on recruitment and retention, and should consider other strategies that may have a stronger, more direct effect on trial participation.	Wakim, P. G., Rosa, C., Kothari, P., & Michel, M. E. (2011). Relation of study design to recruitment and retention in CTN trials. <i>American Journal of Drug Alcohol Abuse</i> , 37(5), 426-433. doi:10.3109/00952990.2011.596972
SUD	Qualitative Two studies designed to assess HIV prevalence and associated risk behaviors among current FSWs and IDUs were	To explore why recruitment with RDS may work in some populations and not in others, we assess the implementation of RDS to recruit	The IDU study recruited 350 participants within 7 weeks, while the FSW study recruited 227 participants over 28 weeks. Implementation modifications that did	We recommend that all RDS studies include a formative research process to involve the participation of target populations and key persons associated with these populations in the study planning and throughout the implementation processes to improve recruitment from the outset and to respond to poor recruitment during data	Uuskula, A., Johnston, L. G., Raag, M., Trummal, A., Talu, A., & Des Jarlais, D. C. (2010). Evaluating recruitment among female sex workers and injecting drug users at risk for HIV using respondent-driven

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	conducted using RDS methods from 2005 to 2007. The methodology included interviews with gatekeepers, members of the target population, mapping, and piloting data collection instruments.	female sex workers (FSWs) and injection drug users (IDUs)	not negatively impact key RDS theoretical and methodological requirements were used to improve recruitment during the FSW study.	collection.	sampling in Estonia. Journal of Urban Health, 87(2), 304-317. doi: 10.1007/s11524-009-9427-7
SUD	Qualitative From October 2005 - October 2007, these cases were traced and invited to undergo interview assessment covering early life experience, substance use, health and social histories.	early life risk factors for later drug injection or about the life course of injection once established including the influence of medical and social interventions	The initial cohort size was 814. At start of follow up 227 had died. Of the remaining 587: 20 had no contact details and 5 had embarked from the UK; 40 declined participation; 38 did not respond to invitations; 14 were excluded by their GP on health or social grounds and 22 had their contact details withheld by administrative authorities. 448 were interviewed of whom 16 denied injection and were excluded.	Injecting drug users recruited from a community setting can be successfully followed-up through interviews and record linkage	Macleod, J., Copeland, L., Hickman, M., McKenzie, J., Kimber, J., De Angelis, D., & Robertson, J. R. (2010). The Edinburgh Addiction Cohort: Recruitment and follow-up of a primary care based sample of injection drug users and non-drug-injecting controls. BMC Public Health, 10, 101. doi: 10.1186/1471-2458-10-101
SUD	quasi-randomized controlled trial among injured patients seen in acute care clinics compared self-administered paper-and-pencil, self-	We compared the effect of three different modes of questionnaire administration on screening for hazardous drinking and acquiescence to	Compared to paper questionnaires, electronic screening produced less social desirability bias and greater acquiescence to trial participation. Oral questionnaires	Of the 370 participants, 22.7% scored > or =4 and 7.8% > or =6 on the AUDIT-C. Electronic questionnaires were more likely than paper questionnaires to identify an AUDIT-C > or =6 (OR = 1.96; 95% CI 1.10-3.48), but not > or =4 (OR = 0.83; 95% CI 0.43-1.62). Oral questionnaires were as likely as paper questionnaires to identify an	Graham, A., Goss, C., Xu, S., Magid, D. J., & DiGuseppi, C. (2007). Effect of using different modes to administer the AUDIT-C on identification of hazardous drinking and acquiescence to trial

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	administered electronic, and orally-administered interview questionnaires.	trial participation	produced greater acquiescence, but barriers to use adversely affected recruitment. Electronic questionnaires may be preferable for screening for hazardous drinking and recruitment into intervention trials in acute care clinics.	AUDIT-C $\geq 4$ (OR = 1.00; 95% CI 0.40-2.51) or $\geq 6$ (OR = 1.94; 95% CI 0.83-4.50). Electronic and oral questionnaires were more likely to elicit acquiescence to trial participation (OR = 1.59; 95% CI 1.23-2.07, and OR = 1.66; 95% CI 1.22-2.26, respectively). Oral questionnaires created problems with confidentiality, privacy, and disruption of patient flow, and reduced recruitment success (OR = 0.51; 95% CI 0.42-0.62).	participation among injured patients. <i>Alcohol Alcohol</i> , 42(5), 423-429. doi: 10.1093/alcalc/agl123
SUD	Quantitative recruitment and enrollment findings for the first 764 participants in an ongoing randomized controlled trial that tested the efficacy of a widely disseminated Internet smoking cessation service (www.QuitNet.com) alone and in conjunction with telephone counseling. Study participants were recruited through Internet search engines using an active user sampling protocol.	This paper reports recruitment and enrollment findings for the first 764 participants in an ongoing randomized controlled trial that tested the efficacy of a widely disseminated Internet smoking cessation service	Internet recruitment provides unique challenges and opportunities for managing sample recruitment, analyzing subsamples to determine generalizability, and understanding the characteristics of individuals who participate in online research.	During the first 16 weeks of the study, 28,297 individuals were invited. Of those, 11,147 accepted the invitation, 5,557 screened eligible, 3,614 were recruited, 1,489 provided online informed consent, and 764 were confirmed eligible and enrolled. Of those who were at least curious about a cessation trial ( $n=11,147$ ), 6.9% enrolled. Of those who were eligible and recruited ( $n=3,614$ ), 21.1% enrolled. Depending on the denominator selected, results suggest that 7% to 21% of smokers interested in cessation will enroll into a research trial.	Graham, A. L., Bock, B. C., Cobb, N. K., Niaura, R., & Abrams, D. B. (2006). Characteristics of smokers reached and recruited to an internet smoking cessation trial: A case of denominators. <i>Nicotine &amp; Tobacco Research</i> , 8 Suppl 1, S43-48.
IPV	Quantitative using surveys	explores ethnocultural considerations at	Minority females with IPV and IPA experiences	Recommendations for greater use of multiethnic samples of IPV from varying nationalities. Enhanced use of mixed-method	Mechanic, M. B., & Pole, N. (2013). Methodological considerations in

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		each step of the research process: (a) conceptualization of the research question, (b) sampling, (c) recruitment and retention, (d) study design, (e) measurement, (f) statistical analysis, (g) interpretation of results, and (h) ethics		designs combining qualitative and quantitative approaches are likely to lead to more nuanced understandings of the ways in which race, class, and culture impact the nature, dynamics, and impact of IPV. More inclusive research questions  and ecologically valid methodologies are necessary for developing culturally competent, data driven policies and practices to promote social justice for minority IPV	conducting ethnoculturally sensitive research on intimate partner abuse and its multidimensional consequences. Sex roles, 69(3-4), 205-225. doi: 10.1007/s11199-012-0246-z
IPV	Quantitative through use of questionnaire and follow-up interviews	examine motivations for, and costs/benefits of, participation in three interviews across  a one-year period among women recently exposed to  intimate partner abuse (IPA).	236 adult female participants who experienced recent IPV.	Recruited from publicly accessible police reports, women were not informed that the study focused on intimate partner abuse (IPA) in recruiting materials or when they scheduled the first interview. Women's ratings on the Response to Research Participation Questionnaire (RRPQ) indicated a positive benefit-to-cost ratio across all three interviews. Negative responses to participation as well as severity of IPA and PTSD symptoms did not predict retention at the next interview. These data demonstrate that studies asking about IPA experiences, even when survivors do not know in advance that IPA will be the focus of study, can be implemented within a stable benefit-to-cost ratio over time.	Hebenstreit CL, DePrince AP. (2012). Perceptions of participating in longitudinal trauma research among women exposed to intimate partner abuse. Journal of Empirical Research and Human Research Ethics, 7(2):60-9. doi: 10.1525/jer.2012.7.2.60.



H-RSC	Study Type and Methods	Study Purpose	Underrepresented Research Groups Identified	Study Findings and Social Justice Implications	Reference
IPV	Quantitative using pilot intervention study (Pre and Post test)	describe the successful recruitment methods of a study focused on a pilot intervention for rural women who were experiencing abuse and who also were at risk for sexually transmitted infections. Initial recruitment into the study was the primary challenge, and strategies to overcome recruitment difficulties are discussed	Women experiencing IPV recruitment and participation in research	After 1 month of recruitment, only 10 women agreed to be screened for IPV. Several creative strategies were utilized in the revision of the recruitment plan, with the most successful being knitting by the research staff and incentives to participants for screening. An additional 77 women agreed to be screened for study participation within 3 months of implementing the recruitment changes.	Sutherland MA, Fantasia HC. (2012). Successful research recruitment strategies in a study focused on abused rural women at risk for sexually transmitted infections. <i>Journal Midwifery Women's Health.</i> , 57(4):381-5. doi: 10.1111/j.1542-2011.2011.00134.x.
IPV	Quantitative through use of self-report questionnaire	examined the reactions of research participants to questions about dating violence. The current study examined the reactions among college students to completing a self-report measure on dating violence	260 college students >18 years of age. Of these participants, 70.4% were female. The mean age of participants was 18.7 (SD = 2.12). Self-identified ethnic/racial background consisted of 90.4% non-Hispanic	The current study examined the reactions among college students to completing a self-report measure on dating violence. Results showed that participants reported numerous positive experiences as a result of their research participation, with only mildly increased negative emotional reactions evident for some. Findings are discussed in relation to IRB proposals and appropriate informed consent for research participants.	Shorey RC, Cornelius TL, Bell KM. (2010). Reactions to participating in dating violence research: Are our questions distressing participants? <i>Journal of Interpersonal Violence</i> , 26(14):2890-907. doi: 10.1177/0886260510390956.

H-RSC	Study Type and Methods	Study Purpose	Underrepresented Research Groups Identified	Study Findings and Social Justice Implications	Reference
			<p>White, 3.1% African American,</p> <p>2.3% Asian, 2.7% Hispanic, and 1.2% identified as Other. The majority of</p> <p>participants, 97.7%, identified as heterosexual, and the mean length in months</p> <p>of a current dating relationship was 17.4 (SD = 15.19).</p>		
IPV	<p>Quantitative Women in the intervention group attended on average <math>3.9 \pm 2.8</math> prenatal sessions, and 53.6% attended at least 4 prenatal sessions. Participants spent an average of <math>35.3 \pm 14.8</math> minutes per session. Women assigned to the usual care group met with their primary care providers as per standard clinic practice.</p>	<p>This report describes the successful strategies of recruitment and retention of African Americans and Latinos in a randomized clinical trial to reduce smoking, depression and intimate partner violence during pregnancy</p>	<p>Targeted recruitment and retention strategies, minority women will participate at high rates in behavioral clinical trials. We also found that women who drop out are different from women who are lost to follow-up, and require different strategies to optimize their completion of the study.</p>	<p>Of the 1,398 eligible women, 1,191 (85%) agreed to participate in the study. Of the 1,191 women agreeing to participate, 1,070 completed the baseline evaluation and were enrolled in the study and randomized, for a recruitment rate of 90%. Of those enrolled, 1,044 were African American women. A total of 849 women completed the study, for a retention rate of 79%. Five percent dropped out and 12% were lost-to-follow up. Women retained in the study and those not retained were not statistically different with regard to socio-demographic characteristics and the targeted risks. Retention strategies included financial and other incentives, regular updates of contact information, which was tracked and monitored by a computerized data management system available to all project staff, and attention to cultural competence with implementation of study procedures by appropriately selected,</p>	<p>El-Khorazaty, M. N., Johnson, A. A., Kiely, M., El-Mohandes, A. A., Subramanian, S., Laryea, H. A., . . . Joseph, J. G. (2007). Recruitment and retention of low-income minority women in a behavioral intervention to reduce smoking, depression, and intimate partner violence during pregnancy. <i>BMC Public Health</i>, 7, 233. doi: 10.1186/1471-2458-7-233</p>

H-RSC	Study Type and Methods	Study Purpose	Underrepresented Research Groups Identified	Study Findings and Social Justice Implications	Reference
				trained, and supervised staff. Single, less educated, alcohol and drug users, non-working, and non-W/C women represent minority women with expected low retention rates.	

Picturing Life: Using Photo Journals to Explore Challenges and Supports for Women

Living with HIV

Toshua W. Kennedy MSN, MPH, PHCNS-BC: Medical University of South  
Carolina

Ida Spruill Ph.D., RN, LISW, FAAN: Medical University of South Carolina

Michelle Teti, DrPH: University of Missouri

Susan Newman D., Ph.D., RN, CRRN: Medical University of South Carolina

Elaine Amella J., Ph.D., RN, FAAN: Medical University of South Carolina

Corresponding Author: Toshua W. Kennedy MSN, MPH, PHCNS-BC

99 Jonathan Lucas Street

Charleston, SC 29425

864-877-0823 (phone and fax)

[kennedtw@musc.edu](mailto:kennedtw@musc.edu)

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## Abstract

HIV continues to create negative public health concerns that affect women in the United States, especially those who are marginalized and vulnerable. Although inequities for gender, race, socio-economics, and other HIV-related difficulties exist for women living with HIV (WL-HIV), few studies have used a participatory research approach with a Photovoice methodology to explore their lives. This project, "Picturing Life" explored challenges and supports for WL-HIV in South Carolina. Participants (n = 5) took photographs to describe personal challenges and supports, attended three group sessions, and participated in a one-one-one telephone interview. An inductive analytical process guided by Creswell's Grounded Theory Approach identified *empowerment* and *spirituality* as major themes for supports and *reinventing self and positive relationships* as subthemes. The major theme for challenges was *stigma* and subthemes were *public silence on HIV and missed opportunities*.

**Key words:** *Challenges, Participatory Research, Photovoice, Supports, Women Living with HIV*

## INTRODUCTION

*"I was told you have to stand for something or you will fall for anything. So here I am standing and speaking out through my pictures" – "Picturing Life" Participants*

In 2011, approximately half of all new HIV cases in the United States were located in the Southern states, despite this region accounting for a little more than one-third of the country's population (Centers for Disease Control and Prevention [CDC], 2013). Current data rank South Carolina as eighth for incidence of AIDS, and in 2012, the prevalence for HIV and AIDS in this state totaled more than 15,000 (South Carolina Department of Health and Environmental Control, 2012b).

In South Carolina, inequities exist among ethnic minority women living with HIV (WL-HIV) as seen in the percentages for women by race: African Americans - 80%, Whites – 15%, and Latinas – 3% (South Carolina Department of Health and Environmental Control, 2012b). 53% of WL-HIV remain in care one year after the initial diagnosis with only 42% reaching viral suppression (Centers for Disease Control and Prevention, 2014). A better understanding of the life experiences that form the context of their health from the perspectives of WL-HIV may help facilitate interventions for positive outcomes (e.g. treatment adherence). Although a few studies used Photovoice as a method of data collection to describe lived experiences (Duffy, 2010; Fortin, Jackson, Maher, & Moravac, 2014; Novek, Morris-Oswald, & Menec, 2012; Valiquette-Tessier, Vandette, & Gosselin, 2015), fewer studies have used Photovoice to help WL-HIV identify their challenges and supports (Teti, Murray, Johnson, & Binson, 2012; Teti, Pichon, Kabel, Farnan, & Binson, 2013). Thus, this study aimed to give a voice to WL-HIV in South Carolina by providing the participants a space and a degree of ownership to explore their experiences and the decisions for disseminating study findings (Centers

for Disease Control and Prevention, 2011) as a means to promote dialogue. Challenges are defined as difficult tasks that test one's ability or character ("Challenges" OED, n.d), and supports keep a person from negative thoughts, and give courage, confidence, or the power to endure ("Supports" OED, n.d).

Photovoice is a qualitative method useful for data collection and commonly used with a participatory approach (Wang & Burris, 1997). Wang and Burris cite the following goals for Photovoice. 1) Enable participants to record and reflect upon strengths and concerns. 2) Promote dialogue about issues through group discussions of photographs. 3) Allow study findings and photographs agreed upon to be shared publically (Wang & Burris, 1997). The Photovoice method emphasizes conversations in the community, which often leads to transforming and liberating participants (Duffy, 2010). Photovoice provides insight for specific health needs of WL-HIV while leading to empowerment and a sense of accomplishment (Teti et al., 2012; Teti et al., 2013; Valiquette-Tessier et al., 2015).

### **Protection of Human Subjects**

The Institutional Review Board (IRB) at the Medical University of South Carolina approved the current study, "*Picturing Life*", in September 2014. Following IRB approval, the PI organized an informal advisory board, which consisted mostly of employees from Aid Upstate, an agency responsible for the program titled Women Involved in Life Learning with Other Women (WILLOW). WILLOW is an intervention program designed to empower sound decisions that improve life, build social-skills, and provide education to WL-HIV (Center for Disease Control and Prevention, 2013; Danya International, 2012). The functions of the advisory board included recruitment of

participants, providing meals for group meetings, and distributing gas cards and bus passes.

## **METHODS**

### **Recruitment and Enrollment**

The WILLOW program facilitator assisted in recruiting participants using flyers, phone calls, and word of mouth. The facilitator asked interested WL-HIV to attend an informational session designed to explain the study's purpose and process. Inclusion criteria were WL-HIV, at least eighteen years old, able to sign informed consent, able to speak and understand English and willing to take and explain photographs of items representing personal challenges and supports.

The current study's sample size ( $n = 5$ ) matched the design and methodology of similar studies. A systematic review on participatory studies using the Photovoice methodology reported sample sizes ranging from four to fifteen when participants were living with HIV (Catalani & Minkler, 2010). Dialogue and photographs provided sufficient data that were rich even with smaller sample sizes (M. Teti, personal communication, March 22, 2015).

The majority of participants (80%) were African American and 20% White. The average age for the group was forty-five and the range was thirty-three to sixty years. The group income level ranged from below \$10,000 to \$29,999, and the average number of years diagnosed with HIV was 8.6 years. See Table 1 for additional demographics of participants.



**Table 1: Study Participants' Demographics**

<u>Participant</u>	<u>Age</u>	<u>Race</u>	<u>Marital Status</u>	<u>Number of Children</u>	<u>Education Level</u>	<u>Income Level</u>	<u>Years Diagnosed</u>	<u>Disclosed Status To</u>
Ms. B	60	AA	Divorced	2	Masters	10,000-19,999	2	2 of 6 Siblings, Friends, Children
Ms. C	44	AA	Single	2	Some College	20,000-29,999	9	Children, Siblings
Ms. D	37	AA	Single	2	Some College	10,000-19,999	10	Partner, Parents, Siblings, Others
Ms. F	33	W	Single	1	Some College	20,000-29,999	10	Partner, Parents, Children Siblings, Friends, Others
Ms. G	50	AA	Married	1	9 <sup>th</sup> Grade	<10,000	12	Spouse

**Photovoice Training.** To take part in “*Picturing Life*” participants partook in a comprehensive informed consent process, which outlined all procedures, requested permission for the use of photographs in public exhibits and publications, and included a release form for taking photographs of others (Teti et al., 2012). Once the researcher obtained informed consent, a group Photovoice training was held and included a discussion on the exclusion of photographs of minors without parental permission and incriminating activities (Schrader, Deering, Zahl, & Wallace, 2011). In addition, the PI presented a “Journal of Life” as an example with explanations of photographs to show an example of how images can represent life experiences. Examples included drawings created by children instead of faces, bibles to indicate a relationship with God, sneakers

to show dedication to physical fitness, and conversely, empty ice cream boxes to show struggles with eating healthy. Although the PI provided suggestions, the final decision of items to include in photographs, selection of photographs for sharing, and the dissemination format, rested with the participants.

## **Data Collection**

**Overview.** *"Picturing Life"* took place over two-months, from October to December 2014. Data sources included three group sessions at Aid Upstate, and a one-on-one interview. A HIPAA approved transcriptionist converted digitally recorded sessions verbatim.

**Session One.** To begin each session, the PI presented icebreakers to create a comfortable setting. To start the first session, participants worked together on a puzzle, and without their knowledge, the PI removed one puzzle piece. Discussions targeted participants' missing pieces and identified solutions and resources. After the discussion, the PI reviewed the study's purpose and procedures and discussed dissemination options for "Journals of Life". Before adjourning, the PI distributed fully charged cameras and participants practiced using them. Following session one, the participants began to take photographs for "Journals of Life", which represented challenges and supports in their lives.

**Session Two.** The icebreaker for the second session was a brief video of a woman with HIV who contracted the virus from her husband, and discussions among the group targeted personal rights and moving beyond the diagnosis. After that, using the SHOWeD method, participants described their "Journals of Life", which were displayed on a large screen. The SHOWeD acronym represented the following

questions. 1) What do you **See** here? 2) What is **Happening**? 3) How does this relate to **Our lives**? 4) **Why** does this problem or strength exist? 5) What can we **Do** about it?

**Session Three.** To begin the third session, the PI initiated a discussion about being selective when disclosing HIV status to others. Following this discussion, participants shared the remaining “Journals of Life”. Before adjourning, the youngest participant voluntarily shared a personal note highlighting her experiences in the study.

**One-on-one Interviews.** The PI conducted the semi-structured one-on-one interviews by telephone. During the interview, the PI sought feedback relative to taking part in the study. Questions posed were the following. 1) How would you describe this experience? 2) What photographs did you exclude from your “Journals of Life”? 3) Did you learn anything about yourself? 4) Did you learn about resources available to you from others? 5) Are you interested in participating in follow-up study? After the questions, the PI offered participants the opportunity to share additional information and to ask questions. In addition, the PI discussed tentative dates for a follow-up meeting for member checking where participants viewed study themes from the data analysis to ensure that findings clearly exemplified participants' intentions. During member checking, the PI presented the traveling exhibit and study themes, and participants confirmed and agreed with findings.

## **Data Analysis**

An inductive analytical process was guided by Creswell's Grounded Theory Approach (Creswell, 2002) as described by Charmaz (Lynn & Nelson, 2005) with the intent of discovering themes within context of the study data (Hutchison, Johnston, & Breckon, 2010). Specifically, the data analysis included 1) transcribing the recorded

sessions which included explanations of photographs; 2) editing for accuracy and the removal of participants' names; 3) entering transcripts and "Journals of Life" (photographs and explanations) into NVivo so commonalities could be identified (QSRInternational, 2013). In the coding process, the PI 1) developed categories (open coding) 2) connected those categories (axial coding), 3) told stories with words and photographs (selective coding), and 4) ended with a distinct set of themes.

Data was stored in a password protected computer and participant' names were not used in transcripts. The PI maintained trustworthy methods to produce valid and reliable findings based on participants' perspectives (Guba, 1981; Krefting, 1991; Schwandt, Lincoln, & Guba, 2007). This researcher confirmed accuracy of transcripts by reading them multiple times while listening to recordings of study sessions and interviews and making corrections as needed. The PI demonstrated credible and transferable results by including WL-HIV who met the criteria, resulting in a study group that matched the prevalence of WL-HIV in South Carolina. The participants confirmed that study themes matched the information that they presented; further demonstrating attention to rigor co-authors verified study findings (Morse, Barrett, Mayan, Olson, & Spiers, 2008). In addition, the PI conducted audit trails for tracking decisions with detailed records (Mays & Pope, 1995; Morse et al., 2008).

## **RESULTS**

Participants decided to capture more than five photographs per person resulting in sixty-six photographs in the analysis. Major themes for supports included *empowerment and spirituality*; and subthemes for supports were, *reinventing self and*

*positive relationships*. The major theme for challenges was *stigma*; and subthemes were *public silence on HIV and missed opportunities*.

### Themes for Supports

**Empowerment.** The first major theme for supports was *empowerment*, which had the following attributes: Personal strength, accepting the HIV diagnosis, self-assurance, disclosing HIV as needed, and living as healthily as possible. For example, one participant said I **“choose my battles, because I can control who I tell [referring to HIV status]”**. The WL-HIV in the study identified medication and adjusting to being compliant with treatment as both a challenge and support, but determined medications to be more of a support because of improved clinical outcomes. **“HIV/AIDS is not going to kill me. So I eat healthy, and I take my meds”**. Another example, the oldest study participant (60 years old) shared the following. **“At the initial diagnosis, I had full-blown AIDS with a CD4 count of 44mg/dl, but after two years of consistent treatment, my CD4 cell count increased to 572 mg/dl”**.

Figure 1, the photograph below, displayed a participant’s empowerment through acceptance of her diagnosis. The participant stated that she had awareness of how past decisions affected her current state, and showed determination for “walking in that truth” (e.g. accepting the diagnosis) by displaying various types of shoes that she owns. Another participant described being responsible in her



Figure 1. Empowerment: “these are not just the shoes that I have, but these are the choices I have made”

intimate relationship by preventing reinfection and avoiding transmitting the virus to her partner through condom use.

The youngest participant (33 years old) expressed empowerment when she read a personal thank you for being included in the study and for having a voice. The group voted for this note to represent them in the public dissemination as a description for how their lives have purpose. *“I was told you have to stand for something or you will fall for anything. So here I am standing and speaking out through my pictures”*

**Spirituality.** The second major theme for supports was *spirituality*, which appeared in multiple “Journals of Life”. Images for spirituality were study bibles, sunny skies, and a mirror depicting a relationship with a loving God. **“You can look in the mirror plenty times a day and you see something else but always base your thinking on how God sees you or the potential that we have in us that God sees”** Other visuals were cups with positive quotations, wall plaques, and



Figure 2. Spirituality: God's presence never leaves

pictures of churches. One participant stated the **“presence of God exists even in storms of life”** and explained that the sun still shines above the clouds. See Figure 2. Some participants chose to include relationships among church parishioners as an extension of spirituality, which included images of church buildings and pulpits. Three participants discussed relationships and the acceptance they felt in church after disclosing to some member.

***Reinventing self.*** Reinventing self was a subtheme for supports and targeted the idea of new beginnings and creating a new start. Included in the description for this theme was the opportunity to be an advocate for others to help them understand HIV. One participant cited she chooses to stay away from negative influences and learned to be selective with whom time was spent. One participant planned to disclose HIV to others using photographs after participating in this study. **“I have something [an understanding of how pictures can share stories] I can work towards and it’s not a whole lot to many people, but it’s meaningful to me.”** Another participant shared plans and the desire to do more for other WL-HIV and for people who are unaware of their risks. **“I am not dying with this [HIV] without helping someone.”**

***Positive Relationships.*** *Positive relationships* were supports among the participant and represented a subtheme. Participants discussed the need for supportive relationships with unconditional acceptance and chose to receive support and be a positive influence. An example of this was visible in a photograph for which the participant explained, **“Hands that encircled one another belong to my Pastor and his wife who provide constant support and unconditional love.”** A different participant shared **“if you look hard enough you can build relationships and they can be a social support for you.”** Further comments about choosing positive relationships were, **“I choose to go about my daily life. I am striving for excellence while maintaining my family, godliness, and my integrity”.** Being a positive influence was an example in the following comment regarding HIV prevention. **“As I talked to my granddaughter, she doesn’t know [my HIV status] but telling her how to be a lady and not let some boy who she thinks loves her at 14, who really**

doesn't know what love is and just to be careful and carry yourself respectful as a young lady".

### Themes for Challenges

**Stigma.** The first theme for challenges was stigma. In "*Picturing Life*", the definition of stigma was fear of rejection and judgment related to being WL-HIV and included the recipients' anxiety over contracting HIV from the person disclosing. This anxiety may connect to an actual threat but often the reaction is erroneous. The WL-HIV discussed



Figure 3. Stigma: Fear and lack of HIV education cause stigma

stigma and one participant said there was reluctance to disclose HIV status because of the attached stigma and the fear for rejection. Figure 3 represented stigma because it demonstrated the exchange of dishes for Styrofoam immediately after disclosing the HIV status to family and friends. Other participants confirmed similar experiences with dishes and utensils relative to others' fear of contracting HIV. On a different note, one participant shared that stigma was perpetuated in "*Picturing Life*" by omitting faces from "*Journals of Life*", especially those of social supporters. Therefore, the PI accepted and displayed photographs in traveling exhibits of participants and other faces with signed consent.



**Public Silence on HIV.** A subtheme for challenges was *public silence of HIV*, which frustrated participants, because they knew the threat for HIV was very real. For example, some participants agreed that silence existed in the church and especially from the pulpit. The perception was that some pastors remain silent because of the effect on many aspects of church culture. For example, participants discussed hidden sexual practices that take place among parishioners placing them at risk for contracting HIV, starting with **“deacons and musicians in the church”**. Figure 4 was a photograph of



Figure 4. Public Silence on HIV: Church Culture

a graphic created by a participant with the caption “shh don’t share your status” depicting the silence encouraged by her pastor after disclosing her status to him. Further, participants asked, **“what will it take for others to be more serious? HIV is still here and people are still affected by it, every day.”** Participants discussed at length the need for more public attention to HIV. **“Have you been tested for HIV? Have you been tested for AIDS? HIV has been here for years, AIDS has been here for years and now Ebola comes and you’re all excited?”**

**Missed Opportunities.** The description for the second subtheme for challenges was *missed opportunities*, which included wishes and things participants had hoped to accomplish. Missed opportunities for three of the mothers in the group focused on their children and concerns about the future, especially **“if something were to happen to me”**. One participant shared information about her family and struggles with drug use that led to negative circumstances. Her “Journals of Life” included a collage depicting

**“family drama”, battles with family court, sobriety, and judgment”**. Some in the group focused on case managers and one wished for a case manager **“who cares”**. The same participant said, **“The case manager’s relationship was disappointing”**, because she hoped for more resources, support, and availability through this relationship. Several participants talked about frustration with the lack of follow-up appointments in the clinic, which connected to the missed opportunities, especially when they were unable to keep schedule appointments because of family or employment obligations. According to participants, the next available appointments were commonly four to six months later.

## **DISCUSSION**

*“Picturing Life”* used Photovoice to explore the lived experiences of WL-HIV in South Carolina, specifically to discover their challenges and supports. Although *“Picturing Life”* focused on challenges and support among women, some of the findings were similar to another exploratory study that included both genders with HIV (Rhodes, Hergenrather, Wilkin, & Jolly, 2008). Each qualitative study used a Photovoice methodology and focused on participants who lived in a southern state disproportionately affected by the HIV epidemic. Although more than half participants were male in that study, themes identified were similar. The subtheme *positive relationships* compared with that study’s description for social supports; *spirituality* was an identical theme; and *stigma* and *public silence* in *Picturing Life* matches the description for community’s fear and ignorance about HIV (Rhodes et al., 2008). However, *“Picturing Life”* highlighted the mother’s perspectives, church culture, and the

major theme *empowerment*, demonstrated personal growth, and accepting the HIV diagnosis.

In "*Picturing Life*" empowerment which highlighted self-awareness and personal strength realized during the use of Photovoice was similar to a study among for mothers with a history of homelessness (Fortin et al., 2014). **"I just see so much more in this experience. Photovoice done gave me big...a new start in life. Like I said, I never had a camera so it just showed me a different, new avenue that I can take and really enjoy myself, seeing the glass half full."** In "*Picturing Life*", participants agreed with the need for consistent medication and HIV care; however, disclosure was a different story. One participant who openly disclosed her HIV status to others stated, it "feels disingenuous when I do not disclose". However, this was not the case for all participants at the beginning because of stigma and fear of rejection anticipated after disclosing to others. By the end of the study, participants were interested in being more open with others in an effort to help them.

During member checking, the PI asked participants for personal goals beyond this study. The oldest participant decided to start a support group for WL-HIV. Another participant who sells cosmetics nationally, decided to share her story in a traveling exhibit. **"Other people in this company living with breast cancer and heart disease have shared conditions"**, and she was empowered to do the same. Additionally, one participant decided to create a documentary showing the faces of HIV, targeting youth, prevention, and early detection.

Studies report, many WL-HIV are not in care one year after diagnosis (Centers for Disease Control and Prevention, 2014), but participants in "*Picturing Life*" cited care

compliance and treatment adherence as supports. A possible influence for medication adherence was case managers who care. In fact, one recommendation from participants was for case managers to be evaluated using scales to measure caring as part of yearly evaluations with financial or merit consequences.

The oldest participant whose CD4 and viral load significantly improved with consistent treatment made the following clinical recommendation. Diagnosed at fifty-eight (two years prior), the participant believed transmission was fourteen years earlier. The absence of HIV symptoms, risks, and no other medical problems led to a late diagnosis. In addition, many participants believed the HIV diagnosis saved their lives and resulted in better health and conscious decision-making. Therefore, to save more lives, annual HIV screenings should apply to all patients regardless of risks. Doing so will lead to early diagnosis, result in a sense of normalcy for HIV testing, and help to eliminate stigma.

Future research could include pre and post measurements for empowerment to test Photovoice as an intervention strategy in a larger community-engaged study (Lightfoot et al., 2014). In the last session, participants discussed the desire to educate others about HIV and to dispel myths and ignorance about its transmission. An intervention study could involve prevention education from the perspective of WL-HIV. Another research recommendation is to measure the influence of Photovoice on CD4 and viral load, since research supports positive associations for empowerment and medication adherence (Johnson, Sevelius, Dilworth, Saberi, & Neilands, 2012).

## **Dissemination**

The participants decided to have a traveling exhibit to disseminate “Journals of Life” publically (Wang & Burris, 1997). The traveling exhibit contained all photographs from “Journals of Life” with participants’ words in a carousel photo album. In addition, the exhibit had a stand-alone display with ten poster-sized collages and the note chosen to represent the group, as a poster-size display. The first location for disseminating findings was Aid Upstate in conjunction with the first meeting of the new WILLOW group. The PI explained the themes and subthemes, and the affirmation from the group was audible from mumbles such as “yes”, and “me too”. The PI held other exhibits, and participants had the opportunity to attend.

## **Limitations**

The sample-size (n = 5) presented the opportunity for participants to become close, find comfort in discussing health-related vulnerabilities, and was adequate for a Photovoice study involving individuals with HIV, according to Catalani and Minkler (2010). Further, “*Picturing Life*” reached informational redundancy to support study themes for challenges and supports among WL-HIV from “Journals of Life”, discussions, and one-on-one interviews. However, the PI acknowledged the limitation that additional study themes could emerge from a larger study sample. In addition, personal bias and/or the “halo effect” may have influenced some photographs taken by participants. To explain the idea of “Journals of Life”, the PI presented a “Journal of Life” with challenges and supports during the Photovoice training session. Therefore, it was possible for participants to mimic the same types of photographs in an effort to receive approval or acceptance and a similarity was visible since photographs of bibles were in

three of the five “Journals of Life”. In addition, because participants were associated with WILLOW, it is possible that the program facilitated more empowerment than the general population of WL-HIV.

### **Conclusion**

In conclusion, Photovoice was an effective method for identifying themes for supports and challenges encountered by WL-HIV. The process of taking and sharing pictures and stories led to self-reflection and identification of strength in a marginalized group. Wherever presented, “*Picturing Life*”, eliminated public silence on HIV, generated thoughtful exchanges in the community, reduced stigma by humanizing participants, and expressed that WL-HIV in South Carolina matter and that their lives have purpose.

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### Key Considerations

- For WL-HIV, actual of perceived stigma can affect the decision to disclose HIV status.
- Photovoice empowers and strengthens participants who are WL-HIV. This method visually goes where words of WL-HIV cannot.
- Thoughts of WL-HIV matter, their lives have purpose, and traveling exhibits make that idea plan for attendants.
- For some WL-HIV Spirituality and awareness of God's presence are supports

## Conclusion

This conclusion links the knowledge gained from the three manuscripts.

According to Arrivillaga and colleagues, women with low social positions have low adherence to HIV treatment (Arrivillaga, Ross, Useche, Alzate, & Correa, 2009).

However, environments that are free of judgment, socially supportive, and tailored for WL-HIV, result in effective care (Carter et al., 2013). Such environments include those that enhance hope because this concept is associated with better health outcomes, increased value for life, and improved survival when facing life-threatening diseases (Phillips & Sowell, 2000).

The dimensional analysis, Manuscript 1, conducted to define the concept of hope in the context of the most vulnerable WL-HIV, AAFs, revealed many important factors. Hope was the combination of desire and expectation based on trust and confidence, and influences for hope among this subset of WL-HIV were both negative and positive public messages about HIV (Kennedy, 2015). In addition, findings stressed the need for truthful messages among AAFs living with HIV to avoid the creation of false hope. Future study implications targeted measuring hopefulness and making connections for improved outcomes such as CD4 and viral load, which are indications for effective treatment adherence for individuals with HIV.

However, the effectiveness of some treatments and interventions for HIV, SUD, and IPV may prove useless and inapplicable to AAFs, because, when developed, African Americans may not have participated in the study. Findings in Manuscript 2 revealed that some barriers to research participation among African Americans and Latinos with H-RSC connected with discrimination, concerns about being a guinea pig,

and recruitment biases. On the other hand, flexible recruitment strategies were among the factors that facilitated participation among individuals with H-RSC. In addition, when research studies were collaborative (e.g. used a participatory design) and allowed participants to be active partners, individuals with H-RSC were interested in participating and believed doing so was worth the risk and gave them a sense of purpose. Furthermore, the review revealed that participatory research studies created an atmosphere of trust, shared ownership, a degree of empowerment for participants who have a personal stake in a study's success, and adherence to principles of social distributive justice.

The PI believed the best route for increasing treatment adherence, creating effective interventions, and identifying specific challenges and supports for WL-HIV was to collaborate with this population to learn their perspectives and experiences. This belief led to the community-engaged participatory study using Photovoice in collaboration with WL-HIV. In this study, participants took photographs of items that represented personal challenges and supports as WL-HIV and took part in one-on-one interview. Two major themes identified for supports among WL-HIV were spirituality and empowerment. Subthemes for supports were positive relationships and reinventing self. The major theme for challenges was stigma and subthemes were public silence on HIV and missed opportunities. Research that tests interventions among WL-HIV should target opportunities for increasing the supports (e.g. empowerment and spirituality) and reducing challenges (e.g. stigma and public silence on HIV), while facilitating their participation to prevent violating social justice principles.

## **Appendix A: IRB Approved Consent Form**

### **Medical University of South Carolina CONSENT TO BE A RESEARCH SUBJECT**

#### **Using Photo Journals to Explore Challenges and Supports for Females Living with HIV**

##### **A. PURPOSE AND BACKGROUND:**

You are being asked to volunteer for a research study, because you are a female in South Carolina living with HIV. This research is sponsored by the Medical University of South Carolina. The purpose of this study is to use photography to identify challenges and supports encountered by females living with HIV. During this time, you will take photos of things identified as challenges and supports and create photo journals. You will discuss your photo journals called "Journals of Life" in a group setting. You are being asked to participate in this study because you are participating or have participated in the WILLOW program held at Aid Upstate. The investigator in charge of this study is Toshua W. Kennedy MSN, MPH, PHCNS-BC. This study is being done at Aid Upstate in Greenville, South Carolina through Medical University of South Carolina and will involve approximately 10 volunteers.

##### **B. PROCEDURES:**

*If you agree to be in this study, the following will happen:*

Today you will meet with the researcher, who will share step-by-step procedures for this study and an explanation of the study. After receiving this information and asking any questions you may have, you will be asked to complete this consent document. Additional screening questions will be asked to make sure you are eligible to participate. If deemed eligible, you will be enrolled in the study. Once enrolled, you will complete a questionnaire to describe yourself. This consent process will take approximately 20 – 30 minutes. Like the WILLOW project, this study will take place among a group of up to ten females.

One day per week for four weeks, the group will meet together at Aid Upstate in the conference room for two hours each time. All sessions will be digitally recorded for the researcher to use after removing any information that can identify you.

1. The first day of the study (week 1), you will receive an overview of the study as a reminder of the study purpose. You will get the opportunity to ask questions as needed. Once everyone understands expectations, the

researcher will distribute digital cameras to each person to take pictures. The researcher will hold trainings for how to use the camera and you will discuss in the training the types of pictures to take. For example, faces or identifiers are to be excluded from photo journals. You will be asked to include 5 - 10 pictures of challenges and support encountered as a female living with HIV. You will explain "Journals of Life" starting with the second week. The following questions will help you to explain the pictures. What do you **See** here? What is **H**appening? How does this relate to **O**ur lives? **W**hy does this problem or strength **e**xist? What can we **D**o about it? These questions form the word SHOWeD and have been used in studies using photographs in the past.

2. On the second and third days (weeks 2 and 3), the group will meet in the same location for two hours. Using a laptop and projector, the researcher will connect the cameras and display pictures on a large screen for all to see. As a group, you will determine challenges and supports for females living with HIV and give suggestions for overcoming challenges.
3. The fourth and last day of the sessions (week 4), you will finalize presenting "Journals of Life" and participate in one-on-one interviews with the researcher to share your experience.
4. A month later, for one - two hours the group will meet to discuss themes identified by the researcher from the analysis of journals and recordings. The group will discuss whether and to share "Journals of Life" publically in an exhibit to share what it is like to live as a female with HIV. Your participation will be optional. The group will determine the location and audience if you choose to participate in the exhibit.
5. All discussions will be digitally recorded, and transferred to a secure password, and protected computer to be store within 48 hours of each meeting. The digital audio files deleted from the recorder after transferred. Identifying information removed when transcribed. Recordings will be stored indefinitely in a secure server through the College of Nursing at the Medical University of South Carolina.

**C. DURATION:**

Participation in the study will take about 5 days for 1 - 2 hours per session over a period of two months. The group will meet each week for four weeks. Then a follow-up meeting will take place four weeks after the fourth and final session.

**D. RISKS/DISCOMFORTS:**

There are no known physical, psychological, social, financial, or legal risks associated with this study.

When creating, reflecting, and presenting the "Journals of Life" and discussing challenges encountered as an HIV-positive female may cause uncomfortable thoughts or feelings. If you experience feelings that make you

uncomfortable or depressed, please let Ms. Kennedy know. There are counselors available from AID Upstate willing and able assist you. Because you will meet with others in a group, there is the potential for a breach in confidentiality by others in the group. Ms. Kennedy will stress confidentiality among the group, though.

**E. BENEFITS:**

There may be no direct benefit to you from this study. However, indirectly you will share with other females with HIV experiences and possibly your method for overcoming challenges and receive the same. Information gained from this study may lead to larger studies designed to support females with HIV in South Carolina.

**F. COSTS:**

There will be no direct costs for you to participate in this study.

**G. PAYMENT TO PARTICIPANTS:**

In return for your time and effort, you will be paid \$50.00 for participation in this study. Each week at the end of group discussions, you will receive a \$10.00 gas card. If you do not complete the study, you will receive \$10.00 gas cards for each week of participation. In addition to gas cards, at the completion of the study and presentations of "Journals of Life", you will receive the digital camera valued at \$70.00.

Payments that you receive from MUSC for participating in a research study are considered taxable income per IRS regulations. Payment types may include, but are not limited to: checks, cash, gift certificates/cards, personal property, and other items of value. If the total amount of payment you receive from MUSC reaches or exceeds \$600.00 in a calendar year, you will be issued a Form 1099.

**H. ALTERNATIVES:**

You can choose not to participate in this study but have access to information from Aid Upstate on life with HIV.

**I. PATIENT WITHDRAWAL**

Results of this research will be used for the purposes described in this study. This information may be published, but you will not be identified. Information that is obtained concerning this research that can be identified with you will



remain confidential to the extent possible within State and Federal law. The investigators associated with this study, the sponsor, and the MUSC Institutional Review Board for Human Research will have access to identifying information. All records in South Carolina are subject to subpoena by a court of law.

In the event that you are injured as a result of participation in this study, you should immediately go to the emergency room of the Medical University Hospital, or in case of an emergency go to the nearest hospital, and tell the physician on call that you are in a research study. They will call your study doctor who will make arrangements for your treatment. If the study sponsor does not pay for your treatment, the Medical University Hospital and the physicians who render treatment to you will bill your insurance company. If your insurance company denies coverage or insurance is not available, you will be responsible for payment for all services rendered to you.

Your participation in this study is voluntary. You may refuse to take part in or stop taking part in this study at any time. You should call the investigator in charge of this study if you decide to do this. Your decision not to take part in the study will not affect your current or future medical care or any benefits to which you are entitled.

The investigators and/or the sponsor may stop your participation in this study at any time if they decide it is in your best interest. They may also do this if you do not follow the investigator's instructions.

#### Volunteers Statement

I have been given a chance to ask questions about this research study. These questions have been answered to my satisfaction. If I have any more questions about my participation in this study or study related injury, I may contact Toshua W. Kennedy at (864) 877-0823. I may contact the Medical University of SC Hospital Medical Director (843) 792-9537 concerning medical treatment.

If I have any questions, problems, or concerns, desire further information or wish to offer input, I may contact the Medical University of SC Institutional Review Board for Human Research IRB Manager or the Office of Research Integrity Director at (843)792-4148. This includes any questions about my rights as a research subject in this study.

I agree to participate in this study. I have been given a copy of this form for my own records.

If you wish to participate, you should sign below.

\_\_\_\_\_

Signature of Person Obtaining Consent

\_\_\_\_\_

Date

\_\_\_\_\_

Signature of Participant

\_\_\_\_\_

Date

**“Picturing Life”**

**Participatory Research Study to explore  
life for females living with HIV**

**Take pictures to share the  
challenges and supports that you  
have encountered living with HIV**

**These pictures will show others  
what life is like for you**

**If interested, plan to  
meet for an additional  
information session  
at Aid Upstate on the  
date indicated or call  
Toshua Kennedy:  
864-415-0661**

**Researcher: Toshua Kennedy,  
MUSG PhD Nursing Student**

## Appendix C: Permission Form to Release Pictures

### Using Photo Journals to Explore Challenges and Supports for Females Living with HIV: Permission Form to Release Pictures (Pictures of others)

**Directions:** The investigator recommends avoiding faces in journal photographs. However, each person has the flexibility to be creative with their pictures. This form allows you to gain permission from others that you would like to photograph.

The remainder of the form will be completed by the person you are choosing to photograph.

I \_\_\_\_\_ [the person in the picture] understand that this picture is part of the Picturing Life Study. Once taken my picture become part of the project and may be used in:

- Nursing education materials
- Project publications
- Project presentations
- Other project data summaries and reports

My real name will not be used in any of these materials.

I have read and understand this agreement. I am over the age of 18. This agreement expresses the complete understanding of the parties.

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Signature: \_\_\_\_\_

**Appendix D: Off Campus Study Site Form**



Office of Research Integrity

19 Hagood Ave, Suite 601

(843) 792-4148

Fax (843) 792-7457

**Off Campus Study Site Form**

PRO/HR # 32809

**STUDY TITLE: Using Photo Journals to Explore Challenges and Supports for Females Living with HIV**

**PRINCIPAL INVESTIGATOR: Toshua W. Kennedy MSN, MPH, PHCNS-BC**

**ADDRESS OF OFF-SITE FACILITY: AID Upstate 13 Calhoun Street Greenville, SC 29602-0105**

*\*\*complete a new form for each off site facility*

**NAME OF NON-MUSC INVESTIGATOR/ INSTITUTIONAL OFFICIAL: Quinn Hamilton, Client Services Director.**

**SECTION I.**

**A. Is the off-campus site “engaged” in human subject’s research pertaining to this study?**

No, the off-campus site is not engaged in human research pertaining to this study.

- Aid Upstate will provide space for the study.
- Counselors from Aid Upstate will be on stand-by if depression or the need to speak with one arises from reflecting on challenges encountered.
- Aid Upstate educators will assist with recruiting participants from the WiLLOW program. This will entail introducing the PI to the group and allowing the PI to distribute fliers to the group.

**1. Check either A or B below: (Completion of A or B is required)**

(A) Activities at the off-campus site are consistent with examples under Category A; the site is engaged in human subjects research

If you checked this section, please identify the specific type of activity or activities to be done at this off site campus by providing the number of the example from the OHRP website. For example: A1, A2, A3, etc.

(B) Activities at the off-campus site are consistent with examples under category B; the site is not engaged in human subjects' research

If you checked this section, please identify the specific type of activity or activities to be done at this off site campus by providing the number of the example from the OHRP website. For example: B1, B2, B3, etc.

B4 and B5

**2. Does the off-campus site have a Federal Wide Assurance (FWA)?**

Yes      If yes, what is their FWA:

No

**3. Does the off-campus site have an Institutional Review Board for Human Research?**

Yes       No

*If Yes, the individual or site must contact that IRB and provide MUSC with documentation on whether IRB approval is required.*

Please provide the name, address and phone number of the IRB:

If Yes, has the off-campus site's IRB approved this study?

Yes       No

If the off-campus site's IRB has not approved this study, will review by that IRB be required?

Yes       No

If no, please explain.

**SECTION II. (Complete this section if you selected Section I.A(1)(A)).**

**A. List all community individuals that will be engaged in the study.**  
N/A

<b>Individual's Name</b> <i>Use full legal name</i>	<b>Individual's Credentials and/or Position</b> <i>(e.g., M.D., Executive Director., recruitment specialist)</i>	<b>Individual's Role on the study</b> <i>(e.g. ,consent, deliver interventions, data analysis)</i>

*To expand table, move to the end of the last row and press the tab key.*

**\*\*Any community individual "engaged" in research will need to complete the CITI MIAMI training course and be listed on the eIRB personnel list.**

**\*\* If any community individual member of a facility is considered "engaged" in research, the site is then considered "engaged in research under section I(A)(1) of this form.**

**B. For each individual listed above who will be involved in the informed consent process, please complete the information below.**

Name:  Current Position/Role at the Facility:  Human Subjects Education/Training:
---

You may copy and paste this box as many times as needed. Box expands.



---

\*\*\*For those individuals and/or sites that do not have their own IRB, MUSC may consider taking on the role of IRB of Record. Please review the guidance provided by SCTR (pg2) on how to apply for a Federal Wide Assurance (FWA) / Institutional Authorization Agreement (IAA). Contact your MUSC IRB administrator if you have questions.

\*\*MUSC may assume IRB responsibilities for non-affiliated institutions and investigators only under certain conditions (i.e., such as when an approved IRB Authorization Agreement exists designating the MUSC IRB to serve as the IRB of Record and the facility applies for and receives and FWA from OHRP).

\*\*If the MUSC IRB takes on the role of IRB of Record, individuals must complete an IRB approved education program (CITI MIAMI) for the protection of human research participants prior to conducting this, or any other, research involving human participants.

## Appendix E: One-on-one Interview Prompts

One-on-one Interviews: PI conducts semi-structured interview with each participant.

1. How would you describe this experience?
2. What pictures did you exclude from your "Journals of Life"
3. Did you learn anything about yourself?
4. Did you learn about resources available to you from others?
5. Interested in participating in follow-up study?

## Appendix F: HIPAA Disclosure Form

Medical University of South Carolina (MUSC)  
Health Insurance Portability and Accountability Act (HIPAA)

Authorization to Use or Disclose

### Protected Health Information (PHI) for Research Purposes

Using Photo Journals to Explore Challenges and Supports for Females Living with HIV

Toshua W. Kennedy MSN, MPH, PHCNS-BC

HIPAA is a federal law that requires the protection of information that can identify you. Protected Health Information includes information that pertains to your past, present or future physical and mental health conditions, or the provision of health care. You are being asked to sign this Authorization because you are in the research study listed above.

The researchers agree to protect your protected health information by using and disclosing it only as permitted by you in the Authorization and as directed by state and federal law.

#### A. What is the purpose of the use and/or disclosure of your protected health information?

Your protected health information will need to be used and/or disclosed to carry out this research study and to review and report study information. The primary purpose of this study is to use photography to identify challenges and supports encountered by females living with HIV.

#### B. What protected health information will be used or disclosed?

You may be asked for health-related information relevant to the study. Your medical or health records may be reviewed and researchers may need to discuss your health information with your treating physicians. Researchers will also generate new information about you as a result of the research procedures, tests, questionnaires, and visits. The information that will be used or disclosed to others includes names, dates, geographical information, medical notes and physical exam, results from laboratory, radiology, and pathology reports, and questionnaires. You understand that this information may include reference to drug abuse, alcoholism or alcohol, testing for or infection with Human Immunodeficiency virus (HIV), or sickle cell anemia.

### **C. Who will disclose your protected health information?**

The researchers and staff of the Medical University of South Carolina who are involved in this research study will disclose your medical/health information for this study.

### **D. Who will receive your protected health information?**

Your protected health information may be used or shared with others outside of MUSC for purposes directly related to the conduct of the research. Once this information leaves MUSC, we cannot guarantee that it will be protected by this authorization.

Your protected health information may be shared with the following:

- **Sponsor of the research study, or its agents such as data repositories or contract research organization;**
- **Other medical centers / institutions/ investigators outside of MUSC participating in the research study;**
- **Federal and state agencies and MUSC committees that have authority over the research, such as:**
  - **The Institutional Review Board (IRB) that oversees human research at the MUSC**
  - **Committees with oversight or quality improvement responsibilities**
  - **Office of Human Research Protections (OHRP)**

### **E. Do you have to sign this authorization?**

You do not have to sign this authorization. If you choose not to sign the authorization, it will not affect your treatment, payment or enrollment in any health plan or affect your eligibility for benefits. You will not be allowed to participate in the research study.

### **F. If you sign the Authorization, can you change your mind?**

You have the right to withdraw your authorization to allow MUSC to use or share your protected health information collected for this research study. Protected health information that has already been used or disclosed cannot be withdrawn. Your protected health information may still be used and disclosed if you have an adverse event. Once authorization is withdrawn and you are no longer participating in the study, no more protected health information will be collected. If you want to withdraw your permission, you must do so in writing to the investigator. The investigator's address is:

Toshua W. Kennedy MSN, MPH, PHCNS-BC  
99 Jonathan Lucas Street MUSC 160  
Medical University of South Carolina  
Charleston, SC 29425

If you withdraw your authorization, you will not be allowed to participate in the research study.

**G. Can you review the information described on this form?**

You will not be allowed to see or copy the information described on this form as long as the research is in progress. When the study is over, you will have the right to see and copy the information described on this authorization form.

**H. Authorization:**

You authorize Toshua W. Kennedy and her staff, your doctors and other health care providers to use and disclose your protected health information for the purposes described above.

**I. Privacy Notice:**

You have been given a copy of the Privacy Notice that describes the practices of MUSC regarding your protected health information. Please initial here: \_\_\_\_\_

If you have any questions or concerns about your privacy rights, you should contact MUSC's Privacy Officer at (843) 792-8744.

**You will be given a signed copy of this form.**

There is no expiration date for this authorization.

**Signature of Research Subject ages 16 & above<sup>1</sup>    Date**

\_\_\_\_\_  
Research Subject's Personal Representative<sup>2</sup>                      Date  
(if applicable)

**Printed Name of Research Subject**

**or Research Subject's Personal Representative (if applicable)**

**Representative's Relationship to Research Subject**

<sup>1</sup> If research subjects are ages 16 up to 18 years of age, signatures of both the research subject and the personal representative are required.

<sup>2</sup> Personal Representative: A person authorized under state or other law to act on behalf of the individual in making health-related decisions. Examples: Court-appointed guardian with medical authority, a health care agent under a health care proxy, and a parent acting on behalf of an unemancipated minor.

**Appendix G: Demographical Collection Instrument**

Please answer the following:

1. What is your age? \_\_\_\_\_
  
2. Are you married? (Check one)  
Yes \_\_\_\_\_ No \_\_\_\_\_ Separated \_\_\_\_\_
  
3. Do you have any children (Check one)  
No \_\_\_\_\_ Yes \_\_\_\_\_ If yes, how many? \_\_\_\_\_
  
4. What is your race? (Check one)  
White \_\_\_\_\_ African American/Black \_\_\_\_\_ Latina \_\_\_\_\_ Native America \_\_\_\_\_ Other \_\_\_\_\_
  
5. What is your ethnicity? (Check one)  
Hispanic Origin \_\_\_\_\_ No Hispanic Origin \_\_\_\_\_
  
6. What is your education level? (Check one)  
Some high school \_\_\_\_\_ High school graduate \_\_\_\_\_ Some college \_\_\_\_\_ College graduate \_\_\_\_\_ Other \_\_\_\_\_
  
7. How many years have you known about your HIV status? \_\_\_\_\_
  
8. Who knows that you are living with HIV? (Check one)  
Spouse/partner \_\_\_\_\_ Children \_\_\_\_\_ Parents \_\_\_\_\_ Siblings \_\_\_\_\_ Others \_\_\_\_\_
  
9. What is your household income? (Check one)  
Less than \$10,000 \_\_\_\_\_  
\$10,000-\$19,999 \_\_\_\_\_  
\$20,000-\$29,999 \_\_\_\_\_  
\$30,000-\$39,999 \_\_\_\_\_  
\$40,000-\$49,999 \_\_\_\_\_  
\$50,000-\$59,999 \_\_\_\_\_  
\$60,000-\$69,999 \_\_\_\_\_  
\$70,000-\$79,999 \_\_\_\_\_  
\$80,000--\$99,999 \_\_\_\_\_  
\$100,000-149,999 \_\_\_\_\_  
More than 150,000 \_\_\_\_\_

## Appendix H: Letter of Support

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July 18, 2014

Dear Members of the Institutional Review Board:

On behalf of the staff at AID Upstate, Inc., I am writing to formally indicate our awareness of the research proposed by Toshua W. Kennedy, a PhD student at Medical University of South Carolina. We are aware that Kennedy intends to conduct her research by working with females living with HIV from the WILLOW project at our facility.

I am responsible for client services at AID Upstate. I and my staff give Toshua W. Kennedy expressed permission to conduct her research in our facility. Kennedy, like all staff, volunteers and associates working with our agency with access to our clients and their protected health information will be held to strict HIPAA Privacy and confidentiality standards of practice.

If you have any questions or concerns, please feel free to contact my office at 864-250-0607.

Sincerely,

A handwritten signature in black ink, appearing to read "Quinn Hamilton".

Quinn Hamilton  
Client Services Director,  
AID Upstate

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864-250-0607 Local

800-755-2010 Upstate

864-250-0609 Fax

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Post Office Box 105

Greenville, SC 29602

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811 Pendleton Street

10 Medical Center

Greenville, SC 29601

[www.aidupstate.org](http://www.aidupstate.org)

*AID Upstate empowers people living with HIV and encourages active community response through advocacy, direct services, education and prevention.*

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