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Qualitative Analysis of the Impact of Participating in an  
HIV-Focused Theatrical Performance Therapy Group

by

Sonja M. Ray

THESIS

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SCIENCE

in

Nursing

in the

GRADUATE DIVISION

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by

Sonja M. Ray

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Qualitative Analysis of the Impact of Participating in an HIV-Focused Theatrical  
Performance Therapy Group

Sonja M. Ray

Abstract

**Background**

In the United States, women living with HIV/AIDS (WLWHA) face high rates of morbidity and mortality despite the existence of effective antiretroviral therapy. A San Francisco-based arts organization, Cultural Odyssey, in collaboration with the Women's HIV Program at UCSF, adapted a performance-based empowerment group intervention to include WLWHA. Participants translated personal experiences related to HIV into vignettes that were performed during a theatrical run of eight shows entitled *Dancing with the Clown of Love (DCL)*, which was seen by approximately 1,000 people. The purpose of this study is to describe the impact of the group intervention on WLWHA and compare these findings to the Disclosure Process Model (DPM), a relatively new framework for understanding the process and impact of HIV-disclosure.

**Methods**

In-depth interviews with HIV-positive participants (n=8) were conducted between May and December 2011. A multidisciplinary team transcribed and analyzed data using thematic analysis. All transcripts were double coded.

**Findings**

Participants were primarily African American (62.5%), with the mean age of 48 (range 23-65), and all had earned a high school diploma. All HIV-positive participants disclosed their HIV-status during the performance. Core themes about the impact of the

intervention emerged from the data, including: forming relationships, decreasing isolation, normalizing HIV, providing a sense of purpose, and personal transformation. The concept of personal transformation was further analyzed and major sub-themes included: gaining a voice, exploring self-identity, catharsis, gaining a sense of accomplishment, and developing self-esteem. The DPM provides a conceptual framework for understanding the impact of this theatrical performance group on WLWHA and several themes were predicted by the model. Additionally, descriptions of disclosure from this study add depth and complexity to the model.

### **Conclusions**

WLWHA are often marginalized and isolated because of continuing HIV-stigma. Women who participated in DCL and publicly disclosed their status reported achieving many aspects of personal empowerment, such as decreased isolation. By participating in a performance group, women found their voice and learned to value their experiences. The findings of this study show that interventions utilizing components from the DPM can have a significant positive impact on the lives of WLWHA.

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## **Chapter One: The Study Problem**

Cultural Odyssey is a community-based organization that recently adapted their longstanding method for empowering incarcerated and formerly incarcerated women through theater to include and focus on HIV-positive women. As a part of this program, weekly group meetings took place between December 2008 and March 2010 in which HIV-positive and HIV-negative participants were prompted to write about and share their experiences with HIV. For many HIV-positive women, this entailed confronting and processing personal memories of stigma, abuse, and trauma as well as identifying and sharing sources of pride and accomplishment. For HIV-negative women, many identified and dismantled stereotypes and misinformation regarding HIV transmission, treatment, and disease course. The content of these group meetings was translated into vignettes that could be acted out on stage. In March 2010, the participants (n=15; 8 HIV-positive, 7 HIV-negative) performed these vignettes in a professional theatrical run of eight shows entitled *Dancing with the Clown of Love (DCL)*, which was seen by approximately 1,000 people. Anecdotally, participants described the group meetings and performances as “transformational” and expressed a desire to expand the program.

### **Purpose**

This study is a collaboration between the University of California, San Francisco (UCSF) Women’s HIV Program, Cultural Odyssey, and UCSF School of Nursing. The purpose of this descriptive qualitative study is to assess the impact of the HIV-focused theatrical performance group on HIV-positive women. Furthermore, this study will ascertain whether the Disclosure Process Model (DPM), a theory describing the impact and process of disclosure, is an effective framework for describing the impact of disclosure in this setting.

The author's role was to conceptualize and execute data analysis and write the report of the study findings.

### **Significance**

This study will examine experiences of primarily African American HIV-positive women, a group that carries a disproportionate burden of HIV/AIDS and AIDS-related mortality and morbidity in the US. In the past three decades, the number of women living with HIV/AIDS (WLWHA) has increased dramatically: the proportion of those diagnosed with HIV/AIDS that are women, 27%, has tripled since the start of the epidemic ("Epidemiology of HIV/AIDS -- United States, 1981 - 2005," 2006; Hall et al., 2008). In 2005, 82% of all new cases in women were among Black or Hispanic women (Center for Disease Control and Prevention [CDC], 2007). Of the women living with HIV in the US, 64% are African American and 15% are Hispanic (CDC, 2007). The high prevalence and growing incidence of HIV/AIDS among women of color highlights the need for research to understand the experiences of WLWHA and interventions to improve their quality of life.

Not only are women a rapidly growing segment of the HIV-positive population; their outcomes are often poorer than their male counterparts. Although effective therapy has become widely available, rates of HIV-related morbidity and mortality among minority women are startlingly high (CDC, 2007; Hessol et al., 2007; D. K. Smith et al., 2003). Part of the reason for these poor outcomes among women could be related to violence, trauma, adverse socioeconomic conditions, and poorly managed and often unidentified co-morbid mental health conditions. For example HIV-positive women who are exposed to trauma have poorer health outcomes (Boarts, Buckley-Fischer, Armelie, Bogart, & Delahanty, 2009; Leserman et al., 2007; E. H. Machtinger, J., 2010; McDonnell, Gielen, O'Campo, & Burke,

2005; Mugavero et al., 2007; Mugavero et al., 2009), including antiretroviral failure and transmission risk behaviors (E. L. Machtinger, Haberer, Wilson, & Weiss, 2012).

Furthermore depression and anxiety, when coupled with drug use, high-risk sexual behaviors, and unmet social needs can also interfere with the use of available HIV prevention and treatment services, leading to poor health outcomes (Hader, Smith, Moore, & Holmberg, 2001). Thus, trauma, violence, depression, and anxiety negatively impact health outcomes and, unfortunately, WLWHA are at increased risk for exposure to these conditions. Among HIV-positive women, rates of trauma and Post Traumatic Stress Disorder (PTSD) are disproportionately high (E. L. Machtinger, Wilson, Haberer, & Weiss, 2012). Similarly, among HIV-positive minority women, rates of depression and anxiety are also alarmingly high (Catz, Gore-Felton, & McClure, 2002). Overall, studies show that many WLWHA experience a number of stressful and traumatic events, some of which include violence; these events contribute to the disproportionately high rates of negative health outcomes seen among HIV-positive women, despite access to effective care.

Given the scope of HIV infection among minority women, and the barriers that prevent them from experiencing optimal health outcomes, the significance of this study is that it describes, in the words of the participants, the impact of a unique community-based intervention designed to improve the lives of HIV-positive women through storytelling. Disclosure is an important component of this intervention because at the heart of the storytelling in this performance group was the action of disclosing personal information, including HIV-status. HIV-disclosure has been linked to improved psychological functioning (i.e. decreased depressive symptomatology, anxiety, and stress) (Armistead, Morse, Forehand, Morse, & Clark, 1999; Fekete et al., 2009; Hays et al., 1993; Vyavaharkar et al.,

2011; Zea, Reisen, Poppen, Bianchi, & Echeverry, 2005), increased use of HIV services (Emlet, 2006; Wohl et al., 2011), and higher rates of adherence to antiretroviral medications (Stirratt et al., 2006; Waddell & Messeri, 2006). Thus, by elucidating the effect of an HIV-focused theatrical performance group designed to encourage HIV-positive women to explore and share their life experiences and then publicly disclose these experiences, the results of this study will provide a unique perspective on the existing knowledge of the process of HIV-disclosure and its possible effects on known predictors of HIV-related health outcomes as well as well-being. The findings from this study will inform care of HIV-positive women by showing how health care professionals may become more responsive to the psychosocial needs of HIV-positive women. Furthermore, this study will be one of the first to use the DPM as a conceptual framework for understanding disclosure events among HIV-positive women. Despite the significant consequences of disclosure, both positive and negative, the DPM is one of the only models that attempts to predict whether outcomes of HIV-disclosure will be helpful or harmful to individuals living with HIV/AIDS (Chaudoir & Fisher, 2010). Theoretically this model can help providers and counselors to determine whether it is appropriate to reinforce or dissuade individuals from further disclosure and provide tools for individuals to facilitate disclosure events with more positive outcomes. The results of this study, then, will provide valuable information related to the use of this new model for understanding the process and impact of disclosure in the lives of WLWHA.

### **Definitions**

Significant terms used in this thesis are defined below

**DCL.** While DCL refers to the final public performance acted out by participants in March 2010; this paper will also refer to DCL to describe the entire process of the



intervention, including the group meetings leading up to the performance. Other terms used to define the intervention include: HIV-focused Medea Project, HIV-focused theatrical performance group, and the HIV Circle.

**Empowerment.** Empowerment has been defined in a number of ways. Generally, to empower someone is to enhance the ability of that person to take control of his/her own life (Rappaport, 1981). For the purposes of this study, empowerment is understood as “building self-efficacy, decreasing self-blame, assuming personal responsibility, increasing assertiveness, and developing communication and negotiation skills to ensure power sharing and equality within a relationship” (Crepaz et al., 2009, p. 2070).

**HIV-disclosure.** HIV-disclosure is typically defined as informing another person of someone’s HIV status by the HIV-positive person or a third-party, with or without consent (World Health Organization [WHO], 1999). However, for the purposes of this study where the disclosure events under investigation are all conducted by the HIV-positive individual herself, HIV-disclosure is defined more narrowly as the act by an HIV-positive person of informing another person of her HIV status. This concept is commonly referred to in the literature as disclosure or self-disclosure (Fekete et al., 2009; Hawk, 2007; Zea, Reisen, Poppen, Echeverry, & Bianchi, 2004); the rest of the paper will refer to disclosure and HIV-disclosure interchangeably, and self-disclosure will not be used.

**Self-efficacy.** Self efficacy is defined as an individual’s belief in his or her capacity to execute behaviors necessary to attain a particular goal or performance; it represents a person’s belief in his/her ability to succeed in a given task or in a given situation (Bandura, 1977). Moreover, self-efficacy reflects one’s confidence in the ability to exert control over personal motivations, behaviors, and social environments (Forsyth & Carey, 1998).

**Social support.** Social support is defined as “perceptions of, or experience with, other people providing emotional support, material or tangible support, and health-related support” (R. Smith, Rossetto, & Peterson, 2008, p. 1267).

**Stigma.** HIV/AIDS stigma is defined as “prejudice, discounting, discrediting and discrimination directed at people perceived to have AIDS or HIV, their loved ones and associates and the groups and communities with which they are affiliated” (Herek, 1990; Herek & Capitanio, 1998, p. 232; Herek & Glunt, 1988; R. Smith et al., 2008).

### **Organization**

Chapter II introduces evidence supporting the use of creative expressive interventions in the treatment of illness, reviews and critiques the literature on the impact of disclosure on the lives of people living with HIV/AIDS (PLWHA) and, presents the DPM as a theory to form the conceptual framework of this study. Chapter III describes the methodology used in the present study. Chapter IV presents the findings of the study. The discussion and conclusions of the study are presented in chapter V, along with the implications for health care providers, and directions for further study.

## Chapter Two: Literature Review

Two literature reviews were conducted to provide a background and context for the present study. The purpose of the first review was to identify the effect of similar, theatrical, or creative expression interventions. Since few similar interventions were reported in the literature, a second review was conducted in order to provide more robust and concrete evidence for the potential impact of HIV-disclosure, a central component of DCL, on HIV-positive women. Together, these two literature reviews provide strong evidence for the potential positive role of an HIV-focused theatrical performance group, like DCL, in the lives of WLWHA. The following discussion first highlights the findings from the review of theatrical and creative expression interventions, and then reviews the evidence for specific impacts of HIV-disclosure on HIV-positive individuals, followed by a critique of the evidence for an impact of HIV-disclosure on psychological functioning. The literature review ends with a discussion of the DPM as a framework for understanding the impact and process of HIV-disclosure.

### **Theater and Creative Expression as Therapy**

**Theater.** There have been few examples in the literature of theatrical performance interventions similar to DCL. Most HIV/AIDS focused theatrical performances are written and performed by HIV-negative individuals with the goal of preventing transmission or increasing HIV/AIDS knowledge (for examples, see Hovey, Booker, & Seligman, 2007; Howard, 1995; Lauby et al., 2010; "Playing AIDS: an experiment in popular theatre in Mali," 1994). Models to guide the development of theater programs for health promotion and HIV prevention have been proposed (for examples, see Santiago, 2000; Seguin & Rancourt, 1996); however, these models, like aforementioned studies, do not emphasize the central

importance of HIV-positive actors. Furthermore, the impact of the performance, as described by these models, is focused solely on the audience, not on the performer. No studies that described or evaluated programs with the goal of allowing HIV-positive women to tell their story through theater were found in the literature.

One study among a different patient population, however, does show the positive effects of theater on people living with a chronic disease. Horwitz, Kowalski, and Anderberg (2010) examined the effect of theater on patients with fibromyalgia and found that a theater program in which patients were trained in body and voice expression and then participated in a performance alongside professional actors resulted in increased self-rated health and decreased reported pain after three months of participation. While the literature on theater is substantially lacking, this finding suggests that theater could play a role in improving the lives of PLWHA and future studies are warranted.

**Creative expression.** While there is a significant gap in the literature on theatrical interventions for PLWHA, there are a few studies that explore the utility of related therapies, such as expressive therapy. Expressive therapy is a broad term that includes the use of writing, performance, art, and other forms of creative expression to reduce disease symptoms and improve quality of life. Expressive therapy has been shown to have a positive impact in the lives of people with a variety of conditions, including: PTSD (Green, 2011), survivors of torture (for a review of expressive arts therapy, including dance and theatre, in this population, see Gray, 2011), diabetes (Stuckey & Tisdell, 2010), breast cancer (Low, Stanton, Bower, & Gyllenhammer, 2010; Mattsson-Lidsle, Snickars-von Wright, Lindholm, & Fagerstrom, 2007), and ovarian cancer (Walker, Bischoff, & Robinson, 2010). Additionally, a recent review of poetry therapy found evidence supporting the use of poetry

in treatment of somatic illness (such as cancer) because it leads to improved coping and quality of life (Silke, 2011). The discussion below describes the effect of expressive group therapy and expressive writing specifically on the lives of PLWHA.

Two main studies have been conducted to examine the role of expressive group therapy in treatment of PLWHA. A series of studies over the course of nine years found that a group cognitive-behavioral stress management/expressive-supportive therapy program delivered to HIV-positive women increased social support, self efficacy, active coping, medication adherence, and relaxation while decreasing distress, risky sexual behaviors, and substance abuse (Weiss et al., 2011). The findings of this culmination of studies suggest that expressive supportive therapy can improve the lives of PLWHA through a number of paths, including improved psychological functioning, social support, and medication adherence. Similarly, Belanoff et al. (2005) conducted a randomized controlled trial (RCT), to examine a physiological impact of expressive group therapy. HIV-positive individuals who received a supportive-expressive group therapy intervention showed a statistically significant increase in CD4 count and decrease in HIV viral load, while the control group showed no significant change (Belanoff et al., 2005). Taken together, these studies suggest that expressive group therapy can impact the psychological and physiological well-being of PLWHA.

Two additional studies have examined the impact of poetry and expressive writing on PLWHA. To determine the physiological impact of expressive writing, Rivkin, Gustafson, Weingarten, and Chin (2006) conducted an RCT among PLWHA. They found that participants in the expressive writing group who included increased levels of causation and insight words in their writing had lower levels of beta2 microglobulin, which is related to slower progression of HIV and better immune control, at the two-month follow-up. While the

sample size was fairly small (n=79), the study suggests that expressive writing, where individuals use words of causation and insight, can result in improved immunological outcomes (Rivkin et al., 2006). To further our understanding of the impact of expressive writing on PLWHA, Abel (2007) conducted an RCT to examine the effect of an emotional writing disclosure intervention on perceived HIV-stigma. The authors found that HIV-positive individuals in the experimental group (the emotional writing disclosure group) reported greater cognitive reorganization and significantly improved perceived HIV-stigma from week one to week 12 (Abel, 2007). Thus, while the long-term effects have yet to be examined, emotional or expressive writing in HIV-positive individuals has been linked to short-term improvements in immune function, and perceived HIV-stigma.

*Summary of findings from creative expression therapy.* The diverse set of interventions described above and DCL share a similar underlying philosophy: that putting traumatic events into words through story can help people to organize and make sense of their experiences. Throughout these interventions, individuals are required to carefully examine a particular experience and then define, develop, and express a story from that experience. Taken together, the literature shows that expressive group therapy, expressive writing, theater, and other similar interventions, such as DCL, may positively impact the lives of PLWHA through a variety of pathways, including: improved immune function, CD4 count, active coping, self efficacy, and social support and decreased perception of stigma, viral load, distress, sexual risk behaviors, and substance abuse (Abel, 2007; Belanoff et al., 2005; Rivkin et al., 2006; Silke, 2011; Weiss et al., 2011).

## **Disclosure as Therapy**

Disclosure and nondisclosure are significant components of day-to-day life with HIV, but only a small segment of the literature attempts to describe the specific impacts of disclosure. A literature search was conducted to find relevant articles published in English between January 1, 1990 and January 31, 2012 using the PubMed database and the following keywords: HIV infection, HIV serostatus, HIV seropositive, disclosure, truth-disclosure, self-disclosure, women, female. The initial search yielded 644 results. Articles were included if they were conducted in the US and examined the effect of disclosure on HIV-positive individuals. Articles conducted outside the US or examining the process of disclosure without identifying an impact of disclosure in the lives of PLWHA were excluded. An additional 21 articles were not individually included because they were addressed in later systematic reviews, which were included. A total of 27 articles suggesting a broad range of impacts of HIV-disclosure were included. The following literature review first describes the findings of the impact of disclosure on the lives of PLWHA in four domains: physiological functioning, risk behaviors, perceptions of PLWHA, and violence. The literature review ends with a critique of the literature examining the association between disclosure and psychological functioning. The findings of this literature review will help frame the interpretation of HIV-positive participants' responses to the HIV-focused theatrical performance group.

**Disclosure and physiological functioning.** HIV-disclosure is often necessary to obtain appropriate social support (Sachperoglou, 2001; Schrimshaw & Siegel, 2003). Lack of social support, increased stress, and stigma can result in delays in seeking HIV care, and poor quality of life, antiretroviral adherence, and clinical outcomes (Burgoyne, 2005; Larios,

Davis, Gallo, Heinrich, & Talavera, 2009; McCoy et al., 2009; Persson, Ostergren, Hanson, Lindgren, & Naucler, 2002). Thus, it is not surprising that disclosure may be related to components of physiological functioning, either directly or indirectly through social support. The following discussion reviews the evidence for an association between HIV-disclosure and physiological functioning in three specific domains: use of HIV services, medication adherence, and immune function.

***HIV services.*** Three studies examined the link between disclosure and use of HIV services and all found a positive relationship. Mellins et al. (2002) conducted a longitudinal study of 128 HIV-infected ethnic minority mothers and found that, while disclosure was not associated with HIV treatment adherence, less disclosure to children was associated with missing medical appointments, indicating that disclosure to children can play a role in HIV care. On the other hand, using a case control study design among men and women living with HIV, Emler (2006) found disclosure to be significantly related to use of HIV services ( $n= 88$ ;  $r = 0.371$ ;  $p < 0.01$ ); however, the definition of HIV services use was not provided in the report. In a larger, cross-sectional study of HIV-positive African American and Latino men who have sex with men (MSM) and women from Los Angeles County ( $n=398$ ), Wohl et al. (2011) found that disclosure to more social network members was the major predictor of retention in HIV care (OR = 1.5; 95% CI: 1.1, 1.9), where retention was defined as two or more primary care visits in the past six months. Interestingly, among all subgroups, but particularly Latinas, retention in HIV care was associated with the number of people disclosed to, but not the actual perceived social support from those individuals, suggesting a direct link between disclosure and use of HIV services (Wohl et al., 2011). Overall, more longitudinal studies in diverse populations are needed to further explore the relationship



between disclosure and use of HIV services among women; nevertheless, current data suggests that disclosure may lead to increased use of HIV services, decreased missed appointments, and retention in HIV care.

***Medication adherence.*** Three studies explored the association between disclosure and medication adherence. R. Klitzman et al. (2004) conducted a qualitative study of 152 HIV-positive adults (52 MSM, 56 women, and 44 IDU men) from four US cities to reveal the interrelationship between highly active antiretroviral treatment (HAART) and disclosure. The authors found that HIV-disclosure led to increased social support, which facilitated initiation of, and adherence to, treatment (R. Klitzman et al., 2004). Similarly, through a longitudinal design, using a sample representative of New York, Waddell and Messeri (2006) reported that a positive association between social support and use of combination antiretroviral therapy is contingent upon HIV-disclosure. For example, for those who disclosed within the household, high social support was associated with a 200% increase in the odds of using combination therapy; on the other hand, for those who concealed their status from at least one household member, high social support was associated with a 48% decline in the odds of the use of combination therapy (Waddell & Messeri, 2006). Data for this study was collected at a time when combination antiretroviral therapy and HAART were not yet universally prescribed; further research to re-examine this relationship now that HAART is the mainstay of AIDS treatment is warranted. Both studies suggest a relationship between disclosure, social support, and medication adherence.

Stirratt et al. (2006) conducted a cross-sectional study, which demonstrated that practical support from others did not mediate the relationship between disclosure and medication adherence. The sample included 215 HIV-positive individuals who demonstrated

poor medication adherence (<80%) and who were in serodiscordant relationships. Overall 19% of participants reported concerns regarding HIV-disclosure as primary reasons for missing medication doses in the two months prior to the study and participants who reported greater disclosure demonstrated higher rates of adherence, regardless of perceived social support (Stirratt et al., 2006).

Future studies conducted primarily in low-income women and examining the temporal relationship between disclosure and medication adherence are needed, but the findings from the current studies suggest that disclosure, with or without social support, may lead to higher rates of medication adherence.

***Immune function.*** Three studies examined the role of disclosure in improved immune function among PLWHA.

O'Cleirigh, Ironson, Fletcher, and Schneiderman (2008) examined the contents of an essay describing a stressful life experience and natural killer cell counts in a relatively rare group of AIDS patients who, despite a CD4 cell count of < 50, remained asymptomatic of AIDS-related symptoms for more than nine months (the Healthy Survivors group, n=37). When compared to an HIV-positive group at an earlier stage of disease (n=100) with CD4 counts between 150 and 500/mm<sup>3</sup>, and no history of CD4 cell <75/mm<sup>3</sup>, or AIDS symptoms, the Healthy Survivors group wrote significantly more words, more positive and negative emotion words, and displayed significantly more realistic cognitive appraisal, positive self-esteem, adaptive problems solving and experiential involvement. Hierarchical linear regression models found that the emotional/cognitive processing variables mediated the relationship between emotional disclosure and group membership. Furthermore, natural killer (NK) cell number mediated the relationship between emotional/cognitive processing and

“healthy survival.” These findings add to that of others that suggest that emotional writing can improve HIV viral load and CD4 lymphocyte count in PLWHA (Petrie, Fontanilla, Thomas, Booth, & Pennebaker, 2004) and that disclosure among HIV-positive children to friends is linked to improved CD4 lymphocyte count (Sherman, Bonanno, Wiener, & Battles, 2000). While the exact link between disclosure and NK cells is unclear, the results of these studies combined suggest that disclosure may provide an immune benefit to PLWHA.

*Summary of physiological function.* Overall, while there is a need for future studies to strengthen our understanding of the link between disclosure and physiological functioning among minority PLWHA, current studies suggest the possibility of such a relationship. Fairly consistent data has been reported regarding the relationship between disclosure and increased use of HIV services (Emlet, 2006; Mellins et al., 2002; Wohl et al., 2011). One study to explore the link between immune function and disclosure suggests that disclosure processing could be linked to improved immune function and fewer AIDS symptoms, potentially through NK cells (O’Cleirigh et al., 2008); others in this field suggest that disclosure and emotional writing can be related to improved CD4 lymphocyte count (Petrie et al., 2004; Sherman et al., 2000). Future work examining a possible role for disclosure in immunological functioning may strengthen our understanding of the link between disclosure and physiology. By directly affecting the immune system, or by facilitating use of HIV services, disclosure seems to have a positive affect on the physical health and well-being of HIV-positive individuals.

Research findings related to the association between disclosure and medication adherence, on the contrary, suggest that this relationship is complex and nuanced. In a qualitative study, R. Klitzman et al. (2004) reported that HIV-disclosure has multiple

associations with medication adherence. On one hand, some patients reported missing doses of antiretroviral medication due to fear of being 'outed'. On the other hand, patients reported that antiretroviral medications helped them to delay disclosing their status by improving their physical symptoms. These findings are similar to other qualitative findings that patients miss doses of antiretroviral medications in order to avoid disclosure and stigmatization (Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000; M. A. Chesney, Morin, & Sherr, 2000; M. A. S. Chesney, A.W., 1999; Demas, Schoenbaum, Wills, Doll, & Klein, 1995; Gibb et al., 2003; Golin, Isasi, Bontempi, & Eng, 2002; Siegel, Schrimshaw, & Raveis, 2000). Furthermore, previous qualitative studies have shown that non-disclosure may socially isolate individuals which can undermine adherence behavior (M. A. S. Chesney, A.W., 1999) and that HIV-positive individuals are concerned about potential side effects of antiretrovirals, such as lipodystrophy, that could reveal their HIV status (Oette et al., 2002), a phenomenon which could lead to non-adherence (Duran et al., 2001). Overall, qualitative studies describe a complex interrelationship between disclosure and medication adherence.

Quantitative studies have also yielded mixed results regarding the relationship between disclosure and medication adherence: some finding an association between medication adherence and disclosure (Mellins, Brackis-Cott, Dolezal, & Abrams, 2004; Stirratt et al., 2006; Waddell & Messeri, 2006) others finding no relationship (Mellins et al., 2002). The inconsistent results among these studies suggest that other contextual factors, such as relationship status, social support, and target-specific disclosure, may affect the relationship between disclosure and medication adherence. Longitudinal studies in diverse populations should be conducted to specifically examine the temporal relationship between disclosure and medication adherence as well as contextual factors influencing this

relationship.

**Disclosure and sexual risk behaviors.** It is estimated that up to one third of HIV-positive individuals continue to have unprotected sex; presumably, on some of these occasions of unprotected sex, the HIV-positive individual had not disclosed his/her HIV-status to a potentially HIV-negative partner (S.C. Kalichman, 2000; Marks et al., 1994; Weinhardt et al., 2004; Wolitski, Rietmeijer, Goldbaum, & Wilson, 1998). The topic of disclosure to sexual partners is a particularly charged debate, as individual privacy seems to clash with public health. Many assume that serostatus disclosure leads to decreased risky sexual behaviors by facilitating the discussion of safe sex practices and motivating uninfected informed partners to use protection. Thus, a possible prevention strategy is to encourage PLWHA to disclose their status to all sexual partners. In fact, the CDC mandates that HIV test counselors discuss the topic of disclosure to sexual partners in posttest counseling ("Public Health Service guidelines for counseling and antibody testing to prevent HIV infection and AIDS," 1987). However, some researchers warn that disclosure may not always lead to decreased sexual risk behavior as individuals may not necessarily use the information to protect themselves, and some individuals may knowingly place themselves at risk for infection (Marks & Crepaz, 2001; Serovich & Mosack, 2003). The link between disclosure and sexual risk behavior, then, is a contested yet critical component of HIV prevention strategies. The following discussion briefly reviews the evidence for the relationship between disclosure and subsequent sexual safety.

J. M. Simoni and Pantalone (2004) conducted a literature review of all studies published through February 2004 to determine whether the link between disclosure and sexual safety is strong enough to warrant HIV-prevention policies that emphasize partner

disclosure. The authors found eight studies with only men in their samples, one study with only women, and six studies with men and women. In total, eight out of the 15 studies showed some relationship between disclosure and safe sex practices. However, as Simoni and Patalone conclude, many of these studies contained significant methodological weaknesses and those that were sound found significant associations only in a subgroup of participants. For example, in two studies among men, disclosure was associated with safer sexual practices but only among partners whose serostatus was known to be negative, not among HIV-positive partners or partners with unknown serostatus (De Rosa & Marks, 1998; R. Klitzman et al., 2007; Marks, Richardson, & Maldonado, 1991). In the one study that examined the relationship between disclosure and sexual safety in women alone, the authors concluded that disclosure was associated with more frequent condom use (Sturdevant et al., 2001). However, the authors of this study did not conduct partner-level analysis, condom use was collected for only up to three partners per participant, and the timing of disclosure in relation to the sexual behavior was not considered. Thus, Simoni and Pantalone argue that, while disclosure may be relevant to the practice of safe sex, there is not sufficient evidence to warrant public health interventions that simplify the association between disclosure and safe sex to a direct cause and effect relationship.

The findings by J. M. Simoni and Pantalone (2004) are consistent with findings from a review published one-year later examining disclosure in the context of HIV-positive men (Sullivan, 2005). Further research including partner-level analysis and assessment of timing between disclosure and sexual risk behavior should be conducted to refine our understanding of the complex interaction between sexual practices and disclosure. Furthermore, factors such as HIV serostatus of the partner, sex and sexual orientation, definitions of unprotected

sex and disclosure, and social desirability of disclosure should be included in future research (J. M. Simoni & Pantalone, 2004).

Studies published after the 2004 review continue to provide mixed results. In one of the few studies to consider women, and heterosexual relationships, Benotsch et al. (2011) found that individuals who had misled a partner reported higher HIV transmission risk behaviors. Contrarily, Parsons, Missildine, Van Ora, Purcell, and Gomez (2004), found the inverse result. In a population of HIV-positive injection drug users (IDUs) from New York City and San Francisco, data showed marginal significance indicating that those who reported always disclosing to sexual partners were more likely to engage in unprotected vaginal sex. The authors noted that 62.2% of consistent disclosers (those who always disclosed), compared to 20% of non-disclosers, had HIV-positive casual sex partners in the past three months and suggested that the HIV-status of the partner may mediate the association between disclosure and sexual risk behaviors.

Poppen, Reisen, Zea, Bianchi, and Echeverry (2005) conducted a cross-sectional study of HIV-positive Latino MSM to explore the effect of the HIV-status of the partner on the relationship between disclosure and sexual risk behaviors. The authors found that HIV-disclosure, HIV-positive serostatus of partner, and the relationship type of primary partner or main relationship were all interrelated and predictive of unprotected anal intercourse. Further analysis showed that seroconcordance is a primary determinant of risky sexual behaviors, specifically unprotected anal sex. Thus, it appears that, in some cases, the HIV-status of the partner may in fact mediate the relationship between HIV-disclosure and sexual risk behaviors.

While partner serostatus may be one mediating factor affecting the relationship between disclosure and sexual behaviors, the consistency of disclosure and relationship type (i.e. casual or primary) may be additional factors affecting the impact of HIV-disclosure on risk behaviors. Parsons et al. (2005) conducted a cross-sectional study of HIV-positive gay and bisexual men to examine the relationship between disclosure and sexual behaviors specifically in casual sexual partners. Disclosure was then categorized into one of three groups: disclosing to all (consistent disclosers), disclosing to some but not all (inconsistent disclosers), and disclosing to none (non-disclosers). Bivariate analysis showed that consistent disclosers were less likely to report sexual risk behaviors than either inconsistent disclosers or non-disclosers. Interestingly, the level of disclosure was not linearly related to the frequency of sexual risk behaviors: inconsistent disclosers were most likely to engage in sexual risk behaviors with HIV-negative or status unknown casual partners. The authors posit that inconsistent disclosers may be prone to more unsafe sexual behaviors because they lack a particular strategy or approach to sexual behavior. The findings of these studies show that a complex set of variables, including partner serostatus, relationship type, and disclosure, interact to effect sexual risk behaviors

Overall, the data supporting a link between HIV-disclosure and safer sexual behavior is inconsistent, suggesting that the relationship between disclosure and sexual risk behaviors may be indirect and mediated by a number of contextual factors. Research among women regarding this topic is severely lacking. Benotsch et al. (2011) conducted one of the few studies in the heterosexual population and including female subjects. No studies conducted after 2004 were strictly among WLWHA, and the one study that included only women conducted before 2004 had significant flaws in its study design (J. M. Simoni & Pantalone,



2004). Furthermore, many of the studies include rigid, dichotomous measures of disclosure, which may not reflect reality (i.e. disclosure is often measured as yes or no instead of how frequently disclosure occurred). Disclosure measures should also account for time of disclosure in reference to the sexual behavior and clear definitions of risky sexual behavior. Additionally, future studies investigating possible confounding variables and mediators such as HIV knowledge, relationship type, seroconcordance, and drug use should be considered.

**Public disclosure and perceptions of PLWHA.** Some research suggests that disclosure itself can improve public perception of PLWHA. In 1991 Earvin “Magic” Johnson, a heterosexual African American basketball player in the NBA, announced publicly that he had tested positive for HIV. This announcement provided a new image of HIV to the public and a flurry of research followed to determine the impact of Johnson’s disclosure on the attitudes and beliefs of the American public. Casey et al. (2003) conducted a meta-analysis to synthesize the findings related to the impact of Johnson’s disclosure on HIV-related knowledge, attitudes, beliefs, and behaviors. Six studies that explored the impact of Johnson’s public disclosure on a participant’s attitude towards PLWHA were included in the analysis. The authors found the average effect across the six studies to be positive (*average*  $r = 0.092$ ,  $K = 6$ ,  $N = 2767$ , *var*  $r = 0.002$ ), suggesting that the public disclosure improved people’s attitudes toward PLWHA. A chi-squared test resulted in a non-significant chi-square, indicating that the level of variability observed across the six studies is consistent with what would be expected due to random chance. Given the potential effect of time between the announcement and measurement, this variable was assessed. The effect for time was found to be negative ( $r = -0.422$ ), indicating that the original improved view of PLWHA decayed over time.

The authors warn that the sample size and number of studies is small, which limits the findings. However, the combined findings highlight public health implications of public disclosure. Furthermore, these findings are consistent with studies showing that contact with PLWHA results in significantly more tolerant attitudes (Takai et al., 1998). Magic Johnson's celebrity status may have played a large role in the impact of his public disclosure on public attitudes towards PLWHA; however, the findings suggest that the effect of repeated public disclosure among non-celebrities on attitudes and perceptions of PLWHA should be explored (Casey et al., 2003).

**Disclosure and violence.** Holt et al. (1998) conducted a qualitative study to examine the role of disclosure in the lives of PLWHA and reported that disclosure can be a double-edged sword: the potential positive impacts of disclosure are weighted against potential negative consequences of revealing HIV status. HIV can lead to stigmatizing reactions such as social ostracism, physical harm, and workplace discrimination. Some negative reactions to disclosure include: refusal of dental services (McCarthy, Haji, & Mackie, 1995), disrupted relationships with families and communities (Grinstead, Gregorich, Choi, & Coates, 2001; Lee & Rotheram-Borus, 2002; Yoshioka & Schustack, 2001), loss of employment (J. M. Simoni, Mason, & Marks, 1997), and violence (Gielen, Fogarty, et al., 2000; Gielen, McDonnell, Burke, & O'Campo, 2000; Gielen, O'Campo, Faden, & Eke, 1997; Zierler et al., 2000). Given that violence is the most extreme negative reaction to the HIV-disclosure, the discussion below summarizes the findings related to the association between disclosure and violence.

While there have been no longitudinal studies reporting the association between disclosure and violence, one qualitative, one mixed methods, and two cross-sectional studies

have confirmed that violence is a possible response to disclosure. Gielen et al. (1997) conducted a qualitative study using key participant interviews among predominantly low-income African American WLWHA and found that six women (12%) cited fear of violence (physical, verbal, and emotional) as a reason for not disclosing and eleven women (22%) reported experiencing rejection, abandonment, or shame at some point after disclosing their status. Two women (4%) reported experiencing violence as a direct result of disclosure. Similarly, Gielen, Fogarty, et al. (2000) conducted a cross-sectional study of predominantly low-income African American WLWHA (n=257) to find that participants reported several negative consequences of disclosure including: loss of friends (24%), being insulted or sworn at (23%), being rejected by family (21%), being physically or sexually assaulted (4%). Further validating the prevalence of violence after disclosure among WLWHA, Gielen, McDonnell, et al. (2000) found that 29% (89) of participants were afraid of disclosure-related violence and that 4% reported physical abuse following a disclosure event. However, 13% of participants reported emotional, physical, or sexual abuse that occurred only after they learned they were HIV-positive and 32% reported experiencing emotional, physical, or sexual abuse at some time after their diagnosis. In the only study to include an ethnically heterogeneous sample of men and women, Zierler et al. (2000) found that 20.5% of HIV-positive women (n=811) experienced violence and nearly half cited their HIV status as the cause of the physical abuse. Thus, overall the results of these studies show that some women experience violence as a result of HIV-disclosure and many cite fear of violence as a reason not to disclose.

It is still unclear whether HIV-disclosure is a significant risk factor for physical, sexual, or emotional abuse, and the prevalence of violence related to HIV-disclosure does

appear to be as low as 4% (Gielen, Fogarty, et al., 2000; Gielen, McDonnell, et al., 2000; Gielen et al., 1997). However, a study of health care providers suggests a higher prevalence of violence related to HIV-disclosure: 24% of providers reported to have clients who experienced physical violence following disclosure of HIV infection to an intimate partner, 38% reported clients who experienced emotional abuse, and 37% reported clients who were abandoned (Rothenberg, Paskey, Reuland, Zimmerman, & North, 1995). In a separate study, HIV diagnosis during current pregnancy was found to be a predictor of violence during pregnancy and six months postpartum (Koenig et al., 2006). Women at high risk for HIV have been found to be at a higher risk for violence than the general population (Vlahov et al., 1998), which makes it difficult to determine if the rates of violence observed in PLWHA are due to disclosure or other HIV risk factors. Regardless, fear of violence is a serious concern that is associated with declining HIV testing (Maher et al., 2000) and non-disclosure (J. M. Simoni et al., 1995). Overall, longitudinal studies in diverse populations should be conducted to determine the relationship between HIV-disclosure and violence and the possible interaction with HIV risk factors.

**Disclosure and psychological functioning.** Studies suggest there may be a relationship between disclosure and improved psychological functioning, specifically through reduced depression, anxiety, and stress (Armistead et al., 1999; Fekete et al., 2009; Hays et al., 1993; Perry et al., 1994; Vyavaharkar et al., 2011; Zea et al., 2005). Understanding the association between HIV-disclosure and mental health is important because depression among PLWHA is associated with poor quality of life and faster progression of the disease (Ammassari et al., 2004; Eller, 2001; Valente, 2003). Furthermore, HIV-disclosure, social support, and mental health have been reported to be associated with

reduced sexual risk behavior (Kelly et al., 1993; Kimberly & Serovich, 1999; Ostrow, Beltran, & Joseph, 1994), medication adherence (Holzemer et al., 1999; Singh et al., 1996), and immune function (Ullrich, Lutgendorf, & Stapleton, 2003). Previous research in the field of disclosure supports the notion that disclosure leads to improved psychological functioning. For example, studies suggest that people who disclose experiences of stress tend to feel better emotionally than those who do not disclose (Greenberg & Stone, 1992). Furthermore, suppressing thoughts or communication about traumatic or difficult life experiences can increase the likelihood of mental health problems related to increased stress (Pennebaker & Beall, 1986; Pennebaker, Colder, & Sharp, 1990). However, given the prevalence of HIV-stigma, possible negative reactions from disclosure could complicate the relationship between disclosure and mental health. In fact, some studies suggest that, high levels of disclosure are related to greater perceived stigma and psychological distress (Clark, Lindner, Armistead, & Austin, 2003). The following discussion reviews several key studies conducted among various populations in the U.S. that have explored the role of disclosure in the mental health of PLWHA.

***Disclosure, depression, and anxiety.*** One of the first studies to suggest an impact of HIV-disclosure was conducted by Hays et al. (1993). Using a longitudinal study design of 163 HIV-positive gay men in San Francisco, the authors found that men who perceived their significant others as responding to HIV-disclosure more helpfully were less depressed and anxious at the time of the interview and one year later. The internal validity of the study findings were limited by the instrument used to measure the degree of perceived helpfulness, which was a five-point Likert scale, with no reported validity or reliability. However, anxiety and depression were measured using the Brief Symptom Inventory (BSI), a well-validated

instrument (Hays et al., 1993). The generalizability of the study findings is limited by the fairly homogenous sample (white, well-educated, middle-class, gay, male). Regardless, these findings suggest that, at least in Caucasian, homosexual, males, disclosure, with a successful or positive response, could be associated with positive mental health outcomes, specifically through lower depression and reduced anxiety (Hays et al., 1993).

Armistead et al. (1999) further examined the relationship between disclosure and depressive symptoms by exploring this relationship in African American women from New Orleans through a longitudinal, mixed methods study design. Using the depression subscale of the brief symptom inventory (BSI) and Hamilton Clinician's Rating Scale of Depression (HRSD), Armistead et al. (1999) found that disclosure of HIV status to partners predicted lower depressive symptomatology. Importantly, disclosure to other social networks, such as children, parents, friends, or extended family, was not associated with BSI or HRSD scores. These results suggest that disclosure is not always associated with reduced depressive symptoms. One key weakness of the study is that disclosure was measured dichotomously by target, and the number of targets was not investigated. For example, researchers asked participants if they had disclosed to their friends, not how many friends they disclosed to. The extent of disclosure to specific target groups (friends, family, coworkers) could affect the relationship between disclosure and depression. The internal validity of this study is strengthened, though, by the use of two scales to measure depression: a self-report measure (BSI) and a clinician observed measure (HRSD). Furthermore, the study provides key insight in a specific previously underrepresented population: African American women (Armistead et al., 1999).

Given the conflicting and limited evidence on the relationship between disclosure and mental health, Comer, Henker, Kemeny, and Wyatt (2000) compared two contrasting models among African American, European American, and Latina WLWHA. One model states that HIV-disclosure predicts enhanced mental health. The second model suggests that, due to HIV-stigma, disclosure actually predicts poorer mental health. A total of 176 women were interviewed in this cross-sectional study. To assess disclosure, participants were asked to list up to 20 of the most important people in their lives, their relationship to each person on the list, and if they had disclosed their HIV status to each person on the list. The Center for Epidemiological Studies Depression (CES-D) scale was used to measure depression and the Symptom Checklist-90 (SCL-90) was used to assess symptoms of anxiety. Among African American (n=72) and European American (n=47) women, disclosure was unrelated to symptoms of depression or anxiety. However, greater disclosure was related to poorer mental health among Latina women (n=57). While these differences could be attributed to cultural differences between Latinas, African Americans, and European Americans, the authors note that the Latinas in this study were significantly younger, less educated, and had a lower monthly income than the African American and European American participants. They also had smaller social networks and had disclosed to fewer people. The study was not designed to elucidate cultural factors that could contribute to differences in the impact of disclosure on mental health. Future research in this area could reveal culturally specific mediating factors affecting the relationship between disclosure and mental health (Comer et al., 2000)

***Social support in men.*** Given the conflicting findings related to the association between disclosure and depression, Zea et al. (2005) conducted a cross-sectional study of Latino gay men to determine the role of social support in mediating this relationship.

Depression was measured using the Beck Depression Inventory (BDI), social support was assessed through the 9-item version of the Quality of Social Support Scale (internal reliability of 0.89), and self-esteem was assessed with the Single-Item Self-Esteem Scale (SISE). Results showed that disclosure was related to greater quality of social support with all individual targets (mother, father, closest friend, main partner). In terms of depression, they found disclosure to mothers and male main partners was associated with lower depressive symptoms. Disclosure to fathers, close friends, family, or friends was not associated with depression scores. Zea et al. (2005) also found that disclosure to partners was related to increased self-esteem, suggesting another avenue of mental health possibly related to disclosure. Further analysis revealed that increased perceived social support mediated the interaction between disclosure and both mental health measures: depression and self-esteem. While the results of this study should not be generalized to women, they do add to the research defining a role for disclosure in symptoms of depression through social support (Zea et al., 2005).

*Social support in men and women.* S. C. Kalichman, DiMarco, Austin, Luke, and DiFonzo (2003) conducted a cross sectional study of 233 HIV-positive men and 98 HIV-positive women to test a model of disclosure practices, perceived support, and emotional distress in both genders. The sample was predominantly African American (72%); just over half had completed 12 years of education or less, and 64% had annual incomes under \$10,000. To measure disclosure, participants were asked to list their relationships (i.e. mother, father, sister, friend A, etc) and then asked whether or not they had disclosed their status to each individual on the list. Participants were then asked to rank how supportive each individual was on a three-point scale. The BDI was used to measure depression. Overall, the



authors found that increased disclosure (disclosure to more people) was associated with higher perceived social support. When examining target specific data, the authors found that increased disclosure to immediate family members was related to increased perceived social support from family members. However, increased disclosure to extended family or friends was not related to increased perceived social support from these individuals. Decreased general perceived social support was related to increased depressive symptoms. Like previous studies, the temporal sequence between these factors cannot be established through the cross-sectional design; however, the study provides preliminary evidence for a link between perceived support, disclosure, and depression. Social support, through disclosure, may act as a buffer for the negative emotional consequences of living with HIV (S. C. Kalichman et al., 2003).

***Social support in women.*** J.M. Simoni, Demas, Mason, Drossman, and Davis (2000) explored the role of social support in mediating the impact of disclosure on physiological functioning among minority women. The sample was an ethnically diverse group of women from New York City (n=230). Forty-six percent of the sample population was black, not Hispanic, and 16% were Hispanic; 92% of participants reported a personal monthly income of \$1,000 or less. Disclosure was measured by asking participants if they had disclosed their status to anyone and, if yes, to indicate whether or not they had disclosed to each of the targets listed (husband or steady male or female partner, mother, father, brother, sister, other relative, friend, other nonrelatives). Mental health was measured by the CES-D and the Profile of Mood States (POMS-TMD). Social support was measured via a modified UCLA Social Support Inventory. Coping, the final variable was measured by the adapted Ways of Coping Scale.

Bivariate analysis showed that social support was strongly correlated with health through reduced depressive symptoms (CES-D) and mood disturbance (POMS-TMD); however, disclosure was not directly related to these psychological measures (J.M. Simoni et al., 2000). Disclosure was associated with the total social support received and the use of adaptive coping strategies, such as spiritual resilience and community involvement. Multiple regression analysis indicated that the relationship between adaptive coping and psychological distress was mediated by satisfaction with social support. The authors proposed that disclosure increases adaptive coping, which in turn reduces depressive symptoms and mood disturbance through an interaction mediated by social support. However, as the authors note, the temporal sequence of these variables cannot be determined given the cross-sectional nature of this study. Regardless of the explanatory model, this study suggest that, in a diverse sample of HIV-positive women, disclosure is associated with adaptive coping and social support, which in turn effects mental health (J.M. Simoni et al., 2000).

Also exploring the role of social support in the interaction between depression and disclosure among women, Fekete et al. (2009) conducted a cross sectional study to examine: 1) whether or not HIV-specific social support modifies the association between HIV-disclosure to specific family members and physiological and psychological functioning (measured via 24-h urinary cortisol and depressive symptoms respectively); 2) how perceptions of general stress can account for the effects of the interaction between disclosure and social support on depressive symptoms and cortisol levels. Based on past research, the authors hypothesized that perceptions of family support would enhance positive effects of disclosure on psychological health. The sample included 82 low-income ethnic minority HIV-positive women. Participants reported the percentage of family members they had

directly disclosed their HIV status to using the HIV-disclosure Scale (HDS), perceptions of HIV-related support from family members using the UCLA Social Support Inventory (UCLA-SS), perceived stress using the 14-item Perceived Stress Scale (PSS-14), and depressive symptoms using the BDI. Cortisol was measured through a 24 hour urinary collection and deemed to be an important component of physiological health because high levels of cortisol is linked to environmental stress (Lundberg, 2005) and may contribute to immunosuppressive effects (Clerici et al., 1997; Norbiato, Bevilacqua, & Vago, 1997) and long-term negative health outcomes in PLWHA (Leserman, 2003).

Consistent with their hypothesis, direct disclosure to mothers, if coupled with high HIV-related support was associated with lower cortisol, fewer depressive symptoms and lower perceived stress (Fekete et al., 2009). Disclosure to spouses and children, on the other hand, when coupled with high levels of family support, was associated with higher levels of perceived stress and depressive symptoms. Disclosure to fathers, brothers, and sisters was not associated with perceived stress and well-being. While the results suggest that disclosure is not always associated with lower depressive symptoms or perceived stress, it does show that a woman's social environment and who she discloses to can modify the impact that serostatus disclosure has on her well being; it also adds to the literature by linking biochemical measures of stress to disclosure (Fekete et al., 2009).

Given the effect of the type of confidant on the relationship between disclosure and mental health, studies examining disclosure to specific targets are warranted. Delaney, Serovich, and Lim (2009) conducted a cross sectional study to explore the psychological differences between HIV-positive women who disclosed their serostatus to all, some, or none, of their biological children. The sample included 90 HIV-positive women (71% were

African American). Results showed no differences with regard to their emotional well-being, as measured via the CES-D, Costello-Comrey Anxiety Scale (CCAS), and Stress-Arousal Checklist (SAC-L). Univariate analyses showed that the degree of perceived family social support was associated with depression scores and the degree of perceived friend social support was associated with all three psychological scores (depression, anxiety, and stress). For example, women were more likely to report depressive symptoms if they had less perceived family support. While the study sample is relatively small and does not differentiate between differences among African Americans, Caucasians, and Latinas (the three main racial groups that make up the study sample), it does add to our understanding of the relationship between disclosure and mental health, specifically stress, anxiety, and depression. The results of this study further support the notion that disclosure does not directly impact psychological functioning; rather, social support can mediate the effect of disclosure on mood and psychological functioning (Delaney et al., 2009).

All prior studies had been conducted in urban settings; Vyavaharkar et al. (2011) conducted a cross-sectional study among 340 African American WLWHA in rural areas of South Carolina, North Carolina, and Alabama to determine the effect of social support on the interaction between disclosure and mental health in this unique population. The following hypotheses were tested: 1) HIV-disclosure mediates the relationship between social support and depression, 2) social support mediates the relationship between HIV-disclosure and depression, and 3) social support and HIV-disclosure have an interactive effect on depression. A 3-point Likert-type response format with a reported reliability of 0.75 was used to measure HIV-disclosure. Three dimensions of social support were measured via two scales: the Medical Outcomes Study Social Support Survey and the Social Support

Questionnaire. The three dimensions of social support examined were perceived availability of social support, sources of available support, and quality of available support. The CES-D scale was used to measure depression.

Higher social support, perceived and actual, and greater satisfaction with the support available were found to be significantly associated with fewer depressive symptoms (Vyavaharkar et al., 2011). Disclosure to children was also significantly associated with fewer depressive symptoms and higher social support. Disclosure to other persons was moderately correlated to increased support, but not to depression. The authors concluded that perceived availability of support and satisfaction with support mediated the relationship between HIV-disclosure and depression. The study relied on secondary data, which imposed inherent weaknesses in the study design. Furthermore, like previous studies in this field, the cross-sectional design limits the establishment of causality and the ability to detect true mediation between variable. However, the findings suggest the importance of social support and disclosure in the mental health of rural African American WLWH (Vyavaharkar et al., 2011).

*Summary of disclosure and psychological functioning.* Overall, results of studies that examine the relationship between HIV-disclosure and psychological functioning are not consistent. There is some evidence to suggest an association between disclosure and lower levels of depression in African American women (Armistead et al., 1999), gay men (Hays et al., 1993; Perry et al., 1994), and Latino gay and bisexual men (Zea et al., 2005). However, there are other studies that suggest no relationship or an inverse relationship between disclosure and mental health. For example, one study found no relationship between disclosure and depression among African American and Caucasian women; however,

disclosure was related to increased depression among Latinas (Comer et al., 2000). J.M. Simoni et al. (2000) found no correlation between disclosure and depression among African American and Hispanic WLWH; Delaney et al. (2009) found no difference in psychological functioning among mothers who disclosed to some, all, or none of their children; S. C. Kalichman et al. (2003) found that disclosure to certain targets was associated with reduced depressive symptomology but not to all targets. Taken together, the research suggests a complex relationship between disclosure and mental health, dependent upon mediating factors such as social support.

Studies examining the role of social support in mediating the relationship between disclosure and mental health are grounded in the idea that disclosure can increase opportunities for social support, and thereby decrease symptoms of depression and anxiety. In the literature, high levels of depression have been predicted by lower perceived social support (Kelly et al., 1993) and low levels of depression have been associated with high-perceived social support (Delaney et al., 2009; Hays, Turner, & Coates, 1992; Vyavaharkar et al., 2011), thus showing a link between social support and mental health. Furthermore, the link between disclosure and social support has been born out in the literature. Non-disclosure has been found to be significantly associated with lower social support (Perry et al., 1994); disclosure, on the other hand, has been found to be associated with higher perceived social support (S. C. Kalichman et al., 2003; J.M. Simoni et al., 2000; Zea et al., 2005).

Only a few studies have explored the potential effect of social support on the relationship between disclosure and mental health, but the results suggest that, in general, the effect of disclosure on depression, anxiety, and stress, may be mediated by perceived social

support (Fekete et al., 2009; S. C. Kalichman et al., 2003; Vyavaharkar et al., 2011; Zea et al., 2005). Further research is needed to establish a temporal relationship between disclosure, social support, and psychological functioning, examine the effect of source-specific support, and determine the effect of time since serostatus disclosure on psychological health outcomes. Furthermore, research would benefit from a standardized measure of disclosure and longitudinal study designs accounting for a variety of possible mediators (i.e. adaptive coping, perceived stress, stigma). Nevertheless, HIV-disclosure has been shown to be beneficial within the context of an environment high in social support.

### **Conceptual Framework: The Disclosure Process Model**

Historically, most models of disclosure describe the process leading to disclosure; they do not predict outcomes of disclosure. The disease progression theory, for example states that HIV-positive individuals are more likely to disclose their HIV status as their disease progresses (Serovich, 2001). The consequences theory of disclosure, on the other hand, argues that people are more likely to disclose their status when they see the benefits of disclosure (i.e. more intimate relationship, help coping with disease) as outweighing the costs of disclosure (i.e. rejection, discrimination) (Serovich, Lim, & Mason, 2008). Both of these models treat HIV-disclosure as an outcome and fail to account for the events following disclosure. Other models of disclosure recognize the effects of social identities, role relationships, and social context on disclosure; while they shed light on why an HIV-positive person discloses his/her status in a given situation, they do little to predict the outcomes of that disclosure event and how these outcomes affect further disclosure events (Bairan et al., 2007; Bird & Voisin, 2011; Mayfield Arnold, Rice, Flannery, & Rotheram-Borus, 2008). Given the wide variety of responses to and consequences of HIV-disclosure, from improved

coping (J.M. Simoni et al., 2000) and psychological function (Armistead et al., 1999; Fekete et al., 2009; Hays et al., 1993; Vyavaharkar et al., 2011; Zea et al., 2005) to disrupted relationships (Grinstead et al., 2001; Lee & Rotheram-Borus, 2002; Yoshioka & Schustack, 2001) and violence (Gielen, Fogarty, et al., 2000; Gielen, McDonnell, et al., 2000; Gielen et al., 1997; Zierler et al., 2000), a model of HIV-disclosure that describes factors affecting consequences of disclosure and, through a combination of those factors, predicts outcomes of specific disclosure events could have tremendous usefulness in the clinical setting when counseling patients about HIV-disclosure.

Chaudoir and Fisher (2010) present the DPM as a model to describe when and why interpersonal disclosure among people who live with concealable stigmatized identities, including but not limited to an HIV/AIDS diagnosis, may be beneficial. To develop this model, the authors reviewed current evidence examining disclosure decision-making and outcome processes among people living with a concealable stigmatized identity, including: abortion, childhood sexual abuse, epilepsy, HIV/AIDS, mental illness, sexual assault, and sexual orientation. While these stigmatized identities differ significantly, the authors focused on the similarities in the processes that underlie disclosure decisions and outcomes. The main difference between the DPM and other HIV/AIDS disclosure models is that it explores disclosure as a single process that involves decision-making *and* outcomes. By connecting these two processes, the DPM is able to predict when and why disclosure leads to positive, or negative, consequences (Chaudoir & Fisher, 2010).

There are five main components of the DPM: antecedent goals, the disclosure event, mediating processes, outcomes, and a feedback loop. There are two types of antecedent goals: approach goals (motivations for disclosing) and avoidance goals (motivations for not



disclosing). These two goals underlie disclosure decisions and shape each successive stage of the disclosure process. The disclosure event itself is characterized by content (length, duration, breadth, and emotional content) and reaction (supportive vs. unsupportive). There are three types of mediating processes: alleviation of inhibition, social support, and changes in social information. The process of alleviating inhibition refers to the well-described process of relieving negative psychological and physiological effects of suppression that occurs with disclosure. However, the DPM suggests that alleviation of inhibition is not the sole process accounting the variety of effects of interpersonal disclosure. Instead, social support and changes in social information are additional mediating processes that account for the more social and interpersonal effects of disclosure. Long-term outcomes include individual (related to psychological distress, medication adherence, health), dyadic (related to the confidant, and the relationship between the confidant and discloser), and/or social contextual (highlighting the larger, societal impact of disclosure). The final component, feedback, provides a model for describing how an individual disclosure event effects future motivations, disclosure events, mediating processes, and consequences (Chaudoir & Fisher, 2010).

The relationship between the five components of the DPM is described as mediated-moderation. Approach and avoidance goals directly impact the disclosure event itself as greater avoidance goals are related to a lower likelihood of disclosure and strong approach goals are related to a more balanced disclosure event in terms of depth, duration, breadth, and emotional content. However, they also interact to moderate, or determine the magnitude, of the effect of disclosure on outcomes. The DPM posits that the balance of approach and avoidance goals can predict when a disclosure event would be beneficial (i.e. when approach

goals outweigh avoidance goals). This effect is further mediated through the three processes of alleviation of inhibition, social support, and changes in social information. All mediating processes can affect the outcome of disclosure independently of approach and avoidance goals. The relationships between antecedent goals and the disclosure event, antecedent goals and long-term outcomes, mediating processes and long-term outcomes, and feedback form a description of why and when a disclosure event is beneficial (Chaudoir & Fisher, 2010).

Chaudoir, Fisher, and Simoni (2011) systematically reviewed the existing HIV/AIDS disclosure literature published through November 2009 and examined 210 studies that supported or failed to support predictions of the DPM. While antecedent goals have not been specifically examined in the literature, studies show that PLWHA are more likely to disclose when they have strong goals for disclosure and/or when their confidant is important to the discloser or an HIV-positive sexual partner. The authors suggest that these factors indicate higher order approach goals. For example, the decision to disclose to an important person may be facilitated by the desire to maintain intimate relationships—an approach goal. Furthermore, PLWHA with strong goals against disclosure or perceiving high levels of stigma are less likely to disclose. These factors are posited to reflect avoidance goals. Very little research was found related to the disclosure event itself. However, the available research supported the model's prediction that positive reactions from the confidant is related to improved long-term outcomes. In terms of long-term outcomes, the authors found research to support the claim that disclosure can lead to a variety of individual (psychological functioning, ARV adherence), dyadic (sexual behaviors), and social outcomes (HIV awareness), and that social support mediates these outcomes, particularly on the individual level. However, no research on alleviating inhibition or changing social information was

reported. The authors posit that the inconsistent findings related to the association between disclosure and medication adherence or between disclosure and sexual behavior reflect lack of research on mediating factors. No research was found to examine the effect of the feedback loop on future disclosure. Overall, the authors argue that the DPM provides a useful framework to interpret HIV/AIDS disclosure findings and points to areas of future research, specifically in the field of the activating approach vs. avoidance goals, the HIV-disclosure event itself and mediating processes (Chaudoir et al., 2011).

The DPM provides a relatively parsimonious description of the disclosure process and has been shown to be a useful framework for evaluating HIV-disclosure research. The main limitation of this model is that it does not take into account the effect of stigma on antecedent goals, the disclosure event, mediating processes, or long-term outcomes. Someone living in an environment where HIV-stigma is high may face extreme barriers to HIV-disclosure and may not benefit from disclosure regardless of individual approach goals. Furthermore, while the DPM was developed through a review of disclosure literature, it is a new model that has not been rigorously tested. Nevertheless, the strength of this model is its ability to link the disclosure process to outcomes and predict when and why a disclosure event will be beneficial. The unique ability for this model to link outcomes to disclosure decision processes makes it an excellent conceptual framework for the current study to explore the process and impact of disclosure through an HIV/AIDS focused theatrical performance group.

### Chapter Three: Methodology

Semi-structured interviews with HIV-positive women who participated in an HIV/AIDS focused performance group were conducted between May and December 2011. The following discussion first provides a background of the theatrical performance group, then outlines how HIV-positive women were recruited to join in order to develop an HIV/AIDS-focused production, and finally describes the design and methods of the present study. The research questions guiding data collection and analysis were: 1) how do HIV-positive women describe the impact of the performance group as it relates to disclosure; 2) does the DPM provide an appropriate framework for understanding the descriptions of the impact of the performance group on HIV-positive women; 3) can the information gained through the interviews with HIV-positive women help further develop the DPM?

#### **Background of the Medea Project**

Cultural Odyssey is an artistic organization based in San Francisco that uses theater as a form of social activism by educating communities and empowering performers. In 1989, Rhodessa Jones founded *The Medea Project: Theater for Incarcerated Women (Medea)*, a series of performances produced by Cultural Odyssey originally featuring stories developed and performed by incarcerated women. The project has evolved and now includes previously incarcerated women and HIV-positive women. The Medea Project was not explicitly derived from a single theoretical framework or treatment modality, such as creative expressive therapy. Instead the structure and format of Medea arose organically from the participants' interest in performance and Jones's ability to facilitate the development and expression of each participant's stories and choreograph them into performances that could be acted out by the participants themselves (R. Jones, personal communication, March 11, 2012). In other

words, the Medea Project was founded in the knowledge of community members and driven by the community; the current research is meant to validate their accomplishments in a scientific way by qualitatively describing the outcomes of their work.

While Medea has expanded to a number of settings, the general process is fairly constant and includes five components: *formation of community*, *writing*, *movement*, *personal transformation*, and *performance*. *Formation of community* occurs by gathering a group of women who have chosen to become part of the project and hosting a series of intensive group meetings where participants develop intimate relationships with one another in an open, honest, and safe environment. The community involves participants naïve to the intervention as well as experienced former cast members, referred to as “core” members. Jones and another co-leader often lead the group meetings. At the beginning of each group meeting, there is always a time reserved for “check-in” where participants share recent life events. The openness of the community, regularity of group meetings, and recognition of current meaningful experiences by “checking-in” facilitates the other four components of Medea. A key component of this process is the openness of Jones. Jones participates in check-in and shares her experiences with the group, modeling the behavior expected of group participants.

*Writing* occurs outside group meetings, in response to a prompt given by Jones. Participants share their writing responses in the group meetings, following check-in. The group provides feedback on the story itself as well as the structure of the story. Then, some of the writing is translated into *movement*. For example, Jones asks the author if there is a shape that she can form with her body to represent a mood portrayed in the story that was just

read. The group works collaboratively to choreograph the performance as writing is married to movement.

During group meetings, and while preparing stories for the meetings, participants process deeply personal experiences, resulting in *personal transformation*. Women learn how to talk about and process meaningful and often traumatic, experiences. They learn to define and embrace their own story and become empowered to express and value their opinions and experiences.

The process culminates with a public *performance*. The performance gives purpose to the group meetings, as women are increasingly motivated to write, share, and practice the movements in order to accomplish their goals of performing on stage and sharing their experiences with others. After the performance, participants are invited to continue to stay involved in future performances with new group members.

The process of this community-driven intervention mirrors several therapeutic approaches. For example, participants learn from the experiences of others living with HIV, a process known as vicarious learning. Participants also experience relief from knowing that their situation and experiences are similar to others, a process referred to as universality. Furthermore, the process also involves instillation of hope, where participants gain a sense of hope in the future after seeing others improve, and interpersonal learning, where participants explore the implications of emotional events. Thus, several components of this innovative process are loosely connected to formally established therapeutic approaches.

### **HIV-Focused Medea Project**

Beginning in March 2007, Jones partnered with Dr. Edward Machtinger, director of the Women's HIV Program at UCSF, to shift the focus of Medea to include HIV-positive women in a performance about HIV/AIDS; in March 2008, Jones and Machtinger received a grant to develop and implement this program. As described below, Dr. Machtinger recruited patients to participate in Medea and was later involved in the study design and data analysis of the present work.

**Recruitment of HIV-positive participants.** Recruitment of HIV-positive women to the HIV-focused Medea project consisted of two phases. In the initial phase, flyers were posted throughout the Women's HIV Program clinic at UCSF and the Ward 86 HIV clinic at San Francisco General Hospital. Dr. Machtinger also personally encouraged his clients to participate. This initial recruitment phase produced approximately 40 potential participants and the first group meeting was held in June 2008. Three months later, after several Medea group meetings, only one HIV-positive participant remained from this initial recruitment. The specific factors influencing the high drop-out rate observed in this initial recruitment phase were not evaluated; however, a second recruitment phase yielded participants with a steady commitment to the project.

The second recruitment phase utilized fliers similar to those used in the first phase, but emphasized physician recruitment. This produced eight HIV-positive participants. The first participant to be recruited in the second round attended her first group meeting in December 2008; the last participant recruited in the second round attended her first meeting in January 2010. Most participants joined the group in 2009. The final performance group

consisted of eight HIV-positive women: one from the original round of recruitment and seven from the second round of recruitment.

**Recruitment HIV-negative participants.** Jones personally recruited seven HIV-negative participants to the HIV-focused Medea project. These participants had prior experience in the performing arts, either through previous productions of Medea (n=5) or through other theatrical performances (n=2).

**Developing a performance focused on HIV/AIDS.** The frequency of group meetings escalated as the March 2010 run of the main performance, DCL, drew nearer. In the initial stages, throughout 2009, the HIV-positive and negative participants met weekly on Thursday evenings for approximately three hours. Towards the end of 2009 and early 2010, the group met twice weekly on Thursday evenings and Saturday mornings for approximately three hours each. In the three to four weeks leading up to the main DCL performance, the group met almost everyday. The group meetings followed the same format as previous Medea group meetings (see above). However, some of the writing prompts were tailored to HIV-positive women. For example, an HIV-specific writing assignment was: “How did you find out you had HIV?” For many HIV-positive women, completing the writing assignments entailed confronting and processing personal memories of stigma, abuse, and trauma as well as identifying and sharing sources of pride and accomplishment.

The level of exposure to Medea cannot be measured and varies greatly among participants. Women were involved in the group for varying lengths of time, with the first woman enrolling in June 2008 and the last in January 2010. Furthermore, the degree of participation in and commitment to the project varied among the women and attendance records are not available for all meetings. However, while each participant may have spent a



significantly different amount of time in Medea group meetings, in order to perform, every participant needed to attend a sufficient number of sessions to master the performance. One HIV-positive woman, for example, was asked to stop participating in Medea because she routinely attended workshops while intoxicated and was unable to complete the performance.

Between 2009 and 2010, the group presented small practice shows at a variety of venues, including a fundraiser for the Women's HIV Program at UCSF. The group meetings culminated in a larger professional theatrical run of eight shows (DCL), which were seen by approximately 1,000 people from March 4 to March 14, 2010. Medea is an ongoing project: of the eight HIV-positive women who participated in DCL, about half remain actively involved in Medea.

### **Research Study**

The present study is collaboration between Cultural Odyssey, the Women's HIV Program at UCSF, and UCSF School of Nursing. It was designed and executed after the main performance, DCL, and seeks to understand how HIV-positive participants describe the impact of this theatrical performance group through the lens of disclosure. The study was reviewed and approved by the Internal Review Board at University of California San Francisco.

**Target population.** The study population for the present investigation consists of all eight HIV-positive women who performed in DCL.

**Design.** Participants were recruited to participate in a singular, in-depth, face-to-face interview to explore the impact of the workshop on their attitudes, behaviors, and well being as well as to describe the workshop from the participant's perspective. An interview design was determined to be appropriate for this descriptive, qualitative study for a number of

reasons. First, an open-ended interview allows participants to report more information than is possible in a written survey or closed-ended questions (Cummings, & Hulley, 2007).

Secondly, an in-depth interview helps participants to fully describe their experiences (Polit, & Beck, 2008). Since the goal of the research study was to understand the meaning of the participant's experience in DCL, an interview is an appropriate tool to address the proposed research questions. Thirdly, semi-structured interviews, while they may be more limiting than unstructured interviews, ensure that a specific set of topics is covered in the interviews. Researchers prepared an interview guide, but the main role of the interviewer was to encourage participants to talk freely about the topics in the guide. This ensured that the main research questions were addressed during the interview while also allowing participants the freedom to respond in their own words with as much detail as they wish.

**Interview guide.** To aid in data collection, an interview guide was developed by the researchers and Cultural Odyssey. The guide was semi-structured and open-ended in order to allow the interviewee to pursue her own ideas and to prevent unintentional limitations from being imposed by the interviewer. The interview guide was created with significant input from Rhodessa Jones, who was interviewed for this purpose by two of the study investigators. Many of the resulting questions were directly derived from suggestions and requests made by Jones. Reflecting the interests of Cultural Odyssey, the interview guide was composed of three main sections: general experience in the performance and workshops; impact of the experience on participants; and disclosure/stigma (Table 1). To examine the impact of the program, HIV-positive participants were asked if the program changed their interactions with people, their relationships, or the way they see healthcare. In the context of disclosure and stigma, HIV-positive participants were asked about how they felt to disclose

their HIV status publicly in the show and if anything bad happened to them as a result of the show and/or group meetings.

Table 1 <i>Sample Interview Questions</i>	
Section	Example Interview Questions: HIV-Positive Participants
General Experience in Medea	<ul style="list-style-type: none"> <li>• Tell me a little bit about your experience with the DCL project</li> <li>• Can you tell me a story of sometime with the project that is memorable?</li> <li>• Tell me more about the workshops.</li> </ul>
Impact of Medea	<ul style="list-style-type: none"> <li>• Did the program change your interactions with people?</li> <li>• Did the program change anything in your relationships?</li> <li>• Did it change the way you see healthcare?</li> </ul>
Disclosure/Stigma	<ul style="list-style-type: none"> <li>• How out were you before the show? Who knows that you're HIV-positive that didn't know before?</li> <li>• Has anything changed in your life because you're more out?</li> <li>• Has anything bad happened because you're more out?</li> <li>• Has being more out changed the way you see yourself?</li> <li>• Has coming out more changed how you feel about being HIV-positive?</li> </ul>

Questions about more sensitive topics, such as stigma, were posed toward the end of the interview, after a rapport was established. Each question was developed to be as clear and specific as possible, to use simple, common words, and to avoid stereotypes or “loaded” words. One researcher interviewed all of the participants. This interviewer had previously attended Medea group meetings and was known by the participants to be an intern working with Dr. Machtinger. This previous relationship facilitated discussion.

To further facilitate a rich discussion, the interview guide included statements to refocus the participant and probing questions designed to elicit more detailed information. Each participant was also asked to share any additional information about the project that was not covered in the interview and if there were any additional questions that should be

included in future interviews. In this way, researchers attempted to give participants ownership of the project.

**Procedure.** The Principal Investigator attended a workshop meeting that occurred after the DCL performance and distributed flyers describing the nature of the present study and indicating a number to call for interested participants. Additionally, the study coordinator contacted participants in the DCL performance individually via telephone, verbally described the study and invited participants to join. Upon agreeing, interviews were scheduled at the participant's earliest convenience. Interviews were held at Cultural Odyssey or the Women's HIV Clinic at UCSF, in a closed, private room. On the day before the interview, participants were given a reminder phone call. Upon arrival at the interview room, the study coordinator again explained the procedure and asked if she had any questions. The participant then signed the informed consent and completed a demographic form immediately prior to the interview. Participants were assigned identification numbers prior to the interviews in order to protect their privacy. All interviews were conducted by one researcher and completed between May and December of 2011. Each interview lasted between 90 and 120 minutes and was digitally audio recorded and then transcribed by an outside party. Upon completion of the interview, the participants were thanked for their time and given a \$65 grocery gift card as compensation for participation. Any names or personal identifiers stated during the interview were removed during transcription. Data analysis began in June, before all the interviews had been completed.

**Data analysis.** The transcribed interviews were imported into AtlasTI, a software program designed for qualitative research, and data processing and analysis were then conducted using thematic analysis. Thematic analysis is one of the most commonly utilized

methods of qualitative analysis. It is a flexible research tool that can be used in a variety of approaches to provide a rich account of the data (Braun & Clarke, 2006). The process of thematic analysis involves identifying and analyzing common threads, or themes, that occur throughout a set of interviews. Themes are abstract categories that describe segments of text. A theme may be explicit or implicit (Morse, 1995). For example, the phrase “I didn’t express my HIV status because back in the eighties it was a terrible illness and a lot of people was dying and I didn’t know I was going to die, if I was going to live or die” (Participant 1) could be coded as both “fear” (explicit) and “stigma” (implicit). In order to identify implicit, or latent themes, analysts must interpret the data beyond what is said by looking for what is implied and by seeing patterns across interviews that point to the latent theme.

The goal of thematic analysis is to illustrate the most important themes or concepts that reappear in qualitative data (Joffe, 2012). By definition, the most important themes in thematic analysis are not necessarily those that recur with the greatest frequency throughout the data set (Braun & Clarke, 2006; Buetow, 2010). A theme may appear frequently in some interviews and not at all in others; it is up to the researcher to judge what a theme is and how significant it is in the data. Thus, consensus among researchers regarding themes evident in the data is a critical component of the rigor of the findings. In the present study, a team of analysts, including Dr. Machtiger, the interviewer, and three other individuals, worked first independently and then collaboratively to code the interviews and summarize meaning from the findings.

In the initial phase, the research team reviewed the first four transcripts individually in order to become familiar with the data. During this phase, researchers made notes of their observations and potential codes to share during the initial team meetings.

During the second phase, a codebook, consisting of the definition, inclusion criteria, and exclusion criteria for each code, was created to aid analysis. Codes were initially developed independently by each researcher through an inductive process of identifying themes that emerged from the interviews of participants 1, 2, and 6: three interviews that had previously been identified as containing rich data representative of the group. From each of these interviews, researchers found naturally occurring themes in the data and created codes to represent those themes. Seven group meetings were held between June and July 2011, each lasting approximately 1.5 hours, to compare independently developed codes for similarity and further definition. A consensus was reached regarding each code, its application and definition. By the third transcript, no new codes were added to the codebook.

In the third phase, each interview was approached using the codebook and codes were revisited and revised as necessary throughout data analysis. All five researchers coded transcripts from participants 1, 2, and 6 independently and met several times in order to reconcile any differences in coding among these transcripts. Two researchers coded each of the remaining transcripts independently and further meetings were held to discuss any differences in coding and to ensure consistency in the application of codes. If the two researchers could not reach a consensus, a third researcher was asked to code the transcript and another meeting was held to reconcile differences. In the end, there was full consensus in the way in which each transcript was coded. The high correspondence between the application of codes across all transcripts strengthens the reliability of the results observed (Joffe, 2012).

In the fourth, and final, phase, the researchers independently identified and described all codes related to the potential impact of the experience on HIV-positive participants. These

codes included: “impact – HIV+ participant”, “relationships within group”, “disclosure”, “empowerment”, and “support from HIV+ women.” The four analysts then met to discuss and synthesize their independently derived descriptions of the impact of DCL. Findings were merged into a final summary and a consensus of core and major themes was developed.

## Chapter 4: Findings

### Demographics and Sample Characteristics

All eight HIV-positive women who participated in group meetings and the DCL performance participated in the interviews. The participants were predominantly African American (62.5%); the mean age was 48 years and all had earned a high school diploma or equivalent (Table 2). All participants were taking HIV medications at the time of the interview and the mean length of time with HIV among participants was 13 years (Table 3), although two participants were diagnosed within the last two years.

	HIV-Positive Participants (N = 8)
Age (years)	
Mean (SD)	48 (13.5)
Median	51.5
Range	23 - 65
Race	
African American	5 (62.5%)
White	1 (12.5%)
Multi-Racial	1 (12.5%)
Native American	1 (12.5%)
Sexual orientation	
Heterosexual	7 (87.5%)
Bisexual	1 (12.5%)
Highest level of education	
Some college	6 (75%)
Completed college degree (BA)	1 (12.5%)
Some graduate school	1 (12.5%)
Parents	5 (62.5%)



Table 3 <i>HIV disease characteristics for study participants</i>	
	HIV-Positive Participants (N = 8)
Years since initial diagnosis	
Mean (SD)	13 (8)
Median	14
Range	1 – 24
Currently taking HIV medications	8 (100%)

While attendance for group meetings was not routinely recorded, participants estimated the number of years they had been involved in the HIV-focused Medea Project; based on this information, the mean number of years that participants were involved at the time of the interview was 2.3 (SD = 0.8) and 50% of the participants remained involved at the time of the interview (Table 4). Most participants had no experience with performing on stage prior to DCL (62.5%) and half of the participants never previously participated in an HIV support group (Table 4).

Table 4 <i>Participation characteristics for study participants</i>	
	HIV-Positive Participants (N = 8)
Number of years involved in DCL	
Mean (SD)	2.3 (0.8)
Median	2
Range	1 – 3.5
Currently involved in DCL	4 (50%)
No history of performance prior to DCL	5 (62.5%)
Experience with other HIV support groups	4 (50%)

### **Qualitative Findings**

The HIV-positive participants consistently described the overall impact of DCL in positive terms and, while the major impact of the project was different for each participant, several common core themes emerged from the data. The core impacts of DCL, as described by the HIV-positive participants were: forming relationships, decreasing isolation,

normalizing HIV, providing a sense of purpose, and personal transformation. Participants described several major themes related to personal transformation, including: gaining a voice, exploring self-identity, catharsis, gaining a sense of accomplishment, and developing self-esteem. The following discussion presents these independent and interrelated themes and the self-reported experiences of the HIV-positive women who participated in this HIV-focused performance and the group meetings leading up to the performance.

**Core theme: forming relationships.** The structure of DCL necessitated frequent gathering of HIV-positive and HIV-negative women to discuss personal experiences with HIV. Throughout the course of these group meetings, the participants formed a strong bond with one another. Some participants called the group a “sisterhood”; others noted that they tell members of the group things that they keep hidden from others. The relationships were described as open, honest, caring, and protective. Every participant, in her own words, attested to the strength of the relationships within the group.

- 1: *You know, that was – I liked that and moving up into the performance working with these women I got very close with them to where I – I am very close to these women to where I'd do anything to help them if I could.*
- 5: *I don't know entirely how to put it in words but it's meant having a sisterhood that I could turn to and sharing basic things like eating, like talking, like giggling with other women who are in a similar or not in a similar situation but work with those of us who are and are indistinguishable.*
- 7: *Like I said, it's a real emotional group but it's full of love though, you know, it's a sisterhood. It's a community within itself, you know.*

**Core theme: decreasing isolation.** Many women described how participating in DCL allowed them to become less isolated as an HIV-positive woman. Within the context of strong relationships with other women, many of whom were also living with HIV, participants described how DCL gave them a new frame of reference and allowed them to contextualize their health. Women diagnosed recently described feeling a sense of gratitude for advances in HIV therapy after hearing stories from women diagnosed in the 80's and early 90's. Women who recently learned that they had a high T-cell count celebrated this news with the group, acknowledging and taking pride in the role of their own self-care in increasing their health status. Women newly diagnosed with HIV learned from and were inspired by those who had lived with the virus for decades.

5: *Well, I never felt - I mean it happens and, you know, you make the best of it but, yeah, I feel better. I know that I'm not alone and that helps. That definitely helps* [in response to the question "how has coming out changed how you feel about being HIV-positive?"]

1: *I remember one person read that [. . .] and she talked about her life, how she look at the flowers and hear the birds sing and, you know, stuff like that, the earth and it's like I never thought about that, you know, and how she cherish her life. She goes through a lot of problems at home, you know, and for her to get away from that drama at home and to write about the outside world, you know. It's amazing, it's amazing. And I think about that because I never pay attention to that, you know, I just go. But to hear her talk about her pain and what she go through, you know, it touches me a lot. It touches me a lot to hear other women go through*

*stuff, more horrible stuff than I went through or something that I never experienced. It's very hard.*

- 2: *They told their stories. Because they just - the way they got it and what they did, how long they have been living with it and so on and so forth and I was just always, always happy that I caught it early on. Because when I then hear - and still to this day when I hear first of all how many pills some of them have to take in the morning, noon, evening and so on and so forth, how low their T-cells are or the percentage, all those things, or how fragile some of them are where you can tell that they are sick just makes me appreciate my whole life more because I am healthy, I just got - my pharmacist called me yesterday and he said, "Your results, they are not good, they are fantastic." He said, "I haven't seen somebody with labs like that in forever." So I asked him how many people do you deal with and he says a few hundred. I thought, "All right. If you deal with a few hundred and you haven't seen that in forever [chuckle] it must be good then. [chuckle] So I'm very grateful of having it caught early and having a support group as well around it and being - The other thing is really [. . .] as well, being excited with somebody else with their T-cell count goes from like, say, 250 to 450. It's just everybody is just so happy about that, you know, and congratulates and "Yea!" and it's exciting and all those things. So it's like you really - you are happy with other people when they are doing better.*

**Core theme: normalizing HIV.** Normalizing HIV was a core impact that emerged from the interviews with HIV-positive participants. Some participants stated that the process of learning about the lives of other WLWHA painted a new picture of HIV, where an HIV

diagnosis did not exclude aspects of a normal life, such as marriage, children, and happiness. Through participation in DCL and the relationships they formed during the project, participants learned that HIV is not an all-consuming negative force in life; an HIV diagnosis is “not a death sentence.”

- 1: *I felt that the whole performance around being and living with HIV, that it's okay. Like one of the performers, she's not particularly in the group right now but she's still part of it, she talked about being young, like in her early twenties, and still having sex and having babies and getting married. That particular person told me she got that strength and hope of getting married - because I am married to a negative man and I never thought that I would be married and really not to somebody that is negative that support me, you know. And so she talked about even being HIV-positive that you could still live your life and still have babies and still get married.*
- 11: *It normalized everything. And a part of that is also just coping and living more with HIV but that the time when I was around a lot of those women at Medea like talking about these issues was just like talking about what happened in your day and - because it was everybody's day-to-day and so it made - it normalized everything, it made everything okay. It made being positive okay. And it also, as cliché as it sounds, it also just emphasized that you're [name], you just happen to be positive. You're not positive and your name is [name]. It really just made everything okay and it was just something else that you deal with in your life, a big thing that you deal with but like everything else.*

12: *Now with the group I can actually talk about it and -I feel so bad that I'm HIV-positive. I don't have to feel like - you know, like it's the worst thing that could ever happen to me. I don't have to feel that way anymore.*

**Core theme: providing a sense of purpose.** The HIV-positive participants expressed a strong sense of purpose that developed from DCL. Simply by meeting weekly, some participants expressed that the project gave them “something to look forward to” and a “get-up-and-go” attitude.

Moreover, by telling their stories in a public sphere, participants developed a sense of altruism. The participants expressed a desire to use their stories to benefit others in several ways: 1) help PLWHA by providing hope as well as information; 2) encourage HIV-negative individuals to get tested and become more educated about HIV; 3) combat HIV-stigma by providing an alternative, positive image of HIV. This sense of altruism developed from an understanding of the impact of the performance on the audience. Altruism strongly affected the tone and intensity of the meetings by giving them a purpose: to prepare for a performance that would have a profound impact on others.

For some women, the experience of helping HIV-positive women and educating the public around HIV shaped their professional goals. Participants 1, 11, and 5 explicitly stated goals of wanting to continue work in the HIV field. Overall, DCL gave HIV-positive women, who often hid negative emotions, experiences, and their own HIV status from others, a forum to tell their story with the purpose of helping others and making a broader impact on society.

4: *It gave me something to do instead of sitting in the house and always just being with myself and my dog and my son. You know, especially when I had stopped*

*working at the club. I had stopped working at the club because I my shoulder had went out and then while my shoulder was out that's when I got involved in the Medea because I had to be doing something, I needed to be doing something.*

12: *And I think that just helped me - Medea Project just put the - how do you call it?*

*Put the ban where it's supposed to be, you know, gave me the get-up-and-go and fight type of attitude.*

1: *So I feel, you know, this group with Rhodessa that it brings me to a place to where*

*I got to step up. So just writing and - because it's not all fun at Rhodessa but it is fun. It's some fun in writing because it allowed me to stand up more, you know,*

*as a woman, a African-American woman that been living with the virus for so*

*long and know that there's not other women to speak out, you know. And I need*

*more women into this group, you know, because we need to put the word out there*

*because the stigma is still out there, people still ignorant to HIV, you know and*

*AIDS.*

12: *Well, you're putting on a show for others. Maybe there's somebody in the*

*audience who's HIV-positive and have not - who have not been tested yet [ . . . ]*

*Maybe we can actually persuade them to go get tested or maybe there's somebody*

*out there in the audience who's HIV-positive and hasn't told anyone, not a soul*

*and they hear us up there and they decide - Actually, that happened to us [ . . . ]*

*Yes, a girl right in the audience admitted she was HIV-positive, had never before.*

11: *I was doing World and Medea simultaneously so it really helped me funnel my*

*interests and like get a better understanding of - like hearing all these women's*

*stories you get more of a fuller picture of the issues that positive women are*

*facing so it helped me want to go into that career path. [WORLD is an organization that uses peer-based education, advocacy, wellness services, and development to improve the lives of women and communities affected by AIDS]*

**Core theme: personal transformation.** All HIV-positive participants described some level of personal transformation. For the purposes of this study, personal transformation is defined as a process of becoming more aware of old and new self-views and refining personal definitions of self-identity. Five major themes related to personal transformation emerged from the interviews: gaining a voice, whereby participants were able to verbalize self-views; exploring self-identity; catharsis; gaining a sense of accomplishment; and developing self-esteem. These themes are related but have distinct qualities, which are described below.

**Major theme: gaining a voice.** One of the major components of this intervention, as expressed by participants, was to give HIV-positive women the opportunity to write and share their life story. Some women described how DCL gave them practical tools, such as help with structural elements of writing, to develop their own voice. Other participants described how DCL simply gave them a forum to express their stories. One participant explicitly described how the writing prompts themselves gave her the opportunity to form opinions on socio-political issues. Another participant conveyed an understanding that she can shape and define her own story: the story of HIV can be beautiful if she makes it so.

11: *I just didn't know what to write about or how to like articulate a lot of the issues but then after being around people who were writing all the time and sharing their work it's - and Rhodessa and [name] giving us prompts on like, "Why don't you explore this issue" or "Come back next time after you think about this topic,"*



*it really helped like with the personal healing process and being like, "Oh, how do I relate to that issue? How do I see that issue?" Like "How do I see my sexuality?" Like those are things that are really hard to, um, force yourself to think about without somebody helping you along.*

*12: The idea, I guess, of knowing that you can actually build a story around something that you probably should be ashamed - or people say that it has a stigma to it. You can actually build a story around it and make it something beautiful. And so [chuckle] that's what we did. We went out there and we talked about HIV but we made a story out of it and made it beautiful and it doesn't look like a stigma and it doesn't look like something that you should be afraid of, scared of, you know.*

*3: The Medea Project gave me the strength, impacted me with the voice to speak out with that and I need to be heard*

In addition to giving participants a voice to tell their stories, DCL also gave participants a voice to disclose their HIV status. While the overall process of the project was to facilitate disclosure, disclosure was also an outcome or impact of the project. All HIV-positive participants acknowledged that more people knew about their HIV status as a result of the performance because, at the minimum, audience members learned the HIV status of the participants. Some participants, however, also acknowledged that they specifically disclosed their HIV status to more close contacts as a result of the project.

*12: The only person I told was my boyfriend but then after the show I told everybody.*

*1: Like I say, I never talked about my HIV status until I got to Rhodessa and I talk about it a lot, you know, and I write about it a lot and it's heavy issue to deal with*

*to have to write about it, you know. It really is a heavy issue but the outcome is very rewarding, you know, and it's empowered me a lot to be who I am. And now I talk about it more, you know. I talk about it when I go get my hair done. I never done that before. You know, if the conversation of HIV come up I seem to have to say something, "Look, I'm a HIV-positive woman." And people look at me like, "What?" you know. And I said, "Yes."*

**Major theme: exploring self-identity.** Women described DCL as a program that allowed them to become more aware of how they define themselves and their self-identity. For some women, performing allowed them to try on different roles and to see themselves in a new light. For other women, DCL allowed them to see themselves as more than HIV-positive. Through the process of sharing stories, reflecting on past experiences, and comparing these experiences to those of others, the participants began to create new definitions of self and incorporate these new definitions into their self-identity.

- 1: *I learned is that, yes, there going to be pain and there going to be some crying and it's a process but the result is that I feel a little lighter, you know, I feel more open. I'm learning more about who I am.*
- 12: *You change - every show you're a different - you're playing a different part, a different role. Even when you're yourself, you don't feel like it's you because you never done that before so it can't be you. It's always different. Even though it's you, it's not you. It doesn't feel like you but it is you. [. . .] Well, the more is - I'm not just HIV-positive, I'm more, I'm something else. I'm other things. I like to write, I like to perform. I'm good in school. [chuckle] I get A's. . .*

11: *And it also, as cliché as it sounds, it also just emphasized that you're [name], you just happen to be positive. You're not positive and your name is [name].*

3: *So it gives me more character of myself, you know, that I'm a good person, that I'm a worthy person, that I'm a funny, likable person, you know, lovable, caring, giving person and got a big heart and that's me*

**Major theme: catharsis.** Through writing, women identified and retold key experiences, such as the moment they were diagnosed with HIV or the first time they disclosed their HIV status. They then verbally shared their written story and further processed their own feelings about their experiences first to a small group of HIV-positive and HIV-negative women in the DCL group meetings, and then to a larger group of strangers through the medium of performance. DCL allowed women to express experiences and feel emotions that have been “shoved down” and buried. Women expressed feeling a sense of relief after bringing these emotions and memories to the surface. Through this expression, women released shame and guilt associated with being HIV-positive.

1: *It was - I can't remember exactly what she wanted us to write on and I wrote on - coming out, not being ashamed, how I felt having this virus for so long and how other HIV women helped me through my process of healing and how to heal, you know. And I found that it was the inside, working on my inside and bringing about my feelings and my thoughts and my ideas out of who I was because I didn't know who I was, you know. And writing that piece, "My Dearest Beloved," it took me back to where I didn't - in jail where I didn't express my HIV status because back in the eighties it was a terrible illness and a lot of people was dying and I didn't know I was going to die, if I was going to live or die. And so I didn't tell*

*nobody about that piece. Being in Dancing with the Clown of Love it allowed me to go back and feel what I you know, pushed down, you know, and being ashamed and not letting nobody know about how I feel about HIV. And being in Rhodessa's group allowed me to release that and grow from that, you know. I'm getting teary-eyed now just thinking about it because that's a feeling that you never want to forget, you know, that I don't know want to forget. So being in a group allowed me to express how I felt.*

- 2: *All of a sudden so many things went clear in my head, everything that I was just - or have been swallowing my whole life, everything all of a sudden came out, all those things that went on. Even though I was raised in a fantastic family and everything I was sexually abused, not family-wise but, you know, and I did get raped and it was so weird because now it's so many years later and I - I hid it so well that I did not even remember that it actually happened because that's the only way how I dealt with situations, I just swallow them and they are just not there. And that time all of a sudden so many things, bam, bam, bam, bam, bam, came back, came out and all of a sudden everything was clear the reason why I act sometimes the way I act and so on and so forth. I had a chronologically - it just fell into place and that - I remember I went home that night and I started crying and that was so weird because I really started crying because of me as a girl, as a teenager and I've never done that in my life because I don't cry. It just came all out but it was not because I felt so bad about me how am now but I felt so bad for that person back then that was not protected and nobody was there. The only reason all that happened was because of Medea because through the*

*whole talking I just grew myself and I got more open and I think somehow all that stuff that was hidden inside - slowly, slowly, slowly I got rid of those barriers and all of a sudden everything came to broad daylight [chuckle] or however you want to say it. And that was such a - that night when I was crying I wrote that one piece that we then actually - that I then performed a few weeks later.*

**Major theme: gaining a sense of accomplishment.** HIV-positive women expressed pride and a sense of accomplishment stemming from the performance. For some participants, the act of staying in the group and completing the performance, which was previously seen as unattainable, led to a positive appraisal of their own work and a sense of satisfaction derived from completing personal goals. In DCL, participants were given a new role (actress/performer/dancer) and successfully attaining that role through performance led to a strong sense of accomplishment. Furthermore, the participants' understanding of the profound impact that the performance could have on the audience gave them a deeper sense of pride in the performance.

2: *So I think it's so important to actually perform and just be on stage. I somehow started feeling proud being on stage telling it because I just thought, "You look at me. You would never think, would you, that I have the virus and I'm telling you right now that it doesn't matter what color you are, how educated you are or - you can have it"*

1: *From doing Dancing with the Clown of Love I am so proud of myself to be a part of that group because I am so relieved that I did touch some people. I know I touched in that audience with this piece. When Rhodessa told me that it was a*

*powerful piece, I couldn't believe it, you know, but it gave me a lot of strength. It gave me a lot of strength and hope.*

**Major theme: developing self-esteem.** Every HIV-positive participant expressed, in some way, that DCL helped her to develop self-esteem. Participants stated they “feel good in [their] own skin”, and can “stand taller” as an HIV-positive women. Through DCL, participants began to accept their HIV status, redefine their self-identity, value their experiences and opinions, and become proud of who they are. Some women specifically linked the self-esteem they gained through DCL directly to the sense of accomplishment they felt after the performances and others linked it to the social support they received from other group members. Regardless of how DCL affected the participant’s self-esteem, it is clear that improved self-esteem was a major impact of the project.

12: *I've changed. I've changed. I've changed to where - ugh, how can I put it? I feel good in my own skin and I didn't used to. I feel more comfortable, more self-esteem. So, yeah, I didn't have all that before. When I found out I was HIV-positive I was just going to go lay in a bed somewhere and just go[. . .]. But, uh, I don't think I'll be doing that with this group. [laughter] They won't let it happen.*

12: *Yeah, it's important because the way it makes you feel, the way, um - you do things you never thought you could do. I mean once you've achieved stuff you never thought you could do doesn't that - that would make anybody feel better about themselves. So it does. It makes you feel good about yourself. It makes you do things you never thought you could do. It gives you confidence, it gives you self-esteem.*

5: *Yeah. Yeah. I feel better about myself, absolutely.*

1: *It allowed me to stand taller and be proud of being HIV-positive.*

For some HIV-positive participants, DCL allowed them to get rid of harmful or unsupportive relationships. This ability to identify and let go of unhealthy relationships represents one significant consequence of developing a positive self-identity and sense of self-worth.

1: *I started being more open about my status and I felt - and every time I got to be open with my status I felt more and more better inside and I felt the growth and this is who I am and it's not going away. And if they accept me then they really my friend; if they not, oh, well, you know, and that's the attitude I had, "Oh, well."*

2: *Now I learned actually - and I always thought it's a bad thing but actually it's a good thing, I learned to cut some people off in my life that are not good to me. I've never done that. I don't cut them off in a bad way I just say, "All right, as for this point this is not healthy to me," and it was a huge step for me actually to say, "I can't deal with that right now and please let's not continue this but I just need my time for myself."*

### **Disclosure Process Model**

Given that DCL is an intervention to facilitate disclosure, the DPM predicts that this HIV-focused theatrical performance group will have positive impacts on HIV-positive participants. For example, according to the DPM, strong approach goals predict positive disclosure outcomes. The framework of DCL encourages participants to recognize and embrace approach goals for disclosure, including goals to educate the public about HIV, reduce stigma, and help other HIV-positive women. The core theme of providing a sense of purpose illustrates how many of the HIV-positive participants internalized these approach

goals, a process which could possibly facilitate positive outcomes of disclosure. Similarly, the DPM suggest that the emotional content, depth, breadth, and context of the disclosure event effects disclosure outcomes. The structure of DCL encourages meaningful, detailed, disclosure events with strong emotional content by first allowing participants to frame their disclosure event in a written assignment. The core theme of catharsis provides a small representation of the emotional processing that occurred with disclosure. Furthermore, disclosure events occurring in DCL group meetings (consisting of HIV-positive and HIV-negative women) ensured positive confidant reactions and social support, two additional factors that facilitate positive outcomes of HIV-disclosure, as described by the DPM. Combined, all of these factors intrinsic to the structure of DCL contribute to a high likelihood of positive outcomes of disclosure on the individual, dyadic, and social levels.

The core theme of forming relationships was predicted by the DPM, which proposes increased intimacy is a possible dyadic outcome of HIV-disclosure. In the interviews, participants repeatedly testified to the honest, intimate, and strong relationships they developed with other participants, and some described the development of these relationships as an outcome of disclosure. However, some participants instead depicted the concept of forming relationships in terms of an approach goal, or a reason for disclosing, and others described the relationships in terms of the social support garnered, with social support depicted as a primary outcome. Thus, the interviews show that this core theme of forming relationships is not fully described by a single discrete construct of the model. While the process and outcomes of disclosure can be described using discrete, independent but interrelated constructs, the process and role of disclosure in the lives of PLWHA may be viewed as slightly more complex where outcomes of past disclosures form the motivations



for future disclosure events and mediating factors serve as outcomes. The DPM accounts for this complexity by providing the feedback loop and a description of the relationships between constructs, however future uses of this model should use flexible definitions of each construct to ensure that the participant's experience is fully represented. The following quotes show the breadth in which relationships were described by a single participant, highlighting that this concept holds multiple meanings for each participant:

*1: You know, just got close with them on an individual basis, you know, of sharing myself with them and allowing them to share themselves with me for the first time, you know. (Disclosure leads to increased intimacy)*

*1: And I got a lot of information of the first time, "Oh, I never told nobody about this," you know, and I felt honored that they trusted me enough to share this stuff with me. But, of course, being a part of Medea and Rhodessa it allowed me to share what they shared because I felt that it was important for the group and Rhodessa to hear. But I got their permission, you know, because it was around being HIV-positive and this is what we do so share that with our group so we could get close. (Increased intimacy used as a goal of disclosure)*

*1: I just know that being a part of Medea and the HIV circle is a good healing place to be. There are some awesome women in that group that - that you could lean on, you know, that's there for you for support any time. It's a amazing group. (Relationships facilitating social support, which in turn mediates the individual outcome of "healing")*

In addition to predicting outcomes, the DPM also provides an explanation for some of the themes that emerged from the interviews. For example, participants repeatedly described

the core themes of decreasing isolation and normalizing HIV as two major impacts of DCL. These themes can be predicted from the DPM through the mediating factor of changes in social information. The model describes changes in social information as a mediating factor that explains how disclosure can have a larger societal impact through increased public awareness and knowledge. It follows, then, that HIV-disclosure in the group meetings would have an impact on confidants, which in this case include other HIV-positive women, by changing the perception and knowledge of HIV. In fact, our study found that disclosing and listening to others disclose positively impacted HIV-positive women, through decreased isolation and normalization of HIV, because these disclosure events resulted in changes in social information. Furthermore, the themes of decreased isolation and normalization of HIV enrich the DPM by providing specific ways in which changes in social information can mediate dyadic and social outcomes of disclosure. Below is an example of how disclosure, by changing social information, can lead to a positive dyadic outcome:

2: *And at the between they were just telling their stories and then I heard so many other stories, which encouraged me again, where I thought, "Wow, they've been living with that for what, twenty years now, twenty-five years or this and that and they do have family." Some of them don't, some of them do. Some of them went through so much and it just helped me to understand that I am not going to die.*

The DPM has been described as a model that can predict and explain several outcomes observed in our study; however, the findings of the present study can also inform the model. As mentioned earlier, our study shows specific outcomes mediated by changes in social information: decreased isolation and normalization of HIV. Furthermore, the major theme of catharsis, for adds to the model's mediating factor of alleviating inhibition because

it provides a more descriptive explanation of how disclosure can liberate individuals from the shame and distress of maintaining a secret stigmatized identity. Additionally, the core theme of personal transformation, represented by several major themes that emerged from our data, adds a new perspective to the DPM by providing a rich description of a previously unreported potential individual outcome of disclosure. Participants vividly described a wide range of individual outcomes of disclosure that are not fully captured by the DPM, including: improved self-esteem, sense of accomplishment, and voice. Women participating in DCL learned to value their experiences and opinions and gained the confidence to share them in a public setting. While these impacts may be related to decreased psychological distress, clinical terms inadequately describe the sense of empowerment gained by HIV-positive women who are allowed and encouraged to tell their story of life with HIV. Future uses of this model may consider broadening the sphere of possible individual impacts of disclosure and include more holistic outcomes.

## **Chapter Five: Discussion**

The results of this study show that an HIV-focused theatrical performance group can have a number of positive impacts on HIV-positive participants, including: forming healthy relationships, decreasing isolation, normalizing HIV, providing a sense of purpose, and personal transformation. Participants described several major themes related to personal transformation, including: gaining a voice, exploring self-identity, experiencing catharsis, feeling a sense of accomplishment, and developing self-esteem. Given the increasing burden of HIV morbidity and mortality carried by women, this HIV-focused theatrical performance group represents a unique way in which the challenges of living with HIV, such as isolation, shame, and discrimination, can be confronted and diminished. Furthermore, the DPM provides a conceptual framework for understanding the effectiveness of this intervention to provide positive outcomes of disclosure; future interventions derived from the DPM may yield similar positive results. The following discussion compares the findings of the present study to those reported in previous studies, describes the strengths and limitations of the present study, further highlights the implications of the study findings for health care providers and public health professionals, and recommends avenues of future research.

### **Comparisons to Previously Published Research**

No studies documenting the impact of participating in an HIV-focused performance group on HIV-positive women were found; however, the themes that emerged from the current study are consistent with the reported impacts of a similar intervention based on creative expressive therapy. Weiss et al. (2011) found that expressive-supportive group therapy can improve self-efficacy, social support, active coping and relaxation and decrease distress among WLWHIV. While these constructs were not specifically measured in the

present study, participants described several general positive impacts of DCL that indicate improved mental health and social support, such as: forming relationships and gaining self-esteem and a sense of accomplishment. Together, these studies suggest that interventions aimed at fostering creativity and expression can profoundly impact the mental health and well being of HIV-positive women.

Given the central role of disclosure, as women disclosed their HIV-status during group meetings and public performances, it is not surprising that the impacts of this intervention are also consistent with impacts of disclosure reported in the literature. Specifically, studies show disclosure is linked to lower levels of depressive symptomatology (Armistead et al., 1999; Hays et al., 1993; S. C. Kalichman et al., 2003; Perry et al., 1994; Zea et al., 2005) and higher levels of social support (S. C. Kalichman et al., 2003; J.M. Simoni et al., 2000; Zea et al., 2005). Constructs to measure mental health and social support were not included in this study, but descriptions from participants imply psychological and social support benefits of disclosure. The findings of the present study are also consistent with the findings of other qualitative studies that disclosure leads to social support (Gielen et al., 1997; Ortiz, 2005; Parsons, VanOra, Missildine, Purcell, & Gomez, 2004), intimacy (Emlet, 2008; Parsons, VanOra, et al., 2004), reaffirmation of self (Parsons, VanOra, et al., 2004) and decreased feelings of isolation (Ortiz, 2005). Furthermore, a meta-analysis of qualitative findings reported that women described feelings of self-understanding, authenticity, empowerment, relief, purpose, accomplishment, and pride after disclosure (Sandelowski, Lambe, & Barroso, 2004). Taken together, the results of the present study are consistent with quantitative and qualitative findings on the positive effects of HIV-disclosure, thus validating current findings.

### **Disclosure Process Model**

While the positive impacts of DCL are consistent with previous findings, the DPM provides an explanatory framework for understanding why an HIV-focused theatrical performance that facilitates disclosure would have a positive impact on the lives of WLWHA. The model predicts that interventions can facilitate positive outcomes of disclosure, especially if the interventions contain the following elements: facilitating the development of approach goals for disclosure, encouraging disclosure events that contain strong emotional content, ensuring positive supportive reactions, and providing a space that fosters mediating factors such as changes in social information, alleviation of inhibition, and social support. While the development of this intervention was not based on the DPM, by applying the model retrospectively, we show that it may be used to develop future interventions to facilitate disclosure events that lead to positive outcomes.

When considered with the DPM, the findings of this study provide rich descriptions of key constructs, including approach goals, mediating factors, and outcomes. While the DPM predicts some of the outcomes that emerged from the interviews, these outcomes clearly have multiple meanings for participants, illustrating the converging and overlapping nature of constructs within the model. For example, forming relationships was a dyadic outcome as disclosure increased intimacy between the discloser and confidants, but it was also an approach goal as participants cited a desire to form close relationships with other group members as a reason for disclosure. Future studies utilizing the DPM should acknowledge that constructs might not act independently or appear at the expected stage of the model. By adapting the DPM in a way that is flexible and allows for multiple

interpretations of each construct, there may be a greater opportunity to more fully understand the individuals' disclosure experience.

The study findings suggest specific examples of outcomes of disclosure that are not well documented in the DPM. For example, the core themes of decreased isolation and normalization of HIV represent unique outcomes of disclosure that are mediated by changes in social information. Additionally, the core theme of personal transformation is an important individual outcome that was previously unaccounted for by the DPM. Future studies should examine these significant impacts of disclosure and their possible effects on health and well-being. These outcomes, as well as the related outcomes of self-efficacy and empowerment, should be considered in the model as possible outcomes of repeated disclosure.

In utilizing the DPM to understand the impact of the HIV-focused theatrical performance group, it is important to recognize that the process of this program encompasses more than a single disclosure. Participating in DCL requires multiple disclosure events through group meetings and performance as well as developing personal disclosure stories through written assignments. In addition to developing and expressing one's own disclosure story, DCL also required participants to adopt the role of confidant as other women disclose their experiences with HIV. Thus, the impact of DCL is more than the impact of a single disclosure event; it is the impact a complex, multifaceted program that provides many avenues to encourage and facilitate multiple HIV-disclosure events through writing, word, and performance. While the DPM accounts for the effect of previous disclosure events on future disclosure events through a feedback loop, this model may be strengthened by more fully depicting the possible effects of repeated disclosure on disclosure outcomes. For

example, outcomes of initial disclosure events may include increased intimacy, while disclosure over time may lead to improved self-efficacy, self-esteem, and empowerment.

### **Strengths of this Study**

There are several strengths of the study design. First, all transcripts were coded independently by two or more analysts. The analytic team reached a consensus regarding all code names and definitions and how codes were to be applied to each passage. This double coding method strengthened the rigor of the findings. Secondly, two members of the analytic team were involved in the development and implementation of the theatrical performance group and had interacted with the study participants on multiple occasions prior to the study, strengthening the credibility of the findings. Thirdly, all participant views were elicited and considered in the analysis, strengthening the authenticity of the findings. Finally, each analyst independently developed a description of impact of DCL on participants, and the final core and major themes were agreed upon after a critical appraisal of each analyst's interpretation. This process enhanced the integrity of the study by providing a checkpoint to ensure that interpretations are grounded in the data.

### **Limitations of this Study**

There are limitations of the study that must be acknowledged. First, the study is of an intervention that facilitates disclosure in a controlled environment. Thus, our findings may not represent the impact of HIV-disclosure in other circumstances, such as at work or home. Secondly, the disclosure occurring in this intervention was not limited to HIV. Women disclosed other personal experiences such as substance abuse, trauma, and assault. Thus, some of the findings may be related to disclosure in general and not simply HIV-disclosure. Thirdly, the data was collected over the course of a single interview; follow-up interviews



specifically addressing themes observed by analysts would enhance the credibility of the findings. Fourthly, given time constraints, the interpretations presented in this document were not reviewed by participants. Fifthly, the HIV-focused theatrical performance group was designed and implemented without intentions of formal scientific evaluation. Thus, detailed consistent attendance records were not kept and the degree and nature of each participant's exposure to the intervention cannot be determined. Finally, this study did not measure the impact of the performance group on individual health outcomes or families and audiences. This study is a small, pilot study with a fairly homogenous population; further studies in different cultural contexts may yield different results. Nevertheless, our findings show, as predicted by the DPM, that WLWHA can experience significant positive outcomes of an intervention to facilitate disclosure in a safe environment.

### **Implications for Health Care Providers**

The results of this study add to the existing knowledge of HIV/AIDS stigma and its effect on health and well-being. Furthermore, it shows the potential impact of an intervention that provides space and support for WLWHIV to develop and reflect on their life story within an intimate group and share these stories with a public audience through performance. WLHIV are often marginalized and isolated because of continuing HIV-stigma. However, women who participated in DCL expressed feelings of decreased isolation and increased support through new relationships. By telling their story on stage, women found their voice and learned to value their experiences. As we strive to address disparities in HIV, especially among women, it is critical to explore new ways of confronting and diminishing the challenges of living with HIV. Through expression and performance, many women living

with a stigmatized condition, such as HIV, may experience improved self-esteem and increased social support.

The positive findings of this study may strengthen and inform similar interventions that use theater and group therapy to improve the lives of PLWHA. While the current theatrical performance group was not strictly grounded in a single theoretical framework, we have shown that future similar programs could utilize aspects of the DPM. For example, performance groups encouraging women to disclose their HIV status should emphasize approach goals for disclosure and establish a safe environment for disclosure that ensures a positive response from the confidant because these components can contribute to positive outcomes of disclosure. Additionally, given that this study is the product of collaboration between a community-based arts organization, Cultural Odyssey, and public university, UCSF, this study shows how academia and community can work together to develop and evaluate programs that improve the lives of WLWHA.

### **Recommendations for Further Research**

Given these findings, future studies should examine the effect of theater and other expressive therapies on depression, anxiety, stress, self-efficacy, empowerment, immune function, viral load, CD4 count, risk behaviors, stigma, social support, use of HIV services, and adherence to medication. Additionally, future qualitative studies should compare the role of disclosure in the lives of PLWHA to the process and outcomes delineated by the DPM in order to further develop this model and ensure that it reflects the experiences of those living with HIV/AIDS. Furthermore, public health professionals planning interventions to facilitate HIV-disclosure should consider utilizing the DPM or components from creative expressive therapy as a framework during the planning and evaluation stages.

## **Conclusions**

The findings of this study suggest that an intervention involving writing and performance can positively impact the lives of HIV-positive women through personal empowerment and reduced stigma. Given the impact of stigma and isolation on PLWHIVA, further studies investigating the role of expressive writing and public disclosure are needed.

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