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An Expressive Therapy Group Disclosure Intervention for Women Living With HIV Improves Social Support, Self-efficacy, and the Safety and Quality of Relationships: A Qualitative Analysis

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Abstract

Women living with HIV (WLHIV) face high rates of morbidity and mortality. HIV disclosure interventions have been identified as a promising but under-evaluated approach for WLHIV to improve their health and well-being. The Medea Project is an expressive therapy group intervention that was first developed to help incarcerated women develop the confidence and skills to tell their stories publicly in theatrical performances. The intervention was subsequently adapted as a community-based disclosure intervention for WLHIV. Our study describes an analysis of the impact of the Medea Project on the lives of the WLHIV who participated. All participating WLHIV publicly disclosed their HIV status during the performances. Five impact themes emerged from the data: sisterhood, catharsis, self-acceptance, safer and healthier relationships, and gaining a voice. Our study identifies a voluntary, effective, and broadly beneficial disclosure intervention for women living with HIV.

In the United States, the proportion of HIV cases affecting women has tripled since 1985 (Centers for Disease Control and Prevention [CDC], 2006). Women now comprise 25%–30% of the approximately 1.2 million Americans living with HIV (CDC, 2012b). Women of color bear a highly disproportionate impact of the disease. More than three quarters (79%) of U.S. women diagnosed with HIV in 2010 were African American or Latina (CDC, 2012a, 2013), despite these groups together representing less than 30% of the U.S. population. Even with the availability of effective antiretroviral therapy (ART) that should render HIV a chronic, treatable condition, in 2009, the most recent year for which definitive statistics are available, HIV was the third leading cause of death for African American women ages 35–44 years (Heron, 2012).

Women living with HIV (WLHIV) also suffer from a number of co-occurring conditions that lead to a considerable amount of suffering. These conditions include high rates of stigma (Sengupta, Banks, Jonas, Miles, & Smith, 2011), social isolation (Machtinger, Haberer, Wilson, & Weiss, 2012), depression (Tsao, Dobalian, Moreau, & Dobalian, 2004), trauma and posttraumatic stress disorder (PTSD; Machtinger, Wilson, Haberer, & Weiss, 2012), and substance abuse (Machtinger, Haberer, et al., 2012). Increasingly, the term “syndemic” has been used to describe the high rates of co-occurring HIV, gender-based violence, substance abuse, and mental illness in this population (Meyer, Springer, & Altice, 2011). Numerous calls have been made by national organizations for novel interventions to more effectively address the psychosocial determinates (e.g., trauma) of the high incidence and poor outcomes of HIV among women (Simoni, Demas, Mason, Drossman, & Davis, 2000; U.S. Positive Women's Network, 2012).

Safe and voluntary HIV disclosure interventions have been identified as a promising but under-evaluated and under-utilized approach to improving the health and emotional outcomes of people living with HIV (Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003). A significant body of literature, including men and women living with HIV, suggests that HIV disclosure is associated with multiple health and emotional benefits. For example, numerous studies document associations between HIV disclosure and improved social support (Kalichman et al., 2003; Ortiz, 2005; Parsons, VanOra, Missildine, Purcell, & Gomez, 2004), improved depressive symptomatology (Kalichman et al., 2003), increased utilization of HIV-related health services (Mellins et al., 2002), improved adherence to ART (Mellins, Brackis-Cott, Dolezal, & Abrams, 2004; Stirratt et al., 2006), and decreased sexual risk behavior (although results are mixed; Clum et al., 2013; Edwards-Jackson et al., 2012).

However, HIV disclosure must be performed well, as the process can also lead to stigmatizing and harmful reactions, including disrupted relationships with families and communities (Audet, McGowan, Wallston, & Kipp, 2013; Clum et al., 2013), loss of employment (Simoni, Mason, & Marks, 1997), psychological distress (Comer, Henker, Kemeny, & Wyatt, 2000), and violence (Gielen, Fogarty, et al., 2000; Gielen, McDonnell, Burke, & O'Campo, 2000; Zierler et al., 2000). The 2012 murder of an HIV-positive African American woman in Texas after she disclosed her status to her partner is a stark reminder that many women face the real possibility of violence if they disclose their status (Terrell, 2012; Wilonsky, 2012). As such, while interventions to help WLHIV disclose their status offer potentially transformative health and emotional benefits, such interventions require a focus on the safety and

consent of participants to ensure that WLHIV independently decide if, how, when, where, and to whom they disclose.

A limited body of literature suggests that prospective interventions to facilitate disclosure by WLHIV can be feasible, safe, and effective in the United States and abroad (Mundell et al., 2011; Murphy, Armistead, Marelich, Payne, & Herbeck, 2011; Norris & DeMarco, 2005; Watt et al., 2011). One possible approach to facilitating HIV disclosure among WLHIV is through the use of expressive therapy (ET), a broad term that includes the therapeutic use of writing, performance, dance, art, and other forms of creative expression to reduce disease symptoms and improve quality of life (Malchiodi, 2005). ET has been shown to have a number of positive impacts on the lives of people with a variety of conditions, including PTSD (Green, 2011), survivors of torture (Gray, 2011), diabetes (Stuckey & Tisdell, 2010), fibromyalgia (Horwitz, Kowalski, & Anderberg, 2010), cancer (Silke, 2011), and HIV (Abel, 2007; Belanoff et al., 2005; Edwards-Jackson et al., 2012; Norris & DeMarco, 2005; Weiss et al., 2011). While a key component of this approach is expression, interventions utilizing ET can include public or private expression and may or may not involve public or interpersonal disclosure of possibly stigmatizing identities, such as disease status. Of the studies evaluating ET in people living with HIV, only one examined the use of this approach to facilitate public HIV disclosure (Norris & DeMarco, 2005). That study was a qualitative study of the experiences of four African American WLHIV who helped develop, and were featured in, an educational HIV-risk reduction video for adolescent girls. The authors reported the experience of public disclosure to be consistently positive, with the exception of a common theme related to the personal pain of reliving the individual's history with HIV (Norris & DeMarco, 2005). Thus, research has suggested that safe and voluntary HIV disclosure interventions are a promising tool to improve the health and well-being of WLHIV, and that ET involving writing and performance may be a particularly effective and broadly beneficial method for such interventions. We conducted a study to determine the impact of a community-based expressive therapy disclosure intervention on the lives of the WLHIV who participated. Our aim was to determine whether the intervention had an impact on participants' social support, self-efficacy, and safety and quality of relationships.

Methods

The Existing Community-Based Intervention: The Medea Project

Cultural Odyssey is an artistic organization based in San Francisco that uses theater as a form of social activism by empowering performers and educating communities. In 1989, Rhodessa Jones, the co-artistic director of Cultural Odyssey, developed the Medea Project-Theater for Incarcerated Women (henceforth Medea) as a group performance intervention to empower women incarcerated at the San Francisco County Jail to value and express their life stories and to reduce recidivism. The structure and format of the original Medea intervention arose organically from the participants' interest in expression and Jones's insight to facilitate the exploration of participants' stories and choreograph them into performances that could be acted out by the participants themselves (Rhodessa Jones, personal communication, March 11, 2012). While Medea has received wide attention and praise for empowering participants and educating audiences over the past 25 years (Adams,

2012; Fraden, 2001; Martin, 2007), its therapeutic impact has never been formally evaluated.

Medea workshops have expanded to a number of different settings and populations of women inside and outside of jails, but all follow a similar format. Specifically, the process consists of a series of intensive workshops that culminate in a theatrical performance. The workshops are designed to build community among women, help women explore and value their life stories, and develop the confidence and skills to translate their experiences into theatrical vignettes. The Medea community involves participants who are naïve to the project as well as experienced former cast members, described as core members. Each workshop begins with a check-in where participants share recent life events.

Writing is a fundamental component of the Medea process and provides the basis of the theatrical vignettes. In response to prompts given by the workshop leader, participants write stories, poems, lyrics, and thoughts outside of group meetings. The prompts direct participants to explore key, often traumatic, life experiences, as well as to identify sources of pride and accomplishment. Participants share their written responses with others in the group meetings. The group then works collaboratively to choreograph selected stories as the women's writing is married to movement and acting. The public performance provides purpose to the group process, as women are increasingly motivated to write, share, and practice the theatrical vignettes in order to successfully perform on stage and share their experiences with others. Beginning in March 2007, Jones partnered with the Women's HIV Program (WHP) at the University of California, San Francisco (UCSF), to recruit WLHIV for a new Medea performance workshop about living with HIV. As described above, Medea was not originally developed as an HIV disclosure intervention. However, Medea's basis in storytelling allowed the process to be adapted for this purpose with little change to its longtime method. HIV-specific writing prompts were added to the usual writing prompts. Examples included: How did you find out you had HIV? Who knows that you are HIV positive? and What does sex mean to you now? WLHIV who participated in the Medea project were informed at the onset that they did not need to publicly disclose their HIV status in the final performances in order to participate in the intervention and that doing so would be optional and at their discretion.

Participants joined this new Medea project in response to flyers placed at the two principal clinics caring for WLHIV in San Francisco: WHP and the Positive Health Program at San Francisco General Hospital. Most participants joined the group in 2009 and the final performance series occurred in March of 2010. The final performance group consisted of eight HIV-positive women and seven HIV-negative women from Medea's core group. In the initial stages, throughout 2009, the group met weekly, and toward the end of 2009 and early 2010, the group met twice weekly, for approximately 3 hours each time. In the weeks leading up to the principal performances, the group met more frequently. The project culminated in a professional theatrical run of eight shows, which were seen by more than 1,000 people in March 2010. A question-and-answer session with the audience occurred after each performance. The intention of this session was to break down barriers between the audience and the performers and allow the participants to feel the impact of their disclosures on the theater audience. Medea participants were

compensated \$100 dollars each time they participated in one of the eight public performances but were not compensated for attending the workshops.

Study Design

We completed a qualitative exploratory study of an existing community-based intervention created and led by a community-based organization. The study was designed and carried out after the intervention culminated with final Medea performances in March 2010. Interviews were conducted with HIV-positive participants to broadly explore the impact of the intervention on their lives and relationships. A 5-member study team experienced in qualitative research conducted the analysis. The team included two clinicians: an academic primary care physician who was instrumental in facilitating the Medea project's involvement with WLHIV and an experienced qualitative nurse scientist who has worked with WLHIV for more than 15 years. The team also included one interviewer/coder and 2 primary coders, who were graduate health profession students at the time of the analysis. The UCSF institutional review board approved all research procedures.

Sampling

Recruitment criteria were: having completed the Medea workshops and having participated in the public Medea performances. Participants were purposively sampled and recruited at ongoing Medea workshops and at the two HIV clinics where the HIV-positive participants received their care. All eight HIV-positive participants in the Medea project consented to participate in this study.

Procedures

An interview guide was developed to elicit the participants' experiences of participating in the Medea project. The guide had two broad areas of inquiry about the participant's experiences with the workshops and performances: What was your experience disclosing your status publicly on stage? and What, if any, impact did this experience have on you, your interactions with others, family, and relationships? While the interview guide included specific questions, the interview process and the questions were open-ended and the interactions were highly inductive and encouraged participants to express their own ideas about the impact of Medea on their lives. Participants were specifically invited to describe any harm that occurred to them as a result of their participation in the intervention and public disclosure of their HIV status. To establish rapport and maintain consistency, one qualitative researcher conducted all interviews.

Data Collection

Between May and December 2011, a semi-structured, face-to-face, interview lasting between 90 and 120 minutes was conducted with each of the eight WLHIV. Interviews took place in a private room in a UCSF building or at Cultural Odyssey. Prior to the interview, each participant signed an informed consent. All interviews were digitally audio-recorded. Upon completion of the interview, each participant was given a \$65 grocery gift card as compensation for her travel and participation in research.

Data Analysis

All interviews were audio-recorded and transcribed verbatim and imported into ATLAS.ti analytic software (ATLAS.ti, Corvallis, OR). A collaborative team of researchers analyzed the data using thematic analysis (Braun & Clarke, 2006) and followed a well-defined, transparent protocol to sift and sort the data (Koester et al., 2007). Transcripts were coded using open coding and discussed during team meetings devoted to data analysis (Charmaz, 2006). The team reached consensus regarding the definition and application of each code. Two members of the team independently coded each transcript to ensure reliability in the coding process. During interviews, participants were prompted to clarify responses in order to make sure the interviewer understood what the participant was saying. This process resulted in thick description of women's experiences of the Medea Project. In addition to memo writing (Lempert, 2007), team members consulted other sources of data, including watching a DVD of the performances, interviews with some of the HIV-negative participants, and an in-depth interview with the Medea director, Rhodessa Jones; these sources were used to triangulate the data, thus adding to the credibility of our data (Lincoln & Guba, 1985). The study team did not actively seek member checks outside of the data collection process, but the rigor of the interviews exhibited multiple instances where the interviewer consulted participants, explored their understanding of what was said during the interview, and clarified and probed further with participants to more fully capture the essence of what the participants were saying. This process of verification, and writing memos and field notes, which was conducted during the data collection process, resulted in data that were not only rich but also added to the credibility of our analytic work and validity of our findings (Morse, Barrett, Mayan, Olson, & Spiers, 2001). Ultimately, these data were reduced into broader themes, which captured the essence of the experience and impact of participating in the project over time, including the performance. For this analysis, we examined all elements of the data that described the impact of the intervention on the lives of the WLHIV who participated.

Results

Participant Characteristics

Of the eight participants included in this study, all were HIV-positive; five were African American (62.5%), one was Caucasian (12.5%), one was Cherokee (12.5%), and one identified as belonging to more than one race (12.5%). Participants were between ages 23 and 65 years (mean = 48; SD = 14). One participant was bisexual (12.5%) and seven were heterosexual (87.5%). The mean length of time after HIV diagnosis was 13 years (range = 1-24 years), and all participants were taking ART at the time of the interview. All had earned a high school diploma or equivalent and attended some college. Two of the participants had earned a college degree (25%), one of which reported attending some graduate school (12.5%). Five of the participants had children (62.5%).

Participants estimated they had been involved in the project a mean of 11.8 months prior to the principal public performances (SD = 5.8; range = 3-16 months). Five participants (62.5%) had no experience performing on stage prior to Medea, and

four (50%) had never previously participated in an HIV support group. No participant had publicly disclosed her HIV status prior to participation in the intervention.

Themes

The participants consistently described the overall impact of Medea in positive terms. While the impacts of the intervention were different for each participant, five core themes emerged from the data that described the impact of the intervention on the lives of the participants: sisterhood, catharsis, self-acceptance, safer and healthier relationships, and gaining a voice (Table 1). The following section describes these themes and includes representative examples of statements that were illustrative of the themes.

Sisterhood.

A key impact of Medea was the formation of deep, honest, and supportive relationships among group members. Participants described sharing profound personal experiences with each other and forming strong interpersonal bonds in the group regardless of HIV status. The term sisterhood came from the participants' own words and attested to the strength and impact of the relationships developed within the group.

So it was very healing, personally going through a process of navigating being newly diagnosed. And it was fun. You know, there was always laughing, always funny stories, always whatever. There was – I mean it did feel like a very close bond with folks. You spend so much time. You reveal some of your deepest secrets that you can't reveal to anybody else. (Participant [P] 6, age 23)

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 (HIV-positive) and are indistinguishable. (P4, age 65)

Catharsis.

Participants expressed that Medea helped them feel a freedom from the burden of secrecy about HIV, childhood and adult traumas, and other stigmatizing experiences. The theme of catharsis was derived from participants' rich descriptions of experiences disclosing their HIV status, past traumas, and feelings of shame, isolation, and rejection to a widening circle of audiences, first to other participants and then, ultimately, to public audiences. Medea provided a safe and supportive structure for women to explore and share painful experiences that had been “pushed down” and “swallowed.” By “opening up” through writing assignments, theatrical workshops, and public performances, many participants described releasing shame and guilt associated with HIV and other traumatic experiences.

It [Medea] 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. Because having that secret for so long and now I don't have that, it – like a big old load had been lifted and I don't have to feel ashamed no more. (P1, age 54)

All of a sudden so many things went clear in my head, everything that I 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, 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. (P2, age 34)

Self-acceptance.

Participants expressed that Medea allowed them to reframe their understanding of what it meant to be a WLHIV, normalize life with HIV, and embrace a stronger and more positive self-identity. Participants described learning that having HIV did not exclude key elements of a normal life, such as school, marriage, children, and happiness. Ultimately, this normalization of HIV was manifested in improved self-esteem and self-acceptance. Every HIV-positive participant expressed, in some way, that Medea helped them to “feel good in [their] own skin,” and to “stand taller.”

When I was around a lot of those women at Medea, 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. (P6, age 23)

I used to see myself as only HIV positive, now I see myself as more than just HIV positive... 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 As. (P7, age 56)

Safer and healthier relationships.

Participants described being more able to develop open, honest, authentic, and fulfilling relationships as a result of participating in Medea. Four participants reported that the Medea process facilitated their leaving or avoiding harmful or unsupportive relationships.

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.” (P2, age 34)

The last one [boyfriend], no way, because they [the other women in Medea] was against it because the way he treated me, you know, they didn't like it and they was hoping that, you know, if I, you know, get – you know, get the initiative to cut him loose. He was no good. Interviewer: Did you cut him loose? Yeah [chuckle]. (P3, age 49)

My family is pretty good. My oldest sister, when I first got diagnosed she didn't want me around her and the kids and stuff like that, so that's another story. But today it changed her. I kind of look at her and she's not standoffish like she used to be, you know, because she heard my story. I have educated her so that kind of changed her a little bit. (P1, age 54)

Gaining a voice.

Participants expressed developing a new sense of purpose and accomplishment as an educator and activist that stemmed from participating in and ultimately performing publicly with Medea. Many participants described learning to value their stories as a tool to help others and to develop a stronger and more confident voice with which to share their experiences. Immediately after each performance, during question-and-answer sessions with the audiences, participants were impressed by the impact that their public disclosures had on others. Participants described becoming motivated to continue in their roles as community leaders. Three participants explicitly stated goals of wanting to work in the HIV field.

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. (P7, age 56)

It allowed me to stand up more, you know, as a woman, an 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. (P1, age 54)

This young lady, we were performing, she was crying in the audience after the Q&A, which is question and answer. She was just crying and said, "I would have never thought I could just be so free with this because I have it and I just found out 2 months ago. I just found out." (P5, age 56)

HIV disclosure.

All participants publicly disclosed their HIV status for the first time during the performances. No participant described experiencing violence, threats, or lasting negative impacts on their families or romantic relationships as a result of participating in Medea. However, one negative incident was reported by the participants; the son of a participant was teased at school for having a mother with HIV by a female student who saw a Medea performance. While stressful and troubling for both mother and son, the son stayed at his school and at home; the girl who teased him eventually left the school and the mother and son were able to move on with their lives and relationship. Other Medea participants who described this incident expressed motivation to expand their work to schools to confront the stigma of HIV.

Discussion

Our study findings are among the first to support the implementation of expressive therapy to facilitate disclosure by WLHIV. Medea facilitated the public disclosure of HIV for all who participated in a way that participants consistently described as positive and empowering. In addition to facilitating HIV disclosure, participants described other broad benefits of participating in Medea, including improved social support, self-esteem, and self-efficacy. Participants described improved self-efficacy in many ways, including an increased sense of purpose, accomplishment, and motivation. Notably, half of the participants described leaving or avoiding unsafe or

unhealthy relationships as a result of their participation in Medea, a particularly important impact given the high rates (Machtinger, Wilson, et al., 2012) and negative outcomes (Machtinger, Haberer, et al., 2012) of gender-based violence among WLHIV and the paucity of evidence-based interventions to reduce, and heal from, violence in this population.

The broadly positive impact of Medea on participants' lives appears to have been related to its use of group ET that included writing, reading the writings aloud to the smaller group of participants, physical movement, and ultimately, public performance. The Medea method centers on the healing and empowering impact of storytelling. While HIV disclosure was a focus of Medea, storytelling included the disclosure and processing of other stigmatizing and traumatic experiences with the support of a diverse group of women. Disclosure of HIV and other traumatic experiences in this setting resulted in social support and intimacy among group members that increased in depth as the process unfolded. The group process resulted in relief from the burden of secrecy and re-evaluation of self-identity. Through public performance, participants became aware of the positive impact that their stories could have on others, gaining a new level of appreciation of their own experiences, fortitude, and potential to positively impact their communities. Participants experienced a desire to change the social norms that created HIV risk, HIV-related stigma, isolation, and trauma; ultimately, the process unearthed a "voice" and confidence with which to do so. Equally important, participants learned to expect more from relationships with others as they more openly shared feelings and experiences in a sisterhood with other Medea participants.

The impact of Medea is consistent with, and adds to, an emerging literature describing the positive impacts of disclosure (of HIV and other stigmatizing experiences) and ET on the health and emotional outcomes of WLHIV (Abel, 2007; Murphy et al., 2011; Norris & DeMarco, 2005; Weiss et al., 2011). For example, Weiss and colleagues (2011) found that expressive-supportive group therapy could improve self-efficacy, social support, active coping, and decrease distress in WLHIV. While these constructs were not specifically measured in our study, participants described several general positive impacts of the project that indicated improved mental health and social support, such as forming relationships and gaining self-esteem and a sense of accomplishment. To the authors' knowledge, only one prior study evaluated an intervention that utilized ET to facilitate HIV disclosure by WLHIV in the United States (Norris & DeMarco, 2005). The impact themes described in that study included: (a) self-acceptance by telling one's own story and hearing the stories of the other women, (b) a sense of liberation by disclosing publicly one's image and message and letting go of others' judgments, (c) feeling supported by meeting other women who shared the same experience, and (d) value of using film to impact or save young people from the pain one has experienced. The concordance of findings between the prior study and our study suggest a validity and consistency of the positive impacts of HIV disclosure interventions utilizing ET with women.

Although there has been limited evidence about ET to facilitate HIV disclosure, expressive writing has been studied in WLHIV with promising results. In one study, expressive writing focused on trauma appraisals resulted in significant reductions in PTSD, depression, and physical symptoms for women (Ironson et al., 2010). Other

studies of expressive writing interventions for HIV-positive women and men have had mixed results or have shown no beneficial impact on psychological well-being or self-reported health status (Wagner, Hilker, Hepworth, & Wallston, 2010). For example, one study of expressive writing in a sample of HIV-positive adults found no impact on emotional adjustment to HIV, but cellular immune function among those who took part in the expressive writing arm improved (Rivkin, Gustafson, Weingarten, & Chin, 2006). While expressive writing was one component of the Medea Project, writing was only one element of a multifaceted intervention that included writing, group support, physical movement and performance. Further study is needed to better understand the contribution of each component of the Medea intervention to the overall impacts described by study participants.

Given the possible negative consequences of HIV disclosure, it is important to identify the components of Medea that facilitated safe HIV disclosure with positive outcomes that motivated further disclosure. While the design of Medea arose organically and was not based on a theoretical framework, the Disclosure Process Model is an existing conceptual framework that describes when and why interpersonal disclosure among people who live with concealable stigmatized identities, including but not limited to an HIV diagnosis, may be beneficial (Chaudoir & Fisher, 2010). According to this model, a number of factors affect the outcome of any given disclosure event, including goals for disclosure; length, breadth, depth, and emotional content of the disclosure event; reaction of the confidant; available social support; available social information; degree of relief from the burden of secrecy; and feedback from prior disclosure events (Chaudoir & Fisher, 2010; Chaudoir, Fisher, & Simoni, 2011). According to this model, Medea was successful because it effectively addressed each of these elements. For example, Medea enabled women to recognize and embrace goals for disclosure, including the desire to educate the public about HIV, reduce stigma, and help other WLHIV. Medea created a space for successful disclosure events in the smaller group of participants that allowed women to provide sufficient detail and emotional breadth to their stories. The positive and supportive reactions from within the group led to a positive feedback loop in which participants developed the confidence and desire to disclose to larger groups of people in public performances and in other parts of their lives.

Nonetheless, it is important to note that there was one reported negative outcome from participating in the intervention in a relatively small sample size of eight individuals. While it appears that the incident had no dangerous or lasting negative impact, this incident serves as a reminder that larger studies of ET to facilitate disclosure for WLHIV need to be voluntary and emphasize the safety and well-being of participants. Such interventions will need to recognize that people face different degrees of stigma and risk associated with HIV disclosure that depend on their individual situations, the communities and cultures in which they live, and the degree to which their life challenges (e.g., substance use, depression) are balanced by their strengths and support. Recruitment for future disclosure interventions needs to include assessments of participants' readiness to handle potential negative reactions to disclosure through an evaluation of their individual balance of challenges and support and by exploring the variety and degree of possible risks they may face by publicly disclosing their HIV status. In addition, the intervention needs to have an algorithmic and supportive response to potential negative reactions at each stage of the intervention that includes oversight by, and access

to, a social worker or therapist with expertise in HIV, stigma, intimate partner violence, and danger assessment.

There are a number of limitations of this study. First, Medea is a community-based intervention that was created and led without the intention of formal scientific evaluation. As such, the degree and nature of each participant's exposure to the intervention were not recorded. Future prospective studies are needed – and now warranted – to clarify the optimal duration of participation in this group intervention. Secondly, the intervention did not have a formal protocol and thus can not yet be directly replicated. Prospective studies need to be developed with a protocol that outlines the procedures of the intervention (e.g., recruitment, numbers of sessions, specific content of sessions) and assesses the fidelity of the intervention to these procedures. Thirdly, the small number of participants in this study, as well as the study method, limits the generalizability of study findings to the larger population of WLHIV in the United States. However, no participant had previously publicly disclosed her HIV status, and most had never been involved in a theatrical production of any kind. Furthermore, the demographic characteristics of study participants were similar to the larger population of WLHIV (e.g., most were women of color). Future studies of Medea are needed that include validated measures of health and emotional outcomes such as substance abuse, PTSD symptoms, depression, empowerment, medication adherence, and viral suppression. In addition, although using only one interviewer created consistency and was a strength, it also brought subjectivity, which could be a limitation of our data. Finally, the Medea project is relatively time-intensive and requires the resources of leaders with expertise in ET using theater. Nonetheless, our study identified core components of an effective disclosure intervention for WLHIV that can inform future disclosure interventions of shorter durations, using larger groups or other forms of ET.

Conclusion

Our study identified a highly promising intervention – the Medea Project – a voluntary, effective, and broadly beneficial disclosure intervention for the WLHIV who participated. The positive impacts of the intervention demonstrated by our qualitative analysis call for larger, more formal, prospective studies of Medea and of similar HIV disclosure interventions utilizing expressive therapy.

Key Considerations

- Safe, voluntary, and well-supported disclosure services can substantially benefit women living with HIV.
- One particularly promising method to support safe and effective disclosure is expressive therapy, which empowers women to explore, express, and embrace their personal stories.
- Disclosure services using group expressive therapy are also promising methods to address other conditions commonly affecting women living with HIV, including isolation, shame, low self-efficacy, substance abuse, and the immediate and lifelong impacts of trauma.

Disclosures

The authors report no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.

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Table 1. Core impact themes of the Medea intervention

1. Sisterhood
The formation of deep, honest, and supportive relationships among group members.
 2. Catharsis
Freedom from the burden of secrecy about HIV, childhood and adult traumas, and other stigmatizing experiences.
 3. Self-acceptance
Reframing the understanding of what it means to be an HIV-positive woman, normalizing life with HIV and embracing a stronger and more positive self-identity
 4. Safer and healthier relationships
Developing safe, honest, authentic, and fulfilling relationships
 5. Gaining a voice
Gaining a sense of purpose and accomplishment as an educator and activist and the desire and confidence to change the social norms that create stigma, isolation and trauma
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