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Women's perspectives on ImpACT: A coping intervention to address sexual trauma and improve HIV care engagement in Cape Town, South Africa

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Abstract

HIV-infected women who have experienced sexual violence face unique challenges in their HIV care engagement and adherence to antiretroviral medications (ARVs). Improving AIDS Care after Trauma (ImpACT) is a brief counseling intervention aimed at reducing the negative impact of sexual trauma and HIV, building coping skills, and improving long-term HIV care engagement. We conducted a randomized controlled pilot trial of ImpACT with 64 women initiating ARVs in Cape Town, South Africa, with results suggesting the intervention can reduce PTSD symptoms and increase motivation to adhere to ARVs. For the current study, we abstracted data from ImpACT worksheets completed by 31 participants during intervention sessions, and qualitative responses from post-intervention surveys, to examine mechanisms, facilitators, and barriers to change in the intervention. Data included participant descriptions of the values informing their care, barriers to participation, and perceived benefits of the intervention related to coping with trauma and improving care engagement. During the first session, women reported feelings of shame, sadness, and anger that led to social isolation, mistrust, and damaged relationships. Barriers to participation included work and school demands, issues with transportation, finances, and discomfort in talking about HIV and trauma, particularly in group sessions. Despite these challenges, several women stated they developed more positive thinking, felt more confident, and improved their interpersonal relationships. Participants also reported substantial positive impact on symptoms of sexual trauma and motivation to continue with long-term HIV care, and clearer understanding of barriers and facilitators to ARV adherence. ImpACT is a promising intervention model for building adaptive coping skills and adherence to HIV treatment, informed by personal values, among women with a history of trauma in this high-risk setting. The data also offer insights into strategies to strengthen the intervention, overcome barriers to participation, encourage the practical application of skills, and promote long-term HIV care engagement.

Keywords

Adherence; Antiretroviral therapy; HIV care engagement; Sexual violence; Retention in care; Traumatic stress

The occurrence and impact of HIV and trauma among women are inexorably linked by common risk factors related to HIV infection and transmission, gender-based violence, and sexual assault (Hatcher, Smout, Turan, Christofides, & Stöckl, 2015). South Africa bears the largest burden of HIV in the world (World Health Organization, 2015), with a disproportionate prevalence among women, who are 1.6 times more likely than males to be infected with HIV (Shisana et al., 2014). Gender-based violence and sexual assault are also widespread in South Africa, with studies reporting lifetime national prevalence for women between 27–56% (Dunkle et al., 2004; Jewkes et al., 2006).

Gender inequality in both HIV infection and sexual violence in South Africa is driven by many factors, including limited economic opportunity, lack of power within relationships, and poor access to support and treatment (Chuah et al., 2017; Gilbert et al., 2015; Watt et al., 2016). These same challenges hinder HIV care engagement and adherence to antiretroviral medications (ARVs), which has important implications for long-term health and risk of transmitting the virus (Chuah et al., 2017; Kagee et al., 2011). Trauma symptoms and systematic inequality may also contribute mental health symptoms such as depression and anxiety, as well as unhealthy coping behaviors such as substance use, self-destructive behavior, and the perpetuation of abusive relationships (Gilbert et al., 2015; Leserman, 2008). With increased recognition of the relationship between HIV and trauma, a variety of interventions have been developed to improve HIV care engagement and address emotional distress (Blashill, Perry, & Safren, 2011; Chuah et al., 2017; Sikkema et al., 2013). One promising intervention model has focused on improving coping with trauma-related stressors to encourage positive HIV care engagement (Sikkema, Choi, et al., 2018; Sikkema et al., 2010).

Improving AIDS Care After Trauma (ImpACT), incorporates four individual and three group therapy sessions and includes culturally salient content for the South African setting, including visuals and study activities tailored to reflect the appearance, lifestyle, and history of study participants (Sikkema, Choi, et al., 2018). For example, in one activity, three emotional aspects of personal safety (power, trust, and self-esteem) are represented using a traditional three-legged cooking pot. In a pilot randomized controlled trial, ImpACT participants reported significant decreases in symptoms of posttraumatic stress disorder, as well as improved motivation to adhere to antiretroviral treatment. However, non-adherence to ARVs and poor care engagement were observed among women in both study conditions (Sikkema, Mulawa, et al., 2018).

The inclusion of participants' voices in research can add valuable insights related to study outcomes and must not be overlooked in the design and delivery of community-based interventions. Participant feedback provides unique and practical information that can improve intervention delivery and positively influence outcomes such as ARV adherence and care engagement. In the current study, we examined the mechanisms, facilitators, and

barriers to change in the intervention through content analysis of the clinical notes and qualitative feedback of participants in the ImpACT pilot trial.

Methods

ImpACT participants were recruited from a primary healthcare clinic located in a peri-urban township in Cape Town between March 2016 and March 2017. The area is densely populated, has few community resources, and has high rates of poverty (Statistics South Africa, 2017). Clinic patients receive free HIV testing and care, including antiretroviral treatment (Department of Health, 2015). Women were eligible for the ImpACT trial if they were (a) HIV-infected, (b) initiating ARVs, and (c) screened positive for sexual trauma at an HIV clinic appointment, including experiences of sexual abuse as a child or sexual assault as an adult. The screening process was described in greater detail by Yemeke et al (2017). The study received ethical approval from the institutional review boards of the University of Cape Town and Duke University.

Procedures

A total of 64 eligible participants were enrolled in the trial and 32 were randomly assigned to the ImpACT intervention, while control participants received the clinic's standard of care adherence counseling. Only intervention participants were included in the current analysis, excluding one participant who did not complete any intervention or follow-up visits. All participants were asked to complete interviewer-administered assessments at baseline, 3 months, and 6 months after enrollment, for which they received 100 Rand in compensation (equivalent to approximately \$8 U.S.). The interventionist, a non-specialist in mental health, was trained in the intervention content and supervised by a licensed psychologist.

The Intervention

The ImpACT intervention, described in detail elsewhere (Sikkema, Choi, et al., 2018), was guided by the evidence-based LIFT intervention (Sikkema et al., 2013) and principles of coping theory (Folkman et al., 1991) adapted to the South African clinic setting. Sessions 1 through 4 are delivered individually, followed by three group sessions. In Session 1, the interventionist guides the participant to recognize the impact of past trauma, address the stress of her HIV diagnosis, and identify values that motivate HIV care engagement. Session 2 focuses on developing adaptive coping skills by exploring stressors and introducing active strategies for addressing them. Session 3 connects the themes of the first two sessions by applying the coping model at the intersection of HIV and trauma, identifying structured goals, and making an action plan to address HIV-related challenges. Session 4 allows time to revisit content, review progress, and reinforce skill development. The three group sessions are conducted over three consecutive weeks after the individual sessions are complete, and are aimed at empowering women to share their experiences with others who have faced similar challenges, including a specific focus on exploring efforts and challenges faced as they apply new skills in their daily lives.

ImpACT employs culturally-tailored visuals and activities to engage women and communicate complex content. The “3H” (head, heart, hands) model was designed to

translate cognitive-behavioral models of thoughts, feelings, and behaviors into a more accessible exercise to help participants identify the effects of trauma and HIV on their lives. During the “Values Bridge” exercise, the participant is asked to reflect on her decision-making surrounding long-term HIV care engagement, and how ARV adherence may become a ‘bridge’ to her personal values. The intervention also introduces a kinesthetic “coping pebbles” activity, which prompts women to physically unpack a bag of pebbles representing their stressors, identify the stressors as changeable or unchangeable, and develop problem-based or emotion-based solutions. Such locally-tailored metaphors and interactive exercises were also designed to support the implementation of ImpACT by non-specialists in mental health, increasing the opportunity for future scale-up.

Participant Workbooks and Open-Ended Survey Responses

Intervention delivery was guided by the ImpACT manual (Sikkema et al., 2017) and a participant workbook, which was completed collaboratively by the interventionist and the participant. For two of the activities, the “Values Bridge” and “3H”, worksheets were completed in the session. Participants in the trial also completed baseline and follow-up assessments at 3 and 6 months after study enrollment. At the follow-up time points, intervention participants were asked to verbally respond to the following three open-ended questions/prompts, and their responses were recorded verbatim: (1) Please describe any logistical challenges (for example, finances, transportation, privacy) that made it difficult for you to participate in the sessions, (2) How did you feel the intervention addressed sexual trauma you have experienced?, and (3) In what ways did your participation in the intervention influence your adherence to HIV care? We used participants’ worksheets and open-ended survey responses to obtain qualitative data on their experience in the intervention.

Qualitative Analysis

Data analysis was conducted using an inductive approach based in applied thematic analysis (Guest, MacQueen, & Namey, 2012) and consensual qualitative research (Hill et al., 2005). We used our data sources (participant workbooks and open-ended survey responses) to create a priori domains for analysis. Given the similarity of many participant responses from the 3- and 6-month surveys, these data were combined to form one response per participant and analyzed concurrently.

After the preliminary qualitative domains were identified, three team members independently reviewed the data and developed a preliminary list of themes. Next, team members held joint sessions to create a final theme structure. Team members then independently coded the data and identified representative quotes within each theme. Coders’ responses were cross-checked for inter-coder agreement and adjusted to consensus.

Results

Participants

Participants frequently described a long history of violence, with over half reporting sexual abuse in childhood/adolescence (n=16, 51.6%), and nearly all reporting a sexual assault

during adulthood (n=29, 93.5%). All participants reported they had experienced physical assault in addition to sexual trauma, including 29 (93.5%) who reported violence perpetrated by an intimate partner. Two-thirds of participants (n=21, 67.7%) attended all four individual ImpACT sessions but only 8 (25.8%) attended any group sessions. More than two-thirds of participants (n=22, 71.0%) completed the open-ended questions at one or both time points. Additional participant characteristics can be found in Table 1.

Intervention Content

3H – Head Hands Heart—The 3H activity was conducted during Sessions 1 and 4 and revisited as needed during other sessions. At the first ImpACT session, almost all women expressed feelings of self-doubt, self-criticism, or self-blame as a result of their trauma and HIV diagnosis (see Table 2). Women often felt “used” by others and questioned their worth. As one participant described her sexual trauma, “I was thinking now I was flawed, less of a woman.” Other thoughts women shared, such as not trusting men, having the desire to hurt others, or “thinking too much,” related closely to the emotions they felt, such as fear, anger, and sadness. These emotions and thoughts sometimes manifested in behaviors such as “lashing out” at others and self-isolation. Participants commonly described their trauma experience as negatively affecting their relationships, including blaming others for failing to intervene, friends they did not feel like visiting, or strangers they felt they could not trust.

At Session 4, women highlighted positive changes across the 3H categories, describing increased self-esteem, more positive thinking, and improved relationships with others. Participants often referred to strategies they had learned from ImpACT, and described the improvements as an ongoing process. One woman shared, “I am learning to practice good relationships with people around me.” Several women described a shift in their thinking from focusing on their past trauma to looking ahead to the future, including taking their ARVs. As one woman noted, “I have noticed that I have stopped thinking about how to hurt myself, but instead I’m always thinking about best I can take care of my health.” At the same time, several women acknowledged that they were still “confused,” thought about their abuse, or held on to negative feelings towards others such as blame and anger.

Values Informing HIV Care—In the Values Bridge activity during Session 1, nearly all participants noted that their family, children, and long-term health were the primary values driving their HIV care engagement. One participant shared, “My family would be sad to see me unable to do things on my own if I’m sick. They would hate to see me dying when there was help available.” A majority of participants also listed their work or school as important drivers to managing their HIV effectively, factors closely tied with their desire to provide for their families. “If I don’t take my ARVs, I will get sick, become unable to work and earn salary to take care of my children.” Women also frequently cited the desire to achieve their personal goals or ambitions, their spirituality, and the desire to maintain their sense of dignity as values that motivated their HIV care. As one woman stated, “If I don’t take my ARVs, I may lose dignity. I’m not a strong person but for me not to take my ARVs, that will be killing me more inside.”

Open-Ended Survey Responses

Challenges influencing participation—Participants described several structural barriers to their participation in the intervention, with work- and school-related conflicts being the most prevalent. Participants highlighted various aspects of their jobs (e.g., engaging in transitory shift work, a strict boss, or working long hours) that made it difficult to attend the intervention sessions. Transportation logistics and costs were also a barrier to participation, such as one woman who borrowed money from her sister to pay for the taxi and expressed worry that she had spent “their last money which could have been used for something important like buying bread or electricity.”

In addition to structural barriers, a few women stated that privacy concerns made it difficult for them to participate in the intervention, especially the group sessions. One participant explained that she was “afraid that I might be seen by a participant who knows me and who might go around discussing my problems.” A small number of women also expressed difficulty talking about past trauma. Women reported weighing the emotional challenge of talking about their trauma against the helpfulness of the support they would receive. As one woman noted, “The sessions would irritate me when we talked about my rape; I hated to talk about it even though when I had talked about it, I would feel better. My heart would feel sore. Even talking about my HIV status irritated me because I still beat myself for infecting my child”. The experience of this participant speaks to the difficulty of addressing multiple complex stressors, which may have caused some women to choose not to participate or not complete the intervention.

Influence of intervention on sexual trauma—When asked about how the intervention addressed their sexual trauma, it was common for women to talk about how the sessions gave them an opportunity to reflect and improve their understanding of what had occurred and how it impacted their lives. One participant described, “I learned more about my anger, why do I get this angry? I got to understand that it is because of the trauma I went through.” The improved understanding resulted in the women feeling stronger and having improved self-esteem. Group participants reported that they felt less alone in their experiences now that they had shared them with others. One participant said she realized that “not talking about [the sexual trauma] made it even more traumatic.” A few of the women said this was the first time they had ever disclosed their trauma. One of these women explained, “I decided to open up to [the Interventionist] as I knew that everything was private and confidential and I would not be judged.” Importantly, several women emphasized that the intervention allowed them to stop blaming themselves for their abuse.

As a result of the intervention, many participants felt they were able to actively cope with the trauma as opposed to avoiding it. One woman who had been avoiding her sexual trauma by frequenting a local bar shared, “Being in the intervention has helped me to understand my pain and to think better thoughts about myself...It’s been 3 months since I stopped drinking as it used to be a way for me to escape reality and trauma.” Specific skills and activities from the intervention were cited as tools that the participants now used to cope. For example, one woman said, “the intervention helped me as I would think of changeable and non-changeable stressors from the pebbles activity”. It is notable, however, that a couple of

participants talked about how their ongoing abuse resulted in a lack of progress. One of these women said, “I still feel shattered inside as I was again sexually abused in the past 4 months.”

Influence of intervention on HIV care engagement—When the women were asked how their participation in the intervention influenced their engagement in HIV care, nearly all of them noted that the sessions improved their motivation to adhere. One participant said, “I don’t think that I would have adhered to my HIV care if I was not part of the intervention. When I started the intervention, that’s when I became stronger.” For many participants, this motivation was directly linked to their new appreciation for how HIV care could help them achieve their goals. “It’s difficult to take ARVs. You feel emotionally heavy and hopeless. So when that happens, I would get irritated by my meds, but that’s when I would also think of my goals and how I need to balance my life. The [Values] Bridge helped me a lot in this regard.” Many of the participants also described how the support of the intervention helped them overcome barriers to getting their care; however, a few participants noted that the benefits of the intervention were outweighed by barriers such as substance use or denial of HIV infection, which ultimately made it difficult to stay engaged in HIV care.

Discussion

ImpACT is a brief intervention aimed at improving active coping and long-term care engagement for women with HIV and a history of sexual trauma. In a pilot trial, we delivered the intervention to 31 women, many of whom reported improved symptoms and that they felt better equipped to implement adaptive coping strategies. This qualitative analysis of women’s perspectives on ImpACT offered valuable insight into the mechanisms, facilitators, and barriers to change in the intervention.

Women described their experience in the intervention as positive and impactful. Their improvement was strongly informed by personal values of maintaining their health and well-being to support their families and achieve personal goals. Despite their overall positive perceptions of ImpACT, women reported substantial barriers that made it difficult to attend sessions, and which may also influence their long-term care engagement. By not completing all of the intervention sessions, many women missed content aimed at assisting them through the trial-and-error process of applying new adherence skills in their daily lives. Additionally, some women reported experiencing ongoing trauma and would benefit from continued support as they seek to navigate these difficult situations. To ensure that we are adequately prepared to address these challenges, we will incorporate the topic of addressing ongoing trauma into the training protocol for future interventionists, informed by principles of trauma-informed care (SAMHSA, 2014).

A longer, more intensive intervention may address several identified concerns by encouraging reinforcement and skill building related to long-term treatment adherence (Cooperman et al., 2012; van Luenen et al., 2018). Therefore, one approach under consideration for future iterations of ImpACT, is to deliver six individual sessions followed by six maintenance sessions emphasizing problem-focused coping and the practical application of intervention skills (Satterfield, 2008). Such a format allows for the

individually tailored application of session content based on the needs and challenges faced by each participant. The longer format could also provide support for ongoing traumas that may occur during the course of treatment and allow more time for rapport-building, which may assist participants in processing the emotional burden of sharing trauma experiences (Schnyder et al., 2015). Participants who attended group sessions felt they were beneficial; however, groups were not well-attended. Because of the reported barriers to groups - including concerns about privacy, shame, and stigma - individual sessions may be more feasible in this setting for new ARV initiators, while group sessions may be made available for more established patients who have had more time and support to accept their diagnosis. Finally, women reported substantial barriers in reaching the clinic for intervention sessions, but we nevertheless had very high attendance for the weekly individual sessions. New ARV initiators appear highly motivated to seek emotional support; however, there is a potential for this motivation to wane over time. To address this potential challenge in a longer intervention, we will align later, monthly intervention sessions with existing clinic appointments to minimize trips to the clinic and time away from normal activities.

The results of the study should be interpreted in light of the following limitations. Intervention participants who did not provide data for this paper were more likely to have been lost to follow-up at the clinic. Additionally, the focus of the pilot trial was to improve care retention among new ARV initiates. Participants who did not complete the intervention, or were not eligible for the study, likely experience additional, and possibly unique, challenges that were not captured in our data. Future studies may seek to explore similar care engagement challenges among these groups.

Interventions for trauma among people living with HIV are urgently needed to improve the long-term health and well-being of this key population. Future studies may see the greatest positive impact with sustained interventions focusing on reducing structural and emotional barriers to participation and emphasizing the practical application of coping skills.

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Table 1.*Characteristics of study participants (n=31)*

Variable	n (%)	Variable	n (%)
Age in years, mean	30	Relationship status	
Range (18–44)		In a relationship, not married	26 (83.9)
Race/Ethnicity		Married	4 (12.9)
Black African	31 (100)	Single	1 (3.2)
Employment Status		Education	
Not employed	19 (61.3)	Less than high school	25 (80.6)
Employed full-time	10 (32.3)	Completed high school	5 (16.1)
Employed part-time	2 (6.5)	Completed university	1 (3.2)

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Summary of themes from ‘3H’ activity examining impact of trauma on thoughts, emotions and behavior at first and last session

Table 2.

		FINAL SESSION (n = 19)				
		BASELINE (n = 31)				
	Themes	Cases (n)	Illustrative quotes	Themes	Cases (n)	Illustrative quotes
Head (Thoughts) 	Self-doubt, self-criticism, regret	29	"I blamed myself." "I thought something was wrong with me."	Less rumination, self-doubt, worry	13	"I have learnt not to overthink things." "I don't think about the trauma anymore."
	Fear, mistrust	11	"I didn't trust men." "I thought the world was not safe."	Positive thinking, hope, self-esteem	9	"I'm learning to love myself." "There's absolutely nothing wrong with me."
	Persistent worry, rumination, wondering why	11	"I was always thinking too much." "I would think 'why me?'" "I asked questions that had no answers."	Motivated for positive change, focused on future	8	"I'm thinking of how I can best take care of my health." "I have learned avoidance can undermine HIV care."
	Hurting self or others, aggression	8	"I thought of killing myself." "I would have the desire to hurt others." "I became very aggressive."	Still ruminating, doubting self	5	"I still think a lot about the abuse from my ex-boyfriend."
Heart (Emotions) 	Sad, empty, unloved, hopeless	30	"I would feel sad all the time." "I would hurt so much."	Content, loved, healed, happy	17	"I now have peace within me." "Less burdened by trauma."
	Anger	21	"Angry at everybody." "I would want to hurt them first instead of them hurting me."	Confident, trusting, clear-headed	10	"I know that it happened, but I feel that it shouldn't worry me." "My confidence is back."
	Fearful, nervous, no trust	18	"Scared that he might do it again." "I couldn't trust men, even my brother."	Still sad, angry, fearful, ashamed	5	"I still feel angry" "I still blame my family." "Still scared of men."
Hands (Behavior) 	Guilt, regret, shame	13	"Felt like everybody knew what happened to me." "I blamed myself."			
	Damaged important relationships	23	"Relationship with my parents was compromised." "Stopped phoning my family"	Seeking/repairing relationships	12	"I changed the way I speak and talk with people." "Now I know what kind of relationship I want to have."
	General social isolation, distance	22	"I shut down and kept in the house, scared to be around people."	Less reactive, less angry	10	"I no longer bully people and my temper is more manageable."
	Outward anger, temper, lashing out	16	"I find it difficult to control my temper and always lash out."	Opening up, more trusting	8	"I'm learning to open up to people and learning to trust people."
Mistrust, suspicion of others	13	"I used to not trust people." "Do not trust men."				
Blame others for not protecting her	9	"I would blame my family for not rescuing me."				"I work with determination and don't put HIV in my way." "I'm able to change the stressors that I have."

Note. n = number of cases where theme was present. '3H' graphics used with permission from Sikkema et al. (2017).

Table 3.

Summary of qualitative themes related to values, barriers and impact of the intervention

Domains and Themes	Cases (n)	Illustrative quotes
Values informing HIV care (n=31)		
Children, Family, Partner	30	"I don't want to lose my children, I don't want them to lose me" "My partner supports me. He may be disappointed in me and hurt if I don't take my ARVs."
Health	28	"If I don't take my ARVs, I risk my life. I may get sick & die" "I'll get sick from opportunistic diseases like meningitis or TB."
Finances, Work, School	23	"I may lose my job and I'll be jobless and penniless" "I won't have energy to go and look for work" "I won't have strength to study"
Achieve Goals/Dreams	11	"I want to become a businesswoman. If I don't take my ARVs, I'll be forever sick." "My dreams of going back to school will be shattered."
Religion/Spirituality	7	"If I don't take my ARVs, I will lose my faith in God and I will start questioning God for things that I could do to help myself"
Maintain Home/Household	6	"I'll become sick and unable to care for my house" "I have a dream of building a home for me and my children"
Dignity, Well-Being	6	"If I don't take my ARVs, I may lose confidence in myself" "I may be stigmatized. I may die. I will lose my self-esteem."
Barriers to Participation (n=22)		
Conflicts with work/school	11	"Had to rush back to work." "Difficult to get a few hours off."
Transportation issues, distance	7	"I now live far away and did not have taxi money."
Financial barriers, cost	6	"Getting to the clinic would be a challenge as I do not work and often had to borrow money."
Concerns about privacy	4	"Might be seen by a lady participant and she might go around discussing (my) problems with people in the community."
Impact on Sexual Trauma (n=22)		
Felt stronger, improved self-esteem, self-understanding	17	"It made me feel better and lighter inside." "I felt relieved in my heart, I feel important."
Improved coping, reduced avoidance, empowered to act	15	"Helped me to deal with emotions that I had been avoiding." "Avoiding a problem is not a solution." "Needed help to empower myself and cope better." "I have since left the abusive relationship."
Benefits of disclosing trauma, receiving emotional support	11	"For the first time I was able to disclose my sexual trauma." "I was able to communicate my feelings and choose what was right for me."
Impact on HIV Care (n=22)		
Improved motivation to adhere	19	"It helped understand the importance of adhering to my HIV Care."
Connected personal values with importance of HIV care	16	"The program made me realize that without HIV Care, my dreams won't come true." "Made me see the importance of my medication."
Felt respected, supported, more confident to overcome stigma	11	"I felt respected and that made me confident in coming to the clinic for my ARVs." "The research staff boosted my morale."
Benefits of the program were outweighed by barriers	4	"I am not taking my medication...because I have no food to eat with them." "I still struggle over the weekends due to my drinking."

Note. n = number of cases where theme was present.