Published in final edited form as:

Glob Public Health. 2013 ; 8(1): 90–105. doi:10.1080/17441692.2012.699539.

“I think my future will be better than my past”: Examining support group influence on the mental health of HIV-infected Rwandan women

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Abstract

Urgent need exists for improved psychological services among HIV-infected women in post-genocide Rwanda. Psychological problems associated with trauma and sexual violence (i.e. depression, PTSD) place women at increased risk for sexual risk behaviour, low health-seeking behaviour, delay of antiretroviral therapy (ART) and reduced ART-adherence. We explored experiences of HIV-infected Rwandan women attending psychosocial support groups and their narratives about how participation affected their mental health and HIV treatment.

Focus group discussions examined why participants attended support groups, whether participants perceived support groups as beneficial to their psychological well-being, influenced ART-adherence, and other influences on health behaviours and attitudes. Rwandan women (aged 18-65) were randomly selected from 10 health clinic-facilitated support groups for HIV-infected trauma survivors in Kigali.

Results identified positive psychological and physical changes as well as behaviour changes in relationships with men, which participants attributed to support group attendance. Data showed significant improvement in mental health, ART-adherence and HIV-serostatus disclosure resulting from group attendance. Participants acknowledged limitations of support groups with respect to addressing poverty and hunger. Implementing psychosocial support groups may leverage clinical outcomes and rejuvenate the well-being of HIV-infected women with interpersonal trauma and/or PTSD and depressive symptoms, particularly those from post-conflict countries.

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Keywords

HIV; Rwanda; post-conflict; mental health; ART-adherence; support group

Introduction

During the 100-day Rwandan genocide of 1994, an estimated 1,100,000-1,900,000 people were murdered and more than 250,000 women and girls were raped, resulting in tens of thousands becoming infected with HIV (Human Rights Watch 2004, 1996, SURF 2012). Rwandan survivors of genocidal rape have a disproportionately high rate of documented HIV-infection (66-80%) compared to the Rwandan population (African Rights 2004, Whetten 2008). Evidence further suggests high rates of chronic mental health problems associated with interpersonal violence among women and girls post-Rwandan genocide contribute to poorer quality of life and elevated rates of morbidity and mortality (Donovan 2002, Uwimana 2007, Cohen *et al.* 2009, Zraly *et al.* 2010). Somatic anxiety, depression and posttraumatic stress disorder (PTSD) can be largely disabling among this population (Hagengimana *et al.* 2003, Cohen *et al.* 2009, Neugebauer *et al.* 2009, Zraly *et al.* 2010). Psychological problems associated with trauma and sexual violence have been repeatedly shown to place women at increased risk for sexual risk behaviour, low health-seeking behaviour, delay or non-initiation of antiretroviral therapy (ART), and reduced ART-adherence. These outcomes can result in rapid disease progression and worse HIV-related prognosis for HIV-infected women (Kaplan *et al.* 1997, Stober *et al.* 1997, Teti *et al.* 2006, Leserman *et al.* 2007, Simbayi *et al.* 2007, Cohen *et al.* 2009).

Culturally appropriate and holistic counselling can improve mental and physical health of traumatised individuals (Mollica 2004). Multiple mental health issues warrant more specific psychosocial services rarely available in sub-Saharan Africa. At best, HIV voluntary counselling and testing services are the closest most African nations have gotten but are inadequate for dealing with individuals experiencing traumatic consequences of war, torture and rape survival (Moreno *et al.* 2003).

Previous studies conducted in sub-Saharan Africa indicate that psychological interventions can reduce mental health problems. A trial conducted in rural Uganda reported that treatments building support were effective in treating depression and dysfunction in female survivors of assault or abuse (Bolton 2003). Psychotherapy-based interventions among internally displaced adolescents in war-affected northern Uganda led to improved depression symptoms among adolescents (Bolton *et al.* 2007). A qualitative study on the effects of counselling for HIV-infected women in Zimbabwe concluded that continuous support group counselling was important in overcoming isolation (Krabbendam 1998).

Despite high rates of anxiety disorders and depression among female trauma survivors, in Africa specifically, mental health remains largely neglected outside the context of clinical trials research (Jacob *et al.* 2007, Saxena *et al.* 2007, Bird 2010). Studies throughout sub-Saharan Africa have shown that treatment of mental health problems is considered a low priority at national and regional levels (Bird 2010). Mental health services are under-resourced and inequitably distributed within and between countries in sub-Saharan Africa.

Seventy percent of countries in Africa spend <1% of their total health budget on mental health, and 90% of countries have <1 psychiatrist per 100,000 people (Saxena *et al.* 2007, Jacob *et al.* 2007). Attempts to provide traditional Western-style concepts of psychological interventions have not been easily accepted among African populations (Ae-Ngibise *et al.* 2010). Stigma and cultural apprehensions surrounding the disclosing of –and treatment-seeking for–psychological issues have been prohibitive. Additionally, fear of gossip and a general lack of privacy have presented challenges in implementing and engaging women in psychological services (Hugo *et al.* 2003, Bruwer *et al.* 2011, Chaumba 2011). Therefore, it is unclear whether support groups would be feasible and acceptable approaches for engaging HIV-infected women in post-conflict settings who are coping with compound traumas of genocidal violence, rape, loss of family and HIV-infection. Also unclear is whether para-professionals trained in trauma counselling are capable of delivering these approaches, and if the dual traumas of genocide-survivorship and HIV diagnosis might be enough to tip the scales in favour of breaking through these barriers.

This study explored the lived experiences of HIV-infected Rwandan women who regularly attended facilitated support groups and explored women's narratives about how group participation affected their mental health and HIV treatment. Through focus group discussions, we examined: (1) why participants attended support groups, (2) whether and how these support groups were perceived by participants as beneficial to their psychological well-being, (3) whether and how support groups influenced their ART decision-making and/or treatment adherence, and (4) other ways the support groups influenced participants' health behaviours and attitudes about their lives and future.

Methods

Participants

Four focus groups were conducted involving 18 women who were randomly selected from 10 support groups of HIV-infected trauma survivors in Kigali, Rwanda. All participants experienced trauma from rape (12 during genocide, six at another time), five from physical abuse/violence during genocide and eight lost family during genocide. Women's Equity in Access to Care and Treatment (WE-ACTx) provides HIV care to Rwandan women, including support groups which have the mission to provide HIV-infected Rwandan women safe places to discuss experiences, fears and shared trauma. Support groups were held weekly in various districts of Kigali and were facilitated by two Rwandan para-professionals trained in trauma counselling. Women were invited to participate in focus groups if they regularly attended for at least one month. Participants were HIV-infected Rwandan patients at the WE-ACTx clinic, aged 18-65.

Procedure

Focus groups were conducted at WE-ACTx in private rooms to ensure confidentiality. No WE-ACTx staff members were present during focus groups. An English-speaking Rwandan assistant trained in focus group facilitation conducted focus groups in Kinyarwanda; an additional observer was present to record discussion group dynamics. Standard questions were administered at all focus groups, exploring issues and concerns among participants,

perceptions of benefits and/or limitations of support groups, beliefs about positive/negative effects of group attendance on their mental and physical health, reports on behaviour changes associated with attendance, and motivations to attend the groups.

Focus groups lasted up to 120 minutes. Discussions were recorded and transcribed into English within 72 hours. Participants were reimbursed for travel. IRB approvals were obtained from Brown University and the Rwandan National Ethics Committee, and written informed consent was obtained prior to participation.

Data analysis

Data were analysed from English transcriptions on a line-by-line basis using both inductive and deductive coding, facilitated by NVivo8 software. Individual trends and crosscutting themes were identified by an initial coder, and discussed with a second coder to validate emerging codes. Codes were organised into thematic categories and secondary subthemes were identified. Data were coded in an iterative manner, constantly comparing and renaming categories and memoing signs of emergent patterns regarding the relationships between the categories.

Results

Four crosscutting themes were identified, each with several sub-themes (Table 1).

Theme 1: Internal psychological changes

Participants described internal changes that initially resulted from support group involvement, establishing a foundation for psychological healing where feelings of safety, stability and trust began to emerge. Participants reported feeling respected and that support group involvement provided opportunities to disclose their personal stories in a safe setting free from abuse or shame.

Perceived safety and validation—Participants described that sharing with and being heard by their HIV-infected peers were core needs that were satisfied by support groups. They reported experiencing less loneliness and increased connection and unity with other group members following their steady involvement in the support groups. Discussing each other's experiences allowed participants to regain a sense of compassion for others, which was frequently diminished after years of compounded trauma during and following genocide. Normative conditions in post-genocide Rwanda provide limited opportunity for HIV-infected women to connect with each other; consequently, the support group provided a setting for establishing camaraderie. Indeed, participants reported having no other places to seek support for HIV-related psychological needs or emotional well-being. One remarked:

“You know when I came to the groups we didn't used to talk about HIV, we didn't have friends. And here we met women who have the same problem, we talk, we discuss, we visit each other. I really like the group discussions so much”.

Another remarked similarly:

“I first came to the support group because before I was living alone and I didn’t have anyone to talk to about my problems. Now I joined the group and I can discuss with the other women. Even if our problem can’t be resolved, we at least share our experience and get feedback from our (peers). For me I didn’t even used to talk to my neighbours because I was thinking that when I talk to them they will think I’m HIV-positive and even might not want to talk to me. But for the support group, because we have the same problem, I talk to them and I tell them my own problems and they help me to resolve (them)”.

Both statements reflect the challenge facing women who lack a setting for freely discussing issues related to living with HIV and the silence they regularly endure. Despite availability of government/church programmes for HIV-infected individuals, participants reported not experiencing openness, unity or lack of stigma before attending these support groups specifically for HIV-infected trauma survivors.

Strengthened interpersonal connections—Several participants frequently described counsellors and peers in the groups as family, sometimes replacing families lost due to HIV stigma or genocide. Post-Rwandan genocide, high levels of dual stigma surrounded victims of rape, which was often associated with HIV-infection. Participants described isolating themselves as means of self-protection from stigmatisation. Therefore, re-emerging feelings of unity and connection with others, as described below, provided a catalyst for improved social functioning and the beginning of psychological healing from compounded trauma:

“You know the group is a kind of family. I came from a family of 17 and they all died and I was alone. I felt loneliness all the time. When I came to the group I took the members as my family, I can express myself. When I have a problem I talk to them and then we share the experience and then I feel I’m not the one who has problems. Ok I was facing the problem of my children, they were saying ‘We don’t want to go to school mom, why study because we don’t have someone to show the results to’. But after joining the support group I made friends and then I told my children ‘Ok you have the aunts, I have these sisters. You go now and show them your results’. So the support group helps. Even my children go and spend the night with their friends and then when my children come back and say ‘Mom, do we have a relationship with that family?’ and I say, ‘Yes, they’re your aunts’. So they go and spend the nights with their kids and then even my children feel happy because we made new friendships from this group”.

Another woman describes complicated social functioning post-genocide and her feelings of freedom within the group from the weight of genocide-related trauma experienced:

“You know those women who are helping us, the counsellors, they are so good and they help us a lot. When we meet them we feel comfortable and they give us advice. Sometimes when we come here most of us we were out of our minds so they tried to calm us down and then discuss with the other group members. Those counsellors taking care of us, nothing bad happened between us – we can even dance with them and cry with them, we can do whatever”.

This support further extends to experiences of HIV medication and psychological stress:

“So, you know when we are here we feel that we can even stay here without going home because the experience we share here, we cannot share with neighbours. Sometimes when I have a problem with my medicines I come and talk to women here but I can’t talk to my neighbours because they don’t take the medicines”.

A shared sense of experience, especially surrounding ART, was a frequent source of connection. Women found relief in having a safe space free of shame or reprisal where they could relate common experiences and concerns, fostering a unique sense of community previously unfulfilled.

Feelings of ‘rebirth’ and motivation to survive—Participants described support group conversations as “life-changing”. Narratives often revealed experiences of ‘rebirth’ among participants, such that prior to group attendance, depression and fear were so great that they frequently questioned their ability and willingness to survive. Through the affirmation and instruction derived from support groups, many women experienced rekindled purpose in their lives. One remarked:

“...When I came the first time I was even thinking of killing myself because I thought ‘Well, I will die, why not kill myself before I die’. Then when I joined the group they told me how life would continue. Sometimes, before I decided to kill myself, I was thinking ‘If I kill myself my children won’t have anyone to take care of them’. So I decided to kill them before me. Then I was planning to kill them one day and to kill myself the next day. But it was (then) I decided to come to the support group and they told me that my life would continue and I have to take care of my children. They really helped me. They told me my children still needed me beside them and so I decided to not kill them or myself. So I think that the group is very important and I’m focused to live”.

Another expressed:

“You know before I came to the support group I didn’t even sleep through the night, I was crying every day in my bed. I didn’t have anyone to help me; I didn’t have anyone to listen to me. But now I see that I can talk and share my experience with the other women – so I think we can keep the debates and conversations in the group. It has saved me”.

Frequent references to being ‘saved’ and motivated ‘to live’ reflects this healing process potentially occurring through effective psychological intervention. A stronger motivation and will to survive appeared to be a fundamental step in coping with the aftermath of multiple traumatic events in the lives of HIV-infected genocide survivors.

Feeling competent to interact with the outside community—After connecting with other women in the support group and recovering motivation and a purpose to life, participants described feeling better equipped to connect and interact outside the groups, including with partners, children and community. Women recounted an improved sense of social functioning, beginning first within the safety of support groups, then inching outside groups extending to their families and eventually communities. Frequent positive

reinforcement was reported from support group peers, even if things did not go well in attempts at interacting with non-group members. One remarked:

“Before I joined the group I was always very sad. If someone came to see me and asked the neighbour ‘Oh, is that the woman who is HIV-positive?’ and when I heard that I was very angry at them, I was really hating them and didn’t even want to talk to them. Since I came to the group I’ve showed them I’m HIV-positive and I talked to them about my sickness. Nowadays after coming to the group I don’t have any conflict with neighbours. I know how to handle them. I’m feeling comfortable when I talk to them and it’s because of the support group”.

Theme 2: Physical and mental health changes

As participants experienced greater self-esteem, hope and self-efficacy, they were able to achieve tangible improvements in their physical and mental health. Achieving and recognising these positive changes demonstrates progression in the healing process –moving from solely internal concentration toward awareness outside of the self.

Perceived relationship between physical health and support group

involvement—Participants identified links between increased emotional connection with other support group members and changes in their physical health. Narratives revealed acknowledgment of personal physical and mental health changes following new support group relationships. One woman realises:

“...Before I came I was suffering from headaches – every day I was suffering from headaches – and then after meeting with counsellors and the other women, we’ve shared our experience and now I’m feeling better”.

Others remarked on attributed changes in their HIV illness and somatic symptoms with support group involvement:

“...When I came back from having the test and saw I was HIV-positive and my husband wasn’t, he decided to tell everybody I’m HIV-positive. Then the people were yelling at me everywhere I go, saying, ‘Oh she’s HIV-positive!’ I was losing my CD4-count every single day. After he left me and I was staying alone, my CD4 was 500, but now it’s more than 1000 because I started talking. I talked to those neighbours and telling them ‘What he said is true, I’m HIV-positive. You just have to ask me, you don’t have to yell at me, and I will give you more information’. So now I see that the group helped me talk about my HIV”.

“I came the first time and I met with a woman who told me that ‘Even if I see that you have so many (health) problems because you didn’t sleep the whole night, but when you come to the support group maybe you will sleep and then maybe you will get better.’ The next day she took me to the support group and now I’ve joined the group like that and now I do sleep and I’m feeling good.”

As participants’ perception of relationships between their physical and emotional health shifted, support group benefits became more tangible, thus, more value was attributed to

their group experiences. As this occurred, perception of a symbiotic relationship evolved between group participation, emotional well-being and their physical health.

Return to health, work and normalcy—Some women described improved mental and physical health functioning permitted them to return to work after periods of extended depression. In turn, work provided an improved sense of personal competence, self-esteem and independence. One woman expresses:

“Since I attended the support group, we have a group of women that weave the bags. Through the business of weaving bags, I get money and then I bring the money home. Now I’m not depending on my husband, we both work mutually. I think that because of the group it’s helped me to deal with that problem at home”.

Notably, some participants reported how involvement in support groups with other HIV-infected women allowed them to transcend their HIV-status by minimising perceived restrictions that HIV poses on their lives. Women described feeling less shame and stigma about their HIV-status, and reported feeling equally capable to engage in the same activities as HIV-negative women. One expressed:

“Before I was thinking that no one could be involved in my life and with my problems. I was not feeling comfortable within my family and friends. But now I’m feeling good and I’m feeling more comfortable with (them). Everything I’m feeling now, I’m feeling as other people do. I don’t feel like an HIV-positive woman. So I don’t feel any difference between me and other people because we are the same”.

Another expresses transcending HIV:

“...When we’re talking about HIV, we’re thinking that we’re not HIV patients. HIV patients are those in hospital, who are suffering. So it means that we’re as strong as other women and we need to talk to people about HIV and we don’t see any reason not to tell people about our HIV. HIV is like a neighbour for us. If you are living with a neighbour and you take him seriously, you don’t fight with him, you can feel better with him...”.

Theme 3: Changes in behavioural choices

Participants described transformative effects on their ability to engage in new behaviours that promote the well-being of themselves and their children as new expressions of internal changes. The opportunity for women to learn something new that directly impacts their lives was highly valued among participants. Participants often reported skills learned from the support group -managing everyday life; ART and health; raising children; improving relationships with partners:

“So those counsellors told us how we could behave in the community. Sometimes people, even if they are HIV-positive, if they don’t have such education, they continue to be involved in bad actions like prostitution. But here they told us how to behave in a community. Those who have husbands how they can care for them....this is the reason we keep coming to the group. Those women are good”.

These behavioural changes illustrate the evolution this healing process has taken for them, which has moved from an internal spark to outward reflections of new thoughts, feelings and health and circling back to inform women's new decision-making. Women described behavioural empowerment in four domains -adherence to ART medications, HIV-status disclosure, relationships with men, and pro-social/helping behaviour.

Reported increase in ART-adherence—Support group members reported improved understanding of the importance of medication adherence, attending scheduled appointments, and behaviours affecting HIV clinical indicators like CD4-counts. Repeated messages received from both counsellors and peers reinforced new behaviours that doctors occasionally mentioned. Opportunities for women to repeatedly receive these health promotion and behaviour change messages in support groups allowed for improvements in HIV treatment. Groups provided forums to better understand HIV disease progression, importance of CD4-counts, and to discuss alternative ways to handle ART complications. This empowered participants with hope and choices in maintaining their treatment. Two participants stated:

“I met with (support group) counsellors and they told me how I will survive with HIV. ...I now learned the importance of taking medicine on time and respecting appointments with doctors. Before I attended, the doctors used to ask me if I was taking the medicine at home and I used to say ‘Yes, I take them’ but I was lying to them. I didn’t take them. Now I want to stay in the support group because everything has been changed in my life”.

“I will keep coming –I will never stop coming to the support group. ...I think that’s because...they teach us how to eat well, how to prepare the good food that will increase our CD4. Also how to behave in order to increase our CD4”.

Increased HIV-status disclosure—Participants reported that support from HIV-infected peers played important roles in increasing their comfort to disclose their HIV-status to family members, especially children. The potential need for women to send children to the clinic to retrieve ART on their behalf if they fell sick was frequently a motivating factor. Support group discussions frequently noted the importance of disclosing to children as a measure of maintaining health. One woman shared:

“I have a daughter who is 18. I didn’t talk to her about my HIV. Before I attended the group I used to have my medicine in my room and I didn’t even talk to her about HIV when she asked me about that medicine. I told her I’m suffering from the stomach; I didn’t want to tell her about HIV. But since I started coming to the group, they told us it’s not good to have a kid who doesn’t know that you’re HIV-positive because sometimes you can get tired and you may not be able to go get your medicine so you can send them to get it. So I decided to talk to my daughter about my HIV”.

HIV disclosure provided opportunity for some to foster improved relationships with children by facilitating parent-child communication and, consequently, alleviating mothers’ feelings of isolation:

“...Before I attended the support group, before or after eating, I’d send (mychildren) to bed at 6pm because I didn’t want them to have any time to talk with me. Now I’ve told them about my HIV. Now when I go home I talk to my children, I want to know how they’re feeling, I want to share my daily experiences with my children. So now I’m feeling comfortable within my family”.

Changes in behaviour with men—These new choices have been empowering decisions that participants have made, despite often difficult and painful ones. Oftentimes women report no longer seeking relationships. Those who are married report educating their husbands on HIV (often aided by trauma counsellors) and insisting on condom use. One woman shared:

“At this time we don’t feel that we need a husband, that we don’t need a man to be with us. Sometimes we discuss in the group and then we don’t see the importance of being with a man every day or having – sleeping with a man. So now we are able to stay and survive without meeting with men. Because of the group our behaviour has been changed about those issues of sexuality”.

Another shares a different experience:

“You know sometimes we don’t have husbands and we can even think of having husbands or partners but the support groups give you advice about having partners with the problem of HIV. That helps us to care about having partners when we are in the group. You know we are HIV-positive and they give you a good way to have partners”.

The decision for women to forego potential relationships, albeit extreme, speaks to underlying steps to personal independence. The choice to not have a partner shows progress in the departure from victimisation/powerlessness in personal relationships. Additionally, this shows a nuanced way that women are reconsidering the roles of relationships in their lives.

Pro-social and community helping behaviour—In contrast to described past isolation, support groups encouraged women to become more involved in the lives of their peers and within their community. Increased concern for, and involvement with, peers serves as a potential indicator of women’s return to ‘normalcy’, emotional stability, and personal empowerment. One woman shared:

“...When we are here we make a special kind of friendship. Suppose one of us fell sick, we go see her, we prepare food for her, try to console her and discuss what we can do to make her better. And when we go to see her in her area, no one will ask why we come, we go there to visit as a friend, not as an HIV-positive person”.

Others remark on feelings of responsibility as support group members:

“...After (the group) gave me that hope, then I want to share that with other people suffering from the same problem as I do”.

“...I have a desire to help people. I used to go to hospitals and then I’d bring food, I bring the milk and give it to the patients because I believe that when you help –

when you are suffering from HIV, you have to help others who are more sick than you because as we participate in the group, we're feeling better".

This pattern of pro-social behaviour reflects the sense of rebirth and motivation, described earlier, manifested in the willingness to help others and exhibited improved social functioning. Indeed, some women emerged as advocates for HIV testing and education, working in local churches and organisations to reduce HIV stigma:

"The experience I have helping others (is) talking to them, telling them about the impact of HIV on their life. Sometimes I have experiences of telling people to come...take the test. If they find that they're sick, then they can join the groups. ... For instance I didn't even used to talk, but now because of support group I can talk... Not because I was shy, because I didn't know how to talk about HIV. But now because of group I'm able to talk with others about HIV, take them to the clinic, and after, telling them that we have a support group too".

"...I have a group of women that I already helped about how they weren't wanting to go to the clinic to do the HIV test. But I tell them 'You have to go to the clinic to see if you're HIV-positive'. Then after...every day the women come to see me because they want me to advise them... They came to me and told me that I helped a lot and then when I help I feel comfortable and I think maybe even God will reward me because I helped other people. So I think I'll keep helping others living with HIV...".

New behaviours since attending the support groups have been significant sources of self-esteem for participants, illustrated by new confidence in caring for their children and husbands, and their ability to reach out and help in their community. Many women reported a sense of pride connected to both their ability to support their family and their ability to re-connect with them.

"Before I came here I didn't even know how to take care of my kid who was HIV-positive but now I know everything I need to know... Now she is...doing well at school...and she's feeling better because I talked to her about HIV and I've taken care of her needs. Everything is because I've participated in the support group and they told me how to take care of her. I believe I'm a good woman because I did my job well and that's because of the group. I hope that will help me and my family to continue to be better".

Notably, several women discussed their involvement in the post-genocide development of Rwanda and expressed hope for change in themselves and their country. Findings speak further to the notion of revitalisation –of both the self as well as the nation –and transcending HIV.

"I think everything has been changed, because when we come to the support group we feel that we're updated in our own development, we're active in our country development, we want to stay to live a long time, we're able to work any job".

Theme 4: Support group limitations

Although participants report receiving numerous benefits from support groups, they acknowledged the groups' limitations to address overarching issues in the context of post-genocide Rwanda and how that affects their quality of life progress.

Poverty and hunger—Many participants expressed that their primary problem was no longer HIV but poverty. Although support groups educated participants on how health is impacted by stress, proper nutrition, etc., they were unable to satisfy needs for income or food sources. Participants reported that poverty in Rwanda is the primary barrier to maintaining a healthy lifestyle and implementing life skills derived from group involvement. One woman remarked:

“The common question that we have is that we’re HIV-positive and we’re poor. We want...to see if there is some suggestion on how we can improve our life. Sometimes if you’re HIV-positive but you have food, you have shelter, you have a house, you can even live alone. But when you don’t have food, you don’t have a house, you can even die before your time. So what we want is to continue to improve our life”.

Another stated:

“Some people they come without eating and then if you don’t eat you cannot even take the medicine as well as the doctor told you”.

Powerlessness in meeting basic life needs represents a glass ceiling for participants; hope for their future as HIV-infected women conflicts with the hopelessness imposed by poverty. Sustainability of positive psychological and emotional effects of the groups is therefore questionable.

Desire to work and support families—After the genocide, many women were left as sole family providers, but their capacity to care for their families was often reduced due to trauma and illness. Gains in physical and psychological health led to sequential desires to provide better care for their families, and to contribute to Rwanda’s general redevelopment. But their abilities to contribute at home and in their communities were stunted due to lack of resources. Women made several requests for support groups to begin income-generating activities. One expressed:

“...Most of us we don’t have something to do as an income generating activity. That is the common problem within the support groups...but we hope that when they bring something like a craft, making bags or baskets, maybe we can make money and then we’ll be able to take care of our family. We’ll pay our school fees for our children, we will pay for houses”.

Similarly, another shared her desire to be productive:

“I think what we need is someone who will come coordinate us, put us together and help us work together. Y’know when we found out that we were HIV-positive we got stressed and then we were feeling weak, but nowadays we are strong. We can work”.

Inadequate resources to empower these women to realise their potential may lead to lost momentum, diminished hope, and reversal in the progress made through support groups.

Support group composition—There were two outlying participants who reported near-consistently different experiences than their counterparts. Both belonged to one atypical ‘mixed youth group’ (young men and never-married young mothers, aged 25-30 -of no relationship) than other participants. Most focus group responses were answered negatively, nor did these women report experiencing the same level of group discussion, trust, friendship or emotional benefits. Causal links reported between developing emotional connections with other support group members and physical health were not made among women attending this ‘mixed youth’ group, highlighting that these instrumental connections with other women are not taking place in this atypical support group, nor have they reported any perceived changes in physical health. Additionally, while these two reported learning similar skills regarding CD4-counts and ART-adherence, there was ambivalence regarding any changes in behaviour (with exception of ART-adherence) and unwillingness to disclose their HIV-status.

Discussion

Our findings reveal capacity for para-professional-led support groups to lead to improved psychological functioning, physical health and behavioural empowerment among participants who have endured compound traumas of genocidal rape, violence, family loss and HIV-infection. Narratives reveal personal transformation of feelings and attitudes, kinship, and personal motivation in participants’ lives. Indeed, women described “coming back to life”, expressed desires to “never stop coming” due to the support and life skills received, and commented, “My future will be better than my past”.

Focus group participants taking ART reported an increase in adherence since attending the support groups. Cross-sectional data from other studies corroborate the effect of social support on ART-adherence (Whetten 2008, Bruwer 2011, Chaumba 2011). Our findings suggest that continued education and repeated messages delivered by counsellors and peers complemented the less frequent communication with doctors about medication adherence, proper diet and health precautions. Women commonly experienced greater capacity to disclose their HIV-status with family, especially children, contributing to improved relationships. Moreover, women described transcending the limitations associated with their stigmatised HIV status, allowing them to be more involved in their communities –including advocating for HIV education and testing. It is unclear if reported successes of group attendance can be attributed to the unique experience of dual stigmatisation -isolation due to both HIV and genocidal traumas. Therefore, common roadblocks of community gossip, lack of privacy, and cultural misgivings to westernised psychological methods in sub-Saharan Africa were perhaps overcome given the unique desperation stemming from compounded traumas not present in other studies employing similar methods.

Themes exemplified evolutionary patterns that mimicked the processes of ‘healing’ as reported by individuals in 12-step fellowships (i.e. Alcoholics Anonymous) (Alcoholics Anonymous 1976, McCrady 1999). As described by participants, a foundation for

transformation was established through heightened self-awareness, followed by improved emotional well-being and physical health, leading to a greater outward focus toward community and family. Similarly, in 12-step settings, members find the sense of unity (disease-centered) among group members paramount, fostering healing and providing opportunity to regularly share experiences, problems, solutions and, consequently, forming personal connections. Thus transpires the beginning of the end of isolation, setting the stage for building a community of healing and, ultimately, to carry that message to others.

Our results show that overcoming stigmas associated with seeking psychological counselling is both feasible and acceptable for HIV-infected women in post-conflict settings. Further, data showed that para-professional-led support groups could be holistically beneficial to HIV-infected women with compound trauma exposure, suggesting the potential for dissemination and implementation of these types of interventions in resource-poor countries.

To extend findings reported here, structures including frequent explanations of medicines and adherence, repetition of new ideas and behaviours may be of maximum benefit. It is recommended that support groups be divided among gender so that all support group attendees may have the same opportunity for emotional and psychological healing. Specifically, since the younger women of the 'mixed youth group' reported fewer support group benefits, yet have a greater lifetime risk of transmitting HIV to children or partners, there should be a particular effort in seeing that this sub-population's needs are met in an effort to curb HIV transmission. Also recommended are income-generating activities, further empowering women to care for themselves and their families, instilling the benefits of pride and self-esteem so critical to their recoveries.

Participants' expressions of interest in long-term participation in support groups raise sustainability questions. As support groups enlarge, challenges exist of ensuring the same attention, care, and quality to growing groups, meanwhile with limited staff. Para-professional trauma counsellors were proven effective in facilitating such groups, which had significant impact among participants. A potential solution to growth may be for longstanding members to facilitate 'maintenance' satellite groups, located in various townships. These may be comprised of members (attending 1 years) where counsellors may visit monthly, retaining the purpose of sharing experiences, emotional support and continued repetition of health messages. Women may feel further empowered to be of service to each other and their community, fostering a sense of long-term independence and emotional sustainability.

Limitations of this analysis must be considered. This was a convenience sample of women already utilising WE-ACTx; results may not generalise to women not voluntarily seeking services or to men. The nature of the focus groups may have introduced social-desirability bias in narrative responses. While careful measures were taken in translating discussions, the possibility exists that nuance and meaning were lost or distorted in translation. Additionally, the small sample size can limit generalisability of findings, although saturation of themes was achieved after conducting four focus groups.

The state of an individual's mental health is a strong driver of their behavioural choices. While HIV transmission and successful HIV treatment depend largely on behavioural choices, it's clear that investment into their predictors is necessary. Shifts in state of mind, behaviour changes and improvements in quality of life reported here are enough to warrant further research in mental health interventions. Larger scale qualitative studies can explore additional themes, and quantitative studies can examine statistical associations in larger community samples of HIV-infected trauma survivors. Well facilitated, regularly attended support groups may be a promising source of hope in overcoming mental health challenges of similar populations, particularly challenges that may impede regular HIV care, and prove to be a valuable tool, as treatment is also prevention against HIV.

Acknowledgments

The following individuals deserve many thanks for their help, support and collaboration during this research and in creation of this manuscript: Brown University Global Health Framework; Sunday Nzita for translation; staff and study participants of WE-ACTx; and, in particular, Chantal Benekigeri and Alice Umutesi.

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Table 1

Identified themes and subthemes from focus group discussions

Theme 1:	Internal psychological changes
Subtheme A:	Perceived safety and validation
Subtheme B:	Strengthened interpersonal connections
Subtheme C:	Feelings of 'rebirth' and motivation to survive
Subtheme D:	Feeling competent to interact with outside community
Theme 2:	Physical and mental health changes
Subtheme A:	Perceived relationship between physical health and support group involvement
Subtheme B:	Return to health, work and normalcy
Theme 3:	Changes in participant behavioural choices
Subtheme A:	Reported increase in ART-adherence
Subtheme B:	Increased HIV-status disclosure
Subtheme C:	Changes in behaviour with men
Subtheme D:	Pro-social and community helping behaviour
Theme 4:	Support group limitations
Subtheme A:	Poverty and hunger
Subtheme B:	Desire to work and support families
Subtheme C:	Support group composition