

Mixed-Methods Evaluation of a Novel Community-Based Support and Education Intervention for
Individuals with HIV/AIDS in KwaZulu-Natal, South Africa

Christopher Kemp

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Deepa Rao

Michele Andrasik

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Abstract

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Christopher Kemp

Chair of the Supervisory Committee:
Associate Professor Deepa Rao
Department of Global Health

People living with HIV in Sub-Saharan Africa face significant challenges to access appropriate care. Many in need cannot access available services. Community-based peer support groups have long been recognized as a key psychosocial intervention to increase treatment linkage. This study aimed to measure the impact of the structured support group intervention Integrated Access to Care and Treatment (I ACT), as implemented by a small community-based organization, on clients' knowledge, attitudes, and practice regarding HIV/AIDS, including their experiences of stigma, willingness to disclose, and uptake of and adherence to treatment services. This study took place in Okhahlamba Local Municipality, KwaZulu-Natal, South Africa. Study participants were people living with HIV attending I ACT groups. Data collection proceeded in two stages: a quantitative component utilized pre- and post-intervention tests, and a qualitative component involved client interviews focused on participants' perspectives on the I ACT program. The pre/post-test measured changes in HIV knowledge, stigma, disclosure, treatment adherence, and linkage to care. Paired t-tests and McNemar's tests looked for significant changes between pre- and post-intervention. Line by line coding according to an inductive approach was used to identify themes in the interview transcripts. Data from 66 clients were collected for quantitative analysis, and 17 participants were interviewed. Paired t-tests did not detect significant changes in the five outcomes between pre- and post-intervention, though McNemar's tests did suggest a limited effect on HIV knowledge and stigma. Qualitative results indicated a psychosocial benefit as participants connected with their peers, expressed themselves openly, and re-engaged with their communities.

However, this study was not designed to measure psychosocial impact, and the results have limited generalizability to men. Nonetheless, this study demonstrated that I ACT can effect psychosocial benefit without requiring intensive financial or human resources, and that it is a powerful complement to clinic-based treatment literacy services.

Introduction

People living with HIV (PLHIV) in Sub-Saharan Africa face significant psychological and physical challenges and must overcome immense social and material hurdles to access appropriate care, support, and treatment. Poverty, lack of insurance, and distance to services are significant barriers, and are compounded by psychosocial factors like HIV-related stigma and discrimination. These impact clients' willingness to disclose, their ability to access and adhere to treatment, and their self-caring behaviors (Karim et al., 2008). HIV-related misconceptions contribute hugely to low treatment initiation and care utilization (Bassett et al., 2010; Coetzee et al., 2011; Finnie et al., 2010; Mitchell, Kelly, Potgieter, & Moon, 2009; Nachega et al., 2006). Stigma compromises adaptive coping and limits access to social support, forcing PLHIV to conceal their status and significantly undermining their ability to adhere to treatment (Katz et al., 2013).

As a result, many who need care, support, and treatment cannot or do not access available services. In Sub-Saharan Africa, only 56% of those in need are accessing Antiretroviral Therapy (ART) (UNAIDS, 2012). Of those who do access ART, Sub-Saharan African programs manage to retain only around 60% in care at the end of 2 years in treatment (Rosen, Fox, & Gill, 2007). ART programs must overcome these barriers by addressing HIV's multitude of social, psychosocial, and economic dimensions, while empowering clients to self-manage their chronic illness (Wouters, Van Damme, Van Loon, van Rensburg, & Meulemans, 2009). Failing this, patients are more likely to discontinue treatment and develop viral rebound and loss of CD4 T lymphocytes, leading to drug resistance, treatment failure, and death (Deribe, Hailekiros, Biadgilign, Amberbir, & Beyene, 2008). Clients need social support, information, and techniques for overcoming stigma in order to access and succeed in treatment.

These same challenges also impact PLHIV who are not yet eligible for ART, preventing them from accessing essential care and support prior to initiating ART. Though the WHO recommends a package of care, support, and prevention services for PLHIV who are not yet eligible for ART, only

18% of PLHIV remain continuously in care until ART eligibility (Rosen et al., 2007; World Health Organization, 2012). This “Pre-ART” phase is a broken link in many Sub-Saharan African health programs (Bergmann, Pitorak, & Cornman, 2013; du Toit et al., 2014). Without adequate linkage to pre-ART services, PLHIV initiate ART with lower CD4 counts and experience much higher rates of mortality and loss to follow-up (Boyles, Wilkinson, Leisegang, & Maartens, 2011). It is essential that pre-ART services enable PLHIV to initiate ART as soon as they are eligible, given that patients with starting CD4 counts below 25 cells/mm³ face three times the risk of death compared to those with higher counts (Brinkhof et al., 2008). They also suffer more morbidity and utilize more medical care resources than patients who started with higher counts (Leisegang et al., 2009).

A number of interventions have attempted to increase treatment linkage in PLHIV in Sub-Saharan Africa by addressing psychosocial barriers to care. Mobile-phone text reminders, peer treatment supporters, directly-observed therapy, education and counseling, and food supplements have all shown to be effective in increasing treatment adherence in Sub-Saharan Africa (Bärnighausen et al., 2011). Several programs have tried task-shifting from professional health workers to lay community health workers in the psychosocial support of ART clients. These have unequivocally documented a positive impact on a wide range of outcomes, including treatment access, coverage, and adherence, along with patient retention, survival, and virological and immunological status (Wouters, Van Damme, van Rensburg, Masquillier, & Meulemans, 2012). Other service models have emphasized engaging patients in peer educator-led community care groups immediately upon testing positive, regardless of eligibility for ART (Boyles et al., 2011). These have shown that patients who are ineligible for ART at the time of diagnosis may benefit from extended ART preparation and social support through these groups, resulting in improved rates of retention once they do initiate treatment (Coetzee et al., 2004). This task-shifting of psychosocial support to lay community health workers is an especially attractive option, given the context of limited financial and human resources to scale up similar programs at health facilities,

compounded by many clients' experiences of stigma at the hands of clinic workers (Bogart et al., 2013).

Community-based peer support groups have long been recognized as a key psychosocial intervention. They have been shown to help PLHIV cope with the stress of their diagnosis, increasing linkage to care, lessening feelings of isolation and shame, improving self-care behaviors, and creating mutually beneficial relationships among participants (Kalichman, Sikkema, & Somlai, 1996; Lennon-Dearing, 2008; Spirig, 1998; Visser & Mundell, 2008; Wood, 2007). Participation in such interventions has been linked to significant reductions in anxiety, depression, psychological distress, stress and anger, and to improvements in coping skills and quality of life (Crepaz et al., 2008; Himelhoch, Medoff, & Oyenyi, 2007; Scott-Sheldon, Kalichman, Carey, & Fielder, 2008).

Remarkably, most of this evidence comes from unstructured and open-ended support groups, without fixed start and end dates, whose topics and enrollment are constantly shifting. Moreover, almost all of it was collected in high resource contexts outside of Sub-Saharan Africa. There is little evidence concerning the impact of short-term, scalable, structured HIV support groups in Sub-Saharan Africa. There is even less concerning the impact of such interventions when implemented independent of health systems, by indigenous organizations, at the community level, with little or no resources. This study aimed to qualify and quantify the impact of the structured support group intervention known as Integrated Access to Care and Treatment (I ACT), as implemented by a small community-based organization in rural South Africa, on clients' knowledge, attitudes, and practice regarding HIV/AIDS, including their experiences of stigma, willingness to disclose, and uptake of and adherence to treatment services.

Methods

Study Setting

This study took place in Okhahlamba Local Municipality, KwaZulu-Natal (KZN), South Africa. Okhahlamba is a mountainous region of KZN bordered on the west and north by Lesotho and the Drakensberg Mountains. It is characterized by remote Zulu tribal settlements, freehold villages, and White-owned farms. At least 98% of the Municipality are Black, 54% are female, 74% are below the age of 34, and 41% are below the age of 14 (STATSSA, 2007). Much of the population is therefore in the age group most vulnerable to new HIV infection. Community members face the crushing dual epidemics of HIV/AIDS and TB while dealing with serious barriers to diagnosis and care. uThukela District, which encompasses Okhahlamba Municipality, has an HIV prevalence among antenatal clients of 36.7% (Massyn et al., 2013). Okhahlamba has only one hospital, six fixed clinics, and three mobile clinics serving over 150,000 people. Health facilities are unevenly distributed across a vast, mountainous area. Mobile clinics travel to remote villages only once or twice each month. Cultural and social norms are such that community members often wait until they are very sick to access health facilities (Henderson, 2011). Many rely on practitioners of traditional medicine or volunteer home-based carers (HBCs), and only seek facility-based care as a last resort. Strong and efficient community-based care and support systems are essential in this context.

Intervention

Integrated Access to Care and Treatment (I ACT) is a structured 6-session support group intervention for PLHIV, developed in South Africa by the NGO South Africa Partners with support from PEPFAR. The aim of the I ACT program is to promote early recruitment and retention of PLHIV into care and support by increasing their knowledge and skills, strengthening referral systems and

complementary care services, keeping PLHIV connected to care and support structures, reducing loss-to-follow-up, and empowering communities to take responsibility for their health care. I ACT consists of 6-session closed support groups delivered weekly or bi-weekly at the facility or community level by trained support group facilitators. These facilitators are usually HIV-positive. Each session has a different focus: HIV basics, self-care, acceptance and disclosure, prevention with positives, treatment literacy, and moving forward. The impact of I ACT on client outcomes has yet to be formally evaluated.

Rollout of the I ACT program began in 2010 and is being coordinated by the South African Department of Health (DOH), supported at the national level by the NGO South Africa Partners and at the KZN provincial level by the NGO Zoe-Life. Zoe-Life is supporting the DOH in KZN to establish I ACT support groups at both the health facility and community levels. In late 2012, Zoe-Life started working with the indigenous community-based organization Philakahle Wellbeing Centre to roll out a community-based I ACT program in rural Okhahlamba Municipality.

Philakahle Wellbeing Centre has operated throughout Okhahlamba Municipality since 2003. It coordinates a Referral Network (RN) of over 150 volunteer community health workers across Okhahlamba. Many of these RN members have been volunteering in their communities since the onset of the HIV epidemic. Philakahle provides the RN members with regular trainings, coordinates their referrals to and from the DOH, and organizes client tracking and monitoring and evaluation activities. Having identified a need for HIV support groups at the community level, Philakahle partnered with Zoe-Life and the DOH to train 40 RN members as I ACT facilitators. Implementation is being coordinated with the municipal DOH so that facilitators receive referrals into their groups from health facilities. Facilitators host I ACT groups in their communities, at homes, churches, schools, or other private spaces. Groups generally contain anywhere from 5 to 15 clients. After six sessions, facilitators graduate the groups and recruit new clients. Facilitators encourage the groups to continue meeting independently after graduation, and many choose to do so.

Study Population

Study participants were people living with HIV, over the age of 18, attending Philakahle RN member-facilitated I ACT support groups across Okhahlamba Municipality. Eligible participants were sampled consecutively into the quantitative component as they completed a routine pre-test at their first I ACT session. Potential participants were excluded from the analysis if they did not attend at least 4 out of 6 I ACT sessions, or if they did not also complete the routine post-test. Eligible participants were sampled purposively into the qualitative component to achieve maximum diversity in age, gender, income level, and geography.

Data Collection

Data collection proceeded in two stages: a quantitative component utilized routine pre- and post-intervention tests, and a qualitative component involved in-depth client interviews. Data collection proceeded from September to December 2013. All data collection activities were completed by the PI with the support of a local research assistant (RA), who had been trained in interview methods and ethical research. All interaction with study participants took place in isiZulu, which is the home language of the region. Both the PI and the RA are conversant in isiZulu.

Quantitative Component:

Clients attending I ACT sessions facilitated by Philakahle RN members complete short pre- and post-intervention tests as part of the organization's routine monitoring and evaluation activities. At the first I ACT session, the trained facilitator introduces the objectives and structure of the I ACT program and conducts ice-breaking and other activities to build trust in the group. Then, the facilitator hands out the short pre-test to every participant and explains that Philakahle uses the questionnaire to monitor the success of its program. The facilitator reads each question aloud, and all attendees complete the questionnaire independently. The pre-test takes no more than 20 minutes. Upon completion of the test by all attendees, the facilitator continues with the first I ACT

session. This process is repeated at the end of the last I ACT session. The completed written test materials are delivered to Philakahle's monitoring and evaluation specialist and entered into a database.

Measures

The pre/post-test questionnaire was designed to measure changes in five main outcomes: HIV knowledge and attitudes, experiences of stigma, willingness to disclose, adherence to treatment, and linkage to care. The English version of the questionnaire is presented in Appendix A.

Sociodemographic and Clinical Variables: The questionnaire includes sociodemographic variables like age, education, work, partnership status, and distance to the nearest clinic. Clients also self-report their year of HIV diagnosis and their CD4 count as above or below 350 cells/mm³, which is the standard cutoff for treatment in South Africa. For the purposes of some descriptive figures below, education was dichotomized into "low education," with no school or some primary school, and "high education," with some secondary school or time at university.

Knowledge of HIV: The questionnaire includes six standardized Demographic and Health Survey questions regarding HIV knowledge and misconceptions, alongside two questions about tuberculosis and nutrition (DHS Program, 2014). For this study, HIV knowledge scores were calculated out of 8 for each participant by totaling the number of correct answers. These knowledge scores were positively skewed, indicating a high general knowledge of HIV. As a result, a second dichotomous variable was generated for further analysis. Participants were divided into those answering all questions correctly, scoring 8, and those answering any incorrectly, scoring 0-7.

Stigma: The questionnaire includes four items from the validated Stigma Scale for Chronic Illness (SSCI), which is designed to measure experiences of stigma in people with chronic illnesses (Rao et al., 2009). Each item is a Likert scale from 1 to 5. For this study, pro-rated stigma scores were calculated out of 20 for each participant by multiplying the mean item score by 4 (total number of items). These stigma scores were negatively skewed, indicating relatively infrequent

experiences of stigma. As a result, a second dichotomous variable was generated for further analysis. Participants were divided into those experiencing no stigma, scoring 4, and those experiencing any stigma, scoring 5-20.

Disclosure: The questionnaire includes a Likert scale for clients to self-report on their HIV status disclosure from 1 to 5.

Adherence: The questionnaire includes the Self-Rating Scale Item, which is a single-item self-report adherence measure that uses adjectives on a 5-point Likert scale (Lu et al., 2008).

Linkage to Care: The questionnaire assesses linkage to care by asking clients to indicate which clinic-based services they intend to use over the next six months. For this study, linkage to care scores were calculated for each client by totaling the number of services marked.

Available pre-/post- intervention data from I ACT clients attending at least 4 out of 6 sessions were de-identified by Philakahle's monitoring and evaluation specialist and sent to the PI for analysis in this study.

Qualitative Component:

Participants were recruited into the qualitative component of the study within two weeks of completing their sixth I ACT session and graduating from the program. The RA phoned potential participants to introduce the study and discuss its goals and procedures. Interested participants had the chance to ask any questions and choose a place to meet with the PI and the research assistant. At the meeting, participants again had the opportunity to ask any questions, and then the RA consented willing participants into the study.

The PI and the RA used an interview guide to conduct a semi-structured interview with each participant, lasting between 30 and 45 minutes. These interviews focused on participants' perspectives on the I ACT program: what worked, what did not, and in what ways the program may have impacted their experiences of stigma, their willingness to disclose, their adherence to

treatment, and their linkage to care. Interviews were tape-recorded with participant consent. The English version of the interview guide is presented in Appendix B.

Data Analysis

Quantitative Component:

Pre-/post-intervention responses were coded and entered into STATA 13 for quantitative analysis (StataCorp, 2013). Preliminary analysis consisted of descriptive frequencies, correlations, and Chi-Square tests. Paired t-tests and McNemar's tests were used to look for significant differences between pre- and post-intervention scores for the five main outcomes, while multiple linear regression was used to determine whether relevant sociodemographic and clinical variables predicted changes in the outcome variables.

Qualitative Component:

Audio-recordings of the interviews were first transcribed and translated into English by the RA. The PI repeated this process of transcription and translation from the original audio-recordings. The PI then considered the two transcripts side-by-side. Any discrepancies were reconsidered by the PI in consultation with the RA and other people from the region until a final consensus was reached. This process enabled an exploration of the choices inherent in translation that ultimately affect the analysis and interpretation of cross-language data (Esposito, 2001; Larkin, Dierckx de Casterlé, & Schotsmans, 2007; Wong & Poon, 2010).

Line by line coding was used to identify themes according to the inductive approach of constant comparison and content analysis of grounded theory (Strauss & Corbin, 1998). The transcripts were first read several times in their entirety to allow for full immersion of the data (Borkan, 1999). They were then examined for patterns, connections, similarities, and points of difference. These were distilled into a list of local categories of meaning as central concepts emerged and key terms and phrases were identified. Categories were then grouped into broader

themes via axial coding (Padgett, 1998). The emergent themes were then reapplied to the data to identify deviant or common patterns. Finally, the themes were used to generate a description of the experiences of the interview subjects regarding the I ACT groups. The whole process was circular, constantly comparing and linking speech content to broader background context, and questioning and reinterpreting findings.

Ethical Considerations

This study received ethical approval from the Human Sciences Research Council (HSRC) of South Africa. Pre-/post-intervention data were already collected as part of routine monitoring and evaluation activities at Philakahle, and did not represent an additional burden to clients. All data were de-identified before being sent to the PI for analysis. Study results will be disseminated to all major stakeholders, including interested I ACT attendees and other community members.

Results

Quantitative Results

Data from 66 clients attending at least 4 out of 6 I ACT sessions were collected for this analysis. The participants were predominantly women (92%) and ranged in age from 19 to 70 years. The average age of participants was 42 years (standard deviation [SD] = 10 years). Participants reported living with HIV from 0 to 9 years, and averaged 4 years (SD=3). 59 (91%) had already initiated ART. Detailed sociodemographic and clinical information is provided in Table 1.

Table 1: Participants

Variable	Mean (SD) or Frequency (%)
Age	42 (10)
Gender	
Female	61 (92%)

Male	5 (8%)
Highest Education	
None	12 (18%)
Some Primary	19 (29%)
Some Secondary	34 (51%)
Some University	1 (2%)
Paid to Work	
Yes	18 (28%)
No	47 (72%)
Partnership Status	
Married	18 (27%)
None	13 (20%)
Long-term Partner	22 (33%)
Short-term Partner	12 (18%)
Many Partners	1 (2%)
Distance to Clinic	
0-10km	42 (64%)
11-20km	11 (17%)
21-30km	3 (4%)
More than 30km	10 (15%)
Years with HIV	4 (3)
CD4 Count	
Do Not Know	24 (36%)
Under 350	15 (23%)
Over 350	27 (41%)
Initiated ART	
Yes	59 (91%)
No	6 (9%)

Changes in HIV Knowledge

Total overall HIV knowledge scores increased from a mean of 6.50 (SD=1.1) at baseline to 6.79 (SD=1.1) at endline. Two-tailed paired t-tests indicated that this trend was not statistically significant ($t = -1.4 / df = 65, p = 0.16$, confidence interval -0.69 to 0.11). However, analysis of the dichotomized HIV knowledge variable suggested a significant effect. Prior to the intervention, 7.6% of participants answered all HIV knowledge questions correctly. Afterwards, 22.7% answered all

HIV knowledge questions correctly. An exact McNemar's test determined that there was a statistically significant difference in the proportion of participants answering all questions correctly pre- and post-intervention ($p = 0.03$).

Further analyses showed that relevant sociodemographic and clinical variables were likely contributing to the non-significance of change in HIV knowledge scores suggested by the t-tests. Multiple regression analysis indicated that CD4 count ($\beta = 0.83$, $p = 0.05$) was approaching significance as a predictor of increased HIV knowledge, adjusting for age ($\beta = 0.00$, $p = 0.82$), number of years with HIV ($\beta = 0.05$, $p = 0.47$), employment status ($\beta = 0.71$, $p = 0.11$), and educational status ($\beta = -0.41$, $p = 0.21$), which were not found to be significant predictors. The overall model fit was $R^2 = 0.15$. The effect of CD4 count is presented in Figure 1 below, which shows the change in HIV knowledge for clients with CD4 counts above and below 350.

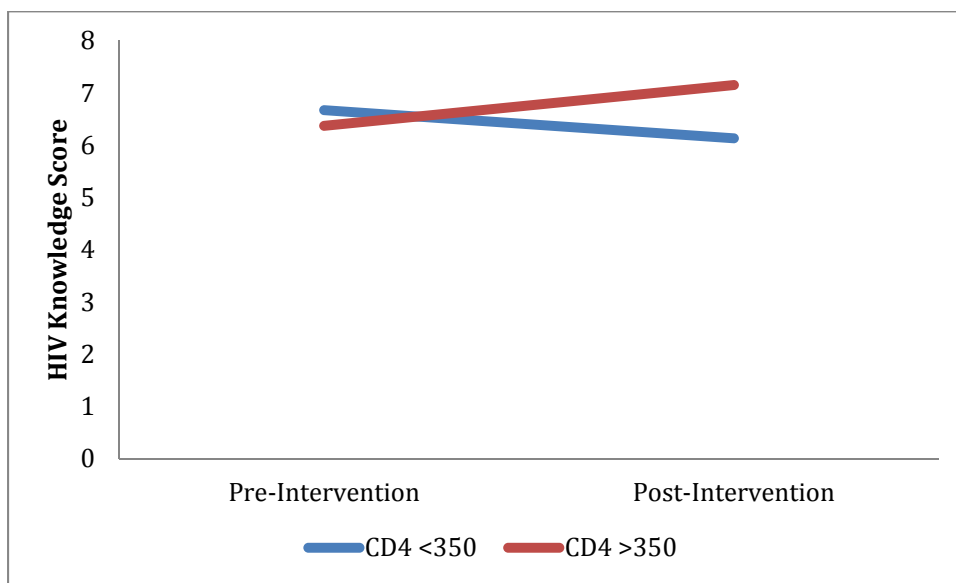


Figure 1: Change in HIV Knowledge by CD4 Count

Changes in Stigma Scores

Total pro-rated stigma scores decreased from a mean of 8.26 (SD=5.1) at baseline to 7.41 (SD=4.4) at endline. Two-tailed paired t-tests indicated that this effect was not statistically

significant ($t = 1.2/ df = 65, p = 0.22$, confidence interval -0.53 to 2.23). However, analysis of the dichotomized stigma variable suggested a statistical trend in the effect. Prior to the intervention, 60.6% of participants indicated that they experienced any stigma. Afterwards, 48.5% did so. An exact McNemar's test determined that there was a statistical trend in the proportion of participants experiencing any stigma pre- and post-intervention ($p = 0.08$).

Here, further analyses showed that sociodemographic and clinical variables likely also helped explain the overall non-significance in change of stigma scores. Multiple regression analysis indicated that educational status ($\beta = -4.03, p = 0.00$) and age ($\beta = -0.23, p = 0.02$) were significant predictors of decreased stigma scores, adjusting for number of years with HIV ($\beta = -0.30, p = 0.28$), employment status ($\beta = -0.32, p = 0.86$), CD4 count ($\beta = -2.16, p = 0.19$), and long-term partnership status ($\beta = -0.46, p = 0.76$), which were not found to be significant predictors. The overall model fit was $R^2 = 0.21$. The effect of educational status is presented in Figure 2 below, which shows the change in total stigma score for clients with secondary or higher education and those with less.

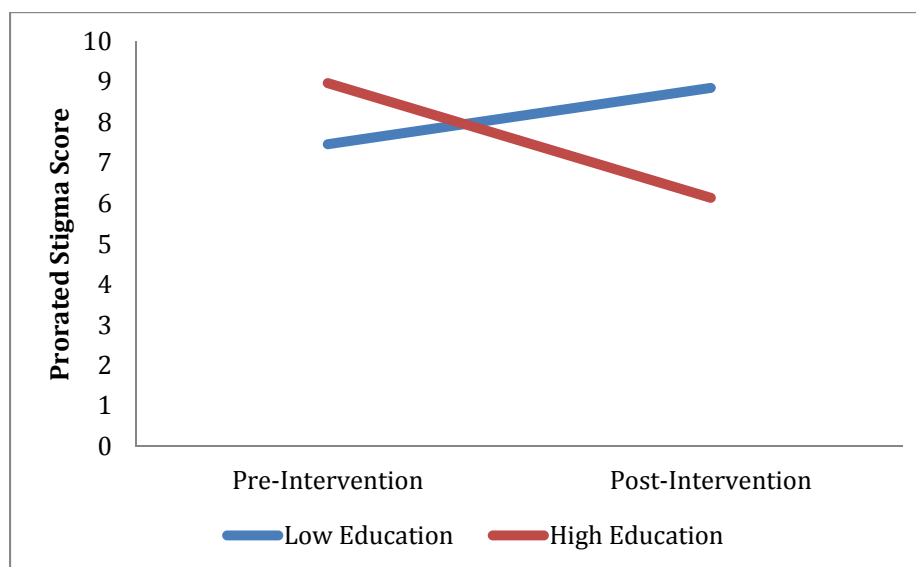


Figure 2: Change in Stigma Scores by Educational Status

Changes in Disclosure Scores

Disclosure scores increased from a mean of 3.49 (SD=1.3) at baseline to 3.51 (SD=1.4) at endline. Two-tailed paired t-tests indicated that this trend was not statistically significant ($t = -0.1/df = 64, p = 0.93$, confidence interval -0.37 to 0.34).

As with the stigma scores, further analyses showed that sociodemographic and clinical variables helped explain the overall non-significance. Multiple regression analysis indicated that educational status ($\beta = 0.80, p = 0.03$) was a significant predictor of increased disclosure scores, adjusting for age ($\beta = 0.05, p = 0.09$), number of years with HIV ($\beta = 0.00, p = 0.98$), employment status ($\beta = 0.69, p = 0.14$), CD4 count ($\beta = -0.04, p = 0.93$), and long-term partnership status ($\beta = -0.11, p = 0.79$), which were not found to be significant predictors. The overall model fit was $R^2 = 0.32$. The effect of educational status is presented in Figure 3 below, which shows the change in disclosure score for clients with secondary or higher education and those with less.

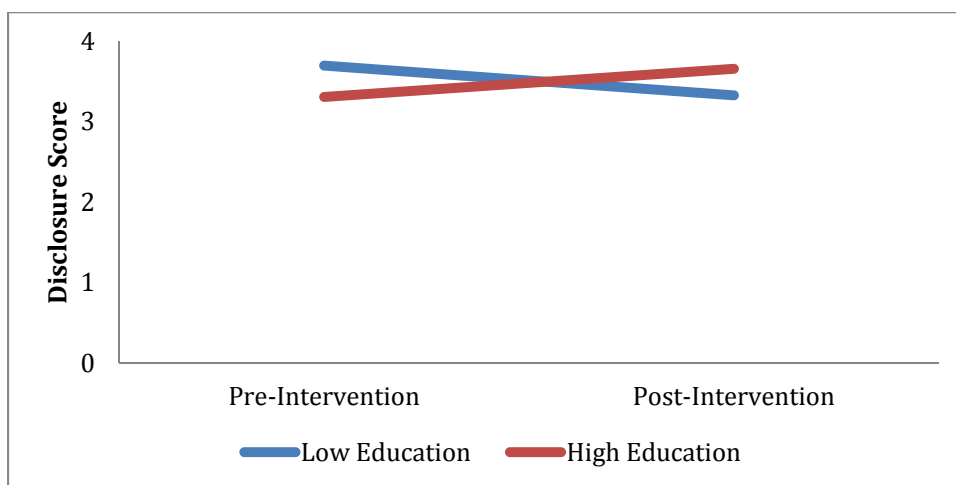


Figure 3: Change in Disclosure Score by Educational Status

Changes in Adherence Scores

Adherence scores among clients on ART decreased from a mean of 4.36 (SD=1.0) at baseline to 4.18 (SD=1.2) at endline. Two-tailed paired t-tests indicated that this effect was not statistically significant ($t = 1.0/df = 55, p = 0.32$, confidence interval -0.18 to 0.54).

Multiple regression analysis including socio-demographic and clinical variables did not reveal further statistically significant trends.

Changes in Linkage to Care Scores

Linkage to care scores among clients increased from a mean of 1.35 (SD=0.9) at baseline to 1.36 (SD=0.7) at endline. Two-tailed paired t-tests indicated that this effect was not statistically significant ($t = -0.1 / df = 65, p = 0.91$, confidence interval -0.28 to 0.25).

Multiple regression analysis including socio-demographic and clinical variables did not reveal further statistically significant trends.

Qualitative Results

17 I ACT clients were interviewed for this portion of the study. Table 2 describes selected socio-demographic and clinical characteristics of the participants who were interviewed. Using the qualitative analysis procedures described above, three primary themes of equal weight were identified. Participants used these themes to describe their experience with the I ACT groups. These themes are described below. Translated quotations are cited using the scheme [ID/Gender/Age].

ID	Gender	Age	Education	CD4 Count
1	F	36	Low	>350
2	F	32	High	>350
3	F	25	High	>350
4	F	30	Low	Unknown
5	F	53	Low	Unknown
6	F	45	High	>350
7	F	41	High	<350
8	F	33	High	>350
9	F	30	High	>350
10	F	52	Low	Unknown
11	F	32	Low	<350

12	F	36	Low	Unknown
13	F	46	High	<350
14	F	43	High	<350
15	M	63	Low	Unknown
16	F	28	Low	Unknown
17	F	38	High	Unknown

Togetherness

Participants were quick to emphasize the powerful effect of simply meeting openly together with people from the same communities with the same status. Often repeating one phrase – *siyafana sonke*, or “we are all the same” – they framed their experiences as a journey from psychosocial isolation around the time of their diagnosis towards total relief at realizing how many others shared their condition.

I found people in the same situation as me, with the same virus as me. I thought I was alone with this virus, but you forget that there a lot of people with the virus, many people living in the same situation as me. [ID11/F/32]

It was realizing that I was not alone, hearing other people say, “me too, friends, I also have HIV.” [ID6/F/45]

Being “in the same boat” as others came with many benefits, including access to advice and immediate psychosocial support and relief. Many participants repeatedly emphasized that they had received none of these benefits from the clinic. At best, they felt ignored by the nurses and other staff, unable to ask questions about their diagnosis or treatment. At worst, they were openly stigmatized and criticized while utilizing clinic-based services, including the health worker-facilitated treatment literacy classes that they had been asked to attend prior to initiating treatment. Meanwhile, the I ACT groups allowed participants to share with each other, support each other, and educate each other.

I had regrets about having the virus but when I met others with it I felt much better. My stress disappeared. [ID9/F/30]

It has made us more communal, as the women in the group now make sure we help each other with food, because we cannot take the medication without eating. We help each other if one is in trouble. [ID12/F/36]

These benefits were reinforced as participants held themselves accountable to their peers. Several suggested that they would stick to their treatment out of obligation to group members who held genuine stake in their wellbeing, despite the fact that the groups are only facilitated for six sessions. Where before participants may have lacked motivation to maintain their health, as they were isolated or ashamed, after the groups several stated their intention to take responsibility for their health. Many felt “encouraged... not to give up” [ID9/F/30]. The sense of solidarity fostered by these groups not only lessened participants’ feelings of isolation and offered new sources of psychosocial support, but also gave them the motivation to make better use of available services and improve their treatment adherence.

Free Expression

Entering these groups for the first time, many participants had assumed that they would feel as they did in their everyday lives: left out, judged, and unable to share. However, almost all described how they found themselves able to quickly and easily relate to and communicate with their peers without risk. Some framed this transition as above, by emphasizing how much they shared in common with other group members. However, most credited the facilitator with promoting the safe space necessary for open and free discussion.

The facilitator told us that holding back our emotions and experiences will only end up harming us and stressing us out even more. She encouraged us to freely express ourselves in the group as we would find relief in doing so, and we did. [ID1/F/36]

If I had a problem, I could bring it to the group to talk about, because everything was taught in that way. [ID11/F/32]

Participants found this freedom hugely beneficial. Several shared their relief at being able to openly discuss their situation for the first time. They told their stories, gained acceptance from their peers, and in turn they learned to accept themselves. Some went even further, realizing through their shared experiences just how much they had endured since their diagnosis. These participants were able to entirely reshape the personal narratives of their disease, shifting focus away from shame and negativity towards pride and confidence.

At first the fright after I found out I had the virus made it hard for me to accept my situation and I was closed up. But after I attended the meeting I became more expressive as I had accepted my situation. [ID12/F/36]

I walk around proud of myself, knowing what I overcame, and I just feel amazing.
[ID1/F/36]

Some participants reported that their newfound ability to talk about their situation extended past the groups into their everyday lives. Once participants discovered that they could share their stories within the groups without fear of judgment, they felt more comfortable being open with and disclosing to family and friends. Moreover, they heard other group members talking about being open with their status as a positive example to the community, and several participants followed suit.

They have given me confidence to express myself within and out of my group, as I was scared at first. [ID15/M/63]

I was the kind of person who hid their status. But now I am able to let people around me know and be a positive example, from the start. [ID3/F/25]

Community Engagement

Indeed, the groups fostered a strong tendency towards volunteerism and community action among the participants. Many described wanting to spread their message of solidarity, advising others to attend the groups, disclose their status, and access and adhere to treatment. Inspired by

the courage of other group members, several mentioned using their status as a tool to overcome stigma in the community and set an example for their friends and family. Rather than keeping their participation in the groups private, they wanted to recruit people into new groups and spread the messages they learnt across the community.

Already it has helped because I have talked with people who have HIV, and I have told them, "I also have HIV, and I take treatment, and we'll live a long life with our treatment."

[ID6/F/45]

Now if I see people with a similar problem, I can talk to them, I can give advice to people with a similar problem, as I am now able to counsel people to do the right thing and become like me, to attend the support groups and go to the clinic. [ID7/F/41]

Several participants discussed wanting to go a step further to support people in their communities directly. They saw themselves as potential teachers, counselors, or caregivers, rather than as patients needing care. They asked about upcoming I ACT facilitator trainings, or wondered what it would take to set up their own groups.

We should encourage the growth of groups like ours in other parts of the province so that we can educate and increase awareness. [ID11/F/32]

I have always wanted to work as a social worker and after attending these groups I have become more motivated to go back to the home-based care classes. [ID7/F/41]

Though not all participants were quite so explicit about their intent to give back to their communities, they were all remarkably consistent in the ways they framed their journeys from isolation to solidarity, openness, and engagement. Through the groups, they found out they were not alone, that they could talk freely to others, and that they had much to learn and to teach. Most importantly, they learned that they could take action, both for themselves and for others. As one participant summarized it, "I saw that we were all in the same situation, and took the same

medication, and I found it beneficial for me to express myself so I could teach and be taught by others.” [ID14/F/43]

Discussion

The aim of this study was to determine whether the I ACT program, as implemented at the community level by an indigenous organization with few resources, had an impact on client HIV knowledge, experiences of stigma, willingness to disclose, treatment adherence, and linkage to care. Though the quantitative results of this study suggested a limited effect, participants in the qualitative portion were unequivocal in their belief that the I ACT groups had been transformative to their health and wellbeing. Moreover, significant effects were seen in certain sub-groups among the participants in the quantitative portion of the study.

One of the primary goals of I ACT is to increase client knowledge and skills around HIV. While the quantitative portion of the study did not detect a statistically significant mean increase in HIV knowledge across all clients, it did reveal a significant increase in the percentage of clients able to answer all of the pre-/post-test questions correctly. This is because most participants entered the groups with relatively high HIV knowledge, and therefore had little room to improve against the questions used. Other studies in South Africa have also found high HIV knowledge among members of rural communities, suggesting that the numerous attempts by government and civil society to educate the public have been effective (Shikwane, Villar-Loubet, Weiss, Peltzer, & Jones, 2013). In this context, I ACT may provide a valuable service by allowing clients to help each other change their beliefs around a few common, stubborn HIV-related misconceptions, rather than by providing clients with large quantities of new information. Indeed, participants in the qualitative component rarely mentioned the didactic components of the groups, instead framing their experiences almost exclusively around the benefits of coming together with other community members to share openly about their experiences. Participants focused heavily on teaching and being taught by their peers,

and not on what they learned from program itself. This is not surprising given that facilitators were community volunteers, not professional trainers. Rather than emphasizing technical knowledge, facilitators fostered safe spaces for the open exchange of ideas and experiences. Participants repeatedly emphasized the value of this exchange, and placed it in direct contrast to clinic-based treatment literacy programs where they felt insecure and uneducated. Other studies in the region underline the importance of creating safe social spaces for dialogue and critical thinking as part of HIV support programs (Campbell, Nair, & Maimane, 2007).

I ACT also seeks to reduce HIV-related stigma, increase disclosure, increase treatment adherence. Again, the quantitative portion of the study did not detect statistically significant mean changes across all clients, though it did reveal a near-significant decrease in the percentage of clients reporting any experiences of stigma. Educational status and age also acted independently to mask overall changes. Older participants and those with more education had significantly reduced stigma scores. Participants with more education had significantly increased disclosure scores. This suggests that age and education make clients more amenable to change through participation in the groups, and that facilitators may need to adjust their approach to better reach younger, less educated clients. Meanwhile, perceptions of reduced stigma and increased acceptance of HIV status were central to the qualitative results. The common narrative from the interviews was that most participants entered the groups feeling isolated and ashamed, but quickly realized that they were part of a much larger community of people living with HIV. They were able to open themselves to their peers, which significantly reduced their anxiety and feelings of embarrassment and shame while increasing their comfort with disclosing and taking their treatment at home. The groups clearly impacted the participants experience of stigma, given that stigma usually limits access to social support and reduces the likelihood of disclosure (Katz et al., 2013). However, that effect was not evenly distributed: both younger and less educated clients did not to achieve measurable benefits.

Lastly, I ACT aims to increase linkage to facility-based care. Again, the quantitative component did not detect significant changes in intent to seek clinical care. However, the qualitative component clearly indicated that participants leaving the groups felt newly accountable to their peers and were therefore motivated to take control of their health. These results agree with a previous, informal evaluation of the I ACT program that suggested clients experienced an increased sense of their responsibility to access appropriate care and treatment (Diesel et al., 2012). It should also be emphasized that in a context like Okhahlamba, with its few under-resourced health facilities, true improvements to linkage to care will not be made without the expansion of services into isolated rural communities.

This program was run at the community level, managed by an indigenous organization, and facilitated by volunteers – an arrangement that had benefits and drawbacks. As respected home-based carers within their communities, facilitators had access to vulnerable, isolated clients who may not have been able or wanted to attend groups at a clinic. Facilitators ran the groups in a considerate, culturally sensitive manner that participants contrasted directly with the treatment literacy courses offered at the clinics, though facilitators did not have the technical education or referral capacity possessed by healthcare staff. Even though the groups were only six sessions, they performed a unique and valuable service by providing participants with safe spaces to connect with their peers – a service participants did not receive anywhere else. As such, community-based I ACT groups may best be viewed as complementary to facility-based services like treatment literacy programs.

Unfortunately, this study was not designed to measure all of the psychosocial benefits of such a service. It was designed in alignment with the primary goals of the I ACT program, and did not include direct measures of client psychosocial health and wellbeing. Nonetheless, the qualitative results suggest that the groups likely affected client outcomes like anxiety and depression, as participants reported decreased stress and increased self-esteem. Many studies of

HIV support groups have published similar psychosocial effects (Crepaz et al., 2008; Scott-Sheldon et al., 2008). Given the likely impact, though future studies should seek to better quantify the psychosocial impact of the I ACT groups, community-level scale-up of the I ACT program should continue without waiting for such evidence.

Meanwhile, the results of this study have limited generalizability to men living with HIV. All of the trained facilitators were women, because almost all members of the RN are women. In the context of rural South Africa, where gender roles are heavily codified, there are formidable psychosocial and structural barriers to male participation in mixed-gender groups facilitated by women. Studies have reported that men feel such spaces are not “male-friendly,” and that they fear the stigma and social rejection that may come from disclosing and sharing openly in front of women (Koo, Makin, & Forsyth, 2013; Madiba & Canti-Sigaqa, 2012). As a result, few men participated in this I ACT program, and the study over-sampled women. Similar programs must recruit and train male facilitators to run male-only support groups, both to offer men the same services and benefits available to women, and to encourage men to deepen their engagement with their families and communities (Montgomery, Hosegood, Busza, & Timaeus, 2006).

This study had several other limitations. It lacked a control group and did not track biological outcomes like laboratory-reported CD4 count, which would have provided better estimates of downstream impact. Long-term follow-up on client outcomes was also not performed, which would have indicated whether the groups had lasting effects. All outcomes were self-reported by the clients and were therefore subject to possible bias. Finally, this study did not assess whether the groups ended after six sessions, or whether clients continued to meet independently. I ACT facilitators are trained to encourage group members to continue meeting after the sixth session in order to maintain the psychosocial benefits described above. Future studies should examine the differences between groups that choose to continue meeting and those that do not, and should measure the added value of ongoing participation.

Conclusion

Despite the limited significance of the quantitative results related to the five main outcomes, this study has demonstrated that a short-term, structured I ACT support group program can have a substantial psychosocial impact without requiring intensive financial resources or highly educated facilitators. Moreover, this study has shown that an I ACT program at the community level, coordinated by a local organization and facilitated by volunteers, can offer unique value not always available at clinics in limited resource contexts. PLHIV need safe spaces to connect with their peers, not just technical HIV-related education. Community-based I ACT groups can be a valuable and affordable complement to clinic-based treatment literacy programs, and should be implemented at scale wherever possible.

Appendix A: Pre-/Post- Questionnaire

Name: _____ Date: ___ / ___ / ___

We wish to learn about your needs and the best way to support you, as well as to see how well our I ACT program helps you. The information you provide will be used to improve our programs. Your answers will remain private. Your name will not be given to anyone else. Your participation is voluntary. Thank you for your assistance.

Instructions: Please circle or write in your answers to each question below.

1. How many years old are you? _____
2. What is your gender?
Male *Female*
3. What is the highest level of education you have completed?
No school *Primary*
Secondary
University *Higher education*
4. Do you currently have paid employment?
Yes *No*
5. How many kilometers is it from your home to the nearest health clinic or hospital?
0–10 km *11–20 km*
21–30 km *More than 30 km*
6. What is your current relationship status?
Married *No partner*
Multiple partners *Long-term partner*
Casual partner *Not started sex*
7. In what year did you test positive for HIV?

8. To prevent HIV infection, a condom must be used for every round of sex.
Agree *Disagree*
9. One can reduce the risk of HIV by having fewer sexual partners.
Agree *Disagree*
10. There is a cure for AIDS.
Agree *Disagree*
11. AIDS is caused by witchcraft.
Agree *Disagree*
12. HIV causes AIDS.
Agree *Disagree*
13. AIDS is cured by having sex with a virgin.
Agree *Disagree*
14. TB can be cured.
Agree *Disagree*
15. I know how to prepare healthy foods to help protect myself from infections.
Agree *Disagree*
16. Because of my HIV, some people have avoided me over the last month.
1 *2* *3* *4* *5*
Never *Sometimes* *Always*
17. Some people acted as though it was my fault I have HIV over the last month.
1 *2* *3* *4* *5*
Never *Sometimes* *Always*
18. Because of my HIV, I felt left out of things over the last month.
1 *2* *3* *4* *5*
Never *Sometimes* *Always*
19. I felt embarrassed about my HIV over the last month.
1 *2* *3* *4* *5*
Never *Sometimes* *Always*
20. How many people you know have you told that you have HIV?
1 *2* *3* *4* *5*
None *Some* *All*
21. Who have you told (circle them)?
Partner *Mother* *Father*
Children *Other Family* *Colleagues*
Friends *Other:* _____
22. Are you currently prescribed HIV medications?
Yes *No*
23. In the last month, how often did you take your HIV medicines in the way you were supposed to?
1 *2* *3* *4* *5*
Never *Sometimes* *Always*
24. Over the next six months, what kinds of things will you obtain from the clinic (circle them)?
CD4 Count *Nutrition Support*
Physical *Counselling* *TB Prophylaxis*

Appendix B: Interview Guide

1. Uneminyaka emingaki? *How old are you?*
2. Uyasebenza yini okwamanje? *Are you currently working?*
3. Waqeda kuliphi ibanga esikoleni? *How far did you go in school?*
4. Waze nini ukuthi une HIV? *When did you learn that you had HIV?*
5. Uyithandandile yini le group obuyayo? *How did you like the group you attended?*
 - a. Kukhona yini oyithandile ngeGroup? Umakunjalo kuyini okuthandile ngeGroup? *Did you like anything about your group? If so, what did you like about the group?*
 - b. Kukhona yini ongakuthandanga ngeGroup? *Did you dislike anything about your group? If so, what did you dislike about the group?*
6. Iziphi izigaba ozifundile? *Which sessions did you attend?*
7. Bukhona yini ubunzima ohlangabezane nabo esifundweni? *Did you have any difficulty attending the sessions?*
 - a. Uma ube nobunzima, iziphi izizathu ezenze kwabanzima eGrouphini obuhlanganyela nayo? *If you had difficulty, what factors made it difficult for you to attend?*
 - b. Uma bekulula ukuhlanganyela, yini eyenze kwaba lula kwezinto ukuthi uhlanganyele? *If it was easy to attend, what made things easier for you to attend?*
8. Esifundweni ubenabo yini ubunzima ukukhuluma ngokuvulelekile? *Did you have any difficulty speaking out during the sessions?*
 - a. Yini ekwenze kwalula ukukhuluma ngokuvulelekile? *What might have made it easier for you to speak out?*
 - b. Yini eyenze kwanzima ukukhuluma ngokuvulelekile? *What made it difficult to speak?*
9. Ucabanga ukuthi ulwazi olutholile luqondene nesesimo okuso? Uma kukanjalo kanjani? *Did you feel the information were applicable to your situation? If yes, how?*
 - a. Lolulwazi lungaba kanjani wusizo? *How could the information be more appropriate?*
10. Unayo yini imicabango ukuthi leWorkshop inga nyusa kanjani izinga? *Do you have any thoughts on how the workshops can be improved?*
11. Ucabanga ukuthi leGroup ingakhona ukusiza impilo yakho ibesezingeni elingcono? Kungani noma kungani ingeke ikwazi? *Do you feel the group has the potential to improve your life? Why or why not?*
12. Kukhona yini osekushintshile empilweni yakho ngenxa ye I ACT program? Uma kunjalo kuyini? *Have you changed anything in your life because of the I ACT program? If so, what?*
13. Ukushintshile yini u I ACT ukuthi ukwazi ukuphumela obala ngomphumela yakho? *Has I ACT changed your willingness to disclose your status? If so, how?*
14. Yini oyiqondayo ngokuthi udinga ukuvakashela iclinic ezinyangeni eziyisithupa? *What do you understand about when and why you need to access clinical care over the next 6 months?*
15. Engabe u I ACT ukwazile yini ukushintsha indlela yokuthi ukwazi ukuthi usilungisa kanjani isithunzi sakho ngeHIV? Uma ukwazile ngayiphi indlela? *Has I ACT changed your ability to handle the stigma of HIV? If so, how?*
16. Ulutholile yini ithuba lokwazisa amanye amalunga emphakathi ngesimo sakho HIV? Uma kunjalo kanjani? *Have you taken the opportunity to share anything about HIV with other community members? If so, how?*
17. Kukhona yini okunye othanda ukukuxoxa? *Is there anything else you would like to share?*

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