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Preliminary results from Hlanganani (Coming Together): A structured support group for HIV-infected adolescents piloted in Cape Town, South Africa

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A B S T R A C T

HIV positive adolescents require unique physical and emotional care as they navigate not only developmental challenges but also HIV-related issues including stigma, prevention, and maintaining long-term HIV health. The Hlanganani Program was created to address these issues and engage adolescents in care using a dynamic, 3-session cognitive behavioral support group facilitated by laypersons. Youth 16 to 24 years old, diagnosed within the previous 12 months, were invited to attend three sessions in clinics or other community spaces. Topics included: 1) Coping and support; 2) HIV health (including CD4 counts and ARVs); and 3) HIV prevention. The program was developed and evaluated for feasibility, acceptability and improvements in participants' knowledge, attitudes and behavior. Impact on linkage to care was measured using participant clinic folders from two local youth clinics and was defined as attending at least one ART clinic visit if eligible (CD4 <200 cells/mm³). 109 participants were enrolled, and follow-up assessments were matched among those retained for 3 sessions (n = 65 compared). Self-reported safe sex practices demonstrated improvement with the proportion of participants affirming condom use at last sex rising from 71% to 83% at follow-up (p = .049). Linkage to care was met by 100% of all ART eligible participants (n = 13), compared to 58% in the comparison group (n = 31). Hlanganani demonstrated that it would be feasible and acceptable to recruit HIV positive adolescents into a support group setting, with measurable improvements in short-term behavioral outcomes including safe sex and linkage to ART care. Results from this pilot show promise that a structured support group for newly diagnosed HIV+ youth could be effective as an entry point for long-term HIV wellness and care.

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1. Introduction

1.1. South African youth and HIV

An estimated 5.6 million South Africans are currently living with HIV, more people than in any other country (UNAIDS, 2011). HIV prevalence among South African youth has remained high in recent years, increasing as youth age and transition into adulthood. According to the 2011 South African Antenatal Survey, prevalence among 15 to 19 year olds was approximately 14% and rose to roughly 27% among 20 to 24 year olds. Among 25 to 29 year olds HIV prevalence increased to a further 37% (South African Department of Health, 2012a, 2012b) reflecting both developmental and epidemic trends over time. In addition, an estimated 36% of all heterosexual HIV transmission in South Africa occurs in 15 to 24 year olds, making youth within this age range especially in need of interventions to both prevent new infections and care for those who have seroconverted (Johnson, Dorrington, Bradshaw, Pillay-Van, & Rehle, 2009).

South African adolescents are at risk for horizontal HIV infection for a number of reasons. Behavioral research indicates that sexual activity is initiated at an early age in South Africa (mean age of 14.6 years), and that young people have multiple partners and use condoms less consistently compared to older age groups (Jaspan et al., 2006; Mathews et al., 2009). For example, research conducted by Mathews et al. among high school students in Cape Town demonstrated that initiation of sexual activity for many youth begins as early as age 13 (13% among girls and 31% among boys). It is estimated that among South Africans aged 15 to 24, more than half have had sex by age 18 (Shisana et al., 2005). Once sexually active, adolescents engage in sexual behaviors that place them at greater risk. In a review of unsafe sexual behavior among South African youth, 50% to 60% reported not using condoms (Eaton, Flisher, & Aaroe, 2003). Findings from a national survey indicated a high incidence of multiple concurrent partners in adolescents and this is often related to a history of substance use and early sexual experience (Mpofu, Flisher, Bility, Onya, & Lombard, 2006; Pettifor et al., 2005). Trans-generational and transactional
sex are not uncommon among South African youth and both are associated with HIV infection (Jaspan et al., 2006; see also Mercer et al., 2009; Parker, Malhubele, Ntabathi, & Connolly, 2007).

In addition to these risk factors for HIV infection, young people are less likely to engage in HIV care upon a HIV positive diagnosis. Jaspan et al. noted in 2009 that only 20% of youth in South Africa have ever had an HIV test, with much fewer having attended a clinic for CD4 monitoring or healthcare maintenance if they test HIV positive. One facet of the problem is that horizontally-infected youth tend not to be in immediate need of anti-retroviral treatment, meaning that many newly-diagnosed individuals become lost to follow-up. A 2010 study among clinics in the greater Cape Town area found that only 62.6% of individuals attended for a CD4 count measurement within six months of testing HIV positive. Among the individuals not yet eligible for ART, only 46.3% had attended for a repeat CD4 screening (Kranzer, Zeinecker, Ginsberg, Orr, & Kalawe, 2010).

HIV infected adolescents experience a unique set of emotional and physical challenges that must be addressed to optimize linkage to/retention in care and their future health outcomes. In addition to the rapid intellectual and physiological developmental changes that young people experience, HIV positive adolescents must cope with compounded issues such as stigma, medication regimens and clinic appointments, fears about life expectancy and sickness, along with a general desire to be ‘normal’ (Brown & Lourie, 2000; see also Jaspan, Li, Johnson, & Bekker, 2009; King, De Silva, Stein, & Patel, 2009). Young people must also reconcile these stressors with an emerging sexuality, fears of rejection or transmission to others, and reproductive health needs. Taking responsibility for new healthcare needs is especially burdensome. Adolescents are typically unequipped with the skills to navigate health systems and to manage what is a chronic, communicable, and potentially life-threatening disease. Studies suggest that adherence to anti-retroviral medication during these ages is lower than in other stages of life (Becker, Dezii, Barute, Kawabata, & Holder, 2002; Nachega et al., 2009; Williams et al., 2006).

Given these multiple stressors, assistance is necessary to support individuals’ ability to understand and cope with the disease, build self-efficacy and agency to follow-through with long-term care, and instill decision-making skills to prevent spreading the virus to others. Moreover, effective interventions need to be developed which are simple and cheap enough to implement in resource-limited settings such as South Africa’s township utilizing local skills and capacities such as lay facilitators. In doing so, interventions should also be replicable in other diverse, low-income settings and attractive to young people.

1.2. Supportive interventions for HIV positive youth

Building upon the premises of both inter-personal and intra-personal theoretical models of behavior change, support groups offer therapeutic platforms that hold potential for providing newly-diagnosed HIV positive adolescents with the emotional and educational support they need. Bandura’s social cognitive theory underpins this concept, which posits that a combination of information, social support, self-efficacy or the belief in one’s capability for change, and decision-making skills are all critical factors in individual-level healthy behavior change (Bandura, 1973). Not only do support group structures provide information and the potential for individual learning in order to develop healthy behaviors, but they also provide the health-enabling “safe spaces” which help to create important networks and social bonds (Campbell et al., 2013).

Increasingly, social capital – or the value derived from social networks in which trust, reciprocal support and cooperation are prevalent – is being purported as a behavioral approach to fostering sustainable, healthy decision-making among individuals and community networks (Campbell et al., 2013; Gregson et al., 2013; Gregson et al., 2011; Putnam, 1995). More specifically to HIV, building social capital is a sociological process which can help to form “HIV competent communities,” or contexts in which individuals and communities are better-able to respond effectively to HIV/AIDS (Nhamo, Campbell, & Gregson, 2010). Campbell et al. outline six psycho-social preconditions to achieving HIV competence: HIV/AIDS knowledge, social spaces for dialogue, a sense of solidarity, confidence in local capacities, collective sense of ownership of programs, and links with external social and economic resources through support and welfare agencies (Campbell, Nair, & Maimane, 2007; Campbell et al., 2013). Safe social spaces, Campbell et al. underline, hold the key for meeting HIV competence insofar as they “enable people to collectively examine ways in which they might use the HIV-related information they have received and to renegotiate social norms that undermine their own and others’ health and well-being” (Campbell et al., 2007; Campbell, Nair, Maimane, & Gibbs, 2009).

Limited data from HIV treatment studies primarily conducted in North America demonstrate the potential of supportive services, including support groups, to encourage at-risk youth to enter and stay in care (Horstmann, Brown, Islam, Buck, & Agins, 2010). In a 2011 report, USAID recommends support groups as a promising measure for meeting the psychosocial needs of HIV-infected adolescents in Africa (USAID, 2011). South Africa’s National Strategic Plan for 2012–2016 prioritizes the strengthening of youth-friendly health services, including support programs to improve linkage into and adherence to HIV care (South African Department of Health, 2012a, 2012b). Further evidence of a support group intervention’s impact, especially among South African youth, would yield information on innovative ways to implement this policy and improve linkage to care and overall health outcomes.

Cognitive behavioral interventions (CBIs) are widely used therapeutic models intended to help participants address the thoughts and feelings that guide their behaviors (Beck, 1976, 2005). Cognitive behavioral approaches assist in becoming more self-aware of problematic thoughts or feelings, and are goal-oriented towards adapting healthier behaviors as a result. Used extensively in mental health interventions, CBIs have also been found to be efficacious in relieving the various psychological states of people living with HIV including depression, stress, and anxiety (Crepaz, Passin, Herbst, Rama, & Malow, 2008).

1.3. Hlanganani “Coming Together” Support Group Program

Hlanganani HIV + Youth Support Groups were developed using a model adapted from an intervention for pregnant women living with HIV called Project Mamekhaya. This program was designed to offer a structured support group setting for newly-diagnosed HIV positive pregnant women in antenatal clinics in the Western Cape, in order to promote a better understanding of and adherence to prevention of mother-to-child transmission programs. Participants attending Project Mamekhaya showed significant psychosocial improvements and increased attendance at follow-up medical visits (Futterman et al., 2010). Pregnant women with HIV attending an antenatal clinic have markedly different motivations for attending supportive and educational groups than newly diagnosed adolescents, however. Many pregnant women are motivated to take better care of themselves for the benefit of their babies, and these participants in particular were already attending antenatal clinics. HIV positive young people, on the other hand, may not sense the immediacy of entering HIV care and treatment in a similar way. Additionally, other health barriers include social exclusion and stigma, denial, and negative reception by clinic staff. Recognizing these social and situational differences, the program was adapted into Hlanganani youth support groups. This program was designed and piloted to explore the possibility of engaging HIV positive adolescents in a compelling, short-term, lay-person delivered support group, and if so, the extent of its impact on the physical and emotional health of HIV positive adolescents, particularly with regards to linking youth into HIV care.

This paper will begin by describing the program design, including its establishment over three phases and its evaluation methods. The
authors then discuss findings from the third phase focused on the following aims: 1) the feasibility of recruiting and retaining HIV positive youth; 2) the acceptability of the support groups; 3) any additional benefits related to knowledge, attitudes, behaviors, and 4) any additional benefits related to linkage to HIV care.

2. Methods

2.1. Phase description

2.1.1. Phase I: groundwork and design

Built upon a framework of participatory development, Hlanganani was established over the course of three phases. Phase I consisted of qualitative, formative work including twelve focus group discussions with youth [FGs (n = 5–7/group)] and key informant interviews [KIs (n = 5)]. Focus group participants were 16 to 24 year old members of Nyanga sub-district and attendees at the Site B and Site C Youth Clinics in the Khayelitsha sub-district. HIV positive FG participants were recruited from an adolescent HIV treatment clinic and from a mobile HIV testing unit. Other FG participants included peer educators from an HIV education program in Cape Town. Key informants were purposively chosen for their expertise on the needs and realities of working with HIV positive youth and included Adolescent Treatment Counselors, Youth HIV Educators, ARV clinicians, and Project Mamekhaya facilitators.

The KIs were conducted first and were used to explore HIV positive adolescents' needs, the challenges of working with this population, and strategies to overcome these challenges. Questions also focused on the KI's recommendations for a support group intervention including suggested content, structure, and recruitment/retention ideas. The FGs were subsequently conducted to further explore youth needs, challenges, and their thoughts on the proposed support group content and structure.

Preliminary data from this formative research highlighted the need for the support groups. Responses from many youth, particularly young women, reflected low self-esteem, self-worth and limited decision-making skills. HIV positive focus group participants demonstrated a general understanding of HIV (i.e. sexual transmission, condoms for prevention), but lacked knowledge about HIV being a chronic manageable disease and the importance of CD4 and viral load measurement. These participants also expressed a fear of disclosing to family and partners, and a desire for a safe space to build a network of peers to share experiences with.

A number of barriers were raised, particularly the challenge of engaging youth in this type of service. The need to ensure confidentiality was strongly stressed by key informants. The youth in the focus groups asserted that they would be unlikely to attend a support group at their local clinic for fear of association with the virus.

2.1.2. Phase II: content and pre-pilot

In Phase II, a three-session, structured support group format and curriculum was devised based on the expressed interests of focus group and interview perspectives. The three sessions, which were designed to each be 2 h long and held once a week, covered three domains: coping and support, HIV health, and positive prevention, respectively. Each session followed a similar rhythm and flow, incorporating both didactic and interactive elements. Facilitators opened each session by performing a role play which was intended to mirror young people's uncomfortable experiences with testing HIV-positive, dealing with stigma and disclosure, and navigating sexual relationships in the future. Role plays would be followed by a group reflection of the issues presented, as well as relaxation exercises. Each session also featured a "learning spot" or interactive discussion covering information on physical and emotional health, such as ways for young people to express their sexuality safely beyond oral, vaginal or anal penetration. Each of the three sessions concluded with setting achievable goals related to the week's topic, such as retrieving one's CD4 count from a clinic, or disclosing one's status to a trusted acquaintance.

Each group utilized a set of cognitive behavioral tools adapted from Project Mamekhaya to facilitate self-awareness, social support, and healthy behavior change. These included "Feeling Cups", "Thanks Tokens", "Candle of Hope", and role plays (see Table 1).

Six lay facilitators were employed to run the intervention in order to utilize affordable, local skills from within the community and contribute to the intervention's reproducibility in other resource-limited contexts. Positions were publicly advertised and recruits were selected based on having basic HIV counseling training and experience working with youth. An even number of males and females were selected in order to represent both sexes in the groups. The majority of candidates were between 25 and 35 years old, with one female facilitator over 50. All facilitators were from the same communities as the target population, were black African and spoke isiXhosa as their home language. One male and one female facilitator were assigned as teams to run each of the various sessions. Facilitators were provided with a week-long intensive training covering the basics of research, the elements of the Hlanganani curriculum and tools, an overview of youth-specific issues, the basics of HIV including transmission, treatment and prevention, and principles of good facilitation skills.

Phase II involved a brief period of piloting the intervention to establish feasibility of recruiting participants and conducting the sessions in order to inform the full-scale implementation of the pilot program in Phase III. A total of 56 participants attended at least one support group session between July and October 2009.

Feedback from this pre-pilot reiterated some of the challenges outlined in Phase I. Reframing from branding Hlanganani purely for HIV-positive youth, while maintaining the exclusively HIV-positive enrollment criteria, required that facilitators discretely screen would-be participants for age and HIV status before starting the sessions. The concerns about young people's reluctance to attend sessions at clinics was verified among the Nyanga district group, an area which lacks a dedicated youth clinic; however, youth in Khayelitsha were more amenable to attending the sessions in a space adjacent to the Site B and Site C youth clinics.

2.1.3. Phase III: pilot

Phase III sessions were held between January and December 2010 in a community hall and library in Nyanga as well as in converted shipping containers adjacent to the Site B and Site C youth clinics in Khayelitsha. Eligible participants were 16–24 year old youth who had been diagnosed HIV positive within the previous 12 months and who consented to participating. Groups were held with a minimum of three and maximum of ten participants to ensure an interactive yet intimate setting. Participants were expected to attend the same three group sessions over three weeks. The intervention was delivered in isiXhosa, the local language.

109 participants were enrolled into the pilot program over eleven months. Recruitment was conducted in the Nyanga and Khayelitsha sub-districts, first by establishing relationships and securing agreements from facility managers as well as manager nurses, and counselors from clinics in these areas. These peri-urban districts in the greater Cape Town region are largely constituted by low-income housing or informal settlements and were selected based on the high burden of HIV on young people, both in terms of prevalence and population-size. The Desmond Tutu HIV Foundation operates a clinical center in the Nyanga district of Crossroads, facilitating operations. Clinic staff in both sub-districts would then refer HIV positive clients to Hlanganani support group facilitators. Facilitators were also stationed in clinic waiting areas during the busy morning hours to provide further program awareness using brief educational presentations and outreach materials. Based on exploratory discussions with HIV-positive youth regarding recruitment, posters advertising a non-HIV-specific youth group and contact information were placed at schools, taxi ranks, clinics and other locations.
public spaces and were also provided to young people testing HIV positive at clinics by VCT counselors and nurses. Facilitators would return the calls and texts received by interested participants and provide more detailed program information including eligibility criteria and what the sessions covered. If interested, facilitators would then schedule a date and time for the participant to enroll in the program.

All consent was informed via oral and written explanation. Parental consent was waived given that some participants may not have disclosed their status to parents, and the intervention aimed to facilitate coping and disclosure. All protocols were approved by the Montefiore Medical Center Institutional Review Board (Bronx, NY) and the University of Cape Town Ethics Committee. Informed consent was conducted prior to starting Session 1. Unique identifiers were assigned to survey data and stored separately from consent forms. Data cleansed of all participants’ names was entered using Excel and saved under password control.

2.2. Evaluation

The program was evaluated in the Phase III pilot. The primary objective was to assess the feasibility and acceptability of engaging recently diagnosed HIV-positive adolescents into a structured support group, and also assessed short-term impact on psychosocial indicators over the course of the three sessions, as well as linkage into HIV care and treatment among a sub-sample of participants from the Khayelitsha district.

Feasibility and acceptability of the intervention were evaluated through attendance registers, post-session surveys, and semi-structured post-intervention interviews with participants and facilitators.

Study tools were initially developed in English and translated into isiXhosa by members of the study team. Qualitative data was collected in isiXhosa, transcribed, and translated back into English by a bilingual study team member.

Baseline and follow-up questionnaires were administered at the start of Session 1 and upon completion of Session 3 in order to assess any self-reported changes in participants’ knowledge, attitudes and behavior. Any baseline data from participants who did not complete all three sessions was omitted, as was any data that could not be matched by personal identification number to pre- and post- session surveys. Participants were asked their age, sex, ethnicity or race, language spoken at home, current school attendance and/or highest grade achieved. Participants were asked to respond to Yes/No questions relating to basic concepts about HIV such as what a CD4 count and viral load indicate; whether ARVs can help to improve health; and whether one can still look and feel healthy with HIV. Yes/No and Likert-scale questions requesting responses ranging from Strongly Agree, Agree, Disagree, and Strongly disagree were asked relating to how participants were coping with their recent diagnosis and perceived levels of social support. Participants were asked whether they had disclosed their status, if so to how many people, and whether they do or do not feel supported in their lives. Yes/No questions regarding knowledge, attitude and behavior around positive prevention were asked including: how HIV is not transmitted; whether it is possible to prevent transmission from mother to child, and self-reported condom use at last sex.

Linkage to care was evaluated using medical records of a sub-sample of all Hlanganani participants recruited from Site B and C youth clinics between January and March 2010 (n = 222). The comparison sample is proportionally larger than the Hlanganani sample as it represents all adolescents testing HIV positive at these clinics during the same period as the intervention versus only the ones who self-selected to join the Hlanganani pilot groups.

Participants’ folders who did not attend all three sessions and who did not meet the study’s eligibility criteria were excluded. The comparison sample was matched for age. Clinic folder data from both sample populations was extracted, including HIV sero-conversion, date of diagnosis, CD4 count, 1st, 2nd, 3rd follow-up visit attendance, ART eligibility, ART referrals, and ART visit attendance. Linkage to care was assessed as being referred for and attending at least one ART visit, if eligible to commence treatment with a CD4 measurement of 200 cells/mm³ or less based on South African national guidelines prior to April 2010 (UNGASS, 2010).

All quantitative measurements were analyzed using STATA. McNemar’s Matched Pair analysis was used to assess before and after impact on knowledge, attitudes, and behavior. Chi-square tests and t tests were conducted on the Linkage to Care categorical and continuous measures, respectively.

3. Result

3.1. Feasibility

Despite the overwhelming fears of stigmatization expressed in Phase I and II by health-workers and young people alike, the successful implementation of the intervention in Phase III demonstrated that it would be possible to recruit adolescents into a structured support group for HIV positive individuals. Baseline characteristics of all participants completing the initial assessment are shown in Table 2. 109 participants completed a baseline assessment at Session 1, with 74 participants returning for all three sessions (68%). In total, the median age was 22 years old. The majority of participants were female (95%), black (100%), and isiXhosa-speaking (99%). A small proportion of participants reported currently attending school (26%). There was no significant difference in baseline characteristics among those participants retained over all three sessions versus those who were not retained.

Enticing adolescents who have been recently diagnosed proved difficult, given the range of possible mental health issues that many youth...
experience following a diagnosis (Whetten, Reif, Whetten, & McMillan, 2008). One female facilitator reported:

When I meet the young people for the first time I see them not feeling happy, maybe because of their status, because they are newly diagnosed and they don’t feel well. Sometimes they are shocked, and sometimes, if the person is not feeling well, it makes me feel uncomfortable and sad.

Also, the mood of each participant could affect the feasibility of engaging the groups as a whole. A male facilitator explained:

It was challenging because when you go to each session you don’t know what to expect because it is this group today and tomorrow it is another group. Sometimes you feel that meeting this group or that group is very encouraging. It depends on the mood of the group that you are facilitating on that particular day.

Other logistical issues unrelated to the exclusivity of an HIV-positive group warranted additional recruitment and retention efforts. Turnover of clinic counseling staff required that relationships be frequently re-established. Retaining participants over the three sessions required routine phone reminders, but participants often shared cell phones with family members or friends, making maintenance of confidentiality difficult. Through trial and error, the recruiters found that nurses tended to be more effective in referring clients than counselors. They also found that having recruiters stationed at clinics providing educational talks in waiting areas, as well as being available in a private consulting room for direct referral following a HIV-positive diagnosis improved recruitment.

3.2. Acceptability

Feedback about the intervention’s acceptability was gathered from post-session surveys. The majority of participants (85%) reported that the information presented was useful, comprehensible, and relevant to their lives. They also reported that they would recommend the support group sessions to a friend, and that the facilitators were approachable and well informed.

Additionally, participant and facilitator interviews upon completion of the three sessions demonstrated important aspects emerging from the support groups.

3.2.1. Coping and support

Despite feedback in Phase I that the groups might expose participants to stigma, Hlanganani offered participants a safe and informative context to disclose their status and their feelings. For some, the support sessions were their first attempt at disclosing to other people, especially peers.

I would recommend this group to other young people because young people could say anything freely, could participate freely; there is no fear because we are all young people. You can share anything with your age group and overcoming problems. (Participant)

I would say Hlanganani group is a safe space for HIV-positive people to be supported and motivated. (Participant)

Many participants reported feeling lonely and isolated following their diagnosis, but found companionship, commonalities and mutual support from their peers and the facilitators.

I made friends – before I was lonely and not well since I found out about my HIV status. Since I’ve been here, I’ve been fine. (Participant)

Coming to the Hlanganani groups made me start talking about my status and I started disclosing to people in my community. Before, I wouldn’t say anything. I disclosed to my neighbor and she told me she was also HIV-positive, so I told her to go and check her CD4 count and now we are going to start ARVs together. (Participant)

Prior to the sessions, many young people were unaware of how to access support from their personal networks or from public social and clinical services. By the end of Session 3, many participants exchanged phone numbers and expressed an overwhelming desire to extend the group into more sessions. Beyond the support they were able to foster for one another, participants reported the ways in which sharing things within the group emboldened them to disclose to others.

3.2.2. Health education

In addition to the social benefits described, participants cited the information they received in the sessions’ didactic Learning Spots as being one of the main benefits. The information on positive prevention and STIs were two of the most popular educational items, according to participant feedback.

When asked about the most important thing this participant learned, she replied:

About CD4 counts and ARVs – that you must know your viral load and CD4 count. After going to Hlanganani I went for a CD4 count test and they found that I had a very low CD4 count, so they told me I should go on ARV treatment, so now I am starting treatment soon. (Participant)

Also, the manner in which the curriculum operationalized lessons learned through a Goal-Setting activity at the end of each session was another reported benefit from individuals.

The most important thing I facilitated was the Goal Setting. For some of the participants it helps when they set themselves goals and they come back to the next session and they say, ‘Hey, I have done A, B, and C’. Or, ‘I have failed to do A, B, and C and now I’m doing this.’ It helps – it means that, for me as a facilitator at least, you managed. You managed to change someone’s life. (Facilitator)

3.2.3. Cognitive-behavioral tools

Participant feedback on the cognitive behavioral tools highlighted the ways in which these techniques elicited thoughts and group communication about one’s feelings.

The role-play touched me and reminded me of my early days when I first tested positive. (Participant)

Participants felt that they found the characters relatable and the narrative emotional, having been through similar experiences.

Afterwards, the Feeling Cups were a useful way for adolescents to quantify their emotional state and assess their feelings. The Feeling Cups were amongst the most popular tool, and helped youth to visualize and decrease their levels of stress and discomfort. They also served as an entrée for group discussion following the role play.

The Feeling Cups are very effective. The way we measure our problems now is very interesting. We can identify exactly how we feel…(Participant)

The Feeling Cups make it easy for you to recognize and see how stressed you are. (Participant)

I loved the Feeling Cups. I’m so happy when I get an empty feeling cup and that means there is no stress. (Participant)

The Feeling Cups are very, very important for them because we can see now, even when we introduce these Feeling Cups from the first session, that when they are comfortable to come and use them. They even show
us that they understand exactly what is the meaning of the Feeling Cups. (Facilitator)

Group facilitation tools like the Thanks Tokens, Candle of Hope and the Talking Stick were also well received, as they provided more cohesion to the group activities.

The Candle of Hope – I like that you can say your reason for lighting it when you light it, and it feels special. It’s not something you usually do every day, and it makes you feel better. (Participant)

Overall feedback about the program’s acceptability was positive, with participants and facilitators stating how the group sessions benefited the youth in multiple ways. They discussed ameliorative qualities like forming bonds with other participants and disclosing to and accessing support networks, along with the relief and confidence this gave them. They also appreciated receiving helpful tools for coping with the stress of their diagnosis, new knowledge about HIV, and ways to live positively. Responses also exemplified how goal-setting can be put into motion, such as encouraging others to test or attend the clinic.

3.3. Impact on knowledge, attitudes and self-reported behavior

Intervention impact on knowledge and attitudes about living healthily with HIV is shown in Table 3. Baseline measures showed that participants enrolled with relatively high levels of HIV information. 83% of participants at baseline correctly answered that a low CD4 count indicates a weak immune system, with little to no change indicated at follow-up. An 11% increase in the proportion of participants understanding the basic meaning of viral load was not statistically significant. However, a trend toward significant improvement in attitude toward HIV as a manageable chronic disease was seen in the 9% increase of participants answering “yes” to “Do people with HIV still live long and productive lives?” at follow-up ($p = .07$).

Disclosure and coping between baseline and follow-up also showed improvements. Six participants disclosed to a friend or family member during the course of the intervention, with the mean number of people that individuals disclosed to rising from 2 to 4. Feelings of being supported in participants’ HIV status also increased by 6.6% ($p = .2$).

Self-reported preventive behavior demonstrated significant improvements, whereas baseline knowledge of HIV transmission remained high (see Table 4). Affirmative responses to the question, “In the last 3 weeks, have you talked to a sexual partner about condoms?” increased from 69% to 83% of the participants ($p = .035$). The proportion of participants reporting condom usage rose by 12% ($p = .049$).

3.4. Impact on linkage to care

The linkage to care sub-sample characteristics and outcomes is indicated in Table 5. After excluding participant folders that did not meet the criteria: clients 16–24 years old, within 12 months of HIV positive diagnosis, attended all three sessions (Intervention arm), or did not attend any sessions (Comparison arm), a total of 35 Intervention arm and 222 comparison arm folders were reviewed. Sample characteristics were similar, with the majority female and a mean age of 22 years. 13 of 33 (37.1%) intervention arm participants were eligible for ART compared to 47 of 191 (24.6%) in the comparison arm. A significantly higher proportion of the intervention participants attended for their first ART visit (100%) versus the comparison arm (58.06%) ($p < .001$ [CI $-66.63, .311$]).

4. Discussion

This pilot study demonstrated proof of concept for Hlanganani HIV positive youth support groups, an innovative, lay-person led, cognitive behavioral intervention consisting of three structured support group sessions.

Support groups have been widely recognized as valuable approaches for mitigating the psychosocial effects of an HIV positive diagnosis (UNAIDS, 2011). South Africa’s National Strategic Plan on HIV, STIs and TB recommends support structures for improving HIV care outcomes though few evidence-based, comprehensive models have been described thus far (South African Department of Health, 2012a, 2012b). Similar models in the US and South Africa have demonstrated the potential for structured support groups in improving the psychosocial outcomes of newly-diagnosed HIV-positive individuals (Futterman et al., 2010; Hosek, Lemos, Harper, & Telander, 2011); however, this concept has previously not been piloted and evaluated within newly diagnosed HIV-infected youths in South Africa. In addition, this intervention uniquely aims to influence healthcare-seeking behavior by offering a bridge between testing and care.

Hlanganani incorporates the structure, curriculum and cognitive behavioral tools from similar interventions and adapts them for a targeted youth audience in greater Cape Town. This intervention also capitalizes on South Africa’s large pool of lay health workers who, with intensive training, can run the sessions in a variety of community-based settings—all of which are valuable components of a comprehensive, adaptable package that could be replicated in a variety of similar, low-resource settings.

This paper describes the development and contents of this comprehensive model. It also reflects on the feasibility and acceptability of engaging young people in this exclusively HIV-positive group, and explores its possible benefits.

The participatory nature of Hlanganani’s development lends itself to the program’s strengths. Together with HIV infected and uninfected young people, the team conceptualized a safe, empowering space to share and learn about HIV based on expressed needs and challenges. Of primary concern was the potential for participants to feel stigmatized for attending a group only for HIV-infected youth. Young people and other key informants repeatedly underlined the fear that youth would likely have in being associated with HIV. Despite these concerns, the pilot process demonstrated feasibility in engaging 16 to 24 year old newly diagnosed HIV positive youth in support groups. While the groups are not for everyone, they are feasible and positive for many HIV + youth.

| Table 3 | Living positively with HIV: % correct answers. |
|---------------------------------|---------------------------------|---------------------------------|---------------------------------|
| Before n = 65 | After n = 65 | Percentage change |
| ARVs are medicines that help HIV positive people to live healthier lives (y) | 54 (83%) | 59 (91%) | 8% ($p = .27$) |
| ARVs can cure people of HIV and AIDS (y) | 48 (74%) | 47 (72%) | 2% ($p = 1$) |
| Do people with HIV still live long and productive lives? (y) | 58 (89%) | 64 (98%) | 9% ($p = .007$) |
| Does a low CD4 count mean someone’s immune system is strong? (n) | 54 (83%) | 54 (83%) | 0% ($p = 1$) |
| Does a low viral load mean that someone’s immune system is weak? (n) | 24 (40%) | 33 (51%) | 11% ($p = .25$) |
| Once you are infected with HIV, you are infected for life (y) | 51 (78%) | 55 (85%) | 7% ($p = .62$) |

Please cite this article as: Snyder, K., et al., Preliminary results from Hlanganani (Coming Together): A structured support group for HIV-infected adolescents piloted in Cape Town, South Africa, Children and Youth Services Review (2014), http://dx.doi.org/10.1016/j.childyouth.2014.03.027
The support group sessions were also shown to be acceptable to participants and intervention facilitators, who spoke encouragingly about the information and psychosocial support provided in the groups. Positive feedback on the curriculum described the information as being comprehensible and relevant, especially lessons regarding safe sexuality and monitoring health through CD4 counts. The cognitive behavioral tools, such as Role Plays and Feeling Cups, were well received and served their purpose of eliciting emotional awareness among the participants. An additional salient benefit that resonated in post-intervention interviews was the strength and support young people received from bonding with other participants, and the encouragement they felt to disclose to other friends or family.

Arguably, the social mechanisms that were observed in and amongst the groups may hold the most potential for Hlanganani’s health promoting effects. This pilot suggests that these “safe spaces” may provide a critical platform for HIV competence. Despite initial concerns about stigma, participants described finding Hlanganani a safe, trusting environment to share concerns and experiences with others like them. They also were able to share and augment each other’s strengths, particularly when it came to disclosing their status to partners, friends or family. Furthermore, data from the knowledge, attitude, and self-reported behavior evaluation and the linkage to care study reflect trends toward healthy improvements.

Pre- and post-intervention surveys with participants completing all three sessions highlighted key areas of impact on HIV-related knowledge, attitudes and self-reported behavior change. Although baseline knowledge of basic HIV information was high amongst the participants, survey data reflected a sizeable shift in perceptions of HIV as being a chronic, manageable disease. The extent to which participants disclosed their status to other friends and family increased, along with reported feelings of support upon disclosure, albeit this may be attributed to the impact of time. Following the intervention, more participants reported discussing condom use with their partners. The linkage to care component, measured as having attended at least one antiretroviral treatment clinic visit if eligible and referred, showed that a significantly higher proportion of Hlanganani participants attended their first ART clinic visit than a sample of youth from the same clinic. This comparison does not show causation, as it is likely that these may reflect two incomparable groups. Those individuals self-selecting to participate in the intervention may also be more motivated to attend clinic visits; however, the results may show potential for the Hlanganani concept to affect youth health outcomes.

The Hlanganani pilot program’s outcomes could be further validated by a larger study that addressed this pilot’s limitations. A randomized controlled trial, which samples a larger number of HIV-infected young people both receiving and not receiving the intervention, would allow for strengthened statistical significance testing. Post-intervention follow-up at multiple milestones, such as 6 months, 12 months, and 24 months would also offer more reliable data on the sustainability of behavioral changes. Detailed recruitment and retention data should be collected in order to improve feasibility assessments and to help support more representative recruitment strategies. Also, although the study suggests an impact on psychosocial outcomes such as coping and anxiety, future evaluations should include validated measurement tools that resonated in post-intervention evaluations that may provide a critical platform for HIV competence.

Although the aim of the support group sessions was to support vulnerable HIV infected young people with care, Hlanganani participant characteristics and baseline data signaled a healthy user bias in effect. Almost all participants were female, which reflects to a large extent the disproportionate number of young women versus young men who present at clinics for HIV counseling and testing in South Africa. How to encourage more young men to test and engage in care remains a critical issue to explore. More targeted recruitment efforts to attract boys to a support group setting should be considered, perhaps outside of the clinic environment. In addition, the majority of participants presented at Session One with a solid understanding of basic HIV information, including the definition of a CD4 count, had already disclosed to at least one person, and knew how they should be using protection during sex. It may be said that deciding to attend a session – with strangers – who are also HIV infected requires a high degree of self-efficacy and agency, particularly for an adolescent. Although eligibility criteria included a positive diagnosis in the previous twelve months, this intervention may only be engaging youth who are already coping with and

Table 4
Positive prevention: % correct answers.

<table>
<thead>
<tr>
<th></th>
<th>Before n = 65</th>
<th>After n = 65</th>
<th>Percentage change</th>
</tr>
</thead>
<tbody>
<tr>
<td>If you are HIV+, can you infect other people by sharing cups, plates, knives, and forks? (y)</td>
<td>59 (91%)</td>
<td>60 (92%)</td>
<td>1% (p = 1)</td>
</tr>
<tr>
<td>If you are HIV+, can you infect other people by coughing or sneezing near them? (y)</td>
<td>57 (88%)</td>
<td>57 (88%)</td>
<td>0% (p = 1)</td>
</tr>
<tr>
<td>Is there a way for someone who has HIV to get pregnant without passing the virus on to her child? (y)</td>
<td>53 (82%)</td>
<td>54 (83%)</td>
<td>1% (p = 1)</td>
</tr>
<tr>
<td>In the last 3 weeks, have you talked to a sexual partner about condoms? (y)</td>
<td>45 (69%)</td>
<td>54 (83%)</td>
<td>14% (p = .035)</td>
</tr>
<tr>
<td>The last time you had sex did you or your partner use a condom? (y)</td>
<td>46 (71%)</td>
<td>54 (83%)</td>
<td>12% (p = .049)</td>
</tr>
</tbody>
</table>

<ref>Table 5</ref>

Linkage to care sub-study.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Hlanganani arm (%)</th>
<th>Comparison study (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>n = 1 (3%)</td>
<td>n = 20 (9%)</td>
</tr>
<tr>
<td>Female</td>
<td>n = 34 (97%)</td>
<td>n = 202 (91%)</td>
</tr>
<tr>
<td>Age</td>
<td>Median = 22 (IQR 20–24)</td>
<td>Median = 21 (IQR 19–23)</td>
</tr>
<tr>
<td>CD4 Count taken (y)*</td>
<td>n = 35 (100%)</td>
<td>n = 191 (86.04%)</td>
</tr>
<tr>
<td>CD4 Count</td>
<td>Median = 396 (IQR 223–540)</td>
<td>Median = 351 (IQR 258–500)</td>
</tr>
<tr>
<td>WHO Stage</td>
<td>n = 32 (91.43%)</td>
<td>n = 184 (82.88%)</td>
</tr>
<tr>
<td>ART eligible (if CD4 taken)</td>
<td>Median = 1 (IQR 1–2)</td>
<td>Median = 1 (IQR 1–2)</td>
</tr>
<tr>
<td>ART referred (if eligible)</td>
<td>n = 13 (37.14%)</td>
<td>n = 47/191 (24.60%)</td>
</tr>
<tr>
<td>Attended first ART visit (if referred)</td>
<td>n = 13 (100%)</td>
<td>n = 31 (65.96%)</td>
</tr>
</tbody>
</table>

* Proportion with CD4 recorded in charts.
| Proportion with WHO staging recorded in charts. |  |

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positively adapting to their new health status, which may account for the differences shown in the linkage to care results. Identifying, recruiting and retaining youth in their earlier, pre-contemplative or contemplative stages of coping with their diagnosis and linking into care will be both very challenging and necessary for seeing real health impacts.

Possible solutions to selection bias could be to individually adapt and target various user groups. This could include a curriculum specifically tailored for adolescent or adult Men who have Sex with Men, perinatally-infected youth who are transitioning into adult care, an all-boys group, or groups orientated toward anyone who has recently attended a HCT service. While the structure, core curriculum components, and delivery could remain the same, the information and actionable goals could be adapted for specific groups of participants.

This pilot study demonstrated proof of concept and the potential to strengthen the link between an HIV-positive diagnosis and entry into HIV care and treatment for young people in the Western Cape. Expansion of participatory, adolescent-focused supportive services is critical to filling the gap in care and preventing further infection.

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