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The VUKA Family Program: Piloting a family-based psychosocial intervention to promote health and mental health among HIV infected early adolescents in South Africa

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Abstract

An increasing number of adolescents born with HIV in South Africa are on antiretroviral treatment and have to confront complex issues related to coping with a chronic, stigmatizing and transmittable illness. Very few evidence-based mental health and health promotion programs for this population exist in South Africa. This study builds on a previous collaboratively designed and

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developmentally-timed family-based intervention for early adolescents (CHAMP). The study uses community-based participatory approach as part of formative research to evaluate a pilot randomized control trial at two hospitals. The paper reports on the development, feasibility and acceptability of the VUKA family-based program and its short-term impact on a range of psychosocial variables for HIV+ pre-adolescents and their caregivers. A ten session intervention of approximately 3 months duration was delivered to 65 pre-adolescents aged 10-13 years and their families. VUKA participants were noted to improve on all dimensions, including mental health, youth behaviour, HIV treatment knowledge, stigma, communication and adherence to medication. VUKA shows promise as a family-based mental and HIV prevention program for HIV+ pre-adolescents and which could be delivered by trained lay staff.

Keywords

Family-based; Psychosocial intervention; Mental health; HIV+ adolescents

Introduction

In 2009, an estimated 334,000 children living with HIV in South Africa were primarily infected perinatally (Republic of South Africa, 2010). With significantly greater access to antiretroviral treatment (ART), children previously not expected to survive childhood will reach adolescence in significant numbers, with improved clinical and nutritional status (Sutcliffe, van Dijk, Bolton, Persaud, & Moss, 2008).

Nonetheless, adolescents born with HIV/AIDS continue to face a stigmatizing and chronic illness (Havens & Mellins, 2008) and have to learn to cope with the effect of HIV on normative developmental challenges, including pubertal delays (Buchacz et al., 2003), neurodevelopmental and cognitive problems (Brackis-Cott, Kang, Dolezal, Abrams, & Mellins, 2009; Nozyce et al., 2006), and a tendency for greater social and emotional immaturity relative to same age peers (Donenberg & Pao, 2005). In addition, they experience multiple family disruptions due to caregiver illness, death, or substance use (Domek, 2010; Havens & Mellins, 2008). These factors may result in poor impulse control or judgment and increased possibility of negative peer relations and early or riskier sexual experimentation (Havens & Mellins, 2008).

Evidence from high-resource settings indicates that as children with HIV enter adolescence they are also at significant risk for mental health problems and substance use (Havens & Mellins, 2008; Mellins et al., 2009; Mellins et al., 2012; Mellins et al., 2011). Although limited, research in African countries, including South Africa, suggests that youth living with perinatal HIV-infection (YLWPHIV) may be equally, if not more, vulnerable to behavioral and emotional problems than comparison controls (Cluver, Orkin, Gardner, & Boyes, 2012; Domek, 2010). South Africa is at the forefront of providing ART but is challenged to meet the complex needs of increasing numbers of adolescents who must now cope with HIV as a chronic, highly stigmatized, and transmittable illness (Domek, 2010; Ledlie, 2001). The challenges adolescents face with non-adherence to medical treatment are compounded for YLWPHIV by HIV stigma, ART side effects, life-long need for medication (Haberer et al., 2010; Mills et al., 2006), sexual development and behavior compromised by early and lifetime exposure to HIV and treatment (Bauermeister, Elkington, Robbins, Kang, & Mellins, 2011), and widespread poverty in sub-Saharan Africa (Reisner et al., 2009).

While families remain the mainstay of providing protection and care for children in sub-Saharan Africa, the loss of many adult caregivers to HIV/AIDS and widespread poverty may compromise the family's ability to meet the needs of children living with HIV/AIDS

(Heymann & Kidman, 2009). Parents may experience feelings of chronic sorrow, fears that HIV/AIDS, stigma, and discrimination will negatively impact their child's health, mortality, and future, and concern about when to disclose HIV to the child (Antle, Wells, Goldie, DeMatteo, & King, 2001).

Psychosocial Programs for Youth Living with Perinatal HIV

While there are programs that have been developed for YLWPHIV, including family social support (Abramowitz et al., 2009), psycho-educational intervention (Bacha, Pomeroy, & Gilbert, 1999), multi-systemic therapy for children living with HIV (Ellis, Naar-King, Cunningham, & Secord, 2006), and more general clinical interventions (Rogers, Miller, Murphy, Tanney, & Fortune, 2001), there are few evidence-based interventions to support families in promoting the health and psychosocial well-being of children and adolescents born with HIV, and even fewer that are not resource intensive and have been tailored to the particular cultural context and needs of adolescents in low-and-middle-income countries (Domek, 2010; Petersen et al., 2010).

The Collaborative HIV prevention and Adolescent Mental Health Family Program (CHAMP) is a developmentally-timed, multi-session, family-based intervention that has been adapted and implemented with HIV- youth in South Africa (CHAMPSA) and with YLWPHIV in the US (CHAMP+US) (Bhana, McKay, Mellins, Petersen, & Bell, 2010; Domek, 2010; McKay & Paikoff, 2007). Multiple randomized controlled trials (RCTs) of CHAMP and a pilot RCT of CHAMP+US have shown that the intervention results in significant improvements in family process variables (e.g., communication, supervision, monitoring, and support) and youth mental health and risk behaviors (e.g., improved externalizing behaviors; less time spent in risky situations), and family and child medication adherence support, with high acceptability by caregivers and youth (Bell et al., 2008; Bhana et al., 2010; McKay & Paikoff, 2007; McKay et al., 2004; Mellins, Brackis-Cott, Dolezal, & Abrams, 2004).

The VUKA Family Intervention

A multi-disciplinary team of physicians, nurses, psychologists, lay counselors, and researchers, together with patients, South African artists, and educators/curriculum developers, reviewed existing CHAMP, CHAMP+, and CHAMPSA materials and conducted formative qualitative interviews with adolescent youth and caregivers to adapt the CHAMP model for YLWPHIV in South Africa (Petersen et al., 2010). In addition to issues related to negative peer influences and poor financial, family and social support, specific psychosocial problems and challenges particular to YLWPHIV and their caregivers emerged in interviews (Petersen et al., 2010). These included unfulfilled bereaving at the loss of biological parents, difficulty accepting and dealing with identity and status issues related to living with HIV, high external stigma, discrimination and disclosure, and difficulties in understanding ART and adherence (Mellins et al., 2012; Petersen et al., 2010). Participant feedback also suggested caregiver-youth difficulty discussing topics such as sexual behavior and loss and bereavement. The revised intervention retained the overall CHAMP structure (multiple child-caregiver pairs) and the use of a cartoon-based storyline (Petersen, Mason, Bhana, Bell, & McKay, 2006) from CHAMPSA, with an altered curriculum to accommodate the unique needs of YLWPHIV. Patient and provider community advisors renamed the intervention "VUKA" ("Let's wake up" in isiZulu).

A new culturally-tailored cartoon storyline and curriculum enabled lay counselors supervised by a psychologist to deliver the intervention in an engaging and structured way. The cartoon storyline tells the story of a 12-year-old boy, orphaned by AIDS, who moves in with relatives and learns about his own HIV diagnosis and treatment needs, while coping

with family loss, stigma, peer relationships, identity, and family functioning (see Figure 1 for examples). The curriculum provides step-by-step guidance for counselors to deliver critical information to facilitate discussions and problem-solving within and between families in multi-family groups. Session topics include: (1) AIDS-related loss and bereavement; (2) HIV transmission and treatment knowledge; (3) Disclosure of HIV status to others; (4) Youth identity, acceptance and coping with HIV; (5) Adherence to medical treatment; (6) Stigma and discrimination; (7) Caregiver-child communication, particularly on sensitive topics such as puberty and HIV; (8) Puberty; (9) Identifying and developing strategies to keep children safe in high-risk situations where sexual behavior and drug use are possible; and (10) Social support. As with the original CHAMP intervention program, HIV-infected youth and their primary caregiver come together with other affected families for sessions, which include both multiple family group activities and separate parent and child group activities.

A pilot RCT of VUKA was conducted to examine the 1) development, feasibility and acceptability of VUKA for health care settings in South Africa and 2) short-term impact of the VUKA family program on a range of psychosocial variables for YLWPHIV and their caregivers.

Methods

Participants and Procedure

The VUKA Family Program was developed and piloted at two clinical sites in KwaZulu-Natal, South Africa: a) a subsidized not-for-profit hospital in Durban with a dedicated clinic serving adults and children with HIV/AIDS and b) a Department of Health regional- and district-level public hospital located in Pietermaritzburg, approximately 100km from Durban, that primarily serves low-income patients and is a primary treatment site for the rollout of ART in KwaZulu-Natal. Both sites afford subsidized or free treatment and represent typical treatment scenarios for YLWPHIV in South Africa.

Caregivers approached in clinic waiting rooms were referred to the study project director (fluent in both English and isiZulu) if they expressed interest and had a child who met study criteria. Inclusion criteria included: a) Child 10-14 years old; b) Child enrolled in HIV care at the hospital; and c) Child aware of his/her HIV status. Families were enrolled only if both the caregiver and child provided written consent and assent. Among the 74 families enrolled, 65 families completed a baseline assessment and were then randomly assigned to receive VUKA immediately (n=33) or approximately three months later, after both groups had completed a post-evaluation (comparison group; n=32). The comparison group data presented here was collected prior to their receiving VUKA.

The intervention was administered in 6 sessions over a 3-month period (2 Saturdays a month) based on participant and provider feedback concerning feasibility and space. Intervention facilitators were primarily lay counselors and one masters-level psychologist, who also provided supervision after initial training by the study team. All participants were assessed at two time points, at baseline and approximately two weeks after the last intervention session (approximately 3 months after baseline); 59 families (91% of participants) completed the post-test assessment. South African and US institutional review boards, including the hospitals involved in the project, approved the study. Self-administered questionnaires were translated into isiZulu using standard procedures for translation and back-translation (Preciagio & Henry, 1997; Tanzer & Sim, 1999). Participants completed research questionnaires (1 hour sessions) in small groups (youth and caregivers separately), with questionnaires read-aloud by trained research staff. These

procedures have been used successfully with children as young as nine years old (Bell et al., 2008; Mellins et al., 2004).

During the evaluation sessions, participants were encouraged to express their level of comfort with the topic under discussion to ensure that children were not experiencing high levels of distress in relation to the questions asked. Training explicitly included sensitivity to such issues with the involvement of a supervising psychologist. However, no such instances were reported. Using a cartoon-based story-line assisted in lending distance to sensitive issues and negative life events. In addition, a referral system was put into place to ensure that any participants in need of further counselling could access such services.

Measures

A summary table of the measures used is presented below.

Descriptor	Inter-item reliability (pre- and post-test)	Measures	Construct
Youth Adherence to ART	Single items	Derived from Pediatric AIDS Clinical Trials Group (Mellins et al., 2006; Usitalo et al., 2010)	How often medications missed over past 6 months
Youth Mental Health	.42 to .54	Strengths and Difficulties Questionnaire (Goodman, 1997; Youth in Mind, 2012)	Emotional symptoms, conduct, peer relations. Hyperactivity/inattentiveness, prosocial behavior
Child Depression	.54	Child Depression Inventory (Kovacs, 1981)	Depression symptoms
Self-Concept	.70 to .58	Tennessee Self-Concept Scale-Short Form (Fitts & Warren, 1996)	Self-identity, self-satisfaction, self-esteem
Youth HIV Treatment Knowledge	.65 to .74	HIV Treatment Knowledge (Levy, Lampman, Handler, Flay, & Weeks, 1993)	HIV causality, transmission, treatment
Youth and Caregiver Communication and Comfort	.88 to .73	Family Environment Scale/Family Assessment Measure (FES/FAM) (Bell et al., 2008)	Comfort and communication around hard to talk about issues
HIV/AIDS Illness Stigma	.82 to .67	Stigma (Westbrook, Bauman, & Shinnar, 1992)	Perceived stigma, disclosure and self-esteem

Analysis

Quantitative Analysis—Generalized linear model (GLM) was used to compare VUKA families to control families on change in key outcomes over time. Generalized estimating equation (GEE) was employed to account for within-subject correlations due to the effect of repeated measures. We report the group difference (VUKA vs. control) in change over time on outcomes (i.e., the regression coefficient (beta) obtained from each of the GLM models) as well as its corresponding p-values.

Process evaluation—Process evaluation involved two focus group interviews with intervention caregiver participants from both sites (n=20) and six in-depth follow-up

individual interviews, conducted after the last session. Interviews focused on participants' experience and perceptions of how participation affected themselves and their children. Following informed consent procedures, interviews were recorded in isiZulu and translated and transcribed into English, with back-translation checks by an independent, bilingual English-isiZulu speaker. The data were analyzed using thematic analysis; data across focus groups and individual interviews were read twice to identify common issues or constructs that were grouped into common themes and used to form a coding framework. The data were then coded according to these common themes by two independent coders using NVivo 8 software (QSR International) to verify and ensure reliability of the emergent themes.

Results

Demographics Characteristics

All participants were Black South Africans of Zulu ethnicity with most speaking both English and Zulu. Ninety one percent of accompanying caregivers were the children's mothers, and 52% of children lived with the mother and 40% with grandparents. Chi-square analysis of the demographic characteristics of the two study sites did not reveal any significant differences except the proportion of families receiving child support grants (100% in site 2 compared to less than 75% for site 1).

Attendance and Feasibility

Among the 33 families randomized to the VUKA arm, 32 attended at least one session, 100% of whom completed it, with 94% attending at least 5 of the 6 days and 55% attending all six days. The most common reasons for not attending were illness and family time conflicts. There were no differences in rates of attendance by sites.

Quantitative Analysis

Despite the small sample size, comparisons between VUKA and the comparison group arms revealed some significant differences and trends on key domains including reported ART adherence, HIV treatment knowledge, and caregiver-child communication, with participants in the VUKA arm improving in all key outcomes (Table II). Youth in the VUKA condition evidenced significantly greater improvements in reported ART adherence than youth in the comparison group post-intervention (reported as change scores), (VUKA = 1.10; Control = -.43 at baseline and follow up, $p < .05$) (Table III). Caregivers in VUKA reported significantly greater change in comfort communicating with their children about sensitive topics (VUKA = .26; Control = -.54, $p < .002$) and a trend for experiencing less stigma (-.21) than caregivers in the control group (.28, $p < .09$) (Table III). There was also a trend for youth in VUKA to show more improvements in treatment knowledge (VUKA = .27; Control = -.74, $p < .08$), and caregiver-child communication than non-intervention group youth (.41 vs -.07, $p < .09$) (Table III).

Process evaluation

A number of common themes emerged in the focus groups and individual interviews post VUKA implementation as presented below.

Adherence to medication—Caregivers indicated that VUKA helped improve adherence as children realized that they were not the only ones on medication and became hopeful about their future:

I'm very happy because he didn't want to take his medication and now [after coming here] he takes it on time, with no difficulties. I think it's also because he

can see other children, he can see that he's not the only one, there are many others ... he now goes out, plays soccer...until seven in the evening and he comes and take his medication and then leaves again.

Improved Self-concept and Future Orientation—Caregivers reported that VUKA helped promote healthy HIV-positive self-identities and future orientation, particularly through the Themba character in the storybook:

...his self-esteem has improved because ... [in the] storybook that we use, there it says that Themba is not sick. He even says that “ma, now I know that I’m suffering from something that anyone could suffer from. Just because I’m HIV+ does not mean I’m sick.”

Improved Social Support—Caregivers reported strengthened social support for both themselves and their children through new friendships with other HIV+ children and their caregivers:

“In the beginning he [the child] was scared but now he has realized that he’s not the only one who has [HIV]... he has made new friends... This program has really helped him.”

“...it enabled us to talk to other caregivers... And from that you’d see that problems that one experiences like having an HIV+ child, you’re not the only one.”

Talking About Sensitive Topics—Caregivers also reported that VUKA helped them discuss sensitive topics with their children:

No, I did not talk to her before we came here; I got help from this program. We were given storybooks that had information on adolescence and on how we as caregivers should sit down with our kids and talk to them about such things.

Diffusion of the Program to Other Family Members—The storybooks were reported to assist in garnering support from other family members who read them at home and then assisted in caring for the HIV+ child:

My older son would tell L (the child) to bring the book and they would read it and talk about it, so it has really helped me a lot... now they understand that even if I’m not home they have to look after the child, and check if she has taken her medication, not to wait for me like before when they would leave everything to me...

Discussion

The pilot study results indicate high levels of feasibility and acceptability of VUKA at both hospitals with high levels of attendance. Although a small sample, the results are promising as VUKA participants improved in all the key intervention outcomes with some statistically significant differences in the RCT. This is particularly encouraging in light of the fact that VUKA was delivered by lay counselors, indicating that with appropriate training and support, a family-based intervention for YLWPHIV is feasible in settings with limited professional staff.

Given the importance of ART adherence (Domek, 2010), several significant related changes were found in this pilot. Among those who received VUKA, ART adherence as a function of the last time they missed taking medication was significantly better than that reported in the comparison group. This variable has been strongly associated with HIV viral load (Usitalo et

al., 2010). Also, HIV treatment knowledge scores and the frequency and comfort of communication about HIV and other sensitive topics increased and perceptions of external stigma were reduced in the VUKA participants. These findings are important given that previous studies have linked caregiver-child communication to reduced adolescent risk behavior and improved adherence (McKay et al., 2004) and studies have also linked reduced stigma to improved mental health and adherence outcomes (Reisner et al., 2009).

There are several limitations to this study, including the use of self-reported adherence measures and the small sample size. Moreover, it is possible that there was selection bias in participants who agreed to be in the study.

Nevertheless, with the increasing roll-out of ART in South Africa, VUKA was deliberately piloted in one public health facility, reflective of facilities available for the majority of South African HIV+ patients, using lay counselors. VUKA shows promise as a family-based prevention program for YLWPHIV to improve behavioral health outcomes such as adherence that can be effectively delivered by lay staff in public health clinics. In South Africa, where there is a dearth of specialists compared to the number of patients, task-sharing has been central to the re-engineered primary health care system (Pillay & Baron, November 2011). Within the context of South Africa's resource constraints, use of lay staff under the supervision of a mental health specialist, enhances the possibility of the program being scaled up in South African care settings and thus warrants further study and potential use. It is noteworthy that VUKA was retained in one of the hospitals as part of standard care after the pilot study was completed, based on participant and provider response.

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1. SURVIVING LOSS AND BEREAVEMENT



2. TREATMENT ADHERENCE



3. YOUTH IDENTITY



Figure 1.

Table 1

Summary Demographics (Youth and Caregivers)

	n	Percent		Site 1	Percent	Site 2	Percent
HIV+ Adolescents (N=66)	47	71					
Durban Site	19	29					
Pietermaritzburg Site							
	Combined		Site 1	Percent	Site 2	Percent	
Gender							
Male	32	49	24	52	9	47	
Female	33	51	22	48	10	53	
Age Distribution							
10 years	15	23	9	20	6	32	
11 years	18	28	13	28	5	26	
12 years	12	18	8	17	4	21	
13 years	20	31	16	35	4	21	
Grade							
2 – 3	3	5	1	2	2	10	
4	10	15	7	15	3	16	
5	18	28	13	28	5	26	
6	21	32	16	35	5	26	
7 – 8	13	20	9	19	4	21	
Living Arrangements – Yes Responses (non-exclusive)							
Mother only	34	52	23	50	11	58	
Father only	12	18	11	24	1	5*	
Mother and Father	8	12	7	100	1	100	
Stepmother only	2	3	2	4	0	0	
Aunt/Uncle	13	20	9	20	4	21	
Grandparents	26	40	16	35	10	53	
Older Sibling	10	15	7	15	3	16	
Caregiver Characteristics (N=66)	n	Percent					
Durban Site	47	71					
Pietermaritzburg Site	19	29					

	n		Percent	
	Combined	Percent	Site 1	Site 2
HIV + Adolescents (N=66)	47	71		
Durban Site	19	29		
Pietermaritzburg Site				
	Combined	Percent	Site 1	Site 2
	Combined	Percent	Site 1	Site 2
Gender				
Male	6	9	5	11
Female	59	91	41	89
Age Distribution				
21-30	5	9	2	5
31-40	23	40	14	36
41-50	17	29	15	39
51-60	4	7	2	5
61-70	6	10	3	8
71+	3	5		
Level of Formal Education				
8 th grade or less	22	35	18	40
Some high school	19	30	9	20
Completed high school	13	21	10	22
Post School	9	14	9	13
Employment Status				
Employed	19	29	14	31
Intermittent employment	6	9	3	7
Unemployed	39	61	28	62
Relationship Status				
Married	21	34	14	32
Single (never married)	29	47	20	46
Separated	3	5	2	4
Divorced	2	3	2	4
Widowed	7	11	5	11
Live in Own Place				

	n		Percent	
	Combined	Site 1	Site 2	Percent
HIV + Adolescents (N=66)	47	58	12	63
Durban Site	19	29		
Pietermaritzburg Site				
Receiving a grant for the child				
Yes	45	82	33	73
No			19	100*
Household Income				
At least one person has job	20	32	16	36
At least one person has pension	19	30	12	27
At least 1 person has job + 1 person has pension	21	33	14	31
No one has a job or a pension	3	5	3	7
Gone without Food in Past Month				
More than 6 times	11	17	7	17
4-6 times	10	16	5	12
2-3 times	12	19	7	17
1 time	5	8	1	2
Never	25	40	20	50
Caregiver HIV Status				
Positive	34	69	25	73
Negative	11	22	8	23
Mother Aware of Child's HIV Status				
Less than 5 years ago	38	60	27	61
More than 5 years ago	25	40	17	39

Table II**Descriptive Data**

Descriptive characteristics of Intervention Group (VUKA) and Comparison participants

Measure	N	Mean	SD	Range
Children Depression Inventory				
VUKA	64	3.25	2.67	0-12
Control	58	2.34	2.35	0-11
Strengths and Difficulties				
VUKA	54	18.80	3.56	11-26
Control	47	17.68	4.34	11-32
External Stigma				
VUKA	62	2.47	.82	1-4
Control	56	2.30	.72	1-4
Caregiver Communication				
VUKA	65	2.43	.77	1-4
Control	55	2.55	.71	1-4
Caregiver Communication Comfort				
VUKA	65	3.26	.65	2-4
Control	55	3.14	.73	1-4

Table III

Multivariate Analysis - VUKA Intervention Outcomes

Item/Scale	Comparison (mean scores)		VUKA (mean scores)		Beta	p-value
	Baseline	Follow-up	Baseline	Follow-up		
Youth Adherence Last Time Missed Meds	4.79	4.36	3.71	4.81	1.527	.05**
Youth mental health (CDI; higher worse)	3.19	2.64	3.31	2.03	-.736	.417
Youth behavior (SDQ; higher worse)	18.80	18.38	18.79	16.96	-1.412	.371
Youth HIV treatment knowledge (higher is better)	4.88	4.14	4.18	4.45	1.002	.079**
Caregiver HIV treatment knowledge (Higher is better)	5.74	6.36	6.36	6.58	-.402	.227
Caregiver external stigma	2.34	2.62	2.71	2.50	-.484	.09**
Caregiver communication frequency	2.49	2.42	2.32	2.73	.478	.09**
Caregiver communication comfort	3.35	2.81	3.16	3.42	.796	.002***

*** significant at $\alpha = .05$

** significant at $\alpha = .10$

* Beta coefficient: Regression Coefficient obtained from GLM model (with GEE method to adjust for within subject correlation) which presents the group differences (VUKA vs. Control) in change in key outcomes over time.