

Identifying Essential Components of Effective HIV Teen Clubs in Namibia

Mary Kirk

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Committee:

Gabrielle O'Malley

Laura Brandt

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Mary Kirk

University of Washington

Abstract

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Mary Kirk

Chair of the Supervisory Committee:

Gabrielle O'Malley

Department of Global Health

Teen clubs are psychosocial support groups based at health facilities that help adolescents living with HIV (ALHIV) learn about their health and engage with their peers. Various nonprofit organizations have set up and funded these clubs in high HIV prevalence African countries to encourage ART adherence and healthy lifestyles among ALHIV. In Namibia, the first teen club was started by local health care workers in 2010. Given the recent push by the Ministry of Health and Social Services (MoHSS) to focus on ALHIV and ART adherence, there has been an increased interest in teen clubs. However, there has been no examinations of Namibian HIV teen clubs and the components required for establishing a sustained and successful teen club. Through twenty-eight interviews with health care workers (HCWs) around the country and observations of four teen club meetings, essential components and potential challenges of teen club implementation were identified. Results from this project were used to develop a “starter pack and activity guide” for future teen clubs in Namibia.

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Introduction

Approximately 1.8 million youths aged ten to nineteen are living with HIV, and 84% of them are living in sub-Saharan Africa (Davies, 2017). Globally, HIV is the second largest contributor to adolescent mortality (Stackpool-Moore, 2017). HIV positive adolescents have worse treatment outcomes than other HIV positive age groups, including higher rates of loss to follow up, poor ART adherence and virological failure. In addition, adolescents living with HIV (ALHIV) have a higher risk of experiencing mental health challenges than their HIV negative counterparts (Mark, 2017). ALHIV face many issues that are compounded by the physical, emotional, and mental developments that all adolescents experience, all of which contribute to a more difficult time being adherent to ART.

Teen clubs are psychosocial support groups for ALHIV based out of health facilities and led by health care workers (HCWs). They are one way that health systems in sub-Saharan Africa have tried to encourage ART adherence among teens, along with creating a safe environment for ALHIV to learn and share their own experiences. A recently published study used a nested case-control study design, with stratified selection using routine medical data from 2004 through 2015 for ALHIV patients, to compare attrition from care between ALHIV who attended or did not attend teen club meetings at a facility in Zomba, Malawi (MacKenzie, 2017). Using a sample of 540 ALHIV, they determined that exposure to the teen club was associated with a 3.7-times lower odds of attrition than not being exposed to the teen club (MacKenzie, 2017).

Adolescents (youth aged 10-19) account for 24% of the Namibian population (Namibia: Statistics, 2015). Among 15-19 year old's, the HIV ANC prevalence is approximately 5% (UNICEF Namibia, 2012). Namibia's Ministry of Health and Social Services (MoHSS) has a new national priority focusing on the social and clinical outcomes of HIV positive adolescents

currently on ART. Approximately 87% of all HIV positive patients currently on ART in Namibia has suppressed viral loads (Mekonen, 2016). However, only 62% of nineteen-year-olds on ART have suppressed viral loads, with suppression rates being better among younger teens (<14) than older teens (Mekonen, 2016). Teen clubs are opportunities for facilities staff to work with teens to support ART adherence and foster positive social connections for ALHIV. The Namibian National Guidelines on Adolescents Living with HIV, published in 2012, define teen clubs as psychosocial support groups and give some basic foundational information on what characteristics a teen club should have. The first teen club in Namibia was established at Katutura Hospital in 2010. To date, there have been no examinations of Namibian teen clubs to identify key components for replication and scale. This project seeks to respond to that gap through an exploration of the components necessary to start a teen club, as well as the potential barriers to implementation in Namibian health facilities. Results from this project were used to develop a “starter pack and activity guide” for future teen clubs in Namibia.

Methods

Questionnaire development

Four different interview questionnaires were developed in consultation with the International Training and Education Center for Health (I-TECH) Namibia clinical director, each appropriate for a different type of interviewee: 1) interviewees currently involved in a well-established teen club but who were not involved in starting it, 2) interviewees involved in a well-established teen club who did help start it, 3) interviewees whose facility does not have a teen club, and 4) interviewees who are part of a recently established club.

These four distinctions were decided upon for the following reasons. The first category, interviewees currently involved in a well-established teen club but who were not involved in starting it, was an important distinction because some HCWs who are actively involved in their facility's club were not working at the facility when the club was started. It would be impossible for them to speak to the process of starting the club, and their current work with the club may be entirely different than the experience of the HCWs who started the club. The second distinction, interviewees involved in a well-established club where they did help start it, is different than the first because the HCW could speak to the process of starting the club, as well as how the club has transformed over time and the overarching challenges and successes of the club. The third distinction, interviewees at a facility without a teen club, is different because they can't answer questions about an entity that does not exist. They can, however, speak to the challenges and barriers facility staff perceive in implementing a club, and the reasons a facility may have for not having a club. The fourth distinction, interviewees who are a part of a recently established club, is important because some clubs are very new and have a different set of challenges and resources than clubs that have been sustained over time. This distinction is crucial because these recently established clubs are more vulnerable to challenges that the well-established clubs have overcome.

Sample Selection

The I-TECH Clinical Director introduced the project at a meeting for clinical physician and nurse mentors in September 2017 in Namibia. The study lead gave an overview of project, answered questions, and circulated contact sheets so HCWs could write their email and phone numbers.

Some HCWs recorded their own names, and some provided names of supervisors or colleagues who were more actively involved in adolescent health or their facility's existing teen club. Along with the contact name, there were sections for their email and phone number. Some left either one of these fields blank. All interviewees were identified through these circulated contact sheets, which led to a sample size of N=28.

Teen Club meeting observations

Four different teen clubs were observed during September and October 2017. These included the Katutura Pediatric Hospital teen club and the Katutura Health Center teen club in Windhoek, Khomas region and the Tamariskia HC ART Clinic teen club in Swakopmund, and the Kuisebmond HC ART Clinic teen club in Walvis Bay, both of which are in Erongo region.

At each of the meetings, the study lead introduced herself and her work with I-TECH to the teen club members, and then simply sat and observed the meeting. Given the sensitive nature and the need to protect the teens privacy, it was decided with each of the staff who arranged the observation that no notes or photographs would be taken at any point during the meeting. However, the observer wrote notes immediately after each meeting.

Results/Discussion

In total, interviews were conducted with staff from eleven of Namibia's fourteen regions (Table 1, Appendix Map 1). Sixteen of these interviewees were with staff at a facility that has an existing teen club, nine interviewees were with staff at a facility that did not have a teen club at the time of the interview, and three interviewees with health professionals who work at a regional, more supervisory level and were able to speak about teen clubs and the necessary

components and challenges to implementation, but not a specific facility’s experience with teen clubs. There were a total of N=28 interviews.

Interviewees represented a broad spectrum of the Namibia health care system, including one HIV expert nurse, sixteen nurse mentors, three “sisters in charge”, four clinic RNs, two clinic health assistants (HA), one CDC field officer, and two clinical mentors (medical doctors). Nurse mentors are not part of facility staff and are not supervisors of any staff at the facility. They often cover multiple facilities, provide a mentoring/coaching function, and are funded through a different mechanism (CDC, Global Fund, I-TECH, etc.; some are “seconded” by the MoHSS). Sisters in charge are the HCW in charge of running the facility and supervising all staff within the facility. They are supervised by a primary health care supervisor, who works at the district level MoHSS office.

Table 1: Geographic Distribution of Interviewees

Region	Number of Interviewees	Region	Number of Interviewees
Khomas	2	Omusati	1
Otjozondjupa	2	Zambezi	1
Hardap	1	Ohangwena	5
Kavango East	3	Erongo	4
Oshikoto	4	Karas	2
Oshana	3	TOTAL	28

Essential components of a teen club:

Size of teen clubs

Consensus among interviewees is that there is no set number of teens required to form a teen club. While it is always advisable to have as many eligible teens as possible join the club, a facility can start a teen club with a small number of teens.

Among the interviewee facilities with teen clubs, two clubs are “small” (<15 teens), four clubs are “medium” (16-30 teens), six clubs are “large” (31-50 teens), and five clubs are “extra-large” (51+ teens). For facilities without teen clubs, the interviewees at six facilities knew or felt that “enough” teens were eligible and willing to participate in a teen club, while interviewees at four facilities knew or felt “not enough” teens were eligible and willing to participate in a teen club.

Eligibility for teen club participation

To participate in a teen club, the youth must be aged ten or older and have received full disclosure of their HIV status. Namibian pediatric HIV disclosure protocol contained in official guidelines dictates that between the age of six and ten, the youth should receive partial disclosure of their status. This means that, in collaboration with their caregiver, HCWs help them understand that they are taking medicines to keep them and their “body soldiers” strong, and that the medicines work to keep the “bad guys” asleep, but without mention of their HIV status. Upon reaching ten years of age, they are supposed to receive full disclosure, where they are told that the “bad guy” is HIV. Though this protocol is supposed to be followed at all health facilities, some interviewees referred to barriers to following the protocol. These include not enough staff trained in disclosure (only having one or two HCWs who can safely fully disclose to youth) or having the parent or caregiver missing from ART appointments (the parent or caregiver must be present for the youth to receive full disclosure).

Health facility staff involved in teen clubs

At all facilities with teen clubs, interviewees reported there were “enough” staff participating in the facilitation of the teen club. At all facilities without teen clubs, each interviewee felt there would be “enough” staff interested or willing to participate in facilitation of the teen club if one were started. Existing teen clubs are facilitated by a mix of nurses, nurse mentors, doctors, counselors, and health assistants. Several teen clubs made a conscious choice to have both male and female staff members facilitate the club meetings, with the goal of encouraging teens of both genders to join and stay in the club. For example, one club put one male HA and one female HA in charge of recruiting teens based on their respective genders.

Interviewees did not report a specific number of staff required to run a teen club, though all interviewees at facilities without a teen club stated they could identify some colleagues they either knew or assumed would be willing to start and facilitate a teen club.

Financial partnerships

In addition to health facility staff to facilitate teen clubs, there are often additional resource needs such as funds to purchase snacks for the monthly meetings, transportation for the teens (in the form of cash for a taxi or bus), money to purchase materials for the club, or funding for a retreat for the teens. Snacks were the most frequently reported components of teen club meetings. They provide a way to model health eating behaviors, provide energy for teens after a meeting, and encourage teens to interact together socially after the meeting formally ends. Existing teen clubs have found multiple mechanisms to help fund these expenses, including partnerships with regional health offices, nonprofit organizations, or private donations.

Of interviewee facilities with teen clubs (N=16), five have current partnerships with Positive Vibes, a Namibian organization that has been supporting community health initiatives

for people living with HIV since 2004. Positive Vibes provides funding for snacks and/or transport for the teen club members. Two teen clubs have partnerships with UNICEF, which provides snacks for the teens. Two teen clubs have formalized partnerships with the facility's regional health office. Five teen clubs currently have no partnerships, and fund snacks through the facility.

Teen club meeting locations

Teen club meetings can take place in a variety of locations. Of the facilities with teen clubs, four host meetings at the hospital/facility chapel or hall, two host meetings at a designated container on the hospital/facility grounds, three host meetings at the hospital/facility ART clinic, two host meetings at a community center, two host meetings in variable locations (depending on venue availability), two host meetings outside under a tree, two host meetings at the hospital/facility conference or staff room.

Seven interviewees from facilities without a teen club reported that they already knew where a meeting could be held or felt confident a secure space could be identified and used. Only three interviewees were uncertain that a secure space could be identified to host a teen club meeting at their facility.

The biggest concern for choosing a location for meetings is preserving the confidentiality of the teens. Given the potential for accidental disclosure of their status to others, keeping the topic of the teen club meetings private is crucial. While a private location within the facility would be ideal, there are other ways of protecting the privacy of the teens involved. Some interviewees stated that if anyone asked who the teens were or what the teen club meeting was, they would state that it's a private teen club and leave it at that. Not identifying the teens as

ALHIV is one way to protect the teens privacy if the physical meeting location cannot provide that level of privacy.

Challenges to teen club participation:

Stigma

Interviewees at facilities both with and without teen clubs mentioned stigma as a barrier to teen club enrollment. Interviewees brought up three different types of stigma related to participation in a teen club: self-stigma, parent or caregiver stigma, and community stigma. Self-stigma is characterized by individuals who live with a condition (e.g., HIV) and are vulnerable to endorsing stereotypes about themselves based on their condition (Corrigan and Rao, 2012). Two interviewees said self-stigma of the teens has prevented teens from enrolling or could prevent teens from enrolling (teens don't want to go because their status will be inadvertently disclosed to others ["people will know I have HIV"]).

Parent or caregiver stigma is characterized as stigma the parent or caregiver of an ALHIV feels will be foisted upon them because of their child's condition. Five interviewees said parent or caregiver stigma about their teen has prevented teens from enrolling or could prevent teens from enrolling (parent or caregiver won't give consent for their teen to join because it will reflect badly on the parent ["my child has HIV, so I must have HIV"]).

Community stigma refers to the perceived or actual community ostracizing an individual or group based on a condition. Two interviewees said their community size would stigmatize teens and prevent teens from joining (small, rural community → "everyone" will know what the teens are doing at the meeting). It should be noted that the two interviewees who said their community size would stigmatize teens are at facilities without a teen club.

To combat self-stigma and parent or caregiver stigma, interviewees suggested the HCW speaking one-on-one with the teen and/or the parent or caregiver. Interviewees said that having these conversations helped tremendously with encouraging the teens and their parents to allow the teen to join the teen club. The interviewees spoke so highly of this method of working through the stigma, there was only one reported case of a parent or caregiver not giving permission for their teen to join after speaking with the HCW.

Parent or caregiver support

This is a particularly sensitive area as well, given that some ALHIV in Namibia do not live with their biological parents. It is not unheard of for a member of the extended family (aunt or uncle, grandmother or grandfather) to be the primary caregiver of an ALHIV. Given that teens need parent or caregiver consent to join a teen club, support from the parents or caregivers of ALHIV is crucial to a successful teen club. Understandably, parents or caregivers may be wary of sending their teen to an HIV support group, especially if they do not know much about teen clubs or are unsure of the purpose of their teen going to one. Interviewees expressed that it was a distinct possibility that parents or caregivers could be hesitant or refuse their teen's invitation to join when first presented with the teen club.

Interviewees recommended multiple ways to bolster parental support for their teen to participate in teen club. During one-on-one conversations with parents or caregivers, HCWs can answer questions about and help explain the role of the teen club. Interviewees also suggested HCWs hosting sensitization meetings as a way for parents and caregivers to come together and discuss their concerns as a group with the health facility staff. Interviewees from facilities which have held these sensitization meetings prior to establishing their teen clubs spoke highly of this

method of engaging the parents and caregivers and speaking with them about the importance of the teen club.

A third method of garnering parent or caregiver support was sending letters home with the teens, stating the purpose of the teen club, what the teen will get out of it, and encouraging the parent or caregiver to contact the facility if they had any more questions. It is important to note that the letter was worded carefully to ensure that accidental disclosure would not happen, by using language that did not directly mention HIV.

Transport

Transportation for the teens to and from the health facility is a concern many interviewees spoke of as a challenge for the teens to attend meetings. Some clubs have utilized partnerships with nonprofit organizations to fund transportation, but it remains a challenge to find funding for the teens to transport themselves to and from the meetings. Given the economic realities of the country (~34% unemployment rate, with the bulk of that in rural communities), it can be hard to ask parents to pay for transportation to the health facility for their teen (Reuters).

These issues are some of the hardest to combat, given that the scope of a teen club and the resources available at the health facility level are limited. One interviewee said their facility was going to start having a main pick-up and drop-off location, where a facility van would be used to collect the teens for the meeting and drop them off afterward, which would hopefully mitigate some of the transportation issues and make it easier for the teens to secure transport to and from one set location.

One interviewee at a rural facility said they had started a teen club a few years ago but had to stop it because many teens who go to that facility live in a village that has one taxi that

only leaves the village once a week, if that. Transportation that is that unreliable is beyond the realm of anything the facility can do or fix and makes it a prohibitive factor in sustaining a teen club.

Conclusion

There is immense potential for teen clubs to succeed in Namibia, as long as certain components are present at the health facility. These include: enough teens who meet the eligibility standards, health facility staff who are willing to spend time starting and facilitating the teen club, ability to finance, at the bare minimum, snacks for the teen club, and a location for the meetings that protects the teens privacy as well as possible.

The challenges that facilities may face when starting a teen club are possible to overcome, but some will require more flexibility and creative problem solving than others. The issues surrounding stigma and parent support of teen enrollment in the clubs may require certain conversational and interpersonal problem-solving skills requiring kindness and open-mindedness about the situation. The issues surrounding resource funding may require initiative in reaching out to local businesses. Transportation issues may require scheduling flexibility, such as arranging teen club meetings on the day most teens have transportation to the facility. Overall, though, the challenges described above should not be prohibitive in starting a teen club.

The information gathered from Namibian HCWs experience and perspectives provided rich information which was used to create a starter pack and activity guide for teen club creation in Namibia. This starter pack has been shared with and endorsed by the Namibian Ministry of Health and Social Services. The availability of this starter pack will encourage and facilitate the development and successful implementation of teen clubs across Namibia.

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Appendix

Map 1: Location of all HCW interviewees



