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Tablet-Based Disclosure Counselling for HIV-Infected Children, Adolescents, and their Caregivers: A Pilot Study

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Abstract

Background: Overwhelmed, under-trained medical staff working in resource-limited settings need efficient resources for HIV disclosure counselling. The objective of this study was to describe providers' experiences using tablet computers for disclosure-related counselling with HIV-infected children and their caregivers in western Kenya, with additional perspectives from adolescents.

Methods: A qualitative study design was implemented at three HIV clinics in western Kenya (Bumala, Busia, and Port Victoria) within Academic Model Providing Access to Healthcare (AMPATH). Twenty-one healthcare providers involved with pediatric disclosure were recruited and enrolled in the study. Initial interviews focused on understanding current disclosure practices and barriers. Tablets containing disclosure-related resources were distributed. Resources included short narrative videos created in this context to highlight issues relevant to child HIV disclosure.

Results: Providers reported tablets improved disclosure, child participation, and medication adherence. All reported that reviewing materials increased their knowledge and comfort with disclosure. The most frequently used materials were the narrative videos and an animated video explaining the importance of medication adherence. Time was a major barrier for using the tablet. Clinician self-education persisted at one-year follow-up. Adolescents expressed enjoyment from viewing the tablet resources and had a better understanding of the importance of medication adherence.

Conclusions: Tablet computers containing resources for disclosure are an acceptable and potentially effective resource to help providers support families with disclosure. Further work is needed to appropriately train the clinical providers in using the resources in a developmentally appropriate manner, as well as to develop new resources on adolescent-specific and HIV-related topics.

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Keywords

HIV; Adolescents; Disclosure; Tablet computers; electronic resources; counselling tools

Introduction

More than two million adolescents are HIV-infected, with approximately 90% living in sub-Saharan Africa (World Health Organization, 2014). While most have been HIV-infected since birth, many do not know their own HIV status (Vreeman, Gramelspacher, Gisore, Scanlon, & Nyandiko, 2013). Timely disclosure of HIV status is critical for adolescents' long-term disease management and transitions into adult care (Vreeman et al., 2013). Best practices for HIV disclosure are not well characterized. However, current recommendations for HIV disclosure include providing gradual, individualized, age-appropriate information about HIV and counselling services for both the child and the caregiver (New York State Department of Health, 2009).

HIV stigma and discrimination make HIV disclosure a challenge worldwide. However, these challenges are exacerbated in resource-limited settings (RLS) due to insufficient numbers of healthcare providers and limited training in HIV disclosure and counselling. The World Health Organization (WHO) reports an average of 2.5 physicians/10 000 people in low-income countries, which is only 1/10 of the rate in the United States (World Health Organization, 2015). Moreover, populations in African countries bear over 24% of the global burden of disease yet only have access to 3% of the world's healthcare workers (AVERT, 2014; World Health Organization, 2015). Overwhelmed, undertrained medical staff working in RLS frequently have little-to-no knowledge of appropriate methods of HIV disclosure and limited culturally appropriate resources to help support caregivers during the process of HIV disclosure to adolescents (Beima-Sofie et al., 2014; Rujumba, Mbasaalaki-Mwaka, & Ndeezi, 2010; Vaz, Eng, Maman, Tshikandu, & Behets, 2010).

In such settings, cost-effective and practical methods of education and patient counselling are necessary to help alleviate this health gap (Ajay & Prabhakaran, 2011; Nicholas, 2008). The use of small electronic devices, such as tablet computers, is a potential avenue to provide healthcare education to this critically underserved population. These devices are also financially feasible and do not add greater burdens on the overstretched healthcare workforce (Aviles, Ortega, Kuan, Coloma, & Harris, 2008; Catalani, Philbrick, Fraser, Mechael, & Israelski, 2013; Clifford & Clifton, 2012; Folaranmi, 2014; Labrique, Vasudevan, Kochi, Fabricant, & Mehl, 2013). Portable electronic devices have proven to be beneficial in providing health education to medical providers and improving healthcare knowledge and clinical outcomes in both resource-rich and resource-limited settings (Finkelstein et al., 2012; Ventola, 2014). For RLS, tablet computers are a particularly well-suited resource, due to their low demands for electricity and functionality not requiring internet connectivity (Catalani et al., 2013; Dowshen, Kuhns, Johnson, Holoyda, & Garofalo, 2012; Finkelstein et al., 2012; Mackenzie et al., 2007). Despite these benefits, a recent systematic review revealed that this technology has not been frequently utilized in RLS (McHenry, Fischer, Chun, & Vreeman, 2017). Possible reasons for this underutilization

may include unfamiliarity with the technology, availability, and concerns about theft and the necessity of internet connections (Lazarus, Sookrajh, & Satyapal, 2017; Witt et al., 2016; Zolfo et al., 2010). In Kenya, where this study takes place, most adolescents do not have access to tablets or computers in their own homes, which limits their widespread use (Pew Research Center, 2016). However, HIV-infected children and adolescents are expected to follow-up regularly at HIV clinics, which provides an opportunity to interact with tablet computers at clinic. Using these technologies may support clinical providers, caregivers, and adolescents during the challenging process of HIV disclosure.

The objective of this study was to evaluate clinical providers' perceptions and experiences of using tablet computers loaded with multimedia resources for disclosure-related counselling with HIV-infected adolescents and their caregivers at several HIV clinics in western Kenya. Additionally, we solicited perspectives from adolescents attending those clinics regarding their experiences with the tablets. We hypothesized that clinical providers would perceive tablet computers as an acceptable resource for HIV disclosure and using the tablet would improve the HIV disclosure process in their clinics.

Methods

Study Design and Participants

This study used a longitudinal, mixed methods research design, with interviews, questionnaires, and surveys with clinical providers at three clinics in western Kenya. The study team contacted the clinic managers at each study site to identify clinical providers that were involved in adolescent disclosure to target for recruitment. The clinic managers were each allowed to identify up to 7 eligible clinical providers, by limited the number of tablets available for use. From this convenience sample, all identified clinical providers were recruited by a research assistant. The research assistant reviewed information about the study in both verbal and written form, and written consent was obtained from each participant. This process occurred within one month of contacting the clinic managers. The clinical providers included clinical officers, nurses, and social support staff. Clinical officers are non-specialized, mid-level providers, similar to a nurse practitioner or physician's assistant, who provide the majority of medical care in these clinics. Inclusion criteria for the clinical providers included: working with HIV-infected adolescents and their caregivers during the disclosure process and working at one of the three study site clinics.

During the one-year follow-up, HIV-infected, disclosed adolescents at each clinic were recruited for a one-time interview regarding tablet implementation in their clinics. In this study, an adolescent was defined as an individual between the ages of 10–19 years (World Health Organization, 2017). Inclusion criteria for the adolescents included: being HIV-infected, between 10 and 19 years of age; knowing their own HIV status; and receiving care at one of the three study site clinics. Convenience sampling was performed by the clinical providers who were caring for adolescents at that clinic. This was performed during a one-month period when clinical providers asked adolescents coming into clinic if they would be interested in participating in a study. If they expressed interest, the clinical provider provided their contact information to the research team. A research assistant then contacted the family to review the study information sheet verbally with the adolescent and their caregiver.

Written consent and assent were obtained from both the caregiver and adolescents, respectively. In cases where the adolescent was 18 years or older, only written participant consent was required. A minimum of 5 adolescent participants per clinic site were targeted for recruitment, as fewer participants may negatively impact the group dynamics required to elicit collective viewpoints (Carlsen & Glenton, 2011). Only one focus group was performed at each clinic due to logistic considerations.

Setting:

This study took place from July 2015 - June 2016 at three rural HIV clinics in western Kenya within Academic Model Providing Access to Healthcare (AMPATH). Born from a 20-year partnership between Indiana University School of Medicine, Moi University School of Medicine, and the Moi Teaching and Referral Hospital in Eldoret, Kenya, AMPATH currently treats over 130 000 adult and pediatric patients with funding from the Presidential Emergency Plan for AIDS Relief at 25 clinics and 40 satellite clinics in western Kenya (Einterz et al., 2007; Inui et al., 2007). AMPATH provides care to over 25 000 HIV-infected and HIV-exposed children, including approximately 6 000 children under the age of 15 years on anti-retroviral therapy.

Non-specialized, non-physician providers (i.e. clinical officers) primarily staffed the clinics included in this study. Prior to initiation of this study, AMPATH had a Standard Operating Procedure (SOP) in place for its clinics outlining a protocol for HIV disclosure practices in which HIV disclosure was supposed to begin by age 10 years. At the conclusion of this study, Study Site 1 had over 6 000 individuals actively in care, Study Site 2 had nearly 3 000 individuals actively in care, and Study Site 3 had approximately 700 individuals actively in care (AMPATH, 2016). Within each clinic, approximately 10% of its population was under the age of 15 years (AMPATH, 2016).

Tablet resources:

Android tablets were donated to AMPATH by a large technology company in 2014. These were loaded with materials developed as part of an ongoing HADITHI disclosure intervention trial (PIs: Nyandiko and Vreeman). Resources on tablets included: general HIV treatment guidelines (Kenya Ministry of Health, 2014), AMPATH Standard Operating Procedures, general educational materials on HIV and disclosure, counselling-based activities to use with caregivers and adolescents, New York guidelines for HIV disclosure for adolescents (New York State Department of Health, 2009), pamphlets developed locally for general and HIV-specific adolescent care issues such as relationships and dealing with stress, Living Positively Workbook (Children's Rights Centre), children's books about HIV, a locally developed, culturally appropriate animation explaining HIV and the importance of medication adherence (Fischer et al., 2015), and eight culturally appropriate video narratives sharing family members' and adolescents' experiences of HIV and disclosure (McAteer et al., 2016) (Materials used in this study and HADITHI are available at: <http://indiana.edu/~hadithi>). The study team members who created and provided the curated tablets were not involved in study procedures to avoid unintentional influence.

Ethical considerations:

An ethical consideration that arose during study planning was the possibility of accident disclosure. Accidental disclosure occurs when an individual unintentionally learns of their HIV status without the appropriate psychosocial support. The resources within the tablet were organized to minimize the likelihood of accidental disclosure occurring. Folders on the tablets were used to distinguish materials appropriate for use in pre-disclosed vs. disclosed adolescents, as well as materials available in English or Kiswahili. Participants were shown how to operate the tablets and access the resources for both disclosed and non-disclosed adolescents during distribution. They were instructed to review the materials on the tablets before using them with adolescents. No further instructions on the use of the materials were given, to facilitate use of the tablets at the participants' own discretion.

This study was approved by the Institutional Review Board of Indiana University School of Medicine in Indianapolis, Indiana, United States of America and by the Institutional Research and Ethics Committee of Moi University School of Medicine and Moi Teaching and Referral Hospital in Eldoret, Kenya.

Data collection methods:

In order to achieve our objective to evaluate providers' perceptions and experiences of using tablet computers for disclosure-related counselling, multiple methods of data collection were utilized, including questionnaires, surveys, and semi-structured interviews. Prior to distributing the tablets, exploratory semi-structured interviews were performed with clinical providers at each clinic to understand the current disclosure environment in their clinics. After distribution of the tablets to participants, data regarding use of the tablets over the prior week were collected via monthly surveys over a 5-month period. The survey questions focused on the following: clinical patient volume; frequency of tablet use (e.g. 'Over the last week, how often have you used the tablets?' with categorical answer options including never, 25%, 50%, 75%, nearly all interactions); materials regularly used with patients on the tablets, time spent using the tablet, populations with whom the tablet is used (with categorical options such as non-disclosed adolescents, disclosed adolescents, caregivers, other clinical staff, as well as a free text option); methods of using the tablet (with categorical options such as giving the table to a client to look through while completing paperwork, showing clients the video then ask questions after the video is completed, watching the video with frequent pauses to discuss what is being viewed, as well as a free text option); adolescents' reaction to the tablet (with options including: confused, sad, angry, quiet, excited, joyful, as well as a free text option); and materials reviewed by the clinical provider on their own time. Free text space was available at the end of each survey for participants to describe their experiences with the tablets. The complete survey is available upon request. Paper surveys were identifiable only by study ID number and were returned to the study coordinators each month. After the 5-month period, repeat semi-structured interviews were performed to understand participants' experiences with the tablets.

One year after implementation of the tablet computers, a follow-up survey was administered to the clinical providers, and the adolescents were recruited for interviews. For all interviews performed within this study, participants were asked their preference in speaking in either

English or Kiswahili (Kenya's two national languages), and the interview took place in their preferred language. Interview recordings were transcribed and translated (if needed) by research staff fluent in English and Kiswahili for analysis.

Data analysis:

Qualitative data: All interview transcripts were analyzed to arrive at a contextualized understanding of the clinical providers' experiences using the tablets for HIV disclosure process with adolescents and their caregivers. For the baseline interviews, *a priori* codes were created prior to data analysis. These codes emanated from the interview guide and were used as a starting point for analysis. We then employed constant comparison, axial coding, and triangulation to identify central concepts (Glaser & Strauss, 1967; Strauss & Corbin, 1990). The initial stage of constant comparative analysis was done through coding by investigators (M.S.M, L.J.F, C.I.M, J.A., R.O.A). Line-by-line coding was individually performed by the investigators (M.S.M, C.I.M) using the qualitative analysis software Dedoose – a web application for managing, analyzing, and presenting qualitative and mixed method research data (“Dedoose Web Application for Managing, Analyzing, and Presenting Qualitative and Mixed Methods Research Data,” 2014). Relevant themes and concepts were developed inductively from these data. Data collected from the follow-up participant interviews and adolescent groups were the result of targeted questioning. Triangulation was used with these to evaluate validity of monthly survey data and the overall experience of clinical providers using the tablets for disclosure. Similar methods were used for analyzing the transcripts from the adolescent interviews. Quotes, edited minimally for clarity, are provided in the text to add descriptive detail and highlight major themes.

Quantitative Data—Fisher's Exact Test was used to evaluate differences between categorical demographic variables within the participants. We analyzed the Likert scale scores using standard summary statistics: mean, median, and standard deviation for the ordinal variables. Wilcoxon signed ranks test was used to evaluate differences of the ordinal data from the Likert scales between differing time points in survey administration. Kruskal-Wallis was used to see if there was a difference between clinics, gender, or clinical position, each as independent groups, for the ordinal variables of comfort, ability, knowledge, impact of tablet, and patient's reaction to the tablet, individually. Level of significance (α) was set at 0.05. Analyses were performed using procedures appropriate for survey data in SAS Version 9.4.

Results

Study Participants' Characteristics:

With the support of the in-charge clinical officer at each clinic, all healthcare providers involved in the disclosure process were identified and recruited for this study. All recruited providers (n=21) agreed to participate in this study. Overall, 62% (13/21) were female and 38% (8/21) were clinical officers with the remainder trained as nurses or in social support roles (Table 1). No significant differences between participant demographics was noted between clinics.

Baseline Interviews:

Participants overwhelmingly believed that it was the adolescent's primary caregiver's responsibility to direct the disclosure process, although they often reported having to initiate the disclosure with the adolescents because of the caregiver's reluctance. They believed the healthcare workers' roles should be to support the caregivers in disclosure, answer questions from the adolescents regarding HIV and treatment, and identify the disclosure status of the adolescents to tailor their visits appropriately. One clinician noted:

“[Caregivers] are the ones who need to be armed with information to support the child when they ask questions or maybe when depressed at home; they are there for them. Maybe the child will see us once in a month and so what happens to the other 27 days while he/she is not with us?”

Many described situations when they had to initiate disclosure when caregivers had not. Providers described being compelled to initiate disclosure when adolescents had poor adherence to medicines, were engaging in risky behaviours, or when unaccompanied adolescents were asking the physicians why they were taking their medications or required to come to clinic.

The disclosure methods used by clinicians were varied. Some described encouraging caregivers to disclose to their child, while others described a more gradual process of educating the child about chronic disease and HIV generally and then progressing to tell the child they have HIV. One clinician noted:

“Health workers may use the methods that best work for them.”

Most were unable to provide specific details of their personal method of disclosing, and none identified a protocol to follow.

Accidental disclosure, or having an individual learn about their HIV status in an indirect or unintended way, appeared to be pervasive in the clinics. One clinician stated:

“Most of the disclosures in [my clinic], I would say are accidental.”

She went on to note that when children become 17–18 years old, the clinics assumed they already know their HIV status when, in fact, the adolescents may have never actually been informed. Other examples of how accidental disclosure occurred in clinics included when patients read their medical charts during a clinic visit or while participating in peer support groups. For example, two of the clinics created adolescent support groups to help support the many adolescents struggling with medication adherence, feelings of isolation, and limited knowledge of HIV care. These groups consisted of adolescents that were both disclosed and those who were not disclosed, which had the potential consequence of accidental disclosure.

Many barriers to adolescent disclosure were identified by participants, both for themselves as clinical providers and what they perceived for the caregivers. Two major themes in clinical provider barriers were clinic restraints (such as time limitations, patient volume, discontinuity with patients, and lack of designation of clinical staff responsible for disclosure) and lack of training in disclosure. Most clinical providers had no training specific to working with children and adolescents, and none expressed familiarity with the AMPATH

SOP for HIV disclosure. Participants perceived discomfort as the primary barrier to disclosure for caregivers in their clinics. This discomfort emanated from caregiver's own lack of knowledge regarding HIV itself or how to disclose a child of their status, their fear of blame or the child's reaction to learning their status, and the HIV-related stigma experienced within the communities where they live.

Implementation of Tablets:

After tablet initiation, monthly follow-up surveys indicated tablets were used during 75% or more of clinic encounters by 67% (14/21) of providers one month after tablet distribution and 85% (18/21) at the end of the study. The overall increase from one month to study completion was not statistically significant.

In the final survey, males indicated the tablet had been more helpful in impacting their HIV disclosure counselling than females ($p=0.05$). Also, in the final survey, there was a nearly statistically significant increase in the perceived enjoyment of using the tablet for counselling for males compared with females ($p=0.06$). No difference was seen among the clinical positions.

A significant improvement in comfort scores was seen between the first and third surveys ($p=0.04$), first and fourth surveys ($p=0.02$), and first and fifth surveys ($p=0.03$). In looking at clinic-specific differences, Clinic Site 2 had significantly lower comfort using the tablet for disclosure in the initial survey compared to Clinic Sites 1 and 3 ($p<0.01$). No other variables were found to be statistically significant. Summary statistics of the first and final monthly surveys' data for comfort, ability, knowledge, impact of tablet, and patient's reaction to the tablet are described in Table 2. Likert scores for all variables were skewed in an upwards direction with little variability in scores within and between variables.

Clinical Provider Follow-up Interviews

During five-month follow-up interviews with staff, all ($n=21$) providers reported tablets improved the clinic disclosure process by providing them access to resources to support their work. One participant noted:

“It has really changed disclosure as it has really helped the whole clinic and even the kids, in that there are so many materials here in the tablet we didn't know, but through reading through it, it has really improved our skills.”

Resources most commonly utilized with patients were the narrative videos (used by $n=21$) and animation (used by $n=19$). The counselling guidelines were used by over half of the participants ($n=12$).

A few providers at each clinic described using the tablet computers in a group setting, but all reported using it one-on-one with adolescents and/or caregivers. Many ($n=16$) reported improved clinical participation and adherence and that the adolescents increasingly attended clinic specifically to watch tablet disclosure videos. One participant described this by noting:

“The children thought it was fun; they would come and then would want to see the tablet...it has helped them understand their status and what HIV is, so it brings a

lively discussion when we are discussing issues of HIV and adherence, because now children can relate HIV with something they have seen on the tablet.”

Clinical providers reported both caregivers and adolescents began initiating dialogue about critical issues such as medication adherence after watching the disclosure videos. One example of such dialogue was described by a provider:

“The caregivers didn’t keep the appointments for their children, and because we have been discussing this over and over and there is no change, so the day they landed, I just opened that [animation video]...and after seeing this, they were weeping. They were like, ‘I have been doing this to myself, I have been doing this to my child.’”

Additionally, all providers reported reviewing materials during their free time, typically outside of work, to increase their own knowledge and comfort with disclosure. One participant noted:

“[The tablet] assisted me to educate the clients, by opening my knowledge about how I should handle kids on disclosure...their challenges and some of the things that [adolescents] want to know. It helped me understand issues about disclosure to children which previously I didn’t really have the grasp of.”

Many of the providers (n=14) also reported discussing the information they learned from the tablet with other clinic providers not involved in the study. One provider described how she shared the tablet to have the resources viewed by more children:

“We have community health workers who are working with the children, so when they are going door-to-door in their work and they encounter issues in disclosure, I always discuss with them and tell them we have a tablet that can to assist them in disclosure, and they either come with the child or I guide them on how to use [the tablet], and then they bring it back the same day and so they have been doing that.”

Many participants (n=15) reported that issues they previously believed were barriers to disclosure for caregivers and providers were improved with the introduction of the tablets. However, time continued to be a barrier for use for some. Half of the participants (n=9) spent an average of 10–15 minutes using the tablet with each client, with most of the remaining participants using it for less time. The time spent in discussion of the materials seemed to be more of a barrier than the time spent viewing the resources. One participant noted:

“After they see the material on the tablet, they have a lot of questions to ask. It’s like you’ve popped them out their mind and they have a lot to ask about HIV and AIDS.”

Another identified barrier for use of the tablets included language of materials. One clinic had patients who neither spoke English nor Kiswahili, thus clinical providers had to actively translate resources into the local language for the patients, which was cumbersome and time-consuming.

Of note, one clinical provider also mentioned that accidental disclosure was a challenge in using the tablets. The participant noted:

“We have been playing these videos to these children, and we sometimes discover that they do not know they have HIV. Now they come [to know their status]. Now we wonder how they behave at home with the caregivers... In most cases, we do follow-up of cases where we felt that we have done accidental disclosure especially, we follow it up with caregivers. What was the behaviour? What did they experience after that? But so far, we have not had anything negative.”

No technical issues were reported, however some participants requested audio speakers and a projector to use the tablets with larger groups. In addition, despite the tablets having Wi-Fi capabilities, several participants requested internet access for the tablets to access additional materials and resources for their patients.

Suggestions for improvement included making more resources available on the tablet, such as additional narrative videos and animations on HIV-related topics, and additional information on puberty/sexuality and general HIV care.

One-Year Follow-Up

Clinical Provider Follow-Up Survey—Eighteen of the 21 initial clinical providers were available and willing to participate in a follow-up survey. Only 28% (5/18) continued to use the tablet during 75% or more of patient interactions, while 94% (17/18) used them in at least 25% of their interactions. The narrative videos and animation were still commonly utilized resources for patients (14/18 and 12/18 of participants utilizing them, respectively), while the number of providers using the counselling guidelines on disclosure of HIV was stable (n =13).

Most providers used the tablets with disclosed adolescents (n=16) or caregivers (n=16), while many (n=14) also used the tablet with adolescents who were in the disclosure process but did not yet know they had HIV. Few (n=6) used the tablet with pre-disclosed children. No episodes of accidental disclosure were reported.

All participants indicated that the tablets improved disclosure in their clinic, either by helping them become more knowledgeable and comfortable about the disclosure process, supporting caregivers to disclose to their adolescents, or helping adolescents understand the importance of medication adherence. A few providers also indicated that it helped the adolescents through the disclosure process as well.

Barriers to using the tablet remained similar to those noted previously: time and language. Technical issues were minimal. Two individuals also mentioned power was an issue because they would forget to charge it. One tablet was dropped, and the touch screen function no longer worked properly. None of the tablets were stolen or lost.

Most were satisfied with the tablet resources in their current form. Other suggestions for further improvement included adding new guidelines for HIV care on the tablets and organizing live disclosure training sessions for clinical providers at the clinics.

Adolescent Perspectives—Three focus groups took place (one at each clinic), which involved 24 adolescents in total (Study Site 1 (n=12); Study Site 2 (n=7); and Study Site 3 (n= 5)). The mean age of the adolescents was 13.8 years, ranging from 10–16 years, and the age at which they were disclosed ranged from 3–14 years, although the average age of disclosure was 10 years. Most adolescents had been disclosed to by a female family member (n=11 by mother, n=6 by grandmother, n=4 by aunt or sister). Two adolescents were disclosed to by their fathers and only one by a doctor.

Most adolescents had been exposed to the tablets during their clinic visits, and nearly all knew their status before being shown the videos. They described instances of using it one-on-one with clinical providers, in a group with other adolescents, or both. Adolescents described only viewing the narrative videos and animation resources on the tablets. They self-reported that their medication adherence was the most significant factor that changed after viewing the videos. One adolescent noted:

“I was not taking my medicine on time but after watching the video am now taking my medicines on time and always.”

Another adolescent further described how these videos impacted him:

“We were shown [a video] about a boy who had been sick and not taking medicines and had no parents and had HIV. He then started taking medicine and never left the medicines, when I saw the video I believed. The doctor told me to go home and take the medicines. After three weeks I was tested and found my [CD4] level was high. The doctor told me now I knew the importance of taking medicines, and I told him now I know why I am taking medicines.”

The adolescents also described that the narrative videos helped them feel like they were not alone in their HIV diagnosis, which they described as an improvement of mood and mental health. One adolescent simply said:

“I did not like to be happy with others but after watching I can now laugh with others.”

Another adolescent added:

“I was referred to this hospital where I was supported and counselled on how to cope with the post disclosure effect. I don’t think of killing myself anymore but [rather] how to keep taking my pills well so that I can achieve my dream of being a productive person in life.”

All adolescents reported enjoying having the tablets as a resource in the clinics. They also all denied any challenges in using the tablets. When asked how to improve the usefulness of the tablets, they suggested that the tablets be used during every clinic visits, that clinicians should not be rushed when showing them the videos, and to include more videos addressing general adolescent stages.

Discussion

We found that tablet computers containing HIV disclosure-related resources may be an acceptable and beneficial resource for clinical providers responsible for HIV disclosure with families at their clinics in western Kenya. The narrative videos and HIV animation were the most commonly used resources with patients. However, all clinicians reported reviewing the counselling training materials, AMPATH SOPs, and treatment guidelines on the tablets for self-education. Perceived challenges to using the tablets included time and language barriers. Although it was only noted by one clinical provider, there was still the possibility of accidental disclosure with tablet use if the tablets were not used appropriately. Both study participants and the adolescents expressed enjoyment in using the tablet computers during their clinic visits, particularly the multimedia videos and animation, and they appeared to be a helpful resource for disclosure counselling, as well as clinic and medication adherence counselling.

This study is the first to evaluate tablet computers for HIV disclosure counselling for adolescents and their caregivers in a RLS. This resource appeared to have the additional benefit of counselling on medication adherence, which was identified as an issue that influenced the clinical providers' decision on when to initiate disclosure of an adolescent. This benefit is consistent with related studies from resource-rich settings. Tablet computers loaded with interactive health communication tools have been shown to be well received and easily usable by young adults for HIV and STD counselling (Mackenzie et al., 2007). Additionally, other means of utilizing portable electronic devices, such as daily text message reminders, have been found to improve HIV medication adherence in Kenya (Lester et al., 2010). While this small study is significant in suggesting that tablet computers may be acceptable and helpful when counselling HIV-infected adolescents in RLS, more research is needed to see if this has benefits to patient outcomes on a larger scale.

A major feature and benefit of this study was the use of unique, culturally appropriate narrative videos and an animation about HIV, disclosure, and medication adherence created through extensive community engagement and contextual input (Fischer et al., 2015). These resources were preferred for use by participants over other pamphlets, guidelines, and workbooks available on the tablets. Adolescents found the videos and animation to be enjoyable and relatable to them in their own lives. These resources featured adolescents who were similar to them in age, interests (e.g. soccer/football, school work), and struggles. These commonalities may have contributed to their expression that they no longer felt alone. The peer groups in which these adolescents viewed the videos may also have worked synergistically with the tablet's perceived benefits, by providing peer support from others faced with the same struggles and facilitating topics for their discussion. Digital-media has shown to have benefits in improving adolescent knowledge and behaviours on various topics, including sexual health and obesity (An, Hayman, Park, Dusaj, & Ayres, 2009; Guse et al., 2012). However, the majority of these studies are performed in resource-rich contexts and nearly all of them require continuous internet connectivity. Our study is innovative in that the tablets did not require internet access to fully access its resources. Further work is needed to develop additional resources that are accessible without continuous internet connectivity for use in RLS.

Within the resources provided on these static tablets were guidelines and SOPs specifically for the clinical providers. By giving clinical providers resources to guide HIV-infected adolescents and their caregivers through the disclosure process, we hoped to empower them to expand their expertise and care of these patients. None of the clinical providers in this study reported any prior training in HIV disclosure. Although AMPATH SOPs exist regarding HIV disclosure and live trainings have been held on this topic, not all clinical providers have had access to these resources. The AMPATH SOPs are available online, but not all clinical staff have availability of the internet to view these materials during or outside of work hours. Paper copies may exist within the clinic setting, but these are easily lost and difficult to maintain. The providers' reports suggest a similar situation to that reported in a study performed in Ethiopia, where they found that SOPs are not routinely followed even when they are available and their use is critical for good medical care (Weldu et al., 2017). While comprehensive HIV disclosure training would be ideal for all those working with HIV-infected adolescents and their caregivers, this may not be an option due to its high cost and Kenya's high rate of clinical provider turnover. With tablet-based resources, providers are able to review materials outside of work hours, and it allows clinical systems the opportunity to easily and routinely update the content.

Accidental, or inadvertent, disclosure of an adolescent's HIV status was a common theme that arose before the tablet intervention was introduced. While there is little literature describing the negative impacts that an accidental disclosure may have on a child, most guidelines recommend that the disclosure takes place over time as a process rather than a single, discrete event (Lesch et al., 2007; World Health Organization, 2011). Upon uncovering the apparent frequency at which accidental disclosure was occurring at the study sites, discussions about the importance of preventing accidental disclosures were included within the education the clinical providers received on the tablet computers. Additionally, the tablets had designated folders of resources to use based on the adolescent's disclosure status. A process-oriented framework to help clinical providers and caregivers navigate the disclosure process was one of the resources available to clinical providers on the tablet (New York State Department of Health, 2009). However, despite these efforts, one of the clinical providers noted that accidental disclosure was still possible with use of the tablets. This was likely due to the limited number of videos that were appropriate for non-disclosed adolescents and the strongly expressed interest in watching the videos from the adolescents. If the clinical provider allowed them to watch the full range of videos available on the tablet computers, the adolescents would be exposed to videos designed specifically for those who know their HIV status. This was addressed with the providers during the interviews. At the one-year follow-up survey, there was no evidence that accidental disclosure was still an issue. Of note, based on the AMPATH SOP and the Kenya Ministry of Health guidelines, all children should have had disclosure initiated by the time they were 10 years of age, meaning that even an accidental disclosure would still be in line with the necessity of eventually disclosing the child's status.

With the increasing interest in improving rates of disclosure for adolescents worldwide, it is critically important that all efforts should be made to adequately train staff on the issues related to accidental disclosure, design resources specific to non-disclosed children, and ensure that HIV disclosure takes place in a thoughtful, developmentally appropriate process.

Currently, there is no guidance on the ideal age for HIV disclosure. However, there is an emphasis on considering a child's cognitive and developmental ability to understand what is being said before HIV disclosure (World Health Organization, 2011). In our pilot study, providers were instructed to choose materials based off of the disclosure status of the adolescent. Further guidance for clinical providers regarding the specific topics to be covered at each developmental stage is needed during HIV disclosure. Additionally, more resources need to be developed for children and adolescents who do not yet know their HIV-status but are initiating the disclosure process. Future work should focus on addressing these issues.

When considering implementation of tablet computers for HIV disclosure counselling on a larger scale or for other educational purposes, a few factors should be considered. First, participants in this study reported that time limitations and patient volume were barriers to disclosure prior to tablet implementation that persisted or possibly worsened after implementation. Comprehensive assessment of clinic flow should be conducted prior to implementation of a new intervention to optimize its integration into current clinic activities without additional burdens. Clinics in this study found solutions by showing them in groups or on "adolescent days," to reduce delays in clinic flow. However, any information provided in a group or public manner, such as media available in waiting areas, should be approached with caution to ensure that patients do not experience accidental disclosure or stigmatization.

Future work in this area should also consider language when developing and implementing electronic devices, such as tablet computers, for HIV disclosure in RLS. The resources on the tablet computers were in either Kiswahili or English, which are Kenya's two official languages. However, in more rural areas of the country, tribal languages or "mother tongues" may be the only languages spoken. This is consistent with many other sub-Saharan African countries as well. Some health inequities these countries experience may be due in part to the lack of important health information provided in a local language and in a culturally sensitive manner (Mphasha & Lebeso, 2015). These individuals are particularly vulnerable, and efforts should be made to ensure that they have equal access to beneficial health interventions.

Additional relevant and culturally appropriate resources should also be developed or adapted to engage adolescents on topics appropriate for their stage in HIV disclosure. Within the year-long study period, it was clear that many of the adolescents had exhausted the use of the materials and were requesting additional resources. While there are substantial benefits to utilizing electronic resources that do not require continuous internet connection, this does require a more concerted effort to systematically and routinely update the resources on the tablet. This could take place either manually or by supplying an internet connection and website where the materials could be downloaded. Regular updates could be supplemented with interrelated live trainings whenever possible. This type of regular contact using an accessible electronic platform allows for the dissemination of continuing clinical and medical education to clinical providers in RLS (Pakenham-Walsh & Bukachi, 2009; Rowe, de Savigny, Lanata, & Victora, 2005). However, it is critical that clinical providers are appropriately instructed on how to use these materials, such as avoiding accidental disclosure of HIV status, to ensure optimal care for patients.

Using Likert scores to track changes in clinic comfort, knowledge, and skills on disclosure after implementation of the tablet computers proved to be a major challenge in our analysis. Although Likert scores have successfully been used in similar RLS, including Kenya (Finstad, 2010; Smit, van den Berg, Bekker, Seedat, & Stein, 2006), it was not found to be an effective means of evaluating the intervention in this study. When participants self-scored their own comfort, knowledge, and skills on disclosure using the Likert scales, they appeared to overestimate their answers compared to the description they provided of their experiences during the interviews. This is supported by the fact that the median scores were nearly all at the top of the Likert scale. This may have inaccurately represented their comfort, knowledge, and abilities. Social desirability bias is a known limitation for study designs utilizing certain types of self-reported questionnaires and surveys (Brenner, Billy, & Grady, 2003; Harrison, 1997). By having additional participant interviews, we were able to triangulate the information, showing that providers did perceive benefits from using the tablets for disclosure counselling.

Our results are limited by the small sample size of only a few clinics and participants, as well as the convenience sampling used to recruit participants. However, this is the nature of a pilot study, as we were limited by both time and the number of tablets available. With these results, we can now consider the possibility of scaling-up the program in the future. Another limitation to this study was that there were no patient outcome data collected. Within the pediatric medical records of the AMPATH clinics, a clinical question exists regarding the child's disclosure status. However, on a data inquiry, it was found that less than half of the adolescents had data captured on that question. Thus, no analyses could be performed on that indicator. Future studies could consider prospectively collecting these data and tracking additional clinical outcomes, such as medication adherence and viral loads. Additionally, adolescent perspectives were limited in number, unequally distributed among clinics, and may not be representative of the experience of all adolescents exposed to the tablets. Also, no caregiver perspectives were included in this study. However, we do believe that the available data provided some key insights on the use of tablets within the clinics and the acceptability of the technology for use in HIV clinical care. Increase representation from both groups would be necessary in a full-scaled study.

Conclusions

Tablet computers with resources for disclosure are an acceptable resource for clinical providers who play a role in HIV disclosure for HIV-infected children and adolescents. They often used it to improve their own knowledge of HIV disclosure, and we found that their comfort in providing HIV disclosure counselling improved over time. Additionally, the adolescents viewed the tablet computers positively and reported improvements of medication adherence and mood resulting from this intervention. Distribution of resources for HIV disclosure should be accompanied with complete and targeted instructions on use, to ensure that specific resources are appropriately used for non-disclosed and disclosed adolescents, as well as their caregivers. Future studies should consider clinical outcomes related to tablet-based counselling resources and aim to gain more perspectives from adolescents and their caregivers.

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Table 1:
Clinical Provider Demographics

Table 1 reports the number and proportion of participants included in the study, by gender and clinic position. These results are also sub-divided into individual clinical sites

Variables:	Clinic Site			
	Total n (%)	Study Site 1 n (%)	Study Site 2 n (%)	Study Site 3 n (%)
Gender:				
Males	8 (38.1)	3 (42.8)	3 (42.8)	2 (28.6)
Females	13 (61.9)	4 (57.1)	4 (57.1)	5 (71.4)
Clinic Position:				
Clinical Officer	8 (38.1)	3 (42.8)	2 (28.6)	3 (42.8)
Nurse	5 (23.8)	3 (42.8)	1 (14.3)	1 (14.3)
Social Support	8 (38.1)	1 (14.3)	4 (57.1)	3 (42.8)

Table 2:
Summary of Likert scores, first and last survey

Table 2 depicts the mean, median, and standard deviation (SD) of the survey results, measuring comfort, ability, knowledge, impact of table, and patient's reaction, within the initial survey and the final survey. The survey used a 10-point Likert scale with 0 indicating the most negative or low score and 10 being the most positive or high score. The p-value was calculated using Wilcoxon Sum Rank, with α set at 0.05.

Variable	Initial Survey	Final Survey	p-value
	Mean, Median, SD	Mean, Median, SD	
Comfort	8.29, 8.00, 1.87	9.33, 10.00, 1.06	0.026
Ability	9.53, 10.00, 0.60	9.67, 10.00, 0.48	0.453
Knowledge	9.33, 10.00, 0.91	9.54, 10.00, 0.75	0.463
Impact of Tablet	9.52, 10.00, 0.98	9.71, 10.00, 0.56	0.516
Patient's Reaction	9.10, 10.00, 1.37	9.62, 10.00, 0.50	0.090