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Retention of South African Adolescents in a 54-Month Longitudinal HIV Risk-Reduction Trial

Larry D. Icard,

Temple University

John B. Jemmott,

University of Pennsylvania

Craig Carty,

University of Pennsylvania

Ann O'Leary,

Centers for Disease Control and Prevention

Lulama Sidloyi,

University of Pennsylvania

Janet Hsu,

University of Pennsylvania

JoAnn Tyler, and

University of Fort Hare

Omar Martinez

Temple University

Abstract

Retention of participants in clinical trials is a central concern of HIV/STI behavioral researchers and research sponsors. This article describes the strategies used for addressing the challenges in retaining South African adolescents for a 54-month longitudinal study. The objective of the South African adolescent health promotion long-term follow-up trial was to test the sustainability of the effects of an HIV/STI risk reduction intervention, “Let Us Protect Our Future,” on young

Correspondence concerning this article should be address to Larry D. Icard, College of Public Health, School of Social Work, Temple University, Philadelphia, PA 19122 icard@temple.edu.

Larry D. Icard, College of Public Health, School of Social Work, Temple University; John B. Jemmott III, Annenberg School for Communication, Center for Health Behavior and Communication Research, University of Pennsylvania; Ann O'Leary, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Centers for Disease Control and Prevention; Lulama Sidloyi, Annenberg School for Communication, Center for Health Behavior and Communication Research, University of Pennsylvania; Janet Hsu, Annenberg School for Communication, Center for Health Behavior and Communication Research University of Pennsylvania; JoAnn Tyler, Department of Statistics, University of Fort Hare; Omar Martinez, Temple University.

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Compliance with Ethical Standards. Disclosure of potential conflicts of interest: The authors declare that they have no conflict of interest. Ethical Approval: Institutional Review Board (IRB) #8 at the University of Pennsylvania, which was the designated IRG under the federalwide assurances of the University of Pennsylvania and the University of Fort Hare, South Africa, approved the study in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki. Informed consent: The informed-consent process covered activities through the 12- month follow-up, 42-month and 54-month follow-up.

adolescents as they aged into middle and late adolescence. Inaccurate contact information, invalid mobile telephone numbers, lack of transportation, transitory family addresses, and family relocation were among the challenges to retaining participants. Despite a significant gap in time of 36 months between the main trial and the long-term follow-up study, 99.2% of 1,057 participants were retained. Solutions used for retaining the adolescents are discussed with suggestions offered for retaining adolescents in longitudinal HIV/STI prevention clinical trials in low resource countries.

Keywords

Adolescents; HIV Clinical; Trials Retention; South Africa

The retention of adequate numbers of study participants in clinical research is vital for maintaining the internal and external validity of a study. The conclusions drawn from studies with low retention rates are questionable because non-participants may respond differently from participants (Bender et al., 2003; Campbell & Stanley, 1963). Failure to retain the projected number of participants can also prolong the time required to complete a study, and drain limited resources.

Several factors have been identified affecting the retention of adolescents in research studies including caring staff, flexibility of the study time, participant age and gender, and contact information (Davis, Broome, & Cox, 2002; Jones & Broome, 2001; Stanford et al., 2003). Using text messages for reminders, providing food and time for socialization have also been suggested for retaining adolescents as study participants (Baxley & Daniels, 2014). DiClemente and colleagues (2010) identified eight successful strategies used in recruiting and retaining adolescents in HIV prevention studies conducted in the U.S. Among the successful strategies identified by these authors were maintaining contact with study participants between appointments, maintaining continuity in research staff, and employing youth-friendly study personnel (DiClemente et al., 2010). While these strategies are useful for retaining adolescents in the U.S. and other resource rich countries retaining adolescents in longitudinal HIV/STI trials conducted in low and middle income countries can be extremely challenging (Geng et al., 2010; Villacorta et al., 2007).

There are numerous challenges to retaining adolescents in low and middle income countries in longitudinal studies including, frequent changes in cell telephone numbers used to contact participants (Villacorta et al., 2007), transportation to study sites (Jewkes; Wendler, Rackoff, Emanuel, & Grady, 2002), and family financial constraints wherein youth are often responsible for contributing to family finances and their work schedules can contribute to their inability to stay in a study (Celentano & Beyrer, 2008; Patel, 2008). Similarly, in order for some parents to be able to work adolescents may often be responsible for providing childcare to their younger siblings as well as older members of the family.

Villacorta et al., (2007) developed several novel approaches to help overcome barriers to retaining young adults in a two-year longitudinal study in Peru. Among the strategies that these researchers found to be helpful was the use of participant driven retention strategies. The participant driven retention strategies included using participants who were members of

cohorts to help spread the word to their friends that project staff were trying to reach participants who missed study visits and encourage them to contact project staff. These authors noted that many of the participants had friends who were participating in the study and that confidentiality was strictly upheld. Installing temporary project offices in communities to help participants overcome transportation problems was another strategy employed by these researchers. Temporary project offices were also used by project staff for conducting frequent tracking appointments with participants between scheduled assessments to update locator information. In return for updated information participants received small tokens and nominal compensation (Villacorta et al., 2007).

As was the case with the two year study conducted by Villacorta and colleagues (2007), longitudinal studies require following participants over an extended period of time for continuous or repeated assessments. Maintaining contact with participants between assessment periods is essential for the success of longitudinal studies. Still, circumstances arise where there is a prolonged disruption in contact with participants between assessments. Notably prolonged disruptions with participants between assessments can have detrimental consequences for the quality of the findings along with placing constraints on the study's staff and financial resources. Such situations may arise for a number of reasons including disruptions in funding; a factor that occurred in the present study that resulted in a significant gap in time between final assessment for the main trial and the initial assessment for the long-term follow-up trial. A noticeable gap appears in the literature in discussing the problem of retaining participants in longitudinal studies when there is a substantial disruption in time between assessments.

This article addresses this gap in the literature using the example of a 54-month follow-up study conducted in South Africa. The main trial included a 12-month assessment with retention rates at 96.7% (J. B. Jemmott et al., 2010). The current study focuses on a long-term follow-up for 42 month and 54 month assessments that originally had 50% retention at 42 months. This article discusses the strategies used to ultimately retain 99.2% of the adolescent participants when a two and a half year gap occurred between the final assessment for the main trial and the 42-month assessment for the long-term follow-up trial. The discussion concludes with points to consider for developing successful strategies for retaining adolescents in HIV clinical trials in low and middle-income countries.

Methods

The "Let us Protect Our Future" study was conducted in Mdantsane, an urban township and Berlin, a neighboring semi-rural settlement, in the Eastern Cape Province, South Africa. Schools serving sixth-grade learners from the general population were eligible to participate in the study. There were 36 primary schools in Mdantsane and Berlin. One school for children with learning disabilities was ineligible, leaving 35 eligible schools: 26 in Mdantsane and 9 in Berlin. All 35 eligible schools agreed to participate in the trial. Seventeen matched pairs of schools were created that had similar numbers of grade 6 learners, classrooms, and classrooms with electricity, including one "pair" consisting of three schools. Urban and rural schools were matched separately. From the 17 matched pairs, we randomly selected 9 pairs: 7 pairs comprised of urban schools; 2 comprised of rural

schools. In a cluster randomized control trial (RCT) design, we used computer-generated random number sequences to randomize within pairs one school to an HIV/STI risk-reduction intervention and one to a health-promotion-control intervention.

We enrolled schools over 13 months beginning in October 2004 (J. B. Jemmott et al., 2010). A cluster-RCT design was used to reduce the potential for contamination between treatment arms that would be present if individuals were randomized within schools. To recruit the participants, recruiters made announcements to all grade 6 learners at the selected schools and distributed letters to parents or guardians. Recruiters followed a common standardized scripted recruitment procedure. School administrators, potential participants, and recruiters were blind to the specific intervention to which the school had been randomized at the time of recruitment. Grade 6 learners at the selected schools who provided written assent and had written parent or guardian consent were eligible to participate. This was done initially and covered activities through the 12-month follow-up. This was done again at the 42-month follow-up to cover activities during the long-term follow-up phase.

The a priori unit of inference in this trial was the individual. A previous article reported the baseline characteristics of the schools and adolescents (J. B. Jemmott et al., 2010). Institutional Review Board (IRB) #8 at the University of Pennsylvania, which was the designated IRB under the federal wide assurances of the University of Pennsylvania and the University of Fort Hare, South Africa, approved the study in accordance with the 1964 Declaration of Helsinki.

Learners who were enrolled in the school completed the pre-intervention questionnaire and attended Session 1 of the intervention. For the main trial, participants completed immediate-post and 3-, 6-, and 12- month post intervention questionnaires by December 2006. The long-term follow-up study included data collection at 42-months which began in April 2008 and at 54-months which was completed in June 2010 (J. B. Jemmott, Jemmott, O'Leary, et al., 2015). As compensation, learners received a notebook, a pen, and a pencil for the 3-month follow-up; a t-shirt for the 6-month follow-up; a backpack for the 12-month follow-up; an umbrella (if female) or a cap (if male) for the 42-month follow-up; and a jacket for the 54-month follow-up.

One of the major challenges to retaining participants for the follow-up study was a two-and-a-half year gap between the time the youth completed the 12-month assessment for the main trial and the beginning of the long-term follow-up study. The two- and-a-half year interval resulted from a gap in time between funding for the main trial and the continuation trial. Of additional concern was that while participants did not provide urine and a blood specimen in the main trial this was a component of the 42 and 54- month follow-up assessments. The inclusion of urine and blood specimens could potentially dissuade participants from returning for the long-term follow-up assessments. An added problem was that participants in the main trial had matriculated to over 200 area high schools by the time the 42–54 month follow-up portion of the study began.

In order to determine the feasibility and acceptability of STD testing, members of the research team collected formative information from a range of key informants, including

former teachers, principals, and the study's Community Advisory Board(CAB)(L. S. Jemmott et al., 2014). The CAB was comprised of teachers, school principals, physicians, and representatives from the Ministries of Health and Education and non-governmental organizations that served adolescents (J. B. Jemmott, Jemmott, O'Leary, et al., 2015). From this feedback, the decision was made to hold meetings with participants, their parents, and teachers.

Parents/guardians meetings were held in area schools to maintain trust and to answer questions about the follow-up study. Participants received letters inviting their parent or guardian to attend an information session at an area school where the project was explained and questions were answered about STI testing. During the information session parents' consented to allow their child to return to two additional follow-ups, 42 and 54 months post intervention. None of the parents or guardians had any concerns with their children being tested for STI's. The only concern that parents expressed was that, although the children would be informed of their test results and treated if positive, the parents would not be informed of their children's test results. The parent/guardian consent form and the adolescent assent form explained that the adolescents' parent/guardians would not be given the results of the STI tests. This is a common procedure in studies of STIs in adolescents (Jaspan et al., 2008; Luseno et al., 2014). The reason for this approach is that if researchers inform adolescents that their parents will see the results of the STI tests, some adolescents will not want to participate because of the fear that they might test positive and their parents might react harshly to their testing positive. Arguably, the adolescents at highest risk might decline to participate. It should be noted that the participation rate of adolescents in the STI testing was high (J. B. Jemmott, Jemmott, O'Leary, et al., 2015). Parents were relieved when they learned that their children would receive treatment if the results were positive. Meetings with available participants along with their parents and teachers were also helpful in obtaining suggestions on how to locate missing participants.

Prior to beginning the long-term follow-up assessments staff called participants to confirm contact information provided on locator forms developed during the main trial. One week prior to the 42-month assessment, participants with updated contact information were phoned and reminded about the follow-up assessment. Participants were contacted again over the phone as a fourth reminder the day before the 42-month assessment session was conducted. Study participants were also asked to remind fellow participants in their schools to attend the session. As described elsewhere (J. B. Jemmott, Jemmott, O'Leary, et al., 2015) interventions were delivered in small groups. Consequently study participants knew the participants in their assigned group. Despite these efforts, many cohorts continued to have low attendance for the 42-month assessment. The average rate of attrition of 50% resulted from inaccurate telephone contact numbers.

Additional retention staff was hired to overcome the high rate of attrition. Several authors stress that staff selection is a key factor for successfully retaining adolescents in HIV clinical trials (Bruzzese, Gallagher, McCann-Doyle, Reiss, & Wijetunga, 2009; DiClemente et al., 2010; Villacorta et al., 2007). The criteria used for selecting retention staff included good communication skills, experience in working with adolescents, and demonstrated involvement with participants' communities or schools. Many of the retention staff had

worked on the main study and were committed to seeing the study to its successful completion. The retention team received extensive training on strategies for tracking and retaining participants and barriers to participation, and brainstormed strategies to overcome barriers specific to target population.

Retention staff met with the teachers of the high schools where participants were currently enrolled. Staff provided teachers with a list of the names of participants, a contact number for the study, along with a reminder card for each adolescent approximately two weeks before each follow-up session was scheduled. Posters and flyers containing contact information for the study were posted and handed out during school hours. Participants were encouraged to contact the study staff to update missing or inaccurate contact information.

A major factor contributing to the successful retention of study participants was the development of a strong collaborative relationship with a local township school. The local township school was centrally located in the most populous area outside of the town. The location was ideal for the longitudinal assessments, which were often conducted on weekends and during school holidays when participants were likely to be home. Some participants made trips in excess of four hours each way to complete follow-up assessments. The township school also provided support to the project by making a teacher available on-site during the follow-up sessions. The school's central location contributed to the participation of parents, guardians, community leaders, and other stakeholders in study CAB and community meetings.

When staff were unable to locate participants in their respective school visits were made to their home addresses. Text messages were sent to confirm new phone numbers. Follow-up sessions were extended to accommodate latecomers. Participants who failed to attend the scheduled follow-up sessions were rescheduled for one-on-one or small group sessions. Transportation was provided to enhance participant retention. The senior primary schools agreed to serve as centralized pick-up locations for participants. In addition, each school arranged for 2 teachers to provide assistance at the pick-up location. A comprehensive tracking database was developed containing frequently updated participant contact information, study attendance logs, logs of staff visits, and information on telephone and written correspondence. Staff utilized the database when they were in the field to help locate missing participants.

A case management approach was implemented whereby each retention staff member was assigned a group of participants they were responsible for tracking throughout the duration of the study period. Participants were divided according to geographic location, more specifically neighborhood units (NUs), and were assigned to retention staff residing in or near the immediate vicinity of the neighborhoods. This approach of pairing retention staff with neighborhoods and communities with which they were knowledgeable proved to be highly effective for retaining participants.

The media were also used to reach out to participants and their parents. Local radio stations and the local free paper were used to announce the return of the study and to remind participants of upcoming sessions. Thank you letters were sent to participants who attended

the 42-month follow-up session. The thank you letters served dual purposes by maintaining contact with participants between the 42-month and 54-month assessments, as well as strengthening rapport with participants. Participants assisted in the retention efforts by providing staff with information to help locate absent participants. Participants also helped to distribute flyers in their communities. For participants who had relocated out of the area, geographic locations were mapped and retention trips were made to towns and cities where clusters of participants resided in close proximity.

Results

A total of 1,056 grade 6 learners participated in the main trial, an average of 59 at each of the 18 participating schools. By the time of the long-term follow-up study, they had matriculated to 200 different high schools. Many of the participants in the main trial had relocated, often to other cities, due to family members seeking work outside of the catchment area. The majority of contact numbers on the tracking forms were cellular numbers, which presented an additional challenge to retaining participants. Ninety percent of the study participants reported having access to a cell phone compared to 25% who reported having access to a fixed landline. Poorer South Africans commonly switch cell phone carriers in order to maintain ownership of a cell phone. The overall return rate at the 12-month follow-up was 96.7% (see Figure 1). Ninety-seven learners were reported missing, of whom six had moved, five were in prison, seven were deceased, and seventy-nine were lost to follow-up or repeated non-attendance.

The 42-month data collection began in April 2008. Before modifying the retention protocol the retention rates for the 42-month data collection session in May 2008 was approximately 50%. After modifying the retention protocol the retention rates for the 42-month data collection session increased to approximately 91% ($N = 960$). Of 1,057 learners 99.2% ($N = 1049$) completed 54-month assessments. Generalized estimating equations logistic regression analysis, adjusting for clustering among participants within schools, revealed that attending the long-term follow-ups did not differ as a function of intervention condition, follow-up time (42 versus 54 month follow-up), sex, father's presence in the household, residing in the semi-rural area, or sexual experience at baseline. However, age group was related to retention at long-term follow-up. Compared with learners ages 14–18 years at baseline, those ages 12–13 years ($p < .0001$) and those ages 9–11 years were more likely to return for long-term follow-up ($p < .0001$) (J. B. Jemmott, Jemmott, O'Leary, et al., 2015).

Discussion

Retention of participants is essential for successful clinical trials. A two-and-a-half year gap between the time the youth completed the 12-month assessment for the main trial and the time the long term follow-up study began was a major obstacle in retaining participants. Other barriers to retaining adolescents in the South African Adolescent Health Promotion Project 54 month study included the matriculation of the learners to a larger number of schools, missing or inaccurate telephone numbers, lack of transportation and family relocation. Similar to other studies (Bruzzese et al., 2009) the retention rates were significantly higher for younger participants.

Some points need to be kept in mind when making inferences from this study's observations. The sample consisted of South African adolescents in the Eastern Cape who volunteered for a health promotion trial; accordingly, our findings may not generalize to all South African adolescents. Ideally having a time lag between implementing the various strategies used to retain participants would provide the opportunity for assessing the effectiveness of each strategy. We cannot say which strategies and for whom each worked best with the available information. The 36-month period of no data collection and the need to re-consent participants are also limitations. Given these limitations the retention rates are especially impressive. The study achieved over 90% retention despite having no contact with participants for 36 months. Apart from these caveats the following suggestions are offered in planning retention strategies for longitudinal HIV clinical research trials with adolescents in limited resource countries.

Developing and maintaining positive relationships with key gatekeepers, especially teachers and principals, is essential for gaining and retaining access to youth for HIV clinical trials. Including teachers, principals, and parents in the study's CAB is important for receiving advice for developing and modifying strategies to re-engage with youth (Coday et al., 2005; Geng et al., 2010; Strauss et al., 2001). CABs are also important for developing and maintaining trust between researchers and the community. The use of a case manager approach in which each retention staff is assigned to a group of participants that they are responsible for tracking for the duration of the study period proved to be beneficial. In order for a case manager approach to be effective it is important that retention staff reside in or within the immediate vicinity of the neighborhoods where study participants reside. Careful consideration is required in the early stages of designing a study to identify measures and analytic plans to assess the effectiveness of strategies for retaining participants in longitudinal studies. Research to assess and improve retention of adolescents in longitudinal HIV prevention trials is severely limited. The success in planning, implementing, and managing efforts to retain participants requires continual monitoring using a database system that includes comprehensive tracking information including frequently updated participant contact information, collateral contacts, attendance records, telephone or correspondence information, and reasons for missed visits. As pointed out in other reports (DiClemente et al., 2010; Villacorta et al., 2007), having staff with good communication skills, experience in working with adolescents, strong commitment, and knowledge of the communities or schools where participants resided are key factors for successfully retaining youth in the South Africa Adolescents 54 month follow-up study. Equally important is the development of strong collaborative relationships with local township schools. Working with a township school that is easily accessible to participants by foot can be very beneficial for retaining participants. Several researchers comment on the importance of parents and guardians for retaining adolescents in HIV clinical trials (DiClemente et al., 2010; Prado, Pantin, Schwartz, Lupei, & Szapocznik, 2006; Villarruel, Jemmott, Jemmott, & Eakin, 2006). Parents and guardians are particularly important for retaining youth in clinical trials in low and middle-income countries. Understanding the cultural norms on parenting and parent-child relationships is especially important for successfully retaining youth in clinical trials in resource limited countries. Utilizing peers is a well-established strategy employed in recruiting and retaining participants for HIV prevention trials (Heckathorn, 1997; Icard,

2008; Kelly et al., 1991). As emphasized by other investigators (Michielsen et al., 2012; Villacorta et al., 2007) the use of peers is essential for retaining adolescents in HIV clinical trials in resource-limited countries. Relocation due to family members seeking work outside of the study area presents unique challenges in retaining adolescents in longitudinal clinical trials in low and middle-income countries (Williams et al., 2008). This can place severe demands on budgets. Anticipating such budgetary obstacles is essential, as the need for additional staff and additional travel expenses to retain adolescents in migrant families for longitudinal clinical trials requires special consideration.

Conclusion

Despite a significant 36-month gap in time between completing the main trial and beginning the long-term follow-up study retention rates exceeded the minimum standard of 70% retention in behavioral studies. Evidence suggests that attrition is directly related to the quality of the protocols and procedures implemented (Chippaux, 2004). By maintaining rigorous adherence to the modified retention protocols, the project effectively overcame several major challenges of retaining the adolescent participants in the South Africa adolescent 54-month follow-up study.

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Figure 1.
Flowchart showing retention of students enrolled in South African HIV Risk Reduction Trial, 2004–2010.