Conducting research with hard-to-reach populations:

Lessons learned from the East African Health Study in Toronto (EAST)

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Study design and background

Communities from countries where HIV prevalence is high are also disproportionally affected by HIV/AIDS in Canada. People from countries where HIV is endemic represent 18% of the 26,627 people estimated to be living with HIV in Ontario (1). Trends also indicate HIV prevalence among these individuals increased 62% from 2003 to 2008, with an annual increase of 10% (1). Furthermore, statistical modelling suggests 22-59% of HIV infections happen within Canada (2).

The East African Health Study in Toronto (EAST), a community-academic partnership, was the first large-scale Canadian survey of African communities from countries where HIV is endemic. Conducted between 2004 and 2008, EAST was conceived in response to the lack of population-based data needed to assess HIV-related issues in these communities and to assist in the development of intervention programs and strategies.

The objective of EAST was to examine HIV/AIDS issues and concerns in the context of general health issues and behaviour in five East African communities. A Community Advisory Committee provided input on community-specific needs, practical advice on study design, and links to the community to facilitate recruitment. This cross-sectional study covered an extensive range of HIV and health-related issues such as immigration and mobility, social support, attitudes and beliefs, screening and testing, health conditions, risk behaviour, and health care utilization. The survey consisted of an interviewer-administered questionnaire (approximately one hour long) and collection of a saliva specimen for an HIV screening component. Data were collected between 2004 and 2006, with 456 participants (230 women and 226 men) interviewed in the Greater Toronto Area (GTA). Over three-quarters of the participants provided a saliva sample for laboratory testing. There were 100 participants from each the Ethiopian, Kenyan, and Somali communities, 101 from the Ugandan community, and 55 from the Tanzanian community.

A study report was produced and contains a broad overview of HIV- and health-related issues in these communities (3). The report has been, and will continue to be, used to initiate community discussions, encourage further interpretation of results, and elicit recommendations for further analysis and community action. The study contributed to the generation of new research knowledge concerning communities in the African Diaspora and the provision of a platform on which to base programs, services and policy decisions for Diaspora communities in the GTA. EAST was also an opportunity for Toronto's African communities to become involved in HIV research, while allowing university-based researchers to learn valuable lessons from community members.

Purpose of report

The purpose of this report is to share key lessons learned from the implementation phase of EAST concerning study design, recruitment, and other practical and logistical issues integral to the success of a survey-based study in hard-to-reach populations. During the course of the study, formal and informal evaluation measures were employed in order to document challenges and subsequent solutions. Documenting these efforts became an objective of EAST because of the gaps in existing HIV research literature concerning research with African, Caribbean, and Black communities. This report is based on data extracted from a recruitment tracking database, on-going qualitative notations concerning the challenges we faced, and interviews with study research assistants and interviewers. It is our hope that the lessons we learned may be useful when designing and conducting future research with East African communities, other communities from countries where HIV is endemic, and other similar hard-to-reach populations.

Lessons learned

STUDY DESIGN

Challenges

Diversity of perspectives
The study sample was drawn from five communities (Ethiopian, Kenyan, Somali, Tanzanian, and Ugandan) that display cultural and social diversity within and between the communities. This translated into differing preferences in how sensitive health and social issues are discussed, which had implications for the acceptability and appropriateness of the survey topics. For example, input from community representatives suggested diverse attitudes toward HIV-related issues, ranging from a willingness to openly discuss them to treating them as taboo and not relevant to the community.

Suitability of research tools
There was a lack of appropriate HIV-related questionnaires and scales for communities in the African Diaspora. Although various tools have been produced for populations in African countries, these were not always applicable for communities that have relocated to Canada nor did they cover the unique issues faced by these populations after settlement.

Solutions

Adapt questionnaires and scales to be more culturally relevant
With input from the Community Advisory Committee, the research team chose to compile and adapt several existing questionnaires and scales, including questions from the *Canadian Community Health Survey, the Ontario First Nations AIDS and Health Lifestyle Survey, and the Pathways and Barriers to Mental Health Care for Ethiopians in Toronto Study*. Furthermore, given the sensitive nature of particular questions, great care and consideration were given to the development of the survey instrument. Literature on maximizing the reliability and validity of sexual behaviour questions was consulted and attention was given to ensuring questions were clear and relevant to the communities. Findings from a pre-test with 25 individuals were used to modify interview questions and further improve the acceptability of the questions.

Create self-completed section for sensitive questions
A separate, self-completed section was created to provide privacy for participants when answering the most sensitive questions regarding sexual behaviour. Participants had the choice to have these read to them as they completed the section on their own, or to complete the section entirely on their own. The majority (68%) of the participants who completed the separate sexual behaviour portion had questions read to them by the interviewer and 31% self-completed entirely[1] .

Provide participants with choice of interviewer
In order to increase participants' comfort with the survey, participants were gender-matched with interviewers and were given a choice of interviewer according to ethnocultural community (i.e., from the participant's own community, a different African community, or non-African). Sixty-three percent of

[1]Although the self-completed section was acceptable to participants, interviewers were unable to reconcile any errors or misunderstandings concerning the section. There were particular issues around terminology concerning regular and casual sexual relationships, which resulted in missing data. This is an area for future research.

the study sample was interviewed by someone from a different African community, 23% by someone from their own country, and 13% by a non-African[2] . At the end of the interview, participants were asked if they would have chosen the same type of interviewer; 93% said they would have made the same choice.

RECRUITMENT/PARTICIPATION

Challenges

Mistrust of research and the research process

During recruitment outreach activities, recruiters documented concerns raised by community members regarding confidentiality and the research process. Community members expressed concern over the targeting of African communities and promoting the stereotype of Africans as carriers of disease. Some community members also felt that researchers take from the community but do not give back (i.e., the research does not benefit the community) and that the survey would not be confidential.

Compiling a representative sampling frame

Based on community consultations, the research team initially intended to develop the sampling frame through existing membership lists from a range of community organizations, supplemented with names located through electronic and telephone directories. From five master sampling frames, one for each community, individuals would be randomly chosen. Two main challenges prevented this approach. First, it became apparent that such lists and directories were difficult to locate and outdated, and access was often limited by confidentiality issues. Second, limited monetary and staff resources prevented building a sampling frame large enough to randomly select the required number of participants.

Insufficient network of recruiters

In order to compile a sample that was as representative as possible, a vigorous and wide-reaching recruiting effort was deemed necessary. Although the Community Advisory Committee assisted with the study design, it was inappropriate and unrealistic to ask individual members, who were already overcommitted with their main work and volunteer activities, to coordinate the vast networks of recruiters necessary to reach a representative sample. Furthermore, the study team felt it was unfair to ask community members to volunteer their time when working on behalf of the study, especially considering the amount of time needed to reach hundreds of community members. This meant that recruitment was slow and sporadic in the early phase of the study, as staff built networks through meeting with a diverse range of community members and attending an array of community events.

Lack of interview sites

One of the most challenging logistical issues was finding suitable locations across the GTA for conducting the interviews. Participants requested that the interviews be conducted close to either their work or home so that they would not incur costs or spend extra time travelling to the interview. It was also difficult to find sites that offered private areas to conduct the interview. HIV organizations were not suitable as this was a population-level survey rather than one focussed on community members living with HIV. Further challenges arose concerning costs associated with site rentals and last minute bookings and cancellations.

[2]There were differences between communities concerning choice of interviewers: Kenyan, Tanzanian, and Ugandan participants were more likely to choose an interviewer from another community (i.e., not their own), compared to Ethiopian and Somali participants.

Diversity of experience amongst interviewers
Because participants were given a choice of interviewer, it was necessary to have a minimum of 12 interviewers (male and female) representing the various communities. Interviewers were geographically dispersed throughout Toronto, which created logistical and financial challenges for travel depending on where interviews were scheduled. Also, interviewers had varying degrees of research experience; almost half of the interviewers had no previous research experience and needed individualized training sessions on an ongoing basis.

Irregularity of interview coordination and interviews
The final sampling frame included over 1,500 names, although contact details were often wrong due to the mobility of the population or errors made during recruitment. It was difficult to reach potential participants during the day and the sheer volume of names meant it was possible to loose track of individuals. We documented an average of 5.5 calls made per person (median 3, range 1-49 calls), which is an underestimate as it was impossible to document every call. Delays between initial contact, through recruiters in the community, and booking the interview often resulted in outdated contact details and/or participants forgetting about agreeing to be contacted for the study. Because interviews had to be booked throughout different times of the day, staff had to be on call to support the interviewers and ensure that study materials were delivered. Additionally, there were periods of time where interviewers were not needed due to slow recruitment or because participants did not chose them (i.e., they were not a match for interviews based on their ethnocultural community). This created challenges for the interviewers who were relying on the work, which translated to staff turnover and further training of new interviewers.

Solutions

Create wide network of recruiters from a variety of sources and provide compensation
To ensure a broad representation from each of the communities, five community working groups were formed to provide advice and support to the Community Advisory Committee on community-specific issues and to assist with recruitment. The research coordinator met with these groups individually, as needed, rather than through a formal committee structure. The working groups provided links to a diverse group of community members who were interested in recruiting. Additionally, many of the study's interviewers became recruiters. Rather than rely on these recruiters to volunteer their time or pay them hourly rates, recruiters were compensated monetarily for each name they collected during their recruitment activities; this improved recruitment efforts drastically. Approximately 50 community members participated in these recruiting efforts while also raising awareness of health and HIV in the wider communities. Using this revised approach to recruitment allowed us to meet our quotas for each community, except for the Tanzanian community [3].

Invest in capacity building and ensure staff and volunteers are knowledgeable about the study
An immense amount of time was invested in staff and volunteer training in order to ensure the team was representative of the communities and knowledgeable about the study. Thirteen EAST interviewers were from East Africa or another African country. We also trained four research assistants, three from East Africa, one of whom was particularly valuable in formulating new recruitment strategies and coordinating the interviewers across Toronto. Training was both group-

[3] The smaller numbers of Tanzanians recruited and successfully interviewed was largely due to a smaller network of available recruiters, the reliance on third party lists, and the same community members attending events. The representatives for the community felt that the initial estimates of Tanzanians living in Toronto was an overestimate, and that many had moved.

based and individualized, taking into consideration personal skills and cultural backgrounds. These sessions included three formal group training sessions, between two and six mock interviews per interviewer, and as-needed guidance and debriefing throughout the study. Interviewers were also hired for other tasks throughout the study, such as the creation of the recruitment database, recruitment, booking interviews, and data entry.

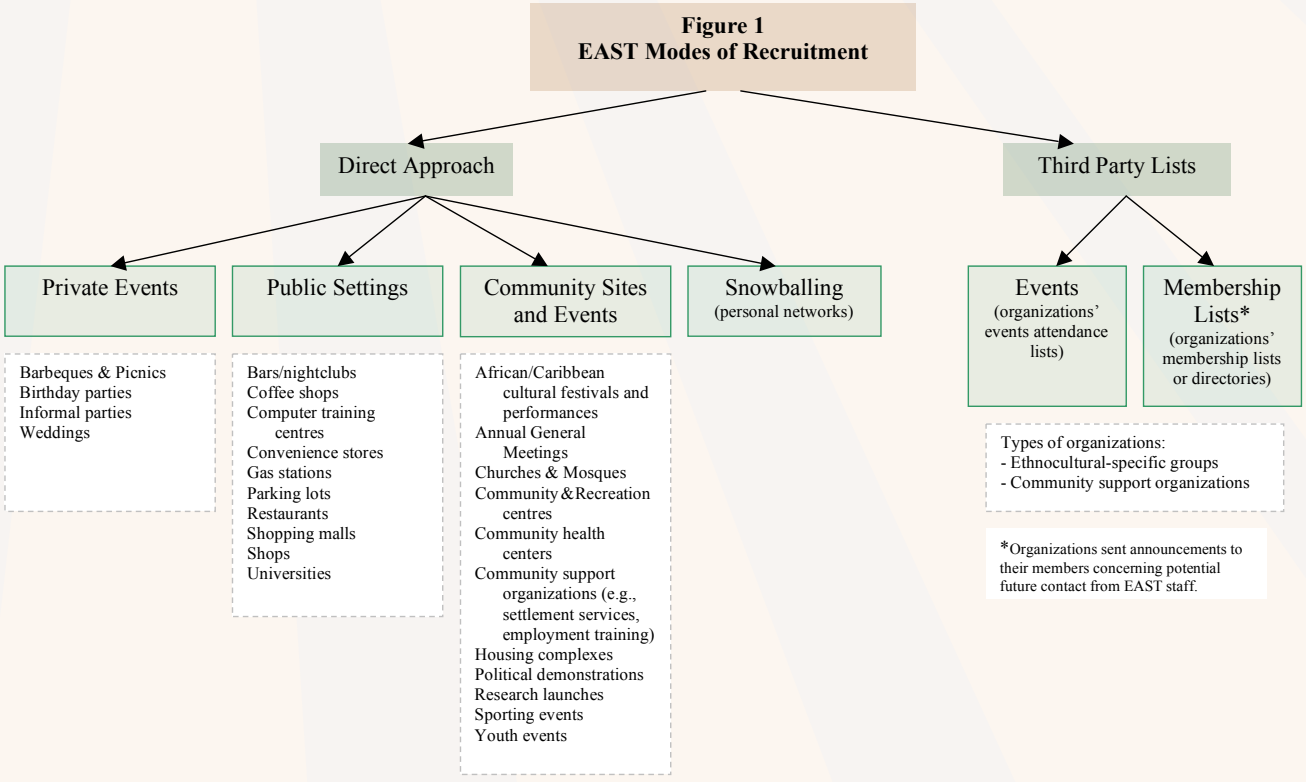
Approach potential participants directly

The modified approach to recruitment involved recruiters approaching potentially eligible individuals at community and social events, public venues, and through community organizations. Recruiters explained that the study was a health-related survey[4] and if the person approached agreed to be contacted by study staff, they would receive full details about the study. Snowballing recruitment techniques were also used by working group members and recruiters to utilize personal contacts. These kinds of direct, face-to-face contact with potential participants were the most effective modes of reaching community members, with the majority (86%) of individuals in the sampling frame being recruited this way. The remaining 14% of the sampling frame was compiled from third-party lists (see Figure 1), a less effective way of recruiting. Only two individuals volunteered because of advertisements posted in the community.

Plan for irregularity, recruit in real time

In order to prevent problems with interviews based on changes in contact details or participants forgetting about the research, recruitment needed to happen in 'real time'. This meant that recruiters would submit names to the study office soon after they were recruited and staff would contact potential participants immediately. In order to reach the potential participants, staff worked staggered

Figure 1
EAST Modes of Recruitment



[4]The study was described as a health-related survey in the community rather than an HIV study. This reflects the components of the survey, as only 1/5 of the sections were solely focused on HIV-related issues. Community advisory committee members were concerned that it would be too difficult to discuss the HIV-related aspects of the study in the general community and that individual conversations with potential participants over the phone would be more appropriate.

hours and in shifts to facilitate efficient communication. A research assistant was hired to coordinate the interviews and to ensure continuity in communication with participants. This allowed the research coordinator time to manage the interviewers in the field, coordinate recruitment efforts, and attend to ongoing data collection issues. Systems were developed to address challenges with dispensing study materials and sending interviewers across a large geographical region, and for safe and confidential collection of completed study materials (i.e., surveys and specimens) outside of regular office hours.

Develop effective electronic tracking systems

To manage the large volume of calls and deal with the multitude of practical issues associated with booking interviews, it was necessary to have efficient systems and diligent recording of communication. Recruiters were provided with forms to record information on the individuals who agreed to be contacted. An IT specialist (who was also an interviewer on the study) was hired to create a database to track this information[5]. Staff could also use the database to track interviewer preferences, site preferences, and details of every call made to the participant, the outcome of calls, and the next steps. Although this added additional costs and took up staff resources in the beginning, the database was indispensable for the study staff to ensure efficient follow-up and to gauge the success of particular recruitment activities. It was a key resource for addressing a multitude of practical issues, including coordinating the schedules of participants and interviewers. The data collected was also a key resource for this report.

Secure a network of community interview sites appropriate for participants

In order to provide participants with the choice of interview location, it was necessary to create a list of suitable sites that were easily accessible. A resource binder with maps and booking details for over 60 sites across the GTA was created. These sites included public libraries, community support organizations (e.g., settlement resource centres, ethnocultural organizations), community health centres, churches, universities, and colleges. Because it was not always possible to match a participant's request for location, it was decided that interviews could be conducted in participants' homes. A safety protocol was developed to accommodate this choice[6]. Consequently, 42% of the interviews were conducted in participants' homes, 41% at an organization or business in the community, and 16% at the University of Toronto. Women were more likely than men to be interviewed at home.

RESOURCES

Challenges

As this was the first large-scale survey conducted with these communities, unforeseen challenges arose during the implementation phase. Consequently, the initial grant was not sufficient to cover the study costs. Two interrelated issues contributed to extra study costs: recruitment and human resources.

[5]Participant IDs could not be linked to completed surveys.

[6]The safety protocol included issues such as: always being accessible (i.e., carrying a phone), checking in with staff after every interview, informing others of interview location, communicating with participants only through the office, interviewing in communal areas (if domestic), adhering to guidelines concerning appropriate behavior, and ensuring that interviewers did not feel uncomfortable with interview locations. Interviewers were also encouraged to use their judgment and terminate interviews if they found themselves in an uncomfortable situation.

Recruitment

Changes in the initial recruitment strategy resulted in increased costs, such as the need for a tracking database and compensating recruiters for their efforts. As resources were limited, it was not possible to compensate organizations that were eager to help with the study, either through advertising the study or providing access to their clients for study recruitment. Because participants mainly chose interview sites either in the community or their home, there were unexpected costs associated with interviewer travel to and from the interviews and with delivery of the study materials to the study office. Furthermore, participant-initiated cancellations of interviews and no-shows resulted in thousands of dollars of unbudgeted costs.

Human resources

Because of the need to recruit and conduct interviews in real time, it was necessary to have more than one staff member involved in the interview booking process. Also, there was staff turnover because recruitment took longer than expected and interviewers could not be guaranteed work. During the course of the study, 18 interviewers were hired and two additional research assistant positions were created (four interviewers occupied these positions at various times). Consequently, substantially more training and staff hours were required than initially budgeted. Furthermore, because this was the first exposure to research and/or HIV-related issues for many of the community members involved in the study (i.e., Community Advisory Committee members, working group members, recruiters, interviewers), extensive group and individual training sessions were required, leading to delays and additional staff resources.

Solutions

Approach different funders for different study components

Because the initial grant was insufficient, we approached a variety of funders throughout the course of the study. Two additional grants, through the Ontario HIV Treatment Network (OHTN) and the Public Health Agency of Canada (PHAC), allowed for us to successfully complete the project. First, the capacity building and training component of the research was large enough to warrant separate attention and funding. The initial study funder (OHTN) recognized the importance of this component and provided sufficient support to address these needs. Second, PHAC determined that the results from EAST were crucial for moving forward with a national surveillance track (E/AC track); therefore, we received funds toward the compilation of the study reports and evaluation of recruitment efforts and lessons learned.

‘Barter’ with organizations

Although few financial resources were available to support the organizations who worked with us during the course of the study, the research coordinator was able to offer in-kind services to those who requested assistance. This involved providing advice with grant writing, faciliating the hiring of volunteer research staff, and brainstorming about the research needs of organizations.

Conclusions - Lessons learned for future research

The success of EAST was a testament to the dedication, creativity, and flexibility of community members and the study team. Taking an iterative approach to the implementation of the study allowed the team to be responsive to the needs of the communities while adhering to research design principles. However, future research projects with similar communities may benefit from the lessons we learned along the way and the following general suggestions:

- **Community involvement and partnerships must be taken seriously from the earliest conception of the research. This includes obtaining adequate funding for training and capacity building and creating opportunities for researchers to deeply and meaningfully engage with community members. Furthermore, building large networks of community partners and volunteers will not only help with the success of the study, but also take the pressure off already over-committed community leaders and stakeholders.**

- **Create a culture of transparency regarding the research process and challenges encountered. This includes building an assessment component into the research design with outcomes that go beyond the study goals to address community needs. Sharing results of formal and informal assessments allows both university- and community-based researchers to critically reflect on community appropriate methodologies and for funders to understand the unique challenges associated with research in the different communities affected by HIV. This process could inform the grant development stage and provide clarity around issues in research design and budgeting, which could help to prevent major challenges during study implementation.**

- **In addition to taking a reflexive approach to the research process, there is a need for qualitative research that explores creative and relevant ways of doing research with communities. This research would help to inform innovative methodologies that both reflect community values and improve the quality of data produced.**

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