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## The HIV SEERs Project: A Qualitative Analysis of Program Facilitators' Experience

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# The HIV SEERs Project: A Qualitative Analysis of Program Facilitators' Experience

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## Abstract

HIV-related stigma creates barriers to HIV testing, medication adherence, and retention in care. Guided by the principles of community-based participatory research (CBPR) and in collaboration with community health workers (CHWs), the Stigma-reduction through Education, Empowerment, and Research (SEERs) project was developed with and for youth living in Nakuru, Kenya to reduce HIV-related stigma. The purpose of this qualitative study was to examine the experiences of the CHWs serving as SEERs facilitators. To evaluate SEERs, 37 facilitators completed open-ended survey questions to gather their experiences and recommendations for future program implementation and sustainability. Participants' mean age was 30.58 (standard deviation = 9.62), ranging from ages 18 to 53. Thematic content analysis was used to categorize (a) facilitators' experiences and the community impact of the SEERs project, (b) lessons learned, and (c) challenges to sustainability. Recommendations will be used to modify the SEERs project, improve implementation and sustainability strategies, and may provide guidance for similar CBPR projects.

## Keywords

HIV-related stigma, community-based participatory research, qualitative research

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### What Do We Already Know about This Topic?

Youth within sub-Saharan African experience a high burden of HIV and HIV-related stigma, yet there are limited implementation and evaluation of stigma reduction interventions designed with and for youth in the region.

### How Does Your Research Contribute to the Field?

Findings from this study aim to improve implementation of the SEERs intervention, which is the first designed to incorporate all 4 effective stigma reduction components identified in the literature.

### What Are Your Research's Implications toward Theory, Practice, or Policy?

Findings from this study provide practical recommendations for implementing a contact-based intervention as an effective and innovative strategy to reduce HIV-related stigma.

## Introduction

HIV-related stigma is a known barrier to HIV testing, adherence to antiretroviral therapy, retention in care, and HIV self-disclosure.<sup>1-5</sup> In addition, people with HIV who are stigmatized often face other issues, such as a lack of or limited access to health care, employment, food, and housing.<sup>6-8</sup> HIV researchers have aimed to better understand the role of stigma in health-seeking behaviors, but there remain gaps in the literature around implementing and sustaining effective HIV stigma-reduction interventions,<sup>9</sup> particularly in low-to-middle income countries (LMICs) such as Kenya where the HIV burden is high. Kenya is one of the countries most affected by HIV in sub-Saharan Africa, which represents 80% of the HIV disease burden globally.<sup>10,11</sup> Kenya is tied with Uganda and

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Mozambique for the highest number of HIV infections.<sup>12</sup> There were 78 000 new HIV infections in Kenya in 2015 at which time 1.5 million people were living with HIV, and there were 36 000 HIV-related deaths despite 59% of adults with HIV in Kenya receiving antiretroviral treatment.<sup>13</sup> Despite the availability of HIV testing and treatment, formative research in Nakuru provided evidence of high levels of HIV stigma, which are, in part, related to religious beliefs and beliefs related to contamination and sexuality.<sup>8</sup>

### *HIV-related Community-Based Participatory Research*

The conjoined expertise of community members, community organizations, and academic researchers is important for understanding and addressing HIV-related health behaviors.<sup>14</sup> Community-based participatory research (CBPR) is one collaborative strategy that places equal emphasis on the expertise and contributions of the community and the researchers.<sup>15,16</sup> Unlike traditional research wherein the researcher acts as the expert, imposing research questions and potential solutions on the target population, CBPR requires researchers to partner with community members to jointly identify problems, develop research questions, implement strategies, and share findings. Community partners are important for improving the cultural appropriateness of the intervention, evaluation strategies, and to place findings in a community context.<sup>17</sup> They are also important for improving HIV knowledge and encouraging healthy behaviors.<sup>18</sup> Successful CBPR-based HIV prevention approaches challenge the social and cultural norms associated with the spread of HIV and improve the self-efficacy of the population to challenge those norms, making them essential for addressing the global HIV crisis.<sup>19</sup> Community-based participatory research approaches have also been effective for improving HIV-related health behaviors, such as increasing condom use, HIV-testing, and medication adherence.<sup>20,21</sup>

### *Challenges and Benefits of CBPR and the Role of Community Health Workers*

Despite the success of CBPR, there exist some challenges to implementation, such as tensions between outsiders (ie, academic researchers) and the community, limitations on community involvement, and dilemmas in sharing findings.<sup>22</sup> For example, in some partnerships, the academic researchers may receive a significantly larger allocation of resources which may create tensions between the community and the research team. If there are any reductions to the budget, the community will be more adversely impacted because they initially received a smaller allocation of resources. Additionally, program goals may differ between the researchers and community members.<sup>23</sup> Researchers may choose not to accommodate the needs of the community. This often occurs when community members are only allowed minimal input and approval of the research while the career and research goals of the academic researcher are met.<sup>23</sup> Conversely, communities may not be able to tolerate research demands (eg, research requiring a control group).

Nonetheless, the defining characteristics of CBPR include co-learning, shared decision-making, and ownership of the research process.<sup>14,15,24</sup> The benefits of CBPR approaches include reflecting on the issues and concerns of the community, improving cultural sensitivity of the research team, and increasing community trust and ownership of the research, all of which contribute to sustainability. Community-based participatory research approaches also increase the rates of research participation, strengthen the external validity of the study findings, and reduce attrition.<sup>16,22,24</sup>

Within CBPR approaches, community health workers (CHWs) can be instrumental. Community health workers or lay health workers are defined by the World Health Organization (WHO) as “members of the community who have received some training to promote health or to carry out some health-care services.”<sup>25(p919)</sup> The WHO supports the use of CHWs in addressing the HIV crisis in sub-Saharan Africa.<sup>26</sup> In the past, CHWs have played key roles in HIV and general health education programs including educating families, caregivers, and communities on the symptoms and treatment of infection and the importance of HIV testing.<sup>26</sup> Historically, CHWs have been used in many areas of health care and prevention,<sup>18</sup> particularly to reach underserved populations, to supplement a limited healthcare system, and to expand the coverage of an intervention.<sup>27</sup> As members of the communities they serve, CHWs are a direct link to HIV services.<sup>26</sup> They are important for addressing social barriers and making health information comprehensible to peers and, as a result, encourage linkage to care and the uptake of services, especially among vulnerable populations.<sup>17</sup> Community health workers living with HIV may be even more effective at implementing HIV-focused interventions. For example, CHWs delivering AIDS palliative care in Uganda reported that having personal experience with HIV increased their compassion for patients.<sup>27</sup>

### *Stigma-reduction through Education, Empowerment, and Research Project*

Formative research in Nakuru, Kenya, employed CBPR strategies to conduct an HIV psychosocial needs assessment involving 268 stakeholders across 5 communities representing 5 tribes and 11 organizations and agencies.<sup>8</sup> Information was gathered from stakeholders via 22 forums including individual interviews, focus groups, and community sessions. Briefings and debriefings were conducted with a core group of community members to identify areas most in need of intervention. Addressing HIV-related stigma among youth was identified as the primary area of need. This led to a conceptual model linking HIV stigma to survival and self-actualization.<sup>8</sup> In response to this and using the existing stigma-reduction literature as a resource, the primary investigator in collaboration with a core team of community members, developed the HIV Stigma-reduction through Education, Empowerment, and Research (SEERs) project. Designed to increase HIV knowledge and decrease HIV-related stigma among youth aged 13 to 24, the HIV SEERs project includes 4 stigma-reduction components:

(1) information, (2) skills building, (3) support/resources, and (4) personal contact with those living with HIV. The initial core team involved an orphanage director and assistant director, a social worker, a teacher, a child services worker, and a minister in Kenya. The team was subsequently organized to include a project manager and 4 team leaders with each team comprised of 7 to 8 team members. The lead author conducted a train-the-trainers workshop on the HIV SEERs project in July 2016, after which teams began delivering the program in their local communities including schools and community centers. Over the course of 1 year, SEERs was administered to 1526 students and local community members in Nakuru, Kenya. Preliminary findings suggest SEERs was effective for increasing knowledge and decreasing stigma.<sup>28</sup>

The purpose of this qualitative study was to examine the experiences of the SEERs facilitators using existing program evaluation data to answer the following questions (a) “What are facilitators’ views and perceptions of the impact of the SEERs program?” and (b) “How can the SEERs program be improved and sustained?”

## Methods

### Study Design and Setting

This study employed a qualitative approach to examine existing SEERs program evaluation data from Nakuru, Kenya for the purpose of understanding the facilitators’ experiences. Nakuru has a population of approximately 300 000 people and is located an estimated 55 miles northwest of Nairobi.<sup>29,30</sup> Approximately 70% of the population is comprised of the Kikuyu and Kalenjin tribes. People from the Luo, Luhya, Kamba, Meru, and Kisii tribes comprise the remaining 30%.<sup>29</sup> The predominant religion in Nakuru is Christianity. A minority of the population practice Islam or Hindu religions. Native languages include Swahili, Gikuyu, and Kalenjin. However, English is the language of instruction in Kenya<sup>31</sup> and is therefore commonly used. Small-scale farming, including dairy farming and horticulture, drives the economy.

### Participants

Participants in this study were the SEERs project manager and CHWs, termed program facilitators (N = 37), who implemented the program from 2016 to 2017. The SEERs facilitators were organized into 4 project teams based on location and were comprised of youth (18-24 years) and older adults (25+ years), all of whom were infected with or affected by HIV. After receiving training, facilitators implemented SEERs in schools and in the community. They received a modest stipend, commensurate with the average daily wage in Kenya, for their time and were reimbursed for transportation costs with SEERs designated funds. More information about SEERs implementation and facilitator responsibilities is included in an article currently in press.<sup>28</sup>

**Table 1.** Selected Questions Categorized by Domains.

Domain	Question
Experiences and impact of SEERs program	How has participating in the HIV SEERs project affected your feelings about yourself?
	If you are HIV positive, how has participating in the HIV SEERs project affected your feelings about living with HIV?
	If you are not HIV positive, how has being in the HIV SEERs project affected how you feel about others living with HIV?
	What positive experiences did you have as a result of your affiliation with the HIV SEERs project?
	What negative experiences did you have as a result of your affiliation with the HIV SEERs project?
	Why do you hope to continue as a SEERs team member?
	Describe your experience of being a member of an HIV SEERs team.
Lessons learned from SEERs leaders	What worked well with the HIV SEERs project?
	Do you believe that you have created change in your community through being a part of the HIV SEERs project?
	What did not work well with the HIV SEERs project?
	What changes do you recommend for improving the HIV SEERs project?
	What training would make you a more effective SEERs leader?
Addressing challenges to sustainability	What resources are needed to improve the HIV SEERs project?

### Data Collection Procedures

This study used existing SEERs program evaluation data collected through an anonymous Qualtrics survey administered via a link on WhatsApp Version 2.16.254 to all SEERs facilitators including the project manager. WhatsApp is a free app for mobile phones that provides simple and secure text messaging and was used by all SEERs facilitators as a primary means of communication. Completion of the survey was voluntary. The survey was administered in English given that all facilitators speak and read English.

The primary investigator developed the survey, which included 15 open-ended interview questions designed to assess facilitators and barriers to SEERs implementation. This study focused on 13 questions aimed at gathering the SEERs facilitators’ experiences including 7 questions eliciting information about the impact of being a SEERs facilitator, 4 questions inquiring about what worked well and what did not work well during SEERs implementation, and 2 questions requesting information about how to make SEERs sustainable (See Table 1). Questions about why the facilitators became involved with SEERs and what questions they had about HIV or related issues were omitted because they were not directly relevant to our research questions.

## Data Analysis

All qualitative data were stored and analyzed in Microsoft Excel (v. 2016). Specifically, qualitative findings were used to characterize the (a) experiences and impact of the SEERs program, (b) lessons learned from SEERs project facilitators, and (c) challenges to sustainability. A team of 7 ethnically diverse (white, black American, Hispanic, African) data analysts comprised of a faculty member, a postdoctoral fellow, and graduate and undergraduate students completed thematic content analysis. This approach was used to explain participants' views and perceptions of the SEERs program impact and areas to address for future implementation. Using an established process,<sup>32</sup> data analysis included 5 steps: (1) familiarization of the data; (2) coding of the data and developing a template of codes; (3) connecting codes and identifying themes; (4) reviewing, validating, and naming themes; and (5) producing a report. In step 1, analysts reviewed all survey text to become familiar with the data. In step 2, analysts developed a template of codes linked to participants' responses. The analysis was guided by but not limited to the selected codes as new codes emerged inductively. During step 3, analysts connected codes to identify themes. During step 4, analysts developed a unique definition for each theme, reviewed, and validated themes by comparing them to the participants' original responses. This was also done to establish confirmability. Analysts used negotiated agreement to determine the final themes, ensure consensus, and to guide the interpretation of findings. In step 5, findings were synthesized to produce a rich description of participants' experiences and recommendations.

## Results

### Demographics

A total of 37 SEERs project facilitators agreed to share their experiences about the program. Participants' mean age was 30.58 (standard deviation = 9.62), ranging from ages 18 to 53. Of those who reported their gender (n = 33), most were female (45.9%, n = 17) and almost all had completed HIV testing before becoming a SEERs facilitator (78.4%, n = 29, see Table 2).

### Experiences and Impact of the SEERs Program

The facilitators were asked 7 questions designed to capture how the SEERs program impacted them and the surrounding community in which it was implemented: (a) "How has participating in the HIV SEERs project affected your feelings about yourself?" (b) "If you are HIV positive, how has participating in the HIV SEERs project affected your feelings about living with HIV?" (c) "If you are not HIV positive, how has being in the HIV SEERs project affected how you feel about others living with HIV?" (d) "What positive experiences did you have as a result of your affiliation with the HIV SEERs project?" (e) "What negative experiences did you have as a result of your affiliation with the HIV SEERs

**Table 2.** Demographics of SEERs Facilitators.

Variable	Response	Percentage	N
Age	Mean (SD) = 30.58 (9.62)	–	37
What is your gender?			
	Female	45.9	17
	Male	43.2	16
	NA	10.8	4
What is the highest level of formal education that you have completed?			
	Primary school	2.7	1
	Secondary school	24.3	9
	Technical college/university	62.2	23
	NA	10.8	4
Which one of these statements best describes your current employment status?			
	Working full-time as an employee	18.9	7
	Working part-time as an employee	13.5	5
	Working full-time but not as an employee (self-employed)	5.4	2
	Doing casual or part-time work (self-employed)	21.6	8
	Unemployed not working at all	24.3	9
	NA	16.2	6
Have you ever been tested for HIV?			
	Yes	78.4	29
	No	5.4	2
	NA	16.2	6
Do you have HIV?			
	Yes	8.1	3
	No	75.7	28
	Wish not to answer	2.7	1
	NA	13.5	5

Abbreviations: NA, not applicable; SEERs, Stigma-reduction through Education, Empowerment, and Research.

project?," (f) "Why do you hope to continue as a SEERs team member?," and (g) "Describe your experience of being a member of an HIV SEERs team?" Four themes emerged to categorize the perceived impact of the SEERs program on the local community and the facilitators: (a) improving knowledge and awareness, (b) positive attitudinal shift, (c) serving the community via stigma reduction, and (d) negative experiences of the SEERs project facilitators. See Table 3 for domains, themes, and supportive quotes.

**Improving Knowledge and Awareness.** Sixteen facilitators reported that the SEERs program increased their own and the communities' HIV transmission knowledge and awareness about the impact of HIV-related stigma on the well-being of those living with HIV. Many facilitators considered the increased HIV knowledge and awareness to be among the most important benefits of the SEERs program. One facilitator said, "It made me . . . understand the serious part [of] how HIV affects people in different ways" (Participant 1). Facilitators distinctly expressed the need for HIV education interventions in their local communities. For example, a facilitator said, "More

**Table 3.** Feedback from SEERs Facilitators: Domains, Themes, and Examples of Supportive Quotes.

Domain	Themes	Examples of Supportive Quotes
Experiences and impact of SEERs program	Improve knowledge and awareness	<i>It has taught me a lot since I do visit and take care of PLWHA almost daily. It has helped me to understand people and help families understand their loved ones living/dying with the disease (Participant 12)</i> <i>Today, I boast of a wealth of experience thanks to SEERs. I still want to learn more from these awesome people if they will offer me a chance to continue sitting under their great teachings (Participant 12)</i>
	Positive attitudinal shift	<i>I have learnt that people living with HIV should be treated well as any other person without facing stigmatization (Participant 3)</i> <i>I feel more acceptance and understanding. More than ever, this is a group I would like to continue being a pillar to (Participant 9)</i>
	Opportunity to serve the community	<i>Lessons learnt in the SEERs programme [program], now helps me to assist other people especially those who have lost hope in life (Participant 11)</i> <i>[I] foster student ability to apply what they learn to their lives and communities, that is help them become active citizens and forces for positive change in the society (Participant 11)</i>
	Negative experiences of SEERs facilitators	<i>Some people fear to shake my hands for fear of contracting AIDS (Participant 1)</i> <i>Some members were not cooperative (Participant 8)</i>
Lessons learned from SEERs leaders	Successful aspects of SEERs implementation	<i>(1) Reached many young people in schools and colleges, (2) teamwork and cooperation from seers management was fantastic, (3) increased level of awareness on hiv stigma, (4) we had good resource material for the program (Participant 11)</i> <i>The school outreaches were the best. The programme [program] content was good. Working as a team was quite good. Generally I would say that in my team, all went well (Participant 9)</i>
	Less successful areas of implementation	<i>The pretest questionnaire was a bit complex for primary school kids, they didn't understand things like oral sex, transgender (Participant 13)</i> <i>I think only time was not enough, since it was always a huge crowd of people questions were so many, that even when our time was up they still followed us behind. It was so bad, but we promised to go back and answer all of them (Participant 25)</i>
	Training needed for sustainability effort	<i>I think more in-depth trainings will be appropriate (Participant 6)</i> <i>There is need to strengthen life skills training for the SEERs team leaders and members to be more effective on the ground since there is a lot of need for knowledge in the society (Participant 13)</i>
Addressing challenges to sustainability	Resources needed for sustainability efforts	<i>I recommend for establishments of our offices. I recommend partnership with other great organizations (Participant 3)</i> <i>Equip us with many information to make us more valuable. Have posters and banners fliers, etc. Have enough money to make our work easier (Participant 1)</i>

Abbreviations: SEERs, Stigma-reduction through Education, Empowerment, and Research; PLWHA, people living with HIV/AIDS.

information needs to be passed on to communities to help educate many concerning the subject” (Participant 7). Another facilitator emphasized the specific importance of stigma reduction, saying, “The programme has been . . . informative when it comes to stigma reduction hence the need to back up its objective” (Participant 15).

**Positive Attitudinal Shift.** As a result of the program, 30 of the 37 facilitators reported a variety of positive changes in their attitudes which included developing humility, open-mindedness, empowerment, positivity, and respect for those living with HIV. One facilitator characterized a feeling of empowerment gained from being a SEERs facilitator, saying, “I have realized I have strength within me, walking and talking to those that have been neglected was something I couldn't dare do but now [I'm] comfortable with [people living with HIV], [I'm] not feeling nervous of anything” (Participant 25). Another facilitator also mentioned feelings of empowerment, saying, “It built my self-confidence and help me grow with love towards people

affected by HIV” (Participant 16). One facilitator captured the common feeling of humility, saying, “It has helped me humble myself to serve humanity” (Participant 11).

**Opportunity to Serve the Community.** The third theme used to describe the SEERs program impact was that it offered facilitators the opportunity to serve their community. This was reported by 19 of the 37 facilitators. Serving the community was particularly important when facilitators discussed reasons they wished to continue their work as a SEERs facilitator. Serving the community was characterized in several ways including passion and motivation to address stigma-reduction, aiding youth impacted by HIV, and being an agent of change. One facilitator said, “I want to be a change agent in my community. Serving humanity is serving God” (Participant 20). Another facilitator characterized the importance of aiding youth impacted by HIV by saying, “[SEERs] has given me a link to reach out [to] young people who are suffering from HIV-related stigma. Also [it] is an opportunity to serve my

community at large” (Participant 23). Finally, a facilitator described the motivational aspect of serving their community by saying, “I would like to continue because of the impact [SEERs] has created in the schools we visited and also it’s something I enjoy doing. Its rewards cannot even be compared to any amount of money” (Participant 9).

**Negative Experiences of SEERs Facilitators.** The final theme characterizing the SEERs program was the negative experiences of SEERs facilitators. The majority of (n = 24) facilitators reported no negative experiences, while 5 reported uncooperative youth, 3 reported stigma associated with being a facilitator, 3 reported the limited reach of the study, 1 reported community distrust, and another reported lack of resources. One facilitator described the stigma associated with being a SEERs team member, saying, “The topic of HIV having a lot of stigma affiliated with it, [is] passing on to those tackling it” (Participant 7). Another described a potential challenge in dealing with youth, saying “Handling the young was quite a challenge. They provided irrelevant information since few of them were not willing to answer the questions” (Participant 3).

### Lessons Learned From SEERs Facilitators

The facilitators were asked 4 questions to assess the lessons learned through their participation in the SEERs program: (a) “What worked well with the HIV SEERs project?”; (b) “Do you believe that you have created change in your community by being a part of the HIV SEERs project?”; (c) “What did not work well with the HIV SEERs program?”; and (d) “What changes do you recommend for improving the HIV SEERs program?” Two themes emerged to characterize the lessons learned from the SEERs program: (a) successful areas of implementation and (b) less successful aspects of implementation. See Table 3 for domains, themes, and supportive quotes.

**Successful Aspects of Implementation.** The project facilitators reported several positive components of the SEERs program including (a) community interaction, (b) materials, (c) teamwork, (d) change in the community, (e) leadership, (f) organization, and (g) communication. Specifically, 15 facilitators reported community interaction, 11 reported SEERs materials, 8 reported teamwork, 5 reported a change in the community, 4 reported leadership and organization, and 2 reported communication as a successful aspect of SEERs implementation. One facilitator characterized the success of the program, saying, “Management worked well because materials were readily available at the right time. Teamwork also worked well because each member [was] very cooperative. Our team leaders really showed true leadership. They ensured all was in track” [Participant 4]. One facilitator described the successful community interactions with youth, saying, “The interactions with the youths has really been fruitful... we got to understand what our youths are going through and what they need” (Participant 18). Finally, a facilitator characterized the successful communication

strategies, saying, “Using informal conversations to talk about HIV stigma, talking about fears and concerns about HIV. This worked so well because it established a network of adolescents and youths living with HIV to address stigma and discrimination.” (Participant 14).

**Less Successful Areas of Implementation.** The second theme describing lessons learned were the less successful areas of implementation. The facilitators reported 3 areas needing improvement before additional implementation efforts: (a) issues with reading level and literacy, (b) limited time, and (c) limited resources. Specifically, 7 facilitators reported limited time, 4 reported limited resources, and 5 reported reading and literacy concerns. One facilitator addressed reading level and literacy, saying, “The questions (some of them) were tough especially for the primary [school] kids and lower secondary forms 1&2. Good questions but need to be put in a language they understand” (Participant 11). Another discussed the importance of having more time allotted to conducting the SEERs program, saying, “I think only time was not enough since it was always a huge crowd of people, questions were so many, that back and answer all of them.” (Participant 25).

### Addressing Challenges to Sustainability

The facilitators were asked 2 questions to determine sustainability needs: (a) “What training would make you a more effective SEERs leader?” and (b) “What resources are needed to improve the HIV SEERs program?” Two themes emerged to capture the challenges to sustainability: (a) training needed for sustainability and (b) resources needed for sustainability. See Table 3 for domains, themes, and supportive quotes.

**Training Needed for Sustainability.** The SEERs facilitators described several areas of training needed to improve the program’s scope and sustainability. These included offering refresher courses to SEERs facilitators over time and providing additional training opportunities. A total of 21 facilitators reported the need for additional training, while 11 reported the need for refresher courses. One facilitator described the importance of refresher courses, saying, “Refresher courses...help sharpen our skills and knowledge” (Participant 11). For SEERs facilitators, desired additional training included more comprehensive information on HIV and related topics, such as intimate partner and gender-based violence (GBV). Facilitators also mentioned the need for training in counseling, writing, and HIV testing, of which guidance and counseling training were most commonly requested. One facilitator said, “Equip us with many information to make us more valuable. I would recommend guidance and counselling training” (Participant 1). Another facilitator said “Training on how to conduct HIV/AIDS testing” (Participant 8) and another said, “Training on social

*norms in relation to HIV, integrated HIV and GBV, [and] paediatric HIV"* (Participant 15).

**Resources Needed to Improve SEERs.** The SEERs facilitators described several resources needed for sustainability and improvement of the SEERs program; 10 facilitators reported the need for funding, 5 reported the importance of advertising the program, and 18 reported more tangible resources such as office furniture, equipment, and supplies. One facilitator said, "*Posters addressing stigma eradication. Writing material (e.g. flip charts and marker pens) for further elaborations*" (Participant 9). Two facilitators also reported the need for less tangible resources such as community partnerships. One SEERs facilitator said "*Working in collaboration with organisations like NEPHAK<sup>1</sup> will help improve our skills*" (Participant 11). Another described resources needed as "*Capacity building [and] institutional strengthening to support groups and [a] network of adolescents*" (Participant 14).

## Discussion

Findings from this study provide insight into the benefits and challenges of implementing SEERs, facilitators and barriers to larger scale implementation, and challenges to sustainability. These findings along with study limitations and future directions are described in the sections to follow.

### Benefits and Challenges of Implementing SEERs

Facilitators reported several perceived benefits of SEERs including increasing the HIV knowledge of the community and the SEERs facilitators, creating a positive attitudinal shift among facilitators toward people living with HIV, and creating opportunities for facilitators to serve the community. These findings are consistent with other studies applying CBPR approaches with CHWs.<sup>26,33,34</sup> Specifically, SEERs facilitators reported a more positive attitude toward people living with HIV citing humility, open-mindedness, and improved respect. This shift in attitude indicates that exposure to accurate HIV knowledge and the skills to address stigmatizing attitudes as provided by SEERs can begin to change HIV stigmatizing attitudes. This is important as CHWs are not only critical for improving the HIV knowledge of the community, they are also essential role models that can demonstrate stigma-free behaviors.<sup>17</sup> Similar shifts in attitudes among facilitators and the community have been reported in a systematic review assessing the outcomes of using CHWs in HIV care in sub-Saharan Africa.<sup>26</sup> Additionally, perceived increases in HIV knowledge reported by SEERs facilitators have also been seen in several HIV/AIDS studies using CHWs.<sup>26</sup>

In one study, researchers identified several social rewards that served as incentives and motivators for CHWs' participation in intervention research. These incentives included workers receiving more greetings, honor, recognition, and more

decision-making responsibilities within their communities.<sup>27</sup> Interestingly, CHWs in our study did not report such motivators. Instead, they reported serving their community as a primary benefit of being a SEERs facilitator, which is consistent with the other findings in the literature.<sup>27,34</sup> Contrastingly, negative outcomes were rare but included dealing with "uncooperative youth," which may support the need for additional training to prepare facilitators for working with youth populations. Additionally, some SEERs facilitators reported feelings of stigma resulting from working with SEERs, and this is believed to be an extension of the stigma associated with HIV.<sup>27</sup> In an HIV/AIDS CBPR study conducted in Jamaica, researchers also identified that participation in their program was associated with stigmatizing experiences and increased the vulnerability of already marginalized groups.<sup>35</sup> Interestingly, despite some reports of stigmatizing attitudes toward SEERs facilitators, facilitators did not report any challenges or stigmatizing experiences from their families or friends. It is unclear how many facilitators shared their participation in the SEERs project with family and friends; therefore, we cannot be sure if all families or friends would be supportive of this research. In a previous study investigating the motivations of CHWs in Tanzania, findings showed that their families' lack of support and disapproval were one of the primary barriers to working as a CHW, yet this was not reported among SEERs facilitators.<sup>34</sup>

### Facilitators and Barriers to Larger Implementation

Facilitators reported several factors they believed would encourage implementation and sustainability including communication quality, leadership team, program materials, community interaction, and teamwork. These findings are consistent with previous research that highlight the importance of teamwork, strong leadership, and resources as key factors for implementation.<sup>36,37</sup> Retaining and improving these components will be essential to larger scale implementation of SEERs. Additionally, facilitators reported literacy levels, limited time, and limited resources as areas to be addressed for future implementation. In previous CBPR studies, lack of resources and time have been reported as consistent barriers to implementation.<sup>37,38</sup> Despite being reported as barriers to CBPR studies with children, the need to compensate community partners and ensuring community participation were not reported as potential challenges for SEERs implementation.<sup>38</sup> Community partners of SEERs included schools and nonprofit organizations which were less likely to require compensation for their participation. Additionally, having a captive audience such as pupils in a school setting created minimal issues with ensuring participation compared to challenges that might exist in other community settings.

### Challenges to Sustainability

Dimensions of sustainability as identified by Israel and colleagues<sup>37</sup> are (a) sustaining relationships and commitments among the partners involved; (b) sustaining the knowledge,



capacity, and values generated from the partnership; and (c) sustaining funding, staff, programs, policy changes, and the partnership itself. Many of our findings supported these dimensions with the exception of policy changes. Despite receiving appropriate training, SEERs facilitators reported the need for additional knowledge and training that would allow SEERs to be sustainable. The suggested areas of training included HIV testing, more comprehensive HIV education, and gender-based violence, all associated with HIV prevention and care. Facilitators also expressed a need to receive counseling training. This finding is not uncommon, as it has been seen in another study exploring the needs and challenges of CHWs in South Africa.<sup>33</sup> Additionally, Kok and colleagues<sup>27</sup> completed a systematic review of intervention design factors that influence the performance of CHWs in LMICs. What has been shown as important for successful implementation were not only initial training but refresher training,<sup>27</sup> which SEERs facilitators discussed as essential for continued implementation. Potential benefits of continuous training also include improved job satisfaction and motivation.<sup>27</sup> Other researchers have found a strong correlation between refresher training, resources, and CHW's performance.<sup>27</sup>

Facilitators also reported the need for sustained partnerships and for community partners to receive personal, community, and organizational benefits, which have been supported as essential components in successful CBPR studies.<sup>17,38</sup> Like findings in our study, incentives and resources were also considered motivating factors in sustainability research.<sup>27</sup> Although not reported in our study, other works have emphasized the need to compensate community partners for their participation as well as a lack of trust as common challenges to sustainability.<sup>38</sup> Overall, CBPR is a great method for sustaining relationships, improving knowledge, and assessing and improving community capacity.<sup>17</sup>

### Limitations

This study has presented some important findings for scaled-up implementation and sustainability of SEERs in Nakuru, Kenya and similar CBPR programs in LMICs. However, there are some important limitations to consider. Social desirability bias among facilitators may have affected survey responses. Also, this study does not incorporate the thoughts, attitudes, or feelings of community participants of SEERs, which may differ from those of facilitators. Furthermore, these results may only be applicable to SEERs implementation in Nakuru, Kenya, and may require alternative approaches in neighboring communities or other LMICs. Despite including all 4 effective HIV stigma-reduction components identified in the literature,<sup>39</sup> SEERs may not address the underlying community-level factors that support stigmatizing attitudes.<sup>40</sup>

### Conclusion and Future Directions

Current findings highlight the importance of partnering with community members to implement HIV programs and the

benefits experienced by facilitators including increased HIV knowledge, improved attitudes toward people living with HIV, and feelings of satisfaction associated with serving the community. Despite these benefits, findings also highlight the challenges inherent in CBPR implementation and sustainability including factors related to funding, training, leadership, and teamwork. Findings from this study will be used to modify and expand SEERs. Future directions include a randomized controlled trial to further assess the efficacy of SEERs. Our study adds knowledge on the value of CBPR in reducing HIV-related stigma. We highlight the need for adequate funding, continued training, strong leadership, team building, and a sustainable plan during the conception of a CBPR project.

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