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Perspectives of healthcare providers and HIV-affected individuals and couples during the development of a Safer Conception Counseling Toolkit in Kenya: stigma, fears, and recommendations for the delivery of services

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Abstract

Reproduction is important to many HIV-affected individuals and couples and healthcare providers (HCPs) are responsible for providing resources to help them safely conceive while minimizing the risk of sexual and perinatal HIV transmission. In order to fulfill their reproductive goals, HIV-affected individuals and their partners need access to information regarding safer methods of conception. The objective of this qualitative study was to develop a Safer Conception Counseling Toolkit that can be used to train HCPs and counsel HIV-affected individuals and couples in HIV care and treatment clinics in Kenya. We conducted a two-phased qualitative study among HCPs and HIV-affected individuals and couples from eight HIV care and treatment sites in Kisumu,

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Kenya. We conducted in-depth interviews (IDIs) and focus group discussions (FGDs) to assess the perspectives of HCPs and HIV-affected individuals and couples in order to develop and refine the content of the Toolkit. Subsequently, IDIs were conducted among HCPs who were trained using the Toolkit and FGDs among HIV-affected individuals and couples who were counseled with the Toolkit. HIV-related stigma, fears, and recommendations for delivery of safer conception counseling were assessed during the discussions. One hundred and six individuals participated in FGDs and IDIs; 29 HCPs, 49 HIV-affected women and men, and 14 HIV-serodiscordant couples. Participants indicated that a safer conception counseling and training program for HCPs is needed and that routine provision of safer conception counseling may promote maternal and child health by enhancing reproductive autonomy among HIV-affected couples. They also reported that the Toolkit may help dispel the stigma and fears associated with reproduction in HIV-affected couples, while supporting them in achieving their reproductive goals. Additional research is needed to evaluate the Safer Conception Toolkit in order to support its implementation and use in HIV care and treatment programs in Kenya and other HIV endemic regions of sub-Saharan Africa.

Keywords

Safer conception; HIV-affected couples; family planning; HIV prevention; prevention of mother-to-child transmission

Delivery of safer conception services in Kenya

Reproduction is important to many HIV-affected¹ individuals and couples and healthcare providers (HCPs) (i. e., medical officers, clinical officers, nurses, and community health workers) have the responsibility of providing resources to help couples safely conceive, while minimizing the risk of sexual and perinatal HIV transmission (Bekker et al., 2011; Gruskin, Firestone, MacCarthy, & Ferguson, 2008). According to the World Health Organization, all individuals have the basic reproductive right to information and the ability to decide and control their reproductive decision-making (United Nations Populations Fund [UNFPA], 1994). In an effort to promote reproductive autonomy and curb HIV incidence, HIV-affected individuals and couples need access to information on safer methods of conception (Mmeje, Titler, & Dalton, 2014; Mmeje et al., 2014; Schwartz et al., 2014). Safer conception strategies are harm-reduction techniques intended to help HIV-infected individuals and their partners achieve pregnancy, while limiting the risk of HIV transmission to the uninfected partner and unborn child (Bekker et al., 2011; Crankshaw et al., 2012; Matthews & Mukherjee, 2009). Safer conception strategies include antiretroviral therapy in the infected partner (i.e., treatment as prevention) coupled with timed condomless intercourse, timed vaginal insemination, pre-exposure prophylaxis, and sperm washing with intrauterine insemination (Bekker et al., 2011; Chadwick et al., 2011; Lampe, Smith, Anderson, Edwards, & Nesheim, 2011; Loutfy et al., 2012; Matthews, Baeten, Celum, & Bangsberg, 2010; Matthews & Mukherjee, 2009; Mmeje, Cohen, & Cohan, 2012).

¹For the purpose of this manuscript, *HIV-affected individual(s)/couple(s)* refers to person(s) that are (1) HIV-positive or (2) HIV-negative and in an HIV-serodiscordant relationship.

Our work in Kenya, along with similar findings from other studies, suggests that many HCPs and most HIV-affected individuals and couples are unaware of safer conception strategies that are currently available (Finocchiaro-Kessler et al., 2014; Matthews et al., 2014; Mmeje, Cohen, et al., 2014). HCP attitudes toward HIV-affected couples and their lack of knowledge about safer reproductive methods are barriers to the availability, provision, and uptake of safer conception services by HIV-affected couples desiring children (Breitnauer et al., 2015; Matthews et al., 2014). To date in Kenya, there is no standardized safer conception training curriculum or counseling guidelines endorsed by the Ministry of Health (MoH) for HCPs to offer HIV-affected individuals and couples.

In order for HIV-affected individuals and couples to fulfill their reproductive goals, they first need education and counseling on safer methods of conception; this has created an urgent need to develop a safer conception training curriculum and counseling guideline for HCPs and their HIV-affected clients. The objective of this qualitative study was to develop a Safer Conception Counseling Toolkit that can be used to train HCPs and counsel HIV-affected individuals and couples in HIV care and treatment clinics in Kenya. Our group developed a novel Safer Conception Counseling Toolkit based on existing resources in the USA (François-Bagnoud Center [FXB Center], 2012; HIVE, 2015). In this analysis, we present the perspectives of HCPs and HIV-affected individuals on safer reproductive methods, and recommendations on how to deliver safer conception counseling and education in this setting.

Methods

Study setting

The study was conducted from February through June 2014 in Kisumu, Kenya, which is located in the Nyanza region, where the HIV prevalence is the highest in the country at 18.7% (National AIDS Control Council of Kenya, 2014). There are an estimated 260,000 HIV-serodiscordant couples in Kenya (National AIDS and STI Control Programme [NASCOP], 2012).

Study design and procedures

This iterative qualitative study was conducted in two phases (Figure 1). In phase one, we conducted focus group discussions (FGDs) among HCPs and in-depth interviews (IDIs) among HIV-affected individuals and couples in the participants' preferred language to inform the content of the Safer Conception Counseling Toolkit. In phase two, we conducted IDIs among HCPs who were trained using the Toolkit, and FGDs among HIV-infected women and HIV-serodiscordant couples who were counseled by trained HCPs using the Toolkit. These IDIs and FGDs provided information to refine the Toolkit. Qualitative interviews explored issues related to the Toolkit's content, HIV-related stigma, fears, and recommendations for the delivery of safer conception counseling.

Study population and recruitment

HCPs and HIV-affected individuals and couples were recruited for study participation from eight Family AIDS Care and Education Services (FACES) and MoH-supported HIV care

and treatment facilities in Kisumu. Some couples were recruited from a pilot study evaluating timed vaginal insemination as a safer conception method; thus, they had prior experience with this specific method. The leadership at each of the facilities was approached to assist with the identification of HCPs for training. Prospective HIV-affected individuals were referred by their HCPs and the study staff offered study-related information prior to enrollment. HIV-infected individuals in stable partnerships were encouraged and supported to bring their partner for participation in the FGDs.

Sample size determination

In order to reach saturation of responses in our qualitative interviews (Dworkin, 2012), we targeted 10 HCPs, 10 HIV-infected women, and 10 HIV-serodiscordant couples for enrollment in phase one. In phase two, 10 HCPs, 10 HIV-serodiscordant couples, and 20 HIV-infected women were targeted for study enrollment.

Inclusion criteria

All study participants self-reported that they were over 18 years of age. Eligible HCPs included medical and clinical officers, nurses, and community health workers currently providing HIV care and treatment to HIV-affected individuals and couples. HIV-affected women were restricted to age 18–40 years. All HIV-affected individuals self-reported being in a monogamous relationship; were fluent in and comprehended Kiswahili, Dholuo, or English; and were able to provide written informed consent. Both female-positive and male-positive HIV-serodiscordant couples were eligible for study participation. HIV status was self-reported and not confirmed by serological assessment or medical chart review. HCPs and HIV-affected individuals involved in phase one were not eligible to participate in phase two of the study. All study participants received 500 Kenyan Shilling (~\$5USD) for their time and travel.

Data analysis

The FGDs and IDIs were recorded, transcribed, and translated verbatim to English. The transcripts were reviewed by study staff to ensure accuracy and consistency. The transcripts were analyzed using an open coding approach with Dedoose® software (v 5.0.11 SocioCultural Research Consultants, LLC, Los Angeles, CA). The principles of grounded theory analysis were fulfilled and thematic analysis was employed to fulfill our study objective. After the interviews were completed, comparative analysis by two independent reviewers occurred with open coding. Similarly coded texts were then grouped into categories and themes to explain the existing barriers and challenges that may limit access to safer conception services in Kenya. Half of the interviews were double-coded to ensure consistency. The final codebook was developed and agreed upon by consensus among the investigators.

Ethical approvals

The Kenya Medical Research Institute and the University of California, San Francisco, granted ethical approval. Study participants provided written informed consent.

The Safer Conception Counseling Toolkit

The Toolkit was adapted from existing safer conception counseling resources developed in the USA (FXB Center, 2012; HIVE, 2015) and was first presented to study participants during this study. The study participants' perspectives and comments helped to shape the development of the Toolkit (Supplements 1–4; Available at: <http://www.hiveonline.org/safer-conception-toolkit-for-hiv-affected-individuals-and-couples-and-healthcare-providers/>) (FXB Center, 2012; HIVE, 2015) that consists of (1) HCP training; (2) an HCP counseling guide; and (3) methods brochures for HIV-affected individuals desiring children. The Toolkit contains the recommended clinical guidelines for providing locally available safer conception strategies for HIV-affected couples attempting to achieve pregnancy, which include timed condomless intercourse, early initiation of antiretroviral therapy, pre-exposure prophylaxis, timed vaginal insemination, and assisted reproductive technologies (i.e., sperm washing coupled with intrauterine insemination). The method brochures review the safer conception options and offer questions for HIV-affected individuals and couples to ask their HCPs in order to initiate discussions on planning their families safely. A mixed methods analysis of the feasibility, acceptability, and impact of the Toolkit on changes in confidence, knowledge, and attitudes among HCPs and HIV-affected individuals and couples are presented separately.

Results

A total of 106 individuals were enrolled; 66 in phase one and 40 in phase two of the study (Figure 1). In phase one, we conducted two FGDs with HCPs ($n = 19$), one FGD with HIV-infected women ($n = 9$), and one FGD with HIV-affected couples ($n = 4$ couples). Thirty IDIs ($n = 20$ HIV-infected women and 10 HIV-affected men) were also conducted. In phase two, four FGDs were conducted; one FGD with HIV-affected couples ($n = 5$ couples), two FGDs with HIV-affected women ($n = 5$ –10), and one FGD with HIV-affected men ($n = 5$). In addition, 10 IDIs were conducted with HCPs in phase two. The median age among all HCPs was 30 years (range 24–42 years), with a median of four years (range 1–6 years) of experience providing HIV care. Among all HIV-affected individuals, the median age was 35 years (range 21–67 years). Among HIV-affected individuals and couples in phase two, 73% self-reported they were engaged in HIV care, 68% were receiving anti-retroviral therapy, and the majority (80%) reported a desire to have a child with their current partner in the next 12 months.

Perspectives before counseling with the toolkit (Phase one)

Fears related to conception among HIV-affected individuals and couples—

HIV-affected individuals feared HIV transmission to the uninfected partner and/or unborn child with attempted conception (Table 1 – *Representative Quotes*). They also experienced trepidation with the safer conception procedures because they were unsure if the recommended procedures or devices employed with attempted conception would cause pain or possible injury.

Attitudes toward HIV-affected couples having children—In our sample, HIV-affected individuals and couples reported that the general public perception is that they

“should not give birth to children”. As a result, HIV-affected individuals and couples experience stigma from the local community when they express their desire to have children. This often stems from difficulty in understanding the concept of HIV-serodiscordance among members of the lay community. Therefore, the common assumption is that all sexual partner(s) and offspring of an HIV-infected individual are inherently also HIV infected. Similarly, HCPs advise HIV-serodiscordant couples to separate because they do not have the knowledge to support their unique clinical circumstance. As a result of this perceived stigma, HIV-affected individuals and couples expressed that they are reluctant to engage with the healthcare system and continue to risk HIV transmission in order to conceive. However, participants indicated that community attitudes are changing with increasing knowledge and access to safer conception services because “they see those who are positive giving birth to negative kids”.

Impact on partnership dynamics—HIV-affected individuals and couples also asserted that the provision of safer conception services would improve their partnership dynamics by fostering a supportive and respectful environment for them to achieve their reproductive goals.

Recommendations on delivery of safer conception counseling—HCPs reported that a formal safer conception training program for HCPs is needed as “there is no policy or tool in place to handle” and support HCPs in assisting HIV-affected couples in achieving their reproductive goals. The majority of HIV-affected individuals and couples reported that they would prefer free “universal access” to safer conception counseling in order to enhance their engagement with the healthcare system; otherwise, the lack of access to safer conception counseling “will impact negatively on [HIV] care and treatment”. On the other hand, some thought “if it is good and affordable [they] will easily pay for the services”.

The majority of HIV-affected individuals and couples support the delivery of safer conception counseling in individualized sessions, which would allow them to “ask questions [they] would not ask if there are many people”. On the other hand, some HIV-affected individuals and couples felt that information should also be delivered in large community-based sessions, such as a baraza (i.e., an organized meeting of thought leaders in the community), “to inform everyone [so that] information [reaches] a lot of people”. Participants expected HCPs to be the primary bearers of safer conception counseling messages because “they play a very significant role in disseminating that information to the people”.

Perspectives after counseling with the Safer Conception Counseling Toolkit (phase two)

Fears related to conception in HIV-affected individuals and couples—HIV-affected individuals and couples believe that the method brochures contained in the Toolkit may help to reduce the fear associated with reproduction in HIV-affected partnerships, specifically the concern of HIV transmission (Table 2 – *Representative Quotes*). HIV-affected couples felt the content of the brochures gave them “courage to face the fear of the unknown ... and face the future without any fear”. The concerns with reproduction in HIV-

affected partnerships are most important in serodiscordant partnerships, “especially for partners who are HIV negative”.

Recommendations on delivery of safer conception counseling—HCPs reported that routine provision of safer conception counseling also promoted maternal and child health by enhancing the couples’ reproductive autonomy and understanding that information and services exist so that “HIV will not be transmitted to the baby”. HCPs and HIV-affected individuals and couples also supported the delivery of safer conception counseling during a couples-based session, because they believed it would be most beneficial for couples to receive the message and ask questions together. Overwhelmingly, HIV-affected individuals reported a desire to receive safer conception counseling and assessment of their reproductive intentions at routine HIV care and treatment visits. Some HCPs suggested that messages about safer conception counseling could be provided during the HIV post-testing counseling visit, “especially if they are in a discordant relationship”. This is “the time when understanding each other is difficult so if you get proper counseling then it will make your life healthy”. They thought that this would help to ensure that all HIV-affected individuals of reproductive age would receive the information, including those who had not considered getting pregnant. Despite support and recommendations for the delivery of safer conception counseling, HCPs reported that the challenge with this approach is that counseling may require more time during a routine clinical visit. For example, in government antenatal clinics with fewer clinical staff and many clients, “one might not get the time to offer [these] preconception services”.

HIV-affected individuals asserted that community members should also be engaged in increasing the awareness of safer conception counseling services through radio announcements, newspapers, and community health workers. However, the general perception among participants is that HCPs should remain the primary point of information, and community extension workers could be used to deliver the messages in the community.

Discussion

HIV-affected individuals and couples experience fears related to HIV transmission with attempted conception. These fears are exacerbated by HIV-related stigma, negative attitudes toward HIV-affected couples, and the lack of knowledge of HCPs and HIV-affected individuals and couples on the safer methods of conception that may allow them to have children while limiting the risk of HIV transmission.

HIV-affected individuals and couples, and HCPs overwhelmingly believe that counseling and education on safer conception services should be provided by HCPs to HIV-affected individuals and couples at the time they initiate HIV care, and at routine HIV care and treatment. Frequent counseling at the time of clinical visits serves as a reminder that information and support are available when, and if, they are needed. In addition to HCPs, other methods of delivery of safer conception counseling include the use of community extension workers, barazas, public radio announcements, and print media.

Future evaluations and implementation of the Safer Conception Counseling Toolkit

It is our expectation that the Toolkit will be further evaluated in urban and rural environments to support its implementation as a component of comprehensive reproductive healthcare services for HIV-affected individuals and couples. As the Safer Conception Counseling Toolkit is evaluated in various settings and communities, challenges to implementation should be considered. All of the safer conception strategies included in the counseling guide and brochures may not be readily affordable, available, or accessible to HIV-affected couples in Kenya or other regions of sub-Saharan Africa (SSA). Nevertheless, information on all safer conception strategies should be made widely available. Over time, technologies may become more affordable, which may enhance the availability and accessibility of these services.

The integration of the Toolkit into routine HIV care and treatment may help to decrease the fears HIV-affected individuals and couples experience as they navigate the healthcare system to realize their reproductive goals. Implementation and training of HCPs with the Toolkit may help fill the gap in comprehensive reproductive care services for HIV-affected individuals and couples desiring children in Kenya.

HCPs may also experience time constraints with the delivery of safer conception education and counseling messages during routine clinical visits. This challenge may be overcome, however, with increasing familiarity with the materials and confidence among HCPs over time. Consideration should be given to a focused safer conception education and counseling visit for HIV-affected individuals and couples after HIV diagnosis and/or when they express a desire for children in order to circumvent the time constraints encountered during a routine clinical visit.

Strengths and limitations

Although this study was conducted in Kisumu, Kenya, where the HIV prevalence is the highest in the country, the findings of our pilot study may be applicable to other regions of SSA, given the noted reproductive desires among HIV-affected individuals and couples in the region (Dunkle et al., 2008; Wekesa & Coast, 2014). To our knowledge, this is the first study to develop a Safer Conception Counseling Toolkit intended for HCPs and HIV-affected individuals and couples planning their families in SSA.

Conclusions

Our hope is that the Toolkit will help to close the gap in clinical services that HIV-affected individuals and couples need to fulfill their reproductive goals while preventing sexual and perinatal HIV transmission in SSA (Goggin et al., 2014), where social identity and value are inextricably linked to reproduction, irrespective of HIV status (Finocchiaro-Kessler et al., 2014; Goggin et al., 2014; Schwartz et al., 2014). The Toolkit may help support the reproductive goals of HIV-affected individuals and couples while empowering them with knowledge to make informed reproductive health decisions.

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Figure 1. FGD and IDI participants. Note: HCP, healthcare provider; FGD, focus group discussion; IDI, in-depth interview.

Table 1

Representative quotes before counseling with the Safer Conception Counseling Toolkit.

Theme	Representative quote
Fears related to reproduction in HIV-affected couples	<p>“They have always said that if you get a child in a HIV-affected relationship, the child will also get the virus.” (IDI, HIV-affected woman, age 47)</p> <p>“A good number of them say that the child will automatically come out positive because the mother is positive.” (IDI, HIV-affected man, age 26)</p> <p>“I think a bigger percentage of our community is illiterate and they normally believe that when you are infected you’ll give birth to a baby with poor health and all that.” (FGD, HCP, age 29)</p>
Perceived HIV-related stigma	<p>“The villagers therefore don’t know anything on discordance. In case the man is sick, people will think that the woman is also sick. There are people who have declared that someone cannot conceive in case he or she is positive. They also believe that the discordant couples cannot have children.” (IDI, HIV-affected woman, age 26)</p> <p>“Some would say that since we are all positive, the only option that we have as a couple is to eat and take our drugs while we wait for our death. If we happen to get a child, he or she will definitely be HIV positive and we will eventually die leaving the child as an orphan.” IDI, HIV-affected woman, age 25</p> <p>“They think that once you are affected [/infected/] it is the end of life. There is no need of having children. Why should you have children when you are already sick?” (IDI, HIV-affected man, age 47)</p> <p>“Right now they believe we have a right coz they see those who are positive giving birth to HIV negative kids.” (IDI, HIV-affected woman, age 25)</p> <p>“People who are educated are the ones who believe so. They are the ones who accept that you can still have children as much as you are HIV positive.” (IDI, HIV-affected man, age 27)</p>
Perceptions on safer conception services – Relationship dynamics	<p>“[Safe conception] is important because we will respect each other in the marriage. He will realize that I respect his life. Secondly, my house will have a better future. There will be no diseases coming into the family just because of me. My family will have a good future. I can be sick. However, my husband and children should remain normal. In case they become sick, I will be the one to blame. They will therefore be happy in case they are in good health.” (IDI, HIV-affected woman, age 30)</p> <p>“The reason why I feel that it important to me is because in any relationship, people come together for procreation and children are source of happiness in any union between a man and a woman. So I feel it would be great if that was to happen.” (IDI, HIV-affected man, age 26)</p>
Recommendations on delivery of safer conception counseling	<p>“The healthcare workers can come to the villages, talk to the people one on one or maybe they can just organize a baraza then they inform everyone regardless of someone’s status in the family for [/so that/] the information passes [/reaches/] a lot of people.” (IDI, HIV-affected man, age 26)</p> <p>“The doctor should therefore initiate the discussion and then the patient will then open up to give out information. You cannot just start discussing some of these things before studying the doctor. I therefore believe that the doctor should initiate the conversation. That will encourage me to open up and disclose some of my secrets to him.” (IDI, HIV-affected woman, age 34)</p> <p>“I think it will be good to have a policy at the same time a tool because up to now I don’t think there is a tool in place or a policy in place on the discordant couples about them conceiving. We have some of the clients saying we will put the positive client on drugs, others say the negative client on drugs and at what category under the policy does putting the negative client on ARVs follow?” (FGD, HCP, age 29)</p> <p>“An individual talk is better since I may be able to ask questions I will otherwise not ask if there are many people for fear of exposing your status.” (IDI, HIV-affected woman, age 38)</p>

Table 2

Phase two: representative quotes after counseling with the Safer Conception Counseling Toolkit.

Theme	Representative quote
Fears related to reproduction in HIV-affected couples	<p>“This session is going to reduce the fear we have in our desires of having children yet we fear that we will give birth in unsafe way and infect the child. But now the fear will be reduced that you can conceive and give birth to a healthy child.” (FGD, HIV-affected couples, age 29)</p> <p>“I think in the current world, people know about HIV and in any case someone picks the brochure somewhere, it can help him to explain to other people like the brother & sister who maybe fear going to the doctor but desire children. So I think the brochure itself can guide someone on what to do.” (FGD, HIV-affected women, age 27)</p> <p>“We have our desires of having children, yet we fear that we will give birth in unsafe way and infect the child. But now the fear will be reduced that you can conceive and give birth to a healthy child.” (FGD, HIV-affected couples, age 29)</p>
Recommendations on the delivery of safer conception counseling	<p>“You should tackle it as a couple and not as one individual. Counseling becomes easier if it involves both.” (IDI, HCP, age 31)</p> <p>“Yes. I think when it comes to safer conception I think the healthcare provider or the nurse or a doctor should do so. Yeah not just anyone around.” (FGD, HIV-affected male, age 25)</p> <p>“I can only add that there is no problem when the provider reminds or talks to me about it every time I visit the clinic just like they always ask about condom use. They will also advice on when to conceive and discuss with you what you should do to give birth to a healthy baby.” (FGD, HIV-affected women, age 31)</p> <p>“It is important that they are given these messages once they are tested especially if they are in a discordant relationship.” (IDI, HCP, age 42)</p> <p>“Okay, I can say that is a good practice to teach every time, because if I was told earlier, I might forget but if they repeat it to me tomorrow, it will keep lingering in my mind. I feel that being reminded is good.” (FGD, HIV-affected women, age 40)</p> <p>“Through community based issues like we can use even the community extension workers to deliver the messages door to door.” (IDI, HCP, age 28)</p> <p>“Whether you are positive or not positive you need to have the information on what is available and it should be available to everyone just like my friend said that radio will deliver it to everyone. Those near the radio will listen to what is being said in the radio, so this information should reach each and every person because life because life continues and it means that you either get infected or infection continues.” (FGD, HIV-affected couples, age 46)</p> <p>“The challenge we have is in the antenatal clinics especially the government clinics that we have are have fever staffs and so many clients, sometimes one might not get the time to offer this preconception services because they will be attending to the clients.” (IDI, HCP, age 30)</p>