Children's Mercy Kansas City

SHARE @ Children's Mercy

Manuscripts, Articles, Book Chapters and Other Papers

2-20-2018

Stigma gets in my way: Factors affecting client-provider communication regarding childbearing among people living with HIV in Uganda.

Jolly Beyeza-Kashesya

Rhoda K. Wanyenze

Kathy Goggin Children's Mercy Hospital

Sarah Finocchario-Kessler

Mahlet Atakilt Woldetsadik

See next page for additional authors

Let us know how access to this publication benefits you

Follow this and additional works at: https://scholarlyexchange.childrensmercy.org/papers

Part of the International Public Health Commons, Maternal and Child Health Commons, Public Health Education and Promotion Commons, and the Women's Health Commons

Recommended Citation

Beyeza-Kashesya J, Wanyenze RK, Goggin K, et al. Stigma gets in my way: Factors affecting clientprovider communication regarding childbearing among people living with HIV in Uganda. PLoS One. 2018;13(2):e0192902. Published 2018 Feb 20. doi:10.1371/journal.pone.0192902

This Article is brought to you for free and open access by SHARE @ Children's Mercy. It has been accepted for inclusion in Manuscripts, Articles, Book Chapters and Other Papers by an authorized administrator of SHARE @ Children's Mercy. For more information, please contact hlsteel@cmh.edu.

Creator(s)

Jolly Beyeza-Kashesya, Rhoda K. Wanyenze, Kathy Goggin, Sarah Finocchario-Kessler, Mahlet Atakilt Woldetsadik, Deborah Mindry, Josephine Birungi, and Glenn J. Wagner



Citation: Beyeza-Kashesya J, Wanyenze RK, Goggin K, Finocchario-Kessler S, Woldetsadik MA, Mindry D, et al. (2018) Stigma gets in my way: Factors affecting client-provider communication regarding childbearing among people living with HIV in Uganda. PLoS ONE 13(2): e0192902. https://doi.org/10.1371/journal.pone.0192902

Editor: Viviane D. Lima, British Columbia Centre for Excellence in HIV/AIDS, CANADA

Received: September 5, 2016

Accepted: February 1, 2018

Published: February 20, 2018

Copyright: © 2018 Beyeza-Kashesya et al. This is an open access article distributed under the terms of the <u>Creative Commons Attribution License</u>, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Data Availability Statement: We have consulted with our IRB and since our consent form did not indicate anything about releasing de-identified data for public use or sharing, we cannot do so; Contact: RAND's Human Subjects Protection Committee, Sandy Berry, Chairman, sandra_berry@rand.org.

Funding: This study was funded by the Eunice Kennedy Shriver National Institute of Child Health & Human Development; to The Rand Corporation, **RESEARCH ARTICLE**

Stigma gets in my way: Factors affecting client-provider communication regarding childbearing among people living with HIV in Uganda

Jolly Beyeza-Kashesya^{1©}*, Rhoda K. Wanyenze^{2©}, Kathy Goggin^{3©}, Sarah Finocchario-Kessler^{4©}, Mahlet Atakilt Woldetsadik^{5©}, Deborah Mindry^{6©}, Josephine Birungi^{7©}, Glenn J. Wagner^{5©}

1 Mulago Hospital Department of Obstetrics and Gynaecology, Makerere University College of Health Sciences, Kampala, Uganda, 2 Department of Disease Control and Environmental Health, Makerere University School of Public Health, College of Health Sciences, Kampala, Uganda, 3 Health Services and Outcomes Research, Children's Mercy Hospitals and Clinics, Schools of Medicine and Pharmacy, University of Missouri–Kansas City, Missouri, United States of America, 4 University of Kansas Medical Center, Department of Family Medicine, Kansas City, Missouri, United States of America, 5 RAND Corporation, Santa Monica, California, United States of America, 6 University of California, Los Angeles Center for Culture and Health, Los Angeles, California, United States of America, 7 The AIDS Support Organization, Kampala, Uganda

These authors contributed equally to this work.
* jbeyeza@gmail.com

Abstract

Introduction

Many HIV-affected couples living in sub-Saharan Africa desire to have children, but few quantitative studies have examined support for their childbearing needs. Our study explored client-provider communication about childbearing and safer conception among HIV clients in Uganda.

Methods

400 Ugandan HIV clients in committed relationships and with intentions to conceive were surveyed. Knowledge, attitudes and practices related to childbearing, and use of safer conception methods were assessed, including communication with providers about childbearing needs, the correlates of which were examined with bivariate statistics and logistic multivariate analysis.

Results

75% of the sample was female; 61% were on antiretroviral therapy; and 61% had HIV-negative or unknown status partners. Nearly all (98%) reported the desire to discuss childbearing intentions with their HIV provider; however, only 44% reported such discussions, the minority (28%) of which was initiated by the provider. Issues discussed with HIV providers included: HIV transmission risk to partner (30%), HIV transmission risk to child (30%), and how to prevent transmission to the child (27%); only 8% discussed safer conception methods. Regression analysis showed that those who had communicated with providers about



Grant R01 HD072633, Principal Investigator: Glenn Wagner. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Competing interests: The authors have declared that no competing interests exist.

childbearing were more likely to have been diagnosed with HIV for a longer period [OR (95% CI) = 1.09 (1.03, 1.15)], while greater internalized childbearing stigma was associated with lower odds of this communication [OR (95% CI) = 0.70 (0.49, 0.99)], after controlling for all bivariate correlates and basic demographics.

Conclusions

Communication between HIV clients and providers about childbearing needs is poor and associated with stigma. Innovations to mitigate stigma among clients as well as training to improve health worker communication and skills related to safer conception counseling is needed.

Introduction

Major strides have been achieved in HIV prevention among HIV-affected couples through advocacy for consistent condom use [1] and use of antiretroviral therapy [2] However, in Uganda up to 60% of people living with HIV (PLHIV) desire to have a child [3–6] and one third of discordant couples have gone ahead to produce children [7]; albeit without the assistance of safer conception practices [8, 9].

In resource-limited settings like Uganda, the dilemma between wanting to have children and limiting risks of transmitting HIV (if partner is also HIV-positive) is common among people living with HIV (PLHIV) [3, 7]. In some couples, the desire to have children sometimes overrides fears of transmission, and they practice unprotected sex in an attempt to conceive [7]. In addition, several studies have reported that many couples are not mutually aware of their HIV status [10, 11]. This limits the use of available opportunities of safer conception methods to prevent HIV transmission.

Globally, there has been an increase in awareness of the reproductive rights of PLHIV and the need to promote use of safer conception methods [12-14]; however, due to lack of guidelines and provider training, provision of safer conception counseling is not yet a standard component of health services in Sub Saharan Africa [15]. The use of antiretroviral therapy is known to markedly reduce HIV transmission if suppression is in undetectable levels [16-19] however uptake of and adherence to ART is often suboptimal [20]. In addition, male circumcision [21] has been rolled out in most health care facilities and could act as an added protective method, although its coverage remains very low in most high prevalence countries in sub-Saharan Africa and thus the for need additional methods to reduce transmission risk. Other safer conception methods that are specific to the context of conception and inexpensive (feasible in low resource settings) include Pre-exposure prophylaxis (PrEP), sexually transmitted disease treatment, manual self-insemination, and timed unprotected intercourse during ovulation [13, 22], which reduce the frequency of HIV exposure by limiting unprotected coital acts. However, despite the widespread demand for safer conception services as a global strategy to reduce HIV incidence, the majority of PLHIV need assistance from health workers to understand and effectively use these safer conception methods, including identifying the timing of ovulation [20]. Some studies have reported low self-efficacy to providing SCC among HIVproviders [8, 23, 24], and therefore, HIV clients and their providers often do not discuss the client's childbearing desires or plans prior to pregnancy [25].

Research from sub-Saharan Africa, including Uganda, shows that only 20–40% of clients with fertility intentions discuss these intentions with their HIV providers [25–29]. Up-to-date, childbearing stigma among both the providers and clients muffles the content and depth of discussions about safer conception practices [27, 30–32]. Historically, HIV infection was

viewed as a terminal disease; therefore providers openly discouraged clients from having children for fear of high mortality risks but also to prevent HIV transmission [24, 27, 30–34]. Most HIV programs largely focused on preventing new infections as a core component of HIV care; therefore emphasizing adherence to condom use. After 2001, the US Centers for Disease Control and Prevention (CDC) encouraged providers to offer information and support to HIV-affected couples to explore their reproductive options [35]. Nonetheless, provider judgmental attitudes that increase stigmatization of childbearing continued [27, 30-32]; manifesting in different forms such as failure to provide reproductive health services or coercing PLHIV to accept sterilization [36]. While infringement on the reproductive health rights of PLHIV through coerced sterilization has attracted lawsuits against such health providers [37], sterilization of HIV-positive women at caesarian section delivery continues to be reported [38]. Such practices could create mistrust among PLHIV and deter them from initiating childbearing discussions with providers. Therefore, on the one hand, clients avoid talking with providers due to perceived provider stigma and their own internalized stigma [34, 39–41], on the other hand, low self-efficacy to provide SCC among HIV-providers (often interpreted by patients as denial of service) contributes to the perceived stigma by clients [23, 24, 42].

In Uganda, there is a challenge because reproductive health counseling for PLHIV mostly focuses on contraception and preventing pregnancy [26]. Limited quantitative information exists on whether and how HIV care providers discuss and offer support for the sexual and reproductive health needs of clients who seek childbearing, including the use of safer conception methods. This paper explored the process of initiation of the discussion and correlates of client-provider communication about childbearing and safer conception among HIV clients who desire to have children in Uganda.

Materials and methods

Study setting

The study was conducted at The AIDS Support Organization (TASO) HIV care and treatment sites in Kampala and Jinja, Uganda. TASO is a non-governmental organization founded in 1987 to provide care and support for Ugandans who are either living with or affected by HIV/AIDS. The Kampala site is located next to the Mulago National Referral Hospital and has over 6700 active clients. The Jinja site is located within the Jinja Regional Referral Hospital campus and provides HIV care to over 8000 clients as at June 2016. In addition to ART and counseling services, TASO has well-established family planning and contraception services at its clinics, but has not integrated the routine delivery of safer conception services.

Participants

Clients at the two study clinics were eligible for the study if they were (1) 18 years or older, (2) married or in a committed heterosexual relationship, and (3) reported an intention to conceive a child with their partner within the next 24 months. Only one member of a couple was allowed to participate to ensure the participants were independent of each other. Partner HIV status was not a part of the eligibility criteria since safer conception methods are also relevant to HIV sero-concordant couples for the purpose of limiting risks of super-infection and transmission of resistant virus. The cohort was recruited between May and October of 2013. Recruitment took place primarily during the triage phase when clients registered their attendance at clinic visits. A brief screening was conducted with adult clients by the triage personnel. Those who were likely eligible and expressed interest were referred to the research coordinator for a more thorough screening and consent procedures. After providing written informed consent, participants were administered the baseline survey questionnaire at the clinic premises after the provider consultation and care. Follow-up surveys were scheduled at 6-month intervals for 24 months, or until the participant (or their partner) became pregnant in which case their participation ended after a post-delivery survey was completed. We present analysis from the baseline data. Participants received 15,000 Ush (\$6 USD) for completing each survey. The study protocol was approved by the Institutional Review Boards at Makerere University School of Biomedical Sciences Research and Ethics Committee, RAND, TASO, and the Uganda National Council of Science and Technology.

Measures

All measures were translated (using standard forward and back translation methods) into and administered in Luganda, the most common native language in the study setting. Trained and experienced interviewers used computer-assisted personal interview software to administer the survey.

Demographics. These included: age, sex, education level (whether or not any secondary education had been completed), and monthly income.

Reproductive health history and current fertility intention. Participants reported their number of living children, including with the partner with whom they were trying to conceive, as well as time frame of when they intended to conceive (within the next 0–6, 7–12,13–24 months). Respondents also indicated whether or not they had discussed their childbearing desires with their partner, and expressed a desire to talk with their HIV care providers. In addition, participants reported on their perception of their HIV provider's willingness to discuss childbearing issues, and which provider would be suitable for the discussion. Whether the client or provider initiated the discussion content of discussion was reported.

Health management characteristics. Date of HIV diagnosis was self-reported, and CD4 count and ART status were abstracted from the participant's clinic chart. Perceived quality of life was assessed by asking participants to respond to the question, "How has the quality of your life been during the past 30 days? That is, how have things been going for you?", using a 1 'very good, could hardly be better' to 5 'very bad, could hardly be worse' response format; scores were reversed so that higher scores represent greater quality of life. To assess satisfaction with their HIV care, participants were asked to respond to the question "How satisfied are you with the HIV-related services provided at this clinic?" using a response format that ranged from 1 'very unsatisfied' to 4 'very satisfied'.

Relationship and partner characteristics. These included marital status, whether respondent or partner had other spouses/partners (monogamous or polygamous relationship), HIV status of partner, and partner's knowledge of respondent's HIV status. Control of decision making in the relationship was measured with the 15-item relationship control subscale of the Sexual Relationship Power Scale [43]; respondents were asked to rate their level of agreement with statements from 1 'strongly agree' to 4 'strongly disagree,' a mean item score was calculated, and higher scores represent greater control in decision making within the relationship (Cronbach's alpha = .82).

Psychosocial functioning. Depression was assessed using the 9-item Patient Health Questionnaire (PHQ-9) [44]; each item corresponds to the 9 symptoms assessed in the depression module of the Diagnostics Statistical Manual and is scored on a 0 'never' to 3 'every day' scale of symptom frequency over the past two weeks; the summary score is the sum of the item scores (Cronbach's alpha = .82). Social support was measured with a single item from the ACTG assessment battery [45]; respondents rated their agreement with the statement, "I can count on my family and friends to give me the support I need" using a scale of 1 'strongly

disagree' to 5 'strongly agree'. Internalized HIV stigma was assessed with an 8-item scale developed by Kalichman et al. [46]; examples of items include "being HIV positive makes me feel damaged", "I am ashamed that I am HIV positive", "friends give me the support I need" and "I hide my HIV status from others", with response options ranging from 1 'disagree strongly' to 5 'agree strongly' and a mean item score is calculated (Cronbach's alpha = .75).

Stigma of childbearing among PLHIV. We developed a 2-item scale to measure the respondent's internalized childbearing stigma: respondents were asked to indicate their level of agreement with the following statements, "I feel ashamed for wanting to have a child" and "I feel selfish for wanting to have a child". Response options ranged from 1 'disagree strongly' to 5 'agree strongly; mean item score was computed, and higher scores represent greater internalized childbearing stigma. We developed a single item to measure perceived provider childbearing stigma: respondents were asked to rate their level of agreement on a scale of 1 'disagree strongly' to 5 'agree strongly' with the statement, "Most HIV providers think that HIV-positive clients should not have children".

Data analysis

Descriptive statistics (frequencies, proportions, means, standard deviations, ranges) were used to describe demographic characteristics. Bivariate statistics [2-tailed, independent t-tests for continuous measures that were examined for normality (no transformations were required); Chi Square tests for binary or categorical measures] were used to examine cross-sectional correlates of client discussions with providers about childbearing intentions. Multivariate logistic regression analysis was used to further examine the correlates, with independent variables consisting of basic demographics (age, sex, any secondary education) and variables correlated with the dependent variable (communication with provider about childbearing intentions) in bivariate analysis at the p < .10 level of significance. Because of the exploratory nature of the analysis, we used P<0.10 instead of P<0.05.

Results

Sample characteristics

In total, 400 participants were enrolled (207 at Kampala, 193 at Jinja), the characteristics of whom are listed in <u>Table 1</u>. Three-quarters were female, and 61% were on ART. Less than half (44%) were married, but all others were in a committed relationship. Thirty per cent were in polygamous relationships, and all but one participant reported trying to conceive with just one partner. The majority (79%) reported that their partner was aware that the respondent was HIV-positive; however, nearly one-third (31%) of the respondents did not know their partner's HIV status. Two-thirds (67%) reported that they planned to conceive within 6 months, 24% in 7–12 months from the time of the interview, and 9% within 13–24 months.

Communication with health providers about childbearing intentions

Nearly all (98%) respondents had both discussed having a child with their partner, and expressed a desire to discuss childbearing with their HIV provider, and 94% perceived that their HIV provider would be willing to discuss childbearing issues. Nonetheless, less than half (44%) had discussed their childbearing intentions with an HIV provider; women (46%) did not differ significantly from men (38%) in the discussion of childbearing intentions with a provider (Chi Square = 2.2, p = .135), nor did those who were married (41%) from those who were not (46%; Chi Square = 1.0, p = .310). When asked about the context in which they would like to discuss childbearing with providers, 95% preferred discussing childbearing with

Table 1. Characteristics of people living with HIV desiring to have children.

Characteristics and other variables of the Sample (n = 400)	$M_{aaa}/E_{aaa}/(D_{aaa})$
Variable	Mean/Freq (SD or %)
Demographics	200 (74.00()
Female	299 (74.8%)
Mean age (years)	33.8 (7.5)
Secondary education and above	179/379 (47.2%)
Operates a small business/sells things	194/399 (48.6%)
Salaried job	58/399 (14.5%)
Average monthly income \$40-\$220 USD	292/391 (74.7%)
Health Characteristics	
Mean years since HIV diagnosis	5.5 (4.7)
Mean CD4 count	435.4 (277.3)
On HIV antiretroviral therapy	242/399 (60.7%)
Reproductive health history	
Have had children	354 (88.5%)
Mean number of children (among parents)	3.2 (2.3)
Have had a child with current partner	195 (48.8%)
Had pregnancy since knowing HIV status	110/284 (38.7%)
Have had difficulty conceiving a child	135 (33.8%)
Relationship/Partner Characteristics	
Marital status:	
Married	175 (43.8%)
In committed relationship	225 (56.2%)
In a polygamous relationship	121 (30.3%)
HIV status of partner with whom trying to conceive	
HIV positive	156 (39%)
HIV negative	122 (30.5%)
Unknown HIV status	122 (30.5%)
Partner knows respondent's HIV status	317 (79.3%)
Childbearing desires, intentions and attitudes	
Time frame for intending/planning to have a child	
(0-6 months)	267/399 (66.9%)
(7–12 months)	97/399 (24.3%)
(13–24 months)	35/399 (8.8%)
Communication with providers about childbearing intentions	
Have discussed their intentions with HIV providers	176 (44%)
Provider initiated the discussion on child bearing	50/176 (28.4%)
Issues discussed with HIV providers	50/170 (20.1/0)
Discussed HIV transmission risk to partner	52/172 (30.2%)
Discussed HIV transmission risk to child	51/172 (29.7%)
Discussed information about PMTCT	
Discussed mormation about PMTCT Discussed safer conception methods	46/172 (26.8%)
<u> </u>	14/172 (8.1%)
Discussion about treatment regimen	7/172 (4.1%)
HIV provider is willing to discuss childbearing	358/ 380 (94.2%)

https://doi.org/10.1371/journal.pone.0192902.t001

an HIV provider compared to a family planning provider (5%) or traditional healer (none); among providers at the HIV clinic, 60% preferred to discuss childbearing with a counselor, while 30% preferred to discuss childbearing with a doctor, and only 8% preferred a nurse.

Among those who had discussed childbearing, a minority (28%) reported that their provider had initiated the discussion. Among those who had discussed childbearing with their provider, the most common issues that were discussed included: HIV transmission risk to partner (30%), HIV transmission risk to child (30%), and information about prevention of mother-to-child transmission (PMTCT; 27%); only 8% discussed safer conception methods (Table 1).

Correlates of communication with HIV providers about childbearing intentions

Table 2 lists the results of the bivariate correlates of communication with HIV providers about childbearing intentions. Greater time since HIV diagnosis (p < 0.001), greater perceived quality of life (p < 0.01), and having an HIV-positive partner (Chi square = 6.5, p < 0.05) were significantly associated with having discussed childbearing intentions with a provider. Greater internalized HIV stigma (p < 0.001) and internalized childbearing stigma (p < .05) were both associated with not having discussed childbearing intentions with providers, and these two types of stigma were also correlated with each other (p < .001); perceived provider stigma of childbearing was unrelated to childbearing discussions with providers, but perceived provider stigma was positively correlated with internalized childbearing stigma (p < .001).

<u>Table 3</u> shows the results of the multivariate logistic regression analysis of factors that influenced communication with HIV providers. Respondents with greater internalized

Variable	Discussed with provider (n = 176)	Did not discuss with provider (n = 224)	Test Stat. (Chi-sqr. /t test)	<i>p</i> value
Demographics				
Age	33.7	33.8	0.193	0.847
Female Sex (%)	78.4	71.9	2.230	0.135
Has any secondary Education (%)	51.8	43.7	2.483	0.115
Health Management				
CD4 cell count	453	421	1.133	0.258
Current on ART (%)	63.1	58.7	0.771	0.380
Length of time since diagnosis (months)	78.4	56.3	3.936	< 0.001
Satisfaction with HIV related services	3.80	3.80	1.930	0.587
Quality of life	3.8	3.6	3.174	0.002
Relationship/Partner				
Decision making power in relationship	2.61	2.59	0.316	0.753
Married (%)	40.9	46.0	1.031	0.310
In a polygamous relationship (%)	30.7	29.9	0.028	0.868
Has children (%)	86.4	90.2	1.409	0.235
Has children with conception partner (%)	47.2	50.0	0.318	0.573
Number of children	3.1	3.2	0.412	0.681
Partner is HIV positive (%)	46.0	33.5	6.515	0.011
Partner knows respondent's HIV status (%)	83.5	75.9	3.489	0.062
Psychosocial well-being				
Depression	3.16	3.46	0.918	0.359
Social support	3.72	3.48	1.851	0.065
Internalized HIV stigma	2.13	2.40	3.378	0.001
Childbearing Stigma				
Internalized childbearing stigma	1.19	1.33	2.018	0.036
Perceived provider childbearing stigma	2.12	2.13	0.118	0.906

https://doi.org/10.1371/journal.pone.0192902.t002

Variable	OR (95% CI)	<i>p</i> value
Background and Demographics		
Age	0.99 (0.95, 1.03)	.544
Female Sex	1.46 (0.83, 2.13)	.193
Has any secondary education	1.38 (0.89, 2.17)	.152
Length of time since diagnosis (months)	1.09 (1.03, 1.15)	.002
Relationship/Partner		
Partner is HIV positive	1.32 (0.81, 2.13)	.261
Partner knows respondent's HIV status	1.30 (0.70, 2.40)	.409
Psychosocial well-being		
Social support	1.14 (0.95, 1.36)	.153
Internalized HIV stigma	0.89 (0.65, 1.21)	.462
Childbearing stigma		
Internalized childbearing stigma	0.70 (0.49, .99)	.048

Table 3. Logistic regression of correlates of having discussed childbearing intentions with HIV provider(s).

https://doi.org/10.1371/journal.pone.0192902.t003

childbearing stigma were less likely to discuss their childbearing intentions with providers [OR (95% CI) = 0.70 (0.49, .99)], while those who had communicated with providers about childbearing had been diagnosed with HIV for a longer period of time [OR (95% CI) = 1.09 (1.03, 1.15)]. The C statistic was equal to 0.662, suggesting that the model is a good fit to the data.

Discussion

This study assessed client-provider communication about childbearing and its correlates among HIV infected individuals in care. While nearly all respondents expressed a desire to talk with their HIV provider about childbearing, less than half had done so. Our findings revealed that internalized stigma regarding both HIV and childbearing, but particularly regarding childbearing, were key barriers to communication between clients and providers about childbearing intentions. HIV clients who wanted to better understand how to prevent HIV transmission during attempts to conceive struggled to communicate with their health workers about childbearing intentions.

Although somewhat higher than the 20-40% reported in other studies [8, 27-29, 47, 48], our finding show that just under half of the sample had discussed their fertility intentions with providers, which reflects an unmet need for patient-provider communication about childbearing and HIV. Our data revealed that internalized stigma regarding childbearing may serve as a particularly key barrier to this communication. Internalized stigma regarding childbearing could be a result of experiences and perceptions of the judgmental attitudes of health workers, family and community who consider childbearing to be inappropriate for PLHIV [39, 40]. Similarly, provider stigma and judgmental attitudes amongst health workers has been shown to hinder provider discussion of safer conception methods with their clients [5, 23, 41, 44, 49, 50]. Studies have reported that childbearing stigma among both the providers and clients alike stifles both the content and depth of discussions about safer conception practices [27, 30-32]. Moreover, among respondents who discussed with providers, under one third talked about the risk of HIV transmission to partner, 30% discussed transmission to child and only 8% discussed safer conception methods. Conversely, other studies showed that low self-efficacy to provide SCC among HIV-providers could be a big contributor to the perceived stigma by clients [23, 24, 42]. It is therefore not surprising that among those who had discussed childbearing needs with providers, such communication was usually initiated by the client and not the

provider, and these discussions rarely ever included instruction on how to use safer conception methods. However it is surprising that perceived provider stigma of childbearing was unrelated to client communication about childbearing needs with their provider, even though internalized childbearing stigma was positively correlated with perceived provider stigma.

Another form of internalized stigma, that being stigma associated with being HIV-infected, was also negatively correlated with having had discussed childbearing desires with providers in the bivariate analysis. Internalized HIV stigma has been identified as a key impediment to health seeking behaviors in other research [51, 52], so it is not surprising that stigma was a barrier to clients seeking childbearing support from providers, particularly if they perceive childbearing by PLHIV to be inappropriate or shameful. If a person feels shameful about their HIV status they may be more likely to believe that their desires for having a child are inappropriate because of their HIV status, as suggested by our data showing a correlation between HIV and childbearing internalized stigma, and thus less likely to discuss such desires with their providers.

Furthermore, our study shows that the clients who had known of their HIV status for a longer period of time were more likely to communicate with HIV providers about childbearing. Although not measured in this study, clients who had known their HIV diagnosis for a longer period of time may have also been in HIV care longer. This may imply that as the clients have more time to develop a rapport and to trust and become comfortable with their providers, they may be better able to overcome any perceived provider stigma and to communicate and articulate their childbearing desires. Similarly, for clients who have been in care longer, providers may interact with such clients in ways that reflect greater trust in and respect for client autonomy, which could lead to clients being comfortable to discuss fertility intentions [53].

Nearly all clients preferred discussing childbearing issues with HIV counselors, rather than family planning providers. In Uganda, this becomes challenging because HIV counselors are largely from social sciences background and have been trained to offer various kinds of HIV care but are not always grounded in other medical care including family planning. Furthermore, the current Ugandan family planning services for PLHIV have limited or no services for those clients who wish to conceive children.

Therefore, it becomes problematic when respondents prefer to discuss childbearing with counselors (rather than doctors or nurses) who typically are not medically trained and not conversant with fertility issues such as the timing of ovulation cycles. Counseling clients on childbearing and how to navigate components of family planning, including use of safer conception methods, warrants specialized training for health workers. However, this opportunity could be harnessed by training counselors to handle the initial childbearing discussions and sessions of navigating through risk reduction methods such as ART adherence, viral load suppression, STI screening and treatment which are imperative additions to other safer conception practices. Then, the counselors would refer the clients to doctors and nurses to handle the more medical methods of ovulation determination.

Clients rely on health providers for knowledge and guidance on how to conceive safely [3]. Moreover, nearly all participants in this study expressed a desire to discuss their childbearing needs with their providers, making it imperative that health workers become comfortable with and acquire the skills to counsel clients about safer conception and methods that can be used to promote safe childbearing. In our research with providers of HIV clients in Uganda, providers expressed a reluctance to discuss fertility desires with clients, despite a yearning to be able to provide safer conception counseling [23]. Provider reluctance to offer safer conception counseling was attributed to the absence of established policy guidelines, recommendations, training and counseling tools from the Ministry of Health for facilitating safer conception counseling.

Limitations of the study

Although our analysis focused on communication between clients and providers, we relied solely on data from the client regarding whether such communication took place, as we had no data from the client's provider regarding whether such communication took place. Furthermore, we relied on self-report, which is subject to recall and social desirability biases, rather than objective methods such as direct observation or audio-recordings. Other measurement limitations include our use of single item measures for constructs such as social support, provider stigma of childbearing, and satisfaction with care; use of more comprehensive, standardized measures would strengthen our ability to assess the relationships between these constructs and client communication of childbearing desires. In addition, our dataset did not have a variable to confirm clients' own provider stigma as an influence to these discussions. However, the fact that clients responded with 'the majority of HIV-care providers' would suggest that their own HIV-care providers are alluded to. Lastly, communication is a behavior that may change over time. This paper reports baseline cross-sectional data, but when the study is completed we will be able to use the longitudinal data to assess whether communication between participants and their providers about childbearing intentions improved over time.

Conclusions

In this sample of PLHIV with intentions to conceive, just less than half had discussed these intentions with their HIV providers. Most discussions about childbearing were initiated by clients, rather than their providers, and a minority included discussion of safer conception methods. Clients' internalized childbearing stigma was a key barrier to their communicating with providers about childbearing intentions. Innovations to mitigate childbearing stigma among clients as well as training to improve health worker communication and family planning skills are critically needed. This would improve provider-client communication about family planning and especially safer conception among those that desire to conceive, and could help reduce transmission of HIV (in serodiscordant couples) or drug resistant viral strains (in concordant couples), as well as promote pregnancy and PMTCT (prevention of mother-to-child transmission) care management following conception.

Acknowledgments

We acknowledge Jimmy Mayatsa and Christopher Tumwine for diligence in coordinating and interviewing clients; and the leadership at TASO Mulago and TASO Jinja who facilitated the study.

Author Contributions

- **Conceptualization:** Jolly Beyeza-Kashesya, Rhoda K. Wanyenze, Kathy Goggin, Sarah Finocchario-Kessler, Deborah Mindry, Glenn J. Wagner.
- Formal analysis: Jolly Beyeza-Kashesya, Rhoda K. Wanyenze, Kathy Goggin, Sarah Finocchario-Kessler, Glenn J. Wagner.
- Funding acquisition: Glenn J. Wagner.

Investigation: Jolly Beyeza-Kashesya, Rhoda K. Wanyenze, Glenn J. Wagner.

Methodology: Jolly Beyeza-Kashesya, Rhoda K. Wanyenze, Kathy Goggin, Sarah Finocchario-Kessler, Deborah Mindry.

Project administration: Rhoda K. Wanyenze, Glenn J. Wagner.

Supervision: Rhoda K. Wanyenze, Josephine Birungi, Glenn J. Wagner.

- Writing original draft: Jolly Beyeza-Kashesya, Rhoda K. Wanyenze, Kathy Goggin, Sarah Finocchario-Kessler, Mahlet Atakilt Woldetsadik, Deborah Mindry, Josephine Birungi, Glenn J. Wagner.
- Writing review & editing: Jolly Beyeza-Kashesya, Rhoda K. Wanyenze, Kathy Goggin, Sarah Finocchario-Kessler, Mahlet Atakilt Woldetsadik, Deborah Mindry, Josephine Birungi, Glenn J. Wagner.

References

- Lyles CM, Kay LS, Crepaz N, Herbst JH, Passin WF, Kim AS, et al. Best-evidence interventions: findings from a systematic review of HIV behavioral interventions for US populations at high risk, 2000– 2004. American journal of public health. 2007; 97(1):133–43. Epub 2006/12/02. https://doi.org/10.2105/ AJPH.2005.076182 PMID: 17138920; PubMed Central PMCID: PMCPMC1716236.
- Cohen MS, Chen YQ, McCauley M, Gamble T, Hosseinipour MC, Kumarasamy N, et al. Prevention of HIV-1 infection with early antiretroviral therapy. The New England journal of medicine. 2011; 365 (6):493–505. Epub 2011/07/20. https://doi.org/10.1056/NEJMoa1105243 PMID: 21767103; PubMed Central PMCID: PMCPMC3200068.
- Beyeza-Kashesya J, Kaharuza F, Mirembe F, Neema S, Ekstrom AM, Kulane A. The dilemma of safe sex and having children: challenges facing HIV sero-discordant couples in Uganda. African health sciences. 2009; 9(1):2–12. Epub 2009/03/01. PMID: 20842236; PubMed Central PMCID: PMCPMC2932519.
- Kakaire O, Osinde MO, Kaye DK. Factors that predict fertility desires for people living with HIV infection at a support and treatment centre in Kabale, Uganda. Reprod Health. 2010; 7:27. Epub 2010/10/13. https://doi.org/10.1186/1742-4755-7-27 PMID: 20937095; PubMed Central PMCID: PMCPMC2964526.
- Wagner G, Linnemayr S, Kityo C, Mugyenyi P. Factors associated with intention to conceive and its communication to providers among HIV clients in Uganda. Maternal and child health journal. 2012; 16 (2):510–8. Epub 2011/03/02. https://doi.org/10.1007/s10995-011-0761-5 PMID: 21359828.
- Matovu JK, Makumbi F, Wanyenze RK, Serwadda D. Determinants of fertility desire among married or cohabiting individuals in Rakai, Uganda: a cross-sectional study. Reprod Health. 2017; 14(1):2. Epub 2017/01/11. https://doi.org/10.1186/s12978-016-0272-3 PMID: 28069056; PubMed Central PMCID: PMCPMC5223449.
- Beyeza-Kashesya J, Ekström AM, Kaharuza F, Mirembe F, Neema S, Kulane A. My partner wants a child: Determinants of the desire for children among mutually disclosed sero-discordant couples attending HIV/AIDS care in Uganda. BMC Public Health 2010, 10:247 https://doi.org/10.1186/1471-2458-10-247 PMID: 20465794
- Finocchario-Kessler S, Wanyenze R, Mindry D, Beyeza-Kashesya J, Goggin K, Nabiryo C, et al. "I may not say we really have a method, it is gambling work": knowledge and acceptability of safer conception methods among providers and HIV clients in Uganda. Health care for women international. 2014; 35(7– 9):896–917. Epub 2014/06/06. https://doi.org/10.1080/07399332.2014.924520 PMID: 24902120; PubMed Central PMCID: PMCPMC4150744.
- Wagner GJ, Linnemayr S, Goggin K, Mindry D, Beyeza-Kashesya J, Finocchario-Kessler S, et al. Prevalence and Correlates of Use of Safer Conception Methods in a Prospective Cohort of Ugandan HIV-Affected Couples with Fertility Intentions. AIDS and behavior. 2017; 21(8):2479–87. Epub 2017/02/24. https://doi.org/10.1007/s10461-017-1732-7 PMID: 28229244; PubMed Central PMCID: PMCPMC5536997.
- Medley A, Garcia-Moreno C, McGill S, Maman S. Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother-to-child transmission programmes. Bull World Health Organ. 2004; 82(4):299–307. PMID: 15259260
- Rujumba J NS, Byamugisha R, Tylleskar T, Tunwine JK, Heggenhougen HK. "Telling my husband I have HIV is too heavy to come out of my mouth": Pregnant women's disclosure experiences and support needs following antenatal HIV testing in eastern Uganda. International Journal of AIDS Society. 2012; 15(2):17,429.
- **12.** Uganda MOH. The National Policy Guidelines and Service Standards for Sexual and Reproductive Health and Rights, Reproductive Health Division. 2012.
- Matthews LT, Mukherjee JS. Strategies for harm reduction among HIV-affected couples who want to conceive. AIDS and behavior. 2009; 13 Suppl 1:5–11. Epub 2009/04/07. https://doi.org/10.1007/ s10461-009-9551-0 PMID: 19347575.

- Mmeje O, van der Poel S, Workneh M, Njoroge B, Bukusi E, Cohen CR. Achieving pregnancy safely: perspectives on timed vaginal insemination among HIV-serodiscordant couples and health-care providers in Kisumu, Kenya. AIDS care. 2015; 27(1):10–6. Epub 2014/08/12. https://doi.org/10.1080/ 09540121.2014.946385 PMID: 25105422; PubMed Central PMCID: PMCPMC4221525.
- Steiner RJ, Black V, Rees H, Schwartz SR. Low Receipt and Uptake of Safer Conception Messages in Routine HIV Care: Findings From a Prospective Cohort of Women Living With HIV in South Africa. JAIDS Journal of Acquired Immune Deficiency Syndromes. 2016; 72(1):105–13. https://doi.org/10. 1097/QAI.00000000000945 PMID: 26855247
- Cohen MS, Chen YQ, McCauley M, Gamble T, Hosseinipour MC, Kumarasamy N, et al. Prevention of HIV-1 infection with early antiretroviral therapy. N Engl J Med. 2011; 365:493–505. <u>https://doi.org/10.1056/NEJMoa1105243</u> PMID: 21767103
- 17. Matthews LT, Baeten JM, Celum C, Bangsberg DR. Periconception preexposure prophylaxis to prevent HIV transmission: benefits, risks, and challenges to implementation. AIDS. 2010; 24:1975–82. https://doi.org/10.1097/QAD.0b013e32833bedeb PMID: 20679759
- Lampe MA, Smith DK, Anderson GJ, Edwards AE, Nesheim SR. Achieving safe conception in HIV-discordant couples: the potential role of oral preexposure prophylaxis (PrEP) in the United States. Am J Obstet Gynecol. 2011; 204:481–8.
- Matthews LT, Smit JA, Cu-Uvin S, Cohan D. Antiretrovirals and safer conception for HIV-serodiscordant couples. Curr Opin HIV AIDS. 2012; 7:569–78. https://doi.org/10.1097/COH.0b013e328358bac9 PMID: 23032734
- Matthews LT, Beyeza-Kashesya J, Cooke I, Davies N, Heffron R, Kaida A, et al. Consensus statement: Supporting Safer Conception and Pregnancy For Men And Women Living with and Affected by HIV. AIDS and behavior. 2017. Epub 2017/05/16. https://doi.org/10.1007/s10461-017-1777-7 PMID: 28501964; PubMed Central PMCID: PMCPMC5683943.
- Gray RH, Kigozi G, Serwadda D, Makumbi F, Watya S, Nalugoda F, et al. Male circumcision for HIV prevention in men in Rakai, Uganda: a randomised trial. Lancet. 2007; 369:657–66. <u>https://doi.org/10.1016/S0140-6736(07)60313-4 PMID: 17321311</u>
- Barreiro P, del Romero J, Leal M, Hernando V, Asencio R, de Mendoza C, et al. Natural pregnancies in HIV-serodiscordant couples receiving successful antiretroviral therapy. JAIDS Journal of Acquired Immune Deficiency Syndromes. 2006; 43(3):324–6. https://doi.org/10.1097/01.qai.0000243091.40490. fd PMID: 17003695
- Goggin K, Finocchario-Kessler S, Staggs V, Woldetsadik MA, Wanyenze RK, Beyeza-Kashesya J, et al. Attitudes, Knowledge, and Correlates of Self-Efficacy for the Provision of Safer Conception Counseling Among Ugandan HIV Providers. AIDS patient care and STDs. 2015; 29(12):651–60. Epub 2015/11/21. https://doi.org/10.1089/apc.2015.0089 PMID: 26588429; PubMed Central PMCID: PMCPMC4684655.
- Goggin K, Mindry D, Beyeza-Kashesya J, Finocchario-Kessler S, Wanyenze R, Nabiryo C, et al. "Our hands are tied up": current state of safer conception services suggests the need for an integrated care model. Health care for women international. 2014; 35(7–9):990–1009. Epub 2014/06/06. https://doi.org/ 10.1080/07399332.2014.920023 PMID: 24901882; PubMed Central PMCID: PMCPMC4150838.
- Schwartz SR, Mehta SH, Taha TE, Rees HV, Venter F, Black V. High pregnancy intentions and missed opportunities for patient-provider communication about fertility in a South African cohort of HIV-positive women on antiretroviral therapy. AIDS Behav. 2012; 16:69–78. <u>https://doi.org/10.1007/s10461-011-</u> 9981-3 PMID: 21656145
- Finocchario-Kessler S, Bastos FI, Malta M, Anderson J, Goggin K, Sweat MD, et al. Discussing childbearing with HIV-infected women of reproductive age in clinical care: a comparison of Brazil and the US. AIDS Behav. 2012; 16(1):99–107. https://doi.org/10.1007/s10461-011-9906-1 PMID: 21359541
- Mindry D, Wagner G, Lake J, Smith A, Linnemayr S, Quinn M, et al. Fertility desires among HIV-infected men and women in Los Angeles County: client needs and provider perspectives. Matern Child Health J. 2013; 17:593–600. https://doi.org/10.1007/s10995-012-1035-6 PMID: 22562286
- Squires KE, Hodder SL, Feinberg J, Bridge DA, Abrams S, Storfer SP, et al. Health needs of HIVinfected women in the United States: insights from the women living positive survey. AIDS Patient Care STDS. 2011; 25:279–85. https://doi.org/10.1089/apc.2010.0228 PMID: 21446785
- 29. Finocchario-Kessler S, Dariotis JK, Sweat MD, Trent ME, Keller JM, Hafeez Q, et al. Do HIV-infected women want to discuss reproductive plans with providers, and are those conversations occurring? AIDS Patient Care STDS. 2010; 24:317–23. https://doi.org/10.1089/apc.2009.0293 PMID: 20482467
- Cooper D, Moodley J, Zweigenthal V, Bekker LG, Shah I, Myer L. Fertility intentions and reproductive health care needs of people living with HIV in Cape Town, South Africa: implications for integrating reproductive health and HIV care services. AIDS Behav. 2009; 13:38–46. https://doi.org/10.1007/ s10461-009-9550-1 PMID: 19343492

- Turan JM, Miller S, Bukusi EA, Sande J, Cohen CR (2008) HIV/AIDS and maternity care in Kenya: how fears of stigma and discrimination affect uptake and provision of labor and delivery services. AIDS Care 20: 938–945. https://doi.org/10.1080/09540120701767224 PMID: 18777222
- 32. Wanyenze RK, Wagner GJ, Tumwesigye NM, Nanyonga M, Wabwire-Mangen F, Kamya MR. Fertility and contraceptive decision-making and support for HIV infected individuals: client and provider experiences and perceptions at two HIV clinics in Uganda. BMC Public Health. 2013; 13:98. <u>https://doi.org/ 10.1186/1471-2458-13-98 PMID: 23374175</u>
- Moodley J, Cooper D, Mantell JE, Stern E. Health care provider perspectives on pregnancy and parenting in HIV-positive individuals in South Africa. BMC health services research. 2014; 14:384. Epub 2014/ 09/13. https://doi.org/10.1186/1472-6963-14-384 PMID: 25212461; PubMed Central PMCID: PMCPMC4167138.
- Agadjanian V, Hayford SR. PMTCT, HAART, and childbearing in Mozambique: an institutional perspective. AIDS and behavior. 2009; 13 Suppl 1:103–12. Epub 2009/03/28. https://doi.org/10.1007/s10461-009-9535-0 PMID: 19326206; PubMed Central PMCID: PMCPMC2836932.
- CDC. Revised guidelines for HIV counseling, testing, and referral. 2001 Nov 9. Report No.: 1057–5987 (Print) 1057–5987 Contract No.: Rr-19.
- Steiner RJ, Finocchario-Kessler S, Dariotis JK. Engaging HIV-care providers in conversations with their reproductive-age patients about fertility desires and intentions: a historical reviewing of the HIV epidemic in the United States. Am J Public Health. 2013; 103:1357–66. https://doi.org/10.2105/AJPH. 2013.301265 PMID: 23763424
- **37.** ReNair P. "Litigating against the Forced Sterilization of HIV-Positive Women: Recent Developments in Chile and Namibia". Harvard Human Rights Journal. 2010; 23(1):223–31.
- Strode A, Mthembu S, and Essack Z. "She made up a choice for me": 22 HIV-positive women's experiences of involuntary sterilization in two South African provinces. Reproductive Health Matters. 2012; 20 (39S):61–9.
- Myer L, Morroni C, Cooper D. Community attitudes towards sexual activity and childbearing by HIV-positive people in South Africa. AIDS care. 2006; 18(7):772–6. Epub 2006/09/15. <u>https://doi.org/10.1080/</u> 09540120500409283 PMID: 16971287.
- Nduna M, Farlane L. Women living with HIV in South Africa and their concerns about fertility. AIDS and behavior. 2009; 13 Suppl 1:62–5. Epub 2009/03/21. https://doi.org/10.1007/s10461-009-9545-y PMID: 19301114.
- Cooper D, Moodley J, Zweigenthal V, Bekker LG, Shah I, Myer L. Fertility intentions and reproductive health care needs of people living with HIV in Cape Town, South Africa: implications for integrating reproductive health and HIV care services. AIDS and behavior. 2009; 13 Suppl 1:38–46. Epub 2009/04/ 04. https://doi.org/10.1007/s10461-009-9550-1 PMID: 19343492.
- Gruskin S, Firestone R, MacCarthy S, Ferguson L. HIV and pregnancy intentions: Do services adequately respond to women's needs? Am J Public Health. 2008; 98(10):1746–50. https://doi.org/10. 2105/AJPH.2008.137232 PMID: 18703432
- Pulerwitz J, Gortmaker SL, DeJong W. Measuring sexual relationship power in HIV/STD research. Sex Roles. 2000; 42(7–8):637–60.
- Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. Journal of general internal medicine. 2001; 16(9):606–13. Epub 2001/09/15. https://doi.org/10.1046/j.1525-1497.2001.016009606.x PMID: 11556941; PubMed Central PMCID: PMCPMC1495268.
- 45. Chesney M, Ickovics J, Chambers D, Gifford A, Neidig J, Zwickl B, et al. Patient Care Committee & Adherence Working Group of the Outcomes Committee of the Adult AIDS Clinical Trials Group (AACTG). Self-reported adherence to antiretroviral medications among participants in HIV clinical trials: the AACTG adherence instruments. AIDS care. 2000; 12(3):255–66. https://doi.org/10.1080/09540120050042891 PMID: 10928201
- Kalichman SC, Simbayi LC, Jooste S, Toefy Y, Cain D, Cherry C, et al. Development of a brief scale to measure AIDS-related stigma in South Africa. AIDS and behavior. 2005; 9(2):135–43. https://doi.org/ 10.1007/s10461-005-3895-x PMID: 15933833
- 47. Schwartz SR, Mehta SH, Taha TE, Rees HV, Venter F, Black V. High pregnancy intentions and missed opportunities for patient-provider communication about fertility in a South African cohort of HIV-positive women on antiretroviral therapy. AIDS and behavior. 2012; 16(1):69–78. Epub 2011/06/10. https://doi.org/10.1007/s10461-011-9981-3 PMID: 21656145.
- Breitnauer BT, Mmeje O, Njoroge B, Darbes LA, Leddy A, Brown J. Community perceptions of childbearing and use of safer conception strategies among HIV-discordant couples in Kisumu, Kenya. Journal of the International AIDS Society. 2015; 18:19972. Epub 2015/06/17. https://doi.org/10.7448/IAS. 18.1.19972 PMID: 26077644; PubMed Central PMCID: PMCPMC4468054.

- 49. Woldetsadik MA, Goggin K, Staggs VS, Wanyenze RK, Beyeza-Kashesya J, Mindry D, et al. Safer Conception Methods and Counseling: Psychometric Evaluation of New Measures of Attitudes and Beliefs Among HIV Clients and Providers. AIDS and behavior. 2016; 20(6):1370–81. Epub 2015/10/22. https://doi.org/10.1007/s10461-015-1199-3 PMID: 26487299; PubMed Central PMCID: PMCPMC5537001.
- 50. Pulerwitz J, Amaro H, De Jong W, Gortmaker SL, Rudd R. Relationship power, condom use and HIV risk among women in the USA. AIDS care. 2002; 14(6):789–800. Epub 2003/01/04. https://doi.org/10. 1080/0954012021000031868 PMID: 12511212.
- Turan JM, Hatcher AH, Medema-Wijnveen J, Onono M, Miller S, Bukusi EA, et al. The role of HIVrelated stigma in utilization of skilled childbirth services in rural Kenya: a prospective mixed-methods study. PLoS medicine. 2012; 9(8):e1001295. Epub 2012/08/29. https://doi.org/10.1371/journal.pmed. 1001295 PMID: 22927800; PubMed Central PMCID: PMCPMC3424253.
- 52. Finocchario-Kessler S, Dariotis JK, Sweat MD, Trent ME, Keller JM, Hafeez Q, et al. Do HIV-infected women want to discuss reproductive plans with providers, and are those conversations occurring? AIDS patient care and STDs. 2010; 24(5):317–23. Epub 2010/05/21. https://doi.org/10.1089/apc.2009. 0293 PMID: 20482467; PubMed Central PMCID: PMCPMC3120085.
- Agbo S, Rispel LC. Factors influencing reproductive choices of HIV positive individuals attending primary health care facilities in a South African health district. BMC Public Health (2017) 17:540. https:// doi.org/10.1186/s12889-017-4432-3 PMID: 28576142