

Discussing Childbearing with HIV-infected Women of Reproductive Age in Clinical Care: A Comparison of Brazil and the US

Sarah Finocchario-Kessler · F. I. Bastos · M. Malta · J. Anderson ·
K. Goggin · M. Sweat · J. Dariotis · N. Bertoni · D. Kerrigan ·
The Rio Collaborative Group

Published online: 26 February 2011
© Springer Science+Business Media, LLC 2011

Abstract Despite long term access to highly active antiretroviral therapy in Brazil and the US, little is known about women's communication with their HIV provider regarding childbearing or the unmet need for reproductive counseling. We utilized identical survey questions to collect data from HIV-infected women of reproductive age in Rio de Janeiro ($n = 180$) and Baltimore ($n = 181$). We conducted univariate analyses to compare findings between samples of women and multivariate logistic regression to

determine factors associated with childbearing desires, childbearing intentions, and provider communication among the combined sample of women ($n = 361$). Over one-third of women in Rio de Janeiro and nearly one-half of women in Baltimore reported the desire for future childbearing. Nevertheless, the majority of women in clinical care had *not* discussed future childbearing with their HIV provider. Even in countries with an advanced approach to HIV care, we found low and inadequate communication between providers and female patients about childbearing.

Resumen Al pesar del acceso a largo plazo a la terapia antiretroviral en Brasil y en los Estados Unidos, hay poco conocimiento al respecto de la comunicación entre las mujeres viviendo con VIH y sus médicos en cuanto a sus deseos de tener mas hijos o la necesidad del consejo relacionado con la reproducción. En este estudio utilizamos preguntas idénticas en los dos estudios para coleccionar datos entre las mujeres infectadas con VIH de edad reproductiva, 180 viviendo en Rio de Janeiro y 181 viviendo en Baltimore. Condujimos análisis univariados para comparar los resultados entre las muestras de mujeres y la regresión logística multivariada para determinar los factores asociados con los deseos de parir, incluyendo las intenciones para parir y la comunicación de los médicos HIV entre 361 mujeres. Más de un tercio de mujeres en Rio de Janeiro y casi una mitad de las mujeres en Baltimore reportaron que desearon parir en el futuro. Sin embargo, la mayoría de las mujeres no había discutido con sus médicos su deseo de parir en el futuro. Aun en los países con un enfoque avanzado en relacion al atendimento clinic para HIV, nos dimos cuenta que hay una comunicación insuficiente acerca del deseo de tener mas hijos entre los médicos de HIV y sus pacientes.

S. Finocchario-Kessler · M. Sweat · D. Kerrigan
Department of International Health, Johns Hopkins Bloomberg
School of Public Health, Baltimore, MD, USA

F. I. Bastos · M. Malta · N. Bertoni
Oswaldo Cruz Foundation, Rio de Janeiro, Brazil

J. Anderson
Department of Obstetrics & Gynecology,
Johns Hopkins School of Medicine, Baltimore, MD, USA

S. Finocchario-Kessler · K. Goggin
HIV Research Group, University of Missouri-Kansas City,
Kansas City, MO, USA

J. Dariotis
Population, Family & Reproductive Health, Johns Hopkins
Bloomberg School of Public Health, Baltimore, MD, USA

F. I. Bastos
Fulbright/CAPES visiting scholar at Brown University,
Providence, RI, USA

S. Finocchario-Kessler (✉)
4825 Troost Ave, #211b, Kansas City, MO 64110, USA
e-mail: kesslersa@umkc.edu

Keywords Childbearing desires and intentions · Fertility · Pregnancy · HIV clinical care · Reproductive counseling · Preconception counseling · HAART · Baltimore · Rio de Janeiro · Brazil

Introduction

In countries with widespread or emerging access to highly active antiretroviral therapy (HAART), many HIV-infected women and men express the desire to have children [1–8]. Children are highly valued for the emotional fulfillment they provide to parents and the solidifying connection they create between partners [9, 10]. For many young women and men HIV infection occurs prior to or during childbearing and family formation [11] leaving many individuals and couples with questions regarding childbearing and HIV.

After dramatic reductions in the risk of mother-to-child transmission (MTCT) were achieved with HAART, research began to focus on the childbearing desires and intentions among HIV-infected women [12–15]. Some of the earliest quantitative data assessing childbearing desires among HIV-infected women came from the United States in 2001 [6] and Brazil in 2002 [16], where antiretroviral therapy has been accessible since 1996 [17, 18]. Experiencing motherhood holds strong value for women in Brazil and the US, regardless of HIV infection status [1, 2, 19–21]. Access to HAART and its associated improvement of maternal health and lowered infant infection rates, has increased the recognition and demand for the reproductive rights of HIV-infected women [19, 22, 23].

Most recently, researchers have begun to explore high and low resource strategies to minimize HIV transmission to an uninfected partner during conception (e.g., sperm washing (when male is infected) and intrauterine insemination (when female is infected) vs. use of HAART to reduce infectiousness, timed unprotected sex or self-insemination) [24–28]. Individually customized preconception counseling is needed to determine which risk reduction strategy is best indicated given the needs and conditions of both partners [27–29]. In order for such specialized counseling to occur, women must have an opportunity to discuss their childbearing goals with their HIV provider.

The recommendation of nearly all studies related to childbearing and HIV call for comprehensive reproductive health services, including open, nonjudgmental communication about childbearing plans as part of HIV clinical care [1, 2, 4, 8, 16, 29–32]. Little is known, however, about the frequency, quality or content of HIV provider communication regarding childbearing. While data from the US is emerging, very little is known about provider communication regarding childbearing among HIV-infected women in Brazil. Preliminary evidence from a national phone

survey of 700 HIV-infected women age 21 and older in the United States indicated that these discussions are not routine and typically take place too late to be helpful (i.e., after a pregnancy has already occurred) [33]. Among respondents who were or had been pregnant, 57% reported no discussion with their HIV provider regarding pregnancy or appropriate HIV treatments for pregnancy [33]. Recently published data from the sample of HIV-infected women in Baltimore document an unmet need for personalized communication about future reproductive plans among 56% of HIV-infected women who want and intend to have a child, but have not discussed this with their HIV provider [34]. While previous findings from HIV-infected women in Sao Paulo reported limited opportunity for discussing childbearing [32], to our knowledge, data specific to women's communication about pregnancy with their HIV provider in the context of HIV care in Brazil is not available in peer reviewed literature. However, recent qualitative findings from 70 HIV-infected women in Rio de Janeiro (in press) found that with a few positive exceptions, most providers did not communicate at all with their patients about sexual behavior, fertility intentions, or contraception. When providers did make the effort, their form of communication was often closed-ended and perfunctory [35].

The purpose of this paper is threefold: (1) to report on findings from Rio de Janeiro, Brazil regarding childbearing desires and intentions, HIV provider communication about childbearing, and unmet need for reproductive counseling; (2) to compare these recent data from Rio de Janeiro (in a middle-income country) to Baltimore (in a high-income country) which have both had long term access to HIV treatment; and (3) to identify factors associated with childbearing desires, childbearing intentions, and HIV provider communication among the combined sample of reproductive aged women living with HIV.

Methods

Study Setting

This study was conducted in two countries in the Americas: Brazil and the United States. Two urban settings; Rio de Janeiro and Baltimore, were the sites for data collection. HIV prevalence is similar at a national level; 0.6% in Brazil and 0.7% in the United States, but differs significantly in the two urban areas of focus; 0.6% in Rio de Janeiro [36] and 2.5% in Baltimore, Maryland [37]. Fertility levels are comparable between the two countries; total fertility rate of 1.8 in Brazil and 2.1 in the United States [38, 39]. As a result of widespread access to HAART in both countries since 1996, rates of MTCT are low in both areas, with approximately 4.9% of infants born to

HIV-infected mothers perinatally infected in Brazil [40] and less than 2% in the United States [41]. The higher transmission rate in Brazil may be due to concentrations of poverty in urban fringe areas where both HIV-infection and birth rates are higher, access to quality primary care services more difficult, and utilization of prenatal care lower [40].

Procedures

In Rio, people living with HIV attending one of six public primary care reference clinics were referred to the study by their health providers between 2008 and 2009. Eligibility criteria included being between 18 and 50 years of age with a confirmed HIV diagnosis and currently receiving HIV treatment and care at one of the designated public clinics. The larger study explored sexual practices, attitudes and beliefs related to HIV and HAART, experiences with treatment adherence, social stigma, and childbearing. The questionnaire was administered face-to-face by trained interviewers in private rooms, and took about 50 min to complete. Participants provided written informed consent, and all study procedures were approved by the Institutional Review Board. For this analysis, we only retained data from non-pregnant, HIV-infected women between the ages of 18–44 years who had not had a hysterectomy.

In Baltimore, HIV-infected women attending two health clinics associated with an academic medical center were recruited from the waiting room or referred by their provider to participate in the study between August 2007 and April 2008. To be eligible for participation, women had to be current clients of the clinic, between the ages of 15–44, have a confirmed HIV diagnosis, and could not be pregnant nor have had a hysterectomy. Oral informed consent was provided by eligible individuals for their participation in the questionnaire and medical chart review. The audio computer-assisted self interview (ACASI) was used to collect data on a range of demographic and behavioral data, including contraceptive use, childbearing desires and intentions, and communication with HIV providers and partners regarding future childbearing. The cross-sectional survey was completed anonymously by participants, using numeric codes to link survey data to medical chart data. A further description of the study procedures have been previously reported [4]. All procedures were approved by the appropriate Institutional Review Boards.

Measures

The childbearing and communication related measures used in the survey in Rio de Janeiro were the same as those used in the Baltimore survey. The measures were translated from English to Portuguese by bilingual study members

through standard forward and back translation procedures. Demographic data, reproductive history, utilization of contraceptive methods, and frequency of condom use were measured.

The questions regarding childbearing distinguished between the desire to have a child in the future and the intention to do so, recognizing the difference between the two may be larger for people living with HIV [4, 6]. Two separate questions were asked: “Would you like to have a child in the future?” (desire) and “Do you intend to have a child in the future?” (intention). Response options were “yes” or “no.” Communication with HIV providers regarding childbearing was measured by the question, “Have you and your HIV doctor spoken about future pregnancies?” The response options were “yes” or “no.” Unmet need for talking with HIV providers about reproduction was calculated as the proportion of women who responded “yes” to having childbearing desires or intentions, but responded “no” to ever discussing them with their HIV provider. As an indicator of women’s attitude regarding the acceptability of childbearing among women living with HIV, women were asked the extent to which they agree with the statement, “It is okay for a women living with HIV to become pregnant and have a child.” Response options ranged from strongly agree to strongly disagree. The item was later dichotomized into agree or disagree based on the response distribution.

Data Analysis

Data from both surveys were merged using STATA intercooled 2010. Descriptive statistics were used to determine the proportion of women with childbearing desires and intentions who had discussed reproductive plans with their HIV provider. To assess statistically significant differences between the samples of HIV-infected women from Brazil and the United States, we used chi-squared tests for categorical variables, t-tests for continuous variables, and rank-sum test to compare median values. Multivariate logistic regression with backward stepwise selection identified predictors of the main outcomes: childbearing desires, childbearing intentions, and communication with HIV provider about childbearing. The primary independent variables were city (Rio de Janeiro vs. Baltimore) and accepting attitude about childbearing among women with HIV. We adjusted for all significant differences between the two samples ($P < 0.05$) and other theoretically potential confounders including: age, parity, race, relationship status, consistent condom use, partner’s HIV status and CD4 count <200 copies. Variables of marginal significance ($P < 0.10$) were initially retained for consideration and variables of $P < 0.05$ were retained in the final model. Given the bimodal distribution of age

among women in Baltimore, we tested for an interaction effect between age and city on the primary outcomes, but found no evidence of an interaction.

Results

Sample Characteristics

The mean age of women in Rio de Janeiro was 35.3 (18–44 years) and the majority were non-white (76%). Sixty-eight percent were receiving HAART; 8% with a CD4 count <200 copies and 43% with a viral load <400 copies. Over two-thirds of the sample had a committed partner, 50% of whom were married. The average number of children was 2.2, and 81% of women had at least one child. Consistent condom use with one's primary partner was reported by 58% of women and 36% reported their partner's HIV status as negative or unknown.

While the majority of women in both samples were non-white, currently on HAART, and had similar rates of contraception use, there were several important differences between the samples (Table 1). The distribution of age varied significantly. The modal age in Rio de Janeiro was

34 years, while in Baltimore, the age distribution was bimodal with a concentration of participants at both ends of the range (ages 18 and 43) with a mean age of 32.4 years. The significant difference in the proportion of childless women (19% Rio de Janeiro, 35% Baltimore) is largely explained by the low proportion of young women (under 30 years of age) in the Rio de Janeiro sample (17% in Rio de Janeiro, 36% in Baltimore). Among the mothers in the sample, women in Rio de Janeiro had a lower average number of children compared to women in Baltimore (2.2 vs. 2.7, $P = 0.005$). Significantly more HIV-infected women in Rio de Janeiro were married or cohabitating with their partner compared to their peers in Baltimore (89% vs. 63%, $P = 0.01$), and were more likely to report consistent condom use (58% vs. 31%, $P < 0.001$).

Differences between HIV-infected women in Rio de Janeiro and Baltimore in regard to the main study outcomes of (1) desire to have a child, (2) intention to have a child, and (3) communication with HIV provider are outlined in Table 2. Given the need to control for several differences between samples, we utilized multivariate logistic regression analyses to identify variables associated with each of the three key outcome variables listed above in separate regression models listed in Table 3. Finally, Fig. 1

Table 1 Sample characteristics of HIV-infected women from Brazil and the United States, Pearson's chi-square (χ^2)

Characteristics	Rio de Janeiro <i>N</i> = 180 (%)	Baltimore <i>N</i> = 181 (%)	<i>t</i>	χ^2	<i>P</i> value
Mean age (range)	35.3 (18–44)	32.4 (16–44)	3.7		<0.001
% under 30 years	30 (17)	65 (36)		17.3	<0.001
Race/ethnicity					
% Non-white	136 (76)	158 (89)		11.5	0.001
Relationship status					
Single (w/out commit. partner)	71 (39)	83 (46)			
Single (w/commit. partner)	20 (11)	35 (19)		8.9	0.01
Married or living together	89 (50)	63 (35)			
% Childless	35 (19)	63 (35)		10.8	0.01
Average # of children ^a	2.2	2.7	-2.84		0.005
Report contraception/STI protection ^b					
In past 6 months (yes)	105 (79)	120 (74)		1.2	0.27
Consistent condom use w/primary partner ^b					
Always (100%)(yes)	77 (58)	51 (31)		9.4	0.002
Tubal ligation (yes)	32 (18)	41 (22)		1.7	0.20
Partner's HIV status (reported)					
Positive	43 (37)	42 (26)			
Negative	55 (31)	102 (56)		24.4	<0.001
Unknown	18 (5)	18 (11)			
Currently on HAART	122 (68)	127 (70)		0.01	0.91
Median CD4	554	461		6.0	0.014
CD4 < 200	14 (8)	35 (19)		10.3	0.001
Median VL	52	400		3.03	0.082
VL ≤ 400	78 (43)	83 (46)		0.23	0.63

^a Average number of children (excludes those who are childless)

^b Percentage of those who had sex in the past 6 months ($n = 133$ Rio, $n = 162$ Baltimore)

Table 2 Pearson’s chi squared tests comparing future pregnancy desires and intentions, and provider and partner communication about childbearing between HIV-infected women receiving clinical care in Rio de Janeiro and Baltimore

	Rio de Janeiro N = 180	Baltimore N = 181	χ^2	P value
Desire a child in the future				
Yes	65 (36)	99 (55)	13.8	<0.001
Intend to have a child in the future				
Yes	29 (16)	76 (42)	30.6	<0.001
Discussed childbearing w/provider				
Yes	33 (18)	56 (31)	7.5	0.006
Attitudes re: HIV and pregnancy				
Accepting/agree ok	106 (59)	122 (67)	2.8	0.09

Table 3 Multivariate logistic regressions of three key outcome variables: (1) childbearing desires, (2) childbearing intentions, and (3) communication with HIV provider among the combined sample of women, n = 361

Characteristics	AOR (95% CI), P
Desire to have a child	
City (Baltimore)	1.7 (0.97–2.9), 0.064
Age	0.92 (0.88–0.96), <0.001
Parity (childless)	4.9 (2.4–10.), <0.001
Consistent condom use	2.2 (1.2–3.9), 0.008
Accepting attitude re: HIV & preg	1.7 (0.92–2.9), 0.07
Intend to have a child in future	
City (Baltimore)	3.0 (1.5–5.9), 0.001
Age	0.92 (0.88–0.96), <0.001
Parity (childless)	5.9 (2.9–11.8), <0.001
Accepting attitude re: HIV & preg	3.6 (1.7–7.4), 0.001
Communication with Provider about future childbearing	
Age	0.95 (0.92–0.99), 0.011
Race (non-white)	0.47 (0.23–0.94), 0.034
Have committed partner	1.9 (1.01–3.8), 0.046
Want to have a child	1.8 (0.99–3.2), 0.052

Controlling for: age, parity, race, relationship status, partner HIV status, CD4 < 200, and consistent condom use

illustrates the unmet need for reproductive counseling among women in Rio de Janeiro and Baltimore who desire or intend to have a child.

Childbearing Desires and Intentions

Among women in Rio de Janeiro, 36% reported the desire to have a child in the future, however only 16% of women actually intended to have a child. When asked if they felt it was okay for a woman with HIV to become pregnant and have a child, 59% agreed. Childbearing desires and intentions were significantly lower among HIV-infected women

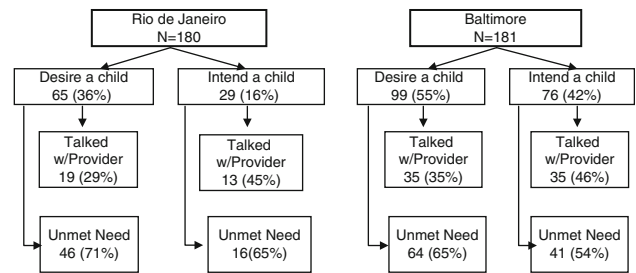


Fig. 1 Provider communication with HIV-infected women stratified by childbearing plans: Identifying unmet need for communication about reproduction

in Rio de Janeiro compared to those in Baltimore (36% vs. 55%, $P < 0.001$ and 16% vs. 42%, $P < 0.001$, respectively). Among all women sampled, agreement that it is okay for HIV-infected women to have children was significantly associated with both the desire and intention to have a child in the future ($\chi^2 = 7.9$, $P = 0.005$ and $\chi^2 = 18.6$, $P < 0.001$, respectively). As a result, this variable was included in the multivariate analyses.

In multivariate analysis, after adjusting for age, parity and other potential confounders, we found no significant differences between women in Rio de Janeiro and Baltimore regarding their desire to have a child. Women in Baltimore, however, were three times more likely to intend to have a child (AOR 3.0 (95% CI 1.5–5.9), $P < 0.001$) compared to women sampled in Rio de Janeiro (Table 3). Attitudes regarding childbearing did not appear to influence desire for a child, however; women with accepting attitudes toward HIV-infected women having children were 3.6 times more likely to intend to have a child compared to women with less accepting attitudes (AOR 3.6 (95% CI 1.7–7.4), 0.001).

Communication About Childbearing

In Rio de Janeiro, among all women sampled, 82% (147/180) had not discussed childbearing with their HIV provider. In fact, 15% of women in Rio de Janeiro reported receiving advice from their HIV provider against becoming pregnant. While the majority of HIV-infected women in both cities had not discussed childbearing with their HIV provider, the proportion reporting a discussion in Rio de Janeiro was significantly lower than the proportion in Baltimore, (18% vs. 31%) $P = 0.006$.

In multivariate analyses, communication with one’s HIV provider did not differ significantly by city. Rather, younger age, and being in an ongoing dating relationship (vs. single or married) were associated with having discussed childbearing with one’s HIV provider (AOR 0.95 (95% CI 0.92–0.99), $P = 0.011$, and AOR 1.9 (95% CI 1.01–3.8), $P = 0.046$, respectively). Non-white women were 53% less likely to report communication with their HIV provider

about childbearing compared to white women (AOR 0.47 (95% CI 0.23–0.94), $P = 0.034$). Women with childbearing desires had marginally increased odds of reporting communication with their HIV provider compared to those not wanting to have a child (AOR 1.8 (0.99–3.2), $P = 0.052$). In summary, provider communication was most likely to occur among women who were younger, white and currently in an ongoing dating relationship.

Unmet Need for Reproductive Counseling

Among women in Rio de Janeiro, the unmet need for reproductive counseling among women who *desire* a child, but have not discussed this with their HIV provider was 71% (46/65). The unmet need among women who *intend* to have a child, but have not discussed this with their HIV provider was 65% (16/29). The majority of HIV-infected women with interest in childbearing in both cities have an unmet need for reproductive counseling which is outlined according to women's childbearing desires and intentions in Fig. 1. In both scenarios, the proportion of unmet need for reproductive counseling is higher in Rio de Janeiro than Baltimore.

Discussion

More than one in three HIV-infected women living in Rio de Janeiro want to have a child in the future although a much smaller fraction actually intends to have a child. In southeast Brazil, our finding that 36% of HIV-infected women in Rio de Janeiro desire a child in the future is higher than the 21% (31/148, mean age 32) in Sao Paulo who reported wanting children in 2002 [16]. Significant improvements in the prevention of mother-to-child transmission as well as increased survival among HIV-infected adults and children due to HAART during the past decade in Brazil [42, 43] have likely influenced women and their partners in terms of childbearing. Our findings are similar to more recent findings from Fortaleza in northeast Brazil where 40% of HIV-infected women reported the desire for a child [1]. In 2005, among a subset of HIV-infected women using reversible contraception in Campinas ($n = 66$), a higher proportion (59%) reported the desire to have a child [44]. This study, however, adds to the literature by distinguishing between childbearing *desires* and *intentions*. This distinction is important given the significant differences observed in this study (36% desire vs. 16% intend to have a child in Rio de Janeiro) and other studies of HIV-infected women in the US reporting varying degrees of distance between what women want and intend in terms of childbearing [4, 6]. Informed counseling from

providers can help HIV-infected women and their partners navigate these decisions and potentially resolve or alleviate conflicting feelings about childbearing.

The largest difference between HIV-infected women in Rio de Janeiro and Baltimore was the intention to have a child. In the adjusted analysis, HIV-infected women in Rio de Janeiro were three times less likely to intend to have a child than their peers in Baltimore. This suggests that women in Rio de Janeiro perceive greater barriers to realizing their childbearing desires. One barrier may be perceived stigma regarding childbearing. Although only marginally significant, women in Rio de Janeiro reported less accepting attitudes about HIV-infected women becoming pregnant than women in Baltimore, which may be due in part to slightly higher rates of MTCT in Brazil [40]. While attitudes about HIV and childbearing did not predict the *desire* for a child in multivariate analysis, those who agreed it was okay for a woman with HIV to become pregnant were over 3.5 times more likely to *intend* to have a child compared to women who disagree with that statement. These findings may reflect that childbearing among the sample of women living with HIV in Baltimore is more normalized, possibly due to a HIV prevalence in Baltimore that is over four times higher than the prevalence in Rio de Janeiro. Even though women in Baltimore experience significantly lower CD4 cell counts and less stable relationships than their peers in Rio de Janeiro, they are more likely to intend to have a child. This may perhaps be due to greater confidence that their child will not be infected or a stronger sense that their HIV status should not compromise their reproductive plans.

Communication with HIV providers about childbearing is inadequate in both Rio de Janeiro and Baltimore. In Rio de Janeiro, communication with one's HIV provider about childbearing was reported by 18% of HIV-infected women receiving clinical care. While data on actual communication in Brazil is not available for comparison, 33% of women in highly urban São Paulo [2] and 88% of women in Fortaleza [1] anticipated a negative response from their provider regarding childbearing desires. Although no direct questions regarding childbearing were asked, a 2006 study in Rio de Janeiro observing provider communication in the context of ART adherence noted communication regarding safe sexual practices was rare and occurred only in cases when patients presented with STI symptoms or were thought to be pregnant [45].

Of greatest consequence is the unmet need for reproductive counseling among women who intend to have a child, but have never discussed childbearing with their HIV provider. The finding that non-white patients were less than half as likely to report discussions about childbearing is concerning. The quality of patient-provider communication has been found to vary by patient race and ethnicity in

many healthcare settings in the US [46, 47]. The US-based Women Living Positively survey found that many African American and Hispanic women feel that their culture, ethnicity or language impacts the quality of care they receive, and that many report suboptimal communication as the reason for changing providers [48]. Better understanding of how providers determine when, why and with whom to discuss reproductive options is needed in both Brazil and the United States.

Given that women who want a child were nearly twice as likely to discuss childbearing with their provider (marginally significant), it is plausible that women often initiated these conversations. Although the same data is not available for women in Rio de Janeiro, 64% of women in Baltimore who reported communication with their HIV provider about childbearing said they initiated the conversation [34]. Persistent stigma surrounding HIV in general, and HIV and childbearing specifically [23, 49, 50], make provider-initiated reproductive counseling essential; thereby removing the burden from the individual who may fear disapproval or reproach.

Future Directions

Safer conception among people living with HIV is an emerging area of preventive medicine. While it is unrealistic to suggest that all HIV providers become trained in biomedical aspects of safer reproduction technologies, it is essential that providers (1) assess childbearing desires and intentions of all women of childbearing capacity on a periodic basis, (2) be knowledgeable about safer conception options for couples (serodiscordant or seroconcordant) who wish to conceive, and (3) provide referrals for more specialized preconception counseling when needed. Recent studies have outlined protocols for reproductive counseling and strategies to reduce risk during conception [27–29, 51]. Yet, overarching health policy on this issue has not been established. As a result, many HIV providers struggle with how to address reproductive choice with patients [52]. Data reflecting providers' perspectives on reproductive counseling is very limited; presenting a gap in this emerging area of research. Essential to the quality of provider communication about reproduction is a commitment to balanced nonjudgmental counseling that is not primed to 'counsel against childbearing' [22]. Existing evidence regarding effective provider-patient communication should be considered for its application to reproductive counseling among people living with HIV. Better understanding of provider barriers to the provision of reproductive counseling and patient barriers to the implementation of risk reduction strategies for safer conception are needed to develop appropriate and effective interventions.

Strengths and Limitations

These findings contribute to the understudied area of HIV provider communication regarding reproductive options and document the need for improved integration of reproductive health in HIV clinical care. A methodological strength of the study is that the same measures were used in each sample. A limitation of this study is the exclusion of HIV-infected men and serodiscordant male partners despite their influential role in reproductive decisions [51] and their own desires to have children [6, 8, 50, 53, 54]. Childbearing was not the primary focus of the research in Rio de Janeiro, so only a subset of key measures regarding childbearing and communication were included for comparison between the two cities. Compared to face-to-face interviews, ACASI minimizes social desirability bias and is considered a more reliable method for obtaining accurate data related to sensitive sexual behaviors [55, 56]. The procedural difference in how the surveys were administered (face-to-face in Rio de Janeiro vs. ACASI in Baltimore) may have contributed to greater social desirability bias among women in Brazil, i.e., fewer HIV-infected women willing to report the desire or intention to have a child. Although controlled for in multivariate analyses, there were several important differences between the two samples of women. It is possible that unmeasured factors such as substance use or cultural differences may have influenced childbearing intentions. As recruitment occurred in clinics, findings can only be generalized to people currently enrolled in HIV clinical care in similar urban settings. Given the large metropolitan area in Rio de Janeiro and teaching university setting in Baltimore, the quality of HIV care and provider communication may be better than that provided in more remote areas in each country. Further, we recognize these data represent preliminary findings in a new and emerging area of study. Larger, representative samples are needed that include the perspective of HIV providers as well as people living with HIV.

Conclusion

These findings highlight the importance of childbearing among women living with HIV and the lack of provider communication and guidance on how to safely plan for a future pregnancy. Even in countries with an advanced approach to HIV care, we demonstrate low and inconsistent communication between providers and female patients about childbearing. Brazil and the United States, two countries that have had access to HAART for over a decade, need to take additional efforts to promote and standardize open and early discussions regarding safe conception and childbearing.

As more people benefit from HIV treatment, particularly in countries with strong cultural pressure for childbearing, the need to respect and openly address childbearing among people living with HIV is imperative. With continued progress in expanding access to HAART and increased uptake of PMTCT services, we must anticipate the prevention needs of people living with HIV who want to have children—particularly those in HIV serodiscordant partnerships. As HIV treatment expands and supportive services improve, it is likely that individual and societal barriers to realizing one's childbearing goals will diminish. Therefore, the medical, public health and public policy communities must work together to establish and implement guidelines for quality reproductive counseling among people living with HIV that respects patient autonomy and empowers couples to reduce transmission risks to each other and their children.

Acknowledgments We thank the women in Rio de Janeiro and Baltimore for their participation in this study and acknowledge The Rio Collaborative Group: Betina Durovni & Rosa Domingues (Municipal Secretariat of Health); Louise Schilkowsky, Lia Adler Cherman, Rosane Messias da Silva, Paulo Roberto N. dos Santos, Naja da Silva Reis, Maria Isabel F. Lima (on behalf of the network of health units); Diego Pacheco & Thais Garcia (field coordinators) and participating clinicians and staff at the study clinics. The study in Brazil was funded by the Ford Foundation, Brazil office. We also thank the HIV Women's Program in Baltimore for their financial support for participant remuneration.

References

- Nóbrega AA, Oliveira FA, Galvão MT, Mota RS, Barbosa RM, Dourado I, Kendall C, Kerr-Pontes LR. Desire for a child among women living with HIV/AIDS in northeast Brazil. *AIDS Patient Care STDS*. 2007;21(4):261–7.
- Paiva V, Santos N, França-Junior I, Filipe E, Ayres JR, Segurado A. Desire to have children: gender and reproductive rights of men and women living with HIV: a challenge to health care in Brazil. *AIDS Patient Care STDS*. 2007;21(4):268–77.
- Panozzo L, Bategay M, Friedl A, Vernazza PL. High risk behaviour and fertility desires among heterosexual HIV positive patients with a serodiscordant partner—two challenging issues. *Swiss Med Wkly*. 2003;133(7–8):124–7.
- Finocchiaro-Kessler S, Sweat MD, Dariotis JK, Trent ME, Kerrigan DL, Keller JM, Anderson JR. Understanding high fertility desires and intentions among a sample of urban women living with HIV in the United States. *AIDS Behav*. 2010;14(5):1106–14.
- Loutfy MR, Hart TA, Mohammed SS, Su D, Ralph ED, Walmsley SL, Soje LC, Muchenje M, Rachlis AR, Smaill FM, Angel JB, Raboud JM, Silverman MS, Tharao WE, Gough K, Yudin MH. Ontario HIV fertility Research Team. Fertility desires and intentions of HIV-positive women of reproductive age in Ontario, Canada: a cross-sectional study. *PLoS One*. 2009;4(12):e7925.
- Chen JL, Phillips KA, Kanouse DE, Collins RL, Miu A. Fertility desires and intentions of HIV-positive men and women. *Fam Plann Perspect*. 2001;33(4):144–52.
- Myer L, Akugizibwe P. Impact of HIV treatment scale-up on women's reproductive health care and reproductive rights in Southern Africa. *J Acquir Immune Defic Syndr*. 2009;52(Suppl 1):S52–3.
- 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(1):38–46. Epub 2009 Apr 3.
- Schoen R, Kim YJ, Nathanson CA, Fields J, Aston NM. Why do Americans want children? *Popul Dev Rev*. 1997;23:333–58.
- Dyer SJ. The value of children in African countries: insights from studies on infertility. *J Psychosom Obstet Gynaecol*. 2007;28(2):69–77.
- United Nations Programme for HIV/AIDS (UNAIDS), United Nations Population Fund (UNFPA) and United Nations Development Fund for Women (UNIFEM). 2004. Women and HIV/AIDS: Confronting the Crisis. Available at http://www.unfpa.org/hiv/women/docs/women_aids.pdf. Accessed 2 October 2010.
- Bedimo AL, Bessinger R, Kissinger P. Reproductive choices among HIV-positive women. *Soc Sci Med*. 1998;46(2):171–9. doi:10.1016/S0277-9536(97)00157-3.
- Santos N, Ventura-Filipe E, Paiva V. HIV positive women, reproduction and sexuality in São Paulo, Brazil. *Reprod Health Matters*. 1998;6(12):31–40. doi:10.1016/S0968-8080(98)90005-2.
- Sowell RL, Phillips KD, Misener TR. HIV-infected women and motivation to add children to their families. *J Fam Nurs*. 1999;5(3):316–31. doi:10.1177/107484079900500305.
- Siegel K, Schrimshaw EW. Reasons and justifications for considering pregnancy among women living with HIV/AIDS. *Psychol Women Q*. 2001;25(2):112–23. doi:10.1111/1471-6402.00013.
- Santos NJ, Buchalla CM, Fillipe EV, Bugamelli L, Garcia S, Paiva V. Reproduction and sexuality in HIV-positive women, Brazil. *Rev Saude Publica*. 2002;36(4 Suppl):12–23.
- Centers for Disease Control, Prevention. Epidemiology of HIV/AIDS—United States, 1981–2005. *MMWR Weekly*. 2006;55(21):589–92.
- Ministry of Health, Brazil. Consenso sobre Terapia Anti-retroviral para Adultos e Adolescentes Infectados pelo HIV. Brasília, DF, Brazil: Brazilian Ministry of Health; 1997.
- Segurado AC, Paiva V. Rights of HIV positive people to sexual and reproductive health: parenthood. *Reprod Health Matters*. 2007;15(29 Suppl):27–45.
- Kirshenbaum SB, Hirky AE, Correale J, Goldstein RB, Johnson MO, Rotheram-Borus MJ, Ehrhardt AA. “Throwing the dice”: pregnancy decision-making among HIV-positive women in four U.S. cities. *Perspect Sex Reprod Health*. 2004;36(3):106–13.
- Craft SM, Delaney RO, Bautista DT, Serovich JM. Pregnancy decisions among women with HIV. *AIDS Behav*. 2007;11(6):927–35. doi:10.1007/s10461-007-9219-6.
- Mantell JE, Smit JA, Stein ZA. The right to choose parenthood among HIV-infected women and men. *J Public Health Policy*. 2009;30(4):367–78.
- London L, Orner PJ, Myer L. ‘Even if you’re positive, you still have rights because you are a person’: human rights and the reproductive choice of HIV-positive persons. *Dev World Bioeth*. 2008;8(1):11–22.
- Semprini AE, Bujan L, Englert Y, Smith CG, Guibert J, Hollander L, Ohl J, Vernazza P. Establishing the safety profile of sperm washing followed by ART for the treatment of HIV discordant couples wishing to conceive. *Hum Reprod*. 2007;22(10):2793–4; author reply 2794–5. Epub 2007 Jul 3.

25. Nicopoulos J, Almeida P, Vourliotis M, Goulding R, Gilling-Smith C. A decade of sperm washing: clinical correlates of successful insemination. *Hum Reprod*. 2010;25(8):1869–76.
26. Vandermaelen A, Englert Y. Human immunodeficiency virus serodiscordant couples on highly active antiretroviral therapies with undetectable viral load: conception by unprotected sexual intercourse or by assisted reproduction techniques? *Hum Reprod*. 2010;25(2):374–9. Epub 2009 Nov 26.
27. Matthews LT, Mukherjee JS. Strategies for harm reduction among HIV-affected couples who want to conceive. *AIDS Behav*. 2009;13(Suppl 1):5–11. Epub 2009 Apr 4.
28. Barreiro P, Castilla JA, Labarga P, Soriano V. Is natural conception a valid option for HIV-serodiscordant couples? *Hum Reprod*. 2007;22(9):2353–8. Epub 2007 Jul 19.
29. Aaron EZ, Criniti SM. Preconception health care for HIV-infected women. *Top HIV Med*. 2007;15(4):137–41.
30. Beyeza-Kashesya J, Ekstrom AM, Kaharuzza F, Mirembe F, Neema S, Kulane A. My partner wants a child: a cross-sectional study of the determinants of the desire for children among mutually disclosed sero-discordant couples receiving care in Uganda. *BMC Public Health*. 2010;10:247.
31. Kanniappan S, Jeyapaul MJ, Kalyanwala S. Desire for motherhood: exploring HIV-positive women's desires, intentions and decision-making in attaining motherhood. *AIDS Care*. 2008;20(6):625–30.
32. Paiva V, Latorre Mdo R, Gravato N, Lacerda R, Ayres JR, Segurado A, Aratany A, Cassia B, Marques HH, França I Jr, Salomão ML. Enhancing care initiative—Brazil. *Cad Saude Publica*. 2002;18(6):1609–20. Portuguese.
33. Bridge D, Hodder A, Squires K, et al. Clinicians fail to routinely provide reproductive counseling to HIV-infected women in the United States. Abstract TUPE0911 presented at the XVII International AIDS conference. Mexico City, Mexico: August 3–8, 2008.
34. Finocchiaro-Kessler S, Dariotis JK, Sweat MD, Trent ME, Keller JM, Hafeez Q, Anderson JR. Do HIV-infected women want to discuss reproductive plans with providers, and are those conversations occurring? *AIDS Patient Care STDS*. 2010;24(5):317–23.
35. Malta M, Todd C, Stibich M, Garcia T, Pacheco D, Bastos FI. Patient-provider communication and reproductive health among HIV-positive women in Rio de Janeiro, Brazil. *Patient Educ Couns*. (in press).
36. Szwarcwald CL, Barbosa Júnior A, Souza-Júnior PR, Lemos KR, Frias PG, Luhm KR, Holcman MM, Esteves MA: HIV testing during pregnancy: use of secondary data to estimate 2006 test coverage and prevalence in Brazil. *Braz J Infect Dis*. 2008;12:167–72.
37. AIDS Administration, Maryland Department of Health and Mental Hygiene. Baltimore City Epidemiologic Profile, Fourth Quarter, 2007. <http://www.dhmh.state.md.us/AIDS/Data&Statistics/NewBalQtrEpi.pdf>. Accessed 16 November 2008.
38. Brasil. Ministério da Saúde. Pesquisa Nacional de Demografia e Saúde da Criança e da Mulher—PNDS 2006: dimensões do processo reprodutivo e da saúde da criança/Ministério da Saúde, Centro Brasileiro de Análise e Planejamento.—Brasília : Ministério da Saúde, 2009.
39. Centers for Disease Control and Prevention (CDC) US National Vital Statistics Report for 2007, published 2009. Available at http://www.cdc.gov/nchs/data/nvsr/nvsr57/nvsr57_12.pdf. Accessed 12 September 2010.
40. Tornatore M, Gonçalves CV, Mendoza-Sassi RA, Silveira JM, D'ávila NE, Maas CG, Bianchi MS, Pinheiro EM, Machado ES, Soares MA, Martinez AM. HIV-1 vertical transmission in Rio Grande, Southern Brazil. *Int J STD AIDS*. 2010;21(5):351–5.
41. Centers for Disease Control and Prevention. HIV/AIDS Fact Sheet: Mother-to-child (Perinatal) HIV transmission. 2007. Available at <http://www.cdc.gov/hiv/topics/perinatal/resources/factsheets/pdf/perinatal.pdf>. Accessed 22 August 2010.
42. Barcellos C, Acosta LM, Lisboa E, Bastos FI. Surveillance of mother-to-child HIV transmission: socioeconomic and health care coverage indicators. *Rev Saude Publica*. 2009;43(6):1006–14.
43. Matida LH, Ramos AN Jr, Heukelbach J, Hearst N. Brazilian Study Group on Survival of Children with AIDS continuing improvement in survival for children with acquired immunodeficiency syndrome in Brazil. *Pediatr Infect Dis J*. 2009;28(10):920–2.
44. da Silveira Rossi A, Fonsechi-Carvasan GA, Makuch MY, Amaral E, Bahamondes L. Factors associated with reproductive options in HIV-infected women. *Contraception*. 2005;71(1):45–50.
45. Fehringer J, Bastos FI, Massard E, Maia L, Pilotto JH, Kerrigan D. Supporting adherence to highly active antiretroviral therapy and protected sex among people living with HIV/AIDS: the role of patient-provider communication in Rio de Janeiro, Brazil. *AIDS Patient Care STDS*. 2006;20(9):637–48.
46. Beach MC, Saha S, Korthuis PT, Sharp V, Cohn J, Wilson I, Eggly S, Cooper LA, Roter D, Sankar A, Moore R. Differences in patient-provider communication for Hispanic compared to non-Hispanic white patients in HIV care. *J Gen Intern Med*. 2010;25(7):682–7. Epub 2010 Mar 18.
47. Johnson RL, Roter D, Powe NR, Cooper LA. Patient race/ethnicity and quality of patient-physician communication during medical visits. *Am J Public Health*. 2004;94:2084–90.
48. Hodder S, Aberg J, Feinberg J, Averitt Bridge D, Abrams S, Storfer S, Squires K. Perceptions of Care by HIV-infected Women of Color in the United States. Presented at the 48th Annual Interscience Conference on Antimicrobial Agents and Chemotherapy (ICAAC/IDSA) Meeting October 25–28, 2008, Washington, DC.
49. Squires K, Averitt Bridge D, Aberg J, Feinberg J, Abrams S, Storfer S, Hodder S. Societal stigma of pregnant HIV-infected women in the United States. Abstract TUPE0908 presented at the XVII International AIDS Conference Mexico City 3–8 August 2008.
50. Paiva V, Filipe EV, Santos N, Lima TN, Segurado A. The right to love: the desire for parenthood among men living with HIV. *Reprod Health Matters*. 2003;11(22):91–100.
51. Barreiro P, Duerr A, Beckerman K, Soriano V. Reproductive options for HIV-serodiscordant couples. *AIDS Rev*. 2006;8(3):158–70. Review.
52. Harries J, Cooper D, Myer L, Bracken H, Zweigenthal V, Orner P. Policy maker and health care provider perspectives on reproductive decision-making amongst HIV-infected individuals in South Africa. *BMC Public Health*. 2007;7:282.
53. Sherr L, Barry N. Fatherhood and HIV-positive heterosexual men. *HIV Medicine*. 2004;5(4):258–63.
54. Oladapo OT, Daniel OJ, Odusoga OL, Ayoola-Sotubo O. Fertility desires and intentions of HIV-positive patients at a suburban specialist center. *J Natl Med Assoc*. 2005;97:1672–81.
55. Williams ML, Freeman RC, Bowen AM, et al. A comparison of the reliability of self-reported drug use and sexual behaviors using computer-assisted versus face-to-face interviewing. *AIDS Educ Prev*. 2000;12:199–213.
56. Ghanem Ghanem KG, Hutton HE, Zenilman JM, Zimba R, Erbeling EJ. Audio computer assisted self interview and face to face interview modes in assessing response bias among STD clinic patients. *Sex Transm Infect*. 2005;81(5):421–5.