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Barriers to Pregnancy Spacing in Women Living with HIV: A Series of Informational Interviews

Rachel K. Scott

MedStar Health Research Institute and Department of Women's and Infants' Services, MedStar Washington Hospital Center, rachelkscott@gmail.com

Piyapa Praditpan

NYU Langone Medical Center, NYU School of Medicine, New York, New York, USA, piyapa.praditpan@nyumc.org

Patricia Tanjutco

MedStar Health Research Institute

Elizabeth Laidlaw

George Washington University

Regina Zopf

George Washington University

See next page for additional authors

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Abstract

For reproductive-age women living with HIV, birth spacing allows for optimization of maternal health and viral suppression to prevent mother-to-child transmission of HIV. We conducted semi-structured informational interviews to explore use of contraception for birth spacing. Interviews were transcribed and analyzed. Audio files were reviewed to capture non-explicit data. We interviewed 18 multiparous HIV positive women. All described experiences with at least one contraceptive method. Six themes emerged: Burden of contraception, Failure of birth control, Impact of youth and lack of life experience, Community beliefs about birth control, Lack of partner cooperation, and Altruism. Women viewed birth spacing favorably. Young age at first delivery, contraceptive side effects, non-adherence to short-acting methods, lack of partner cooperation, and prior contraceptive failure were identified as barriers to ideal birth spacing. Additional outreach is needed in women living with HIV to overcome barriers to planned pregnancy and birth spacing.

Keywords

HIV; Pregnancy Spacing; Birth Spacing; Inter-Pregnancy Interval; Dual Method; Contraception; Family Planning; Miles, Huberman and Saldaña Analytic Framework

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Authors

Rachel K. Scott, Piyapa Praditpan, Patricia Tanjutco, Elizabeth Laidlaw, Regina Zopf, and Manon M. Schladen

Barriers to Pregnancy Spacing in Women Living with HIV: A Series of Informational Interviews

Rachel K. Scott

MedStar Health Research Institute, Hyattsville, Maryland, USA
MedStar Washington Hospital Center, Washington DC, USA

Piyapa Praditpan

NYU Langone Medical Center, NYU School of Medicine, New York, New York, USA

Patricia Tanjutco

MedStar Health Research Institute, Hyattsville, Maryland, USA

Elizabeth Laidlaw and Regina Zopf

George Washington University, Washington DC, USA

Manon M. Schladen

MedStar Health Research Institute, Hyattsville, Maryland, USA
Georgetown University Medical Center, Washington DC, USA

For reproductive-age women living with HIV, birth spacing allows for optimization of maternal health and viral suppression to prevent mother-to-child transmission of HIV. We conducted semi-structured informational interviews to explore use of contraception for birth spacing. Interviews were transcribed and analyzed. Audio files were reviewed to capture non-explicit data. We interviewed 18 multiparous HIV positive women. All described experiences with at least one contraceptive method. Six themes emerged: Burden of contraception, Failure of birth control, Impact of youth and lack of life experience, Community beliefs about birth control, Lack of partner cooperation, and Altruism. Women viewed birth spacing favorably. Young age at first delivery, contraceptive side effects, non-adherence to short-acting methods, lack of partner cooperation, and prior contraceptive failure were identified as barriers to ideal birth spacing. Additional outreach is needed in women living with HIV to overcome barriers to planned pregnancy and birth spacing. Keywords: HIV; Pregnancy Spacing; Birth Spacing; Inter-Pregnancy Interval; Dual Method; Contraception; Family Planning; Miles, Huberman and Saldaña Analytic Framework

The optimal inter-pregnancy interval, the time lapse between birth of one child and subsequent conception, is at least 24 months (World Health Organization, 2005). Although much of the literature on pregnancy intervals is older, shorter inter-pregnancy intervals have been consistently associated with poorer maternal outcomes, including maternal obesity, gestational diabetes, preterm labor, increased risk of hemorrhage and anemia, and adverse neonatal outcomes, including low birth weight and cerebral palsy (Cleland, Conde-Agudelo, Peterson, Ross, & Tsui 2012; Conde-Agudelo & Belizán, 2000; Hanley, Hutcheon, Kinniburgh, & Lee, 2017; World Health Organization, 2005; Zhu, 2005). For women living with human immunodeficiency virus (HIV), pregnancy planning yields the additional and vital benefit of optimizing maternal health and prevention of mother-to-child transmission of HIV (Chersich et al., 2006; Wilcher & Cates, 2009). There is a dearth of literature on birth spacing

in women living with HIV in the developed world. In this study, we conducted interviews with inner-city multiparous women living with HIV to identify barriers and facilitators to maintaining ideal inter-pregnancy intervals and to explore women's attitudes towards and experiences with dual method contraception.

Literature Review

Women who plan their pregnancies are more likely to remain adherent to medical treatment for HIV during the inter-pregnancy interval, resulting in suppressed maternal HIV viral load (the detectable level of the HIV virus in the maternal blood) and significantly decreased risk of mother-to-child-transmission of HIV (Raifman et al., 2014). In the United States (US), however, only one in six HIV positive women at risk of pregnancy reports current use of long-acting reversible contraception, such as an intra-uterine device or progesterone implant, which have been shown to be the most effective methods of unplanned pregnancy prevention (Sun et al., 2012). The rate of unintended pregnancy in Washington, D.C. (DC) is similar to the high national rate (58 v. 54 per 1,000 women aged 15 – 44; Kost, 2013). Rates of unplanned pregnancy and birth in HIV positive women are high but tend to reflect local rates in the uninfected population (Massad et al., 2004; Sutton, Patel, & Frazier, 2014). The rate of unplanned births to African American women living below the federal poverty limit is six-times higher than of women with higher incomes, and twice that of non-Hispanic White women (Finer & Zolna, 2014).

For people living with HIV seeking to avoid pregnancy, the World Health Organization recommends dual method contraception—namely use of condoms to reduce the risks of HIV and STI transmission along with an additional more effective birth control method to prevent unwanted pregnancy (World Health Organization, 2015). Despite this recommendation, the majority of women living with HIV in the US who do not seek pregnancy do not practice dual method contraception (Massad et al., 2007; Wilson, Koenig, Walter, Fernandez, & Ethier, 2003), leaving them at risk for unplanned pregnancy and/or transmission of HIV and STIs.

Few investigators have explored trends in dual method contraceptive attitudes and behaviors among these HIV positive women. Most recently, Haddad and colleagues used a large US healthcare claims database to describe trends in prescription-based contraceptive use in HIV positive women (Haddad et al., 2017). Of the 1,185 women they identified, only 28.9% were linked to claims for prescription-based contraception, including short- or long-acting reversible contraceptives and female sterilization. The remainder and majority could not be linked to claims for these methods, which are the types most often used in addition to condoms. Massad and colleagues (2007) analyzed 2,784 structured interviews conducted as part of a multi-center prospective cohort study of women living with HIV, in order to describe trends in contraceptive use. They found that over an 11-year period, HIV positive women chose condoms (30.5 – 36.3%), followed by tubal ligation (21.8 – 26.5%), and then hormonal contraceptives (<10%) as their preferred mode of birth control; the rate of intrauterine device use remained steady at less than 5% per year (13). Wilson and colleagues (2003) interviewed 258 HIV positive women at 6-months postpartum to assess their attitudes and behaviors towards dual use contraception; among women who reported at least one act of sexual intercourse since childbirth, 86.6% reported condom use. They found that only 57.4% of HIV positive women reported use of either female sterilization or hormonal contraceptives. When Wilson compared women who were consistent dual users with inconsistent dual users, they found that women in the former group were more highly motivated to avoid rapid repeat pregnancy (OR 2.4, 95% CI 1.05 – 5.37). Chen, Phillips, Kanouse, Collins, and Miu (2001) found that HIV positive women's fertility desires and attitudes towards pregnancy can be incongruous; 69% of the HIV positive women interviewed did not desire children in the future,

however despite certainty in not wanting additional children, 27% would not choose to terminate an unintended pregnancy.

Barriers and facilitators to birth spacing and dual contraception use among women living with HIV in resource rich countries, such as the US, are poorly understood. Medical providers must know the determinants of successful birth spacing and contraception use if they are to facilitate planned pregnancy and reduce mother-to-child-transmission of HIV. The goal of our study is to address this knowledge gap and to better understand HIV positive women's experiences with birth spacing and dual contraception.

The study was designed by Drs. Rachel Scott (R. S.) MD, MPH and Regina Zopf (R. Z.) MD, obstetrician-gynecologists who provide prenatal and gynecologic care for women living with HIV at an urban hospital in DC. Our research was born out of the desire of Drs. Scott and Zopf to better understand the high rates of short-interval unintended pregnancy in their HIV positive patient population. Patricia Tanjutco (P. T.) MD, a research coordinator with several years' experience working with women living with HIV, recruited patients from Drs. Scott and Zopf's clinic and conducted the patient interviews. Piyapa Praditpan (P. P.) MD, an obstetrician-gynecology resident, and Elizabeth Laidlaw (E. L.), a Masters of Public Health – Physician's Assistant student, facilitated interviews and assisted with data analysis as part of their medical research training. R. S. and R. Z. did not participate in interviews secondary to concern that it would bias participants' responses. Manon Schladen (M. S.) PhD, a qualitative researcher working primarily with individuals from underserved, urban African-American communities, consulted on study methodology and served as the primary qualitative analyst. Dr. Schladen's research focus over the past several years has been on crystalizing the patient perspective to support health care that is increasingly patient-centered. The only non-clinician on the study, Dr. Schladen brought the personal perspective of a multiparous woman with equivocal experiences of contraception and birth spacing to provide counterpoint to the research team.

Research Question

What are the barriers and facilitators of optimal birth spacing and dual contraception use among underserved, urban women living with HIV in the United States?

Methods

Approval

This study received approval from the institutional review board for the medical center where it took place.

Recruitment and Participants

For this study, we sought a convenience sample of patients who received outpatient obstetric and/or gynecologic care at the major urban hospital in DC where R. S. and R. Z. are in practice. Women who receive care at this institution are largely representative of our population of interest: inner city, African American, and living below the federal poverty level. Study personnel (R. S., P. T., E. L.) identified and recruited female patients living with HIV. P. T. and E. L. reviewed patients' demographic and medical information in the electronic medical record to screen for eligibility. We included women who were of reproductive age (18 – 45 years), multiparous, HIV positive, and English-speaking. Patients meeting the inclusion

criteria fell into two categories of interest: (1) those with inter-pregnancy intervals greater than two years apart and (2) those with inter-pregnancy intervals less than two years apart.

Semi-Structured Interviews

After written informed consent was obtained, women participated in face-to-face, individual or paired, semi-structured interviews (conducted and audio-recorded by P. T.). A professional transcription service provided electronic transcripts of the interview audio. We designed interviews to take place within a 30-minute time window to make it feasible for our patients to participate before or after their scheduled clinic appointments. The study team conceived this approach to reduce potential burden on participants, for whom transportation and family issues often create barriers to coming to the clinic. Women received a \$50 gift card and transportation reimbursement in appreciation of their participation. Interview questions focused on women's use of short-acting and long-acting reversible contraceptives and barriers and facilitators of birth spacing. Beyond the initial screening done to establish eligibility, we did not compare participants' descriptions of their experiences with contraception or pregnancy spacing to what may have been recorded in their medical records. Our intent was to give primacy to how participants experienced and made sense of those phenomena.

Analytic Framework and Process

We adopted the broadly applicable framework described by Miles, Huberman, and Saldaña (2014) to analyze participants' interviews. The framework defines three major phases of data analysis: *data reduction*, *data display*, and *conclusion drawing and verification*. Data reduction is the iterative process of selecting and focusing data in relation to one's research questions. Data display may be graphical or text-based, but its essence is organization and compression, characteristics that promote visualization of emerging themes and relationships. Conclusion drawing and verification is the culmination of the research process and the phase where the researcher interprets and ascribes meaning to the analyzed data.

The primary qualitative analyst (M. S.) used NVivo (version 10, qualitative data analysis software; QSR International Pty Ltd, Docaster, VIC, Australia) (QRS International, 2015) to reduce the data, which consisted of participants' interview audio files and transcripts. She memoed the transcripts while listening to the audio of the interviews both as a verification step and to capture non-explicit data (e.g., hesitation, tone of voice). Where she was in doubt as to what was said or meant, M. S. consulted with the research team member(s) who had conducted the interview in question. She first coded each transcript to the interview questions, which were developed a priori and did not vary across interviews. M. S. subsequently engaged in a continual, reflective process of iterative memoing, theme identification and exploration. She kept a research journal to track how her understanding evolved over time as she increasingly immersed herself in the interview data. Maintaining a reflective journal throughout a study exposes the degree to which the researcher is able to *bracket* (Tufford & Newman, 2010), transcend his/her personal biases, in qualitative analysis. Journaling is a best practice that introduces transparency into the research process and enhances confirmability (Trochim & Donnelly, 2008) and credibility (Morse, Barrett, Mayan, Olson, & Spiers, 2002) of findings. Further, the process of making sense of qualitative data *as it emerges* is essential to its coherence (Morse et al., 2002; Reigeluth & Frick, 1999). Because emergence is non-linear, Morse et al. (2002) advocate a specific aim (reminiscent of quantitative approaches) of "methodological coherence" in study designs. The function of methodological coherence is to continually bring the researcher back to the question or questions guiding the study to promote recognition that how the emerging data is taking shape may require revisiting earlier coded

passages and exploring them in a new light. To promote methodological coherence, M. S. adopted a deliberate practice of reflecting on whether each subsequent interview cast previous ones in a different light and committing her thoughts to the journal.

M. S. developed a classification scheme based on themes and participant characteristics to delineate the similarities and differences in participants' experience of child spacing and adherence to the dual method of birth control prescribed for persons who are HIV positive. The scheme gave rise to the development of a series of displays to help visualize themes and trends in women's experience with dual method contraception and birth spacing.

The clinical research team (R. S., P. P., P. T., E. L.) reviewed the displays to verify, question, or further explore the experiences and perceptions that M. S. saw in the data. After discussion, M. S. used a trace-back approach to provide greater about which themes adhered to which participants and to aid in drawing conclusions, the final step of the Miles, Huberman, and Saldaña framework (2014). To protect their privacy, we assigned pseudonyms to all women interviewed in the study and reviewed the data presented to assure that there was not sufficient information provided about any individual to allow recognition. We did not create composite profiles as we believed that the characteristics presented in each woman's history were relevant in understanding her experience of using dual method birth control and spacing her children and contrasting it with that of other participants.

Results

Organization of Results

In presenting our results, we first provide an in-depth description of the women who participated in interviews to familiarize the reader with the range of participants' experiences with pregnancy spacing and dual method contraception after HIV infection. We delineate which women spaced their pregnancies at the prescribed interval and which had not done so to point up individual differences in women's experience that may help explain adherence and non-adherence to recommended practices. Finally, we explore the major and minor themes that emerged from interviews and which may help better understand the barriers and facilitators to dual method contraception use and pregnancy spacing in underserved, urban women who are HIV positive.

Interview Cohort Descriptive Statistics

Eighteen, HIV positive women participated in this study. Participants' motherhood experience ranged from four to 25 years. Cumulatively, they reported 65 children (Table 1). Seven women were pregnant at the time of their interview. Their unborn children were included in the total number of children (twins counted only once). Women reported birth-spacing history in years, thus we used a conservative approach to differentiate between pregnancies spaced at less than or greater than two-year (24-month) intervals. Unless specified, we counted participants' children as spaced less than two years apart if their difference in ages was reported as two years. Women reported 13 pregnancies spaced ≤ 2 years apart and 34 pregnancies spaced >2 years apart.

Table 1. Descriptive Statistics on Participants (Self-report)	
Total Number of Women Responding	18
Total Number of Living Children ¹ and Current Pregnancies (twins counted once)	65
Range in Years of Motherhood	4 – 25
Total Inter-pregnancy intervals > 2-years	34
Total Inter-pregnancy intervals ≤ 2-years	13
Pregnant at Time of Interview	7
Child Spacing as Result of Not Being in a Relationship or Stated Periodic Abstinence	4
Married Status Rationale for Choices	2
Attributed a Child (Unplanned) to Not Using Birth Control	8
<i>Experience with Long-term Birth Control Methods</i>	
Oral Contraceptive Pills (OCPs)	13 ²
Depot medroxyprogesterone acetate (DMPA) “Depo Provera”	15
Intrauterine device (IUD)	6 ³
Implant	1 ⁴
Patch	6
Ring	2 ⁵
Tubal Ligation	3 ⁶
Hysterectomy	1 ⁷
Other	1 ⁸
<i>Experience with Condoms</i>	
Male Condoms	17
Female Condoms	1

These 18 HIV positive women fell into two, basic patterns of child spacing: Pattern A ≤2 years spacing for a woman’s older children, but >2 years spacing between her younger children; Pattern B consistent spacing of children >2 years apart (Table 2)

Patterns	A	B
	≤-year spacing with older children, >2-year spacing with younger children	Consistent >2-year spacing through reproductive years
Women	Althea, Collette, Eve, Georgia, Helen*, Joanne, Karen, Olivia, Quiana	Bethany, Denise, Flo, Isabelle, Lisa, Marie, Noreen, Polly, Regina
	*Consistent child spacing of ≤2 years	

¹ Some women alluded to perinatal deaths of children and having miscarriages but they did not elaborate on them. These children/pregnancies are, therefore, not part of this tally unless the woman specifically included them in her description of child spacing.

² One additional woman considering OCPs

³ Two additional women considering IUDs

⁴ One additional woman considering an Implant

⁵ One additional woman considering the ring

⁶ Two additional women planning tubal ligations after delivery of current pregnancy

⁷ Not intended as birth control, performed due to complications after delivery

⁸ Lunelle (information volunteered)

All women reported some experience with a birth control method. The majority (11) reported prior use of two reversible methods of contraception. Four women reported experience with three of these methods and two women reported use of four. All but one woman reported experience with male condoms; one participant reported experience with female condoms. Of hormonal contraceptives, most women (13) reported experience with Depo-Provera (depot medroxyprogesterone acetate) followed by oral contraceptive pills. Less than half of women (6) reported experience with the contraceptive patch and a couple reported experience with the contraceptive ring. Less than half of the participants reported use of a long-acting reversible contraceptive method; six had used an intrauterine device and one had used a progesterone implant. Three women were using tubal ligation as contraception, while two others planned to undergo this procedure after delivery of their current pregnancies.

Identified Themes

Five major and three minor themes emerged from analysis of women’s interviews. The themes in this study are attitudes, experiences, or perceptions that have influenced more than one woman’s actions with respect to using dual method contraception and spacing of pregnancy.

Theme 1: Incomplete understanding of rationale behind recommendations for pregnancy spacing and use of dual method birth control when HIV positive.

Women provided highly variable responses when asked what they considered to be the “ideal” interval for pregnancy spacing after HIV (see figure 1). No woman recommended an interval shorter than the recommended 24 months, but neither did any woman identify prevention of mother-to-child transmission of HIV as a factor important in her decision-making relative to pregnancy spacing. Maternal well-being was identified, but not with reference to the special needs of maintaining health after HIV infection. Though all participants were living with HIV, they uniformly re-focused the question, and provided reasons for child spacing that might apply to women generally, rather than on the special health requirements relevant to HIV positive women.

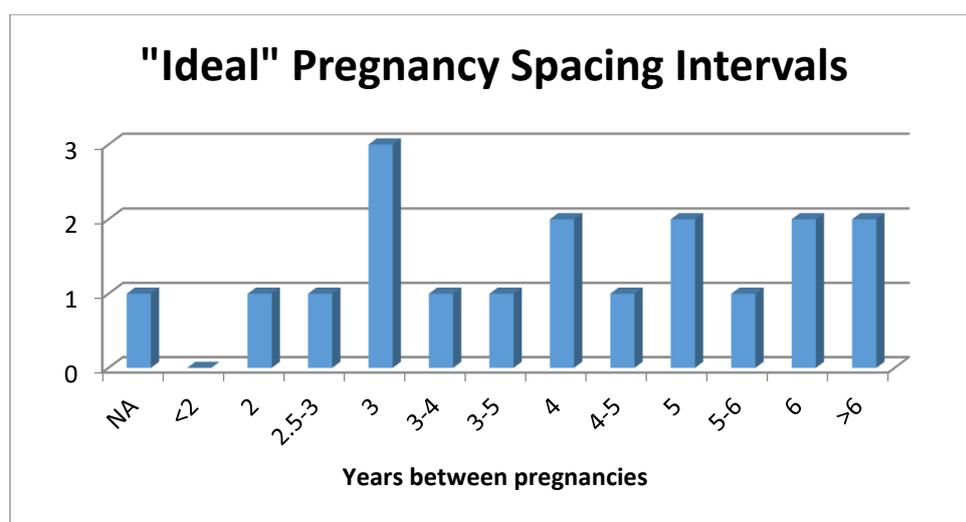


Figure 1. Participants’ assignment of ideal pregnancy spacing intervals

Isabelle's responses, with respect to her second and third pregnancies, may be illustrative. Her focus is on issues of finances and independence from her family, not on the risks inherent in her HIV-positive status.

Interviewer: What do you think is a good number of years to wait between children?

Isabelle: In my opinion, I spaced my children. I had my 10-year-old when I just turned 21. I was not really financially ready, I was still living at home with my mom, and I waited until I got on my own to have my 3-year-old and I waited again to have this baby...

Interviewer: So, what do you think is a good number of years to wait?

Isabelle: The space that I did, the 10 and 3.

Though they did not include the reference to personal practice "that I did" that Isabelle did, most women endorsed the spacing of their own children as ideal. Women's lack of focus on the urgency of pregnancy spacing for prevention of mother-to-child-transmission of HIV may be rooted in an overall sense of resentment, not wanting to be reminded of their HIV-positive status that Flo expressed in a different context, noting that having to use condoms with one's husband was just a continual reminder of living under the specter of HIV.

We asked women who had longer inter-pregnancy intervals to describe what helped them wait between pregnancies. Again, participants responded with reasons not related to their HIV status. Rather than explaining the motivators and facilitators of birth spacing they experienced as HIV positive women, they noted maternal physical recovery and the difficulty of parenting many young children as motivators for child spacing. The follow two quotes are typical.

Quiana: I say: you have to give your body basically a rest. You cannot keep having babies. You are trying to mess you up. Every pregnancy is not the same.

Lisa: The age span is, like, you don't want to have 'em back to back because of the growing process. I done seen people have two babies, maybe three, in pampers.

Four women further attributed longer spacing between their pregnancies to being out of a relationship or abstinence from sexual relations. Again, neither of these situations takes HIV into account.

Of the 18 women interviewed, 13 reported that they were aware of the recommendation to practice "dual method" contraception after HIV. Three women were unaware of the meaning of this contraceptive strategy. When discussing the use of condoms with a long-acting reversible contraceptive, half of women stressed the importance of condoms for STI prevention while half stressed their importance as back up to long-acting reversible contraception. Only two women acknowledged condom use for both STI and pregnancy prevention. Regardless of their ability to articulate awareness of the term "dual method" contraception, nine of the participants described contraceptive practices consistent with this method, although half expressed reservations about its efficacy.

Overall, understanding of the need to space pregnancies at 24 months or greater to protect one's child from HIV transmission appeared to be lacking, though women articulated other, common sense reason for child spacing at that interval. Understanding of and commitment to dual method contraception was likewise weak to absent. Women showed a strong tendency to hold the special requirements of longer interval child spacing and use of

dual method contraception apart from their thinking about family planning in general, casting a veil of normalcy and personal choice over the patterns they reported.

The following theme (2) deals with locus of control, personal differences in action that result from the perception of one's power to act and make a change. These differences in individuals' perspectives did not clearly emerge in women's demonstration of understanding of the need for longer interval child spacing and use of dual method birth control after HIV. Nor did these differences appear to impact our participants' "drive to normalcy" when questioned about ideal child spacing.

Theme 2: Successful pregnancy spacing and locus of control.

Individuals who exhibit a strong internal *locus of control* are likely to believe they have the capacity to achieve a desired health outcome (Wallston, Osborn, Wagner, & Hilker, 2011). Essentially, persons with a strong *internal* locus of control believe that they have control over what happens in their lives. Conversely, persons with a strong *external* locus of control believe that what happens to them is outside of their control. We observed that women whose child spacing history conformed to Pattern B, spacing of pregnancies >2 years apart, expressed more statements suggesting an internal locus of control than did Pattern A women, those with a history of pregnancies spaced \leq two-year intervals. Regina and Flo, both Pattern B child spacers, provide examples of attitudes suggesting strong internal locus of control.

Regina: I do not feel good with the shot (Depot medroxyprogesterone acetate), but I *have* to take it because I do *not* want to get pregnant.

Flo: I am thinking I could have a child that is negative, *which I do*. BOTH of my kids are negative!

Regina is able to sublimate her issues with the Depot medroxyprogesterone acetate shot because of her resolve to avoid pregnancy. She makes a decision and assumes control. Likewise, Flo, knowing that if she follows the recommended medical regimen, she can prevent HIV transmission to her children, resolves to follow the approved regimen. She presents the results of her resolve with pride: neither of her children have HIV.

In contrast, Georgia and Karen, Pattern A child spacers, evidence more passive perspectives.

Georgia: Whatever God brings to you, it is a blessing. My children are a blessing. The sickness that I have is only God, baby, believe me, that is a blessing...

Karen: Stuff just happens, things just happen between you and your male friend.

Georgia takes whatever life brings to her, believing that it is as it should be. Karen, likewise, is comfortable with her belief that male-female relationships simply chart their own course. The four women quoted here stood out in their demonstration of the poles of external/internal locus of control in their descriptions of their experiences with HIV. Notably, other participants' discourse presented more neutral perspectives.

Theme 3: The burden of contraception in HIV positive women.

The theme of the burdensomeness of contraception was ubiquitous across interviews. Burden was associated with both long-acting reversible contraceptives and condom use.

Women cited several known side effects of contraception as barriers to use. They are summarized in the display provided in Table 3. Women reported fewer undesired side effects with oral contraceptive pills than Depot medroxyprogesterone acetate injections. Two women, however, described a sense of being overwhelmed by the prospect of taking oral contraceptive pills in addition to their HIV medications. Of the six women who had used the patch, one participant associated patch use with a history of stroke. Another participant reported that her Intrauterine Device migrated outside of the uterus and required surgical removal.

Table 3. Reported side-effects with long-acting reversible contraceptives methods

Women who reported	Method	General malaise	Weight gain	Bloating	Nausea/GI disturbance	Headache	Change in menstruation	Pain	Hair loss	Other physical complaints	Serious medical complications
15	Depot medroxyprogesterone acetate	1	10	3			2	1 ⁹	4		
13	Oral contraceptive pill				2	1	1			2	
6	Intra-uterine device						1	3	1		1 ¹⁰
6	Patch										1 ¹¹
2	Ring						1				
1	Implant						1				

The potential impact of certain hormonal contraceptive side effects on women's self-image was also a barrier to use, specifically with short-acting reversible contraceptives, including oral contraceptive pills and Depot medroxyprogesterone acetate. Participants described fear of weight gain and hair loss as problems with consistent use of these methods. One participant shared the following:

Althea: This is going to be kind of superficial to say, but a lot of the birth controls now tend to put a little extra weight on you and so for that reason, myself and a lot of other women do not want to use it.

Althea identifies distaste for putting on extra weight as "superficial," not equal to the greater good of optimal child spacing. At the same time, however, she reveals insult to a women's self-image as a potent disincentive to contraception use.

⁹ Pain at injection site

¹⁰ Extrauterine migration necessitated surgical removal

¹¹ Informant reported stroke

Multiple women identified adherence to short-acting reversible contraceptives as a barrier to ideal pregnancy spacing. Nine women stated that adherence to daily dosing of oral contraceptive pills and routine maintenance of clinic appointments for Depot medroxyprogesterone acetate injections were barriers to successful use of these methods. Four women discussed the “intrusiveness” or “unnaturalness” of condoms as well as lack of cooperation from partners with use. One participant reported adherence to condom use, however described doing so as an undesired reminder of her HIV positive status.

In summation, burden emerged as a multi-faceted theme from women’s interviews. It included long-acting reversible contraception side effects, those causing women to feel physically unwell and also those impacting their self-image, such as weight gain and hair loss. It also included distaste for the disruption of the natural flow of sexual relations due to required condom use and the continual reminder of one’s HIV positive status that condom use inflicted.

Theme 4: Failure of birth control in women living with HIV.

Our interviews yielded numerous definitions of “birth control failure.” Women who reported experience with hormonal short-acting reversible contraceptives defined failure as the experience of an unplanned pregnancy. Other women referred to Intrauterine Device migration and male condom breakage as method failure, whether or not these resulted in unplanned pregnancy.

Women with both patterns A (children spaced at ≤2 years) and B (children spaced at >2 years), of child spacing experienced birth control failure. They reported failure to adhere to their chosen method as well as device failure. Four of the six women who had used Intrauterine Devices, reported device failure. Women who adopted Pattern B birth spacing reported experience with a greater variety of long-acting reversible contraceptive methods and twice the number of birth control failure descriptions as women who adopted Pattern A birth spacing (Table 4). Eight women explicitly attributed an unplanned pregnancy to not using birth control.

Table 4. Self-reported failure¹² of birth control methods			
RED= Pattern B; BLUE= Patterns A			
Method/ Reports	Failure Reasonably Related to Method Failure Itself	Failure Related to Improper Use	Failure Mentioned, Circumstances Not Elaborated
Depot medroxyprogesterone acetate (3)		<i>Georgia:</i> “I think that issue, because I had missed a month and I went back to go get the shot.” <i>Helen:</i> “I was taking Depo for a second and then I stopped. It	<i>Polly:</i> “I was on ... the shot and I got pregnant ...”

¹² “Failure,” when used in conjunction with methods *more* readily controlled by the woman, e.g., OCPs, Depo, the patch and the ring, signifies that an unplanned pregnancy occurred. In these cases, the woman’s indication that the method has *failed* is pregnancy. “Failure,” when used in conjunction with methods less likely to be under a woman’s *direct* manipulation, e.g., the IUD and male condoms, includes migration (IUD) and breakage (condom) with or without accompanying incidence of unplanned pregnancy. In these incidences, it is obvious that the method isn’t doing what it’s supposed to do without a pregnancy having to occur.

		seemed like as soon as I stopped, I got pregnant.”	
Oral Contraceptive Pills (OCPs) (1)		Polly: “I just forgot ...and I got pregnant.”	
Intrauterine Device (IUD) (4)	<p>Bethany: “I had it for two years ...I just got pregnant while I was on it.”</p> <p>Collette: “Actually, after I had my daughter I tried a new form of birth control, which was the IUD. I got pregnant with the IUD still inserted with my son. I was in the low percentile of that possibility of happening.”</p> <p>Eve: “The only problem I had was it fell out.”</p> <p>Flo: “The Mirena, they had to surgically remove it because it came out of my uterus and wrapped around my intestine.”</p>		
Patch (3)		<p>Noreen: Same thing (as the NuvaRing, e.g., stopped using it due to confusion).</p> <p>Karen: “(I) didn’t know it wasn’t working.”</p>	Bethany: “I got pregnant with my oldest.”
Ring (1)		Noreen: “That was my fault with the NuvaRing because I thought after I go off I was supposed to put it on, but I was supposed to wait exactly seven days then pull it, so I just stopped taking it.”	

<p>Condoms, Male (6)</p>	<p>Polly: “It broke, that is why I use two.” Noreen: “It broke.” Quiana: “No challenges, except for the breaking.”</p>	<p>Noreen: “The father felt a little bit happier about himself, got a bigger size than what he needed. It came off. That is how I got my little girl.” Georgia: “I just hate that part when you just get it stuck in you.”</p>	<p>Regina: “No, I have had no problem with condoms. Well, yes one time my last baby's father. That is why I got pregnant.”</p>
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The experience of birth control failure, both failure of the method/device itself and failure related to proper use, was reported by both women who spaced their children at >2 year intervals and those who did not. That long birth spacers explored more methods of birth control than did short spacers may be significant and related to a possible greater tendency toward internal locus of control.

Theme 5: The impact of youth and lack of life experience.

All of the participants cited youth and lack of life experience as barriers to ideal pregnancy spacing. Two women with Pattern A birth spacing cast their own, youthful failures in recommended child spacing in that light.

Olivia: My oldest ones, with them I just got pregnant. With the first three kids I got pregnant, I was young. You know, at 21 I had three kids, so I was just humping. Honestly, that is the truth in that. ... With the last two, it was different.
Georgia: I was young. I was young when I had them. I was 18 and 19 when I had them.

Both Olivia and Georgia attribute their inability to space their early pregnancies to youthful nescience. Interestingly, their later children were spaced at the recommended >2-year interval.

Some women related the degree of parental guidance they received as youths to prevention of HIV infection and pregnancy planning. Isabelle lamented that her mother had provided her no guidance at all and she was left to learn from her sad experiences.

Isabelle: As females, we have daughters and when they get of age, you should be talking to them. My mother didn't talk to me. I had to find out the hard way.

Flo, likewise, endorsed parental involvement, even the intimidating engagement modeled by her mother.

Flo: It was different for me because my mother, she kind of scared me too. She scared me half to death, so I did not have sex until I was 18, but she scared me half to death and everything. She would go into the doctor's office. I went right over there to the adolescent clinic, I had Dr. Smith (pseudonym) and she would ask her, “Make sure her hymen is still there.” My mother was just in the room and wanted to know. Even though I told her, "I am still a virgin, mom," she did not believe me.

Georgia, on the other hand, recognizes that there is only so much a parent can do given the freedom of choice that adolescents increasingly have.

Georgia: Nowadays there are little girls of age, because I have a 16-year-old, and I can want for her all day to have some type of birth control, but she has to want to have it. In other words, if she says no, the doctor cannot give her something that she is refusing and I do not think that is fair, as a parent. ... I mean, we can encourage, but today's society, these young girls they are running wild rapidly and some parents are not even paying attention to most children and that is pretty much how a lot of things are happening, but, like I said again, my daughter is 16. I went to (the hospital clinic). I wanted her to have the Depo. If she refuses it, I cannot go in the room with her, they cannot tell me if she has sex. I think that is very emotional for me because I am a mother with HIV.

In the absence of parental guidance, women endorsed schools and health clinics as important surrogates. Generally, women agreed that teaching should occur in a realm of authority like the health clinic, school, or home. They also acknowledged that media played an important role in sexual and reproductive health education.

Olivia: I always say it (education about sexuality) should start in your home, but I think it needs to be exposed more in schools and they really need to start it in elementary honestly. It is out of control. You would be surprised what these young girls ask, these questions and stuff they know at 12 and 13, and this is stuff that their parents do not know.

Regina: Educate them more so they can pick (condoms) up, because some young girls do not like using them and they do not pick them up. ... They are not educated at all about using condoms. They think that having sex is okay with that person without using a condom ... I think educating them more when they come in the clinic and talking to them and letting them know it is good to use condoms, do not be ashamed to use condoms so you will not catch anything!

Women identified youth and lack of guidance as a significant problem in responsible sexuality. Here, as in much participants' narrative, the line blurs between generally responsible behavior and the stricter behaviors that are necessary after HIV infection.

Theme 6 (Minor): Community beliefs about birth control.

Participants expressed skepticism about the efficacy of birth control, regardless of adopted pattern of birth spacing. Lack of confidence in the efficacy of dual method birth control was rooted in a personal sense of its burden and sustained by peers' anecdotes of birth control failure.

Isabelle: I hate (dual method contraception). The condoms are for protection against HIV and other sexually transmitted diseases, which I agree. The birth control is just to stop the pregnancy, but birth control is not always accurate. Because I have heard some of my female friends say they got pregnant on their shot. They got pregnant on the IUD (Intrauterine Device).

Polly: No ... you end up pregnant just like, I know a young lady she got that thing up in her thing and she got that and got pregnant.

Community beliefs and experiences of birth control failure like those expressed in the peer anecdotes shared by Isabelle and Polly appear to significantly influence participants' opinions of contraceptive efficacy and decision-making regarding their use.

Theme 7 (Minor): Lack of partner cooperation with family planning in reproductive aged women living with HIV.

In addition to youth and contraceptive failure, several women reported lack of partner cooperation as a barrier to family planning and pregnancy spacing. Several women reported that lack of cooperation with condom use from sexual partners is common. Quiana described intentional sabotage by former partners:

Quiana: Sometimes they will put a hole in it or then wait until the last minute and tell you.

Interviewer: Intentionally put a hole in it?

Quiana: Yes, they will if you are not paying attention and watching them. They will put a little hole in it and whatever. That happened to me plenty of times.

Isabelle recounts lack of cooperation as well, but with a somewhat different tone.

Isabelle: You are going to put it on (a condom). If you don't put it on, you're not getting nothing.

Quiana and Isabelle describe the same reluctance of their partners to use condoms. Their attitudes and responses are different, however. Quiana is the victim of deception whereas Isabelle enforces her rule about condom use. Interestingly, Quiana is a Pattern A child spacer and Isabelle, a Pattern B. In this case as in earlier cases, the Pattern B spacer shows stronger internal locus of control than does the Pattern A spacer.

Theme 8 (Minor): Altruism and contraception in women living with HIV.

Altruism, expressed as the desire to reduce the risk of partner and mother-to-child transmission of HIV barely emerged as a motivator for adherence to dual method contraception. It was present most palpably in Isabelle's recounting of condom use with her partner.

Isabelle: I use condoms now with my partner, even though I'm pregnant. There is still a slight chance he could still catch HIV, so we have been using condoms. ... I feel that since I got infected with HIV seven years ago, before that I didn't care. I didn't give a man a choice to put on a condom, but now since I've been infected and since I've been more careful, I have a choice now.

Isabelle recounts how her priorities have changed since she has been HIV positive. She didn't offer her partners a condom before she was infected, but now, in consideration of his well-being, she does. Consideration, altruism toward her partner, provides a motivation to adhere to condom use.

Discussion

Although a recent large retrospective review called into question the causality of short interpregnancy intervals on several previously attributed adverse pregnancy outcomes, there do appear to be clear maternal and neonatal benefits to birth spacing (Hanley et al., 2017). For women living with HIV, the opportunity to optimize HIV status through planned pregnancy and ideal birth spacing can yield significant benefits to maternal and neonatal health (Chersich et al., 2006; Raifman et al., 2014; Wilcher & Cates, 2009).

The vast majority of our study participants reported male condom use for protection against both unplanned pregnancy and HIV transmission. Even so, women's narratives described the challenges of consistent condom use. Women cited unnaturalness, difficulties with partner cooperation, and anecdotes of condom failure (e.g., popping, slipping off) as factors impeding consistent use. Their narratives also conveyed a sense of fatalism regarding the inevitability of product malfunction and development of interpersonal tension.

Though reports of both anecdotes and personal experience with condom failure were largely universal among interview participants, their decisions relative to adherence to condom use was not. Personal factors that may relate to individuals' locus of control emerge from their narratives. This hypothesis is consistent with the findings of Wallston and colleagues, who demonstrated the validity of the construct of locus of control/self-efficacy as measured by the Perceived Medical Condition Self-Management Scale (PMCSMS) in HIV positive patients (Wallston et al., 2011).

Our findings of low uptake of highly effective contraception among HIV positive women susceptible to rapid repeat high-risk pregnancy is consistent with Wilson and colleagues' findings (2003) of relatively low utilization of hormonal contraception and sterilization. Similarly, the incongruity described by Chen et al. (2001) is also reflected in our small sample of HIV positive women. The theme of the burden of contraception permeates our participants' experiences and may account for reduced condom use. Our participants' narratives suggest belief in one's ability to achieve a goal may be a critical component to consistent use of condoms with highly effective contraceptives. We observed that strong feelings accompany fertility, childrearing, relationships with life partners and sexual partners, and HIV positive status. Women from our small sample underscore the need for personalized counseling regarding contraception and family planning.

Pregnancy spacing and prevention of HIV transmission is an exercise in health care self-management. The physician prescribes the birth control method, but with short-acting reversible contraceptives, the individual woman must implement its use. Our study suggests that provider awareness of women's reproductive plan and sociocultural contexts of her life are essential to helping her select and remain adherent to an effective form of birth control. Additional research on locus of control and self-efficacy with dual method contraception in the setting of HIV, utilizing a validated measure such as Perceived Medical Condition Self-Management Scale (PMCSMS) would likely offer additional insight into contraceptive choices and pregnancy spacing.

The limitations of the analysis include those inherent in single-encounter semi-structured interview research—understanding is emergent, so questions that arise in later interviews cannot be readdressed to participants who completed their interviews. Similarly, one cannot re-interview women to assess whether they agree with the conclusions we reached. In addition, some women answered at length while others provided terse responses. Therefore, our analysis is more heavily weighted to responses from the former group.

Our analysis is limited by the small sample of women from a single, inner city hospital from a single geographical area. This said, our findings are likely generalizable to the many of women living with HIV in urban areas of the US. Due to the recruitment environment of a

single hospital program, sensitive nature of HIV, and privacy considerations embedded in the consent agreement with participants (e.g., the risk that the narrative of one participant who only agreed to participate individually might be identifiable to another participant), there was no formal member-checking (i.e., explicit validation of themes or conclusions drawn in this report by participants). Lastly, participants' responses regarding their contraceptive experiences over a lifetime are affected by recall bias. Several women alluded to the influence of HIV on their contraceptive choices, however none clearly differentiated between practices before and after diagnosis. We did not enquire about differences in contraceptive practices before and after HIV diagnosis directly, a further limitation.

Implications of Our Research for Clinical Practice, Policy, and Further Research

Our study demonstrates that inner city, women living with HIV of childbearing age may not have an articulable understanding of the precautions they need to take to protect their sexual and reproductive health, that of their sexual partners, or of the implications for future pregnancies. Practitioners should take great care to make sure patients living with HIV have a comprehensive understanding of the contraceptive and reproductive health recommendations for planned pregnancy/pregnancy prevention and prevention of HIV and STIs. From our participants' accounts, instruction at home was seen as primary, though the variability in home situations was also pointed up as a problem in transmission of knowledge about reproductive health behaviors after HIV. There is an unmet need for additional and improved reproductive health education for women particularly among at-risk underserved urban populations both in schools from early years and through Public Health programming such as wide-reaching social marketing campaigns.

Beyond patients' understanding, practitioners may want to consider the issue of trust and credibility in how their patients will put recommendations into practice. Our participants demonstrated the power that perspectives and anecdotal information coming from their communities had on their behavior. This trust gap suggests that practitioners reflect on what they do to build relationships with their patients. Our participants with HIV showed us that, even though they came to our clinic faithfully, they did not necessarily believe or act on our recommendations for health-preserving reproductive activity.

Clinicians may also want to recognize and address the equivocal nature of contraception: that it brings a desired goal (healthy child spacing, prevention of disease transmission) on the back of practice that creates burden. Many of our participants did not feel well as a result of using long-acting reversible contraceptives. Use of long-acting reversible contraception often caused discouraging body changes such as hair loss and weight gain. Adherence to short and long-acting reversible contraceptives required discipline in terms of remembering to take pills and make arrangements (scheduling, transportation, etc.) for clinic appointments. Use of condoms to prevent disease transmission also interfere with the natural flow of sexual relations and, in the case of a woman with HIV, bring her back to the conscious realization of her status, a memory she may prefer to avoid. Addressing the burden of maintaining healthy reproductive practices after HIV may require more support than can be provided in typical clinic visits. At the policy level, clinics may consider how they might implement more personalized inquiry and follow-up to find out how individual women are coping with their prescribed contraceptive regimens.

Lastly, our study suggests that personal factors, such as internal versus external locus of control, may play a key role in individuals' ability to plan to use dual method contraception after HIV and to adhere to the plan once in place. Further research in this area is recommended.

The women living with HIV who participated in our study viewed dual method contraception favorably. However, these women also discussed significant barriers to

contraceptive adherence, including side effects, lack of partner cooperation, and perceived risk of contraceptive failure. Prevention of HIV transmission during pregnancy and to partners as well as the need for maternal recuperation between pregnancies were identified as motivators. Additional research and outreach is needed to address continued barriers to pregnancy planning in women living with HIV.

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Author Note

Rachel K. Scott, MD, MPH, is with MedStar Health Research Institute, Washington, D.C. and the Department of Women's and Infants' Services at MedStar Washington Hospital Center, Washington, D.C. Correspondence regarding this article can be addressed directly to: rachelkscott@gmail.com.

Piyapa Praditpan, MD, MPH, is with the Department of Obstetrics and Gynecology, NYU Langone Medical Center, NYU School of Medicine; Brooklyn, New York. Correspondence regarding this article can also be addressed directly to: piyapa.praditpan@nyumc.org.

Patricia Tanjutco, MD, is with MedStar Health Research Institute, Washington, D.C.

Elizabeth Laidlaw, PA-C, MPH, received her PA-C and MPH from George Washington University and was an MPH student at the time of this study, Washington, D.C.

Regina Zopf, MD, is an assistant professor with George Washington University School of Medicine, Washington, D.C.

Manon Maitland Schladen, EdS, PhD, is with MedStar Health Research Institute, Washington, D.C. and Georgetown University Medical Center, Washington, D.C. Correspondence regarding this article can also be addressed directly to: mmschladen@gmail.com.

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