Title:
Controlling Fertility and Managing HIV: Complexities of Disclosure for Young Women Living with HIV in Chitungwiza, Zimbabwe

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BACKGROUND

In the context of high HIV risk and prevalence, young women under age 25 in Zimbabwe, as throughout sub-Saharan Africa, face multiple challenges in managing their health and fertility. Despite the United Nations' Millennium Development Goals aimed at ensuring universal access to sexual and reproductive health (SRH) services, there is considerable evidence that young women desire to limit fertility beyond what they currently experience [1-3], with rates of unintended pregnancy reaching 40% [4].

This situation takes on critical importance in Zimbabwe, where young women's HIV prevalence is considerably higher than their male counterparts [5], peaking at 35% by age 29 [6]. Myriad contextual factors, particularly poverty and gender inequity, contribute to this higher HIV prevalence, while also complicating fertility control. Challenges to achieving desired fertility include gender norms that place sexual decision-making in the realm of men [7-8]; the perceived need to prove fertility before starting contraceptives [9]; lack of integrated and affordable SRH and HIV services [7;10-11], and limited SRH services for unmarried youth [2;11-13]; unstable partnerships, often with older men [2;10]; and resistance among men to engage in their own and their partner's health [15-17].

For young women living with HIV, preventing, delaying and/or spacing pregnancies is an essential component to managing health and preventing onward transmission [7;11;18-22]. Given the high regard for childbearing in the Shona culture of Zimbabwe [23] and strong pressure from partners and families to have children [24], disclosure of HIV status as a strategy to garner support becomes critical to achieving desired fertility. However fear of stigma, violence, or divorce poses a barrier to disclosure for many women [25-27]. Despite this, studies find that in a majority of cases, women disclose to supportive or neutral responses from partners [26-34].

However, understanding connections between disclosure and fertility outcomes remains a research gap. Little is known regarding how young women living with HIV weigh the risks and benefits of disclosure in the context of achieving desired fertility. Using in depth interviews among young women living with HIV in urban Zimbabwe, this paper aims to generate theory to help policy and programs better understand and respond to the complicated realities of this population in Zimbabwe and throughout the region where similarities exist.

METHODOLOGY

SHAZ!-PLUS

This qualitative study is nested within the ongoing SHAZ!-Plus intervention trial. SHAZ! (Shaping the Health of Adolescents in Zimbabwe) has been working with orphaned and vulnerable (OVC) young women in Zimbabwe since 2000, testing the effects of combined life skills education and economic opportunities on HIV outcomes. Results of a prevention trial of SHAZ! found significant improvements in economic indicators and some HIV risk factors (transactional sex, condom use and experience of violence), and a 40% reduction in unintended pregnancy of borderline statistical significance [HR=0.62, 95% CI (0.38, 1.02)] [35-36]. The current SHAZ!-Plus study evaluates the same model on treatment adherence, HIV/SRH outcomes, and secondary prevention among young women aged 16-19 living with HIV. Participants are randomized to either receive health education and medical care (comparison

group) or these services plus an additional life-skills intervention, vocational training, and micro-grant (intervention group). The life skills curriculum was adapted for the target population from *Talk Time* and *Stepping Stones* [37-39], addressing issues related to gender, culture, physical and sexual violence, HIV and reproductive health in a 10 part series. Participants elect vocational training from courses offered through accredited programs, receiving a mini-grant and business advice upon completing their training to help them develop economic opportunities. At the time of the qualitative interviews, approximately 400 participants (out of a target of 700) had enrolled in the study.

Study Setting

The study population lives in Chitungwiza, a high prevalence, urban setting on the outskirts of the capital city, Harare. The estimated HIV prevalence for the community is 25% as compared with a countrywide prevalence of 14.3% [CI 13.4% - 15.4%] [40].

Eligibility

Participants for the qualitative sub-study were recruited from those enrolled in SHAZ!-Plus, resulting in 28 young women between the ages of 16 and 19, not currently in school, and living with HIV. Half of the subsample was selected from the intervention group and half from the control group. We oversampled participants with a history of pregnancy (21/28) to ensure a range of experiences with fertility. All participants provided informed consent and ethical review committees in Zimbabwe and the US approved the research.

Data Collection

Zimbabwean women researchers experienced in qualitative data collection conducted in depth interviews in Shona, the participant's preferred language, using a semi-structured, open-ended guide. Previous rapport existed among the participants and the researchers due to their interaction through SHAZ!. The interview guide, written first in English than translated into Shona, addresses topics such as: pregnancy desires and decision-making; community norms related to childbearing; disclosure of HIV status; contraceptive use; perceptions of SRH and HIV services and experiences with providers; and future plans for childbearing. Interviewers used probing questions to delve more deeply into the logic, perceptions, and emotions of participants. Each interview was tape-recorded, and involved a participant, a facilitator and a note taker**.** Interviews ranged from 23 minutes to 62 minutes, with the majority lasting 45 minutes or longer (26/28). Quantitative data reported on the 28 enrolled in the sub-study in Table 1 was collected among all participants at the time of enrollment.

Data Analysis

Tape-recorded interviews were transcribed in Shona and translated into English**.** The SHAZ!-Plus study director (I. Mudekunye-Mahaka), who conducted interviews, checked transcript translations for accuracy. Two coders, the study director (I. Mudekunye-Mahaka) and one outside coder not involved in data collection (S. Zamudio-Haas), collaborated with the larger analysis team to analyze the transcripts using a multi-stage process in accordance with a grounded theory approach to identify and understand emergent themes [41-42]. Regular emails and weekly conference calls between the US and Zimbabwe facilitated communication. Data were coded by hand and then copied into word documents, organized by code and category. Coders utilized memos at each stage of the process to develop salient theoretical categories and explore relationships among categories.

In the initial phase of analysis, one coder worked with Shona transcripts and one with English translations, employing line-by-line coding with gerunds to a few transcripts. Coding in Shona occurred at this stage to identify key concepts that might lose meaning in translation. Coding

with gerunds (e.g. “pressuring for pregnancy” and ”hiding test results”) sought to summarize and capture action in each piece of data in accordance with the analysis process described by Charmaz [41] to develop grounded theory. Focused coding followed the first stage, applying the most significant and frequent codes to larger amounts of data. At this point in analysis, all Shona codes were translated into English and both coders used the English transcripts, as the coding in Shona yielded no further additional insight. In the third stage of coding, codes were grouped under axial codes and entered into a standard codebook with a definition, inclusion criteria, exclusion criteria, and examples for each code in accordance with CDC recommendations for team coding [43]. Each coder then used the standard book to code three of the same transcripts. Discrepancies in coding were discussed until consensus was reached and the inclusion and exclusion criteria were clarified to ensure uniform coding for the entire sample of interviews.

In the final stage of analysis, disclosure emerged as the crux of all four theoretical categories (Fertility Control, HIV Management, Strategizing for Survival, and Relationships, Power, Sexual Behavior). Coders returned to the data and conducted comparative analysis with participants who had disclosed to a current or past partner and participants who had never disclosed. Comparative analysis by disclosure status focused on the effects of disclosure on: participants’ relationships with male partners (including risk of violence and abandonment, as well as on the potential for increased support), contraceptive use, and PMTCT and infant care (among those with previous pregnancies). We also explored participants’ experiences with providers.

RESULTS

Quantitative Information

Study participants at the time of the qualitative interviews ranged in age from 16-20 years, with a mean age of 18 (Table 1). Most participants have lost one or both parents (21/28). A little over a third report history of physical abuse (10/28) or sexual abuse (2/28). Most have had a previous pregnancy (21/28) and of those, 12 have a living child. A little under half of interview participants report any contraceptive use (11/28), with condoms (6/28) and oral contraceptive pills (6/28) the most popular methods used. Most participants are currently in relationships; 11 are cohabiting or married and of the remaining 17, ten have boyfriends.

Qualitative Data

Overview of Fertility Desires

Spacing, limiting, and deferring pregnancy emerged from the data as a central theme, described as a strategy to protect health and provide for the well-being of their current or future families. Of participants interviewed, the majority (19/28) reported a desire to limit their families to one to two children. A few participants who had never been pregnant described wanting three or more children. Among participants with previous pregnancies, many reported a desire to limit their families to the child or children they already have. Others described a preference to wait three to five years before becoming pregnant again. All participants want to have children even though they are living with HIV. Their desires to space or limit pregnancies are linked to perceived increased health risks during and after childbirth and to past experiences with infant loss. Almost half of women who had given birth lost their infant before the second birthday (9/21) and many fell ill themselves following pregnancy. The following quote illustrates the tension expressed in many interviews between fear around perceived increased risks and desire for a child.

"*I'm afraid that if I have another child that he may die. I did not expect my second child to die. So I'm now hesitant. I'm ambivalent because on the one hand I want to have a child but on the other I fear that I will have a child who will die like the others" -Age 20*

While the desire to control fertility is strong, perceived norms and expectations for childbearing constrained the ability of participants to act in accordance with their intentions to defer, space and/or limit pregnancy; while also complicating the issue of disclosure. Young women, many newly married or in partnership, describe the difficulty in pushing back against these expectations. Participants report that their partner's family and community closely watch new couples, and if they fail to show pregnancy soon after marriage, community gossip places blame on the woman. Furthermore, participants describe pressure from male partners to have multiple children, sometimes to ensure the birth of a male infant. If a young woman does not become pregnant closely after joining her partner's family, participants describe verbal abuse and threats to end the relationship or to take on additional wives. In-laws deride a young wife who does not bare children as *"wasting our food*." As one participant said:

"There will be pressure because people expect that after a marriage a couple will have children…If they are unaware of it (HIV positive status), they will keep piling on the pressure. The man's family will suggest to him that he takes in another wife who can have children since this one can't have children" -Age 18

At the same time, participants describe community perceptions that HIV positive couples should not bear children. While some participants note the potential for communities to come together in support of raising children born to HIV positive parents, interviews more commonly document community perceptions that an HIV positive woman would give birth to a "better *nahsi* (better today)" or "rotten" baby, revealing stigma against infants born to HIV positive mothers. Others describe the common perception that couples with HIV should avoid having children as they might not live long. These norms make it difficult for young women, newly brought into their partner's family and experiencing a low-status in comparison to others in the household, to use disclosure as a means for enlisting partners, families or the larger community to support their fertility desires.

Disclosure with Male Partners

Participants acknowledged that disclosure is central to carrying out fertility intentions and an essential part of preventing secondary transmission to partners and infants. The majority (19/28) of participants had disclosed their HIV-positive status to either a current or past male partner, some to more than one, and they describe disclosure as a critical step in a committed relationship. However, experiences with disclosure were not uniform. Over half of disclosures described during interviews resulted in adverse reactions from partners, ranging from anger to abuse and/or abandonment. Verbal abuse included threats to throw the participant out of the house or take away custody of their children. Eight women describe severe abuse following disclosure; in two cases abuse drove participants out of the home. Four others were abandoned, sometimes without notice as described in the quote below.

"We were staying together and he left me when I was 7 months gone (pregnant) after I told him…He just said he was leaving for work and would come back. I haven't seen him since" -Age 19

Involuntary disclosure to extended family is often part of negative reactions to disclosure. Participants describe their partners angrily announcing their status to extended family, causing humiliation and increasing experiences of stigma and discrimination. The participant quoted

below recounts how her partner took her to the shopping center where his family works following her HIV test, sharing her results without her consent to relatives who then suggested he throw her out of the home.

"My husband kept saying things to me like, 'Pack your things and go, I don't love you anymore' His relatives told him: 'How can you stay with a snake in your house...Leave her at the roundabout close to the taxi rank; she will figure out where to go'"- Age 19

On the other hand, a number of participants describe accounts of supportive responses from partners after learning their HIV status. These participants shared that their partners help them adhere to treatment or take them to the clinic when they need care. Others note reassurances of love. The quote below, recounting a positive experience with disclosure to a boyfriend, exemplifies the desired reaction many young women describe in interviews.

"I disclosed to him and he said he had no problem with that…He said we would both go for the test but he loves me anyway. He sometimes calls me to ask if I have taken my medication" -Age 20

Participants who are currently in a relationship but who have not yet told their partners that they are living with HIV describe the stress and fear they have around disclosure. Young women talk about the fear that their partners will stop loving them, take on another wife, or throw them out. They describe feeling out a boyfriend before disclosing, weighing the risk of break-up. Particularly for young women who are cohabiting in relationships that are currently supportive, or where their families have received *lobola* (bride price) in formal marriage, disclosure becomes high stakes. One young women recounted her family's fears that they would have to return *lobola* if he found out her status. Another, married nine months, describes having *"heart palpitations*", physical signs of stress as she worried that he might have found out her status before she was ready to disclose.

Pregnancy Prevention, PMTCT, and the Importance of Disclosure

Participants emphasize the importance of a positive disclosure experience for partners to understand why young woman want to defer, space and limit pregnancy despite cultural norms that place a primacy on multiple children. Condoms were discussed as participants' preferred type of contraception, given their usefulness in both preventing pregnancy and disease transmission. Couples where young women have disclosed and received support from male partners seem more likely to use condoms and other forms of contraception. Many participants who have had positive disclosure experiences talk about using dual methods (contraceptive pills and condoms), as a means to protect against transmitting HIV and to prevent unplanned pregnancy. Among disclosed couples where the partner has reacted negatively, many still refuse condoms, despite knowing the risk of transmission. In some cases, suggestions by participants to use condoms were met with threats of infidelity and forced unprotected sex.

"He would tell me that he wanted us to have sex and not use condoms. I would tell him that if we had sex without condoms we would compromise our health. He would say that I turn him down when he wants unprotected sex so he would get that from another woman." -Age 18

In cases where women had not disclosed, a few participants describe covertly using contraception to prevent pregnancy and maintain control over their fertility. Long term hormonal contraception, such as injections or implants, were the preferred method for women-initiated contraception. In interviews young women who used such methods without their partner's knowledge assert that ultimately the woman has the power to decide to use contraception.

"My husband hasn't been tested and I haven't disclosed to him. I have planned in ernest to disclose to him this weekend. Until then, we don't use condoms and I use the depo provera injection to prevent pregnancy."-Age 19

Participants demonstrate strong knowledge of PMTCT strategies, yet many with previous pregnancies describe challenges to accessing these services. Most tested before hospital delivery and took ART to prevent transmission, but a few gave birth at home as they could not pay medical fees, resulting in lack of testing and prevention services. Still others who knew their status but were not ready to disclose, had not accessed PMTCT and some had older relatives disregard requests to exclusively breastfeed. Given that mixed feeding starts as early as one month as the norm in Shona culture, this practice leads to high risk of HIV transmission to the infants post delivery.

"I was so afraid to tell him that I would panic whenever I thought about it. I decided to tell him that I wanted to exclusively breastfeed our child for only 6 months. However my sister in law would take him and feed him foods like potatoes without my knowledge…my mother in law would lash out at me saying that my child should be fed porridge. This went on until he was so sick that we took him to the hospital" – Age 20

When and How to Tell: Strategizing for Optimal Outcomes

Many participants describe strategies to ease the difficulty of disclosure. Testing as a couple arises as a disclosure strategy for cohabiting couples and boyfriend relationships; however participants share that many of their partners resist testing. Partners express fear about results, denial of risk, or a sense of fatalism. Two of the participants noted that their partners suspect they are also HIV-positive and follow the medical advice that the young women receive at the clinic, one even requesting that she share her medicine. The following quote exemplifies partner resistance to testing.

"He says he will go for an HIV test one day, when he is ready…He tells me, "Either way we are all going to die one day…Death is inevitable, whether one dies from AIDS or from an accident, it's all the same" –Age 19

To combat resistance to testing or to gauge the climate for disclosure, participants describe enlisting a family member as an ally. One participant mentions her brother-in-law as a supportive ally, sharing with him her desire to test with her partner and asking him to encourage the partner to test. In another case a participant shared that her husband first told her sister about his positive status, who then passed on the news to the participant. When she asked him why he had not told her directly, he expressed fear that she would react badly to the news. Living closely with extended family can be an asset to assist with disclosure.

Provider Advice: Disconnect with Young Women's Complex Realities

Participants generally describe satisfaction with their care providers, yet they also note a one-size-fits-all approach that comes up short of responding to the challenges they face. Many participants mention that providers encourage them to disclose their status to partners or bring partners in for testing, however care providers are not able to offer support in ensuring a positive disclosure experience. Given the risks associated with disclosure, some participants express frustration with this advice, feeling that it puts the responsibility on them but does little to provide helpful tools. Two participants described experiences when they tested positive before delivery and providers encouraged their partners to test; in both cases the partners' turned hostility against the young women, as indicated in the quote below.

"When it comes to the issue of disclosure there is a difference between what I want to do and what they (providers) tell me. They say that they want to advise my husband that we both be tested. I don't want to do that because I'm not comfortable with that." -Age 19

Participants also describe a lack of advice from providers on what to do when they want to base fertility decisions on their health status. Young women report that providers recommend they wait to conceive until good CD4 and viral load tests offer evidence that HIV is being managed through treatment; yet these tests are unaffordable for many in the study. Participants describe a need for more guidance on how to reduce the risk of transmission to partners during attempts at conception. The quote below illustrates an opinion expressed in a number of interviews.

"I have not yet gotten what I want. I have been told only how to prevent transmission of HIV from the child to the mother. I have not yet been told about what to do when I want to get pregnant again." –Age 19

DISCUSSION

During interviews, young women describe complex ways that disclosure of HIV status factors into their ability to control fertility, in particular the tension between desire to control fertility as a strategy to promote health, and cultural norms that pressure them into childbearing soon after marriage. These results expand on previous research from similar epidemiologic contexts showing disclosure as central to safer sexual practices and PMTCT [3;33-34;44].

While the majority of young women interviewed had disclosed their HIV status to either a current or past partner, experiences were generally stressful, often with negative outcomes. Our findings reveal abuse and abandonment from male partners following disclosure in over half the instances described, a much higher prevalence then that found in previous studies [27-29;31]. In a review article of published literature on disclosure in developing country contexts, Medley et al found negative responses ranging from 4%- 28% [3]. Another study in Chitungwiza, Zimbabwe found strikingly lower reports of adverse experiences following disclosure than described by our study participants; only 6 out of 193 reported negative responses [32]. There are two key reasons that could explain the different responses to disclosure revealed in our study compared to the current literature.

First, our study population is younger than the ANC and general population samples described in most other studies [3]. While research documents that disclosure is associated with younger age and lower income [27;45], there is less available information on how these factors might influence partner response to disclosure. It is possible that the lack of power young women face in their partnerships with men, and in the home, contributes to the high prevalence of adverse experiences following disclosure and the subsequent stress described. A perception that young women hold little value to family and community without bearing children weaves throughout the interviews, sending a message that young women occupy a low-status, replaceable position.

Second, previous studies relied primarily on data gathered using a structured questionnaire or focus groups, two methods that might contribute to underreporting of negative responses to disclosure [3,32]. Our open-ended qualitative interviews, conducted by research associates who have worked with SHAZ! for years, draw on rapport and trust with the study participants. Furthermore, open-ended interviews allowed the young women to tell their story in their own way, a method that has been shown to illicit candid responses to sensitive questions [46-47]. Most participants responded to interview questions with rich detail, discussing in-depth experiences with family violence, sexual communication, and infant loss. Interviews were

conducted at SHAZ! offices, the same location where the study participants go for support services and an environment in which they feel comfortable and at ease. The design used to gather data in this study encouraged detailed reporting of adverse experiences, data that possibly goes underreported using other methods.

Given the central role of disclosure in fertility control and health management, mitigating the risks of disclosure and mediating the conditions under which it occurs should be a central goal of programs and services for young women living with HIV. The high rates of adverse experiences following disclosure among our young study population, suggest that counseling with young women must be different than counseling for a different demographic. Study participants express comfort talking with their care providers, but also note frustration with the unilateral messaging around family planning for women living with HIV that encourages partner involvement, CD4 and viral load testing, recommendations out of reach for many young women. Further, implementation research with care providers could help identify ways to best train and support care providers to screen for domestic violence, and work with young women on contingency planning in the event of abandonment. However, overburdened care providers and lack of sufficient resources to meet the demand might contribute to the one size fits all advice offered study participants.

Enlisting supportive family, particularly mothers-in-law comes up as a key way to mediate the risky situation of disclosure, suggesting an opportunity to utilize the extended family to maximize positive responses to disclosure. Messaging on disclosure in Zimbabwe emphasizes the importance of disclosing in relationships [48]. However given the risk of violent reactions, abandonment and discrimination described in interviews, media tailored to the vulnerabilities of young women that draws on older family members cultural responsibility to protect them might help to nuance and adapt the discourse around disclosure to better support optimal outcomes.

Despite the covert use of long acting hormonal contraceptive methods reported in a few interviews, most young women in our study prefer using barrier methods with partner involvement. Desire for male partner engagement in contraception fits with findings from earlier research exploring perceptions of partner approval for female-initiated contraceptive methods and positive associations with consistent contraceptive use [49]. The low prevalence of covert use, despite reported partner resistance to condoms and desire to control fertility, seem to come from a preference for open communication around contraception and the risk of negative response upon discovery. Results from the MIRA trial of diaphragm use suggest that covert use of contraception falls on a continuum, with women choosing to disclose use in some occasions and not others as they weigh the risks and benefits of telling/not telling partners [50]. Young women in our study who reported covert use talk about it in the context of women's rights to control fertility, rather than as a strategy to combat partner resistance to contraceptives.

While this study has multiple strengths, for example the uniqueness and importance of the study population, the rapport between interviewers and participants, and rich interview data, it is important to also note its limitations. Interviews were conducted with a small sub-sample of the total study population and may not represent trends among the general population of young women living with HIV in Zimbabwe. While the small sample size utilized in the study precludes the generalizability of results to the greater population, the study design supports the goals of exploratory research aiming for analytic generlizability to inform future research [41-42;46-45;51].

Further research continuing to build understanding on what factors might influence positive or negative outcomes following young women's disclose of HIV status to male partners is needed

to help identify the most salient points for future intervention. Once quantitative data from the umbrella SHAZ!-PLUS study are ready for analysis at the end of the intervention, that data set can help explore relationships among disclosure, intimate partner violence, relationship power, and contraceptive use in the context of fertility desire. In addition, research utilizing in depth interviews with male partners could help strengthen understanding of reactions to disclosure. Fear and stigma, suggested by perceived resistance to testing and verbal abuse following disclosure, seems to be at the heart of negative responses. However, only through exploratory research with male partners can we gain insight into the reasoning and logic behind these actions. Research with male partners might also help to identify optimal ways to integrate men into family planning and HIV care services, a strategy that can support women to carry out fertility intentions, yet risks fostering male perceptions of control over family planning decisions [52].

CONCLUSIONS

Current SRH and HIV care services fail to respond to the complicated realities and conflicting pressures facing young women living with HIV in Chitungwiza, Zimbabwe, offering instead an approach that leaves clients without the information and resources they need to control fertility. The study population expresses a strength and resiliency that weaves throughout their stories, reflected in their clear desire for spaced and limited pregnancy as a way to protect themselves and plan for future healthy and prosperous families. HIV and SRH services for young women in Zimbabwe and in similar settings should consider comprehensive programs including those that explore what is different among young women and their partners that could lead to positive disclosure experiences, tapping into existing community level forum (e.g. church groups, burial societies) to raise these challenges, targeting education and interventions with mothers-in-law to support changes in norms at the household level, and provider training. These interventions could be tried and evaluated, as they might have the potential to bolster the decision-making capabilities of this key population as they navigate the complexities of disclosure in the context of achieving desired fertility.

Table 1

Table 1: Demographics, Relationships, and Contraceptive Use	N = 28 (%)
Demographics	
Age, mean years (Std. Dev)	18 (1.0)
Ever been pregnant	21 (75%)
Has a living child *(among those ever been pregnant)*	12 (57%)
Loss of parent(s)	21 (75%)
History of Abuse	
Physical abuse	10 (36%)
Sexual abuse	2 (7%)
Relationships	
Cohabiting/Married	11 (39%)
Single with Boyfriend	10 (36%)
Single wihout Boyfriend	7 (25%)
Contraceptive Use	11 (39%)
Contraceptive Methods Used	
(among participants reporting contraceptive use, n = 11)	
Pill	6 (55%)
Male Condom	6 (55%)
Norplant	2 (18%)
Injectable/ Depo	1 (9%)
Female Condom	1 (9%)

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