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"We have to try and have this child before it is too late": Missed opportunities in client-provider communication on reproductive intentions of PLHIV

D.L. Mindry[a,*], **T.L. Crankshaw**[b], **P. Maharaj**[c], **C. Munthree**[c], **T. Letsoalo**[c], **C. Milford**[d], **R.M. Greener**[d], **L. Rambally**[d], **S. Carpenter**[e], and **J.A. Smit**[d,f]

[a]Center for Culture and Health, Semel Institute, University of California, Los Angeles, USA

[b]Health Economics HIV/AIDS Research Division (HEARD) University of KwaZulu-Natal, Durban, South Africa

[c]School of Built Environment and Development Studies, University of KwaZulu-Natal, Durban, South Africa

[d]MatCH Research, Department of Obstetrics and Gynaecology, Faculty of Health Sciences, the University of the Witwatersrand, Durban, South Africa

[e]Don Mc Kenzie Hospital, eThekwini Health district, KZN Department of Health

[f]School of Pharmacy and Pharmacology, Faculty of Health Sciences, University of KwaZulu-Natal, Durban, South Africa

Abstract

Men and women living with HIV with access to ARVs are living longer, healthier lives that can and often do include bearing children. Children occupy a key space in men and women's personal and social lives and often play a fundamental role in maintaining these relationships, irrespective of illness concerns. Couples living with HIV need to balance prevention needs and ill health while trying to maintain healthy relationships. Health care providers serving the reproductive needs of HIV-affected couples need to consider the social and relational factors shaping reproductive decisions and associated periconception risk behaviors. This paper based on qualitative research at three hospital sites in eThekwini District, South Africa, investigates the childbearing intentions and needs of people living with HIV (PLHIV), attitudes and experiences of healthcare providers serving the reproductive needs of PLHIV, and client and provider views and knowledge of safer conception. This research revealed personal, social, and relationship dynamics shape the reproductive decisions of PLHIV and "unplanned" pregnancies are not always unintended. Additionally, conception desires are not driven by the number of living children, rather clients are motivated by whether or not they have had any children with their current partner/spouse. Providers should consider the relationship status of clients in discussions about childbearing desires and intentions. Although many providers recognize the complex social realities shaping

[*]Corresponding author: D.L. Mindry. dmindry@ucla.edu.

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their clients' reproductive decisions, they have outdated information on serving their reproductive needs. Appropriate training to enable providers to better understand the relationship and social realities surrounding their clients' childbearing intentions is required and should be used as a platform for couples to work together with providers towards safer conception. The adoption of a more participatory approach should be employed to equalize client-provider power dynamics and ensure clients are more involved in decision-making about reproduction and conception.

Keywords

safer conception; people living with HIV; reproductive decision-making; health care providers; South Africa

Introduction

In South Africa, 29% to 57% of people living with HIV (PLHIV) desire children (Cooper et al. 2007; Kaida et al. 2011; Myer, Morroni and Rebe 2007). Despite strong motivations to have children, less than half of PLHIV discuss fertility intentions with providers (Cooper et al. 2007; Schwartz et al. 2012; Wagner, Linnemayr, Kityo and Mugyeni 2012). Ignoring pregnancy desires creates missed opportunities for safer conception services and for reducing the risks of HIV transmission (Schwartz et al 2012).

Research on couples and families living with chronic or communicable illness has highlighted the complexities in balancing prevention needs and ill health while trying to maintain healthy relationships (Cusick and Rhodes 2000; Persson 2008; van Campenhoudt 1999). Children occupy a key space in men's and women's personal and social lives (Morrell 2006; Preston-Whyte 1993) and often play a fundamental role in maintaining and securing heterosexual relationships (Jewkes, Vundule, Maforah, Jordaan 2011; Mindry et al. 2011). In South Africa, having biological offspring is significant in establishing social status (Mkhize 2006; Morrell 2006; Preston-Whyte 1993) and serving the reproductive needs of PLHIV should consider these social and relational factors.

This paper is based on research at three hospital sites in eThekwini District, South Africa, investigating the childbearing intentions of PLHIV, and attitudes and experiences of healthcare providers serving the reproductive needs of PLHIV.

Methods

Research was conducted in with healthcare providers and clients in two urban and one rural ARV clinics, between May 2011 and August 2012. We recruited clients attending a rural and an urban site through announcements in the clinic waiting room. Participants completed a survey to determine whether they were HIV-positive, aged 18 to 55 years, and either had a child since being diagnosed with HIV or desired a child in the future. In depth interviews (IDIs) were conducted in isiZulu or English in private rooms within the clinics. We interviewed 21 women and 22 men; all Black South African.

Additionally interviews with 20 different providers, comprising 13 participants in two focus group discussions (FGDs) and 12 IDIs were conducted (Table 1). We informed providers about the study at staff meetings, requesting volunteers for participation in IDIs and FGDs. IDIs were conducted before FGDs to allow provider attitudes and experiences to be shared without the influence of colleagues. Providers included doctors, nurses and lay counselors. Interviews were conducted in English.

Providers and clients provided signed informed consent individually prior to interviews which were audio-recorded, translated as needed, and transcribed. Client and provider experiences regarding reproductive desires and needs of PLHIV were examined, as well as their views on delivering safer conception (SC) services.

Analysis

Transcribed interviews were coded in Atlas.ti (version 6.2). The coding scheme developed by the lead author was revised and refined based on consensus agreement with other research team members. The themes developed for the semi-structured interviews informed the dominant themes in the coding while new themes and subthemes emerged in our grounded approach (Miles and Huberman 1994, Ryan and Bernard 2003).

Approval for this study was obtained through the ethics committees at the University of the Witwatersrand, University of KwaZulu-Natal, and University of California, Los Angeles. The KwaZulu-Natal Department of Health approved the study, and participant clinic sites provided study support/approval.

Results

Eleven of 43 clients reported having a child after being diagnosed with HIV (Table 2). All clients reported a desire to have a child in the future while eight reported actively trying to conceive; one woman was currently pregnant. There were no notable differences regarding reproductive decisions based on partner's HIV status.

Not just clinical care: Social and relationship dynamics shaping reproductive desires

Personal, relational and social reasons underpinned clients' desires for children. Some clients indicated that SC services would help normalize the lives of PLHIV (Table 3, quote 1). Having or not having an existing child was not necessarily a key factor underlying clients' desire for children, rather factors within relationships (partner desire for children, and/or their own desire to secure a relationship/have a child) were stronger motivators underlying wish for a child (Table 3, quotes 2 and 3). Desire for another child of the opposite sex was another motivator. (Table 3, quote 4). Men were also likely to cite finances as a consideration in childbearing decisions.

Providers expressed awareness of the social expectations motivating client childbearing desires (Table 3, quote 5) and gender and family dynamics shaping women's childbearing decisions, as well as client health concerns (Table 3, quote 6). Addressing clients' childbearing desires touches on sensitive topics, such as willingness of the individual's

partner to participate in SC care, complex relationship dynamics, social and economic issues, that providers felt ill-equipped to address (Table 3, quote 7).

Providers' clinical priorities and safer conception training

Providers' primary concern was to ensure clients' health and viral load suppression before attempting conception (Table 4, quote 1). Some providers expressed anxiety about adding pregnancy-related complexities to ART care (Table 4, quote 2) (as did some female clients). Providers' prior training emphasized discouraging clients from having children though availability of ART was shifting this position (Table 4, quote 3).

Clients and providers had common concerns about client health status with specific attention to the well-being of the child regarding risks of vertical HIV transmission, ARV-related teratogenicity, and whether parent/s would be well enough and stay alive to care for their child(ren) (Table 4, quotes 4 and 5).

Missed opportunities to address client childbearing desires

Despite providers and clients common concerns about clients' and children's health, providers indicated that clients did not seek preconception counseling and only sought advice once pregnant (Table 5, quote 1). While viewing clients' lack of apparent pregnancy planning negatively, providers reported they did not routinely initiate childbearing discussions with their clients. One provider observed that the tendency to focus on current pregnancies led to missed opportunities to discuss SC strategies for future pregnancies (Table 5, quote 2). Power differentials between provider and client may result in client reluctance to discuss fertility desires with providers in advance of a pregnancy (Table 5, quote 3). Another provider reported that despite trying to address reproductive intentions and SC, clients only returned when pregnant (Table 5, quote 4). Only one provider reported actively assisting a client and her partner to use timed intercourse to achieve safer conception.

Some clients reported discussing their reproductive desires with providers. A few were encouraged to return when they wanted to conceive (Table 5, quote 5). Only one of the eight clients actively trying to conceive had spoken with a provider. The couple were tired of being told by the provider to wait and had discontinued condom use to attempt conception (Table 5, quote 6). Though clients and providers had similar concerns there was a marked lack of communication around reproductive desires and planning pregnancies.

Discussion

The results highlight how social and relationship dynamics shape reproductive decisions for PLHIV. Importantly, childbearing desires were not driven by the number of children clients had but rather by whether they had any children with their current partner/spouse. Contrary to provider views, "unplanned" pregnancies are not always unintended (King et al. 2011). Social expectations are strong motivators in childbearing descisions (Beyeza-Kashesya et al. 2010; Crankshaw, Mindry, Munthree, Letsoalo, Maharaj 2014; Mindry et al. 2010). Providers need to consider the current relationship status of clients in discussing childbearing intentions.

Providers noted that clients may feel uncomfortable initiating discussions. Since reports of client-provider reproductive discussions are low (Finocchario-Kessler et al. 2010; Matthews et al. 2012; Schwartz et al. 2012), providers need to routinely initiate such discussions. One doctor's suggestion that current pregnancies provide good opportunities to discuss future childbearing could be usefully integrated into reproductive care for PLHIV.

Providers lacked appropriate training and confidence to engage with client desires to have children and to leverage these desires to prevent horizontal and vertical transmission. Local clinical guidelines (Bekker et al. 2011) can be utilized to develop policies for provider-initiated delivery of SC care for PLHIV. An equally important aspect of SC care requires attention to the provider-client relationship. Studies have indicated that a positive provider-client relationship is associated with positive medical outcomes for clients (van Ryn and Burke 2000). Providers, will unavoidably be drawn into the personal and social lives of their clients, and need to be supported in dealing with these unique challenges entailed in SC care (Beyeza-Kashesya et al. 2010; Harries et al. 2007). Acknowledging the relationship and social realities informing childbearing intentions and using this as a platform for couples to work with providers towards SC strategies may yield better outcomes (Crankshaw et al. 2014). Providers need to assist clients in developing specific SC plans to meet their reproductive goals.

Conclusions

Provider-initiated discussions with clients regarding their reproductive intentions are essential to support reproductive decision-making prior to pregnancy. Clients and providers are equally concerned about the client's health status and about transmission risks. This provides a good foundation for client-provider communication to make appropriate reproductive decisions. Providers need appropriate training to enable them to deal not only with the reproductive needs of PLHIV but also to better understand and address the social and relational expectations which inform clients' decisions. The adoption of a more participatory approach towards SC counseling for PLHIV should be employed to equalize client-provider power dynamics and ensure clients are actively involved in conception decisions.

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Table 1

Provider participants by site

	Site 1	Site 2	Years of Experience			
	Rural Clinic*	Urban Clinic**	0–3	4–6	7–10	>10
Focus Groups	3 nurses	4 nurses	NA	NA	NA	NA
	4 counselors	2 counselors	NA	NA	NA	NA
Individual Interviews	3 nurses	2 nurses	2	0	3	0
	4 doctors	1 doctor	2	1	0	2
	1 counselor	1 counselors	0	1	1	0

* Three FGD participants at this site also participated in individual interviews prior to the FGD.

** Two FGD participants at this site also participated in individual interviews prior to the FGD.

Table 2

Client survey results

	Site 3 (Urban)		Site 1 (Rural)		Total
	Male	**Female**	**Male**	**Female**	
ART (Yes/No)	9/3	10/0	10/0	10/1	39/4
Relationship status (Discordant/Conconcordant/Don't Know)	1/9/0	2/5/2	2/5/2	2/7/1	7/26/5
Status disclosed (Yes/No)	8/0**	7/2	7/2	9/1	31/5
# of children (0/1–2/>3)	3/5/4	1/7/2	3/5/2	3/8/1	10/25/9
Child post HIV (Yes/No)	2/10	2/8	1/8	6/5	11/31
Desire child (Yes/No)	12/0	10/0	10/0	10/1	42/1
Currently trying (Yes/No)	1/7**	3/7	2/8	3*/8	9/30

** Missing data or not currently in a relationship, so some not relevant

* One of these women had just been notified that she was pregnant.

Table 3

Not just clinical care: Social and relationship dynamics shaping reproductive desires

Client Perspectives:	
1	I know that I am HIV positive, yes, but I can still have a child, I can still live a normal life. (male, 23, urban)
2	I do have children; their father is no longer around, so if I would be married I will need a child from marriage. (female, 34, urban)
3	I can say that it is her, the person who never had children ever since she has been a person. And now she is the person who desires to get a child, even if it is [only] one. (male, 55, urban)
4	I think that they [providers] might have that question or wondering, "Why do you want to have children because you are sick." And then I would have to explain that now that I am married and the child that we do share is a girl, now we have got to try for a boy, so that everything balances in the family. (female, 32, rural)
Provider perspectives:	
5	A lot of the women here already have children […] it's difficult as people can't come to the clinic because they don't have enough money and at the same time because they have a new partner who wants a child. (female, doctor, rural)
6	… a lot of, mainly, women worry about wanting to start a family, pressure from their partner. They hear they are positive, fears of having positive children, wanting to know what [ARV] medication you shouldn't have when you're pregnant. (female, doctor, rural)
7	I need more [training] because now I deal with HIV only and people don't come with HIV problems only. They have families and children and I can't help them if they have problems in their families. (female, counselor, rural)

Table 4

Providers' clinical priorities and safer conception training

Provider perspectives:	
1	My one concern is that there is pressure on women to fall pregnant before they are physically ready to do so. I've had some women who are in really difficult situations, got engaged or married and now they have found out that they are HIV-positive and the mother-in-law and the family wants them to have a baby. So to try and get them to postpone falling pregnant for as long as possible is difficult…. But once women are healthy and their viral load is suppressed, then by all means. (male, doctor, rural)
2	It is a challenge, as you have many patients whose CD4s are not high enough. CD4 are not more than 200, viral load is not suppressed, and partner has not even tested. They still have unsafe sex. They do want to conceive. (female, nurse, urban)
3	In the past it was always said you shouldn't have a child, before the ARVs came along. (female, nurse, urban)
4	Like is this child going to have a future? How long is the ARV going to be effective for the parents? And then the child is going to be parentless; like orphans basically. … I always think of the child. (female, nurse, urban)
Client Perspectives:	
5	I think about my HIV status, am I going to affect the child? Is it possible to have another baby or not? That is what bothers me the most. What should I do to protect my baby from getting the virus? (female, 26, rural)

Table 5

Missed opportunities to address client childbearing desires

Provider perspectives:	
1	… if they decide to fall pregnant they don't ask us and they come after the damage has been done. (FGD, nurse, rural)
2	… that's our opportunity to then talk, but to be honest we get sort of fixed on this pregnancy. We think let's get this baby healthy and then we can talk about it. But very often by then they are kind of stable on their treatment, they are doing well, and their baby may be negative. Well, there we go. Meantime, we should probably see this as a red flag, as these are young people who are falling pregnant, young people who aren't condomising, and they are actually the high risk individuals. (female, doctor, rural)
3	… I've had a few [women] who didn't want to tell us that they were pregnant because … for fear […] I mean we feel like we are really approachable but […] it's the culture of the difference between the doctor and patient, respect, and I won't question [the doctor].(female, doctor, rural)
4	I would sort of advise her to bring her partner but then very often they promise to bring their partner, but you see them a few months later already pregnant without consulting us. Sometimes they think we are telling them not to fall pregnant. (female, doctor, urban)
Client perspectives:	
5	With being positive and having children they told us that even if you are positive you can still be able to have a child, but what is important is that you should visit the clinic quite often, go to the doctors for explanation. (female, 34, urban)
6	As we come to the clinic we see other people carrying babies and being pregnant. We decided the nurse is wasting our time telling us to wait. We have to try and have this child before it is too late. (male, 50, rural)