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Fertility intentions of HIV-infected women in the United Kingdom

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Abstract

In the United Kingdom (UK), the number of pregnancies in HIV-infected women has increased dramatically over the last decade, but attitudes towards childbearing among infected women have not been previously described. The aim of this survey was to explore fertility intentions among HIV-infected women, and to assess the effect of HIV treatment and interventions for prevention of mother-to-child transmission (PMTCT) on these intentions. HIV-infected women, aged between 16 and 49 years, attending one of seven HIV clinics in the UK between July 2003 and January 2004 were asked to complete a questionnaire. Information on demographic factors, HIV test history, pregnancy history and fertility intentions (i.e. desire for children) was collected. Eighty-six percent of eligible women (450/521) completed the questionnaire. Three quarters of women (336/450) reported that they wanted (more) children. Forty-five percent (201/450) reported that HIV diagnosis did not affect their fertility intentions, 11% (50/450) that it made them want children sooner, and 10% (44/450) did not know or reported other views. About one third of women (155/450) decided they no longer wanted children after their HIV diagnosis, but 41% of these (59/144) had changed their mind following advances in HIV management and treatment. Factors associated with an increase in fertility intentions after advances in HIV management and treatment were being in a partnership and having fewer than two children. In this survey of HIV-infected women, the majority wanted children, and women were more likely to want children after improvements in HIV management and treatment. These findings highlight the need for specialized family planning and reproductive health services targeting this population.

Introduction

In the United Kingdom (UK), the number of new HIV diagnoses in women has increased substantially over the last decade, as has HIV prevalence among women giving birth, which rose from 0.06% in 1997 to 0.21% in 2008 (Health Protection Agency, 2009). Following the successful implementation of routine antenatal HIV screening throughout the UK from 1999 onwards (Townsend et al., 2006), reports of pregnancies in diagnosed HIV-infected women increased from around 130 in 1997 to almost 1400 in 2006 (Townsend et al., 2008). Studies prior to the advent of highly active antiretroviral therapy (HAART) showed reductions in live birth rates and increases in termination rates after HIV diagnosis (Stephenson and Griffioen, 1996; van Benthem et al., 2000; De Vincenzi et al., 1997), but included little information on the women themselves. Likewise, in African settings where women have limited access to antiretroviral therapy, HIV diagnosis is associated with lower fertility intentions in HIV-positive than HIV-negative women (Kaida et al., 2010; Taalo et al., 2009; Yeatman, 2009).

Since 1996, availability of HAART and improvements in HIV management have led to significant reductions in AIDS-related disease and mortality, and in the risk of mother-to-child transmission (Mocroft et al., 2003; European Collaborative Study, 2005; European Collaborative Study, 2001). Some studies subsequently showed an increase in pregnancy incidence among HIV-infected women (Blair et al., 2004; European Collaborative Study, 2005), and a corresponding decline in terminations (Massad et al., 2004; Townsend et al., 2008). Recent studies in resource-rich settings suggest that

around a quarter to a third of HIV-infected women of reproductive age intend to have children in the future, with rates approaching those in the general population (Ogilvie et al., 2007; Myer et al., 2007; Stanwood et al., 2007; Heard et al., 2007). Furthermore some studies in Africa have shown an association between use of HAART and increased fertility intentions (Maier et al., 2009; Cooper et al., 2009).

In the UK, the impact of improvements in HIV management on reproductive decision-making in HIV-infected women has not been quantified. The aim of this study was therefore to explore fertility intentions in HIV-infected women, and to assess the effect of HIV diagnosis and advances in treatment and PMTCT interventions on these intentions.

Methods

All HIV-infected women between the ages of 16 and 49 years who were attending one of seven HIV clinics on designated study days between July 2003 and January 2004 were invited to participate in the study. The seven participating National Health Service clinics (three in London, and one each in Nottingham, Leicester, Manchester and Edinburgh) were chosen according to their HIV case load, in order to include the larger centres and a balance of patient risk factors (black African ethnicity and use of injecting drugs). All women received an information sheet about the study prior to questionnaire completion. Those who agreed to participate in the survey were asked to sign an informed consent form and complete a questionnaire while waiting for their

appointments. Questionnaires could be taken home for completion and were also available in French to facilitate responses from women born in French-speaking countries in Africa. Participants received a retail voucher on completion of the questionnaire. The study was approved by the London Multi-regional Research Ethics Committee and local research ethics committees of institutions involved in the study.

The structured questionnaire was piloted before the study commenced and focused on demographic factors, HIV test history, pregnancy history and fertility intentions, and additional information was collected on factors that may have influenced pregnancy decision making, including partner's feelings, migratory status and financial situation. No identifying information was requested. For women who declined to participate, basic demographic details (age, area of residence, ethnicity, parity and reason for declining) were requested, to inform assessment of potential bias.

Two main outcomes were measured: (1) the impact of HIV diagnosis on fertility intentions, and (2) the effect on these intentions of improvements in HIV treatment and PMTCT interventions. The relevant questions were "Would you like any (more) children?", "Having had your HIV diagnosed did you change your mind about wanting (more) children?", and "Have treatments and interventions made you change your mind about wanting (more) children?" Women classified as having fertility intentions were those who had responded yes to the question "Would you like any (more) children?"

The statistical power of the survey, based on recruitment of 400 women, was assessed prior to implementation, and power calculations were explored focusing on the key

outcomes of the study. Data were analysed in Stata versions 8.2 and 11.0 (Stata Corporation, College Station, Texas, USA). Univariable analysis was performed to determine factors associated with intention for children. In addition to ethnicity, which was included a priori in all models, factors found to be associated ($p < 0.1$) with wanting children after HIV diagnosis and/or, among women who did not want children after diagnosis, with a change in attitude towards childbearing after improvements in HIV treatment and interventions were included in multivariable logistic regression models.

Results

A total of 521 women were invited to participate in the survey, and 450 (86%) completed the questionnaire, representing about 40% of all women receiving HIV-related care at the participating centres over a one-year period (1160 women were seen in 2002). Limited data were available on 28 (39%) of the 71 women who were invited to participate in the survey but did not complete a questionnaire. These women were similar to those who responded to the questionnaire in terms of age and parity and the most common reason for not completing a questionnaire was lack of interest (data not shown). Of the remaining 44 women, 26 had taken the full questionnaire home for completion but failed to return it, and 18 had no interest in the project.

Population characteristics

Women in the survey were predominantly black African (72%) (Table 1). Of those born outside the UK (79%), median duration of residence in the UK was 4.5 years

(interquartile range [IQR] 2-11 years). Few women had a history of injecting drug use (8%). Median age was 35 years (IQR 31-39 years) and median time since diagnosis was three years (IQR 1-8 years). Thirty-six percent of women (160/450) described themselves as married or co-habiting, 16% (73/450) had non-cohabiting partners, 27% (123/450) were single and 21% (94/450) were widowed, separated or divorced. Of 233 women in a partnership, 46% had an HIV-infected partner, 38% had an uninfected partner and 16% did not know, often because the partner had not been tested (Table 1). Most women were taking antiretroviral therapy (68%), predominantly triple therapy (53%, 162/304).

The majority of the survey population had been pregnant (84%) and 25 women (6%) were pregnant at the time of the survey. About 30% of all women had been diagnosed with HIV during pregnancy (Table 1). The median number of children was 1.5 (IQR 0-2) and median age at first child was 22 years (IQR 20-27 years). Three quarters of women (336/450) stated that they would like (more) children, of whom over one fifth (73/336) reported that they had experienced a period of 6 months or longer when they had tried unsuccessfully for a pregnancy (Table 1). Of these, 63% (46/73) had sought medical help for fertility.

Compared with other women, black African women were more likely to live in London (72%, 233/324, versus 40%, 51/126, $p<0.001$), less likely to have a partner (49%, 158/324, versus 60%, 75/126, $p=0.041$), more likely to have three or more children (20%, 66/324, versus 13%, 16/126, $p=0.020$) and more likely to have a history of trying for a pregnancy for more than six months (25%, 59/237, versus 14%, 14/99, $p=0.032$).

Of those women in a partnership, Black African women were more likely to have an HIV-positive partner than other women (62%, 79/128, versus 43%, 29/68, $p=0.011$). Black African women were also slightly older at diagnosis (median 29 years versus 28 years, $p=0.026$) and more likely to have had a recent diagnosis (i.e. in the last four years) (74%, 230/311, versus 46%, 56/122, $p<0.001$) compared with women born elsewhere. The presence of HIV symptoms was not related to ethnicity.

Effect of HIV diagnosis on fertility intentions

In 45% (201/450) of cases HIV diagnosis had reportedly not affected fertility decision-making (Table 2); of these, 36% (72/201) had already had all the children they wanted at the time of diagnosis, 6% (12/201) had never wanted children, and 58% (117/201) intended to carry out their childbearing plans regardless of being infected with HIV. Of the 72 women who stated that they had all the children they wanted at the time of diagnosis, 85% (61/72) had two or more children. Eleven percent of women (50/450) reported that their HIV diagnosis had made them want to have children earlier than they would have otherwise, a third (155/450) no longer wanted to have children, and 10% either did not know or reported other views (Table 2). There were no statistically significant differences in the effect of HIV diagnosis on fertility intentions by ethnicity ($p=0.08$), although black African women were slightly more likely to report no change in fertility intentions (Table 2).

In univariable analysis of factors associated with not wanting children after diagnosis (excluding 44 women who did not know or gave other responses), age at diagnosis,

years since diagnosis and number of children were significantly associated with no longer wanting children (Table 3). Factors other than those shown in Table 3 that were not associated with no longer wanting children after HIV diagnosis included region of birth (UK or other), years in the UK, history of injecting drugs, CD4 count and current HIV therapy. In multivariable analysis including ethnicity, age at diagnosis, area of residence, years since diagnosis, number of children, current HIV symptoms and partnership status, the only factors significantly associated with not wanting children after HIV diagnosis were the number of previous children and time since diagnosis (Table 3).

Effect of improvements in treatment and PMTCT interventions on fertility intentions

The majority of women were aware of the availability of HIV treatment (95%, 423/447) and PMTCT interventions (91%, 402/443). The impact of improvements in treatment and interventions was explored for women who stated that an HIV diagnosis made them not want children any more and provided information on the effect of treatment and interventions on their fertility intentions ($n=144$). Of these, 41% (59/144) changed their mind after improvements in treatment and interventions (Table 2). In univariable analyses, women with fewer than two children and those in a partnership were significantly more likely to change their mind following improvements in treatment and management (Table 4). Women with severe HIV symptoms were significantly less likely to change their mind than asymptomatic women (Table 4). In addition, although not statistically significant, a lower proportion of black African women, and a higher

proportion of London residents, women under 29 years old and those diagnosed for more than five years changed their mind about not wanting children (Table 4). In multivariable analysis of women who initially did not want children after HIV diagnosis, women in a partnership were over three times more likely to have changed their mind than women without a partner, and those with two or more children at the time of the survey were half as likely to have changed their mind about wanting children as those with fewer than two children (Table 4).

Discussion

In this survey of HIV-infected women, over half reported that their HIV diagnosis either did not affect their fertility intentions (45%) or in some cases made them want children sooner (11%). While a third of women decided they no longer wanted children after HIV diagnosis, nearly half of them changed their mind once they had become aware of advances in HIV management and treatment. Decreased fertility intentions associated with HIV diagnosis have also been reported in other studies in the pre-HAART era (Bedimo et al., 1998; van Benthem et al., 2000; Stephenson and Griffioen, 1996; De Vincenzi et al., 1997), and more recently in Africa, where access to HAART remains limited (Taulo et al., 2009; Yeatman, 2009). Qualitative studies have shown that childbearing intentions in HIV-infected women are affected by personal health-related concerns, fear of transmitting HIV to the child, and societal influences and stigma (Craft et al., 2007). The observed change in childbearing intentions associated with improvements in HIV treatment and PMTCT interventions concurs with reports of

higher pregnancy rates and lower termination rates among HIV-infected women since the advent of HAART (Massad et al., 2004; Townsend et al., 2008; Blair et al., 2004; European Collaborative Study, 2005). Although we did not specifically ask women why their attitudes had changed, likely reasons include increased survival and slower disease progression (Blair et al., 2004), as well as changing perceptions around the risk of mother-to-child transmission.

We found that among women who initially did not want children after HIV diagnosis, being in a partnership and having fewer than two children were associated with a change in intention for children following advances in treatment and interventions. Few studies in resource-rich countries have explored the association between partnership status and fertility intentions among HIV-infected individuals. In a Canadian study, Ogilvie *et al* found that women with regular partners were more likely to intend to have children in the future (Ogilvie et al., 2007), but in two cohort studies in Europe and the United States, partnership status was not a predictor of repeat pregnancy (Bryant et al., 2007; European Collaborative Study, 2005). Our findings are consistent with two studies in South Africa, which found that having fewer children and being in a relationship were associated with increased fertility intention (Myer et al., 2007; Cooper et al., 2009). Other economic and social factors may also influence an HIV-infected woman's pregnancy decisions following diagnosis. Many of the women in this study had recently arrived in the UK, and almost half were not in a partnership. Therefore, while these women may want children, they may have to delay childbearing. Indeed, although fertility intentions have been shown to increase as a result of access to

HAART, this does not necessarily translate into an increase in live births rates (Maier et al., 2009).

Approximately one third of the women in this study were diagnosed with HIV when they sought antenatal care. The introduction of universal antenatal screening has meant that more women are now diagnosed for the first time in pregnancy. In the UK and Ireland, the proportion of HIV-infected pregnant women who were newly diagnosed in pregnancy increased from one third before 2000, when routine antenatal screening was introduced in England, to 60% between 2001 and 2003 (Townsend et al., 2008).

In this survey, nearly a quarter of women who expressed an intention for children stated that they had previously tried to conceive for more than six months. With an increasing number of HIV infections among heterosexual men and women in the UK (Health Protection Agency, 2009), and increasing desire for parenthood, the need for reproductive health services, including assisted reproduction, has already been rising (Frodsham et al., 2006). UK guidelines recommend pre-conceptual counselling for HIV-infected women wishing to become pregnant, in order to minimise the risk of transmission, both to their infants and to HIV-negative partners (Fakoya et al., 2007). For women who are on antiretroviral therapy before they conceive, changes to drug regimens may be required to avoid fetal exposure in early pregnancy (Coll et al., 2008). In this survey, over one third of women reported having an HIV-negative partner and about half of these reported a desire for children, highlighting the importance of ensuring safe conception among serodiscordant couples. Fertility evaluation is recommended for women who have not conceived after 6 to 12 months, with assisted

reproduction techniques available in specialist centres (Fakoya et al., 2007). There is therefore a clear need for integrated sexual and reproductive health services, to ensure that women have access to HIV care and treatment, as well as to appropriate advice on contraception and methods for safe conception and assisted reproduction if required (Fakoya et al., 2007). Qualitative research into the factors driving fertility intentions among HIV-infected women of different ethnic groups, as well as their partners, would further inform health service requirements.

Although a high response rate was achieved in this survey, women who opted out may have differed in some way from those who participated. Since lack of interest was the main reason for non-participation, it is possible that women who opted out were less interested in fertility issues, and therefore less likely to desire children. Furthermore, as the clinics were selected to include women with a specific risk profile, they were not necessarily representative of the wider population of HIV-infected women in the UK. The majority of women in this survey were black African (72%) and 53% of women were taking triple antiretroviral therapy, consistent with UK and Ireland national surveillance data (Townsend et al., 2008; Health Protection Agency, 2009). In contrast, women surveyed were slightly older (median age 35 years, IQR 31-39 years) than HIV-infected pregnant women as a whole in the UK and Ireland in 2004-2006 (median age 30 years, IQR 26-34 years) (Townsend et al., 2008). As this survey relates to reported fertility intentions and not necessarily to the likelihood of future pregnancies, this age difference was not considered important. In this survey which did not address current contraception, it was not possible to address the role of unplanned pregnancy, which is

known to be an important issue in this population. For example, in one study of HIV-infected women in Italy, only half had planned their pregnancies (Fiore et al., 2008). Although this survey was conducted in 2003-2004, use of effective antiretroviral therapy and programmes for prevention of mother-to-child transmission were already well established in the UK at that time, and results from this survey are therefore still relevant.

In conclusion, the majority of the HIV-infected women interviewed in this study wanted to have children, and about half of the women who initially did not want children after HIV diagnosis changed their mind following improvements in HIV management. These findings highlight the need for integrated health services linking HIV care and treatment with sexual and reproductive health services.

Table 1: Summary of demographic and clinical details

	Demographic Factor	<i>n</i> (%)
Area of residence (<i>n</i>=450)	London	284 (63%)
	Rest of England	120 (27%)
	Scotland	46 (10%)
Ethnicity (<i>n</i>=450)	Black African	324 (72%)
	Other	126 (28%)
Born in UK (<i>n</i>=450)	Yes	95 (21%)
	No	355 (79%)
Years in UK¹ (<i>n</i>=310)	≤5 years	175 (56%)
	>5 years	135 (44%)
Years since diagnosis (<i>n</i>=433)	≤5 years	286 (66%)
	>5 years	147 (34%)
Ever injected drugs (<i>n</i>=445)	Yes	35 (8%)
	No	410 (92%)
Age (<i>n</i>=430)	<29 years	88 (20%)
	≥29 years	342 (80%)
In a partnership (<i>n</i>=450)	Yes	233 (52%)
	No	217 (48%)
HIV status of partner² (<i>n</i>=233)	Positive	108 (46%)
	Negative	88 (38%)
	NK/Not tested	37 (16%)
Current HIV symptoms (<i>n</i>=433)	None	234 (54%)
	Mild/moderate	173 (40%)
	Severe	26 (6%)
CD4 count (<i>n</i>=345)	<350 cells/μl	194 (56%)
	≥350 cells/μl	151 (44%)
Current HIV therapy (<i>n</i>=445)	Yes	304 (68%)

	No	141 (32%)
Ever pregnant (n=450)	Yes	377 (84%)
	No	73 (16%)
Pregnant at HIV diagnosis (n=450)	Yes	130 (29%)
	No	320 (71%)
Number of children at diagnosis	0	124 (28%)
	1	130 (29%)
	2+	196 (43%)
Previous miscarriage/TOP (n=450)	Yes	181 (40%)
	No	269 (60%)
Tried for a pregnancy >6 months³ (n=336)	Yes	73 (22%)
	No	263 (78%)

Restricted to: ¹ women born outside the UK (year of arrival not known for 45 women);

² women who had a partner; ³ women who had wanted to become pregnant.

NK, not known; TOP, termination of pregnancy; UK, United Kingdom.

Table 2: Effect of an HIV diagnosis and improvements in HIV treatment and PMTCT interventions on desire for children

Response	Total	Black African women	Other women
No effect	201 (45%)	152 (47%)	49 (39%)
Wanted children earlier	50 (11%)	32 (10%)	18 (14%)
Did not want children after HIV diagnosis	155 (34%)	114 (35%)	41 (33%)
<i>Improvements in treatment and interventions have not affected this</i>	85 (19%)	65 (20%)	20 (16%)
<i>Improvements in treatment and interventions have made me desire more children</i>	59 (13%)	41(13%)	18 (14%)
<i>Not known if treatment and interventions have made me desire more children</i>	11 (2%)	8 (2%)	3 (2%)
Not known/Other *	44 (10%)	26 (7%)	18 (14%)
Total	450 (100%)	324 (100%)	126 (100%)

* Examples of 'Other' included felt too old, no partner, or not yet on treatment

Table 3: Odds of not wanting a child after receiving an HIV diagnosis¹

	Total (<i>n</i>)	Did not want children <i>n</i> (%)	OR	95% CI	<i>p</i> - value	AOR (<i>n</i> =379)	95% CI	<i>p</i> -value
Residence								
Non-London	145	57 (39%)	1.00			1.00		
London	261	98 (38%)	0.93	0.61-1.41	0.726	0.75	0.47-1.19	0.222
Ethnicity								
Other	108	41 (38%)	1.00			1.00		
Black African	298	114 (38%)	1.01	0.64-1.59	0.957	1.27	0.75-2.16	0.374
Age at diagnosis								
≤29 years	186	82 (44%)	1.00			1.00		
>29 years	220	73 (33%)	0.63	0.42-0.94	0.025	0.74	0.46-1.19	0.216
Years since diagnosis								
≤5 years	256	88 (34%)	1.00			1.00		
>5 years	134	62 (46%)	1.64	1.07-2.52	0.022	1.72	1.03-2.85	0.037
Partnership status								
No	196	82 (42%)	1.00			1.00		
Yes	210	73 (35%)	0.74	0.50-1.11	0.143	0.69	0.45-1.07	0.100
Current HIV symptoms								
None	211	77 (36%)	1.00			1.00		

Mild/moderate	154	64 (42%)	1.24	0.81-1.89	0.327	1.35	0.85-2.14	0.202
Severe	24	10 (42%)	1.24	0.53-2.93	0.619	1.04	0.42-2.58	0.926
Number of children at diagnosis								
<2	225	98 (44%)	1.00			1.00		
≥2	181	57 (31%)	0.60	0.40-0.90	0.013	0.55	0.35-0.87	0.010

¹ Includes 406 women where clear information on desire for children was reported (excludes 44 women from Table 2 for whom desire for children after HIV diagnosis was classified as Not known or Other).

AOR, adjusted odds ratio; CI, confidence interval; IDU, injecting drug use; OR, odds ratio; UK, United Kingdom.

Table 4: Odds of wanting a child since improvements in HIV treatment and PMTCT interventions among women who no longer wanted children after HIV diagnosis¹

	Total (<i>n</i>)	Desire children <i>n</i> (%)	OR	95% CI	<i>p</i> - value	AOR (<i>n</i> =137)	95% CI	<i>p</i> -value
Area of residence								
Non-London	53	17 (32%)	1.00			1.00		
London	91	42 (46%)	1.82	0.89-3.69	0.099	2.11	0.88-5.10	0.095
Ethnicity								
Other	38	18 (47%)	1.00			1.00		
Black African	106	41 (39%)	0.70	0.33-1.48	0.351	0.79	0.29-2.16	0.646
Age at diagnosis								
≤29 years	74	34 (46%)	1.00			1.00		
>29 years	70	25 (36%)	0.65	0.33-1.28	0.213	1.02	0.44-2.38	0.954
Years since diagnosis								
≤5 years	81	31 (38%)	1.00			1.00		
>5 years	59	27 (46%)	1.36	0.69-2.69	0.375	0.97	0.37-2.56	0.948
Partnership Status								
No	74	21 (28%)	1.00			1.00		
Yes	70	38 (54%)	3.0	1.50-5.98	0.002	3.73	1.70-8.19	0.001
Current HIV symptoms								
None	68	34 (50%)	1.00			1.00		
Mild/moderate	62	24 (39%)	0.63	0.31-1.27	0.197	0.60	0.26-1.42	0.246

Severe	10	1 (10%)	0.11	0.01-0.93	0.042	0.13	0.01-1.14	0.065
Number of children at diagnosis								
<2	89	43 (48%)	1.00			1.00		
≥2	55	16 (29%)	0.44	0.21-0.90	0.024	0.41	0.18-0.94	0.036

¹ Excludes 11 women who did not provide information on the effect of treatment and interventions.

AOR, adjusted odds ratio; CI, confidence interval; IDU, injecting drug use; OR, odds ratio; UK, United Kingdom.

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