

The double burden of HIV and infertility in Rwanda: what lessons can we learn for infertility care in sub-Saharan Africa?

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Abstract

Introduction: When planning infertility services in sub-Saharan Africa (SSA) the management of HIV infected couples needs careful attention. Very little is known about the potential demand for infertility services among HIV infected couples, the interplay between HIV infection and infertility and the specific counselling needs of this group.

Methods: A review of the literature was combined with data from own field research, a case-controlled study in an infertility clinic in the Kigali University Teaching Hospital in Rwanda.

Results and discussion: Based on the limited available evidence it can be hypothesized that in SSA a substantial number of HIV infected couples suffer from decreased fertility but no firm conclusions can be drawn on the actual prevalence of infertility in HIV infected couples, or their potential demand for fertility services. The interaction between HIV and fertility desires is complex and varies considerably between individuals. The severe psychosocial problems HIV infected infertile couples face and the ethical dilemma between the right or desire to reproduce and the risk or fear of transmitting the virus adds considerably to the complexity of the infertility care of these patients.

Conclusion: The management of patients, carrying the double burden of HIV and infertility is challenging from an ethical, psychological and medical point of view and requires specific counselling skills.

Key words: Counselling, ethics, HIV, infertility, sub-Saharan Africa.

Introduction

Infertility and HIV infection are affecting a large number of couples in sub-Saharan Africa (SSA) and several studies have shown that both conditions are linked in various ways. In 2009 it was estimated that HIV prevalence in SSA among adults (15-49) was 5.0 % with more than 22 million people living with HIV, 68% of the global total (UNAIDS, 2010). The prevalence of infertility is more difficult to estimate due to lack of proper prevalence studies and the use of different working definitions of infertility. The overall prevalence in SSA is about 9 % with certain countries reaching 30% with the rate of secondary infertility being responsible for the large variation (Boivin et al., 2007). The WHO estimated that in 2002 more than 186 million ever-married women of reproductive age (15 to 49) in developing countries (excluding China) were infertile because of primary or secondary infertility (Rutstein and Iqbal, 2004).

The relationship between HIV and fertility is bi-directional and highly complex (Zaba and Gregson, 1998).

Population based surveys in Uganda and analyses of data from antenatal clinics in a number of countries have suggested that fertility is lowered, between 25-40%, in women with HIV (Gray et al., 1998; Ross et al., 2004; Zaba and Gregson, 1998). From these studies it is difficult to ascertain the mechanisms through which HIV affects fertility, since infertility investigations were not part of the study procedures and many of the postulated mechanisms remain to be elucidated.

What are possible mechanisms explaining the association between HIV prevalence and infertility? Infertility in SSA is mainly caused by ascending genital tract infections, acquired through sexual transmission or after obstetrical and post abortion complications (Belsey, 1976). Since HIV is also sexually transmitted, co-infection with STIs could

partly explain the association. Moreover, research indicates that besides co-infection with STIs, there could be a direct effect of HIV on fertility through increased clinical and subclinical pregnancy wastage and anovulation in the female, and hypogonadism and impaired spermatogenesis in the male (Crittenden et al., 1992; Dondero et al., 1996; Gray et al., 1998; Lasheeb et al., 1997; Muller et al., 1998; Nicopoullou et al., 2004; Temmerman et al., 1992). There is also some limited evidence that HIV worsens the tubal damage caused by pelvic inflammatory disease (PID) (Kamenga et al., 1995; Moodley et al., 2002); whether HIV can directly cause tubal damage is not known.

The reverse - infertility increasing the risk of acquiring HIV infection - could also be true. In a cohort study of HIV infected and uninfected women in rural Uganda, subfertility existing before seroconversion to HIV accounted for almost 50% of the observed association between HIV and lowered incidence of pregnancy (Ross et al., 1999). From social research it is known that infertility causes marital breakdown and makes couples engage in extra marital affairs which exposes them to an increased risk of HIV infection (Barden-O'Fallon, 2005; Favot et al., 1997; Gerrits, 1997; Ikechebelu et al., 2002).

While the exact association between the prevalence of HIV and infertility is not known, the above clearly shows that efforts to plan infertility care in SSA will need to take on board the issue of HIV infection. To be able to do so the following questions need to be answered.

- What is the prevalence of HIV among infertile couples in SSA?
- What is the burden of infertility and the potential demand for infertility services among HIV positive couples in SSA?
- How does HIV infection interact with fertility desires in infertile couples in SSA?
- What are the challenges for the counselling of HIV infected infertile couples?

The current article, based on a literature review and our own research in Kigali, Rwanda, intends to address these questions.

Methods

Literature search

Medline was systematically searched for relevant peer-reviewed English language articles, combining two or more of the following search terms: infertility, fertility or childbearing or pregnancy intentions or desire, reproductive decision, counselling, HIV, Africa. We identified four papers reporting on HIV

prevalence among infertile couples but no papers on the prevalence of infertility among HIV infected couples in SSA. On fertility intentions or child-bearing intentions among HIV positive women and men over 100 papers were found but none among HIV positive infertile couples. There is no literature on the counselling of HIV infected infertile couples in SSA. A few papers from resource rich countries report on their experience with treating HIV infected couples, including counselling.

Case control study among infertile and fertile couples in Rwanda

Between November 2007 and May 2009, an infertility research clinic was opened at the Kigali Teaching Hospital in Rwanda (the largest public hospital in Rwanda). The primary objective of the study was to evaluate risk factors and determinants of infertility in Rwanda, including HIV and other reproductive tract infections. As secondary objectives the outcome of infertility investigations, the socio-cultural consequences of infertility and treatment-seeking behaviour in infertile couples were examined. Sexually-active women aged 21 to 45 years presenting with infertility problems at the infertility research clinic were invited to participate in the case-control study. Fertile controls that recently delivered were recruited from the community. In both groups 312 women were included. After inclusion, women invited their male partners to participate, of which 254 and 189 responded in the infertile and fertile groups respectively. In a face-to-face interview, participants were asked about socio-demographic characteristics and their sexual behaviour, and tested for HIV and STIs. Additionally, infertile couples underwent infertility investigations and, when feasible, infertility treatment and follow-up in the clinic. The methodology of this research has been described in detail elsewhere (Dhont et al., 2010, 2011a, 2011b).

Results and discussion

What is the prevalence of HIV among infertile couples in SSA?

The few studies that systematically measured HIV infection in African infertile couples all indicate that HIV prevalence is much higher in infertile couples than in the general population. In Tanzania, HIV infection was threefold higher among infertile women compared to fertile controls, 18.2% and 6.6% respectively (adjusted odds ratio (AOR) for age, residence and occupation 2.7; 95% CI = 1.4-5.3) (Favot et al., 1997). Similarly, in Nigeria, HIV infection among women undergoing laparoscopy

evaluation for infertility was fivefold higher compared to HIV prevalence among pregnant women and threefold higher in women with tubal factor infertility compared to the general population (Adesiyun et al., 2008; Ikechebelu et al., 2002).

In our case-control study in Rwanda the HIV prevalence was 16% among fertile women, 18% among primary infertile women (women who had never been pregnant before), and 43% among secondary infertile women (women who conceived at least once before). In fact, only secondary infertility but not primary infertility was associated with HIV infection for women (AOR = 4.03, 95%CI = 2.44-6.65; AOR = 1.63, 95%CI = 0.90-2.96, respectively) (Dhont et al., 2011a). Also remarkably, there were many more *newly* diagnosed HIV positive cases among men and women in infertile relationships compared to fertile relationships. Of the 312 women and 254 men in infertile relationships, 49 and 62 respectively had never been tested for HIV before and 79 new cases of HIV infection (48 women and 31 men) were diagnosed, representing more than half of all HIV infections in this group. In the fertile group only four women and 13 men had never received a HIV test and 16 new positive cases of HIV (11 women and five men) were detected in this group.

Although based on limited reports it can be hypothesized that in many regions of SSA, especially those with a high HIV prevalence, a considerable number of infertile couples will be HIV infected, making HIV testing compulsory for the infertile couples that visit the clinic for infertility examinations and treatment. In fact HIV counselling and testing of infertile couples may identify new HIV infections and considerably increase opportunities for HIV care and prevention.

What is the prevalence of infertility and the potential demand for infertility services among HIV positive couples in SSA?

Recently it has been recognized that the reproductive health needs of HIV infected couples deserve more recognition and attention (Delvaux and Nostlinger, 2007). Although calls are made by several authors to respect the fertility intentions of people living with HIV (PLWHIV), so far no attempt has been made to measure the burden of infertility among PLWHIV in SSA.

There are two studies from resource rich countries reporting on infertility factors among HIV infected couples. An audit of the Chelsea and Westminster HIV fertility clinic demonstrated a 40% prevalence of tubal factor infertility in HIV infected women, which is considerably more than the 14% prevalence

found 20 years earlier in an unscreened UK population (Gilling-Smith et al., 2006). In Spain HIV positive women (not necessarily with history of infertility) were examined for tubal abnormalities in a preconception counselling clinic and a 28% prevalence of tubal blockage was found (Coll et al., 2007).

In a population based survey in Uganda, a history of subfertility – defined as the inability to achieve a pregnancy for two or more years – was significantly more often reported by HIV infected women compared to uninfected women (14.8% versus 7.8%, $p < 0.001$) (Gray et al., 1998). In our cohort of women in infertile relationships, HIV infected women were more likely to have tubal factors than non infected women (OR = 1.84; 95% CI = 1.00-3.37). To our knowledge other studies on this subject have not been performed in SSA. It seems reasonable to hypothesize that in SSA, with its background of high PID incidence, prevalence of tubal factors among HIV positive women will be high.

The only data on the demand for infertility services in HIV infected patients comes from a survey in the United Kingdom (UK). It was found that 16% of men and 4 % of women attending HIV specialist clinics had enquired about fertility treatment (Frodsham et al., 2006).

In conclusion, based on the limited available data it can be speculated that fertility is considerably decreased in HIV infected couples, but the actual prevalence of infertility and the demand for infertility services among these couples remains largely unknown.

How does HIV infection interact with fertility desires in infertile couples in SSA?

When examining the interplay between HIV and infertility two different situations can be distinguished. First, HIV infected couples (concordant or discordant and aware of their diagnosis) wanting children and subsequently faced with the situation of the inability to conceive; and secondly, couples suffering from infertility, faced with the diagnosis of HIV infection in one or both partners during infertility work-up.

Referring to the first group of couples the question arises: how does HIV infection impact on the fertility desires of these couples and how does infertility care seeking behaviour of HIV infected couples differ from non-HIV infected couples? The answer is very short: we know next to nothing about this. Studies on the impact of HIV on fertility desires among couples of reproductive age indicate that HIV can negatively influence the wish for childbearing, but for many couples especially those without any children and/or on highly active anti-retroviral therapy

(HAART) and/or in good health, the need to reproduce often overrules the fears of HIV transmission (Myer et al., 2007).

HIV programs in SSA are currently emphasizing the prevention of unwanted pregnancies among their clients and links with family planning services are currently being strengthened in several ways (Gillespie et al., 2009; Duerr et al., 2005). For those HIV infected couples who want to continue to bear children and are unable to do so, no services are yet in place. It is not known how many are expressing their desire and difficulties bearing child with the health care workers. It is possible that due to the ambivalent attitudes of health care workers towards their pregnancy desires, HIV infected women are more likely to underreport their desire for children (Nduna and Farlane, 2009). In Rwanda, formal policies do not forbid HIV infected couples to become pregnant but the integration of family planning with HIV services is currently a top priority. In our own experience many health care workers in Rwanda are reluctant to help HIV infected couples with infertility problems. In our study HIV positive women were less likely to have looked for infertility treatment in the past than HIV negative women, though the association was not statistically significant (33/51; 65% versus 194/162; 74%, respectively; $p = 0.16$).

The second situation raises the question on how infertile couples cope with the diagnosis of HIV and whether their desire for children is altered subsequently. Our literature search identified reports on this topic among a general population but not among infertile couples. In Ethiopia voluntary counselling and testing (VCT) clients were asked about their fertility intentions before and after receiving their HIV test results. Mainly discordant couples ceased desiring children (Bonnenfant et al., 2012). It remains to be seen whether this intention is a long-term one and whether this also applies to infertile or childless couples in whom the desire for children tends to be strong.

In our study we followed 98 HIV infected women in an infertile relationship throughout their infertility investigations and in some cases throughout their infertility treatment. Half of these women had received their HIV diagnosis in our clinic. Although we did not systematically investigate attitudes and behaviours of these couples with regards to their HIV status, reviewing the medical chart notes that were recorded by study staff during follow-up visits, we identified the following key findings:

- Disclosure of HIV diagnosis towards the partner is often very problematic; many couples have still not disclosed the diagnosis to their partner after

one year of follow-up. This was the case for both women and men.

- In a few couples individual -and often intensive- counselling had a positive impact on the disclosure of one's HIV diagnosis to his/her partner and the general communication between partners.
- HIV discordant couples struggle with the wish to bear children and the fear of infecting the HIV negative partner when having sexual intercourse.
- Many HIV negative women cannot negotiate condom use with their HIV positive partner if he wants to bear children.
- The male partners of HIV positive women are less likely to participate in the infertility work-up than partners of HIV negative women (70/98, 71% versus 181/208, 87%).
- Many infertile couples in our cohort had marital and relational problems and these were exacerbated when HIV infection was found in one or both partners (especially when discordant).
- In some cases HIV infection makes one or both partners stop wanting children, but often there is disagreement between partners about this.
- Loss to follow-up is a problem among all infertile couples but even more so among HIV infected couples.

What are the counselling needs of HIV infected infertile couples?

The presence of an HIV infection in one or both partners adds to the often considerable medical, psychological and ethical complexity of infertility care (Tschudin et al., 2008).

First, from a medical point of view, HIV is a chronic disease associated with considerable morbidity and mortality, though potent antiretroviral therapy has drastically improved the prognosis of PLWHIV.

Second, the conflict between the desire and/or right to reproduce and the risk of transmitting the virus to the partner or the offspring is a major ethical dilemma both for the patient and the health care workers. This dilemma is at the core of the troubles HIV infected persons face with their intimate partners, often leading to domestic violence and disruption of their relationships. Furthermore they are often victim of stigmatisation and discrimination in their communities, adding considerably to the psychological burden of HIV (Bos et al., 2008; Ehiri et al., 2005).

Combined with the suffering caused by infertility these couples carry the double burden of conditions which have both tremendous negative impacts on psychological wellbeing and social relationships

(Dyer et al., 2002; Dyer et al., 2005; Gerrits, 1997; van Balen and Bos, 2009).

Based on insights gained in our study in Rwanda, we will focus in this section on two aspects of the counselling needs of HIV infected infertile patients: first, HIV diagnosis related issues such as disclosure to partners and need for treatment adherence and second, infertility treatment related issues.

If infertility clinics provide testing for HIV, as they arguably should do, many couples will learn for the first time their HIV positive diagnosis. The breaking of this news needs to be provided in a sensitive way. Issues which need to be emphasized and discussed at the first post-test counselling include: the fact that HIV is a chronic disease and will need lifelong treatment and follow-up; the prevention of the risk of HIV transmission to sexual partner(s) and child(ren); and the need of disclosing the diagnosis to one's partner.

Some patients will react in disbelief and will not accept this diagnosis immediately. It might need repeated testing and counselling to convince them to register in a HIV clinic for treatment. Disclosing the diagnosis to the partner and/or convincing the partner to take the test are often problematic, as was seen in our clinic. Many of these couples face already severe marital problems due to infertility and they fear that the diagnosis of HIV will scatter any hope to reconcile. That disclosure of one's HIV status to his/her intimate partner can be problematic has been described in numerous reports. A review of 15 studies from sub Saharan Africa and Asia found that disclosure rates among HIV positive women ranged from 17 to 80% (Medley et al., 2004). It has been recognized that health care workers need support as they negotiate the difficult balance between encouraging disclosure and keeping HIV status confidential. A number of reports indicate that trained counsellors can help with disclosure (Obermeyer et al., 2011).

In deciding which couples are eligible for infertility treatment there are always several aspects which need to be considered, including medical factors such as age, aetiology and available ARTs and ethical considerations about parenthood capacities. For couples where one or both partners are HIV infected, some additional elements have to be taken into account, making the decision even more complex. Questions to be addressed when considering infertility treatment for these couples and when counselling them include the following:

- Is the patient on HAART and adhering to treatment?
- Health status: stage of AIDS?
- Which partner is infected?

- Is the couple aware of each other's HIV status?
- How is the couple's relationship?

If the patient is treated with HAART there is less risk of transmitting the virus to the partner and from the mother to the child (from 30% without to less than 2% with HAART) and there is an increased life expectancy. In some sub-Saharan African countries HAART treatment is not readily available. In these cases it might be hard to justify infertility treatment for HIV infected couples and counselling should be directed towards double protection (against pregnancy and infection).

In a couple with a diagnosis of bilateral swollen and blocked tubes (hydrosalpinx) in the woman or absence of sperm (azoospermia) in the man, the chances of conceiving without any reproductive technologies are very slim. If these technologies are not available the couple should be counselled toward the point that the risk of infecting the partner is much higher than the chance to conceive and they should be strongly advised to use barrier methods in order to prevent HIV transmission.

Reproductive technologies (IVF, ICSI, IUI and sperm-washing) can help these couples to prevent transmission of the virus to the partner and/ or the child and their use can be life saving for the discordant couple, even in the absence of subfertility. If only the woman is infected, bed side insemination at home with sperm of the male partner (sperm of man is collected and drawn into a syringe and injected in his partner's vagina) could be an option. If only the man is infected, the woman could be inseminated with washed semen.

Conclusion

When planning infertility services in sub-Saharan Africa the issue of how to manage HIV infected couples needs careful consideration. At present very little is known about the prevalence of infertility and the demand for infertility services among these couples. Clinical studies investigating the prevalence of infertility and the different causes of infertility among HIV positive couples and their fertility seeking behaviour are needed to answer this question.

The provision of fertility treatment to HIV infected couples is challenging from an ethical, psychological and medical point of view and special counselling skills are needed to manage these couples appropriately. Further quantitative and qualitative research evaluating the interplay between fertility desires and HIV infection in these couples could provide useful insights in the counselling skills needed for the management of these couples in fertility clinics.

Against this backdrop, protocols for the management of infertile couples in resource poor countries, including the management of HIV infected infertile couples are urgently required and a prerequisite for the scale up of infertility treatment in SSA.

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