

## Exploring the Reproductive Decision-making Process of HIV Positive Women in County Victoria, Trinidad and Tobago

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### ABSTRACT

**Objective:** The community-based Prevention of Mother to Child Transmission (PMTCT) programme in Trinidad and Tobago offers care and support to HIV-positive (HIV<sup>+</sup>) pregnant women and their families for their lifetime. This study explored the factors influencing repeat childbearing by PMTCT enrollees.

**Method:** In-depth qualitative interviews were conducted with purposively selected and consenting HIV<sup>+</sup> women who enrolled in the PMTCT programme (n = 10) in County Victoria and four healthcare workers (HCWs). Transcribed interviews were analysed and coded using thematic content analysis.

**Results:** Though women desired children and motherhood, some did not intend to conceive fearing HIV, age-related ill-health and vertical transmission. Others had not considered pregnancy and conceived through accident and partners' disregard for the women's HIV status, particularly if such partners were inebriated. Partners' desire for children, especially in new relationships, led to planned pregnancies. Nine of the 10 HIV<sup>+</sup> women did not seek family planning advice; the one that did was advised about partner infection but not risk reduction, vertical transmission or reinfection. Though HCWs supported HIV<sup>+</sup> women's reproductive rights, they agreed that HCWs stigmatized and discriminated against HIV<sup>+</sup> mothers. Both parties saw the PMTCT programme as an effective programme in vastly reducing HIV transmission from mother to child.

**Conclusion:** The PMTCT programme and family planning services should be integrated with tailored services toward HIV<sup>+</sup> women and their partners to help them safely achieve their reproductive goals. Healthcare workers should be given training and skillsets to address stigma and discrimination against persons infected with HIV/AIDS within Trinidad and Tobago's health workforce.

**Keywords:** Caribbean, HIV positive women, repeat pregnancy, reproductive decision-making

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### INTRODUCTION

The Prevention of Mother to Child Transmission (PMTCT) programme, rolled out in 2000 in Trinidad and Tobago (TNT), aimed to reduce vertical transmission of HIV from HIV<sup>+</sup> women to their unborn babies or exposed infants (1). In TNT, the PMTCT programme enrolls women diagnosed with HIV during their pregnancy. The sexual and reproductive health of these women, and by extension, of their sexual partners, must be addressed to assure that they can meet their reproductive goals for more children with reduced risk of infection and re-infection for themselves, their partners and children (2).

Reproductive decision-making by HIV<sup>+</sup> women is very complex, being influenced by their desire for motherhood and personal fulfilment (3). In the United States of America (USA), HIV<sup>+</sup> women expressed a strong desire to have a child even if some did not intend to conceive (4). In India, the desire to have children was the motivating factor for HIV<sup>+</sup> women to improve their health before conception (5). A pilot study of 50 HIV<sup>+</sup> women and 44 HIV<sup>-</sup> women in Burkina Faso found no difference in the desire for children between the two groups (3). Another study in Burkina Faso of a cohort of 306 HIV<sup>+</sup> women found that they conceived despite family planning advice against it (6). Stigma and discrimination against HIV<sup>+</sup> pregnant women was also recorded in Cape Town, South Africa (7).

Women's social status in South Africa depended on their ability to conceive, which may override the reproductive decision of a woman who does not want to conceive (7). Women in that study were strongly influenced by their partners' desire to have children. Married HIV<sup>+</sup> women

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feared infidelity or rejection if they did not comply with their husbands' wishes to have children. HIV<sup>+</sup> men in South Africa, irrespective of their sexual orientation, desired fatherhood, especially if they were childless (7–8). Similarly, in Vietnam (9), men had a desire for children to carry on the family line despite having HIV<sup>+</sup> wives.

Some HIV<sup>+</sup> women saw the provision of antiretroviral therapy (ART) in the PMTCT programme as a chance to have healthy infants, especially if they already had an HIV<sup>+</sup> child (9). This study, set in County Victoria, TNT, explores the role of the PMTCT and family planning services in the decision-making process of women who conceive subsequent to their HIV diagnosis. From this study, policy formulation and guidelines may come on stream to offer services tailored to HIV<sup>+</sup> women of reproductive years, which are sensitive, non-judgemental and free from stigma and discrimination.

## SUBJECTS AND METHODS

Ten HIV<sup>+</sup> women who had been part of the PMTCT programme in County Victoria for at least two years and who delivered babies between January 2011 and March 2012, and four healthcare workers (HCWs) with at least three years' experience caring for HIV<sup>+</sup> persons were purposively recruited. Interviews with the women focussed on their reproductive decisions for the last pregnancy. All 14 participants consented to taped, open-ended interviews. Data were coded and analysed using a thematic content analysis. The University of Liverpool (UoL) and South West Regional Health Authority (SWRHA) gave ethical approval for this study.

## RESULTS

The HIV<sup>+</sup> women were between 20 and 34 years old and most were of mixed race, religious, co-habited with their partners, and had completed secondary education. Unemployment was high because most of the women chose to stay at home with their children. The women had between one and six pregnancies and had all their children living with them. The overarching themes relating to reasons for conception were women's and partners' desire but lack of planning for children; and those relating to healthcare norms were on stigma and discrimination, reproductive rights and the PMTCT programme.

### Reasons for conception

Six of the 10 women had desired a child while four had not given thought to having a family before their last pregnancy. Some women said that they would consider having more children in the future. Four women did not want to have more children because of their HIV<sup>+</sup> status, fearing to put their children at risk and deterioration in personal health with each pregnancy, particularly as they aged.

The six women desiring their own children wanted their love, their care in old age and to experience joy and contentment. One mother had her last child because she felt that her eldest son needed a "boy company". The women

commented that "children are a legacy you leave behind when you are not there", "it is nice even though time consuming" and "enjoyable but challenging". Others remarked that they wanted children to love and liked everything about motherhood. Healthcare workers concurred that some HIV<sup>+</sup> women decided to have children because they felt that having children completed them.

### Partner influence

Nine of the 10 partners of the women knew of their seropositive status. Six of the pregnancies were unplanned, with women explaining that their partners wanted to engage in unprotected sex under the influence of alcohol or just did not consider the women's HIV<sup>+</sup> status and treated them "normal". For others, "it just happened".

In all four planned pregnancies, partners' influence appeared to be the most significant motivation, especially in new relationships and at the new partners' request. A comment by one of the HIV<sup>+</sup> women, echoed by HCWs, was that "...I wanted to give him his own...his own baby...." One mother also added that her husband wanted a child as his eldest daughter had passed away and having another child would help to replace her. A partner, unable to have free visitation rights to his children from a previous relationship, asked his new wife to have a child by him.

### Healthcare norms

Eight of the 10 women said that they were treated well when HCWs learned of their HIV status and when interfacing with health institutions. However, there was an instance where an HIV<sup>+</sup> woman was referred to as a 'tornado' by one doctor to another, when she attended antenatal clinic. This HIV<sup>+</sup> participant thinks that the use of the word tornado is a derogatory statement made in reference to her being seropositive:

*...at antenatal clinic, when they pull my file and they realized, they tried to talk in code...I'm not stupid...they referred to me as a 'tornado'... "uh, ah see you get ah 'tornado' today, boy".*

Some women had heard and seen HCWs 'shooing' [gossiping] about them. Two HIV<sup>+</sup> women were told that they should not have become pregnant. Different precautionary measures were taken by different HCWs. For example, full universal precautions were used when caring for HIV<sup>+</sup> women. Some HIV<sup>+</sup> women saw this as the nurses protecting themselves, so it was not viewed as discrimination. However, the few women who encountered this, when probed, went on to say that all nurses should use the same precautionary measures for all women in labour and delivery.

### Approaches to reproductive rights

Six of the nine women who did not seek family planning advice had unplanned pregnancies. Only one HIV<sup>+</sup> woman sought advice before becoming pregnant with her last child. Unfortunately, she was not informed about risk reduction

strategies. All HCWs confirmed that HIV<sup>+</sup> women do not usually seek family planning advice, and those who did were not given any risk reduction strategies, nor were they told of their partners' risk of infection from unprotected sex. Healthcare workers did not even discuss vertical transmission when counselling on family planning. However, an HCW who provided advice on risk reduction echoed the other HCWs' sentiments that HIV<sup>+</sup> women did not usually seek family planning advice before conceiving.

Healthcare workers recognized the reproductive rights of women who were diagnosed as HIV<sup>+</sup> during the antenatal period and agreed that they should keep their pregnancy. Three HCWs agreed that HIV<sup>+</sup> women should have more children but were concerned that social deprivation or poor adherence to ART would increase the chances of vertical transmission. A comment by one of the HCWs was that it was up to the couple to decide about the pregnancy.

### **The PMTCT programme**

Only a few HIV<sup>+</sup> women were not sure about the overall PMTCT programme. Some HIV participants expressed that it is "a good programme", "an excellent programme" and "I give them an A". Most of the women understood the supporting role of the coordinators, and some HCWs understood the role of the PMTCT coordinators in supporting HIV<sup>+</sup> women and their families through the women's lifespan.

All HCWs who are associated with the PMTCT programme expressed job satisfaction, especially when there were few complaints about the service, when very ill patients had positive outcomes, and when there are positive outcomes due to a team approach to the decision-making process. Healthcare workers also expressed that the most important ingredients in customer service were having current information on HIV/AIDS, such as new medication, orientation of the patient to the clinical area, openness and maintaining confidentiality.

### **DISCUSSION**

This small scale qualitative study in TNT is the first to attempt to explore reproductive decision-making by women post HIV diagnosis. Though desiring children, most of the participants did not think about having or not having children. Consequently, all but one did not seek family planning advice. Most conceived by accident and due to partners' disregard for their HIV<sup>+</sup> status and partners' inebriation. Those who consciously conceived did so for their children or partners' sake. Partners desired children to cement a new relationship or to replace children who had either died or to whom they were denied visitation rights. Though HCWs were supportive, they agreed that HCWs might discriminate against HIV<sup>+</sup> women who were pregnant. Family planning advice was limited to risk of partner infection and did not address vertical transmission, risk of re-infection and risk reduction strategies.

Most of the women had positive views on motherhood before having children and had desired children before their HIV diagnosis – factors linked with HIV<sup>+</sup> women's desire to have children (10). Though perceived as innate, motherhood is socio-culturally constructed (11), especially in deeply rooted and entrenched cultures (12). Being HIV<sup>+</sup> may dampen (13) but it does not eliminate a woman's desire to have children (14). Conversely, some women may not want any more children, independent of their HIV<sup>+</sup> status (10).

As found elsewhere (3, 15), HIV<sup>+</sup> women in TNT conceive even after learning about their HIV status for many reasons including the influence of their partners. Men want to experience fatherhood just as women want to experience motherhood (7, 16). One father wanted a child because his eldest daughter died, suggesting that the child replacement theory applicable to HIV<sup>+</sup> women (8) may also be applicable to men. If men have a desire for fatherhood, then women, especially if economically or emotionally dependent, may go along with that desire (10).

Though not found in this study, HCWs elsewhere (17) encouraged women to abort if diagnosed HIV<sup>+</sup> during pregnancy. In some countries, HIV<sup>+</sup> women may be told that they should not have conceived because of the risk of infection to the baby (3, 17). In this study, some HIV<sup>+</sup> women experienced stigma and discrimination when midwives used universal precautions around them as opposed to just gloves for other women. Training and skills building is necessary to ensure HCWs' compassionate and appropriate management of patients including those living with HIV (18).

Most of the HIV<sup>+</sup> women and their HCWs thought that TNT's PMTCT programme was effective in reducing vertical transmission. This government initiative could empower HIV<sup>+</sup> women to make informed decisions with respect to family planning [19]. As the results showed, all HCWs experienced job satisfaction which is linked to HCWs interaction with clients/patients and customer satisfaction (20).

The results of this study are not generalizable, being based on a purposively selected and small sample not representative of all HIV<sup>+</sup> women in TNT or elsewhere. Nonetheless, the qualitative methods used revealed the participants' extensive experience with TNT's PMTCT programme and the personal circumstance around their last pregnancy. Understanding the reproductive decisions of HIV<sup>+</sup> women along with appropriate training and skills building may lead HCWs to assist HIV<sup>+</sup> women make informed reproductive decisions without being judgemental (2). In the absence of 'silver bullet' policies to address sexual and reproductive decision-making, HIV<sup>+</sup> women should be offered empowerment programmes to help them make informed reproductive choices (2). Trinidad and Tobago needs collaborative and synergistic, if not integrated, PMTCT, ART and family planning services, so that HIV<sup>+</sup> women and their partners can

space their children appropriately and safely, and prevent unwanted pregnancies (21). Family planning advice, support and counselling should be extended to partners and should help HIV<sup>+</sup> women evaluate their own feelings, goals and needs with respect to reproductive options (3, 22).

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