

Reproductive Decisions among People Living with Human T-cell Lymphotropic Virus Type 1 (HTLV-1)

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Abstract

Background: Human T-cell Lymphotropic Virus type 1 (HTLV-1) infection is a neglected public health problem. The majority of carriers is asymptomatic and may have a low risk of developing related diseases. The aims of this study were to discuss reproductive decisions of women and men living with HTLV-1 infection to assess their perception of infection and associated diseases, expectations regarding Mother-to-Child Transmission (MTCT), and whether health care conditions may affect their reproductive decisions.

Methods: A qualitative study with 13 adult HTLV-1-seropositive subjects without co-infections. For data analysis, life history trajectories and categories of discourse were constructed for each respondent.

Results: Reproductive decisions required the reassessment of life projects in the new context of HTLV-1 infection. Thus, a child remains representative of a “new meaning to life”. There is a need for accurate information regarding the risk of MTCT and the transmission risk to a serodiscordant partner while trying to conceive. It was also observed that a couple’s relationship and emotional dynamics were crucial in the process of making reproductive decisions. It was emphasized that the inhibition of breastfeeding was seen as a reliable method in preventing transmission, favouring the decision to have a child.

Conclusions: Reproductive decisions were influenced by information transmitted by healthcare providers that only rarely does a person with HTLV-1 become sick due to the infection. Because this infection is incurable, reproductive decisions are crucial. The importance of reproductive decisions highlight the need for accurate information dissemination and infection prevention, perhaps only made possible through effective interdisciplinary means.

Keywords: Human T-cell lymphotropic virus type 1 (HTLV-1); Reproductive decisions; Public health; Interdisciplinary approach

Brief Summary for the Table of Contents

HTLV-1 infection is incurable and a neglected public health problem. The need for accurate information regarding the risk of MTCT is critical. This scenario shows the importance of accurate information, since reproductive decisions are crucial for infection prevention.

Introduction

In terms of public health actions and policies, human T-cell lymphotropic virus type 1 (HTLV-1) infection is often neglected [1]. Brazil has been successful in its national HIV/AIDS Programme [2,3] which has received international recognition. This success could indicate a favourable scenario for overcoming other sexually transmitted diseases (STDs). Regardless of this favourable context, endemic HTLV-1 infection has become a problem “invisible” to the eyes of public health [4].

The infection or disease caused by HTLV-1 can be considered a public health problem and is endemic to several parts of the world such as Africa, the Caribbean, South America, Japan and Brazil [5]. The prevalence of HTLV-1/2 among donor blood banks in Brazil is 0.46% [6]. The largest number of carriers is in Salvador, where 40,000 individuals are estimated to be infected with HTLV-1 [7].

The most frequent diseases associated with HTLV-1 infection are the Adult T-Cell Leukemia/lymphoma (ATL) and HTLV-1-Associated Myelopathy/Tropical Spastic Paraparesis (HAM/TSP). There is no accurate number of ATL or HAM/TSP cases since these diseases are not reportable by the World Health Organization (WHO). The majority of people living with HTLV-1 are asymptomatic and have a low risk of developing related diseases [8,9]. A health care model centred solely on the risk of illness suggests that it is not justifiable to invest in the

prevention and training of health professionals regarding HTLV-1 specific issues [4]. This lack of knowledge has serious implications for health care and perpetuates the virus’ social “invisibility”. Complex health demands are neglected, and, as a consequence, there is no identification or active prevention of new infections in society [4].

One such demand is reproductive decisions among HTLV-1-infected people. To reduce the long-term prevalence of the virus, knowledge regarding sexual and mother-to-child transmission (MTCT) is an important tool in preventing HTLV-1 infection. Prevalence data of HTLV-1 infection among pregnant women are rare. In endemic areas, approximately 25% of breastfed children born to HTLV-1 seropositive mothers may acquire this virus [9,10]. At one time, Japan had high rates of MTCT, ranging from 15 to 25% [11]. However, through the systematic serological screening of pregnant women and by avoiding breastfeeding, the MTCT rate recently decreased to approximately 3% [11-13]. Thus, one action which prevents transmission is not breastfeeding. This is important because HTLV-1 infection does not respond to antiretroviral therapy as HIV infection [9].

In Brazil, prenatal serological HTLV-1/2 testing is not conducted systematically, as in blood banks. There are few studies on the

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prevalence of HTLV-1 among pregnant women. For example, in the city of Campo Grande at Mato Grosso do Sul (in central Brazil), the prevalence was 0.13% [14]. In the city of Salvador, at Bahia (in the northeast of the country, considered an endemic area for HTLV-1), the prevalence ranged from 0.7 to 0.9% [10,15]. A recent study in São Luís at Maranhão (in northeast Brazil) stated that the prevalence of HTLV-1/2 was 0.3% in women [16].

There are no specific public policy actions regarding the prevention of HTLV-1 infection by sexual transmission or by MTCT in Brazil. In most cases, policies addressing HIV/AIDS are used to address HTLV-1 as well. Access to artificial milk formula for nursing mothers and male condoms for use by people living with HTLV-1 is provided due to legal resolutions that consider the HTLV-1 a STD. However, the inherent specificities of HTLV-1 infection are not taken into consideration.

Counselling on reproductive decisions and actions is essential to prevent the transmission of STDs [17]. In the context of human rights and public health, there is a need for health services and legal support systems to ensure sexual and reproductive health. The overall weakness of health systems is responsible for many gaps preventing the full enjoyment of sexual and reproductive health and rights [18]. Because HTLV-1 is incurable, informed reproductive decisions are crucial for people living with HTLV-1 to prevent virus transmission to their partners and offspring.

The aims of this study were to discuss the reproductive decisions of women and men living with HTLV-1 infection, to determine their perception of infection and associated disease and expectations regarding MTCT, and, finally, to assess if health care conditions affect their reproductive decisions.

Material and Methods

This article is part of a larger qualitative study [19] with several methodological strategies. First, there was a participant observation [20] in an outpatient care clinic for people living with HTLV infection at the Emilio Ribas Institute of Infectious Diseases, Sao Paulo, Brazil. This is a state-run public hospital specializing in diagnosing and treating people with infectious and parasitic diseases. The period of participant observation was June 2006 to April 2008. We also conducted in-depth thematic interviews that included questions about socio-demographics, perception of infection/disease, sexuality and reproductive decisions. We conducted 17 interviews with 13 HTLV-1-seropositive adult women and men without co-infections (Table 1). The subjects were selected from a convenience sample [21] irrespective of clinical and socioeconomic status, during the period of the participant observation.

For data analysis, categories of discourse analysis content and life trajectories were constructed for each respondent, with reference to oral history technique [22]. This study was approved by the Public Health Faculty–University of São Paulo Ethics Committee (Protocol 1536). Patients signed an Informed Consent Form (ICF) that followed the Declaration of Helsinki.

Results and Discussion

The symbolic place of the child, as a “tactic object” that should complete the couple, is connected to the idealized conception of family [23]. These traditional views are present in the interviewee’s comments. For example, Martha says, “I want to have a child because it is part of life”. Lydia believes that a child “is a blessing” or a “gift that God gives to women”. The role of a son is also connected to concepts of family and marriage. Ana says that a “child completes the marriage”, and Alba believes that “one son strengthens the couple’s bonds”. Walter points out that a child is the “happiness and fulfilment of life”. He declares, “After my daughter was born, I became a better person within this family. I need a family. How can one get married and not have children”?

For women with HIV/AIDS, motherhood may represent an additional effort for self-care, and a child may represent the meaning of life [17,18]. HTLV-1-infected persons make similar comments. Maria explains that becoming a mother seemed to help her overcome the suffering caused by the discovery of her HTLV-1-positive status and improved self-care.

Being a mother is a joy. As a mother, I am fulfilled. I feel stronger and feel more prepared to deal with HTLV. Now everything is about my daughter. But today I have to, every day, be stronger than before the HTLV disclose (Maria, who was eight months pregnant when she discovered that she was HTLV-1 positive, infected by her husband).

Other considerations, such as practical and financial concerns, planning ahead for the ideal number of children or advanced maternal age, also influence the decision to have a child. The existence of a family support network may also influence this process. With regards to people living with HTLV-1, family support may be even more relevant. Some individuals said if a patient becomes ill and thus are unable to care for the offspring; the existence of a family support network appears to be crucial in the decision to have children.

It is not reasonable to address reproductive decisions without an understanding of pre-and post-test counselling. Guiltinan et al. [24] noted that such counselling is often inefficient because most health services do not know the specificities of HTLV-1 and erroneously

Name	Age (years)	Marital status	Education (years)	Symptomatic	Children	Relatives tested	Modes of transmission
Alba	27	married	6	yes	None	no	MTCT
Alice	23	married	11	no	None	no	MTCT
Ana	27	married	11	yes	1	no	MTCT
Angelica	26	divorced	5	yes	3	no	blood transfusion
Carolina	61	widower	11	no	2	no	unknown
Fabiana	27	married	16	no	None	no	unknown
Lydia	34	single	8	yes	None	no	MTCT
Maria	27	married	11	no	pregnant	yes	sex
Maria Rita	27	married	11	no	1 and pregnant	no	unknown
Martha	31	married	16	no	None	no	unknown
Sylvia	42	married	11	no	3	no	unknown
Victor	47	divorced	5	yes	3	no	unknown
Walter	33	married	11	yes	wife pregnant	no	MTCT

Table 1: Study respondents’ socio-demographic characteristics and HTLV-1 infection status.

associate it with HIV. In a more recent study, it was noted that in pre- and post-test counselling, the patient was advised not to worry about the virus transmission risk for partners or children because HTLV-1 infection rarely causes a serious health hazard [4]. This study's author also observed that health teams, even those with knowledge of the HTLV specificities, conduct follow-ups after HTLV diagnosis in terms of its low illness risk rather than preventive transmission processes. This practice has been criticized from public health and preventive viewpoints because of its effect to perpetuate endemic HTLV-1 infection in the community [4].

There are biomedical recommendations for HTLV-1-positive couples who wish to have a child [9]. These patients revealed that their reproductive decisions were part of a process of "risk management" that weighed the risks of virus transmission to partners or children against the benefits of having a son. In addition, it was observed that when weighting the risk of virus transmission to partners, patients considered the guidance of health professionals who counselled, "Men rarely become infected with HTLV". In cohort studies with discordant couples in Japan reported a transmission risk 60 times higher for men than for women [25].

In one study, serodiscordant couples attempting to have a child said the transmission risk to the partner was considered, but their decision was a complex process and also depended on if the partner was aware of the risks and agreed that to have a child was a kind of "adventure" [26]. Although all subjects were warned of the importance of condom use in preventing HTLV-1 transmission, couples reported that when they decided to have a child, they would discontinue the use of oral contraceptives because they, even serodiscordant couples, did not use condoms.

Despite the health team's recommendation for condom use, couples did not adopt condoms in practice. Women were found to be more likely to consent to this higher risk of HTLV exposure, further complicating matters when the man is the HTLV carrier. This gender issue is widely discussed by HIV/AIDS researchers. These individuals, who also reported difficulty in using condoms, relayed the understanding that women should submit to their partner's decisions on the grounds that this "passive" posture was suitable for females in a society still very marked by macho men behaviour [27-29]. However, men may have greater difficulty in the use of condoms because one of the first symptoms of HAM/TSP is erectile dysfunction [30]. Taken together, simply orienting the health team to indicate condom use to prevent transmission did not address the specific needs of these individuals.

The couple's relationship and emotional dynamics are crucial. Issues such as responsibility and guilt arose even in couples who had children and did not know they were seropositive for HTLV-1, as Lydia emphasizes hereafter.

Interviewer: And your parents, how did they feel since they transmitted HTLV-1 to you?

Lydia: Oh! (Pause) My mother, she feels responsible.

Interviewer: Responsible? Why?

Lydia: Because she infected me, it was because of her, you know?

Interviewer: But you said she did not know that she had HTLV.

Lydia: She knew nothing of it, but she still feels guilty (Lydia, who was infected by her mother).

Another interviewed called Martha also said that she felt guilty

because she infected her son despite not knowing she was HTLV-1 positive.

Interviewer: Is it different having a child when you are HTLV-positive?

Martha: I think it is different because it involves guilt. This is terrible feeling.

Interviewer: Why are you feeling guilty?

Martha: I wanted to have a child, but I wished he had no disease. I could have avoided getting pregnant. But what could I do to prevent the transmission of the infection; you do not breastfeed, for example. But it is useless, I wanted to have a child, so I feel responsible and guilty (Martha, who has one of three children with HTLV infection).

Another issue was the risk that children might develop a disease as a result of HTLV-1. Overall, interviewees highlighted the idea conveyed by the health team that a person rarely would become sick because of an HTLV infection. Among symptomatic or asymptomatic relatives, it is interesting to note that the child had the role of being "a person to help in the care of a sick relative". This seems to reinforce the idea that the resulting child would be healthy enough to take care of another relative. Nevertheless, some individuals said their decision to have a child was influenced by contact with symptomatic individuals (family or spouses). Information from their health team regarding the low risk of developing HTLV-1-related disease was questioned. Thus, some of the interviewees decided to give up the motherhood, as illustrated by Alba's speech.

I dreamed of being a mother, but I gave it up. My child can't experience what I am suffering along with my father. So, I do not want to have a child. Sometimes, I would like it, but at the same time I refuse. I gave up my dream of being a mother (Alba, who was infected by her mother, who recently died of ATL; her father has HAM/TSP).

Such feelings of guilt and responsibility appear to be unconscious and involuntary. It can be inferred that in cases where a person did not know that they were infected with HTLV-1, they could be "forgiven" for transmitting it. However, these respondents felt guilt as well. These feelings are not objective and pragmatic features of the subject's conscious decisions. The desire to have a child can itself become the "cause" of the transmission risk; therefore, the problem of guilt arises.

The subjects' experiences were so remarkable that some of them revealed that they would not have other children due to HTLV-1 infection, as the experience and the risks involved generated inescapable anxieties.

"I pray that my newborn daughter does not have HTLV. But we do not know yet. I would like to have another child. The temptation of having another child would exist. But when I think about HTLV experience in my life, I prefer to say no. I do not want taking the risk again, because the risk is too high in my opinion, although the doctors don't say too much about it" (Walter, who was infected by his mother and his wife just had their first child).

The interviewees believe that society would not criticize their decision to have a child because "people do not know what this virus is". The lack of knowledge of HTLV-1 by general health professionals leads to intense feelings of insecurity among patients, as well great fear that, because of this "alleged association with HIV," patients would be stigmatized [4].

The situation is too complicated! And very scary! How can I have a child while still dealing with a virus that no one knows about? And

what if they think that it is HIV? And what if the gynaecologist does not know what HTLV is? Must I explain that? Nobody deserves to go through this! It is so unfair and the government does not do anything about it! (Alba, who was infected by her mother, who recently died of ATL; her father has HAM/TSP).

Another aspect that may influence the decision to have children is the possibility that individuals can take action to minimize the risk of MTCT. Accordingly, using alternatives to breast-feeding was seen as a positive action taken by an infected person to regain some control of the situation. However, this action raises anxieties because of an idealization of breastfeeding as both representative of maternal care and an essential concept of femininity [31] and maternity [32]. This also indicates the need for specific studies in the future.

Final Considerations

Sexuality and reproductive issues still seem to be taboo and the interviewees' comments reveal difficulties in discussing these issues - both by the health team and by the HTLV-1-infected patients themselves. Thus, addressing HTLV-1 and related reproductive issues can generate extra challenges in a context where a lack of proper communication exists.

The guidelines regarding the reproductive decisions of individuals with HTLV-1 [8,9] raise more questions than answers. There are few studies on this topic, and, as was observed in subjects' statements, there is a need for accurate information regarding the risk of MTCT and the transmission risk to a serodiscordant partner while trying to conceive. These questions have not been sufficiently investigated by the biomedical field. In addition, both the healthcare team and patients appear apprehensive and insecure, indicating a need for emotional support as well.

It was observed that the couple's relationship is a crucial factor influencing the reproductive decision-making process. From the patients' standpoint, the decision of whether or not to have a child required the reframing of previously constructed concepts (the place of motherhood, family and child) within the new context of HTLV-1 infection and probably altered their life goals. Thus, the child as representative of a "new meaning to life" is evidence that the couple has joined a project of "risk-adventure". Some participants emphasized that using alternatives to breastfeeding was a reliable method in preventing viral transmission, supporting their decision to have a child. This decision to "run the risk" and have a child does not always result from rational and conscious processes because many responses exhibited great ambivalence and guilt. As much they try to perform "calculations" to seek some guarantee of success, in practice, most subjects went through this "adventure" thoughtless and distressed. This resulted in negative consequences for their emotional health, indicating the need of specific support.

Reproductive decisions were related to information explained by health care team providers, highlighting the importance of education and preparation to this issue. We could also assume that the subjects welcomed the input of healthcare providers, as their decisions were largely based on medical discourse. However, it was clear that this input was not sufficient. It was noted that in current healthcare practices, the themes of sexuality and reproductive decisions and, as a result, prevention of viral transmission to partners and children remain a secondary issue. This is an important public health policy issue because, although the relative risk of developing disease is low, HTLV-1 infection is incurable and has no effective treatment. This fact makes it essential to prevent HTLV-1 transmission. Healthcare shortfalls concerning reproductive decisions highlight the need for

comprehensive health care. This situation requests the involvement and promotion of transmission prevention, only possible due effective interdisciplinary approach.

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