

HIV POSITIVE MOTHERS' BELIEFS ABOUT MOTHER-TO-CHILD TRANSMISSION¹

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Beliefs can influence health behavior. This qualitative study aimed to understand the beliefs that influence HIV positive mothers' behaviors towards prevention methods against mother-to-child transmission. Fourteen women were interviewed. Our research was based on the theoretical Health Belief Model, formed by the following dimensions: perceived susceptibility, perceived severity, perceived benefits and perceived obstacles. Data analysis showed reflections that evidence the paradox in the AIDS epidemic: knowledge does not change behavior; gender relations; fear of death; fear of stigma; financial problems; disbelief in the virus' existence. Identifying beliefs and understanding how to influence the conduction of the health problem can help services to promote patients' adherence.

DESCRIPTORS: HIV; acquired immunodeficiency syndrome; disease transmission, vertical

CREENCIAS DE LAS MADRES SEROPOSITIVAS RESPECTO A LA TRANSMISIÓN VERTICAL DEL HIV

Las creencias son capaces de influenciar el comportamiento del hombre. El objetivo de este estudio cualitativo fue comprender las creencias que influyen el comportamiento de las madres HIV respecto a las medidas profilácticas de la transmisión vertical. Fueron entrevistadas 14 mujeres portadoras de HIV. Los datos fueron analizados utilizando como referencial teórico el Modelo de Creencias de la Salud, que es compuesto por las dimensiones de susceptibilidad percibida, severidad percibida, beneficios percibidos y barreras percibidas. Fueron observadas las contradicciones de la epidemia de SIDA: el conocimiento no muda comportamiento; miedo de la muerte; subestimación del HIV; dificultades financieras; no creer en la existencia del virus. Identificar y comprender las creencias puede ayudar los servicios de salud a promover la adhesión de la clientela.

DESCRIPTORES: VIH; síndrome de inmunodeficiencia adquirida; transmisión vertical de enfermedad

CRENÇAS DAS MÃES SOROPOSITIVAS AO HIV ACERCA DA TRANSMISSÃO VERTICAL DA DOENÇA

As crenças parecem influenciar diretamente nas atitudes dos seres humanos. Neste estudo qualitativo buscamos identificar as crenças que influenciam a adesão das mães portadoras do HIV às medidas profiláticas da transmissão vertical. Foram entrevistadas 14 mães soropositivas. A análise foi feita utilizando-se como referencial teórico o Modelo de Crenças em Saúde, composto das dimensões: susceptibilidade e severidade percebida, benefícios e barreiras percebidos. Dos dados emanaram reflexões que evidenciam as contradições da epidemia: o conhecimento não determina mudança de comportamento; relações de gênero; aids como doença do outro; medo da morte; evitar pensar na doença; medo do estigma; dificuldades financeiras; descrença na sua existência. Concluímos que a identificação das crenças e a compreensão de como estas influenciam o comportamento humano frente a um problema de saúde pode determinar a ação dos serviços e a forma como esta ação deve se processar.

DESCRIPTORES: HIV; síndrome de imunodeficiência adquirida; transmissão vertical de doença

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INTRODUCTION

HIV infection rates among women have been increasing all over the world, causing concern about mother-child transmission.

It is estimated that between 15 and 30% of seropositive mothers' children catch the virus during pregnancy, delivery, birth or breastfeeding. Based on the ACTG 076 protocol, the Ministry of Health implemented prevention measures and, despite difficulties, incidence levels of aids in children have displayed a progressive decrease in Brazil in recent years. The adopted measures include: offering the anti-HIV test to all pregnant women; specialized care with antiretroviral therapy (ARV) to women diagnosed as HIV positive; administration of injectable ARV to parturient women during delivery; administration of oral AZT to newborns until the sixth week of life; suppression of breastfeeding; specialized follow-up of children until the diagnosis has been defined⁽¹⁾.

The combination of recommended interventions for the prophylaxis of vertical HIV transmission has brought down transmission levels to less than 1%⁽¹⁾.

Achieving and maintaining decreased infection risks in children requires not only trained professionals to follow mothers and children, but also the mothers' actual participation to carry out all of the recommended interventions. However, mothers will only adhere to preventive treatment if they are sensitized to the idea that their baby can be infected and that, to avoid this infection, they need to follow all recommendations. The mothers' adherence is fundamental to decrease infection risks in children.

Adherence is a process of learning how to deal with economic, social and individual difficulties, considering the fact that, nowadays, the most affected population comes from lower social classes, with low education levels, confirming the epidemic's impoverishing tendency⁽²⁾. The complexity of aids does not only involve the cognitive side of knowledge and information, but also behavioral changes.

In our professional practice, working with seropositive pregnant and puerperal women, we found that, although most mothers adhere to preventive treatment, some of them do not attend prenatal care or do not adequately follow health professionals' recommendations. These observations gave rise to a series of reflections: do the mothers consider aids as a serious disease? Do they believe

they can transmit the virus to their child? Do they believe that correct follow-up can benefit the child?

These reflections motivated us to develop a study aimed at understanding the reasons that made HIV positive mothers adhere to vertical transmission prevention measures. This means understanding the influence of environmental and psychosocial factors in these mothers' behavior. Among these factors, beliefs seem to exert direct influence on human beings' attitudes.

Thus, in this article, we aimed to identify the beliefs that influence HIV positive mothers' adherence to vertical transmission prophylactic measures.

METHODOLOGY

We carried out a descriptive study with a qualitative approach, which emphasizes the world of meanings of human actions and relations, an aspect that cannot be quantitatively perceived or caught⁽³⁾. The Health Belief Model - HBM⁽⁴⁾ was used as the theoretical framework, which seeks to explain the adoption of preventive behaviors and establish relations between individual behavior and some individual beliefs.

The preliminary characteristics of the HBM consider that, for individuals to adopt preventive measures, that is, to avoid diseases, they need to believe in three aspects: that they are susceptible to the disease; that the occurrence of the disease will cause at least moderate changes in some components of their life; that taking a particular action should exert beneficial effects, reducing these persons' susceptibility to a specific condition, decreasing its severity and detaching it from more important barriers, such as cost, convenience, pain, embarrassment⁽⁴⁾. The HBM basically involves of four dimensions: perceived susceptibility, perceived severity, perceived benefits and perceived barriers.

The target population consisted of HIV positive women, whose pregnancy resulted in live births in Ribeirão Preto in 2004. The following inclusion criteria were considered: realization of birth in Ribeirão Preto; living in the city of data collection; good physical and emotional conditions; the child should be at least six months old and under the mother's care; agreement to participate in the study. In 2004, 49 children of HIV positive women were born, 20 of whom attended to the inclusion criteria. Due to difficulties to locate some

addresses at the moment of data collection, the final sample consisted of 14 women.

Data were collected through semistructured interviews, recorded at the women's home and guided by a specific instrument. This instrument was divided in two parts: the first aimed to characterize the participants, and the second asked guiding questions, based on the theoretical reference framework: what are your beliefs and perceptions about HIV/aids and the possibility of transmitting it to your child? What benefits can the baby receive from you doing treatment correctly? What are your difficulties to realize treatment adequately?

During the visit, the free and informed consent term was read, and secrecy and confidentiality of data was guaranteed. Participants' names were replaced by flower names to guarantee their anonymity. Data were collected between November 2004 and January 2005.

The recorded interviews were transcribed by the researcher. The Content Analysis method⁽⁵⁾ was used for data analysis, covering pre-analysis, data exploration and result interpretation. Contents were selected, coded and inserted in the dimensions of the theoretical framework.

The project was assessed by the Ribeirão Preto Municipal Health Secretary and approved by the Research Ethics Committee at the University of São Paulo at Ribeirão Preto.

RESULTS AND DISCUSSION

We interviewed 14 mothers, who were between 15 and 37 years old; ten of them had a fixed partner. Only two participants possessed more than ten years of education and five had waged work; family income corresponded to up to three Brazilian minimum wages in 12 cases. Two participants did not attend prenatal care, despite knowing that they were HIV positive; all women participated in specialized follow-up for the child.

The semistructured interviews revealed units of meanings, originating categories that were inserted in the dimensions of the theoretical framework.

Perception of Susceptibility

Susceptibility refers to the individual's subjective perception of existing risks. The acceptance

of susceptibility varies, with people who can deny any possibility of contracting a disease; acknowledge the possibility, but little probability; or perceive a true risk of contracting it⁽⁴⁾. We identified the following categories: knowledge, gender relations, concept of risk groups, susceptibility of children.

Knowledge

When we asked the interviewed women about their knowledge on HIV, almost all of them indicated they knew about transmission forms, even before getting infected.

I know it's transmitted through the blood and other things as well, like sexual relation, contaminated syringe (Rose).

You catch it by having sex with another person, or taking injectable drugs (Hydrangea).

It is transmitted through contact with blood and in sexual relations like I had (Petunia).

I know it's transmitted through sexual relations, contacts with injuries, through blood (Geranium).

A recent Brazilian study of the adult population's knowledge about HIV infection points out that 91% mention sexual relation as a transmission form⁽⁶⁾. However, knowledge alone does not guarantee that this information will actually be understood and incorporated into behavior.

Gender relations

In sexual HIV transmission, gender relations make both partners fragile and vulnerable. In our culture, men need to be virile and powerful, while women have to be submissive, creating a social context that makes negotiations about safe sex difficult and turns women more vulnerable to HIV infection.

I only used a condom during pregnancy, afterwards I stopped. He doesn't like it (Marigold).

I knew I should use one (condom), but I got involved with a person from São José dos Campos and he didn't like to use one, and then I got pregnant (Camomille).

The ideal of romantic love and trust in one's partner are still determinant factors in women's vulnerability to HIV infection. In maintaining a stable affective relation, they do not perceive the risk, as illustrated by the following statements:

It's transmitted through sexual relations, and I believed that, as it was only one person, but I had it, I was confident (Jasmine).

I didn't use a condom because I was married, I like him a lot, I couldn't imagine that. I blamed my husband because he already knew but didn't tell me because he was afraid of losing me; I even wanted to leave him, but then we talked and things went better (Petunia).

Long relations give women the feeling that they are immune, and trust in their partner, the basis of love relations, does not consider men's earlier life. Fidelity and the marriage situation emerge as immunization against infection; living with someone you love and trust in one's partner facilitate risk denial. Trust and fidelity are the main reasons why the couple does not use a condom to prevent sexually transmitted infections and aids⁽⁷⁾.

Concept of risk groups

Although the epidemic was discovered 25 years ago, risk group concepts persist in the social imaginary, contributing to the perception of aids as the other person's disease, and giving the false feeling of distance from danger.

Study, we always study, know, we always know, everything. I knew it was through sexual relations, that you couldn't have different partners, drugs use, but I never expected it would happen. I was shocked when I went for prenatal care, because I had never expected this, neither did he by the way, because he had another girlfriend before me who was also very correct (Jasmine).

The initial belief that aids is a disease restricted to certain "risk groups" is still one of the impediments for prevention in women, who imagine that "only other people can contract HIV". This false rationalization is closely related to the fact that, for a long time in the history of the epidemic, information about aids was transmitted with the idea that risk groups existed, which referred to highly stigmatized types - promiscuous people, addicts, perverts⁽⁸⁾. Nobody wants to identify with these risk types.

Therefore, prevention actions need to cover gender differences and the deconstruction of the risk group concept for women to understand and perceive their susceptibility to HIV/aids.

Susceptibility of children

Women who already knew they were HIV positive before getting pregnant demonstrated the perception of susceptibility related to the child:

I thought it was very risky, thanks God his test was negative. I knew I could pass on the virus, but it happened, I wasn't using a condom (Begonia).

Once, he was dying to have a kid, but I said, you know, I don't have the courage, to stop taking the pill by myself; if I have to get pregnant one day, it will happen by taking medication. And it happened... (Marigold).

I was so scared that I kept on going to church there, in the cathedral, the whole nine months, and I kept asking oh my God, don't do that to my child (Hydrangea).

They were aware of their babies' susceptibility and expressed the fear they felt about getting pregnant. Women with high-risk pregnancy are afraid and hold onto medical and/or divine power to keep up the hope of seeing their healthy baby⁽⁹⁾. In the same way, seropositive women are afraid of transmitting the virus to their children and know that this is a concrete possibility.

Perception of Severity

The perception of severity is related to the emotional stimulus created by thinking about a health problem and the consequences people believe this could provoke in their lives. Feelings related to the severity of contracting a disease or leaving it untreated make people assess the resulting clinical and physical consequences, such as pain, temporarily or permanently decreased physical and mental functions, possible social consequences, as implications for work, family life and/or social relations, or even death⁽⁴⁾. This dimension revealed three categories: not thinking about HIV, fear of death and religious belief.

Not thinking about HIV

There are two clearly delimited periods in the history of aids: before the 1990's, when the image of aids connected to despair and death prevailed; and after, with the use of antiretroviral medication. The arrival of this therapy in 1996 brought the perspective that aids would turn into a chronic disease, compatible with survival, which had been unknown until then, and, mainly, with considerable preservation of quality of life. This perspective was confirmed in studies that show a significant increase in the survival rates of aids patients after this period, together with a decrease in aids-related hospitalization and mortality rates in Brazil⁽¹⁰⁾.

This perception is felt by women with HIV who have not manifested any symptoms yet, dismissing the existence of the virus to a secondary level.

She said that I only have HIV, and that I shouldn't think about it. That's a relief (Daisy).

You take it, the viral load gets down and you continue living normally, it's chronic. It's something that won't kill me (Jasmine).

Ten years ago there was nothing to do; today there's the cocktail (Violet).

They know that they have the virus, but struggle against getting in contact with this reality which, besides being painful, imposes a new direction in their lives. This reveals the contextual complexity of aids, loaded with contradictions and incoherence of human beings' feelings.

I prefer not to get so worried, if not I'll get depressed. So I prefer not to concern myself too much, because it's already here in my God, you see. I have to lead my life (Marguerite).

If I put it into my head that I'm gonna die, it's no use, I'm gonna get depressed and die anyway (Marigold).

Due to the fact that aids is still associated with death, one way for patients to survive with an HIV positive diagnosis is to dismiss HIV to a secondary level, not allowing it to occupy a large space in their lives.

Fear of death

At the same time as considering HIV as a lesser evil and, again, highlighting the complexity of aids and its contradictions, the fear of death and depression, which some women try to get away from, may even seem a normal reaction to these women, to the extent that it manifests the feelings of "loss" deriving from the disease:

I've seen people in very bad conditions at the hospital, if you don't take care, it's over (Lily).

I think that, if the child is born with the virus, it has little chance of living (Violet).

I know that aids kills, that HIV kills and that it causes a lot of diseases and that, if you don't protect yourself, if you go out with a man you'll pass aids to the others. If you put it into your head, you're gonna die faster (Hydrangea).

Hydrangea's statement reveals that the presence of HIV brought the certainty of death, anxiety and the fear of dying, a possibility that is accentuated in view of the possibility that the child will get infected and ill.

Despite the evolution in aids treatment, which increased patients' survival and turned it into a chronic disease, in popular representations, the association between aids and death is very present. The association infected women establish with death is mainly manifested in the revelation of the diagnosis.

Later, when they get in contact with health professionals and other persons in the same situation, associated with the absence of symptoms of the disease, they consider that death is not as immediate as they thought. Thus, "the invisibility of the disease also allows for the invisibility of death itself"⁽¹¹⁾.

Religious belief

The reality of women living in less favored situations is marked by a constant fight for survival, often mobilizing feelings of attachment to a religious belief. This attachment can also turn into an alternative to cope with the disease:

I handed it over to God, he is the one who's going to give me this answer (Camomille).

...it's his health that is at stake, even if I knew that he was negative, but we have to do our part, it's like Jesus says, do your part and I will help you (Marigold).

Religion appears as a form of support, representing an important emotional support network. Faith in the divine is one way of explaining the world, of overcoming and bearing daily existence, associating it with hope. Faith in cure is based on the belief in a superior power that gives them hope, as observed in the following statements:

...who knows further ahead, God will prepare a drug that cures... (Daisy).

I kept going to that church in the cathedral for 9 months and I asked "oh my God, don't do that to my child"; we cannot lose hope, we have to take the boy and believe in God (Hydrangea).

Religion is a system of symbols that acts to establish powerful and long-lasting intentions and motivations in human beings⁽¹²⁾. In a way, women benefit from their religious belief, to the extent that it turns into a way of coping and relief from suffering and anguish, imposed by a disease that is perceived as very severe.

Perceived Benefits

Perceptions about susceptibility and the severity of the disease can motivate people to adopt particular conducts, although it does not define what course of action will be taken. What guides action are personal beliefs related to the efficacy of available alternatives to decrease the threat of the disease or the perceived benefits of taking a certain actions⁽⁴⁾. The categories that emerged among these benefits were: growing up healthy and not being like me.

Growing up healthy

All participants' children were followed at a specialized outpatient clinic, although two women did not receive prenatal care. When asked about the benefits the child would receive by taking the treatment, they reported in different ways that the greatest benefit was the chance of not being infected by HIV and leading a healthy life.

The possibility that he will not develop the disease, so that he won't have HIV (Lily).

I wish he would not catch it, I could not jeopardize his life by passing the virus on to him (Violet).

For her to grow up healthy, not to have anything! (...) I think she will grow up, she will play, do everything she wants to, you see. While I'm here working, I want to give her everything she want, everything possible and that's it (Marguerite).

The possibility of growing up, playing and leading a healthy life stimulates the mothers to follow the health professionals' orientations, in order to decrease the chance of infection in the child.

Follow-up at a specialized outpatient clinic is recommended by the Ministry of Health as an important measure for newborns exposed to vertical transmission, as it determines what actions will be taken during this period⁽¹⁾. These children should be systematically followed, even after the confirmation of negative serology, as they were exposed to possibly carcinogenic agents.

Not being like me

Knowing that you have a chronic disease, that you will need medical care, taking medication and following some restrictions for the rest of your life is not a calm situation.

At least I knew that she wouldn't be like me, having to go to the doctor, having to take medication, that was a relief (Rose).

I prayed to God so much to get a negative result because that would weigh on us, knowing that he caught it from us, he's a child who has no idea (Hydrangea).

Women who already live with a routine of frequent medical appointment, medication treatments and occasionally with opportunistic diseases in their lives do not want their child to have the same. In the case of aids, that is strengthened by the fact that this disease still possesses stigmatizing characteristics for society. The stigma is a social construction legitimized by the other person's look, which symbolically or concretely restricts the territories of normality. If some

persons move beyond the line that separates these norms, this represents a deviation that is accompanied by accusation, isolation and even punishment⁽¹³⁾.

With respect to HIV/aids patients, we have to consider the way society referred to them at the start of the epidemic: as victims, in the case of people infected by blood products; or as guilty, in the case of homosexuals, prostitutes and drugs users. Seen as promiscuous, they were charged with the responsibility for the infection. Despite changes in the trajectory of the epidemic, nowadays, stigma and prejudice are still fears in infected individuals' daily life.

The benefit that treatment will permit a decreased possibility of infection by HIV, still a stigmatizing disease, becomes an important factor in treatment adherence.

Perceived Barriers

People can believe in the efficacy of a certain action to reduce the threat of the disease and, at the same time, can perceive this action as inconvenient, costly, dangerous in terms of negative side effects or iatrogenic results, unpleasant, painful, uncomfortable or time-consuming. These negative aspects of health actions or perception of barriers can act as impediments for the adoption of recommended behaviors and can create conflicts in decision making⁽⁴⁾. In this dimension, we identified the following categories: disbelief in HIV, financial difficulties, not breastfeeding.

Disbelief in HIV

One important aspect that needs to be discussed and that can jeopardize the maternal adherence process, thus constituting a barrier, is disbelief in HIV. When the infected woman does not manage to acknowledge that her HIV positive status can entail serious consequences for herself and her child, she does not take any care, neither of herself nor the child. We consider this disbelief in the existence of the disease as a barrier that stops her from realizing her child's and her own follow-up. One example is the statement of Tulip, who is illiterate, has 13 children, is pregnant of her 14th and has never received prenatal care:

I have never seen anyone with aids. Nobody believes I have it, neither do I, so that's it. I take her to Clinicas because she had a small problem when she was born, she drank birth

water and was hospitalized at the ICU of the Santa Casa Hospital for a month; then they told me to take her to hospital and I did. I have never taken the other kids because they don't have anything, they were born well, they're all strong, they don't even need drugs (Tulip).

This statement exposes a situation in which disbelief is associated with illiteracy and the life context this woman is inserted in. A significant part of the population only takes action after the fact has happened, that is, after the manifestation of a symptom. When patients already now they carry HIV, the presence of the virus does not have a concrete meaning, as there are no apparent symptoms yet to prove its existence.

Making a decision in health is a process in which the individual moves through a series of stages during which interactions with people or events in each of these stages influence that individual in making decisions about his/her health⁽¹⁴⁾. A relation of trust needs to be established with people for them to exert some influence on decision making.

The observation of the aids epidemic has demonstrated that individual behaviors play a crucial role in HIV transmission, and that strategies to prevent its increase need to take this factor into consideration.

Financial difficulties

Most participants mentioned financial difficulties to carry out all preventive actions, especially in terms of attending prenatal and child return appointments. Sometimes, these difficulties can represent a barrier.

Everybody's unemployed here, the bus is hard and I don't have a driver's license; I often take her on foot. Sometimes it rains, sometimes the sun is too hot, but I do it (Rose).

The biggest difficulty is the bus, sometimes you have money and sometimes you don't. I even lost a return because I didn't have money (Lily).

The Brazilian population displays great socioeconomic and demographic disparities. Hence, these disparities are expected to reflect in the way HIV spreads in the population. The statements above evidence the social vulnerability people from the lowest social layers are subject to. These people's high vulnerability levels in terms of socioeconomic complexity must be taken into consideration in aids prevention and control programs⁽¹⁵⁾. Most participants referred to the importance of help from public and philanthropic institutions to maintain treatment.

The inexistence of intersectorality in the elaboration of Brazilian public policies jeopardizes a comprehensive response to the double vulnerability created by the superposition of poverty and aids⁽¹⁶⁾. Participants' statements confirm the need to implement intersectoral public policies, covering not only health and social care, but also education, work, culture and leisure for individuals with HIV, as a way of decreasing the financial barriers affecting adherence to treatment.

Not breastfeeding

One aspect to be taken into consideration is the suppression of breastfeeding. Besides increasing the financial problem, this is also related to the emotional issue of maternal desire.

That milk is expensive and we can't breastfeed... (Begonia).

The milk helps a lot until today, but what I would really like to is to breastfeed him... (Petunia).

Breastfeeding is broadly disseminated in publicity campaigns and health services as one of the aspects responsible for the healthy growth of newborns and always associated with protection, greater bonding with the mother and maternal love⁽¹⁷⁾. For women with HIV who cannot breastfeed, what often remains is the image of failure to protect the child. The follow-up of mothers and children should also address this aspect. Health professionals should support women to "deconstruct" the desire to give breastfeeding, providing information on how to establish, maintain and strengthen the affective bond with their child and advising them on how to prepare and administer the infant formula and on the gradual introduction of other foods.

FINAL CONSIDERATIONS

Advances in medication therapy, in combination with other procedures, have considerably reduced mother-child transmission rates. However, to achieve these results, mothers have to be stimulated to carry out the procedures health professionals recommend.

The identification of perceptions about HIV/ aids infection revealed nuances, which allowed us to understand the beliefs that influence this adherence.

Some aspects of maternal perceptions can be considered as facilitating as well as complicating

factors for adherence, and are influenced by educational level, social class, personality and living context.

Determining what behavior each woman should adopt is only possible when her individual beliefs and values are taken into account. Identifying and understanding how they influence the handling of a health problem can determine

health services' action and how this action should take place.

Care services for HIV/aids patients, especially women and children exposed to vertical transmission, should implement programs that go beyond the biological dimension and also consider clients' values and cultural baggage, with a view to more solidary and participative care.

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