



Project Zero Perinatal HIV Transmission: partnership between public and private agencies*

Transmissão Vertical Zero: parceria entre o serviço público e o terceiro setor

Transmisión Vertical Cero: sociedad entre el servicio público y el Tercer Sector

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ABSTRACT

Objectives: To describe a multidisciplinary partnership experience between public and private agencies that provide care for HIV positive pregnant women, and to characterize the risk factors for HIV among pregnant women who were participating in the project “zero vertical HIV transmission” in the district of Sorocaba. **Methods:** A retrospective study was conducted using records of 120 pregnant women who participated in the project between 1998 and 2004. A form was used to gather demographics and risk factors for HIV. **Results:** Partnership between the public and private agencies was an efficient alternative to provide better care for HIV positive pregnant women. However, the majority of women (56.7%) was not aware of their partner HIV status and almost three fourths of them (73.3%) had never used contraceptive devices. **Conclusion:** The partnership between the public and private agencies contributed to the reduction of HIV Vertical Transmission in Sorocaba, SP.

Keywords: Disease transmission, vertical; Intersectorial action; Quality management; Health organizations; Non-governmental organizations

RESUMO

Objetivos: Divulgar experiência multidisciplinar de parceria entre gestores da rede pública de saúde e organizações não-governamentais voltadas à atenção à gestante HIV positivo; e caracterizar as situações de exposição ao HIV por gestantes atendidas pelo Projeto Transmissão Vertical Zero do Município de Sorocaba - SP. **Métodos:** Estudo retrospectivo com emprego de fontes documentais, e com levantamento de dados para caracterização sócio-demográfica e situações de exposição ao risco de infecção pelo HIV de 120 gestantes atendidas pelo Projeto, entre 1998 e 2004. **Resultados:** O compartilhamento de ações entre o público e o terceiro setor constituiu-se em eficiente alternativa de assistência à mulher soropositiva para o HIV, ainda que 56,7% das gestantes desconhecem a sorologia do parceiro e 73,3% nunca terem usado preservativo. **Conclusão:** A parceria contribuiu para a redução da transmissão vertical do HIV em Sorocaba - SP.

Descritores: Transmissão vertical de doença; Ações integradas de saúde; Gestão de qualidade; Organizações em saúde; Organizações não governamentais

RESUMEN

Objetivos: Divulgar la experiencia multidisciplinaria de sociedad entre gestores de la red pública de salud y organizaciones no gubernamentales dirigidas a la atención de la gestante VIH positivo; y caracterizar las situaciones de exposición al VIH por gestantes atendidas por el Proyecto Transmisión Vertical Zero del Municipio de Sorocaba - SP. **Métodos:** Se trata de un estudio retrospectivo realizado con el empleo de fuentes documentales, y con el levantamiento de datos para caracterización socio-demográfica y situaciones de exposición al riesgo de infección por el VIH de 120 gestantes atendidas por el Proyecto, entre 1998 y 2004. **Resultados:** El compartir acciones entre el público y el tercer sector se constituye en una eficiente alternativa de asistencia a la mujer seropositiva para el VIH, aunque el 56,7% de las gestantes desconociese la serología de la pareja y el 73,3% nunca haya usado preservativo. **Conclusión:** La sociedad contribuyó a la reducción de la transmisión vertical del VIH en Sorocaba - SP.

Descriptores: Transmisión vertical de enfermedad; Acción intersectorial; Gestión de calidad; Organizaciones en salud; Organizaciones no gubernamentales

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INTRODUCTION

The history of AIDS epidemics has an important landmark in its evolution. Protocol 076 conducted by the Pediatric Aids Clinical Trial Group (ACTG 076) of the Center for Disease Control, in Atlanta, determined changes in women's care during pregnancy and in the care to newborns. This multi-center study showed that the risk for HIV infection is decreased by 67.5% if these changes are regularly followed⁽¹⁾.

In a global level, ACTG 076 protocol ended a time of uncertainties, of attempts and errors to reduce mother-to-child transmission of HIV virus. In 1996, in Brazil, health managers took actions to reduce mother-to-child (vertical) HIV transmission effective by adopting the treatment recommended by the referred protocol in the health units and with a complementary legislation to identify and report HIV positive pregnant women.

From a biological perspective, HIV associated with pregnancy makes it high risk, demanding adequate and complete approach during the prenatal period, delivery and puerperium, to reduce the levels of infection risk⁽²⁾.

To improve care to women and their babies during pregnancy, delivery and puerperium, to reduce HIV vertical transmission, and to eliminate congenital syphilis, the Brazilian Ministry of Health started in 2007 the *Plano para Redução da Transmissão Vertical do HIV e da Sífilis* (Plan to Reduce HIV Vertical Transmission and Syphilis), actions and goals were placed to be met based on the contributions and shared responsibilities of the three levels of government – federal, state and municipal⁽³⁾.

Before the plan was created, in 1998, there was already a partnership between the federal, state and city level in Sorocaba, a city in the state of São Paulo, where a team from the STD/AIDS Municipal Program, concerned by the growing number of women and pregnant women infected by HIV, made one of the first partnerships with the Ministry of Health obtaining resources and support to intervene in the rates of HIV vertical transmission. With this objective, there was a partnership with the third sector and both public service and Non-Governmental Organizations (NGOs) adopted, as a strategy, measures involving care in the pregnancy-puerperium cycle - *Projeto Transmissão Vertical Zero* (Zero Vertical Transmission Project -PTVZ).

This initiative was a proposal to face the situation of HIV dissemination and its social implications. Playing an important role in the development of public policies for care and prevention demonstrates the strong presence of civil society in the areas of health, education and social service, when individuals and institutions gather in a participative way to fight for the same cause⁽⁴⁻⁵⁾.

From what was said, and due to the relevance and scope of the Zero Vertical Transmission Project in care

of HIV positive women and their babies, the present study has the following objectives.

- To show a successful multidisciplinary experience of partnership between the public health service and non-governmental organizations that care for HIV positive women in the pregnancy-puerperium period; and
- To characterize the situations of HIV exposure by pregnant women seen in the Zero Vertical Transmission program in the city of Sorocaba, SP.

METHODS

The actions to prevent vertical transmission in the city of Sorocaba, recommended by the Zero Vertical Transmission Project have been described by documented information of the STD/AIDS Municipal Program, by mentions, articles in local newspapers, personal memories and reports of the professionals involved⁽⁶⁻¹¹⁾.

To reach the second goal of the present study, the 120 pregnant women enrolled in the Zero Vertical Transmission Project from 1998 to 2004 had their data collected in 2007, in the PTVZ Database in Sorocaba Municipal Health Secretariat, forming the studied population. Focus was given to sociodemographic variables (age, schooling, family income, marital status, occupation, and number of children), and to data regarding HIV transmission (exposure factors, partner's serologic situation, use of condoms and number of partners). Data have been statistically treated; whenever important, frequencies, mean and confidence interval have been estimated.

To obtain data, the project has been approved by the Research Ethics Committee of the Escola de Enfermagem da Universidade de São Paulo (Process # 499/2005/CEP-EEUSP) and authorization was obtained from the coordinators of the Zero Vertical Transmission Project and of the Municipal STD/AIDS of Sorocaba, SP.

The city of Sorocaba has a population of 600 thousand inhabitants. In 2004 it ranked 21st in number of cases of the syndrome in the country⁽¹²⁾.

RESULTS

The Zero Vertical Transmission Project is developed by the Municipal STD/AIDS Program and its introduction had several phases, starting with the training of professionals, physicians and nurses of the 27 Basic Health Units (UBS) involved in the Women's Health Program, together with the training of the obstetric team at Maternidade da Santa Casa de Sorocaba, one of the institutions serving the Brazilian National Health System (SUS) of the region.

Since the beginning, it was established that all pregnant

women cared for at the UBS would take HIV test. Next, care flow was implemented and those who had the virus received medication. Then, follow-up of newborns was defined, those whose mothers were HIV positive until diagnoses was confirmed. This follow-up is performed at the Specialized Care Center - STD/AIDS clinics.

The Project also established volunteer HIV test in the first quarter of pregnancy to all pregnant looking for prenatal care in the municipal health care service and, since 2004, the protocol recommends that a second test be performed in the 3rd quarter both followed by pre and post testing.

Positive or undetermined HIV test results demand pregnant women at the UBS to be sent to the *Centro de Orientação e Apoio Sorológico de Sorocaba* (Sorocaba Center for Orientation and Serologic Support - COAS) to receive counseling by qualified university level professionals and to take a confirmatory test. When HIV is detected, the pregnant woman is sent to be treated in the STD/AIDS clinics and high risk prenatal care starts.

Pregnant women personal data are incorporated to their chart, named COAS – Pregnant woman Chart – making it possible to gather information on COASGES data base where all HIV positive pregnant women have their data recorded.

Follow-up of HIV positive pregnant women entails CD4 (Cluster of Differentiation 4) counting and viral load, as well as the application of ACTG 076 protocol for prophylaxis of HIV vertical transmission. It also entails pregnant women follow-up and a joint effort with the *Programa Recém-Nascido de Risco* (Risky Newborns Program), information is sent and pregnant women are visited at home in the 34th week of pregnancy to reinforce the guidelines and to refer them to maternity.

From the beginning of the Project around 41 thousand pregnant women were seen by the Prenatal Program, there were around 2% of refusals to take the test. HIV tests were performed in pregnant women and there were about 45 thousand tests. In the second semester of 2004, the second HIV test was introduced, performed in the third quarter of pregnancy.

HIV prevalence rate in pregnant women has been constantly decreasing since 2000, and in 2005 the rate was 0.17%, whereas in Brazil it is 0.41%⁽¹⁰⁾.

The Risky Newborn Program started in June 2000 seeing all mothers and newborns in public maternities from the city. Some of its activities are to classify babies according to risks (social and biological), guide mothers, and schedule appointments at UBS to mothers and babies. The Program health team, formed by a neonatologist, a nurse, nursing assistants, a psychologist, and a social server, provides specialized care at Policlínica and visits the households of newborns with high biological risk. In this work there is also the backup of

other specialists.

After delivery, HIV positive women seen by the Zero Vertical Transmission Project are sent to the STD/AIDS clinics for appointment and follow-up of newborns with a monthly appointment with a pediatrician until diagnoses is defined.

In the city of Sorocaba, HIV infection diagnoses in children follows the schedule of viral load counting from the 3rd month of life, with a quarter periodicity until the 18th month, when Elisa test is performed to confirm diagnoses and, if it is negative the baby is discharged from the Project.

As one of the pioneer cities with this strategy of mother-child care, Sorocaba received 60 qualitative PCR-like examinations (test used by babies from HIV positive mothers to detect HIV), from the São Paulo State Health Secretariat in 1999.

Another aspect that should be highlighted in the design and work of the Zero Vertical Transmission Project is the joint work with NGOs, such as the *Grupo de Prevenção e Apoio à Aids do Município* (City Group for AIDS Prevention and Support) which until 2002 provided milk formula to babies vertically exposed to HIV. As of 2003, artificial milk supply became a responsibility of the city with the financing from the Ministry of Health *Projeto Nascer Maternidade* (Maternity Birth Project).

Another NGO – Associação Crianças de Belém -, founded in 1996, with the mission to contribute to the improvement in quality of life of HIV positive children and adolescents, care for children in nurseries, shelters and elementary schools, it also offers professionalizing and craft courses to family members to enable income generation. This NGO also provides psychological and social care to asymptomatic or HIV symptomatic individuals, it gives a basket of staples and medical follow-up to provide family support.

In 1999, the Associação Crianças de Belém presented the project “*O amor que vem da prevenção*” (Love comes from prevention), with resources from the American Presbyterian Church, in a partnership with the Municipal STD/AIDS Program, with the objective of supporting the Zero Vertical Transmission Project by performing systematic follow-up of pregnant women that agreed to take part on the project.

This work aims to decrease economic shortcomings by providing transport tickets and a basket of staples; it also addresses psychosocial aspects and increases the adherence to medication treatment with AZT. Near delivery, it gives the baby clothing and offer spiritual support to women/family, by giving them a Bible. This project has been acknowledge as an example for financing purposes by the United Nations Fund (UNAIDS) in the 2002 edition of the World Economic

Forum held in New York(11).

When the public health system and NGOs unite care to HIV positive pregnant women and care to children exposed to the virus, nursing courses from the region are favored since the practical classes enable contact with the issue of HIV vertical transmission and clinical teaching occurs directly with HIV positive mothers and exposed newborns.

Before presenting the findings regarding exposure to HIV virus, it is worth remembering that they refer to 120 pregnant women enrolled in the Zero Vertical Transmission Project from 1998 to 2004. Next, the most relevant data from each variable selected are presented.

Mean age of HIV positive pregnant women was 27.2 years old, confidence interval was approximately 1.05 year, for 95% probability, ages ranged from 16 to 42 years old; 11 pregnant women (9.2%) were less than 19 years old, 77 (64.2%) were between 20 and 30 years old and, 32 pregnant women (26.6%) were in the age group over 31 years old.

As for schooling, 22 pregnant women (18.3%) finished primary school, 68 pregnant women (56.7%) finished elementary school, 14 (11.7%) completed high school, 10 (8.3%) were illiterate, 3 said they had completed university, and 3 gave no answer.

Regarding family income, 15 pregnant women (12.5%) received up to 1 minimum wage (MW), 39 women (32.5%) received from 2 to 5 MW, 48 women (40%) received above 5 MW, and 18 women (15%) did not report their incomes. As for marital status, 96 (80%) declared they were married, 16 (13.3%) were single, 7 (5.8%) were divorced, and only one was a widow.

Of the total, 74 pregnant women (61.7%) said they were "housewives", 33 (27.5%) worked with services, 9 were unemployed, one was retired, one was a student, and one did not provide information.

Mean number of kids per pregnant woman was 1.64; with a confidence interval of 0.28 children, median and mode were 1. Of the total, 90 pregnant women (75%) had up to two kids. Fourteen pregnant women said they had more than 4 children; two of them had six and eight children respectively.

Even though data have been obtained as of 1998, pregnant women were required to mention three reasons related with risk factors since 1980. The main situations presented by women were: sexual intercourse with a male partner (119 mentions – 32.5%), promiscuous partner (97 mentions – 26.5%), partner using blood components (33 – 9.02%), HIV positive partner (27 mentions – 7.4%), partner is an ex-prisoner/prisoner (27 – 7.4%), sexual intercourse for money (21 – 5.7%), bisexual partner (7 – 1.9%), injection drug user (5 – 1.4%), homosexual relations (2 – 0.6%), being a victim of sexual abuse (2 – 0.6%).

As for sexual orientation, 115 pregnant women (95.8%) were heterosexual, three (2.5%) were homosexual, one (0.8%) was bisexual, and one did not provide information.

Number of male partners in the last year before entering the Zero Vertical Transmission Project was not higher than one to 102 pregnant women (85%), 14 (11.7%) mentioned 2 to 4 partners, 3 (2.5%) referred 5 or more partners in the period and one did not provide information. Among the 102 pregnant women referring 1 partner, 3 of them said they had no partners in the year before enrolling the Project.

As for partners' serum condition, 68 pregnant women (56.7%) were not aware of it; in turn, 29 (24.2%) mentioned their partner was HIV positive, 16 (13.3%) said their partner were HIV negative, 7 partners were being investigated and 2 pregnant women did not provide information.

Regarding the question "condom use in the last year", 88 pregnant women (73.3%) said they had never used condoms; occasional use was reported by 21 women (17.5%), and only one (0.8%) said she always used it, 9 women said they used it frequently, and one did not provide information.

Pregnant women exposure to HIV/AIDS, checked by data obtained, confirms the main risk situations experienced by women in the country presented by studies approaching the experience of women regarding AIDS epidemics⁽¹²⁾.

The comparison of information on the use of condoms and partners' serologic situation revealed decreased adoption of measures to prevent HIV transmission in sexual intercourse, especially when the partner is steady, contributing to the increase in infection risk⁽¹²⁾.

The question "have you been tested for HIV before pregnancy?" there were 115 answers, among them, 51 (44.3%) answered yes and 64 (55.7%) answered no to HIV test before pregnancy. Among the 51 pregnant women undergoing the test, 13 (25.5%) said the result was positive; 37 (77.6%) reported the results had been negative, and only one pregnant woman (1.9%) did not receive an answer on test result.

DISCUSSION

Data presented show that, regarding age of the pregnant women enrolled in the Zero Vertical Transmission Programs results are in agreement with findings from other studies on the issue, where young adults are prevalent⁽¹³⁾. Another condition that is similar in pregnant women from the present study and other studies is schooling, reinforcing the association between low schooling and disease incidence⁽¹³⁾. Low schooling

is reflected on the type of occupation performed by these pregnant women, most of them perform activities that demand a low level of education such as: household chores, and working with services and in shops.

Mean number of children shows that the fertility rate for these mothers is below the national standard which is 2.1 children per couple⁽¹³⁾.

When results were compared – test performance and partners' serologic situation – it is seen that women usually do not do the exam voluntarily. This may be to avoid diagnoses, to avoid interference in the relationship, or because they trust their partners.

Unprotected sexual intercourse with partners at risk characterizes the behavior of these pregnant women. This fact is not relevant enough for them to be a reason to take HIV test. Therefore, data shows that these pregnant women present unsafe sexual practices as the main risk for HIV infection exposure.

Exposure of pregnant women to HIV/AIDS, seen by the data obtained, confirm the main risk situations experienced by women in the country that are presented in studies approaching the experience of women regarding AIDS epidemics⁽¹⁴⁾.

Comparing information regarding the use of condoms and partner's serologic situation showed decreased adoption of measures to prevent HIV infection through sexual intercourse, especially with a steady partner, contributing to the increase in infection risk⁽¹⁴⁾.

Information the factor of exposure and the performance of HIV test shows a contradiction since some women reported having sex for money as a factor for HIV/AIDS exposure; however, the number of women who were reported being a prostitute was small and did not correspond to the former statement.

The experience of this partnership between the public and private sector and NGOs enabled a shared answer, which contributed to build an efficient alternative to provide social and medical care. The relationship established between the Third Sector and the health is especially to fight AIDS – NGOs/AIDS partnership is a renovation of the social solidarity bonds created by the epidemic⁽¹⁵⁻¹⁶⁾, confirmed by the practices and analysis performed⁽¹⁵⁻¹⁸⁾.

Creation and participation of the Third Sector in the public health care system created a new movement in society which is a new form of social intervention, contributing to stop discriminatory and segregation actions. They are also responsible for mobilizations for rights, formation of networks and empowering

programs⁽¹⁸⁾, as well as for the creation and implementation of support houses. That is, they influenced the valorization of individuals by providing accessibility to all citizens.

CONCLUSION

Characterization of pregnant women seen by the Zero Vertical Transmission Project in Sorocaba, SP, exposes the reality of these women, living in a middle sized city with a defined health service structure geared to prenatal, especially to training and treatment of HIV positive pregnant women.

This characterization shows risk situations that led these women to become infected by HIV. They are women who do not look for protection adopting measures for safer sex. Overall, their characterization is not different from the identification found in other groups of HIV positive pregnant women in other studies, or from the data presented by the Ministry of Health.

Partnership between municipal and federal health managers with non-governmental organizations demonstrated the efficiency of a conscious work of integration that aims to provide total care for HIV positive pregnant women and their families and to reduce vertical transmission of the virus in the city.

Adoption of the measures recommended by the health manager to treat HIV vertical transmission aims especially to offer pre-natal test available in all primary care. This is a valuable opportunity for diagnoses in women and for treatment when necessary. Multidisciplinary work and nursing work are coordinated and integrated with the objectives proposed by the Project which was also an important model for graduating nurses.

Thus, taking actions to reduce vertical HIV transmission and involving managers through the action of health professionals integrated to the actions performed by the Third Sector are a great example of joint work to meet the demands of the population involved in AIDS epidemics.

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