

Abandonment of health monitoring of babies of mothers with vertical transmission grievance*

Abandono do acompanhamento em saúde de bebês de mães com agravo de transmissão vertical

How to cite this article:

Shibukawa BMC, Merino MFGL, Lanjoni VP, Brito FAM, Furtado MD, Higarashi IH. Abandonment of health monitoring of babies of mothers with vertical transmission grievance. Rev Rene. 2021;22:e60815. DOI: <https://doi.org/10.15253/2175-6783.20212260815>

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*Extracted from the dissertation "Acompanhamento de crianças de mães com agravo de transmissão vertical", Universidade Estadual de Maringá, 2019.

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EDITOR IN CHIEF: Viviane Martins da Silva
ASSOCIATE EDITOR: Renan Alves Silva

ABSTRACT

Objective: to analyze the abandonment of the health monitoring of babies of mothers with vertical transmission grievance. **Methods:** a retrospective documental study. The data came from children's records stratified as high risk by the Paranaense Mother Network Program, due to being daughters of women diagnosed with syphilis, toxoplasmosis or Human Immunodeficiency Virus in the gestational period, attended in a reference center of maternal-infant care. For the analysis of factors associated with abandonment of treatment, univariate analysis and Fisher's Exact Test with sociodemographic variables were performed. All ethical precepts were observed. **Results:** a total of 136 medical records were analyzed. The cases with the highest abandonment rate were the children of women with toxoplasmosis and gestational syphilis, presenting rates of 48.4% and 45.7%, respectively. **Conclusion:** the abandonment of baby health monitoring is recurrent. The reasons for frequent abandonment were: lack of active search, lack of transportation and unforeseen family events.

Descriptors: Child Health Services; No-Show Patients; Health Services Accessibility; Patient Dropouts; Continuity of Patient Care.

RESUMO

Objetivo: analisar o abandono do acompanhamento em saúde de bebês de mães com agravo de transmissão vertical. **Métodos:** estudo documental retrospectivo. Os dados foram oriundos de prontuários de crianças estratificadas como alto risco pelo Programa Rede Mãe Paranaense, devido serem filhas de mulheres com diagnóstico de sífilis, toxoplasmose ou Vírus da Imunodeficiência Humana no período gestacional, atendidas em centro de referência de atendimento materno-infantil. Para a análise dos fatores associados ao abandono do tratamento, realizou-se análise univariada e Teste Exato de Fisher com as variáveis socio-demográficas. Todos os preceitos éticos foram observados. **Resultados:** foram analisados 136 prontuários. Os casos com maior taxa de abandono foram de filhos de mulheres com toxoplasmose e sífilis gestacional, apresentando taxas de 48,4% e 45,7%, respectivamente. **Conclusão:** o abandono do acompanhamento de saúde dos bebês é recorrente. Os motivos de abandono frequentes foram: falta de busca ativa, falta de transporte e imprevisto familiar.

Descritores: Serviços de Saúde da Criança; Pacientes Não Comparecentes; Acesso aos Serviços de Saúde; Pacientes Desistentes do Tratamento; Continuidade da Assistência ao Paciente.

Introduction

Vertically transmitted diseases are a major challenge for public health, the most common being syphilis, toxoplasmosis and Human Immunodeficiency Virus (HIV). In order to adequately address these, it is necessary to ensure the correct approach of the pregnant woman and her partner for treatment, with a view to interrupting the chain of transmission⁽¹⁻³⁾.

In the world, in 2016 there were about 2 million pregnant women infected with syphilis and, of these, 1.2 million transmit the bill of review to their children through a transplacental route, generating unfavorable outcomes⁽¹⁾. Every year, 190,100 cases of congenital toxoplasmosis appear in the world, which can cause hydrocephalus, epilepsy and loss of vision in babies⁽²⁾. It is also estimated that if untreated, 20.0% of children with HIV may die before they are even six months old, and 50.0% before they are two years old⁽³⁾.

Intrauterine exposure to the above mentioned diseases predicts its stratification as a high risk due to the unfavorable outcomes that may result from them. Therefore, to ensure the safety of a growth assisted by a multidisciplinary network, it is of paramount importance to systematically monitor its development⁽⁴⁾.

It is not yet clear in the literature all the unfavorable outcomes that these children may develop during their childhood; however, it is known that they have a higher risk of mortality, which makes them a vulnerable group⁽¹⁻⁴⁾. Specialized monitoring is a right of the vulnerable child, guaranteed through national maternal and child health programs, which should be offered to those responsible, generating the linkage of the child to this network of services, ensuring access to it⁽⁴⁾.

The systematic monitoring of the baby's health in conditions of vulnerability due to the upside down transmission can guide the decision process for the implementation of measures that contribute and

stimulate the mothers to maintain the monitoring of their children.

However, evidence in the literature points to high rates of abandonment of treatment and monitoring in health services⁽⁵⁻⁸⁾. In this context, and considering the specific scenario of these programmatic actions, the question of the study that arises is: what are the reasons for abandoning the monitoring of babies of mothers with vertical transmission diseases in the high risk pediatric outpatient clinics of the Paranaense Mother Network?

Therefore, and in view of the possible complications to the global health and growth/development process resulting from the abandonment of specialized monitoring, the objective was to analyze the abandonment of the health monitoring of babies of mothers with vertical transmission grievance.

Methods

This is a retrospective documental study. The data comes from the medical records of all children referred and accompanied by the high-risk outpatient clinic, a reference of care of the Paranaense Mother Network for 30 municipalities in northwestern Paraná, from January 2015 to December 2018, whose mothers were diagnosed with syphilis, toxoplasmosis or Human Immunodeficiency Virus. The inclusion of data from 2015, is justified by the date of implementation of electronic records of the high risk ambulatory.

The theoretical basis that conducted the study was anchored in the concepts recommended by the Paranaense Mother Network Program, guided by the Paranaense Mother Network Guide Line. This manual defines the functioning of maternal and child care in Paraná, through the early capture of the pregnant woman and monitoring of newborns with up to one year of life⁽⁹⁾.

The manual foresees the stratification of the of death for children in usual, intermediate and high

risk. After stratification, they are linked to health services. Low-risk children are consulted only in primary health care; intermediate-risk and high-risk children are consulted in secondary outpatient clinics, which promote consultations with pediatricians, specialists, and multi-professional teams, in addition to making available all the prescribed examinations⁽⁹⁾.

The only inclusion criterion was the medical records of babies from mothers diagnosed with syphilis, toxoplasmosis or HIV during pregnancy, as recommended by the Paranaense Mother Network Guide Line⁽¹⁰⁾. No exclusion criteria were adopted.

During the study period, 908 children were referred to the high-risk outpatient clinic, of which 772 were initially excluded because they did not meet the inclusion criteria: having been referred due to syphilis, toxoplasmosis and HIV/ maternal Acquired Immunodeficiency Syndrome (AIDS). Therefore, 136 records of children who met the inclusion criterion were included in the sample. Of these, 81 were referred for being daughters of women with gestational syphilis, 31 daughters of women with toxoplasmosis and 24 daughters of women with HIV/AIDS.

The data collection took place from September 2018 to January 2019, through prior scheduling with the responsible sector. With the list of codes referring to children in hand, the researcher proceeded to the reading of all the records, with selection only of the cases of interest for the research, according to the established eligibility criteria.

To assist the collection, the records were categorized according to the reasons for referral (type of bill of review for vertical transmission): syphilis, toxoplasmosis and HIV/AIDS. The high risk outpatient clinic studied monitors these children only up to the first 12 months of life, general age limit for the high risk foreseen in Guide Line⁽⁹⁾.

The data was collected by consulting the patients' electronic records, and the information collected with the help of a structured form prepared by the

researcher, which contemplated both infant and maternal variables.

For the infant variables, data was selected regarding the time of birth, birth route (normal and cesarean section), gestational age (≤ 36 and ≥ 37 weeks), Apgar at the 1st and 5th minutes of life (≤ 7 and ≥ 8), as well as the reason for referral to the high-risk outpatient service (being children of women diagnosed with syphilis, toxoplasmosis or HIV/AIDS during pregnancy), psychomotor development reported in a consultation without a specific instrument described (normal and altered), and interurrences during the monitoring at the high-risk outpatient clinic.

Regarding maternal variables, we collected data regarding age (< 19 , 19 to 34, and ≥ 35 years), education (< 8 and ≥ 8 years of study), race/color (white and non-white), marital status (with and without partner), nationality (Brazilian and foreign) and religion (evangelical, catholic, and others).

All children must be monitored for up to 12 months of life and have at least four consultations. However, the child may have more consultations at medical discretion, but will only be discharged after one year of life. Therefore, regarding the abandonment of monitoring in the Paranaense Mother Network, all cases where the children did not attend the scheduled appointments for a period of nine months were considered abandonment, since the first visit to the outpatient clinic usually takes place until the baby's third month of life, and the high-risk outpatient clinic performs the monitoring until they complete one year.

As recommended by the Paranaense Mother Network⁽⁹⁾, the high risk ambulatory at the end of each day of care sent an e-mail to all health units/municipalities, informing the name and phone number of the noncomparent patient, since it is the responsibility of the ambulatory to make an active search for the children and to carry out this return to the high risk ambulatory.

These returns were registered in medical recor-

ds and analyzed by the researchers, who classified the records in eight reasons, being them: responsible claimed not to know of the existence of the consultation; child was hospitalized on the day of the consultation; responsible forgot the consultation; lack of transportation; unforeseen family; change of municipality/reference; could not make the exams requested (so they chose not to go to the consultation), and finally, were classified as “no response to active search” those cases in which there was no return of active search by primary health care.

For the analysis of factors associated with abandonment of monitoring (maternal and infant variables mentioned above), univariate analysis and application of Fisher’s Exact Test were performed. The result of the factors associated with the abandonment of monitoring was expressed by means of odds ratio (OR), with 95% confidence interval (CI), and the data were processed by means of the software Statistical Package for the Social Sciences (IBM SPSS®).

This research had its project approved by the Permanent Committee on Ethics in Research with Human Beings of the State University of Maringá, under opinion No. 2,287,476/2017. All formal requirements contained in the regulatory rules of ethics in research involving human beings were respected.

Results

In total, 136 children’s records were analyzed, of which 81 (59.6%) were gestational syphilis, 31 (22.8%) gestational toxoplasmosis, and 24 (17.6%) gestational HIV/AIDS. Most were female (except syphilis), with gestational age at birth equal to or greater than 37 weeks, Apgar at the first and fifth minute of life equal to or greater than seven, weighing at least 2,500 grams. The prevailing age range of mothers was 19 to 34 years, with schooling of eight years or more, white and with partner, except in cases of syphilis referral, in which the mothers were mostly non-white and without partner, as described in Table 1.

Table 1 – Sociodemographic profile of mothers and characterization of children. Maringá, PR, Brazil, 2019

Variables	Syphilis	*HIV/AIDS	Toxoplasmosis
	n (%)	n (%)	n (%)
Age (years)			
<19	11 (13.6)	1 (4.2)	0
19-34	67 (82.7)	20 (83.3)	26 (83.9)
≥35	3 (3.7)	3 (12.5)	5 (16.1)
Education (years)			
< 8	31 (38.3)	11 (45.8)	15 (48.4)
≥8	50 (61.7)	13 (54.2)	16 (51.6)
Ethnicity			
White	39 (48.1)	14 (58.3)	20 (64.5)
Non-white	42 (51.9)	10 (41.7)	11 (35.5)
Marital status			
With partner	37 (45.7)	17 (70.8)	18 (58.1)
Without partner	44 (54.3)	7 (29.2)	13 (41.9)
Clinical variable			
Cesarean	43 (53.1)	24 (100)	15 (48.4)
Normal	38 (46.9)	0	16 (51.6)
Sex			
Female	36(44.4)	13(54.2)	16(51.6)
Male	45(55.6)	11(45.8)	15(48.4)
Gestational age			
< 36	10 (12.3)	4(16.7)	4(12.9)
≥ 37	53(65.4)	16(66.7)	21(67.7)
Blank	18(22.2)	4(16.7)	6(19.4)
Apgar 1 st minute			
< 6	10(12.3)	2(8.3)	3(9.7)
≥ 7	56(69.1)	19(79.2)	23(74.2)
Blank	15(18.5)	3(12.5)	5(16.1)
Apgar 5 th minute			
< 6	-	1(4.2)	1(3.2)
≥ 7	66(81.5)	20(83.3)	25(80.6)
Blank	15(18.5)	3(12.5)	5(16.1)
Weight (grams)			
< 2.499	8(9.9)	3(9.7)	6(25)
>2.500	55(67.9)	23(74.2)	15(62.5)
Blank	18(22.2)	5(16.1)	3(12.5)

*HIV: Human Immunodeficiency Virus; AIDS: Acquired Immunodeficiency Syndrome

There was a high number of monitoring abandonments in this study. The distribution of the abandonments according to the cities of origin showed that the majority of those responsible for the children who abandoned the monitoring came from the host city, representing 44 (54.3%) and 14 (45.2%) children, respectively, for cases referred for syphilis and toxoplasmosis. The exception were the cases referred for HIV/AIDS, which presented seven (29.2%) cases of evasion among residents of the surrounding municipalities.

Abandonment has reached almost half of monitoring, except in cases of HIV/AIDS. The frequent reasons for abandonment listed by the service were: no response to active search, lack of transportation, and unforeseen family events, as shown in Table.

Table 2 – Prevalence and reasons for abandoning child care. Maringá, PR, Brazil, 2019

Abandonment	Syphilis	Toxoplasmosis	*HIV/AIDS
	n (%)	n (%)	n (%)
Abandonment of monitoring	37 (45.7)	15 (48.4)	7 (29.2)
Reasons for abandonment			
Guardian claimed not to know of the existence of the consultation	1 (2.7)	-	-
Child was hospitalized on the day of the consultation	1 (2.7)	-	-
Guardian forgot about the consultation	2 (5.4)	2 (13.3)	-
Lack of transportation	7 (18.9)	3 (20)	3 (42.9)
Unforeseen Family emergency	7 (18.9)	3 (20)	1 (14.3)
Change of municipality/reference	1 (2.7)	-	-
Not being able to do requested exams	1 (2.7)	-	-
No response to active search	17 (45.9)	7 (46.7)	3 (42.9)

*HIV: Human Immunodeficiency Virus; AIDS: Acquired Immunodeficiency Syndrome

By analyzing compliance with the guideline regarding the minimum number of four consultations carried out, it was possible to evidence the abandonment of monitoring long before the recommended one. In relation to the abandonment of accompaniment of children of women with syphilis, 73.0% gave up in the second consultation, 21.6% in the third and 5.4% in the fourth; there was no abandonment in the

fifth consultation. In relation to the abandonment of monitoring of children of women with toxoplasmosis, 40.0% gave up in the second consultation, 33.3% in the third, 20.0% in the fourth, and 14.3% in the fifth consultation. In relation to abandonment of monitoring of children of women with HIV/AIDS, 28.6% gave up in the second consultation, 28.6% in the third, and 42.9% in the fourth; there was no abandonment in the fifth consultation.

The reasons that may justify the abandonment of the monitoring are related to particular situations; however, through these findings, it is also reflected on failures in the fulfillment of the actions recommended by the program, such as the carrying out of visits to children who are absent from the scheduled activities and the scheduling of new consultations, with priority given to children at risk.

In an attempt to find a pattern in abandonment, it was decided to perform calculations of the association of maternal (age, schooling, ethnicity, marital status, and birth route) and infant (sex, gestational age, first and fifth minute Apgar, and weight) variables with the bill of review for vertical transmission, given the population size. However, the only statistically significant association identified was between males and the occurrence of vertical transmission ($p=0.002$).

Discussion

As a limitation of this documental study, one can highlight the data source itself, the medical records, since the necessary information is conditioned to the quality of the records made. However, the study allowed discovering weaknesses in the field of child health monitoring, highlighting critical nodes for future interventions. By identifying the main fragilities of child health monitoring, health professionals are provided with a theoretical basis to help in the formulation of activities in health education, in order to improve the effectiveness of the Paranaense Mother Network program.

The findings related to maternal variables,

such as age, education and ethnicity, are in line with the profile found in literature, ratifying the importance of valuing prenatal monitoring and treatment of children, which should be prioritized by public policies in order to disseminate pertinent information to avoid abandonment of health services, with a view to reducing vertical transmission, in addition to raising awareness of the importance of adherence to and permanence in child health monitoring, in order to avoid unfavorable outcomes⁽¹⁰⁻¹¹⁾.

The only maternal characteristic that diverged from the literature was ethnicity, since in this study only syphilis indicated the predominance of non-white color, while HIV/AIDS and toxoplasmosis presented a majority of white women. It should be noted that these results may be due to or influenced by socio-geographical factors, given the predominance of European colonization in the State of Paraná^(5,12).

Regarding the families' municipalities of origin, the most frequent were those with a maximum distance of 30 kilometers from the consultation site. The number of patients referred to the reference service, however, was lower than expected, considering the notifications at birth in the Grievances Notification Information System. The literature highlights, among the possible reasons for this numerical discrepancy between notifications and referrals, confusion, or even lack of knowledge and training on the references and counter-references to be practiced between the levels of health care⁽¹³⁾.

Not being referred to the expected level of attention causes unnecessary exposure to the risk of death, in addition to representing a deprivation of the right to enjoy specialized monitoring. Not proceeding with the referral, constitutes an act of negligence on the part of professionals and services, and an inadmissible omission in view of the consensus in the literature, which points to early capture and child monitoring as major allies against child mortality⁽¹⁴⁻¹⁵⁾.

The reasons found to justify the abandonment are often related to aspects of personal and family daily life of those responsible, highlighting the importan-

ce of all levels of health being committed not only to the children, but also to their families, who are ultimately directly responsible for adherence to the monitoring process. In addition, it is emphasized the need to reinforce the importance of this monitoring in every consultation of the child in the high-risk outpatient clinic or of the family in primary health care⁽¹⁴⁾.

Although the stigma of "severity" in syphilis and HIV/AIDS cases is still visible in our society⁽¹⁶⁾, The prevalence of abandonment of the program by the mothers of the present study was observed in the second consultation of the children, reaching 73 and 28.6%, respectively. The high rates of abandonment of baby monitoring in the first year of life are, in general, observed in preventive monitoring of the child. In these cases, mothers tend to present such behavior because they believe there is no imminent danger in the health of their children. This profile was presented by a study of the southern region, which investigated the frequency of child care consultations, showing that only 73.0% return to the second, being 40.0% children of one and two months, 69.8% children between three and four months, and 88.8% older than five months⁽¹⁵⁾.

A study on abandonment of child monitoring, involving mothers with HIV/AIDS, showed an average of four consultations, a result similar to that obtained by this research, which obtained an average of three consultations⁽¹⁶⁾. No studies have been found in the literature describing the reasons why the percentages of abandonment at the second consultation by children whose mothers had syphilis and gestational toxoplasmosis were so high. However, it is known that abandonment from high-risk clientele, regardless of the reason for stratification, is on average 39.0%⁽¹⁷⁾.

The abandonment of monitoring causes major logistical problems within the service, as it generates schedule gaps, which cannot be filled at the last minute. The lack without prior notice to the service provider also favors the creation or increase of the queue of those who are waiting for a vacancy to enter the system⁽¹⁶⁻¹⁷⁾.

Several reasons for abandonment were listed in this study, but the most emphasized aspects were related to the lack of active search and transportation. In this context, it is important to emphasize the importance of the active search for the offenders, which is one of the pillars of the Paranaense Mother Network⁽⁹⁾. This strategy seeks to understand the reason for the patients' evasion, in order to make possible the good progress of the high risk service through direct and assiduous contact with the parents, and by making them aware of the importance of the consultations⁽⁴⁾.

In this way, the non-fulfillment of this activity hurts not only the guidelines of the Paranaense Mother Network, but also the already guaranteed right of priority for rescheduling the offenders, thus breaking the cycle of functioning of the network and collaborating for the abandonment^(4,9).

Another worrying factor is the number of absences attributed to transport problems, referring to issues of accessibility to the population, such problems being attributed to the State^(4,9). The unforeseen family situation was also cited as a reason for absenteeism, a factor over which the health team has no control. However, the reference to it should serve as a warning sign for primary health care, as an indication of eventual need of care in that residence. This brings relevance, again, to issues involving the articulation between health care levels, in favor of assistance with inclusion of the family in care, considering its vulnerabilities, establishing and strengthening the professional-patient bond^(13,18).

The number of consultations planned within the high-risk outpatient clinic is very limited, which in itself hinders the creation of a bond of trust between the women who take their children for consultations and health professionals⁽³⁾. Thus, it can be inferred that the lack of bond, associated with the lack of transportation and problems with active search, ends up creating an assistance scenario that predisposes to the abandonment of monitoring.

Although the analysis of all cases of abandon-

ment in 30 municipalities belonging to the regional health of the study was performed, the sample size did not allow the association test to reveal connections between the variables, except for males. This data can be associated to the cultural factor, since there is a predominance of protective posture in relation to females, considered more fragile when compared to males⁽¹⁹⁾, which may influence the care and protection of babies by relatives.

Studies on the issue of abandonment of monitoring in the health services are scarce, and in general are restricted to studies with interviews with mothers who use the network, or who describe suggestions and complaints from users, coming from opinion surveys forms filled out at the time of care, confirming the importance of this survey^(2,4,6,15,17).

Conclusion

The abandonment of baby health monitoring is recurrent. The cases with the highest abandonment rate were children of women with toxoplasmosis (48.4%), syphilis (45.7%) and Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (29.2%), respectively. The reasons for frequent abandonment were lack of active search, lack of transportation and family unforeseen.

Acknowledgements

The *Coordenação de Aperfeiçoamento de Pessoal de Nível Superior*, Funding Code 001, for the grant to Bianca Machado Cruz Shibukawa through the Postgraduate Nursing Program of the *Universidade Estadual de Maringá*.

Collaborations

Shibukawa BMC and Higarashi IH contributed in the conception and design, analysis and interpretation of the data, writing of the article, relevant critical

review of the intellectual content and final approval of the version to be published. Merino MFGL, Lanjoni VP, Brito FAM and Demitto MO contributed in the writing of the article, relevant critical review of the intellectual content and final approval of the version to be published.

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