

# Follow-up of high risk babies in health services: a commitment for life

**RESUMO** | Objetivo: identificar os motivos que levam as mães de bebês de alto risco a abandonarem o acompanhamento no Ambulatório de Alto Risco, ao longo do primeiro ano de vida. Método: estudo descritivo e exploratório, de natureza qualitativa realizado com 16 mães de bebês que foram acompanhados no Ambulatório de Alto Risco vinculado ao Programa Rede Mãe Paranaense. A coleta de dados ocorreu entre os meses de agosto e setembro de 2020, mediante entrevistas semiestruturadas e submetidas à análise de conteúdo, modalidade temática. Resultados: Emergiram duas categorias: Abandono do acompanhamento infantil de alto risco: desconhecimento atrelado a falta de apoio social; Ansiedade frente ao desconhecido: vivência das mães após o nascimento. Conclusão: os motivos referentes aos aspectos maternos, familiares, sociais e características dos serviços de saúde podem influenciar no abandono do acompanhamento infantil.

**Descritores:** Saúde da criança; Serviços de Saúde Materno-Infantil; Desenvolvimento infantil; Pacientes Desistentes do Tratamento.

**ABSTRACT** | Objective: to identify the reasons that lead mothers of high-risk babies to abandon follow-up at the High-Risk Outpatient Clinic, throughout the first year of life. Method: descriptive and exploratory study, qualitative in nature, conducted with 16 mothers of babies who were followed at the High Risk Outpatient Clinic linked to the Rede Mãe Paranaense Program. Data collection took place between August and September 2020, through semi-structured interviews and submitted to content analysis, thematic modality. Results: Two categories emerged: Abandonment of high-risk child monitoring: lack of knowledge linked to lack of social support; Anxiety in the face of the unknown: mothers' experience after birth. Conclusion: the reasons related to maternal, family, social aspects and characteristics of health services can influence the abandonment of child care.

**Descriptors:** Child health; Maternal and Child Health Services; Child development; Treatment Dropout Patients;

**RESUMEN** | Objetivo: identificar los motivos que llevan a las madres de bebés de alto riesgo a abandonar el seguimiento en la Clínica Ambulatoria de Alto Riesgo, a lo largo del primer año de vida. Método: estudio descriptivo y exploratorio, de carácter cualitativo, realizado con 16 madres de bebés que fueron seguidos en la Clínica de Alto Riesgo vinculada al Programa Rede Mãe Paranaense. La recolección de datos se realizó entre agosto y septiembre de 2020, a través de entrevistas semiestructuradas y sometidas a análisis de contenido, modalidad temática. Resultados: Surgieron dos categorías: Abandono del monitoreo infantil de alto riesgo: desconocimiento vinculado a falta de apoyo social; Ansiedad ante lo desconocido: la experiencia de las madres después del nacimiento. Conclusión: las razones relacionadas con aspectos maternos, familiares, sociales y características de los servicios de salud pueden influir en el abandono del cuidado infantil.

**Descriptores:** Salud infantil; Servicios de salud materno-infantil; Desarrollo infantil; Pacientes que abandonaron el tratamiento.

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## INTRODUCTION

Most of the deaths at enfance period are concentrated at the first year of life, above it all at the first month of life. There is an increased influence of the perinatal causes, such as prematurity, which evidences the importance of the factors related to the pregnancy, labour and post-labour, in general preventable through quality health assistance. Those happen as a combination of biological, social, cultural factors and failures at the health system (1).

The last few decades the world has passed through many progresses, although, child mortality is yet a matter that brings preoccupation for public health. The global child mortality rate of childrens with less than five years old has decreased from 93 (92, 95) in

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1990 and 76 (75, 78) in 2000 to 39 (37, 42) deaths for 1.000 born alive in 2018 - 59% and 49%, respectively (2).

Brazil has reduced its child mortality between 1990 and 2015, one of the Millennium Develop Goals (ODM) aims. However, in 2016, the child mortality rate had an increase, a fact that hasn't happened in 26 years. According to the Brazilian Institute of Geography and Statistics, the 2018 mortality taxes were 12,4 for each 1.000 born alive. Although the mortality rate has decreased in a half from 1990 to 2018, those are not yet considered high, and millions of childrens are dying every day (3).

In regions with bigger economic development, such as Brazilian South and Southeast, the mortality rates are lower. In the North and Northeast there are the bigger mortality rates, while in the Midwest the rates are medium (4).

Regarding child and maternal morbimortality, in 2011, the Health Ministry of the federal government instituted the "Rede Cegonha" (Stork System) plan at the Brazilian Public Health System (SUS). The "Rede Cegonha" have as aim organizing the maternal-child care in Brazil, ensuring that every woman has right to reproductive planning, as well as integral assistance at pre-birth, during the labour and also at post-labour period, beyond guaranteeing the child's full growth and develop (5).

In 2012, the state of Parana implemented the Paranaense Mother System, following the same principles of the Rede Cegonha (Stork System). One of the program strategies is identifying and preventing risk conditions through the babies and mothers classification in three groups: high risk, moderate risk and low risk (6).

According to the Mortality Information System of Parana 's Health Secretariat, in 2010, before the Paranaense Mother System implantation, the child mortality coefficient was 12,65/1.000 born alive. In the year of 2014, after the program implantation, the rate

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has slightly reduced, for 11,65/1.000 born alive. In 2019 the registered death numbers were 10,62/1.000 born alive. This is a non-significative reduction, if considered that a big part of the deaths happened for preventable causes (7).

Whereas the fact that the program aims the monitoring continuity after the children's birth, for reducing the child mortality rate, majorly of preventable causes, it is indiscutible the need of studies about the reasons that take the mothers to abandonate the Paranaense Mother Program's monitoring (7).

Due to the fragility scenario, the mothers and babies bond with public politics who transform their life's condition after the birth becomes essential and provide a prevention of risk conditions in which the binome mother-son meet. Even though there exists a specific public politiqu assistance for risk cases, the neglect of the children's assistance at the first month of life still happens at the Paranaense Mother System(7-4).

In that way, the study justified itself for searching the mother's perceptions for leaving the newborn child assistance, of risk, despite the existence of a health care program for this specific group. The present study has, then, as an objective, identifying the reasons who take mothers and babies at risk to abandon the assistance at High-Risk Outpatient Clinic, throughout the first years of life.

#### METHOD

Exploratory and descriptive study, of qualitative approach, made with 16 mothers who abandoned their babies medical supervision at High Risk Ambulatory. The COREQ (Consolidated Criteria for Reporting Qualitative Research) guideline was used as a direction for its production (8).

The study 's participants were mothers with babies up to 12 months of age registered at Paranaense Mother

System, at the High Risk Ambulatory reference to a Health's Regional of Parana's State. The inclusion criterias was children's stratified as high-risk according to the Paranaense Mother System criteria and guided to the assistance at specialized clinic at the second semester of 2019, and the informer being the child's primary caregiver. The baby's mothers who died in this period were excluded from the study.

At knowing, high-risk childrens are those who present risk factors related to: perinatal disorders (prematurity ≤ 34 weeks gestational age; low weight at birth < 2.000g; perinatal asphyxia- apgar < 7 at the 5° minute), hyperbilirubinemia with exchange transfusion, birth defects/ chromossomopathies/ genetic diseases, positive newborn screening, confirmed vertical transmission diseases, high subnutrition, obesity, delayed psychomotor development and recurrent complications with clinic repercussion (6).

From a total of 75 registered children 's (2 twins), 26 mothers were not localized for changing at telephone contact. From 48 localized mothers, 32 have refused to participate in the study, for the sampling was composed by 16 mothers.

The data collection has happened during the months of august and october 2020, through previous scheduling for the semi structured interview applying with questions that concerns about the reasons who leads the mothers of the babies in health risk to abandon the medical supervision at the High-risk Ambulatory, during the first year of the baby's life.

After reading the Free and Clarified Agreement document for the mothers and their consent in participating at the study, the interviews were tapped and, after that fully transcript. The transcript material was submitted to content and thematic modality análise (9), sendo assim emergiram duas categorias intuitivas: Abandono do acompanhamento

infantil de alto risco: desconhecimento atrelado a falta de apoio social; Ansiedade frente ao desconhecido: vivência das mães após o nascimento.

For the present research realization, all of the ethical and legal processes present at the regulament norms determined by the resolutions 466/2012, 510/2016 of the Brazilian National Health Council were followed, as well as the established ethical guidelines for human beings studies realization. The study had the ethical appreciation advice by the Maringa' s Estadual University Permanent Ethical Committee of Research Involving Humans Subjects under the register nº 3.766.436, CAAE: 24906719.9.0000.0104.

With the aim of preserving the anonimata at the results presentation, the participant's related extracts were identified by the letter "M" as in Mother, and a number who informs the order of interviews realization.

**RESULTS**

16 mothers of children led to High Risk Ambulatory reference for a Health Regional of the State of Paraná were interviewed. Between the study participants, 12 belonged to the medical supervision abandon group, 2 belonged to the medical supervision accession and 2 were from non-accession group. Nine of them were living in Maringa's city and seven were from close cities which belonged to the 15° Parana's Health Regional.

From the analized pronctuaries, seven (43,75%) childrens were from feminine sex and other nine (56,25%) from the masculine. The reasons of leading were majorly for prematurity, corresponding to 43,75% and vertical transmission diseases (syphilis, toxoplasmosis and B hepatosis), with approximately 37,5%, as shown in table 1.

Concerning the ambulatory supervision time, 50% (8) of the childrens were supervised through four mon-

**Table 1. Leading for the Mother Paranaense System Leading reasons.**

Reasons for leading	n	%
Prematurity	7	43,75
Vertical Transmission diseases	6	37,50
Kidney diseases	1	6,25
Pneumonia	1	6,25
Syndromes	1	6,25

Source: research data (2020).

ths or less, 18,75% (3) from five to eight months and 31,25% (5) of nine months or more. The average number of appointments for children was 2,37%.

From the data analysis process emerged two theme categories that will be described at the following paragraphs.

High-risk child monitoring abandon: unknowing related to missing social support.

It was observed that some mothers had not acknowledgement about the monitoring protocol by the Paranaense Mother System for the childrens classified as High Risk, as well as the reasons of her children's inclusion at the program.

If they had explained everything correctly, I would have gone. Especially being my son, we always want their good, we do what we can and if they had explained to me best what should i do, because, you understand? I absolutely would have gone, everything for him. (M1)

The lady who gave us discharge, yes, she just said like, that he would be accompanied only to be sure that everything was ok, but that he was just fine (M2)

It is believed that the mother 's orientation is important for the monitoring adherence. Although, there are other reasons that influence the abandonment and those weren't related only to maternal factors, for the service's conditions also directly influence

the child and mother's situation at the appointments.

When asked over the reason for the monitoring abandon the justifying were: incompatibility with the job's agenda; lack of flexibility of the health service; trouble entering the service; perception that the children's development was good; personal matters and the COVID-19 pandemic.

I tried to schedule the appointment again many times, but i couldn't, because they didn't want to schedule by telephone and, how i worked, i couldn't miss a day of work to schedule the appointment. (M1)

Because of the job, because I couldn't take my son, because I'm not from Maringa, I am from Paçandu. (M10)

Her development was really good... She hadn't any problem anymore, she was even without any sequel, because of her prematurity. (M14)

There were some times that it was because of my appointment and others because he was with a flou, I didn't take him, then and I also didn't want. (M13)

I just stopped going because of the coronavirus, otherwise I would be going to the appointments, as I always have done. (M16)

As presented at the representations of the discours above, the mother's acknowledgement concerning their child's condition is decisive for the childish monitoring, for it will bring the consensus about the needs, decreasing the misses.

### **Anxiety in front of the unknown: mother's living after the birth**

The post-labour is a delicate moment for some mothers. A mixture of feelings appeared in the instant that those mothers became aware of the need for monitoring even during the consultations. Some of the mothers feared the



Even though there 's still negative feelings related, many mothers also expressed positive feelings with the appointments. The feelings of trust, safety and satisfaction were related by most of the interviewed. The professionals of the High Risk Ambulatory were many times praised for its services and attendiments offered

results of the exams and the well-being of the children. Fear and worry were negative feelings, inevitables, initial and common to most of the mothers during their first appointments.

I was afraid when i got there at the appointment and the result of the exam wasn't good, you know? Although, I always got there and the exams were good. They, like, that agony that was inside of me, the doctors, at the appointment, the people that attended her, always settled me down, giving a good result, you understand? (M4)

The exam 's results and doctor's conduct were conditions that also generate anxiety in one of the mothers, since those are uncertain situations that might give the baby some damage.

"Each appointment i get, i get anxious, nervous with what the doctor was saying to me, with the exams results she did, but at the end i always got relief (M6)"

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I felt great, I felt safe, I felt that I wasn't alone to take care of her, that any, any problem that maybe appears after, I wouldn't have to run alone with her or discover what she had by myself. (M3)

I've felt a lot of trust at the pediatrician and her trainees and i have no complaints concerning the ambulatory attendance, i always was well treated and i had just a few fear, because of these alterations in his exams (M8)

Regardless of the positive perspective of high risk child monitoring, the lack of accompanying and the consequent abandon seems inevitable. For these matter it is emphasized the presence of the health professional at the adhering of the program. It was obser-



ved that a half of the mothers related some deficiency at the active search as an important factor for de abandon.

I didn't receive any calls or messages to reschedule, so I guess they could have called me to, yes, say if they were still attending even with the start of the pandemic. (M7)

If they had called me, told me, of the importance of the monitoring, I guess I would have continued, right. (M10)

The active search of missing children has shown itself fragile corroborating for the increasing number of child monitoring abandon cases.

DISCUSSION

The major number of childrens of the masculine sex led to the ambulatory, is consistent with the lowest number of childrens born of the sex feminine in all country, that in 2019 showed a proportion of 2,6% more births of boys at the analysed period(10).

It was observed that the average number of appointments by child was 2,37, resulting inferior to the preconception by Paranaense Mother System GuideLine. The program defines that the child stratified as high risk must make monitoring till 12 months of life and with 4 multi professional appointments at minimum (6).

According to the reports, the abandon to their child monitoring reasons were diversas, including the fact that some mothers hadn't the acknowledgement about the accompanying at High Risk Ambulatory. The program previews orientation to the mothers about the leading reason, the importance of appointments and the risks that the child may face without the proper professional assistance. However, the service professionals are the great responsables for its orientations, not only at the moment of discharge, but in all of the ambulatory returns. The education in health must be promoted, for the

families develop a critical look over the children's health(7).

The anxiety faced by the son 's disease causes, in general, apprehension for his parents. Many mothers, upon being informed about their son 's diagnosis show sadness and guilt for being responsible for his disease and fearing



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its complications. The absence of a initial diagnosis generates at the mothers an experience of impotence and extreme anguish for mothers and sick sons (11).

New situations acceptance must be defined by the health professional who approaches the diagnosis sensibility, as well as all the multipro-

fessional support with the families. The possibility of finding a professional with humane posture that, even in face of doubts, search calm down, give hopes and comfort the mothers helps at their son's health accompanying process leading. These conduct represents a attentive calling to effectivate the humanizing public politic in health care (12).

Other reasons were pointed out by the mothers who justified the son 's monitoring abandonment. The lack of flexibility of the health services and the difficulty of access are factors mentioned by the participants. The appointment schedule of the health services matches the commercial and job times of many mothers, making the missing flexibility for the attendance responsible for the abandonment (13).

The women 's insertion at the labour market owes to the wars which marked human history, in which the men had to go to the battles and the woman took care of the family's business. In that way, with the passing time, women progressively grew and conquered their space in the job market. But, beyond sustaining their houses, many women still have their house and children to take care of. It is necessary for the health services to understand the reality of their users for they might adequate the offered attendance, as well as the infrastructure, and guarantee this way the quality and integrity of the health service (13).

Beyond that, the maternal perception about the growth and her son's adequate development, in terms of the disease's absence and for considering that the child was healthy, was one of the factors most related. This perception is influenced by the sociocultural matter and by the dispoñible resources, which influence the meaning of what the mother attributes as necessary or not for her son. It is understood that the knowledge and practices need to be shared between the professionals and

families, recognizing their differences and contributions for the children's needs(14).

The COVID-19 pandemic was another factor that had a big influence on the monitoring abandonment. The mothers relate that at the beginning of the pandemic they had fear in taking their children to the hospital, since they hadn't too much information about the disease. In function of this disease, many children have left to be monitored, being exposed to risk situations in function of their fragile condition (15).

COVID-19 is an infectious disease, highly liable to transmission, caused by SARS-CoV-2, a pathogen classified as a new variation of the gender Beta Coronavirus. Many cases were witnessed, which soon spread out faster through the world, arriving in Brazil in february 2020, where many measures were taken to contain the disease's progression. The transmission occurs by direct contact with secretions or droplets from an infected person, shaped during speaking, coughing or sneezing. The clinical manifestations may vary, being asymptomatic, lighter or severe, this last one for its time. may occur with higher frequency in older people, childrens and risk-groups, as immunocompromised individuals. Therefore, due to social isolation recommendation as a form of fighting against the virus trans-

mission, the lack of information about the disease and fear over the unknown, many mothers have chosen not to take their children for the appointments, causing the treatment's interruption (15-16).

The discontinuance is expected, and that way, the active search is and important part of the Paranaense Mother System Program, although it has shown itself deeply non-efficient at the present study, majorly after the pandemic. Its major goal is identifying the individuals from a specific territory health needs, for beyond the spontaneous demand, guaranteeing the care's integrality. This action is fundamental for the child's full development and growth. Through this action, it is possible to localize the missing children, bring them and maintain them till the appointment discharge. Beyond that, the active search allows the socioeconomic and territorial conditions understanding that may lead to the abandonment (17).

The monitoring abandonment of the children considered more fragile may lead to severe health risks, even though they do not present non-observed symptoms by their mothers. In that way, the health services must browse a better understanding of the population's characteristics, for they must adequate their health services (18).

It stands out as a limitation of the present study, the fact that it has been made in only one high risk, which must have limited its results to their participants' perspective, who lived the abandonment experience. Despite that it is believed that this study results must subside reflections about the elements involved at the high risk babies accompanying process, pointing to the main aspects to be considered at this public care.

## CONCLUSION

The study allowed at the identification of the reasons in what concerns the maternal, familiar, social and health services aspects which must influence at the child's treatment abandonment. By those factors acknowledgement, it is possible to define new strategies and actions in order to provide this population's needs.

It stands out the professional's importance at the users reception and their permanence at the program. The professionals have an important role at the service's adeering and must be always searching for acknowledgement and capacitation for receiving the mothers and babies, creating bonds and motivating them to go to the appointments each time more.

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