Perinatal asphyxia: factors associated with noncompliance in the specialized outpatient treatment
ABSTRACT

Perinatal asphyxia is a leading cause of preventable brain injury. Between four and nine million newborns develop birth asphyxia. It is estimated that 1.2 million evolve to death and at least the same number develops important disabling neurological sequels. These children need to be accompanied by experts, especially in the first year of life. The continuity of care after hospital discharge should be guaranteed so that there is follow-up care to those who are at increased risk of morbidity and mortality. To identify factors associated with dropout of outpatient specialized treatment of children diagnosed with perinatal asphyxia. The study was conducted in neonatal care clinic specializing in a reference hospital for high-risk births in the state of Sergipe. 98 children with perinatal asphyxia discharged from the Neonatal Intensive Care Unit of this hospital participated in the study. Results: the children who were followed up were between two months to two years old, and predominantly male 69. Ten children were discharged at age 24 months and had important neurological sequels. Thirty-one children were discharged aged 10 to 20 months without deficit and 35 remained in regular monitoring. There was a record of 22 cases of noncompliance, before the sixth medical consultation. Among the reasons for the doctor following the abandonment of the follow-up service, there were more reasons regarding the absence of symptoms (and distance from home). The absence of symptoms and distance from the capital were associated with the abandonment of outpatient treatment of anoxic children. Outpatient services should be organized to minimize the follow-up abandon situations.

Keywords: Ambulatory Care, Asphyxia Neonatorum, Health Planning.
INTRODUCTION

The reduction of child mortality and morbidity is still a challenge for health services and society. The morbidity with long-term neurological disability generates a social impact, constituting an important public health problem\(^1\,\,^2\). The 2010 demographic census identified that 24.5 million people (14.5% of the population), had some type of disability, since some difficulty walking, hearing and seeing, until serious disabling injuries\(^3\).

A survey carried out in the period from 1981 to 1990 in the state of Rio de Janeiro, with 850 people bearing disabilities, found that 76.94% of the cases were patients with mental disabilities, 12.47% of patients with motor disabilities (cerebral palsy) and 10.58% of multiple disabilities (mental and motor). The study concluded that multiple factors were the etiological agents of mental deficiency, being that the perinatal asphyxia figured as the third cause of disability in the studied group\(^4\).

Asphyxia of perinatal anoxia is among the most frequent causes of neonatal death in the world\(^5\). It is caused by lack of oxygen (hypoxia) and/or lack of perfusion (ischemia) in various organs of magnitude and duration enough to produce biochemical and functional changes.\(^6\)

It affects two to four newborns (NB) in every 1,000 live births, with higher incidence in premature babies. Among the affected NB, 20% to 60% may present hypoxic-ischemic encephalopathy (HIE)\(^7\).

HIE is caused by the association between hypoxia and ischemia, it is developed when there is significant tissue hypoperfusion and decreased oxygen supply resulting from perinatal asphyxia\(^8\). This association, accompanied by metabolic changes, leads to biochemical, biophysical and physiological changes, resulting in secondary clinical manifestations to physiological or structural impairment, with multiple organ dysfunction and the presence of severe cerebral lesion\(^9\). The HIE prevalence is 1.7 per 1000 full term live births, reaching a percentage of mortality between 50% to 75%\(^10\).

Among those who survive, approximately 25% evolve with permanent neurological sequelae, with or without mental retardation, learning disorders, visual or motor dysfunction, hyperactivity, epilepsy and cerebral palsy\(^11\). HIE is the main cause of brain damage and neurological sequelae in NBs born between 37 and 42 weeks; it is the main responsible for the development of motor, sensory and cognitive dysfunctions, generating high individual, family and social cost\(^12\,\,^14\). The severity of the lesion in the brainstem is strongly associated with death during or after the neonatal period, lesions in the basal ganglia and thalamus are correlated with the inability to wander without aid, at two years of age\(^15\).

The most relevant risk factors for the occurrence of perinatal asphyxia are directly related to lower maternal age, prematurity, lower birth weight (<2500g), history of previous neonatal death, primiparity, threat of premature birth and clinical and/or obstetrical intercurrences,
highlighted the cases of diabetes, toxicemia gravidarum, anemia, placenta praevia, isoimmunization, alcoholism or addiction on any type of drugs and low socioeconomic level\textsuperscript{14,16}.

It is characterized by metabolic or mixed acidemia (respiratory and metabolic) with a pH lower than 7 and may be associated to an Apgar score of 0 to 3 for more than 5 minutes and neurological sequelae of severe neonatal convulsions, coma, hypotonia or multiple organ failure\textsuperscript{17}. NBs who present the Apgar score lower than seven in the fifth minute of life have a 5.33 times greater risk of death than those with higher Apgar score of seven, being this parameter, an indication of the number of children who need specialized resources, such as the admission to neonatal intensive care units (NICU)\textsuperscript{18}.

Despite technological and scientific advances in perinatal care to high-risk NB, specific therapeutic approaches for the prevention or reduction of brain damage associated with asphyxia was restricted only to the provision of general care with the maintenance of oxygenation, blood pressure control and homeostasis, treatment of seizures and control of intracranial hypertension. Currently, new neuroprotective strategies are being investigated taking into consideration the clinical significance and the socioeconomic impact caused by neonatal brain damage\textsuperscript{19}.

In order to assure the continuity of care for the child after hospital discharge, following the guidelines of the Ministry of Health\textsuperscript{20}, the follow-up service of Maternidade Nossa Senhora de Lourdes (MNSL) performs specialized clinical follow-up of children leaving NICU, allowing the early perception of changes in their development, preventing further complications, as well as the identification of psychological and emotional problems in children or in the family, as well as the provision of guidance to parents and guardians regarding the possible difficulties they face during the care\textsuperscript{21}.

Follow-up is concerned, in checking the cognitive and motor skills, executive functions, vision, hearing, speech and language, attention, behavior and educational gains of those children, evaluating the long-term results of neonatal intensive care\textsuperscript{22}.

According to the service statistics information, over the past three years, 21,714 children were cared for in the unit. The follow-up criteria to the service are all the NB weighing less than or equal to 1,500 g or gestational age greater than or equal to 33 weeks; time spent in the NICU exceeding 8 days; severe neonatal asphyxia or severe neurological sequel; severe intracranial hypertension diagnosed by transfontanelle ultrasonography, neurological examination presenting alterations and seizures; congenital infection (excepting the acquired immunodeficiency syndrome); neonatal hyperbilirubinemia with indication of exchange transfusion; metabolic hereditary diseases or inborn errors of metabolism and congenital malformations. The children who were serviced have as main diagnosis the prematurity,
the service receives cases of congenital syphilis, toxoplasmosis, genetic syndromes and congenital malformations.

**MATERIAL AND METHOD**

This was a cross-sectional, descriptive and analytical study. The population of interest in this study corresponds to the set of full-term NBs diagnosed with perinatal asphyxia (98 children) serviced in the follow-up service of MNSL in the city of Aracaju - Sergipe, in the period from January 2012 to January 2015.

The outpatient follow-up program for high-risk newborns discharged from the NICU in the state of Sergipe works annexed to MNSL, with weekly service. Approximately 230 children and their families are serviced per month. The admission of children in the service is performed by the medical professional responsible for hospital discharge.

The follow-up service of MNSL has a multidisciplinary team composed by pediatricians (05), neuro-pediatrician , ophtalmologist (01), nurse (01), physiotherapist (02) , social workers (02), nursing assistants (05) and administrative technician (01). During the outpatient care, the children were conducted to different professionals of the team depending on the needs they presented.

It was considered as abandonment of the follow-up to the service, the non-attendance to medical consultation after 180 days from the date of appointment of the same.

The follow-up service adopted the method of active search of children as a measure of redemption and guarantee of the continuity of the treatment. The search attempts were made by professionals of the social service of the institution, using as search strategy the phone contact.

When it was not possible the realization of redemption through the social service, because of the children’s vulnerability, the intervention was requested of the Guardianship Council of the municipality of residence of the family.

The identifying information of the children, number of consultations, the proposed treatment regimen, and the presence of neurologic dysfunction were collected from medical records.

The study was approved by the Ethics and Research Committee of the Federal University of Sergipe under the number CAAE 03963812.9.0000.0058.

**RESULTS AND DISCUSSION**

In the period from January 2012 to December 2014, MNSL recorded the occurrence of 13,313 deliveries. 2,734 NBs were sent (20.5%) for hospitalization in NICU, after having been diagnosed with diseases that could cause death or cause injuries that interfere in their
development. Among those admitted to NICU, the occurrence of 232 cases were recorded of mild, moderate and severe asphyxia, and 124 cases in premature NBs and 108 cases in full term NBs.

It was worked in this sample with the full term NBs diagnosed with perinatal asphyxia, with the aim of minimizing bias of assessment, since the premature NB presents comorbidities common to this situation, leading to the use of assistential methods for prolonged periods (for instance mechanical ventilation) and may promote the onset of neurological injuries.

In relation to gender, the majority of full-term NB was of the male gender 69 (63.9%). The birthweight ranged from 2,035 to 4,440 grams and gestational age between 38 to 42 weeks. The predominant type of delivery was cesarean 59 (54.6%). There was a record of 10 deaths (9.2%). Being verified the maternal variables, it was observed that the age ranged from 16 to 35 years (average 24.1 years). In relation to the provenance 39 (36.1%) were from the capital city, 58 (53.7%) were from the municipalities in the interior of the state and 11 (10.18%) came from neighboring states. Regarding schooling, most women 82 (75.9%) had secondary education. Regarding the monthly income ‘per capita’, it was observed that 77 (71.2%) of the families had incomes between one to three minimum wages. Most mothers 102 (94.4%) had performed from 1 to 6 prenatal consultations.

Among the 108 full term anoxic NB, 98 were referred to the outpatient clinic and return from the follow-up after hospital discharge. The children were assisted by a multidisciplinary team. The service was done individually, with specialized care to diagnosis and needs of children and their families.

Regarding their clinical conditions, 21 children (21.4%) had episodes of seizures in the neonatal period. Ten (10.2%) were discharged by age for 24 months, presenting neurological sequelae of type epilepsy, motor deficit or cerebral palsy. The most frequent symptoms of neurologic dysfunction in the follow-up of these children includes the behavioral disorder; cognitive deficits, attention, learning, seizures, epilepsy, hyperactivity or hypoexcitability and hypotonia.

Thirty-one children (31.6%) were discharged without deficit, aged 10 to 20 months without deficit and 35 remained in regular monitoring. Among the 35 who were still in follow-up, seven were using anticonvulsant medication (Phenobarbital) and 28 remained without a deficit. There was a record of 22 cases of noncompliance (22.4%), before the sixth medical consultation.

Regarding the reasons for the abandonment of the medical follow-up in the follow-up service, predominated the reasons related to the absence of symptoms (13) and the distance from home (9), despite having been made the request for free transportation to the Department of Health of the municipality of residence of the child through the social service.
In one case, the responsible for the child (mother) justified as a cause of abandoning the demand for treatment in another health service, this being related to access to private health insurance and in another case, the responsible for the child (mother) justified as a cause of abandonment to the delivery of the child for adoption.

It was found that the abandonment of the service occurred between the first and fifth medical consultation; observing greater adherence to treatment from the sixth consultation.

Sergipe state has territorial extension of 181.857 Km$^2$. The most distant municipality from the capital Aracaju is 190 km away. Among the 75 municipalities that compose the state of Sergipe, 21 municipalities had children serviced. The capital presented the highest percentage of noncompliance with treatment, 13 (59%), followed by the neighboring municipality of Nossa Senhora do Socorro 2 (9%), distant only 13 km from the capital. There was a greater occurrence of abandonment of treatment among children living in poor neighborhoods of the city of Aracaju, such as Santa Maria, São Conrado and Bairro Industrial.

It was not possible to evaluate the clinical-neurological prognosis of children who abandoned treatment, however, out of 22, seven had a history of seizures in the neonatal period.

The present study evaluated the monitoring and the permanence of the full term born child with a diagnosis of perinatal asphyxia, with ages ranging from two months to two years in a follow-up service.

Ratifying the literature, perinatal asphyxia was directly related to gestational age$^{12-14}$ but had no relation with birth weight$^{16}$. The mortality rate of the sample, as well as the percentage of children presenting neurological sequelae was lower than that reported by other studies. Surveys have indicated a rate of mortality and permanent neurological sequelae as well superior to our findings$^{11,23,24}$.

The multidisciplinary intervention is essential for the improvement of the life perspective of high-risk NBs, with reduction of morbidity rates and consequent improvement of the neurological prognosis of those children$^{25}$. It is observed in Brazil and in the world the evolution of care through the development of programs of public policies aimed at the wellbeing and health of that population$^{26}$. However, it is verified that a lower family income is associated with a greater need for medical care, thus, the effect of the socioeconomic status of the family reflects on the child’s health$^{27}$. It was observed in the sample that families assisted by the follow-up service were socioeconomically more needy.

In addition, the therapies for children undergo great influence of parents or guardians, once they decide the time to take them to the consultation. It is faced with the challenge of dealing with the abandonment of the follow-up and interruption of care$^{28}$. Research has shown that the abandonment of treatment of children is associated with a socioeconomically disadvantaged families, young mothers and with low schooling$^{28,29}$. Corroborating those studies,
our results showed high occurrence of abandonment of treatment among children of young mothers living in poor neighborhoods of the city of Aracaju. These neighborhoods have a population dependent on Single Health System.

It was recorded in a sample case of abandonment by handing the child for adoption. Many parents give their children with disabilities for adoption, by lack of information and financial conditions for care. In some cases, the mother believes that nobody, besides her, can take care of and protect the child with a lesion in the central nervous system. However, during the socio-assistencial care, parents of children diagnosed with neurological problems reported concerns, uncertainties, frustration, stress, disinformation or misinformation about the pathology of their children, as well as anguish for not knowing how to deal with the sick child.

The follow-up of high-risk NBs is of fundamental importance and must be carried out by a specialised service that can count on an habilitated multiprofessional team. Care must be taken to convince their parents about the importance of such monitoring. The follow-up outpatient clinic is a specialized unit and has state reference. It is located in the state capital of Aracaju, being, therefore, far from some Sergipe state municipalities. In the routine of MNSL, it was observed that the care of patients coming from interior cities of neighboring states such as Bahia and Alagoas, which by their proximity, seek medical care in the municipal network of Aracaju.

In the healthcare units, it is observed that the distance between the housing and the service is an obstacle to the follow-up, since the proximity governs the orientation of segments for the use of health services. The occurrence draws attention of a higher percentage of abandonment of service in their own municipality headquarters of outpatient follow-up and the supply of addresses are non-existent.

Although, excellence of offered service has been observed, using the caregiver to cope with the impacts of the child’s pathology and its treatment, an analysis of data on local file revealed that, only in the year 2014, there were a total of 308 cases (22.95%) of treatment dropout, for all other cases of monitoring in the follow-up service of MNSL.

The service recognizes the importance of maintaining the follow-up process of the treatment. It was observed the great effort and commitment of the team to keep the children adherence in the service, however, adherence to medical follow-up does not define the quality of care, once the responsible for the child may seek other services or other treatments.

It was also observed that the adherence to medical treatment is affected when it comes to low-income population, with financial difficulties, the child’s disease generates an impact on caregiver, resulting in frequent absences to commitments. In some cases of abandonment, the service used the intervention of the Guardianship Council of the municipality of the family residence. The Constitution of the Federative Republic of Brazil of 1988 and the Statute of
the child and adolescent (ECA) provide that it is a duty of the family, society and the State to ensure the child, with absolute priority, the right to life and health, as well as save her from all forms of negligence\textsuperscript{34,35}. The assistance services may count on the Guardianship Council to make the rights of the child be provided, applying to those responsible, the protective measures and ensuring the referral of the child to treatment when necessary. These bodies may require judicially the suspension or loss of family power, as established by ECA\textsuperscript{35}. Some of the children who have abandoned the follow-up presented episodes of seizures in the neonatal period. The convulsions in this period are acute manifestations of dysfunction of the central nervous system\textsuperscript{24,36}. The occurrence of epilepsy after neonatal seizures have wide variation in frequency\textsuperscript{36} (from 3.5 to 56%), being strongly associated with other permanent neurological changes, such as mental retardation and cerebral palsy\textsuperscript{37}.

The mortality of neonates with seizures varies between 7\% and 35\%, being that this incidence has fallen in recent years, possibly due to the improvement in obstetric care and neonatal intensive care unit, however, the prevalence of neurological sequelae and delay in the neuropsychomotor development remains stable\textsuperscript{24}.

Since it is a population exposed to risks in neurological development, the outpatient services should be arranged to minimize the situation of abandonment of the follow-up period. To do so, it is fundamental the achievement of quantitative assessments for the research of the dropout rate and identification of possible failures of the service or the care service organization. Such data may identify problems that hinder the clientele adhesion, serving as guidelines for the formulation and implementation of actions that minimize this percentage. It is extremely important that the service registration data of children be updated, with proof of address and viable means to find her. In the case of addresses outside the territorial limits of the state, reference should be carried out to other specialized health units, being kept the guarantee to the provision of assistance.

\section*{CONCLUSION}

The absence of symptoms and the distance from the capital, even though there was free transportation for the child, were the main factors associated to the abandonment of the outpatient treatment of anoxic children. The outpatient services must be organized to minimize the situation of the follow-up abandonment, adopting a method to convince their parents about the importance of that monitoring. The main limitation of this study was the impossibility of performing the follow-up on all eligible children from birth, due to the difficulty accessing them after hospital discharge. It was evidenced that in some situations the responsible for the child resided outside the state of Sergipe, providing not locatable addresses or flatly refusing to remain in the service.
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