ABSTRACT

Objective: to draft the profile of children with congenital heart disease assisted in a public maternity in a hospital in João Pessoa, Paraíba, Brazil, within the period from January to December 2008. Method: research with a retrospective documentary design and a quantitative approach was used. The population consisted of medical records of children with congenital heart disease, born alive within the period from January to December 2008, who were hospitalized in the neonatal ICU. The sample was built through the analysis of five medical records of children who were born with a severe heart disease and who were assisted in the neonatal ICU. The instrument used for the data collection was a form, which is a script of questions asked by the interviewer and filled in by him. The data were analyzed through the quantitative method, using a statistical procedure, where they were arranged in a numerical order. This research was approved by the Research Ethics Committee of the College of Nursing Nova Esperança, under the Protocol 23/2009 and CAAE: 0370.0.000.351-09. Results: 6,883 babies were born alive in 2008. Of the total number of births in the maternity hospital concerned, there were 420 (6.10%) newborn infants with malformation. Overall, five newborn infants were hospitalized in the ICU, due to severe congenital heart disease. Conclusion: congenital heart disease is a condition which presents a high morbimortality rate, leading to a great concern with the early detection of causes, in order to provide a quick solution to the problem. Descriptors: newborn infants; coronary disease; congenital abnormalities; intensive care units.

RESUMEN

Objetivo: trazar el perfil de niños con cardiopatía congénita. Método: pesquisa do tipo documental, retrospectiva, con abordagem quantitativa. A população foi constituída por prontuários de crianças portadoras de cardiopatías congénitas, nascidas vivas no período de janeiro a dezembro de 2008, que se encontravam hospitalizadas na UTI - neonatal. A amostra foi construída a partir da análise de cinco prontuários de crianças que nasceram com cardiopatia grave e que foram atendidas na UTI - neonatal. O instrumento utilizado para coleta de dados foi um formulário, que se trata de um roteiro de perguntas enunciadas pelo entrevistador. Os dados foram analisados pelo método quantitativo, por meio de procedimento estatístico, onde foram dispostos de forma numérica. Esta pesquisa foi aprovada pelo Comitê de Ética em Pesquisa da Faculdade de Enfermagem Nova Esperança, sob o Protocolo n° 23/2009 e CAAE: 0370.0.000.351-09. Resultados: 6,883 bebês nasceram vivos em 2008. Do total de nascimentos na referida maternidade, houve 420 (6,10%) neonatos com má-formação. No total, cinco neonatos deram entrada na UTI por nascerem com cardiopatia grave. Conclusão: a cardiopatia congênita é uma doença que possui alta taxa de morbi-mortalidade, levando a grande preocupação com a detecção das causas de forma precoce, para que ocorra resolução do problema rapidamente. Descriptores: recém-nascidos; doença das coronárias; anormalidades congênitas; unidades de terapia intensiva.
INITIAL CONSIDERATIONS

The cardiovascular disorders in children can be divided into two groups: congenital heart disease, including anatomic abnormalities present at birth and leads to an abnormal cardiac function and cardiac disorders acquired, consisting of disease processes that occur after birth and can be seen in the normal heart or in the presence of congenital heart defects. They are the result of several factors such as infection, autoimmune response, environmental factors and familiar trends.\(^1\)

Congenital malformations are determined in general by structural defects present at birth or detected even intra-uterine.\(^2\)

Beyond prematurity, heart insufficiency is the leading cause of death in the first year of life, including 4 to 10 children at each 1,000 live births. The incidence of congenital cardiac malformations and generally evaluated by the number of children with heart disease in each 1,000 born alive. It is generally agreed that in every 1,000 children born alive at birth, 08 have heart disease.\(^1,2\)

Congenital malformations are a major cause of infant mortality and of general mortality in several countries, accounting in 1997 for about 495,000 deaths worldwide. Most of these deaths occur during the first year of life, influencing thus the mortality rate. In Brazil, since 2001 congenital anomalies are the second leading cause of mortality in children under one year old, according to the Information System about Mortality (ISM), of the Ministry of Health.\(^3,4\)

The health care of children affected by congenital heart disease requires a more specific care, especially if this is detected in the first days of life of the newborn, being this period the most sensitive to extrauterine changes.

As part of the health team that assists the child with congenital heart disease, the nurse develops some activities in the Intensive Care Unit (ICU), among them are the render care and management activities. It is understood that these are key activities to ensure the quality, continuity and integrity of care, ie the performance of the management function of the nurse under the focus of the care to the patient.\(^5\) Another aspect that gives quality to the practice of the nursing team together to this client is the systematization of the assistance. Realizing the nursing process is possible to identify the child's needs, and from that to establish priorities interventions, and conduct periodic evaluations prioritizing the quality of this assistance.

For nursing care to a child with congenital heart disease to be effective it is essential that the nurse has a broad view of the disease, that valorize the biopsychosocial aspects that integrate the life of the human being. The comprehension that each child, its illness and hospitalization are singular, allows the nurse to aboard his patient in an individualized form.\(^6\)

It should be emphasized that the main purpose of the use of the scientific method in the planning of nursing care to the child, especially if that is stricken with a disease that impairs significantly, as is the case of grave cardias, it is essential that nurses know the real necessities of this attended clientele and what are their health needs that the nursing professionals can act, basing his assistance in a competent manner in order to contribute to a better resolution of the problem within the multidisciplinary team. So the research has as objective to define the profile of the children with congenital heart disease.

METHODOLOGY

The research was a retrospective documentary with a quantitative approach. The study population consisted of records of children with congenital heart disease, born alive in the period of January to December 2008 who required ICU because it was born with grave heart disease.

The sample was built from the analysis of five medical records of children who were born with grave heart disease and were treated in neonatal ICU of the maternal and child maternity.

The data were collected in a public hospital, located in the city of João Pessoa-Paraiba, which is a reference in the state, in the assistance to the newborn at high risk. It attends the majority of the population of the city of Joao Pessoa and surrounding cities, looking to assist their demand from pre-natal, birth, postpartum and child care.

The data collection was initially done through a survey of informations in the register book of congenital malformations that the institution disposes. The criteria for sample selection were: medical records of newborns whose diagnosis was congenital heart disease; the newborns had been treated at the Neonatal Intensive Care Unit and had been born alive in the period from January to December 2008.
The instrument used for data collection was a form that treats of a script of questions set out by the interviewer and filled by him.  

The data were analyzed by the quantitative method by means of statistical procedure, where they were arranged in a numerical form. After making the discussion about the results of the research they were analyzed and interpreted according to the literature.

The research project was approved by the Ethics Committee in Research of the Faculty of Nursing at Nova Esperança - FACENE under the Protocol No. 23/2009 and CAAE: 0370.0.000.351-09, according to the Resolutions 196/96 of the National Health Council and of the Resolution COFEN 311/2007 establishing the Code of Professional Ethics of Nursing.

The analyzed data were referring to the alive born, to the alive born with malformations, to the alive born births with congenital heart disease in the period from January to December 2008.

Were born alive in 2008, 6883 newborns. The large number of births is due to a maternity of reference in the city of João Pessoa and surrounding towns.

Of the total of births in the referred maternity, were 420 (6.10%) newborns with malformations, noting that it was a large number of children born with malformations in the period of 2008. Since heart defects represent the most common congenital malformation among the malformations. Early recognition of these defects is important because of its implication in the prognosis due to the rapid clinical deterioration and its high mortality rate.

RESULTS

Figure 1.- Distribution of the alive born who were interned in the Neonatal Intensive Care Unit, patients with congenital heart disease in 2008 (n = 5). Maternity Candida Vargas, João Pessoa, Brazil, 2008. Source: Direct Research

<table>
<thead>
<tr>
<th>Age</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>14-18</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>19-23</td>
<td>1</td>
<td>20%</td>
</tr>
<tr>
<td>24-28</td>
<td>4</td>
<td>80%</td>
</tr>
<tr>
<td>29-33</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>&gt;34</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>5</td>
<td>100%</td>
</tr>
</tbody>
</table>

Source: Direct Research
In an analysis performed on 3664 newborns, twenty infants showed some congenital health disease until the first month of life. According to the data of the Health Ministry, in Rio Grande do Sul in about 180,000 births per year, an estimative that occurs 2000 new cases per year of heart disease in this state.\(^{10}\)\(^{11}\)

The cardiac malformations present a broad clinical aspect, including from defects that develop asymptptomatically to those that determine important symptoms and high mortality rate. The analysis of prevalence presents different results, sometimes very discordant, depending on the age of the analyzed population.

Discordant results arise from factors such as the inclusion of defects that may go completely unnoticed by the physical examination.\(^{12}\) It can only be diagnosed after hospital discharge after the neonatal period, ie they would no longer be treated in neonatal intensive care unit (NICU) of the institution, making difficult the real analysis of the births of cardiopathic patients during the hospitalization.

But it is reported in researches that congenital heart diseases affect on average between eight and ten infants per 1,000 live births. Another research says that there is an incidence of congenital heart diseases, estimated from 3.5 to 12:1000 alive born.\(^{13}\)\(^{14}\)

Corroborating with the literature by means of chained results, were only obtained the data of the children who needed NICU early, and, given the diverse manifestations and different periods of diagnosis, the incidence tends to be compatible with the data found in various analyzed literatures.

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DISCUSSION

Figure 2. Distribution of Apgar scores of the newborns with congenital heart disease in the first minute of life on a scale of 1 to 10 (n = 05). Maternity Candida Vargas. Joao Pessoa, Brazil, 2008. Source: Direct research.

Figure 3. Distribution of Apgar scores of the newborns with congenital heart disease in the fifth minute of life from 1 to 10 (n = 05). Maternity Candida Vargas, Joao Pessoa, Brazil, 2008. Source: Direct research.
The figure 1 depicts that the newborns with severe heart disease who require specialized care in the NICU in the immediate postnatal period from January to December 2008, were a total of 05 children, corresponding (0.07%) of the total of live births in the maternity in the same period (6883), two children were born in March, in April, October and November was born one child in each month with the same disease. This demonstrates that the diagnosis of severe heart disease, soon after birth, occurred less than a ratio of approximately 1:1000 live births in this hospital. It was not possible to account the total number of children born with heart disease in this maternity, as this diagnosis is often only performed after the discharge from the hospital for not having presented the severe form of the disease in the period in which was assisted in the institution.

The table 1 shows that most mothers that participated in this study were aged between 24 and 28 years old (80%). Studies report that age extremes, mainly less than 14 years old and superior to 34 years old are risk factors for the birth of newborns with congenital heart disease; however this relationship was not observed in this study. Mothers aged over 35 years old are part of a risk group, contributing with the greatest childbirth with heart disease. 15

All the mothers lived in Joao Pessoa. What attracted the attention in relation to the records relating to the maternal data was that these were unfilled appropriated, although there is an instrument of collect of informations that is filled during the admission of the mother. So, it was not possible to obtain the informations on the number of pregnancy, abortions, and maternal complications during pregnancy, prenatal care, number of consultations and gestational age at birth. Providing a great difficulty on the analysis of the maternal data, since these informations could lead us to more reliable considerations, because these informations could have been confronted with other published researches on the subject.

The records are intended to communicate information about the patient, providing education, research, audits and verification of legal aspects. The records have several indispensable factors to express the provided assistance to the patient, based on the quality and quantity of notes, among them, there is the possibility of action planning, guiding therapy, reaching a full and qualified assistance to the patient, describe the route of the patient during his hospital stay, provide informations regarding the continuity of care, monitoring the evolution of the patient. 16

According to the Figure 2, the five analyzed alive newborns showed in their first minutes of life the low standard of Apgar. Showing that 80% (4) of the children were born with Apgar 3, and 20% (1) with Apgar 8 in the first minutes of life. On a scale of 1 to 10, Apgar 3 is not a good result, showing already a difficulty child adjustment in the postnatal period. When a baby has Apgar 3, their behavior follows a pattern of life, apparently disorganized, as it is trying to gain control over their state of consciousness. 15

Analyzing the Figure 3 it was seen that the 5 neonates born alive in its fifth minute of life: 20% (1) of the children showed Apgar 5, 60% (3) evolved for Apgar 8 and 20% (1) for Apgar 9. The number of the Apgar in the fifth minute increased in relation to the first minute, being a favorable factor for these children in adapting to extraterine life.

Of the 5 newborn with congenital heart diseases who were admitted to the NICU, 20% (1) of the children were one day old of life, 20% (1) were 2 days old, 20% (1) were five days old of life, 20% (1) were 12 days old and 20% (1) were 14 days old. This showed us that there was an early diagnosis, still in the neonatal period, due to the severity of the illness of these children. Generally, the age at diagnosis of heart diseases ranges from 4 to 115 months old, with an average of 59.23 ± 43.01 months old and median of 63 months old. 17

When revisiting the medical records of the newborns with congenital heart diseases, were analyzed that of the 5 children diagnosed, 60% (3) of them also presented a diagnosis of respiratory insufficiency, 40% (2) presented streptococcal septicemia. Remaining the diagnosis of respiratory insufficiency, which is closely associated with the first sign of congenital cardiopathy, as seen in the searched literature. Respiratory insufficiency is a clinical condition that must promptly be recognized and treated, because it represents a great threat to the life of the patient. 15

According to the analysis of the documents of the 5 newborns affected by congenital cardiopathy who were admitted to the NICU, was obtained the stay under the intensive care: 20% (1) spent 62 days in the hospital, 20% (1) 32 days, 20% (1) spent 22 days, 20% (1) spent 15 and 20% (1) spent 14 days in the NICU. Considering that most children spent on average 29 days hospitalized in the NICU, the length of hospitalization for congenital
malformations is not similar for all establishments and occurs in large variation. 18

Relating to the clinical prognosis of the 5 cardiopathic studied, 60% (3) discharged to the ward, 20% (1) were transferred to another sector to continue the treatment and 20% (1) died. It appears that the morbidity and mortality of children with this disease is high, because the earliest deaths are mainly associated with the presence of complex congenital heart diseases. On average 35% of child deaths are related to congenital heart disease; so, this disease is an important theme in the neonatal and infant mortality. 10

To obtain the diagnosis of congenital heart disease, was used the X-Ray, as an accessible method to the institution and evaluated the clinical signs. The chest radiograph can be helpful in severe cases, when there is a sudden worsening of the respiratory symptoms or when there are cardiac or pulmonary previous diseases. 15

In relation to the proposed treatment, during the period of stay in the institution, all patients received medications for the treatment. The medications used to treat children less than 2 months old are based on antibiotics: penicillin or ampicillin combined with aminglycoside (amikacin, tobramycin or gentamicin) in those under two months old. After a week of life, the scheme can include third-generation cephalosporin associated with ampicillin. The lack of response or clinical deterioration requires repetition of chest radiography and changing of the therapeutic scheme. 15

The congenital heart defects show a broad aspect of the heart defects, many factors and mechanisms remain unclear, but the current researches have indicated that this malformation is, in most of the cases, produced by a genetic-environmental interaction.

At the time of the analysis of the data referring to the newborns with congenital heart disease who were admitted to the NICU was found that the diagnosis of heart diseases were performed in the first days of life, corroborating with the literature by means of chained results and given to diverse manifestations, these tend to be compatible with the data reported in the studied literature.

For pediatricians and cardiologists, the early diagnosis is crucial for the success of a treatment plan, but the perceived congenital heart disease by the parents goes over the cardiac anatomy and physiology. 19

During the period surveyed, the city of João Pessoa had not yet owned support for high-risk surgeries in newborns, and had often, the Public Ministry, to intervene with the Municipal and State Health Departments, to be conducted for these children means of transfer to other States.

The last two decades provided a considerable advance in the treatment of congenital heart defects, and are available now, pharmacological and invasive features specifically created to treat these heart diseases. 20 When applied properly and in the required time for the course to be taken, increase the chances of successful treatment.

**FINAL CONSIDERATIONS**

We believe that the evaluation of the newborn with suspected congenital heart disease should be carried out in a very elaborate and careful manner. The clinical cardiological examination is still a valuable element that can provide critical information for the diagnosis.

Used routinely in these cases, the electrocardiogram and chest radiography are often very useful for investigating these patients, who will have their diagnosis confirmed, in most cases, by the echocardiogram. Particularly in the neonatal period, the benefits of interventionist catheterization and cardiac surgery are remarkable and are well documented. However, the use of these resources will only be fully appreciated if the heart disease is early suspected by the clinician.

It is hoped that this research contributes importantly to researchers who are interested in the subject. Because heart disease is a disease that has a high rate of morbidity and mortality, causing great concern to detect the causes early. For this to occur with the quick minimization of the problem from the disease prognosis. It is important to consider a network of expert assistance, so that will be an effective promotion of health at all levels of complexity. Therefore, further studies are essential to deepen the knowledge about the incidence of this disease.

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