

ORIGINAL

Prenatal care and profile of mothers/caregivers of newborns with congenital heart disease

Pré-natal e perfil de mães/cuidadores de recém-nascidos com cardiopatia congênita Atención prenatal y perfil de madres/cuidadoras de recién nacidos con cardiopatía congénita



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ABSTRACT

Objective: to describe the sociodemographic and clinical characteristics of mothers/caregivers of newborns with congenital heart disease and their prenatal care. **Method:** a cross-sectional quantitative approach study of the descriptive type, with a non-probabilistic convenience sample. Research carried out between August and September 2018, through recruitment in Facebook® groups of mothers of children with congenital heart diseases. Data collection was digital, using Google Forms®, and consisted of sociodemographic and clinical characterization questions. **Results:** there was a predominance of female mothers/caregivers, who are employed, of white race/color, of Catholic religion, with family income above two minimum wages. They performed prenatal care in public hospitals, with more than six consultations, and preferred medical assistance. There was also a predominance of diagnosis of malformation up to 28 days of life. The most frequent congenital heart disease was ventricular septal defect and the treatment adopted was surgical, with most newborns not having another malformation. **Conclusion:** by verifying the sociodemographic and clinical profile of mothers/caregivers and prenatal care, it was possible to know who are those who need qualified care and assistance. **Descriptors:** Caregivers. Congenital Heart Defects. Prenatal Care. Nursing Care. Medical Care.

RESUMO

Objetivo: descrever as características sociodemográficas e clínicas de mães/cuidadores de recém-nascidos com cardiopatia congênita e seus pré-natais. **Método:** estudo de abordagem quantitativa de corte transversal do tipo descritivo, com amostra não probabilística do tipo por conveniência. Pesquisa transcorrida entre os meses de agosto a setembro de 2018, por meio de recrutamento em grupos do *Facebook*® de mães de filhos com cardiopatias congênitas. A coleta de dados foi digital, por intermédio do *Google Forms*®, e composta de questões de caracterização sociodemográfica e clínica. **Resultados:** houve predomínio de mães/cuidadores do sexo feminino, que trabalham, da raça/cor branca, de religião católica, com renda familiar superior a dois salários mínimos. Elas realizaram o pré-natal em hospitais públicos, com mais de seis consultas, e preferiram assistência médica. Também houve predomínio de diagnóstico da malformação até 28 dias de vida. A cardiopatia congênita mais frequente foi a comunicação interventricular e o tratamento adotado foi o cirúrgico, não tendo a maior parte dos recém-nascidos apresentado outra malformação. **Conclusão:** por meio da verificação do perfil sociodemográfico e clínico de mães/cuidadores e de pré-natais realizados foi possível conhecer quem são aqueles que necessitam de cuidados e assistência qualificados.

Descritores: Cuidadores. Cardiopatias Congênitas. Cuidado Pré-Natal. Cuidados de Enfermagem. Cuidados Médicos. RESUMÉN

Objetivo: describir las características sociodemográficas y clínicas de las madres/cuidadoras de recién nacidos con cardiopatía congénita y sus cuidados prenatales. **Método:** estudio descriptivo transversal de enfoque cuantitativo, con muestra no probabilística por conveniencia. Investigación realizada entre agosto y septiembre de 2018, por medio del reclutamiento en grupos de Facebook® de madres de niños con cardiopatías congénitas. La recolección de datos fue digital, a través de Google Forms®, y consistió en preguntas de caracterización sociodemográfica y clínica. **Resultados:** hubo predominio de mujeres madres/cuidadoras, que trabajan, de raza/color blanca, de religión católica, con renta familiar superior a dos salarios mínimos. Realizaban atención prenatal en hospitales públicos, con más de seis consultas, y preferencia por asistencia médica. También hubo predominio del diagnóstico de malformación hasta los 28 días de vida. La cardiopatía congénita más frecuente fue la comunicación interventricular y el tratamiento adoptado fue el quirúrgico, con la mayoría de los recién nacidos sin otra malformación. **Conclusión:** por medio de la verificación del perfil sociodemográfico y clínico de las madres/cuidadoras y del prenatal, fue posible saber quiénes son las que necesitan atención y asistencia calificada. **Descriptores:** Cuidadores. Cardiopatías Congénitas. Atención Prenatal. Atención Médica.

INTRODUCTION

During the gestational period, the embryo goes through a series of changes until it is generated and ready to be born. It begins to develop its organs and create forms within the intrauterine environment until the moment of delivery. This development is provided by several factors, such as: genetics; environmental; or possible complications/infections that can compromise the formation and development of the baby, which can cause some genetic malformation or deficiency. ⁽¹⁾

From this perspective, congenital malformation can be defined as a failure that occurs precisely during this phase, that is, during pregnancy. This ends up compromising the complete development of organs or limbs and, consequently, causes complications or even loss of functions, impairing the baby. ⁽¹⁾

These malformations are detected in 3% to 5% of newborns (NB) and are considered the main cause of death in early childhood. Among them, congenital heart disease stands out, a structural abnormality in the heart or the great intrathoracic vessels that are responsible for approximately 40% of all congenital anomalies. ⁽²⁾ In Brazil, for example, the prevalence is 25,757 cases/year, distributed throughout the national territory. ^(3,4)

These anomalies are often detected with adequate prenatal care, and the recommendation is to start this follow-up prior to the 12th week. The early start of prenatal care is a predictor factor for the detection of diseases and allows the monitoring and a healthier development of the embryo until the end of pregnancy, in view of the great impact of congenital anomalies, especially heart diseases, in terms of mortality and quality of life for children and families. ⁽⁵⁾

The family, especially mothers/caregivers, is an indispensable figure in the health care of these children, as they need specific and increased attention throughout childhood, a fact that makes them very dependent.⁽¹⁾ Based on this context, it is necessary to know the profile of these mothers/caregivers and the prenatal care performed, in order to personalize the nursing care aimed at this public.

Therefore, this study pursues to describe the sociodemographic and clinical characteristics of mothers/caregivers of newborns with congenital heart disease and their prenatal care.

METHOD

This is a study with quantitative approach, crosssectional, of the descriptive type, carried out with groups of mothers/caregivers of congenital heart disease patients on the social network Facebook®. To this end, a manual survey was carried out within the platform in search of the groups with the greatest number and with more interactions between members. Three groups were found and only two were selected, which, together, totaled 1750 mothers and caregivers eligible for the study. After the authorization of the administrators of the groups, recruitment invitation posts were made.

Therefore, among the participants of the aforementioned groups, individuals over 18 years of age who had access to the Internet were included, through registration on the Facebook® digital platform. Thus, the non-probabilistic convenience sample consisted of 232 participants.

Data collection, in turn, took place between August and September 2018, through weekly recruitment invitation posts, which contained the link to the digital form via Google Forms®. This structured form, composed of 13 objective questions developed by the researchers, based on the study by Becker ⁽⁵⁾, presented questions of sociodemographic and clinical characteristics about prenatal care and congenital malformations.

The sociodemographic variables analyzed were: sex; employment; race/color; religion; and family income. The clinical variables were: whether they had prenatal care; number of consultations; professional preference during consultations; birthplace; period of diagnosis of congenital heart disease; type of heart disease; treatment adopted; and presence of other malformations.

For the organization and descriptive analysis, the data were allocated in a database in the Excel program (Office 2018). The variables were presented in descriptive measures as absolute (n) and relative (%) values.

Such instruments could only be answered after digital confirmation of acceptance to participate in the study, upon acceptance of the Free and Informed Consent Term. In addition, this research complied with the ethical precepts recommended by resolutions 466/12 and 512/16 and was approved by the research ethics committee under opinion number 1,919,242 and CAAE: 63469616.2.0000.8007.

RESULTS

Table 1 below shows the sociodemographic characterization of mothers/caregivers of newborns with congenital malformations. There is a predominance of female participants (n=203; 87.5%), who are employed (n=143; 61.6%), of white race/color (n=108; 46.6%), of Catholic religion (n=115; 49.6%) and with a family income above two minimum wages (n=75; 41.8%).

Table 2 shows the results of the clinical characterization. There is a predominance of mothers/caregivers who performed prenatal care (n=228; 98.2%) with six consultations or more (n=204; 87.9%) and who preferred doctors in consultations (n= 152; 65.5%) and place of birth in the public service (n=132; 56.9).

In the sample, there was a predominance of diagnosis of malformation when the NB was up to 28 days old (n=75; 32.4%); the most frequent congenital heart disease was ventricular septal defect (n=100; 25.6%); and the treatment adopted was surgical (n=73; 31.5%), with most newborns having no other malformation (n=167; 72.0%).

 Table 1 - Sociodemographic characterization of mothers/caregivers of newborns with congenital malformations. GO, Brazil, 2018, (n=232).

Sociodemographic variables	n (%)
Sex	
Male	29 (12.5%)
Female	203 (87.5%)
Employed	
Yes	143 (61.6%)
No	89 (38.4%)
Race/Color	
White	108 (46.6%)
Indigenous	1 (0.4%)
Black	35 (15.1%)
Yellow	10 (4.3%)
Brown	78 (33.6)
Religion	
Catholic	115 (49.6%)
Catholic and Evangelical	1 (0.4%)
Spiritualist	19 (8.2%)
Evangelical	79 (34.1%)
Umbanda	4 (1.7%)
Other	14 (6.0%)
Family income	
Up to 1 minimum wage	75 (32.3%)
More than 2 minimum wages	97 (41.8%)
Above 3 minimum wages	60 (25.9%)

 Table 2 - Clinical characterization of prenatal care in mothers/caregivers of newborns with congenital malformations. GO, Brazil, 2018 (n=232).

Clinical Variables	n (%)
Did you do Prenatal care?	
Yes	228 (98.3%)
No	4 (1.7%)
How many prenatal consultations?	
Six or more consultations	204 (87.9%)
Less than six consultations	28 (12.1%)
Preference in prenatal consultations?	
Nurse	80 (34.5%)
Doctor	152 (65.5%)
Birthplace	
Private hospital	100 (43.1%)
Public hospital	132 (56.9%)
Period of diagnosis of congenital heart disease	
Child from 2 to 5 years old	41(17.6%)
Gestation	68 (29.3%)
Breastfeeding from 30 days to 2 years	48 (20.7%)
NB up to 28 days old	75 (32.4%)
Type of congenital heart disease*	
Interatrial Communication	64 (16.4%)
Ventricular septal defect	100 (25.6%)
Aortic coarctation	42 (10.8%)
Patent Ductus Arteriosus	33 (8.5%)
Didn't know how to answer	151(38.7%)
Treatment Adopted*	· · /
Medicated only	42 (18.1%)
Catheterization/Angioplasty and Surgery	51 (22.0%)
Surgical only	73 (31.5%)
Other Malformation	×
No	167 (72.0%)
Yes	65 (28.0%)

DISCUSSION

It was found that 87.5% of the care provided to children was performed by female mothers/caregivers, in line with similar studies carried out in the regions of Fortaleza, Ceará⁽⁶⁾, and in the central region of Rio Grande do Sul⁽⁷⁾, who also evaluated the family and clinical sociodemographic profiles of children with congenital heart diseases and with special needs cared for in hospital institutions. It is believed that this is due to the fact that, historically, the role of educating and caring for children has been attributed to women, which has made them more responsible than fathers for their offspring and home.⁽⁸⁾

Regarding work, 61.6% of mothers/caregivers reported that they were employed. Another study carried out in the state of São Paulo ⁽⁹⁾, with 24 mothers of newborns with congenital anomalies, also showed that 58.3% of the interviewees were employed. The reasons that led them to work may be related to the search for better living conditions.

In this regard, a study carried out in 2014, which aimed to investigate the meaning of paid work and its relationship with motherhood for women, showed that, from the 1970s onwards, due to the period of economic inflation that Brazil was going through, the gradual difficulties financial generated а impoverishment of families. This, added to the increase in schooling of the population in general, especially of women, has made a significant contribution to changes in the labor market, in the relationships between the sexes in the family context and in the improvement of the quality of life at home. (9)

Another factor that stands out, with regard to who with children are born congenital malformations, is the impact that birth generates on mothers/caregivers, caused by surprise and fright, when the condition is not identified in prenatal care. Therefore, this change, provided not only by the presence of a child, who already requires a lot of care, but because they have a heart disease, needs to be incorporated into the daily lives of mothers/caregivers, which cause many to leave their formal jobs to take care of their sons. ⁽¹⁰⁾

With regard to race/color, about 46.6% of respondents self-declare as white. According to a study carried out between 2005 and 2014 in the state of Rio Grande do Sul with 1,386,803 participants about congenital anomalies in the state, it was observed that the average rate of black or mixed-race mothers and caregivers prevailed over the white race/color (about 11.8 per thousand people), in contradiction to the results obtained in this research.^(10,11)

Regarding religion, of the 232 participants, about 49.6% said they were Catholics, followed by 34.1% Evangelicals. Religion contributes to a process of acceptance of the situation experienced, as it represents a form of support and emotional balance and constitutes a significant instrument in the reorganization of these families.⁽¹²⁾ Thus, religion plays a fundamental role in the way of dealing with

the events developed by the disease and is directly related to the quality of life of these families.⁽¹³⁾

In addition, the Religiosity/Spirituality dimension in clinical practice has already been observed as a relevant factor within an integralist model, which incorporates spiritual and care aspects, making it more widely accepted as a need of patients and their families. In this context, religion is intrinsically linked to the form of acceptance of the disease and to the characteristics that influence the habits and customs of a particular population. It also has a great role in supporting the rehabilitation of people, being intertwined with the development of characteristics that lead to the well-being of individuals, corroborating the reintegration of subjects who are on the margins of society. ⁽¹⁴⁾

Regarding income, about 41.8% of respondents had an income greater than two minimum wages. In a study carried out in the region of Fortaleza - CE, 82.6% of the interviewees had an income between one and two minimum wages (6), indicating divergence from this study. It is believed that this can be explained due to the study being carried out on social networks, in this way the income of a particular country (along with its respective states) directly influences digital inclusion. This shows that more developed regions with higher income rates have a higher percentage of people who have access to internet-related resources (telephone lines, computers, cell phones, etc.) in relation to the poorest states⁽¹⁵⁾, a fact that also allows for better quality in childcare.

When observing the clinical variables, it was found that 98.3% of mothers/caregivers had prenatal care, so that 87.9% had six or more consultations. Prenatal care is fundamental in the prevention or early detection of pathologies, both maternal and fetal, which provides the healthy development of the baby and the mother, aiming at reducing risks and the adequate development of the fetus. Therefore, prenatal care is highlighted as an essential factor in the identification of possible malformations. ⁽¹⁶⁾

Furthermore, the recommended number of consultations is equal to or greater than six, and they must be monthly until the 28th week; biweekly between the 28th and 36th weeks and, from the 37th week of pregnancy on, prenatal consultations become weekly until delivery takes place, either spontaneously or until there is a need for hospitalization, in line with the recommendations from the Ministry of Health and the World Health Organization (WHO).⁽¹⁷⁾

In the survey "Born in Brazil", carried out between 2011 and 2012 in the five Brazilian macroregions about the amount of prenatal care performed in the country, it was observed, in 23,940 interviews, that about 98.7% of the women interviewed had a high coverage of pregnancy care, and about 75.8% started prenatal care before the 16th week⁽¹⁸⁾. The early start of prenatal care, up to the 12th week, provides greater adequacy of the guidelines provided by professionals and allows greater guidance, which significantly contributes to the fall of infant mortality and premature births. ⁽¹⁹⁾

However, a study published in 2020 showed that, of the 230 cases of congenital anomalies, 35.8% of mothers had fewer consultations than recommended, which highlights how necessary prenatal care is in the process, not only in the identifying of anomalies and malformations, but also in supporting children and mothers/caregivers.⁽²⁰⁾

Regarding the professional who provides care, the study showed that 65.5% of respondents had preferences for consultations performed by doctors, and only 34.5%, by nurses. The Ministry of Health recommends that consultations in primary care should be carried out alternating between doctors and nurses, however, according to a survey on the perceptions of pregnant women, there was a great prominence and protagonism of the nurse professional. This shows that the service goes far beyond a simple consultation, as the professional goes deeper into the clinic and seeks to listen to complaints, resolve doubts and guide pregnant women throughout the pregnancy-puerperal cycle, thus developing a relationship of trust between the professional and their patient. ⁽²¹⁾

In this context, another research made in the Western Region of Bahia, on the feelings and experiences of childbirth, reported that pregnant women had a good perception of the care provided by nurses. The nurse's work is, therefore, based on humanization and, consequently, constitutes a fundamental key for the reception of the parturient, both in prenatal care and in obstetric units, usually being the first contact of the woman in the health services. ⁽²²⁾

Furthermore, it is noteworthy that the Prenatal Humanization Program (PHP) establishes that the nurse is a fundamental member, along with the health team, in the assistance to the mother-baby binomial. Therefore, they must be the core and the structure of articulation of care both in prenatal care and in other periods of the pregnancy-puerperal cycle.⁽²³⁾ Likewise, the Stork Network establishes that the nurse must be present throughout the entire gestation period, together with the multidisciplinary team, and should address biopsychosocial aspects from the first meeting. In this way, it is possible to establish a relationship of trust between the pregnant woman and the professional, so that the pregnant woman can be educated and guided throughout the pregnancy cycle until the birth of the baby. ⁽²⁴⁾

As for the place of birth, 56.9% of deliveries were performed in the public network, and 43.1% in the private network. In a study carried out in 2016, on the expectations of pregnant women about childbirth and their perceptions about preparing for childbirth in the Federal District, of the 18 interviewees, all chose the public health network, not only for financial reasons, but also for following specific recommendations and protocols for prenatal, delivery and postpartum care.⁽²⁵⁾

In this scenario, with regard to the normalization of cesarean sections, a survey that had the participation of 33 women, aged between 18 and 35 years, carried out in the city of Rio de Janeiro and São Paulo, in the private network, found that about 73% opted for cesarean section because it is considered a modern, safe and "normal" route. Added to this, they reported that vaginal delivery appears exceptionally and, thus, they could establish a planned itinerary for the birth. ^(26,29)

In Brazil, studies of morbidity in children indicate that genetic diseases and congenital defects represent 37% of pediatric hospitalizations in tertiary health care centers⁽³⁰⁾ and are responsible for high rates of cesarean sections and prematurity.⁽³¹⁾ In accordance, a study carried out in Atlanta, United States, showed that congenital heart disease is the most common disease, occurring in 81 of every 10,000 births.⁽³²⁾

If, on the one hand, there is a tendency to indicate cesarean section in cases of congenital heart disease, for fear of hemodynamic changes related to labor and the expulsive stage, on the other hand, in cesarean sections, there is a greater risk of blood loss, infections and thromboembolic phenomena, which must be taken into account at the time of indication.⁽²⁸⁾ And, according to a published study on factors related to determining the mode of delivery in pregnant women with children with heart disease, cesarean delivery was the chosen route in 57.1% of revealing controversies cases(29), about its indication in these situations.

Regarding the period of diagnosis of congenital heart diseases, there was a higher frequency of newborns up to the 28th day of life (about 32.4%). In a previously mentioned study ⁽⁶⁾, the period of identification of changes in the diagnosis of these heart diseases was less than six months, which is in line with the findings, but which also reveals that somehow the assistance received by the investigated population seems to be better, as it was identified earlier than the in the compared study.

This fact is consolidated through neonatal screening, which aims to briefly identify diseases or disorders in newborns up to the 28th day of life, in order to allow timely management and treatment, through red reflex tests (little eye test), foot test, hearing screening (little ear test) and pulse oximetry (little heart test).^(33,34)

Among these tests, the little heart test should be performed within the first 24 or 48 hours after birth. It is operated using an external sensor (oximeter) that must be placed first in the right hand and then in one of the baby's feet to check the oxygen level. If the saturation is less than 95%, the child is not discharged from the maternity hospital and is under observation. From there, other diagnostic tests should be performed, according to medical prescriptions, to rule out the possibility of congenital heart disease. It is an important method of neonatal screening, considered the gold standard in the identification of heart diseases. ^(33,34)

Regarding the type of heart disease, a study carried out in São Luís-MA, referring to the sociodemographic profile of patients undergoing heart surgery at the Materno Infantil University Hospital, in 2017, revealed that, of the 31 children with heart disease, most were acyanotic (64.5%) and, among them, the most frequent were interatrial communications (13%) and patent ductus arteriosus $(10\%)^{(35)}$. This result goes against the findings of this research, in which the distribution was greater in ventricular septal defect (25.6%). However, it is noteworthy that 37.8% could not answer about the health condition of their children.

Another study that agrees with the findings also showed that in the evaluation of 335 caregivers of children, aged between 8 and 13 years, about 50% reported that they were not sure about the name of the disease, much less explain it to researchers. (36) Nevertheless, in order to define the best type of treatment, an accurate diagnosis is necessary, which will assess not only the type, but also make a holistic assessment, for the best intervention and treatment, which can consist from catheterization to surgical interventions, determined by the complexity and care required.⁽³⁷⁾ Another equally important fact is the participation of mothers/caregivers during the relationship, thus therapeutic enabling the perception of the disease so that they can be informed about all treatment options, in order to help in raising awareness about the pathology.⁽³⁸⁻⁴⁰⁾

Still looking at the types of treatments adopted, surgery was the most used (31.5%). According to data from the Ministry of Health, between 2017 and 2018, the number of surgical procedures in the country increased by about 8%, according to the National Plan for Assistance to Children with Congenital Heart Disease, launched in June 2017. This plan aims to establish guidelines and integrate actions that favor access to diagnosis, treatment and rehabilitation of children and adolescents with congenital heart disease, as well as the reduction of morbidity and mortality of this public. ^(41,42)

Therefore, it is emphasized that this study is limited to a target audience with average age and privileged social level, as it is a research carried out in groups of social networks and with people who have access to the internet, excluding those with possible limitations. However, the study elucidates sociodemographic characteristics of mothers/caregivers of newborns with congenital malformations and expresses the importance of quality care focused on personalized prenatal care.

CONCLUSION

In this research, there was a predominance of female mothers/caregivers, who are employed, of white race/color, of Catholic religion and with a family income above two minimum wages. They performed prenatal care in public hospitals, with six consultations or more, and preferred medical care. The diagnosis of congenital heart disease in newborns was performed until the 28th day of life, with ventricular septal defect being the most frequent. The treatment adopted was surgical, and the majority did not present any other malformation.

By checking the sociodemographic and clinical profile of mothers/caregivers and prenatal care, it was possible to know who are those who need care and qualified assistance. From this perspective, prenatal care is shown to be an important tool for an early and targeted approach to the family that will experience this problem.

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