SPECIAL ARTICLE

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Congenital cardiac disease in childhood x socioeconomic conditions: a relationship to be considered in public health?

Cardiopatia congênita na infância x condições socioeconômicas: uma relação a ser considerada na saúde pública?

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Abstract

Introduction: **Congenital heart defects, cardiac malformations that occur in the embryonic period, constitute a serious health problem. They cover a proportion of 8-10 per 1000 live births and contribute to infant mortality.**

Objective: **To identify the socioeconomic status of children undergoing cardiac surgery at the Hospital Universitário da Universidade Federal do Maranhão, in São Luis, the existence of material elements that contribute to worsening conditions.**

Methods: **We conducted a retrospective study with a quantitative approach, descriptive and reflective, from the interviews conducted by the Social Service Social with families of children with heart disease from January 2011 to July 2012.**

Results: **A total of 95 interviews, the results reveal that (75.79%) of children have elements that suggest poor socioeconomic conditions. It also shows that only 66.33% lived in brick house, while (31.73%) in mud, adobe and straw houses. With regard to income, it showed that only 4.08% received 1-2 minimum wages, while the remaining (95.9%) with benchmarks oscillating half the minimum wage (27.55%), ¼ of the minimum wage and (24.48%) and income below 70 dollars per person, featuring extreme poverty. On the social security situation prevailing at children with no ties to 61.22%. With respect to benefits, we found that only (12.24%) of children were in the enjoyment of the Continuous Cash Benefit – CCB.**

Conclusion: **Poor socioeconomic conditions listed as major obstacles in meeting the needs, resulting in the maintenance of health conditions and even allowing the aggravation of an existing pathology.**

Descriptors: **Child. Socioeconomic Factors. Heart Diseases.**

Resumo

Introdução: **As cardiopatias congênitas, são malformações cardíacas que ocorrem no período embrionário e configuram um sério problema de saúde. Incidem numa proporção de 8 a 10 em cada 1000 crianças nascidas vivas e contribuem para mortalidade infantil.**

Objetivo: **Identificar na situação socioeconômica das crianças submetidas à cirurgia cardíaca no Hospital Universitário em São**

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Abbreviations, acronyms & symbols	
CETICCCs	Integral Treatment Centers for Children with Congenital cardiopathies
IAC	Interatrial communication
IVC	Interventricular communication
ACP	Arterial channel persistence
BSCVS	Brazilian Society of Cardiovascular Surgery
SCA/ECA	Statute of the Child and Adolescent
SETRACCC	Special Secretariat for the Treatment of Children with Congenital cardiopathies
SUS	Unified Health System
UNICEF	United Nations Children's Fund

Luís a existência de elementos materiais que concorrem para o agravamento desta afecção.

Métodos: **Realizou-se um estudo retrospectivo, com abordagem quantitativa de caráter descritivo-reflexivo, a partir das entrevistas sociais realizadas pelo Serviço Social junto às famílias das crianças cardiopatas no período de janeiro de 2011 a julho de 2012.**

Resultados: **De um total de 95 entrevistas, os resultados revelaram que pelo menos 75,79% das crianças apresentaram elementos que sugerem condições socioeconômicas precárias. Evidenciaram que somente 66,33% viviam em casa de tijolo, enquanto 31,73%, em casas de taipa, adobe e palha. No que concerne à renda, foi constatado que apenas 4,08% das famílias recebiam de 1 a 2 salários mínimos, enquanto os demais 95,9% possuíam aferimentos oscilantes de 1/2 salário mínimo; 27,55% de ¼ do salário mínimo e 24,48% renda inferior a 70 reais por pessoa, caracterizando situação de extrema pobreza. Sobre a situação previdenciária prevaleceram as crianças sem vínculo com (61,22%). No que tange a benefícios, observou-se que somente 12,24% delas estavam em gozo de Benefício de Prestação Continuada - BPC.**

Conclusão: **condições socioeconômicas precárias figuram como importantes obstáculos no atendimento das necessidades infantis, impactando nas condições de saúde e até possibilitando o agravamento de uma afecção existente.**

Descritores: **Cardiopatias Congênitas. Fatores Socioeconômicos. Criança.**

INTRODUCTION

Brazil has a population of 200 million people, which at least 29 million are from 0 to 9 years old, and approximately 45 million are from 10 to 19 years old, which is equivalent to almost one third of all population of children and adolescents of Latin America and Caribbean. There are tens of millions of people which have rights and duties and that need conditions to develop themselves using their full potential[1].

Children are especially vulnerable to violations of rights, to poverty and to iniquity in the country, even with the uncountable legal advances acquired like the Statute of the Child and Adolescent (SCA/ECA)[2]. According to the United Nations Children's Fund (UNICEF)[1], 29% of the population live in poor families, but, among the children, this number comes to 45.6%. Black children, for example, have almost 70% more chance to live in poverty than the white ones; the same can be seen in children who live in rural areas. In the semi-arid region, where 13 million children live, more than 70% of children and adolescents are classified as poor.

In Maranhão, this reality about childhood worsens as the State, historically marked by the extreme concentration of income and by the meager results obtained from the public policies, where many families live in miserable conditions. In 2000, 68.42% of the people who live in Maranhão were included in the hunger map of Brazil. In relation to childhood in 2002, 74.2% of children and adolescents from 0 to 17 years old were included in families with per capital income of up to half minimum wage, experiencing a growing situation of indigence[3,4]. Faced with this social conjuncture, that certainly permeates the childhood of Maranhão's people, that concerns were present, in the sense to understand in what measure a restrictive conjuncture limits the possibilities of healthy growth of the children who live (or survive) in those conditions. In this scenario, characterized by the absence of basic elements, for example the health, habitation, feeding, income, besides overcoming these obstacles, how are these people who were born with cardiac malformation living?

Considering that the childhood is the phase of life which the human being is more exposed to iniquities and to poverty, being easy targets to the most diverse forms of domination and exploration[5,6], we intended to perform an analysis of the socioeconomic conditions of a part of these children, the cardiopathic that, besides the limitations imposed by the disease, face limited life conditions by the absence of material and financial resources.

The congenital cardiopathies can be defined as cardiac malformations that occur in the embryonic period, associated or not to genetic factors and/or chromosomal alterations. It happens in a proportion of 8 to 10 for each 1000 children born alive, represent a percentage of 25% of all congenital malformation and are the cause of child mortality in the proportion of 15%[6]. They can still be corrected with surgical procedures, allowing a better quality of life[7].

Data from the Brazilian Society of Cardiovascular Surgery (BSCVS) (SBCCV in Portuguese) review that only 30% of the children with congenital cardiopathies have access to surgical treatment, generating a 65% deficit and that, in the north and

northeast regions, this deficit can reach to a fraction of 97.5% in the first one and 92% in the second[8]. This occurs because of a set of elements, such as the process of universalization of the Unified Health System (SUS in Portuguese), which presents the necessity of an upgrade in the number of hospital beds, qualified professionals, as well the construction of more service centers that allow accessibility with quality.

In Maranhão this reality is far more serious, since there is only one Unit of Public Health that can be taken as reference, the University Hospital (HUUFMA in Portuguese) which, for more than a decade, daily attends several children from the whole State in order to subject them to surgeries for correcting congenital cardiopathies.

The hypothesis that appeared with the research is that the socioeconomic conditions, when applied in poverty situations, may contribute to the worsening of a pathology, in the specific case of this work, represented by congenital cardiopathy. Thus, it is considered that the non-treatment of basic needs of these children might, in a certain way, interfere in their process of recovery and health maintenance.

METHODS

Quantitative research based on a retrospective study of descriptive-reflexive character. The present method was elected to consider that everything can be counted, translating in numbers informations that create useful knowledge to the advance of science[9]. The data were obtained from social interviews performed by the Social Service of HUUFMA with 95 families of cardiopathic children. These interviews are usually applied in the reception process, after the admission in the hospital unit, and remain stored in a computerized data bank counting with socioeconomic data, housing, environmental, health indicators, pension situation, diagnostic and hospitalization period. It needs to be mentioned the implementation of a computerized registry to the Social Service Division that was created from the project "The construction of the Information Policy and computer science in Health of SUS, with the goal to advance in the use of computer science to improve the productivity and quality in health.

The results were quantified in statistic based on percentage in the Microsoft Office Excel 2007, analyzed and interpreted by using theoretical references, to characterize the socioeconomic conditions of the research subjects and show, in what measure these conditions compete to its social vulnerabilities.

The research presented as inclusion criteria: children from 0 to 12 years old submitted to cardiac surgery in the period of January 2011 to July 2012 and of exclusion: children who had been through surgery to correct their acquired cardiopathies; hospitalized children only for clinic compensation.

The secrecy of the informations was properly respected by the means of the non-identification of the involved parts, as well the commitment term undersigned by the responsible researchers. The research was submitted and properly approved by the Research Ethics Committee of the University Hospital –UFMA (process 177.580).

RESULTS

In the period of 2011 and the first semester 2012 were registered, in the data bank of Social Service of the University Hospital Presidente Dutra, 95 social interviews performed with the children's families who were submitted to surgery for correction of congenital cardiopathies from 0 to 12 years old.

In relation to the initial diagnoses of children, 26.31% had interventricular communication (IVC); 25.26%, interatrial communication (IAC); 16.84% arterial channel persistence (ACP); 5.26% Fallot's Tetralogy; 22.10% with associated cardiopathies (those composed by two or more cardiopathies); 2.10% with pulmonary atresia and 1.05% tricuspid atresia.

Concerning to the children profile, it was observed the predominance of the female gender with the percentage of 53.68%, while the male gender corresponded to 46.31%. In relation to age, the majority belonged to the group of 0 to 3 years old with the percentage of 38.94%; from 4 to 6 years old in 22.10%;from 7 to 9 years old in 24.21% and from 10 to 12 years old in 15.78%.

About the origin, It was observed that 69.47% belonged to continental cities (countryside) and 28.42% belonged to the capital city; 1.05% came from another State. Among children who came from other cities, 13.68% didn't have any family or governmental support in the treatment space.

Regarding religion, the largest group belonged to Catholics with 57.89%, followed by protestants with 22.10%; 9.47% mentioned other religions; in 10 interviews the religion option was not marked. About ethnicity, the brown group was the largest number with 58.94%; the white group represented 16.84%; black 16.84%; yellow and indigenous presented 0%. In 8 interviews the ethnicity option was not marked.

Concerning the scholarity variable, most of the children, 57.89%, were not alphabetized. Followed by children with incomplete fundamental education (1st to 4th grade), represented by 21.05% of the total; 10 children were attending middle school (5th to 8th grade), with a percentage of 10.52%; followed by the group of alphabetized with 10.52% of the children.

With respect to dwelling, data showed that 94.73% of the children had a house as living option, followed by apartment with 3.15% and room with 2.10%. About the financial condition, 81.05% have their own house; followed by 7.36% with rental housing, 5.26% granted housing, 2.10% buying their own home, and 44.21% other situations non-specified. Concerning to the conditions of housing wall (Figure 1), 66.31% lived in a brick housing, 26.31% mud, 4.1% adobe and 1.05% of table.

Concerning the housing roofs, 80% were cover with tile, 11.57% of straw, 3.15% of slab and 5.26% of tile lining; others

were counted as 4.21%. Concerning the number of rooms, 62.10% had a home with 4 to 6 rooms, 17.89% had from 1 to 3 rooms, 17.78% from 7 to 9, and 4.21% with more than 9 rooms. Still about home, 58.94% referred that their homes did not have coated floor; the ones who had it represented 41.05%.

Concerning per capita income (Figure 2), 44.21% had an income of ½ minimum wage, 27.36% up to ¼ minimum wage, 24.21% with an income lower than 70 reais per person, only 4.21% had income between 1 and 2 minimum wages; it didn't occur families with more than 3 minimum wages per person.

In the health indicators, specially referred to trash collection, it was observed that 63.15% had trash collected by the public service, 28.47% burn their trash, 2.10% bury and 5,26% throw it at open sky. Information related to trash destination can be found in Table 1.

About the conditions of water use, 55.78% used public network water, 43.15% used water from well, and 1.05% from river. About the treatment of this water, 75.78% filtered it, 13.68% did not take any previous care, 6.31% took mineral water, and 3.15% boiled it.

About the welfare situation (Figure 3), prevailed the children without welfare bonds with the percentage of 60%; followed by children with welfare bonds as dependents of INSS in the proportion of 35.78%; and 4.21% were in condition of dependent with state bond. None of the interviewed had private welfare assistance.

Among those who possess welfare bonds, 18.94% were dependent of parents who had formal jobs; 6.31% special insured; 2.10% facultative insured. Concerning benefits, it was observed that only 12.63% of the children had the Continuous Cash Benefit (CCB - BPC in Portuguese).

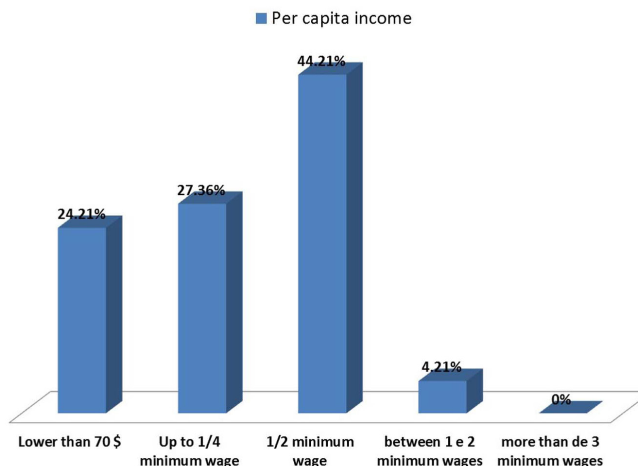

Fig. 2 - Per capita income of the families of the children with congenital cardiopathies in São Luís (2011 and first semester 2012).

Table 1. Distribution of trash destination of children with congenital cardiopathies in São Luís.

Trash destination	Quantity	%
Septic Tank	42	44.21%
Cesspit	21	22.10%
Sewer	23	24.21%
Open Sky	09	9.47%
Total	98	100.0

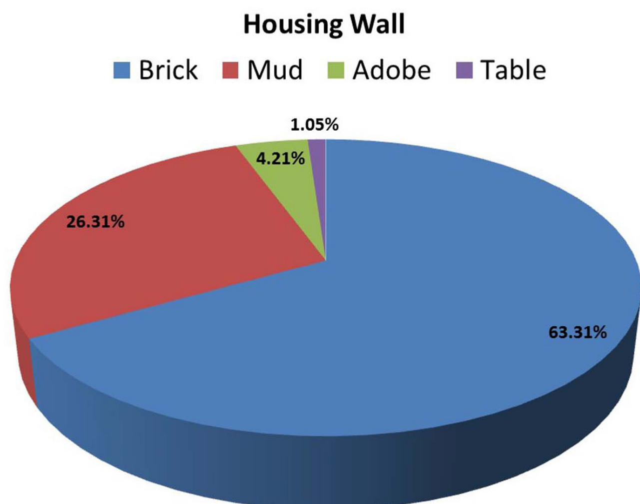

Fig. 1 - Housing wall of children with congenital cardiopathies in São Luís (2011 and 1st semester 2012).

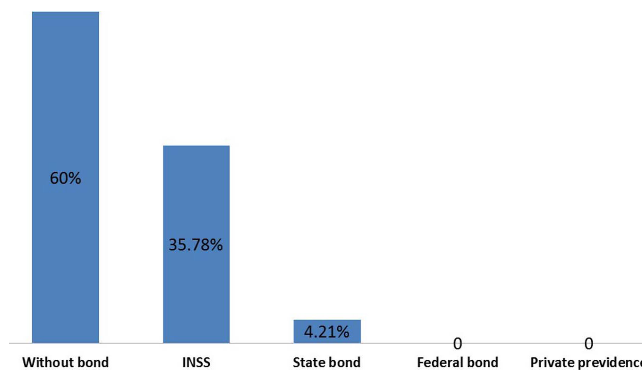

Fig. 3 - Welfare situation of children with congenital cardiopathies hospitalized at HUUFMA in São Luís (2011 and first semester 2012).

DISCUSSION

It was observed that the incidence of congenital cardiopathy keeps the same proportion between the genders, with a light domain of the female gender. About age, it is predominant the age group of the first childhood that goes from 0 to 6 years old, representing a little more than half of all children. This condition is probably because in this initial childhood phase that is performed the surgical procedure to correct the pathology in a palliative or definitive way. However, it should be consider too the proportion of children in a high age (24.21%) to this correction by surgical procedure is highly probable since this kind of surgery should be performed in the first years of life. The late submission to surgical procedure can be deriving from the difficulty to access the health service, once that in all state there is only one public unity taken as reference to correct congenital cardiopathy.

About the origin, the great majority belongs to cities in the countryside, having even the presence of children from another State (1.05%). It is also revealed that the children who did not count on family or governmental support, which means, have no presence of family members in the treatment city and do not count on support from their hometown which should ensure the minimum of attendance to their needs through the program Out of House Treatment (TFD in Portuguese).

Still referring to children's profile, prevailed those considered brown, fact that happens due to ethnic mix so present in the State or to the lack of racial identity. In the religious aspect, the catholic are still more frequent in the religion option.

In relation to children scholarity, this study shows that the majority was not alphabetized yet. This data is justified by the fact of children that are not yet in school age. According to UNICEF[1], the premature scholarity intervention in children of 4 to 6 years old can make a difference in the upgrade of chances of achieving a higher level of scholarity, reducing school failure and achieve a higher income in the future.

Concerning the dwelling conditions, the findings of this study show that the majority of children live in their own house made of bricks. However, it is relatively remarkable the expressive number of mud houses, without coated floor, with straw roof with the percentage of 26.21%, 58.94% and 11.57% respectively. This shows that the housing conditions of these children are still precarious, with poor infrastructure since 31.57% of these children do not live in a brick house. This indicator is a reflex of the absence or low range of a habitational policy to the low income families.

The study also revealed that the great majority of children live with a per capita income up to ½ minimum wage, which, according to IBGE[10], represents a poverty condition. Other fraction lives with an income lower than seventy reais, revealing a situation of extreme poverty. Thus, even with the economic growth of the country and the gradual reduction of social inequities through income transfer policies, the poverty still characterizes as a present problematic and exacerbated by neoliberal adjustment. It is worth to highlight that the State assumes a minimum role up to the social cut policies, and even the monetary aspect revealing itself to be one of the constraints of poverty, it is characterized as a multidimensional phenomenon, presenting a theoretical construction full of concepts that, many times, were conflicted or continued.

According to Araujo[11], initially, the poverty presents itself as something of moral and natural order; posteriorly, it begins to be seem as structural, showing itself as an reflection of the way of production and consumption adopted. More recently, it became object of State official organisms, being one element that teaches other social programs.

Another relevant aspect in the survey of socioeconomic conditions of children with congenital cardiopathy that can contribute to the aggravation of their pathology refers to the sanitation issue, such as: sanitary sewage, sewers' collect network, as well trash collection as fundamental elements to a decent life and, specially, healthy. The results show that only a reduced number of families of children have a sewer network (24.21%), being the great majority dependent to the fosse system or even open sky at the proportion of 75.78%. This reality is above the average of all country, once that 30.06% of the national population, represented by 16 million people, do not have homes with access to appropriate sanitation[12].

Concerning water distribution, the results show that the largest part of children use water from the public system, but an expressive number 43.15% of them use water from the well. It is important to say that these waters do not always have an appropriate treatment to human consume due to the absence of sewers network or satisfactory garbage collection, which results in the contamination of the groundwater which represents a large risk to children.

It is important to say that this chain of services is not simultaneous, because, despite the majority has water from the general network, do not possess the sanitation sewers network and satisfactory garbage collection. This is seen in all national territory. In 2011, according to IBGE[12], 48.5% of children up to 14 years old, 21.9 million approximately lived in houses that at least one sanitation service was not appropriate (water, sewer or trash). It is noted that there wasn't refueling of water through the general network, or septic tank linked to the collector network, or trash that wasn't collected. When these inequality forms of sanitation existed simultaneously in houses, around 4.8 million children in the proportion of 10.7% were seriously exposed to disease risks, and this indicator concerned 17.2% of children of Northeast region and, in contrast, 3.7% in the southeast region[12].

Taking this scenario into consideration, the closer follow-up of this public by the basic care teams (health family strategy and community health agents) is extremely important, in order to better assist the children with this kind of pathology and speed up in case of bigger complications, taking to reference hospitals. And also to identify risk factors to these individuals health, among so many already mentioned, proceed and articulate to this network may function through the intersectoriality

among educational public policies, social assistance, health and previdence.

Associated to other social indicators, the welfare situation is another element that is worth to be considered as a factor of social vulnerability. It was observed in the study that most of the children did not have a welfarebond, which means, that their parents or responsibles do not contribute with the social welfare, and this can happen due to a difficulty of insertion in formal jobs, specially in a conjecture such as the neoliberal in which the unemployment in these conditions becomes a growing problem.

Still in the welfare matter, it is important to mention about the concession of the Continued Render Benefit (BPC) to these children. The BPC is a benefit in effect since 1993 which concedes the unconditional income transfer in an amount of a minimum wage to elders and people with deficiency whose per capita income is inferior to ¼ of a minimum wage, independent of previous contributions to the welfare system. For the elders, the concession of the benefit is made under two conditions: being 65 years old and be considered poor[13]. Concerning people with deficiency, beside the condition of poverty, it is necessary a limitation to an independent life and to work that are confirmed through some tests performed by experts of INSS, evaluating both the social status as the deficiency with systematic revaluations each 2 years to verify the persistence of the conditions that originated the benefit.

However, a study reviews to exist a controversy of the adopted model to the comprehension of what is a deficiency[14], what can, in some way, interfere in the beneficiary selection. The decree nº 6.214 of 2007[15,16] , establishes the person with deficiency as being "the one unable to independent life and to work, because of irreversible anomalies or injuries of hereditary nature, congenital or acquired that forbid the performance of activities of the daily life and work". Thus, the more severe congenital cardiopathies can be scaled in the list of possible deficiencies that can be selected to the BPC. However, the present study showed that only 12.24% of the children were using this benefit.

Analyzing the factors of concession of the benefit becomes a hard task, because involves evaluation, besides the social condition, the level of deficiency and how much it can limit the independent life of this child. This means that the analysis of the benefit concession brings into consideration not only the level of the deficiency, but, above all, the complex relation between the limitation of the body and the impositions of society. Thus, in case of congenital cardiopathy, the frontier between the deficiency (notion of permanence) and disease (notion of temporality) is latent and that, depending on subjective factors of each requiring subject and evaluator expert, can affect the benefit's deferring[16]. In the other hand, it is worth noting that social assistance is a constitutional right that also support children.

Although the real conditions of existence of great part of these children from Maranhão's State be permeated by the most diversified precarious forms of social and economic conditions and specially the appropriate access to medical treatment, it is important to mention that some efforts have contributed in some measure to call the attention to congenital cardiopathy and its treatment forms. They are: the creation of the congenital cardiopathies consciousness day, celebrated since June 12th 2012, with the goal to inform the general population about diseases caused by cardiac malformation and the medical class mobilization to create the Special Secretariat to the Treatment of Children with Congenital cardiopathies (SETRACCC) with by the Ministry of Health, whose primordial objective will be to enable the integral attendance of the child with congenital cardiopathy, aiming to reduce the high levels of mortality by the lack of access to surgical and percutaneous treatment by the creation of Integral Treatment Centers to Children with Congenital cardiopathies (CETICCCs)[17] in all national territory.

LIMITATIONS

It was considered as limitation to our study the impossibility to measure data referred to characteristics of the progenitors or responsibles for children with congenital cardiopathies, because these pieces of information were not available in the studied data bank.

CONCLUSION

Regarding all indicators of social economic conditions of children with congenital cardiopathies registered in this research, it is evident that material elements such as income, basic sanitation, housing conditions and welfare situation make it more difficult to deal with their needs[18]. The lack of their basic needs has direct implications on the health conditions of these individuals, resulting in the obstruction of people to obtain favorable living conditions for their participation in society. It is worth remembering that the health policy preconized in the country has intersectoral and inter institutional character, and they become effective which implies a strengthening of Brazilian social security system.

Another problem is what concerns income access, which in scholar children, represents one of the largest faced obstacles, once that the bigger the income of their families, better their housing and sanitation conditions are. These precarious conditions of housing, sanitation and also access to information that can contribute to aggravate the health conditions of the infantile public, because of its natural fragility, putting their development at risk.

The challenge that is presented with this study is how to guarantee the satisfaction of these children's needs. Brazil has legal devices of childhood and youth protection as the Law nº 8069 of 1990[2] by understanding that life quality of this population group is the source of national development. Therefore it has invested in income transfer Programs such as Bolsa Família (Family allowance), BPC and, more recently, the

program Brasil carinhoso (Fond Brazil) that aims to overcome extreme poverty in the first step of the childhood. Although the importance of these actions, it is important to go beyond them and guarantee the satisfaction of these public needs in all life segments in society through the strengthening of jobs generation policies, housing policies and basic health with housing expansion with sewer sanitation network, public water and garbage collection and, more important, the strengthening of education policy so that even more children have the opportunity to grow in a health environment, overcoming these iniquities that affect so much this population group. Finally public policies of social cut that exercise a fundamental role in this process are expected, reason which arises a need of more debate, evaluation and, specially, monitoring so that the childhood becomes more assisted and indeed have an advance in the effectiveness of social rights in citizen perspective.

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Authors' roles & responsibilities	
TLVB	Manuscript drafting, analysis and interpretation of data
MJSD	Analysis and critical review
RVAHN	Study design and search for references

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