

# The Impact of the Diagnosis on the Socioeconomic Conditions of the Families of Children and Adolescents with Solid Tumors

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*O Impacto do Diagnóstico nas Condições Socioeconômicas das Famílias de Crianças e Adolescentes com Tumores Sólidos*  
El Impacto del Diagnóstico en las Condiciones Socioeconómicas de las Familias Niños y Adolescentes con Tumores Sólidos

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## ABSTRACT

**Introduction:** Child and youth cancer is the disease that kills most children and adolescents in Brazil and the second leading cause of death in this age group. It is estimated that this type of cancer represents 1% to 4% of the incidence of all cancers in most populations, with approximately 80% of pediatric cancers occurring in low Human Development Index countries. **Objective:** Identify and reflect about the implications of the diagnosis on the socioeconomic conditions of the families of children and adolescents with solid tumors. It is attempted to understand the socioeconomic changes that occur in the lives of families and which social policies they look for during the pediatric oncologic treatment. **Method:** Quantitative, descriptive, prospective and longitudinal cohort study, which addressed two moments with the parents/guardians of children and adolescents with solid tumors enrolled at the National Cancer Institute José Alencar Gomes da Silva (INCA), from 8/1/2018 to 3/31/2019, with a sample of 55 participants. **Results:** One of the study findings shows that, after diagnostic confirmation, the family *per capita* income reduced, 63.6% of the participants trying to survive in extreme poverty with *per capita* income below ¼ of the minimum wage, compared with 25% (p-value<0.004) who survived in the same conditions at the time of admission. **Conclusion:** Therefore, it is understood that, even after three months of diagnostic confirmation, users do not access the assistance and social security benefits essential to ensure better conditions for the oncologic treatment.

**Key words:** Neoplasms; Diagnosis; Social Conditions; Child; Adolescent.

## RESUMO

**Introdução:** O câncer infantojuvenil é a doença que mais mata crianças e adolescentes no Brasil (8% do total) e a segunda causa de óbito nesse grupo etário. Estima-se que esse tipo de câncer represente de 1% a 4% da incidência de todos os tumores malignos na maioria das populações, sendo que aproximadamente 80% dos cânceres pediátricos ocorrem em países com baixo Índice de Desenvolvimento Humano. **Objetivo:** Identificar e refletir sobre as implicações do diagnóstico nas condições socioeconômicas das famílias de crianças e adolescentes com tumores sólidos. Pretende-se compreender as mudanças socioeconômicas que ocorrem na vida das famílias e quais as políticas sociais são acessadas por estas durante o tratamento oncológico pediátrico. **Método:** Trata-se de um estudo quantitativo, descritivo e de coorte longitudinal, do tipo prospectivo, que contemplou dois momentos com os pais/responsáveis de crianças e adolescentes com tumores sólidos matriculados no Instituto Nacional de Câncer José Alencar Gomes da Silva (INCA), no período de 1/8/2018 a 31/3/2019; a amostra consistiu em 55 participantes. **Resultados:** Um dos achados da pesquisa demonstra que, após a confirmação diagnóstica, há redução da renda familiar *per capita*, com 63,6% dos participantes sobrevivendo na extrema pobreza com renda *per capita* inferior a ¼ do salário mínimo, em comparação com 25% (p-valor<0,004) que sobreviviam nas mesmas condições, no momento da admissão. **Conclusão:** Assim, compreende-se que, mesmo após três meses da confirmação diagnóstica, os usuários não acessam os benefícios assistenciais e/ou previdenciários que são primordiais para garantir melhores condições à realização do tratamento oncológico.

**Palavras-chave:** Neoplasias; Diagnóstico; Condições Sociais; Criança; Adolescente.

## RESUMEN

**Introducción:** El cáncer pediátrico es la enfermedad que mata a muchos niños y adolescentes en Brasil y es la segunda causa de muerte en este grupo de edad. Se estima que este tipo de cáncer es responsable del 1% al 4% de la incidencia en las poblaciones, con aproximadamente el 80% de los cánceres pediátricos que ocurren en países con un bajo índice de desarrollo humano. **Objetivo:** Identificar y reflexionar sobre las implicaciones del diagnóstico sobre las condiciones socioeconómicas de las familias de niños y adolescentes con tumores sólidos y para comprender los cambios socioeconómicos que ocurren en la vida de las familias y las políticas sociales a las que acceden durante el tratamiento del cáncer. **Método:** Estudio prospectivo de cohorte cuantitativa, descriptiva y longitudinal, que incluyó dos momentos con las cabezas de niños y adolescentes con tumores sólidos registrados en Instituto Nacional de Câncer José Alencar Gomes da Silva (INCA), del 1/8/2018 al 31/3/2019; La muestra es de 55 participantes. **Resultados:** La investigación muestra que, después de confirmar el diagnóstico, hay una reducción en el ingreso familiar, con el 63.6% de los participantes que sobreviven en la pobreza extrema con un ingreso *per capita* inferior a ¼ del salario mínimo, en comparación con el 25% (valor p <0.004) que sobrevivieron en las mismas condiciones al momento de la admisión. **Conclusión:** se entiende que, incluso después de 3 meses de diagnóstico, los usuarios no acceden a los beneficios de asistencia y seguridad social esenciales para garantizar las condiciones para el tratamiento del cáncer.

**Palabras clave:** Neoplasias; Diagnóstico; Condiciones Sociales; Niño; Adolescente.

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## INTRODUCTION

Child and youth cancer is the disease that kills more children and adolescents in Brazil (8% of the total) and the second cause of death in this age range<sup>1</sup>. It is estimated that this type of cancer represents from 1% to 4% of the incidence of all malignant tumors in the majority of the populations<sup>2</sup>, and approximately 8% of pediatric cancers occur in low Human Development Index countries (HDI)<sup>3</sup>.

The most important prognostic factor for a child with cancer is the place where it was born<sup>3</sup>. The survival estimates in the age range from 0 to 19 years old in Brazil reach 64%, well different than economically developed countries, where it surpasses 80%<sup>4</sup>.

While analyzing the rates of incidence of child and youth cancer in Brazil, considering the socioeconomic status (SES), or socioeconomic levels of the regions for embryonic tumors as retinoblastoma, neuroblastoma and tumor of Wilms, regional variations directly associated to the socioeconomic conditions are noticed, mainly for the rates of neuroblastoma and retinoblastoma<sup>5</sup>.

Child and youth cancer is not a preventable disease. No scientific evidences exist to affirm clearly the association between the disease and environmental factors. The approach for pediatric cancer must be provided in the early diagnosis and with timely referral for proper and quality treatment, which grants more odds of cure<sup>4</sup>.

The International Agency for Research on Cancer (IARC)<sup>6</sup> indicates that for every year in global scale, 215 thousand cases are diagnosed in the age range from 0 to 15 years and nearly 85 thousand between 15 and 19 years. In World Health Organization (WHO) global initiative for child cancer, IARC is developing some actions that attempt to reduce the inequality of access to diagnosis and improve the quality of the treatment, mainly for children and adolescents living in the periphery of the capital<sup>6</sup>. Countries of peripheral capitalism historically are considered those who assume a subordinate position in relation of how the capital production determines the insertion of countries in the International Division of Labor, as Brazil is seen as a dependent and peripheral economy, considering the characteristics of development subordinated to the interests of the international capital<sup>7</sup>.

Among IARC initiatives, the incentive to governments to develop high quality cancer centers with technical support for the construction of information systems and utilization of data about incidence, survival and mortality stands out, because within the global initiative, IARC is recommending new approaches to improve the quality of these data, that are indispensable for the implementation of government effective public health policies and that

meet the actual necessities of the population. IARC is important for the development of tools and patterns that guide the planning and implementation of interventions for accurate and early diagnosis, effective treatment and palliative care to children and adolescents with cancer.

The motivation for the study is based in the action of the Oncology Pediatric Sector of the National Cancer Institute José Alencar Gomes da Silva (INCA) because of the situations lived in the daily work with the families of children and adolescents who face socioeconomic changes after cancer diagnosis.

Several factors are involved since the perception of symptoms until the diagnosis of child and youth cancer, making it a complex process and many are the variables that apparently influence this process. The precarious socioeconomic context of the families and the lack of effective support of social policies impact the oncologic treatment.

In this line of thought, the present study attempts to reflect about the implications of the diagnosis over the socioeconomic conditions of the families of children and adolescents with solid tumors, identifying the social policies utilized during the oncologic treatment and the costs of transference of the care (financial and social) for the families, mostly, in special, to the women.

## METHOD

Quantitative, descriptive, prospective, longitudinal cohort study inserted in a large study called Prospective Study of the Impact of Sociodemographic and Clinical Factors in the Diagnosis and Treatment of Pediatric Solid Tumors: a Multidisciplinary Approach. The Institutional Review Board has approved the study on July 16, 2018, through report number 2,772,154 and CAAE number 90227518,3,0000,5274.

The dialectic materialism is the theoretical reference adopted in this study that starts from the apparent phenomenon, immediate and empiric and proposes to reach the essence of the object, that is, that pursues to capture the dynamic structure and contradictions of the concrete reality through successive abstractions<sup>8</sup>.

The dialectic materialism in the interpretation of the social phenomena has been the only trend that presents principles, laws and categories of analysis<sup>9</sup>. To perform this study, the object was studied in its essence, that is, in all its aspects and connections. The complete analysis of the phenomena and social processes was pursued, considering the dialectic transit between the individual and the general and vice-versa, trying to grasp its unity.

The present study encompassed two moments targeted to parents/legal guardians of children and adolescents

with solid tumors enrolled in INCA from August 1, 2018 to March 31, 2019 and charts review. Parents/legal guardians of children or adolescents younger than 19 years after the diagnosis of solid tumors, enrolled at the Pediatric Oncology Sector of INCA who signed the Informed Consent Form (ICF) were included. Parents/legal guardians of children or adolescents enrolled at INCA for exclusive radiotherapy treatment (who undergo oncologic treatment in another institution) and those who had already been treated were excluded.

INCA is a High Complexity Oncologic Assistance Center (CACON) located in the municipality of Rio de Janeiro which receives children and adolescents with strong suspicion of malignant neoplasm from every part of the country, even with unconfirmed diagnosis.

The study team collected the data between August 2018 and June 2019 in the Pediatric Oncology Sector of INCA (Outpatient, Infirmarium and Intensive Care Unit). The source of the data were the interviews with parents/legal guardians and review of the physical/electronic chart concomitantly and complementary to the data collected in the interviews.

The interview was conducted in two moments. First, it was considered the date of admission, since children and adolescents are referred to INCA for diagnosis tests. Secondly, after three months of diagnosis, excluding those unconfirmed.

Two questionnaires were applied to collect the data consisting of the following blocks of questions: (a) general information – identification of the main caretaker, formation of the family group and family income *per capita*; (b) sociodemographic data of the mother (genitor); (c) sociodemographic data of the father (genitor); (d) sociodemographic data of children/adolescents; and (e) conditions of access/urban mobility and dwelling.

For being a study included in a larger trial, several variables were grouped in three blocks to facilitate the analysis: (a) components related to time of onset of the symptoms until diagnosis and beginning of the treatment; (b) socioeconomic profile/family dynamic; and (c) social policies more accessed by users and their families.

During the collection period, 213 children and adolescents were enrolled with suspicion of malignant neoplasm; of these, 147 were censored because they had no diagnostic confirmation (145) or were previously treated in another institution (2). Thus, 66 participants were eligible for the study.

The sample consisted of 55 participants. In the first interview, 11 participants were excluded because of difficulties to contact the families during the period of data collection. In the second interview, the sample consisted of 50 participants as four died before the estimated time to

conduct the interview and one abandoned the treatment. For clarification purposes, in case of abandonment of the treatment<sup>10</sup>, the health team followed legal measures.

The descriptive analysis was used for the characteristics of the child/adolescent and of the mother. The categorical variables were expressed as absolute (n) and relative (%) frequency and the numerical variables through mean, median and standard deviation. For the statistical analysis of the categorical variables, the chi-square method was utilized. To compare the numerical variables between the two groups, it was utilized the test “t” of Student and the Mann-Whitney test. The significance level was defined when the p-value <0.05. The data were analyzed in SPSS version 21.0.

## RESULTS

It is observed that 58.2% (n=32) of the children and adolescents are males and 41.8% (n=23) females; 56.5% (n=31) are illiterate, 34.5% (n=19) attend elementary school and 9% (n=5) are enrolled in high school, the median and mean of the ages encountered were 6 and 8 years, respectively.

69.1% (n=38) are originated from the Capital/Metropolitan Region of Rio de Janeiro and 45.5% (n=25) have diagnosis of tumors of the central nervous system (CNS), 14.5% (n=8), bone tumors and 40% (n=22) of other solid tumors as shown in Table 1.

Table 2 presents the sociodemographic tables at the admission only of the mothers of children/adolescents diagnosed with solid tumors at INCA. Later, the data of the fathers of children/adolescents will be presented.

38.2% (n=21) of the mothers are in the age-range of 30-39 years and the mean age is 34.6 years. Regarding education, 40% (n=22) and 52.7% (n=29) completed the elementary and high school, respectively, only 7.3% (n=4) have completed the university. In the variable number of children, the mothers with two to three children reached 67.2% (n=37).

In the first interview, it was established that married women and/or in stable union reached 58.1% (n=32) and singles corresponded to 36.3% (n=20). Also, it is noticed that 50.9% (n=28) of the mothers at admission were working.

In relation to the parents of children/adolescents, 37.2% (n=19) and 62.7% (n=32) completed the elementary school and high school/university, respectively, the mean age was 39 years.

Table 3 presents the comparative data between the socioeconomic profile and access or not of the families of children/adolescents with solid tumors in INCA to social rights. The period between the first and second interview were compared to show whether alterations occurred.

**Table 1.** Sociodemographic and clinical profile of users admitted between August 1, 2018 and March 31, 2019 in Pediatric Oncology of INCA. N=55

Characteristics of the Users		N	%
Gender	Female	23	41.8
	Male	32	58.2
Age	0-2 years	13	23.6
	3-6 years	15	27.2
	7-12 years	11	20.0
	>12 years	16	29.0
Diagnosis	Tumors of the central nervous system	25	45.5
	Bone tumors	08	14.5
	Other solid tumors	22	40.0
Distance (household – treatment center)	0-50 km	38	69.1
	51-100 km	05	09.1
	>100 km	12	21.8

**Table 2.** Sociodemographic profile of mothers of the children and adolescents at the admission to INCA diagnosed with solid tumors. N=55

Characteristics of the mothers		N	%
Age	<30 years	16	29.1
	30-39 years	21	38.2
	>40 years	18	32.7
Education	Until incomplete high school	22	40.0
	Complete high school	29	52.7
	Complete university	04	07.3
Number of children	1	09	16.3
	2 - 3	37	67.2
	>3	09	16.3
Marital Status	Single	20	36.3
	Married/Stable Union	32	58.1
	Separated/Divorced	02	03.6
	Widow	01	01.8
Job	Yes	28	50.9
	No	27	49.0

In the second interview it is noticed that the number of mothers of children/adolescents who were married and/or in stable union is similar to the singles, 46.7% (n=21), which shows a discrete increase of dissolution of conjugal bonds during the chronic sickening of the children.

For family income *per capita* at the admission at INCA, it was revealed that 52.3% (n=23) of the study participants lived with income between  $\frac{1}{4}$  and one minimum wage and 25% (n=11) survived with lower than  $\frac{1}{4}$  of the minimum

wage; however, after three months of the diagnostic confirmation, 63.6% (n=28) started to survive in this same income range. Therefore, it was evidenced that the diagnosis of the disease resulted in the impoverishment of these families, with statistical relevance (p-value=0.004) for this comparison.

The socioeconomic profile of the parents/legal guardians of children/adolescents at the moment of enrollment at INCA indicated that the main financial providers of the family group were the men (fathers, grand-fathers and brothers), representing 52.8% (n=28) followed by women (mothers, grand-mothers and aunts) with 20.7% (n=11) and women (mothers and grand-mothers) were identified as main caretakers representing 78.1% (n=43). Regarding family arrangements of the study participants, the composition consists of four and five individuals (n=35), including the children/adolescent.

It is noticed that women after three months of diagnosis – and in the peak of the oncologic treatment – reduced their workload. As for the origin of the income, the main type of bond among women who continue to work after the diagnostic confirmation is the informality, reaching a percent of 15.5% (n=7); but among men, the formality (single legal regimen and consolidation of labor laws) reached 55.5% (n=20).

Still in Table 3, in the first moment, 95.1% (n=39) claimed they had no social security benefit and 62.2% (n=28) did not have any assistance benefit, in relation of access to social policies; in the second moment, there were no significant changes since 60% (n=27) affirmed not having any assistance benefit, even having the profile to apply for the Social Assistance Program (PBF)<sup>11</sup> and to the Continuous Cash Benefit (BPC)<sup>12</sup>.

The access to the treatment unit was provided by the own family group. 77.7% (n=45) had car and/or funded the public transportation fare even after three months of diagnostic confirmation and with the profile to be granted the transportation vouch (Special Riocard)<sup>13</sup> and/or Social Vouch<sup>14</sup>. Still, 57.7% (n=26) did not use the overnight supporting house.

In relation to the living conditions of the study participants families, 100% of the participants had access to electricity in their households in the two moments of the interviews. In the second interview, there were significant modifications of basic sanitation, because only 69.0% (n=29) and 73.1% (n=30) affirmed they had access to running water and sewer services, respectively. These data demonstrate that the impoverishment of these families after the diagnostic confirmation impacts their living conditions, mainly because they are unable to access social rights/benefits for which they paid for to ensure better conditions for the oncologic treatment.

**Table 3.** Comparison of the sociodemographic conditions of the families of children and adolescents diagnosed with solid tumors in INCA and access to social rights

Characteristics	At admission		After three months of admission		p-value	
	N	%	N	%		
<b>Marital status – mother (N=45)</b>	Single	16	35.6	21	46.7	-
	Married/Stable union	27	60.0	21	46.7	
	Separated/Divorced	01	02.2	01	02.2	
	Widow	01	02.2	02	04.4	
<b>Work – mother (N=46)</b>	Yes	24	52.2	15	15.2	-
	No	22	47.8	31	60.9	
<b>Family income per capita (N=44)</b>	None	06	13.6	07	15.9	<0.004
	0 until ¼ minimum wage	11	25.0	28	63.6	
	¼ until 1 minimum wage	23	52.3	09	20.5	
	>1 minimum wage	04	09.1	00	00.0	
<b>Access to assistance benefits (N=45)</b>	Yes	17	37.8	18	40.0	-
	No	28	62.2	27	60.0	
<b>Access to social security benefits (N=41)</b>	Yes	02	04.9	03	07.3	-
	No	39	95.1	38	92.7	

Note: Statistic relevance (p-value<0.05).

In this study, it is also noticed the correlation of the diagnosis/age of the child and of the adolescent with education/maternal age, in addition to family income *per capita* with the time between the onset of the first signs/symptoms and the arrival at INCA. Table 4 presents these data and describes the correlation through mean/median in days.

Concerning the time between the identification of the first signs/symptoms and the access to the Oncologic Treatment Center of INCA – trying to understand this relation with the socioeconomic conditions of the families – the study demonstrates that the time between the onset of the symptoms and arrival at INCA was higher in adolescents (>12 years), with median of 211.5 days. Children and adolescents diagnosed with CNS tumors took more time to access the treatment, the median was 121.0 days. About the median of the time of beginning/perception of the first signs/symptoms until the arrival at INCA, CNS tumors took 121 days and bone tumors, 86 days.

Mothers older than 40 years and higher education level take more time to arrive at INCA, median 311.5 and 248.5 days, respectively.

## DISCUSSION

According to data from INCA<sup>4</sup>, the pediatric solid tumors consist in a very heterogeneous group of neoplasms. In Brazil, the CNS tumors, in the age-range of 0 to 14 years are the second most frequent with 16%; it is estimated that nearly 8% to 15% of the pediatric

solid tumors are represented by this group and although the sample of the present study is small, it is noticed the similarity with the national findings.

One of the main factors that can interfere in the likelihood of survival of pediatric cancer is the delay of the diagnosis. However, the early diagnosis associated to the guarantee of fast and correct diagnosis is the most effective manner to control the disease in children/adolescents.

Therefore, the difficulty of access to the diagnosis can result from conditions related to the patient and its family, to the health system and the disease’s biologic behavior<sup>15</sup>. In this study, only the obstacles of access associated to the conditions of the patient and its family were considered in the scope of the analysis. The categories considered were age of the child, education of the mother and the family economic conditions.

In relation to the children’s age, the study is similar to others<sup>15,16</sup> that show that the adolescents took more time to access the treatment center<sup>17</sup>. Different studies<sup>15,17</sup> identify that the parents low education and poor family income influence the diagnosis delay in the context of the family socioeconomic conditions and maternal education; the present study, however, did not show these results, indicating the necessity of analyzing other factors deeply as those related to the health system and the disease’s biologic behavior that were not addressed in this study. Although no association of low family income and delay to access the diagnosis was found, the data show the impact over the family income *per capita* after the diagnosis definition and changes in the organization and family dynamic.

**Table 4.** Comparison of the sociodemographic and socioeconomic data of children/adolescents with solid tumors and of the mothers with the time of onset of the symptoms and arrival at INCA

Variables analyzed		Time of onset of the symptoms and arrival at INCA (days)		
		Mean	Median	Variation
Diagnostic of the children	Tumor of the central nervous system	281.0	121.0	33-2,932
	Bone tumor	112.0	086.0	52-479
	Other solid tumors	175.0	115.0	07-722
Age of the children	0-2 years	171.0	079.0	33-664
	3-6 years	236.0	059.0	07-1,608
	7-12 years	179.4	101.0	41-982
	>12 years	448.4	211.5	69-2,932
Family income per capita	None	082.1	066.0	089.6
	0 until ¼ minimum age	369.8	083.0	789.7
	¼ until 1 minimum age	297.1	123.0	332.9
	>1 minimum age	120.8	127.0	164.2
Maternal age	<30 years	197.3	058.0	909-24
	30-39 years	127.3	091.5	479-07
	>40 years	556.1	311.5	2,932-33
Maternal education	Until elementary school	331.4	235.0	331.4-348.2
	High school/university	099.0	248.5	248.5-489.7

From the 1990 decade on, the families have become more heterogeneous with plurality of forms and arrangements, many of them based more in fondness and relations of mutual care than in kinship bonds or consanguinity<sup>18</sup>. The study ratifies these contemporaneous changes of organization and family dynamics, mainly in what concerns the reduction of the number of children because of the increasing participation of the women in the labor market.

It is clear that care is an ontological necessity of the social being<sup>19,20</sup> and in our form of sociability, children/adolescents need other individuals to provide for their survival. The ethics of the care comprehends the sharing of their responsibility with other members of the society, making it as democratic as possible<sup>21</sup>; however, according to the Brazilian Institute of Geography and Statistics (IBGE)<sup>22</sup> data, women who work in the Southeast Region dedicate in average 18.4 week hours to care for persons and/or household tasks, as opposed to 10.7 week hours for men, consistent with the findings of this study, because women were identified as main caretakers.

In the current study, it is noticed that the mothers were identified as main caretakers in the moment of the oncologic sickening of children/adolescents. Nonetheless, three months after the diagnostic confirmation, the women quit working to dedicate exclusively for caring/follow up of their children during the treatment.

Federal Law 13,257 dated March 8, 2016<sup>23</sup> rules about personal time of one day per year to follow up

children of up to six years old in medical consultation as prescribed by the physician. While living the sickening of their children by cancer these women compromise even more the already affected family income because the social security legislation does not provide any benefit to the responsible who leaves the job to follow up the child during oncologic treatment.

Care, as understood in this study, is individualized, within the contemporary capitalist production, that is, occurs privately and assigned to the families accountability<sup>24</sup>. The focalization of the care in the woman happens by unequal relation of genders and is supported by sexual and racial division of the work, that delegates to women a job which is precarious and unpaid, but it is functional for the process of capitalism reproduction. Care is not new, since taking care of children has always been a part of the daily living, especially healthcare, where it becomes natural "the *continuum* between medical care and housework, because everyone contributes for the promotion of health"<sup>24</sup>.

Furthermore, the study revealed that women are predominant as caretakers. Because of full time caring requirements, this demand can cause overload in women and still provoke substantial changes in the family dynamics considering that in the beginning of the process of children's oncologic sickening, the mothers initially reported they had spouses, but along the routine of the treatment, the number of spouses reduced.

Caring, so idealized in health, is not necessarily a good/satisfactory relation. The typification of the female

work and especially the maternal work can often express as imposition, compelling and wearing forms. Patriarchy “qualifies” women and makes them more able for this work, nevertheless, “for women, caring is almost an obligation and because of this some feel guilty when not performed as expected”<sup>19,20</sup>. Therefore, the concept of considering natural that women are responsible for caring contributes to obfuscate the implications of the work overload in the life of these women<sup>25</sup>.

In the present study, it was identified that women had higher levels of education, when compared with men but with lower income, mainly considering the typification of the employment bond with women performing more informal jobs, that is, precarious employment bonds, unprotected and without social rights. However, in relation to university education, the study revealed that four women had completed college, showing the existing relation between the economic conditions of the population and education levels of the different social segments, since the difficulties of access to university in Brazil are but one face of the social inequality.

The current form of social and sexual division is a mark carved deeply in the patriarchate and hetero-normative society that tends to contribute for sex-based social construction<sup>26</sup>. The chauvinist speeches domineering the capitalist society reinforce the salary unbalance in relation to men justified because, within the universe of private life, women’s salaries can only work as complementation of the family income components.

In the bourgeois sociability, female work is incorporated unequally and differentiated with more intense levels of exploration and precarious working conditions<sup>27</sup>. The National Household Sample Survey (PNAD)<sup>28</sup> demonstrates that women study more, work more and earn less than men; in 2016, women earned 76.5% of men’s earnings.

Still, the work assigned to women within the reproductive cycle represents a political problem as the accountability implies in disadvantages that ensure an unbalanced position for women and these disadvantages are institutionalized in the political and State actions<sup>29</sup>.

Capital is shrewd in relation to the intensive appropriation of the polyvalence and multi-activity of the female workforce<sup>20</sup>, when transfers the costs of caring to the families, especially post 1970 with the neoliberal ideology. The social policies, while recognizing the important role of the families in the social protection of its members, also tends to overbear them with attributions, with strong appeal to the predominance of women as family reference, subject to the implications and social accountability over its protective role without the required state support for its fulfillment.

In the present study, it is verified also that the economic profile of children and adolescents treated in INCA’s Pediatric Oncology Section is predominantly marked by extreme poverty. It is clear that poverty is not a marginal aspect of the capitalism development, but a founding element of the capitalist accumulation and necessary for its maintenance. However, although this phenomenon is historical and structural in the social daily life, it presents itself as multidimensional. The synthesis of the Brazilian Institute of Geography and Statistic (IBGE)<sup>30</sup> social indicators reveals an alarming increase of the number of poor and miserable in Brazil with more than 50% of the population in extreme poverty, reaching 14.83 million individuals or 7.2% of the total population.

In Brazil, the Michel Temer government determined through Decree 9,396 dated May 30, 2018<sup>31</sup>, the limit of until R\$ 89.00 monthly *per capita* (extreme poverty) and of R\$ 89.01 until R\$ 178.00 monthly *per capita* (poverty). In addition to the Social Assistance Program<sup>11</sup>, which stands out as monetary compensation program of income transference from the State to the families – with extremely low resources that are barely enough to the reproduction of the basic necessities of the beneficiary, another resource of the social assistance policy of income transference in the rural area is the Continuous Cash Benefit<sup>12</sup> for disability that covers children/adolescents with cancer, with monetary transference equivalent to one minimum wage and that required until March 23, 2020 as approval criteria – in addition to the disability – that the family income *per capita* should be lower than  $\frac{1}{4}$  of the current minimum wage (R\$ 249.50), following the same conception focalized in poverty and the monetary and restrictive perspective of the Social Assistance Program (PBF)<sup>11</sup>.

The study made clear that all the participant families had low income, which is defined by Decree 6,135 dated June 26, 2007<sup>32</sup> as that with monthly income of until  $\frac{1}{2}$  minimum wage per person or total month income of until three minimum wages (R\$ 3,135). It is emphasized still that great part of the families of this study survives with family income *per capita* of until  $\frac{1}{4}$  of the minimum wage as shown in Table 2. Based in this, it is identified that these families have socioeconomic profile consistent with misery because the overwhelming majority, until the period the study was performed, failed to access any assistance program or benefit – considering the minimalist and focalization characteristics of these resources, especially the Continuous Cash Benefit<sup>12</sup>, whose obstacles are clear for the families who face a morose and bureaucratized process in their application.

The criteria to access assistance programs and benefits in the country follow the conception of poverty elaborated

by the World Bank for social policies of peripheral countries and formulation of indicators for the creation of the HDI<sup>33</sup>.

Since the decade of 1990's, the social policies in Brazil were elaborated according to the neoliberal prescription called Consensus of Washington equally influenced by the recommendations of international bodies as the World Bank<sup>34</sup>, that defines the state action and focalization of policies to extreme poverty having in mind the interests of capital value in all the peripheral capitalist countries<sup>7</sup>.

It is understandable that poverty is not measurable just by the level of income, but as deprivation of the basic capabilities involving access to goods and services; it is important to consider poverty in its multidimensionality<sup>33</sup>. Illiteracy, disease, misery, no access to credit, lack of public services and exclusion of social and political participation, among others, reveal themselves as privation of capabilities that hamper the overcoming of poverty<sup>33</sup>.

Although in the formulation of social policies it was attempted to analyze poverty under the multidimensional perspective, in the concreteness of daily life, it was noticed the persistence of the income criteria – that leaves traces of an ideologic component that leads to fragmentation, focalization and categorization of the public-target – in palliative actions of fight of poverty, centered in assistance programs and benefits of income transference.

It cannot be denied that the transference of income has worked as a drive to include these population groups into the circulation of goods through increase of consumption and services they had no access so far. But these programs and assistance benefits are limited to focused actions because they fail to reach the entire target population leaving behind even those who benefit into their eligibility criteria.

The criticism to this analysis is that these assistance measures failed and continue to fail to resolve the problems created by the high informality of the labor and increase of unemployment. The fight of extreme poverty has been conducted through compensatory social programs guided by an individualistic vision of holding the poor accountable for its pauper condition.

The capitalist State cannot eliminate pauperism because this is the result of societies divided in social classes; poverty is understood as consequence of social production relations<sup>35</sup>. From this perspective, it is possible to infer that any attempt of State intervention in the social order of the capital either in capital centers or peripheral countries is doomed to failure in the elimination of poverty.

Therefore, there are inconsistencies in the implementation of the policies and programs for the working class, especially when some family member

is sickening and failure of the State in ensuring social protection to them, sometimes neglecting the direct impact this restriction bears upon the guarantee of access, adherence and continuation of the oncologic treatment.

The study also reveals other factors that are measured beyond the income gap and has been contributing to the escalation of the intensity of poverty as low education, work precarization, disease, poor access to public services, political shunting, poor basic sanitation and water supply, underserved living conditions – not always favorable to children/adolescents chronically sickened living in the household – difficult to travel daily to INCA because of poor financial resources to pay for public transportation and/or the difficulty to access social policies, especially those related to free-cost public transportation granted to passengers in treatment of chronic diseases<sup>13,14</sup>. Even after three months of diagnostic confirmation, the patients do not access social rights that are essential to ensure better conditions for the oncologic treatment.

## CONCLUSION

This study corroborates the perspective that oncologic sickening of a family group member impacts its entire structure because in an unequal society who holds the family accountable – especially the women for their caring work – is clear that the absence of the State in its constitutionally defined responsibilities implies directly in the socioeconomic conditions of the families of the children and adolescents diagnosed with solid tumors.

The present article is part of an ongoing study; however, the data about the socioeconomic conditions and changes the pediatric cancer treatment provoke in the families consulted at INCA are utterly relevant, since the public policies that should provide better social conditions for the treatment are not available for these families which indicates the urgency to mobilize the civil society in pursuing the widening and materialization of social policies, programs and benefits.

Further to social mobilization, it is emphasized as important strategy of follow up of the families that live the obstacles of access to social rights, integrality of the actions among the members of the health team aiming the socialization of the information and mobilization of health resources and services of the social protection network.

## CONTRIBUTIONS

All the authors contributed substantially for the conception and study planning, collection, analysis and interpretation of the data, wording and critical review and approved the final version to be published.



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## DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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