

# Family knowledge about the legal rights of children and adolescents with cancer

*Conhecimento familiar sobre direitos legais de crianças e adolescentes com câncer*  
*Conocimiento familiar sobre los derechos legales de niños y adolescentes con cáncer*

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## ABSTRACT

**Objective:** Identify the knowledge of family members of children and adolescents with cancer about their legal rights, difficulties, and concessions to ensure them. Method: Quantitative study, survey type, of intersectional design. A questionnaire drawn up by the researchers was applied in order to characterize the minor and their family and also to identify the family's knowledge about legal rights. Descriptive statistics were used to analyze data. **Results:** 61 family members who participated know some more rights to the detriment of others and are especially motivated to search for information when negative impacts on the financial life increase, with repercussions beyond family health. **Conclusion:** the studied population requires more information and demands knowledge about some rights guaranteed by law. Guidance on rights empowers the family and guarantees the necessary care, searching to have an intersectoral action qualify care and assist in restructuring family dynamics to deal with chronic conditions.

**Descriptors:** Patient Rights; Defense of Children and Adolescents; Neoplasms; Family; Pediatric Nursing.

## RESUMO

**Objetivo:** identificar o conhecimento de familiares de crianças e adolescentes com câncer sobre os seus direitos legais, dificuldades e facilidades para assegurá-los. **Método:** Estudo quantitativo, do tipo *survey*, de delineamento interseccional. Aplicou-se questionário elaborado pelas pesquisadoras para caracterização do menor e de sua família, e identificação do conhecimento do familiar sobre os direitos legais. Utilizou-se estatística descritiva para analisar os dados. **Resultados:** Participaram 61 familiares. Os familiares conhecem mais alguns direitos em detrimento de outros, sendo especialmente motivados a buscar por informações quando aumentam os impactos negativos na vida financeira, com repercussões para além da saúde familiar. **Conclusão:** a população estudada requer mais informações e demanda por conhecimentos sobre alguns direitos assegurados por lei. A orientação quanto aos direitos empodera as famílias e possibilita a garantia dos cuidados necessários, sendo preciso atuação intersectorial para qualificar o cuidado e auxiliar na reestruturação da dinâmica familiar para lidar com a condição crônica.

**Descritores:** Direitos do Paciente; Defesa da Criança e do Adolescente; Neoplasias; Família; Enfermagem Pediátrica.

## RESUMEN

**Objetivo:** Identificar el conocimiento de familiares de niños y adolescentes con cáncer sobre sus derechos legales, dificultades y facilidades para asegurarlos. **Método:** Estudio cuantitativo, del tipo *survey*, de delineamiento interseccional. Aplicó encuesta elaborada por las investigadoras para caracterización del menor y su familia, e identificación del conocimiento del familiar sobre derechos legales. Utilizó estadística descriptiva para analizar los datos. **Resultados:** Participaron 61 familiares. Los familiares conocen más algunos derechos que otros, siendo especialmente motivados a buscar por informaciones cuando aumentan los impactos negativos en la vida financiera, con repercusiones para además de la salud familiar. **Conclusión:** La población estudiada requiere más informaciones y demanda por conocimientos sobre algunos derechos asegurados por ley. La orientación cuanto a los derechos empodera las familias y garantiza los cuidados necesarios, siendo preciso actuación intersectorial para calificar el cuidado y auxiliar en la reestructuración de la dinámica familiar para lidiar con la condición crónica.

**Descriptorios:** Derechos del Paciente; Defensa del Niño y del Adolescente; Neoplasias; Familia; Enfermería Pediátrica.

## INTRODUCTION

Although the incidence of cancer in childhood has reached high survival rates<sup>(1)</sup>, it is still associated to loss, suffering, pain, and family breakdown<sup>(2)</sup>. Its repercussions are diverse and may cause psychological and emotional impacts in distinct dimensions of the family life<sup>(3)</sup>, including socioeconomic, usually impaired by costly cancer treatment<sup>(4)</sup>.

Financial repercussions are significant in the care of children with cancer, due to the changes in the family routine, and the disruption in your daily life. They are present both during the hospitalization due to the treatment and also taking care in the home environment, where family members keep their previous responsibilities, plus new demands imposed by the disease<sup>(5)</sup>. Many times, a parent/caregiver, or both need to be absent from work activities to accompany the sick child and meet these demands, which contributes to the reduction of the purchasing power of the families<sup>(4)</sup>.

In Brazil, the regulation of the Law N° 8069, the Children Act (ECA), guarantees to children and adolescents specific rights since 1990<sup>(6)</sup>. Recently instituted, the National Policy for Comprehensive Child Health Care (PNAISC) has, in its strategic axis IV, actions that qualify the assistance to prevalent diseases, and chronic conditions in childhood<sup>(7)</sup>. According to these and other provisions of law, this population has the right to receive dignified care in health institutions, which gives him attention and respect<sup>(6)</sup>. Also, it has granted the right to receive clear and objective information about the diagnostics, therapeutic actions, length, and particularities of treatment<sup>(6)</sup>. Another important aspect for maintaining a healthy childhood and adolescence is the right to continue school activities<sup>(6)</sup> and enjoy a recreation space, for example, a playroom<sup>(8)</sup>. Moreover, they can be accompanied during the whole time of treatment, and also in exams and appointments, and the public health units must provide conditions of permanence for the companion<sup>(9)</sup>.

The countless factors that interfere in families' finances highlight the need to use means that assist them to minimize this impact. In this sense, Brazilian law guarantees specific rights to children with diseases considered severe, like cancer<sup>(10)</sup>. The rights that may economically help their families are Assistance for the Disabled or Continuing Benefit Conveyance (CBC), which provides a monthly minimum wage, priority progress in judicial proceedings<sup>(11)</sup>, right to permanent assistance, acquisition of import drugs, exemption from municipal, intercity, interstate and sick transportation charges<sup>(10)</sup>.

In addition to these, which are focused on children and adolescents with cancer, others may be required by their parents, like withdraw of the Government Severance Indemnity Fund for Employees (FGTS), and quotas of the worker registered in the PIS/PASEP<sup>(10,12)</sup>. However, despite the range of rights granted to this population, the Brazilian law is very vast and difficult to consult<sup>(10)</sup>, which may difficult for the parents and legal representatives to access these rights. In the study<sup>(13)</sup> to evaluate the knowledge of cancer patients about their legal rights, only three out of the 23 patients in a public hospital had received information on this topic from a health professional. It shows a possible lack of knowledge on the part of professionals concerning these issues or, still, lack of interest and involvement in this subject.

The National Policy for the Prevention and Control of Cancer, instituted by the Ordinance N° 874, from May 16, 2013, provides training and continuing education for health professionals to gain knowledge, capabilities, and attitudes proper of quality assistance to oncologic patients. It also provides the construction and promotion of information about the control and treatment of cancer, in addition to the monitoring and improving access to health services and creation of strategies that promote better communication with the community, in partnership with programs and social actors. Thus, the training for practitioners to know the oncologic patient rights and its dissemination among those clients is essential<sup>(14-15)</sup>.

Since damages to the caregiver's life may impact the relationship he or she maintains with the child, the intervention of the health team may have an empowering role as it provides support and health monitoring. Also, the child allows identifying the needs that indirectly affect the family health, like the needs related to the infringement of the legal rights of this population<sup>(16)</sup>. It demands investments by the government and hospital institutions in the training and updating of their practitioners to make them aware of their role as mediators, disseminating the rights of cancer patients and assisting them in guaranteeing and accessing these benefits<sup>(13)</sup>. Having this information, the parents or the caregivers will be empowered about their rights and may minimize the significant impacts caused by the disease in the family environment. Also, the knowledge of the parents regarding the legal rights of their sons with cancer is little investigated in the literature, and it is noticed the lack of national researches with this topic, which reaffirm the need to explore this subject.

## OBJECTIVE

Identify the knowledge of family members of children and adolescents with cancer concerning the legal rights of these clients and analyze the facilities and difficulties they face to ensure them.

## METHODS

### Ethical aspects

The study obtained ethical approval for its development by the proposing and co-participating institutions. Participants were guided using clear and objective language about the survey objectives and had ensured the confidentiality of their identities. Those who accepted participate signed the Informed Consent Form (ICF).

### Design, period, and place of study

A research study with a quantitative approach or survey type of intersectional design. This type of investigation aims to collect, explore and analyze data for the creation, formalization, or renewal of the areas of knowledge; the intersectional design describes that the data collection was performed in a single period of time and aims to obtain data or information from a certain group of people, in a certain period of time and scenario<sup>(17)</sup>.

The collection of data was held between September 2014 and February 2015, at Hospital das Clinicas of Ribeirao Preto Medical

School of Sao Paulo University (HCFMRP/USP), at Pediatric Hospitalization Unit and Ambulatory, where children and adolescents with cancer continue their treatment.

### Population

For the recruitment of participants, the inclusion criteria were defined as: be the father, the mother, the main caregiver, or the legal representative of the children and/or adolescents with cancer and be involved in their care. Children and adolescents should be between zero and 18 years of age and be in therapeutic monitoring (treatment or follow-up) in the mentioned hospital for at least two months, regardless of the type of cancer. This last criterion was established considering that from this period, the families would have more experience in the search for the legal rights, and also to describe the facilities and difficulties faced during this process.

Fathers, mothers, main caregivers, or legal representatives with age below 18 years or without a minimum ability to understand the procedures and the survey's question were excluded. In this study, the direct observation was used to analyze the participants' ability to understand and queries to the health team, which had a bond with potential participants. With the team, it was explored aspects such as education level, literacy, and perceived difficulties during the health orientations early provided. When the understanding of the questions was unclear, the interviewer repeated the question only once, and the participant's final answer was respected.

### Study Protocol

To collect data, a questionnaire elaborated by the authors and previously submitted to the evaluation of three experts were used: an accounting sciences professional, specialist in the elaboration of questionnaires for surveys, and two lawyers, one specialist in rights of the person with disabilities and other serious illnesses, especially children. After considerations of the specialists, the questionnaire was adapted, and its final structure for the application had 22 questions, divided into four sections: I – definition of the child or adolescent; II – definition of the participant family member; III – definition of the family; and IV – participant's knowledge about the rights of the child or adolescent with cancer. In this last session, a question was addressed to the difficulties and another one to the facilities in the search for the guarantee of rights. To grasp these elements, obstacles, and facilitators related to access to information about rights, as well as an understanding of legislation were considered. Another aspect referred to the time available for the necessary proceedings and the acquisition of documents for the guarantee of such rights. A field with the alternative "Other. Please specify" was included in both questions, so that participants with different experiences could describe them in this topic.

Information about types of oncologic diagnoses and time of treatment was collected from the patient records, with the authorization of the institution. The average time for the application of the questionnaire was 30 minutes. At the end of each application, all participants received guidelines about doubts related to the subject of the survey.

### Data analysis dos dados

Data was analyzed using descriptive statistics, with the help of the software SPSS (*Statistical Package for the Social Science*) for Windows, version 16.0. We obtained distributions of absolute frequencies and percentages of categorical variables (nominal and ordinal). Database was typed in an Excel spreadsheet (*Microsoft Office*) and validated by double typing.

### RESULTS

70 parents and responsible for the children and adolescents with cancer were invited to participate in the survey, though eight refused and one exclusion. The reasons for the refusals: a mother reported feeling tired; another had to leave, and it was not possible to contact her again, even confirming availability to participate in another moment; three mothers refused to participate for not being interested in the survey, and two mothers and one father alleged refused because of the difficult moment they were experiencing and for the unpleasant experiences they had trying to search for the children's rights. A participant was excluded for not understanding the content of the questionnaire after the second Reading of each question by the researcher.

In total, 61 questionnaires were applied, though one participant left some answers blank, being considered as missing. Table 1 shows the characterization of the participants and index cases. Of the total number of participants, 55 (90.2%) were from municipalities in the interior of Sao Paulo, 16 (26.2%) lived in Ribeirao Preto, 4 (6.5%) were from the State of Minas Gerais, 1 (1.6%) lived in the State of Mato Grosso do Sul, and 1 (1.6%) in the State of Tocantins. Most of them, 45 (73.8%), therefore, did not live in the city where the child received the treatment.

Regarding diagnoses, leukemia was the most frequent, 20 (32.8%), and Acute Lymphoid Leukemia present in 15 (24.6%) of cases; 15 (24.6%) children and adolescents had the diagnosis related to the Central Nervous System. Regarding the time of diagnosis, 31 (50.8%) had 13 months or more; 24 (39.4%), from 3 to 12 months, and 6 (9.8%), between 2 and 3 months.

Results showed that 42 (68.9%) families were composed of three to four people, and only 5 (8.2%) had more than six members living in the same house. The income of 36 families (59.1%) before the diagnosis varied from one to three minimum wage, i.e., between R\$724,00 and R\$2172,00, and 12 (19.7%) earned more than three minimum wages. After the diagnosis, the number of families that earned more than three minimum wages decreased, 11 (18%), and those families that earned from one minimum wage up to three minimum wages increased, 37 (60.7%), having R\$724,00 the amount corresponding to the minimum wage during the period of the survey<sup>(18)</sup>.

Some more relevant variables approached by the questionnaire can be highlighted: "activating the ombudsman's office;" "knowledge of legal rights;" "search experiences and attempt to the effectuation of the right;" "facilitators aspects and obstacles in the process of guarantee of the rights;" "means of access to knowledge of rights", and "motivations to assert the rights." Participants were questioned if during the treatment of their children they had searched for the ombudsman service of the

treatment center unit anytime. Although aware of this possibility, 52 (85.2%) confirmed never searched. For those who searched (N=9), 4 (44,4%), the main reason was the lack of communication between the team and the family members since they needed information about the health condition of their children.

**Table 1** - Characteristics of the participants, children and adolescents, Ribeirao Preto, São Paulo, 2014

	n	%
Characteristics of the participants		
Gender		
Female	55	90
Male	6	10
Relationship with the children and adolescents		
Mother	51	83.6
Father	6	9.8
Grandmother	03	4.9
Stepmother	01	1.6
Age		
< 30	16	26.2
30-40	33	54.1
40-49	9	14.8
50-59	2	3.3
≥ 60	1	1.6
Marital status		
Married	42	68.9
Single	12	19.7
Widower	5	8.2
Divorced	2	3.3
Education		
Complete primary education	6	9.8
Incomplete primary education	17	27.8
Complete high school	17	27.8
Incomplete high school	13	21.3
Complete higher education	8	13.2
Characteristics of the children and adolescents		
Gender		
Female	28	45.9
Male	33	54.1
Age		
1-5 years	21	34.3
6-10 years	15	24.6
11-15 years	22	36.2
> 16 years	3	4.9

Regarding the rights to which they were aware, 58 (95.1%) knew the child's right to remain accompanied during consultations, examinations, and hospitalizations, with the companion having the right to food. The right to the acquisition of financial aid BPC was known by 50 (83.6%) participants and the universal and equal access to health services through the Single Health System (SUS) by 49 (80.3%). The least known right was that of priority progress in legal proceedings, cited by only 14 (23%) family members. All respondents knew at least one right, as shown in Table 2.

Forty-seven participants (77%) tried to guarantee at least one right for their children with cancer. Of the total (n=61), 34 (56%) requested the BPC; 19 (32%) the exemption of public transport tariffs (urban, inter-municipal, interstate, and patients' transportation) for the patient and a companion; and 10 (17.6%) the right of parents or guardians of the children/adolescents to withdraw from the FGTS. Still on BPC, 22 (43.1%) of those who requested it had their requests denied in the first attempt, mainly because the family income *per capita* was higher than the maximum required by the law.

Of the total participants, 45 (73.8%) did not live in the same city where the child received the treatment, and 34 (55.7%) of them knew the right to exemption from public transportation charges. Only 17 (27.8%) of the participants from other cities requested this benefit.

During the process of requesting or guaranteeing of any rights, they experienced difficulties and facilities. The difficulty in making time available for the procedures necessary for the request was mentioned by 22 (36.1%) participants and understanding the legislation by 19 (31.1%) of them. On the other hand, the most mentioned facility by 33 (54.1%) of the family members was to gather the documents required by the child's own treatment institution, like medical reports and models of certificates. Seven (11.5%) family members confirm they never faced any difficulties, and 5 (8,2%) did not identify any facilities during this process.

The main means by which family members have referred to obtaining knowledge about the sick child were: social worker from the hospital of the study field of this survey or the family's city, by 46 family members (75.4%); and family members of other children com cancer, also under treatment in the same center,

**Table 2** - Distribution of the answers related to the rights known to family members of children and adolescents with cancer, Ribeirao Preto, São Paulo, 2014

Rights known to family members of children and adolescents with cancer	n	%
Right to remain with a companion during consultations, exams, and period of hospitalization and right to food.	58	95.1
Right to the Continuous Cash Benefit (BPC) or Disability Assistance.	51	83.6
Right to universal and equal access to health services, through SUS.	49	80.3
Right of parents or guardians of the child/adolescents to withdraw from the Government Severance Indemnity Fund for Employees (FGTS).	39	63.9
Right of exemption of public transport tariffs (urban, intermunicipal, interstate, and patients' transportation) for the patient and a companion.	34	55.7
Right to continue school activities during periods of hospitalization.	33	54.1
Right to purchase imported medicines.	33	54.1
The right to have some form of recreation, such as toys in hospitals and health centers that serve children and adolescents.	26	42.6
Right to continue school activities during periods of home stay.	25	41.0
The right of parents or guardians of cancer patients up to 21 years of age, who are workers registered with PIS until 10/04/1988, to withdraw the PIS/PASEP quotas.	20	33.0
The right to a caregiver and/or mediator together with the child in the classroom of the school where he/she is studying.	16	26.2
Right to priority progress in lawsuits.	14	23.0
Other	3	4.9

totaling 35 family members (57.4%). When the obtaining of information in this regard was analyzed only by health professionals, the psychologist was mentioned by 8 (13.1%) family members, and the nutritionist and occupational therapist were the least mentioned, by only 2 family members (1.6% for each professional).

The main motivation to search for or assert their rights was the significant increase of the financial costs after the cancer diagnosis, representing 51 (83.6%) cases. Thirty (49.2%) mentioned a decrease in family income and, for 11.5%, that situation was aggravated by the impossibility of maintaining work due to the need to accompany the sick child. Other 5 (8.2%) interviewees confirmed that knowing the rights was a decisive factor in the attempt to secure them.

At the end of the application of the questionnaire, participants reported the desire to receive more information about those rights, which was promptly met by the researchers. Only 5 (8.8%) mentioned not having an interest in obtaining other information on this subject, and the others received general guidelines, such as website addresses, booklets available online, and printed materials for those who did not have access to the internet, as requested by the participants.

## DISCUSSION

The oncologic diagnosis of a child modifies the family dynamics, which can damage personal life, work, and family relationships<sup>(19)</sup>. In this study, the main caregivers were represented by the mother figure, a family member who usually takes over the care of the sick child and adolescent<sup>(20-21)</sup>. She is the one who most submits to the changes caused by her child's illness, as she takes on new tasks and deprives herself of the activities carried out before the diagnosis<sup>(20)</sup>.

Most parts of the family members interviewed had low education, in addition to not being from the same city as your children's Treatment Center. The scientific literature highlights that small children's mothers with low education levels who come from cities of medium and high population density are more likely to not keep a job after the child's diagnosis of cancer<sup>(21)</sup>. These characteristics provide the family exposure to certain social risks, though, can be mitigated with adequate guidance concerning the rights of this population.

Some interviewees reclaim to the ombudsman of the Treatment Center more information on the condition due to failures in the communication between the multidisciplinary team and the family. The ombudsman's office aims to evaluate customer satisfaction and identify problems that arise in the health institution, configuring itself as a mechanism of social control over SUS, since it promotes citizen participation. However, the fact that only a small portion of the population knows this mechanism of social participation<sup>(22)</sup> can justify the low demand for this instance by the participants. In a previously published investigation, in the patients' and family members' view who require information about their rights, the practitioners needed to show proactivity, offer practical help and active assistance<sup>(23)</sup>.

The results of this study show that gathering documents necessary to request benefits or ensure rights was the greatest facilitator experienced by participants. On the other hand, it was also evident that the second greater difficulty throughout this process was understanding the legislation that guarantees their rights and that of their children. Although Brazilian legislation benefits cancer

patients, from a practical perspective, there are problems in the interpretation, implementation, and dissemination of these rights to these clients<sup>(24)</sup>. Additionally, many legal regulations are directed to the taxpayer worker of the National Social Security Institute, which does not include the pediatric population.

For the family members that experienced to effectuate any rights to their children, the greatest difficulty was to make time available for the necessary. You can also relate this difficulty to the notorious lack of knowledge about the priority progress in lawsuits identified in this study. It is known that the parents, as caregivers, have their responsibilities increased, which reduces the time available<sup>(25)</sup>. This factor could explain the data related to the most difficulties shown here, i.e., it is possible that family members did not have time to take documents in the indicated places, consult a lawyer and appeal to legal results, as they could not be absent from the care of the sick child. Also, the recognition about the priority access to their judicial cases could face this time-related difficulty. In this sense, it is essential for the government support and also the development of studies that highlight the importance of public policies turned specifically to this population to facilitate the process of acquiring rights and benefits<sup>(24)</sup>.

This survey showed that the right to BPC or the assistance support to the disabled was requested by 47 (68.6%) family members, of which 26 (43.1%) had their requests denied on the first request. Although it is not specific to people with cancer, they can receive BPC as long as they can prove their inability to guarantee their own livelihood or have it guaranteed by their families. To require this benefit, the monthly family income per capita should be lower to a quarter of the minimum wage, and the conditions that prove their incapacity and limitations need to be reevaluated every two years<sup>(10)</sup>. Thus, it benefits only people in extreme poverty<sup>(26)</sup>. It is possible that the families in this study who did not attempt the benefit were aware that the *per capita* rate was over the limits laid down on the legislation. However, the need to reformulate the criteria included in the law is emphasized, since they do not foresee the increase in family costs, reported by 51 (83.6%) participants, nor the decrease in income, reported by 30 (49.2%) family members.

According to the study in Sweden, this reduction in the family's income is even more significant when the financial provider is the mother<sup>(21)</sup>. In general, the increase in costs brought about significantly by the studied population was reported in other surveys, which pointed to extra expenses for the treatment of childhood cancer, including bus tickets (transport), food, and accommodations<sup>(20,24)</sup>. The loss or removal from paid activity and the absence of any financial benefit are aspects that may interfere in the evolution of the treatment of the disease, according to the reports of a survey that verified the low family financial condition as a negative prognosis indicator in childhood cancer<sup>(27)</sup>.

In this study, 45 (73.8%) participants did not reside in the same city where the child received the treatment and, although they knew the right to exemption from public transportation charges, less than half had requested this benefit. This result calls for new surveys since not requesting such an exemption guaranteed by law requires families to allocate resources, which can be scarce.

Additionally to childhood cancer implications in the caregivers' lives, the treatment affects the child, for depriving his/her of daily

activities like attending school and interacting with family and friends, this being one of the most stressful experiences for the child or teenager<sup>(2)</sup>. Data show that 33 (54.1%) family members know that their children had the right to continue keeping school activities during the periods of hospitalization or home care, and 16 (26.2%) were aware of the child/adolescents' right to have a caregiver/mediator on their side in the classroom when returning. These data are of concern because most of the children and adolescents in this survey were in school, that is, they were between 4 and 17 years of age<sup>(28)</sup>, and the lack of knowledge of these rights can lead family members not to demand their compliance, with the risk of discontinuity and even abandonment of the schooling process. The break of school activities can impose aggravating factors on the education and health of these students, since the school is a propitious environment for learning and provides opportunities for growth and development, and it is essential to include the participation of the health and education sectors in its implementation<sup>(29)</sup>.

In this study, the social worker role showed more significant compared to other health professionals, to provide information to family members about these rights. However, these results are different from those found in a survey held with adult cancer patients, which identified the doctor as the main informant, followed by the nurse and the social worker<sup>(30)</sup>. In another study, the nurse was the most cited professional for the orientation of oncologic patients regarding their rights and their referral to social rights services<sup>(23)</sup>.

The nurse also performs the role of educator in the spaces where he/she works. For being closer to the family and to the patient, he/she can act according to the needs raised by the clients, meeting the requirements that may interfere in the health of the population<sup>(31)</sup>. The understanding of the individual as a social subject and the understanding of the health-disease process make the nurse a valuable agent of transformation in the lives of his patients, however, in this study, this potential was not highlighted by the participants regarding the promotion of information on the rights.

However, all multidisciplinary team role is essential in the care and identification of oncologic patients and their families' needs. Thus, the inclusion of the patient's rights in the protocols of oncologic services is recommended as a way to encourage the exercise of the right of citizenship of the users and, consequently, to improve their financial, psychological, and social conditions<sup>(30)</sup>.

Most part of the participants requires more information on the children and adolescent's rights. However, professionals from the health and legal areas, most of them, have a diffused knowledge about the guaranteed rights to oncologic patients, which makes it important to promote debates about the interpretation of the laws. It is also necessary to create spaces for skills exchanges among these practitioners<sup>(27)</sup> so that precise guidance is provided to patients and their families.

### Study limitations

This study presents limitations related to the sample, considering the proportion of children and adolescents with cancer in the whole country related to the number of participants. Also, it is restricted to the moment, context, and culture experienced

by the population of the study. Thus, due to the different types of culture and scenarios present in Brazil, results may vary, and rights may be more or less known and searched by the family members. Despite this, results motivate new investigations to expand the knowledge of the family members of the children and adolescents with cancer regarding the rights guaranteed by law to this portion of the population. In parallel, studies that investigate this theme may help professionals of the health, education, and legal areas to be sensitive to the problem and in the elaboration of intervention strategies.

### Contributions to the fields of Nursing, Health or Public Policy

Family members of children and adolescents with cancer face difficulties to know their rights and the process required to guarantee them. Considering the financial impacts and other experienced situations throughout the youth cancer treatment may deepen the social vulnerabilities, pediatric oncology services professionals, including nurses, and the legal area must get closer and develop their work in partnership. It includes the elaboration of joint strategies able to help this population regarding their needs and rights, in a way to interfere in their social context, guaranteeing them proper support. It highlights the nurse's work, whose capabilities make him a key element in the identification of the health needs of these clients, to favor the planning of care about the needs and availability of this population.

### CONCLUSION

The study sets forth the knowledge of the family members about the rights of children and adolescents with cancer and emphasized that this population still needs more information regarding the legislation and possible aids and benefits as well as support from the multidisciplinary team to face the difficulties to guarantee them. It identified that the family members are especially motivated to search for their rights due to the financial impacts coming from the care with their children. One of the most known rights was the Continuing Benefit Conveyance (CBC), and one of the less cited was the right to have a caregiver/mediator on the side of the children in the classroom. Also, the main difficulties and facilities experienced by the family members throughout the process were shown, in addition to the main means by which they received information related to their rights. It is important to highlight the interest of this population in obtaining a better understanding of their rights and, at the same time, the little involvement of nurses in relation to the provision of such information. The guidance regarding the rights empowers the families, as it expands the possibility to guarantee the necessary care to their sick children and, consequently, makes work qualified and helps to restructure family dynamics to deal with this chronic condition.

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