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Brazilian social protection and demands of children and adolescent cancer treatment

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Abstract *This article discusses the issue of social protection against the demands presented in the treatment of children and adolescents in Brazil. It aims to problematize the advances and limits of the Brazilian social protection system in face of the social demands arising from the treatment of children and adolescents that go beyond the specific limits of health care. It is a qualitative study that was structured based on the analysis of official documents, Laws, Decrees, Ordinances and Policies and the literature destined to children and adolescents in cancer treatment whose incapacitating consequences produce social demands that impact, above all, family life. The paper presents social policies as a fundamental resource for treatment, considering the demand for income and displacement, in order to enable an effective health care. However, the reflections indicate that there is now a retraction of social policies by the State that was expressed in the focus and transfer of responsibilities of the State to other sectors of civil society.*

Key words *Children, Teenager, Cancer, Defense of people with disability, Social policy*

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Introduction

At present, cancer is a disabling chronic disease due to complex and continuous treatment. The child or adolescent in cancer treatment is exposed to repeated invasive medical procedures resulting in side effects and pain, as well as suffering from interruption of school and social routine, suspension of leisure activities, altered eating habits, changes in self-image, feelings of uncertainty about treatment, frequent hospitalizations, losses that impair their socialization and adversely interfere with the maintenance of their daily relationships[1]. These consequences extrapolate the individual scope and achieve family life as a first nucleus of socialization and support for individuals[2], especially for children and adolescents whose degree of autonomy in decision-making and maintenance of material conditions of existence is limited. Therefore, child and adolescent cancer can be considered as a disability, based on a critical perspective to the concept traditionally defined by the medical model of disease[3] which limits it to biological aspects. The critical concept of disability incorporates the vision of a complex and multifaceted phenomenon, and expresses social, cultural and economic inequalities[4].

Historically the definition of disability has shifted from the biomedical model to the social model, which understands it not only as a limitation of the body, but as the relation of inequality imposed by environments with barriers to a body with disabilities[5]. From this expansion, the concept of disability becomes an umbrella concept that encompasses, in addition to the biological body with disabilities, the limitations of activities or restrictions of participation. In Brazil, however, the biomedical model of disability still seems to support welfare actions and social policies, regardless of the advance of the theoretical debate around the social model.

Therefore, disability appears as a theme for public policies, especially those of a distributive and social protection nature[6]. In this conceptual and expansion of the concept review, genetic, chronic and serious infectious diseases are now classified as disabilities[7]. It is worth pointing out, in this new scenario, the different senses and the tensions at stake in the redefinition of this concept in what concerns the construction of identities and self-classification of social groups that are not always concordant.

Based on these reflections, our intention was to contextualize briefly the reason why cancer, as a limiting disease and long-term treatment, is linked to what is called disability in the public policy area, although it does not fit as a disability in itself. In this direction, the expression of this understanding in a recent change in public policies is highlighted, Law 12,470 / 2011 – Organic Law on Social Assistance[8] is an example – where the concept of disability has changed in the sense of extending it.

The experience of cancer illness in children and adolescents is very complex and condenses several meanings. It often expresses profound changes in the network of family members involved, due to: financial difficulties, estrangement between family members, intra-family conflicts and the forced reorganization of daily family life. The demands highlighted by caregivers of children with leukemia, in a study carried out by Kohlsdorf and Costa Júnior[1], include the need for greater patient care and monitoring; changes in the professional routine of caregivers who need financial adjustments due to increased expenses; and, changes of residence due to treatment requirements. For these reasons, it is extremely important to understand the social demands generated in the oncological treatment of children and adolescents and the current responses of the Brazilian social protection system to these situations that have a peculiar impact on the collective and individual existence of the children and adolescents in treatment and their families.

This article aims to problematize the advances and limits of the Brazilian social protection system against the social demands arising from the treatment of children and adolescents that go beyond the specific limits of health care. The need for this reflection was imposed in the context of the first author's experience in a pediatric ward of a public reference hospital in oncology in the city of Rio de Janeiro, which accompanies children and adolescents with cancer and their families, which resulted in the study on the subject in the scope of a Post-graduation in Public Health in the same city. This part of the recognition of the complexity of this disease characterized by severe clinical demands and several repercussions in family daily life and social life. The article deals with the social rights of this part of the population.

Child and adolescent cancer, access to cancer treatment and social demands: a brief overview

Access to oncological treatment permeates several areas of the patient's and family's life, and is not only related to the medical-biological aspect of the disease. Socioeconomic, emotional and cultural conditions can also influence access and continuity of treatment. This is because, from the child and adolescent sickness, there are several social demands that emerge for the family every day. Literature has already pointed out in our recent past the relevance of discernment regarding health demands and needs as particular historical concepts related to a particular type of economy and social organization model, as well as its importance for the planning of health actions[9]. The social demands discussed here are within the scope of concerns related to the guarantee of constitutionally established social rights and the responses of public authorities in situations involving public health policies such as child and adolescent cancer. In this direction, the relevance of social protection systems is discussed as a fundamental resource for effective treatment. At this point, it is important to estimate the new cases of cancer in children and adolescents up to the age of 19 in Brazil, which justifies the need to discuss the growing demands of this social group in a context of considerable social inequality. A total of 420,310 new cases of cancer are estimated for Brazil in 2016. As the median percentage of pediatric tumors observed in Brazilian Population Base Cancer Registries (RCBP) is close to 3%, it appears that there will be approximately 12,600 new cases of cancer in children and adolescents up to the age of 19 years old[10]. The neoplasias occupy the second position of deaths occurred in 2013 for children / adolescents (from 1 to 19 years), falling below only deaths from external causes, becoming the most lethal disease[11]. These data highlight the importance of this chronic noncommunicable disease, in the formulation of policies and actions to promote the health of children and adolescents[4].

For Monteiro and Pimentel[12] the dynamism of the disease health processes is referred to the recognition of the interferences of the conditions of existence both in the production of diseases and in the recovery of the health of the individuals. This perception has been demanding the overcoming of the traditional model of care centered on biomedical care, which implies admitting how much the treatment should attend to the social aspects that go through the health and disease processes. It can be noticed that if the incidence of cancer is not directly related to socioeconomic factors, the effectiveness of treatment certainly is[13]. From this perspective, the conditions of access to treatment and its maintenance determine the possibilities of coping with the disease[14].

Oncological treatment of children and adolescents, in general, generates numerous social demands that express the social inequalities present in contemporary society. In this sense, the emerging demands after chronic illness, according to Silva et al.[13] are related to these socioeconomic conditions of individuals and their family support network. The process of sickness of the child and the adolescent is presented, first as a private and family issue, hence the importance of giving attention to aspects of everyday life, changes in routine, organization of care[15]. The impact of the disease on the patient and his family needs to be understood, since it is in this context that the disease arises, and it is with this sociofamiliar structure that they will respond to the disease situation[14].

Therefore, the experience of chronic illness, including cancer, is also influenced by externalities related to social policies that provide access to health services and other conditions that interfere with their lives[16]. The effective accomplishment of the oncological treatment presupposes the satisfactory attendance of a set of necessities such as: housing, transportation, food, income and the access to social goods and services. For Silva and Fonseca[16], the formation of social protection systems originates in the needs of societies to prevent or reduce the impact of certain risks on individuals or social groups. Such risks arise from certain vicissitudes of social life, such as old age, childhood, illness, disability, deprivation, etc.

In this perspective, "the vital exercise of families is similar to the functions of public policies: both aim to account for the reproduction and social protection of the groups that are under their tutelage"[17], the difference is that one is effective in the private sphere and the other in the public sphere, in the field of the rights to social protection. But, as the author points out, if, in traditional and pre-capitalist societies, the family occupied these functions almost exclusively, in contemporary societies they must be shared with the State.

Based on these considerations, the centrality of social protection policies can be seen as a fundamental resource to respond to social demands and, thus, make treatment effective. Social policies are here considered as the result of complex and contradictory relations established between the State and civil society in the context of the conflicts and class struggle that involve the process of production and reproduction of capitalism[18]. However, in recent years, social policies have been suffering from the lack of accountability on the part of the State and the regression in the gains obtained with the promulgation of the Constitution of 1988.

Materials and methods

This study was structured based on a qualitative perspective[19] from the analysis of official documents that present the social rights of people with cancer, such as: Laws, Decrees, Ordinances and Policies added to the literature on children and adolescents with cancer. The purpose of the analysis was to describe the documents related to the rights guarantee system of cancer patients and their relatives in Brazil. This design aimed to broaden the understanding of the demands in relation to the group studied. The research project was submitted to the evaluation and approved by the Ethics Committee of the National School of Public Health.

Based on the qualitative approach, the official documents allow to compare, from the content, the current guidelines and their possible gaps. It is a question of making possible through the analysis the realization of weights and modifications to the current interpretations on the subject. In the present documentary research, a closer approximation with reality is sought through the analysis of the documents collected, described and presented below, which, due to their intrinsic characteristics, promote a better knowledge of the organization and dynamics of the society in relation to the subject, allowing new interpretations of related events[20].

Data organization and analysis were performed in two stages. The first one consisted in the survey of the documents themselves whose characteristics met the following criteria: (1) relevance in explaining the social rights of the person with cancer (2) potential scope of the disclosure of information for managers, health professionals and society; (3) express the objective of protecting children and adolescents and the clear commitment to guarantee access to public services, especially health services. That is, the documents that make up the corpus of analysis are those that are related to the broader objective of making access possible and guarantee the maintenance of the oncological treatment of children and adolescents. In order to meet these criteria, INCA's open access virtual portal was used to identify and collect documents. In this portal, documents related to the social rights of the person with cancer and to the issue of social protection for children and adolescents with cancer, available until March 2016, were accessed in the section on patient and family guidelines. From this first screening were also rescued the legislation on the websites of the Federal Government and the State Government of Rio de Janeiro.

In the second stage, the organization and classification of the material was carried out in order to describe and comment on it critically. The collected material makes up a total of eight documents described in Chart 1. It was observed that the selected documents are largely of national scope. Only the legislations regarding gratuitousness in collective public transport are the responsibility of the governments of the states and municipalities.

Results and discussion

Among the regulations for the social protection of children and adolescents with cancer in Brazil, the National Policy for the Prevention and Control of Cancer (PNPCC) stands out. Since the 1930s a concern has been raised with the prevention and control of cancer, taking it as a public health problem. At that time, a broad-based national cancer-fighting policy was idealized, capable of guiding preventive and assistance actions on a large scale, correcting the tendency to prioritize individual therapeutic actions, as occurred in medical-hospital settings. The objective was to promote the early detection of cancer and allow access to a quality and equitable treatment throughout the national territory[21].

The PNPCC aims to "reduce the mortality and disability caused by this disease and also the possibility of reducing the incidence of some types of cancer, as well as contribute to the improvement of the quality of life of users with cancer." It also aims to promote multiprofessional care for diagnosed patients, offering compatible treatment at each level of attention and evolution of the disease, as well as offering timely treatment as close as possible to the person's home[22]. This policy recognizes cancer as a chronic disease, which requires comprehensive care, also highlights the importance of identifying and intervening on the determinants and conditions of cancer types through intersectoral actions that promote health and quality of life[22]. Thus, it goes through the various aspects addressed by the other documents presented here.

Chart 1. Documents intended to care for children and adolescents with cancer.

	Definition	Objective	Target Audience	Response offered
LOAS Law No. 8,742, of December 7, 1993. Provides for the organization of Social Assistance and provides other measures[8].	Social Assistance, citizen's right and the duty of the State, is Non-Contributory Social Security Policy, which provides social minimums, carried out through an integrated set of actions of public initiative and society, to guarantee the basic needs.	I- social protection, which aims to guarantee life, harm reduction and prevention of incidence of risks, especially: a) protection of the family, maternity, childhood, adolescence and old age; b) the protection to children and adolescents in need; c) the promotion of labor market integration; d) t he training and rehabilitation of people with disabilities and promoting their integration into community life; and e) the guarantee of 1 (one) minimum monthly benefit salary to the disabled person and the elderly who prove that they do not have the means to provide their own maintenance or have it provided by their family; II - socio-welfare surveillance, which aims to territorially analyze the protective capacity of families and in it the occurrence of vulnerabilities, threats, victimization and damages; III - the defense of rights, which aims to guarantee full access to rights in all socio-welfare provisions.	To the family, to maternity, to the child and the adolescent, to the elderly and to the disabled.	Universalization of social rights, in order to make the recipient of the assistance action reachable by other public policies. Granting the Continued Benefit. Granting of eventual benefits, in case of birth, death, situations of temporary vulnerability and public calamity. (It varies according to the states and municipalities).
Bolsa Família Program Law No. 10,836, of January 9, 2004. Creates the Bolsa Família Program and provides further[32].	Conditional income transfer program for families living in poverty and extreme poverty.	Goals: Promote access to the public services network, especially health, education and social assistance; Combat hunger and promote food and nutrition security; Stimulate the sustainable emancipation of families living in poverty and extreme poverty; Combating poverty; and Promote intersectoral approach, complementarity and synergy of the social actions of the government.	Families in poverty and extreme poverty, which have in their composition pregnant women, nursing mothers, children and / or adolescents.	Provides income to families living in poverty and extreme poverty.

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	Definition	Objective	Target Audience	Response offered
Withdraw FGTS Law No. 8,922 of July 25, 1994. Adds dispositions to art. 20 of Law No. 8,036, of May 11, 1990, to allow the movement of the linked account when the employee or any of its dependents is affected by malignant neoplasia[33].	Allows the movement of the linked account when the worker or any of their dependents is affected by malignant neoplasm.	Allows the movement in the worker's linked account in the FGTS.	The worker, which he or any of his dependents is stricken with malignant neoplasm.	It offers the possibility of the worker having another source of income when he he or any of his dependents is performing cancer treatment.
Intermunicipal pass Law No. 4510 of January 13, 2005. Provides for the exemption of the payment of fares in the intercity transportation services of passengers by buses of the State of Rio de Janeiro, for primary and secondary school students of the state public school system, for people with disabilities and carriers of chronic disease of mental or physical nature requiring continued treatment and whose interruption in treatment may be life-threatening, and provides further[35].	Provides for the exemption of the payment of fares in the intercity transportation services of passengers by buses of the State of Rio de Janeiro, for primary and secondary school students of the state public school system, for people with disabilities and carriers of chronic illness of physical or mental nature requiring continued treatment and whose interruption in treatment may be life-threatening, and other measures.	The exemption from the payment of fares in conventional intercity bus services by buses of the State of Rio de Janeiro, as well as in the collective waterways, rail and subway transports, which are not selective, under state administration, for primary and secondary school students in the state public network, for people with disabilities and for people with chronic physical and / or mental illness whose interruption in treatment may be life-threatening.	Primary and secondary school students in the state public network, people with disabilities and people with chronic illness.	Gratuity in collective public transportation for health treatment.

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The preparation and approval of the PNPCC can be considered a significant gain for the general population. However, the policy alone does not guarantee concrete conditions for its implementation. In the analysis of actions for promotion, prevention and early detection for the control of cervical cancer Carvalho[23] identified a mismatch between the PNPCC proposal and the implemented actions, concluding that this policy has not yet been implemented at the municipal level. The author also indicates the absence of scientific work on the PNPCC, therefore, a gap

Chart 1. Documents intended to care for children and adolescents with cancer.

	Definition	Objective	Target Audience	Response offered
Municipal Pass Law No. 3650, of September 21, 2001. Provides for the granting by the executive branch of a transportation pass to people with disabilities and chronic physical, mental or psychiatric illnesses, in the transportation administered and / or granted by the State Secretariat of Transport[36].	Concession by the executive branch of a transportation pass for people with disabilities and chronic physical, mental or psychiatric illnesses, in the transportation administered and / or granted by the State Secretariat of Transport.	Ensure that people with chronic physical or mental illnesses and disabilities who require continuous and / or daily treatment and whose interruption may lead to life-threatening and / or worsening of health status, as well as recognized difficulties of locomotion, and who need for their therapy or treatment the use of public passenger transport services to be exempt from the payment of the fares, by presenting the special pass for people with chronic diseases and disabilities.	People with chronic illness and disabilities.	Gratuity in the municipal public transport for the accomplishment of the health treatment.
CLT Decree-Law No. 5,452, of May 1, 1943 Approves the Consolidation of Labor Laws[27].	Regulates the individual and collective relations of work, provided for therein.	Its purpose is to regulate labor relations.	Workers with ties to the social security.	Does not guarantee dismissal of the worker to accompany the child in medical treatment.

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in the production of knowledge on the subject. It is added to this observation as to the limits of its comprehensiveness when pondering the reflexes of this incapacitating disease in the familiar instance as an object also little contemplated in the production of knowledge on the subject.

One of the first and main impacts of child and adolescent cancer treatment on the family is the loss or decrease in family income, since in most cases a parent or guardian is forced to leave work to follow the child's treatment. Most serious situation in cases where the provider is also the sole responsible for the child or adolescent. Studies indicate that the cancer illness of one of the children, with the reorganization of daily life, can lead to a breakdown of the employment relationship and compromise the family income[24] due to the difficulty in reconciling the activities of care and work. Prolonged residence of the caregiver often leads to a decrease in family income, making it difficult for the whole family to reproduce socially, as well as maintaining patient care[25]. In a study, on caregivers / relatives of children with cancer, Beck and Lopes[26], found work loss in all those in work activity when the child fell ill and all said that it is very difficult to reconcile care and work activities.

Regarding the family demand for income, it is important to highlight that, as shown in Chart 1, the Consolidation of Labor Laws (CLT)[27] guarantees only the worker's remoteness due to illness (Article 473 of the CLT), and does not extend to a person in the family who is ill. Public servants differently, but with limitations, are entitled to paid leave to accompany a sick child for a certain period followed by unpaid leave[28] (Law nº 8,112 / 90 - Chapter - Licenses - Legal Regime of Civil Servants of the Union, of the Autarchies and of the Federal Public Foundations).

Therefore, faced with the precariousness of the working and living conditions of the population, it is paradoxical, in the context of health

Chart 1. Documents intended to care for children and adolescents with cancer.

	Definition	**Objective**	**Target Audience**	**Response offered**
National Policy for the Prevention and Control of Cancer Ordinance No. 874, of May 16, 2013 Establishes the National Policy for the Prevention and Control of Cancer in the Health Care Network of People with Chronic Diseases within the Unified Health System (SUS)[22]	It is the National Policy for the Prevention and Control of Cancer in the Health Care Network of People with Chronic Diseases within the Unified Health System (SUS).	Reduce the mortality and disability caused by this disease and also the possibility of reducing the incidence of some types of cancer, as well as contribute to the improvement of the quality of life of users with cancer, through actions of promotion, prevention, early detection, timely treatment and palliative care. Identify and intervene on the determinant and conditioning factors of cancer types and oriented to the development of intersectoral actions of public and civil society responsibility that promote health and quality of life. Eliminate, reduce and control physical, chemical and biological risk factors and intervention on its socioeconomic determinants, as well as integrating actions of early detection of cancer.	It is intended for the whole population.	Promote timely and safe treatment of patients diagnosed with cancer and precursor lesions as closely as possible to the person's home; Multiprofessional care for all users with cancer, offering compatible care at each level of attention and evolution of the disease; Realization of treatment of rare or very rare cases that require a high level of specialization and greater technological importance in national reference health establishments; and Rehabilitation and palliative care offer.
OHT Odinance / SAS / Nº 055 of February 24, 1999. It deals with the routine of Out-of-Home Treatment in the Unified Health System - SUS, with inclusion of the specific procedures in the SIA / SUS Outpatient Information System procedures table and other measures[34].	It is the legal instrument that enables the referral of patients with non-treatable diseases in their municipality / state of origin to other municipalities / states that perform the necessary treatment. OHT may be inter-municipal or interstate.	It aims to guarantee the access of patients from one municipality / state to care services of another municipality / state. Carry out the expenses related to transportation, daily food and lodging for the patient and companion. Is responsible for expenses in case of death of the patient.	All people who need to move from their municipality / state of origin to carry out health treatment in another municipality / state.	The OHT will cover expenses related to air, land and inland waterway transportation; daily for food and overnight for patient and companion, and must be authorized according to the budget availability of the municipality / state. In case of death of the user in Out-of-Home Treatment, the State/ Municipality Secretariat of Health of origin shall be responsible for the expenses incurred.

care, the demand for continuous follow-up of a caregiver during the child and adolescent cancer treatment. This is because there is no endorsement of labor legislation that guarantees the maintenance of the job or the income of the person in charge. That is, in comparative terms, there is by the Statute of the Child and Adolescent (ECA)[29], the guarantee / need for follow-up by those responsible for the children or adolescents in health care, but there is no provision in the Consolidation of Labor Laws (CLT) for social security or work benefits for such caregivers responsible for this responsibility.

It is also necessary to consider the parents or guardians who carry out informal labor activities, that is, without any labor or social security bond. For them, the societal transformations of the last decades have intensified social inequalities, subjecting a large contingent of workers to dependence on social assistance to ensure their survival and that of their families[30] and excluding another large share of these benefits.

The omission of policies regarding caregivers / family members who need to leave the job in favor of child or adolescent cancer care represents one of the limits of the Brazilian social protection system. The alternative that presents itself to those situations where the relative needs to leave the job to follow the treatment of the sick child or in cases where the parents are unemployed is to access the Social Assistance Policy through the Continuous Provision Benefit (BPC) and / or the *Bolsa Família* Program (PBF). The Organic Law of Social Assistance provides for the granting of the Continuous Provision Benefit (BPC)[8], which is the transfer of income destined to the elderly or people with disabilities, incorporating people with serious genetic, chronic and infectious diseases whose family income per capita is less than ¼ of minimum wage. The transfer amount is a monthly minimum wage. Such transfer is independent of contributions to the social security system and is not conditional on the fulfillment of counterparts.

The possibility of the user in cancer treatment requesting such benefit occurs effectively with the amendment of LOAS by Law 13.146 / 2015. From this amendment, it was considered a person with a disability *Those who have long-term physical, mental, intellectual or sensorial impediments which, in interaction with various barriers, may obstruct their full and effective participation in society on an equal basis with other people*[31]. The BPC guarantee for low-income or non-income families whose child or adolescent is undergoing oncological treatment is essential, as they are consumed by the treatment process, without income and without working conditions, and are in a state of social insecurity. However, the BPC has selectivity criteria that must be met to grant the benefit. The main one is per capita family income that can not exceed ¼ of the minimum wage. It is also necessary to undergo social and clinical evaluation performed by technicians of the National Institute of Social Security (INSS). These circumstances expose users, according to Silva et al.[13], to situations of uncertainty regarding the guarantee of the benefit and the maintenance of the income itself.

Also in relation to meeting the demand for income, we highlight Law 10,836 of January 9, 2004, which governs the *Bolsa Família* Program (PBF) and the FGTS withdrawal. As for the former, this is the largest income transfer program currently in the country, assuming centrality in the Brazilian Social Protection System. The PBF "is aimed at the population that lives in a situation of fragility due to poverty, lack of income, precarious or null access to public services or weakening of affective bonds[32]". However, the families served by the PBF must comply with basic requirements, such as: participating in actions to monitor the health and nutritional status of the children, enroll and follow the school attendance of children and adolescents in elementary education and participate in the socio-educational activities offered by Reference Centers for Social Assistance (CRAS). PBF was included because of its significance for the subsistence of the families of children and adolescents with cancer, from the point of view of those who assist in the service users.

It should be noted that both the BPC and the PBF are intended for families in situations of vulnerability, with per capita income as the main criterion. It is important to point out that focused and selective social programs, with restricted and inflexible criteria, tend to limit users' access to the benefits and services of this policy. In this way, they exclude portions of the population that, even though they are in a situation of vulnerability, do not meet the established criteria[13].

In relation to the second, it is legislation that guarantees the withdrawal of the FGTS for the worker whose dependent has cancer[33]. The withdrawal from the FGTS is the possibility of obtaining extra income, at a time when family expenses are rising. However, we must consider that it is a punctual income and the possibility of access only exists for people who at some point worked with social security bond.

As far as the treatment is concerned, there is another crucial demand related to the necessary travelling from the home to the health unit. For this situation was created Ordinance / SAS / No. 055 of February 24, 1999, which deals with the routine of Out-of-Home Treatment (TFD) in the Unified Health System (SUS). It facilitates the referral of patients with non-treatable diseases in their municipality / state of origin to other municipalities / states that perform the required treatment. It is a way of guaranteeing the patient's access to the necessary treatment, even when it does not exist in his municipality or state[34]. TFD finances transportation, lodging and food expenses. However, this ordinance emphasizes that municipalities and states will pay for the above-mentioned expenditures according to budget availability, which may lead to the non-implementation of this right.

It should also be noted, as shown in the data presented, the Laws concerning gratuitousness in collective public transport of the municipal and intermunicipal network[35,36], which together with the TFD, aim to ensure patient access to the health facility which performs treatment. However, gratuity in collective public transport also has some limits, they do not fit all types of buses; has a number of pre-determined tickets per month; and, the process for its concession is delayed. And, there are still cases of patients who do not have clinical conditions to use public transportation, making their access to the health unit an issue to be resolved within the family and community.

In a study, Maldaner et al.[37] stresses that the distance between the residence and the health unit has a financial burden on the family, which can contribute to the discontinuity or interruption of treatment.

Finally, it is considered that social protection policies have not been able to meet the demands imposed by cancer treatment, which, in addition to those already mentioned, we can highlight: adequate housing and basic sanitation; hygiene conditions - sewage system and drinking water; healthy eating; accessibility; access to social goods and services[13].

Final considerations

As presented in this article, oncological treatment for children and adolescents generates a number of demands, such as: reorganization of the family routine to accompany the child or adolescent, alteration of the work situation of those responsible, the need to maintain family income, travelling to the health unit, among others. These are complex questions that go beyond the scope of this work. The survey of Laws, Decrees, Ordinances and Policies added to the literature on children and adolescents with cancer highlighted aspects related to the demand for income and displacement.

PNPCC can undoubtedly be considered a breakthrough for the control and prevention of cancer, however, as a recent policy, it finds barriers in its implementation in the current context of public health in Brazil. It is also clear that the distance between written policy and the realization of the guarantee of the right to those who should actually benefit from it.

In relation to the demand for accompaniment of the child or adolescent, public employees are guaranteed by law to accompany their sick children, even for a limited time. The other workers, who perform formal or informal work activities, have no guarantee of maintaining their jobs or their income during the period of treatment of their children, which stands out as an important limit of the current Brazilian social protection policy.

Regarding BPC, great advances were made, such as the expansion of the concept of disability, changes in the concept of family and evaluation mechanisms, which included social evaluation beyond medical examinations. These provided greater access to benefit for cancer patients. However, some challenges are presented, such as: the granting of the benefit according to the per capita income, as the main criterion, limited to a very low value and the granting of the benefit that still very much depends on the evaluation criteria used by the medical expert. For these reasons, although this is one of the main social protection policies, its scope is still small.

Still in relation to income, the creation of the PBF meant an advance in the scope of the Brazilian System of Social Protection, as a mechanism to combat poverty in the country, characterizing itself as the only source of income for many families. However, it is focused on the poor and extremely poor population, with the main criterion of access being per capita income, which demonstrates its restrictive nature. It should also be noted that one of the counterparts for receiving the benefit is school attendance, which may be compromised due to the treatment of children and adolescents. Therefore, families that were included in the program before the child's illness can be excluded from the program due to non-compliance with this criterion.

Regarding the legislation that guarantees transportation for the movement of the patient from his home to the health unit, both TFD and gratuitousness in public transportation constitute important mechanisms to guarantee the treatment of children and adolescents, but both have significant limits. In the case of TFD, the legislation defines that the actions of states and municipalities in this area will depend on budget availability, leaving loopholes for the non execution or partial execution of what is recommended in the Ordinance. In relation to free public transportation, the approval of this right has been delayed, restricted to some types of vehicle and has a reduced number of passages, compromising the patient's access to the health unit.

It can be seen that the current Brazilian social protection system is an important instrument for ensuring the treatment of children and adolescents. However, in view of the magnitude of the cancer situation in Brazil, there is now demand for more comprehensive public policies and with less inflexible criteria that allow the necessary conditions for treatment and care to be carried out.

Based on the collected material, it should be reiterated that this study is restricted to the issue of cancer-related social protection among children and adolescents and its impact on family relationships from a specific set of official documents chosen using the criteria presented. Although it has been considered a relevant dimension of the problem, it is not reduced to this, because it is a complex and multifaceted phenomenon. It was not the purpose of the study, for example, to contemplate a discussion of the interfaces and interrelations between social demands and health demands in the broader scope of public health policies in Brazil, which could be considered here as a limit of the study. However, it is important to highlight the urgent need to expand public policies that support these families, allowing them full access to health, understanding that the guarantee of social and financial support are essential factors for the promotion of health. The studies on the child and adolescent population in oncological treatment demand the aggregation of knowledge, which has as the north the integral attention, involving patients and family. Thus, it is necessary to deepen the knowledge about the demands presented, in their singular and collective character, and the social protection destined to this part of the population, aiming at the improvement of the quality of the oncological assistance.

Finally, it is necessary to draw the attention of health professionals, civil society and public authorities to the collective issues of child and adolescent cancer, which are beyond the biological and psychological aspects addressed as inherent to the disease in this social group. These are fundamental issues related to social rights that have a profound impact on the life of the patient and his family as we intend to indicate and contribute to the debate. In addition, this study can contribute to a greater visibility of official documents available as an auxiliary tool in the approach of professionals dedicated to health care.

Collaborations

IM Huesca participated in the design of the study, analysis and interpretation of the data and writing of the article. EP Vargas and MM Cruz contributed to the writing of the article, carried out their critical review, approved the final version of the manuscript and assumed responsibility for all aspects of the work.

References

1. Kohlsdorf M, Costa Júnior AL. Cuidadores de crianças com leucemia: exigências do tratamento e aprendizagem de novos comportamentos. *Rev. Estudos de Psicologia* 2011; 16(3):227-234.
2. Sarti CA. A família como ordem simbólica. *Psicologia USP* 2004; 15(3):11-28.
3. Amiralian MLT, Pinto EB, Ghirardi Maria IG, Lichtig I, Masini EFS, Pasqualin L. Conceituando deficiência. *Rev Saude Publica* 2000; 34(1):97-103.
4. Senna MCM, Lobato LVC, Andrade LD. Proteção Social à Pessoa com Deficiência no Brasil Pós-Constituinte. *Rev SER Social* 2013; 15(32):11-33.
5. Diniz D, Barbosa L, Santos WR. Deficiência, Direitos Humanos e Justiça. *Sur, Rev. int. direitos human.* 2009; 6(11):65-77.
6. Diniz D. *O que é deficiência*. São Paulo: Brasiliense; 2007.
7. Diniz D, Squinca F, Medeiros M. Qual deficiência? perícia médica e assistência social no Brasil. *Cad Saude Publica* 2007; 23(11):2589-2596.
8. Brasil. Lei nº 8.742, de 7 de dezembro de 1993. Dispõe sobre a organização da Assistência Social e dá outras providências. Diário Oficial da União 1993; 8 dez.
9. Campos O. O estudo da demanda e das necessidades e sua importância para o planejamento de saúde. *Rev. Saúde Públ.* 1969; 3(1):79-81.
10. Instituto Nacional de Câncer (INCA). *Estimativas da Incidência de Câncer no Brasil. Estimativas 2016*. Rio de Janeiro: INCA; 2016.
11. Instituto Nacional de Câncer (INCA). *Diagnóstico Precoce do Câncer na Criança e no Adolescente*. Rio de Janeiro: INCA, Instituto Ronald McDonald; 2009.
12. Monteiro MVC, Pimentel MG. Câncer infanto-juvenil – Reflexões acerca da Intervenção do Serviço Social. In: Figueiredo EMA, Ferreira A, Monteiro M, organizadores. *Tratado de Oncologia*. Rio de Janeiro: Revinter; 2013. p. 1795-1886.
13. Silva RF, Chaves ARM, Monteiro MVC. Os limites da política de seguridade social brasileira frente às demandas dos usuários com leucemia aguda: reflexões do serviço social. *Rev. Vértices* 2013; 15(1):149-164.
14. Carvalho CSU. A necessária atenção à família do paciente oncológico. *Revista Brasileira de Cancerologia* 2008; 54(1):97-102.
15. Canesqui AM. *Estudos antropológicos sobre os adoecidos crônicos*. São Paulo: Hucitec, Fapesp; 2007.
16. Silva RR, Fonseca TMA. Proteção social: notas críticas sobre a interface entre Estado e família na contemporaneidade. In: *Anais da III Jornada Internacional em Políticas Públicas Questão Social e Desenvolvimento no Século XXI*; 2007; São Luís, Maranhão.
17. Carvalho MCB. Famílias e políticas públicas. In: Acosta AR, Vitale MAS, organizadores. *Família: redes, laços e políticas públicas*. São Paulo: Cortez, PUC-SP; 2005. p. 267-274.
18. Behring ER, Boschetti I. *Política Social: fundamentos e história*. 6ª ed. São Paulo: Cortez; 2009.
19. Victora CG, Knauth DR, Hassen MNA. *Pesquisa Qualitativa em Saúde: uma introdução ao tema*. Porto Alegre: Tomo Editorial; 2000.
20. Silva LRC, Damaceno AD, Martins MCR, Sobral KM, Farias IMS. Pesquisa documental: alternativa investigativa na formação docente. *IX Congresso Nacional de Educação – EDUCERE III Encontro Sul Brasileiro de Psicopedagogia*, PUC Paraná, 2009, 4554-4566.
21. Kligerman J. Fundamentos para uma Política Nacional de Prevenção e Controle do Câncer. *Revista Brasileira de Cancerologia* 2002; 48(1):3-7.
22. Brasil. Portaria nº 874, de 16 de maio de 2013. Institui a Política Nacional para a Prevenção e Controle do Câncer na Rede de Atenção à Saúde das Pessoas com Doenças Crônicas no Âmbito do Sistema Único de Saúde (SUS). Diário Oficial da União 2013; 17 maio.
23. Carvalho DL. *A organização dos serviços de atenção ao controle do câncer de colo do útero a partir da atenção primária à saúde: um estudo no município do Rio de Janeiro – RJ* [dissertação]. Niterói: Universidade Federal Fluminense; 2015.
24. Santo EARE, Gaiva MAM, Espinosa MM, Barbosa DA, Belasco AGS. Cuidando da criança com câncer: avaliação da sobrecarga e qualidade de vida dos cuidadores. *Rev. Latino Am. Enfermagem* 2011; 19(3):515-522.
25. Santos MCB, Silva LB, Estalino ES. Processo de Trabalho do Serviço Social no Campo da Oncologia: notas para reflexão. In: Senna MCM, Zucco LP, Lima ABR, organizadores. *Serviço Social na Saúde Coletiva: reflexões e práticas*. Rio de Janeiro: Garamond; 2012. p. 251-272.
26. Beck ARM, Lopes MHBM. Cuidadores de crianças com câncer: aspectos da vida afetados pela atividade de cuidador. *Rev. Bras. Enferm.* 2007; 60(6):670-675.
27. Brasil. Decreto-Lei nº 5.452, de 1º de maio de 1943. Aprova a Consolidação das Leis do Trabalho. *Diário Oficial da União* 1943; 9 ago.
28. Brasil. Lei nº 8.112, de 11 de dezembro de 1990. Dispõe sobre o regime jurídico dos servidores públicos civis da União, das autarquias e das fundações públicas federais. *Diário Oficial da União* 1991; 19 abr.
29. Brasil. Lei Nº 8.069, de 13 de Julho de 1990. Dispõe sobre o Estatuto da Criança e do Adolescente e dá outras providências. *Diário Oficial da União* 1990; 13 jul.
30. Batista LS, Nogueira ACC. Serviço Social e Oncologia: algumas considerações sobre determinantes sociais do adoecimento. In: *Anais do XX Seminário Latinoamericano de Escuelas e Trabajo Social*; 2012; Córdoba.
31. Brasil. Lei nº 13.146, de 6 de julho de 2015. Institui a Lei Brasileira de Inclusão da Pessoa com Deficiência (Estatuto da Pessoa com Deficiência). *Diário Oficial da União* 2015; 7 jul.
32. Brasil. Lei nº 10.836, de 9 de janeiro de 2004. Cria o Programa Bolsa Família e dá outras providências. *Diário Oficial da União* 2004; 12 jan.
33. Brasil. Lei nº 8.922, de 25 de julho de 1994. Acrescenta dispositivo ao art. 20 da Lei nº 8.036, de 11 de maio de 1990, para permitir a movimentação da conta vinculada quando o trabalhador ou qualquer de seus dependentes for acometido de neoplasia maligna. *Diário Oficial da União* 1994; 26 jul.

34. Brasil. Portaria/SAS/nº 055, de 24 de fevereiro de 1999. Dispõe sobre a rotina do Tratamento Fora de Domicílio no Sistema Único de Saúde – SUS, com inclusão dos procedimentos específicos na tabela de procedimentos do Sistema de Informações Ambulatoriais do SAI/SUS e dá outras providências. 1999 fevereiro. *Diário Oficial da União* 1999; 25 fev.
35. Rio de Janeiro. Lei nº 4510, de 13 de janeiro de 2005. Dispõe sobre a isenção do pagamento de tarifas nos serviços de transporte intermunicipal de passageiros por ônibus do estado do rio de janeiro, para alunos do ensino fundamental e médio da rede pública estadual de ensino, para as pessoas portadoras de deficiência e portadoras de doença crônica de natureza física ou mental que exijam tratamento continuado e cuja interrupção no tratamento possa acarretar risco de vida, e dá outras providências. *Diário Oficial* 2005; 22 mar.
36. Rio de Janeiro. Lei nº 3.650, de 21 de setembro de 2001. Dispõe sobre a concessão pelo poder executivo de passe de transporte aos portadores de deficiência e de doenças crônicas de natureza física, mental ou psiquiátrica, nos transportes administrados e/ou concedidos pela secretaria de estado de transportes. *Diário Oficial* 2001; 24 set.
37. Maldaner CR, Beuter M, Brondani CM, Budó MLD, Pauletto MR. Fatores que influenciam a adesão ao tratamento na doença crônica: o doente em terapia hemodialítica. *Rev Gaúcha Enferm* 2008; 29(4):647-653.

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