RIGHT TO HEALTH: A STUDY OF THE CHALLENGES FACED IN HEMATOPOIETIC STEM CELL TRANSPLANTATION

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ABSTRACT

This article has as its object the challenges faced by SUS users in accessing Hematopoietic Stem Cell Transplantation HSCT in the interface with the social issue. The theoretical concepts researched were: Social Issue, Health Policy and Access. Dialectical historical materialism was adopted as a method, and as for the methodological path, it is a qualitative research, using some quantitative data; covering bibliographic research – about the conceptual categories; Documentary research (in Laws, decrees, among others); and the Field Research, with SUS users who underwent HSCT as participants. The inferences of this study indicate the challenges experienced by the participants in the search for the right to access health in an integral way in its interface with the social issue. In this sense, the construction of public health policies must be based on the reality and needs of the subjects who use it, built from processes of struggles and mobilizations that reiterate the forms of collective confrontation expressed in the social issue, having as a guiding thread the realization of the rights to health.

Keywords: Access. Health. TCTH. Social Question.

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INTRODUCTION

This article is the result of concerns that were established in the daily experience as a resident, Social Worker, in the Multiprofessional Residency Program in health, Hematology and Hemotherapy axis of concentration, at Hospital das Clínicas HC-UFG/EBSERH[3] in the years 2017 to 2019.

In this scenario, users of the HC-UFG/EBSERH are referred to the Institute of Cardiology of the Federal District (ICDF), located in Brasília-DF, to perform the Transplant procedure[4] - Hematopoietic trunk cells (TCTH)[5]. Considering the daily experience of care at the hematology outpatient clinic, several social consultations were carried out with users and their families before referral for HSCT, thus, it was possible to mature some reflections about the object.

It is noteworthy that through social struggles in the 1990s that the population conquered the right to public health for all. In the past, health services in Brazil were based on the campaign and social security models. This time, the current health model was enacted in the Federal Constitution of 1988 and is configured as an important achievement of the population through the Unified Health System (SUS).

Transplantation is a highly complex procedure made available by the Unified Health System (SUS). Aiming to give materiality to its various principles such as integrality, equity, popular participation and universality. The SUS offers the population numerous health services and procedures at all levels of care.

Regarding its composition, the Unified Health System was organized according to levels of complexity, namely: low, medium and high complexity. With regard to low complexity, also called Primary Health Care (PHC), the following stand out: basic health units (UBS) or health centers and posts – characterized by simple services made available to the population (SORRENTINO, 1997). These constitute gateways to the SUS, being responsible for referrals when necessary to the other levels of health care.

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[3] The Hospital das Clínicas of the Federal University of Goiás (UFG), founded on February 23, 1962, is a University Hospital, a federal public institution that provides free care through the Unified Health System (SUS). Linked to UFG, in 2014 it started to be managed by the Brazilian Company of Hospital Services (EBSERH), which manages federal university hospitals throughout Brazil (information from the HC-UFG/EBSERH website, online, 2018).

[4] ICDF located in Brasília, until the first half of 2018, received these patients referred for transplantation as an "open door" without the need for regulation, being required as a conditionality, only that they went with the TFD open. The medical team referred the patient to the ICDF with the indication of HSCT and, after initial evaluation, the ICDF admitted and transplanted the patient. However, as of the second half of 2018, the ICDF team issued a statement that it would no longer receive patients with open doors, requiring the request for regulation, placed as a new requirement of the Health Department of the Federal District. The referral flow has not yet been reestablished, nor defined until the beginning of 2019.

[5] There are other transplant centers located in other states in Brazil that perform this type of transplantation, however, in this study, we chose to analyze only patients referred to the ICDF Brasília.

It is noteworthy that the medium complexity, or secondary level, is made up of specialized services that require more specific treatment resources. The high complexity or tertiary level, on the other hand, is characterized by a network that is more specialized in its complexity in serving the population. A hospital can aggregate the secondary and tertiary levels, as well as research and specific treatments, so-called quartenary level – inserted in high complexity (GONÇALVES, 2006).

These last two levels of complexity are inserted in the HC-UFG/EBSERH of Goiânia-GO, a public university hospital, serving 100% SUS. Regarding the particularity of this study, this hospital is a state reference in treatment in the specialty of Hematology (a specialty that deals with diseases related to blood cells), but the unit does not have a transplant service, which requires referral, when necessary, to other units.

The transplantation of organs and tissues is a right to health regulated in the SUS through Law No. 9,434, of February 4, 1997, which "Provides for the removal of organs, tissues and parts of the human body for the purposes of transplantation and treatment and provides for other provisions" (BRASIL, 1997).

With regard to human tissue transplantation, as is the case with HSCT, they are classified as autologous (when the progenitor cells come from the patient himself); allogeneic (when the progenitor cells come from a compatible donor. The latter, for the most part, are family members or donors registered in the bone marrow banks REDOME – National Registry of Bone Marrow Donors), and finally there is syngeneic transplantation (a characteristic of transplantation in which the donated cells come from an identical twin brother) (PASQUINI AND COUTINHO, 2013, p.711).

According to the official website of the Institute of Cardiology of the Federal District (ICDF), the implementation of this procedure in the institution is very recent, it began in 2013 as accreditation for autologous HSCT and later in 2014 the allogeneic HSCT was implemented. Since the implementation of this procedure at the ICDF, the Hospital das Clínicas de Goiânia HC-UFG/EBSERH has referred SUS users for transplantation at this institution.

It is worth mentioning that HSCT is considered a complex procedure,

> [...] aims to graft the Hematopoietic Stem Cell (HSC) with the aim of correcting a quantitative or qualitative bone marrow defect. In the last 30 years, HSCT has been used in the treatment of malignant and non-malignant hematological diseases, immunodeficiencies, inborn errors of metabolism, solid tumors, as well as autoimmune diseases [...] HSC may originate from bone marrow, peripheral blood or umbilical cord blood (PASQUINI AND COUTINHO, 2013, p.711).

However, not all patients undergo HSCT. The indication is only made when other therapies do not present satisfactory responses, so bone marrow transplantation is usually the last alternative for successful treatment. The need for its performance according to (PASQUINI AND COUTINHO, 2013) "is based on the superiority of this therapy over the others available, taking into account the age of the patient and the donor, basic disease, clinical stage, previous complications and those present in the pre-transplant phase".

Goiânia has a transplant unit that serves the SUS, located at the Araújo Jorge Hospital (HAJ). There is a service in the unit for HSCT and a team serving in this specialty, the physical space has four individual wards, in this sense the HAJ prioritizes HSCT beds for patients who have already been monitored and treated at the HAJ. The unit receives patients referred by the network via regulation, but considering the low turnover of beds – due to the characteristics of the transplant that require longer hospitalization time – the wait in line for patients from other hospitals can take a considerable time; characteristics that lead the HC medical team to resort to other services that also perform HSCT, in the specific case to be analyzed, the ICDF.

When HC users are referred to Brasília, they undergo several consultations with the ICDF multiprofessional team, with a view to evaluating the conditions for transplantation. It is noted that there are patients who do not have stable levels in the exams and in the general evaluation, being considered unfit for transplantation, temporarily or permanently.

Contemporaneous with this process, there is a significant number of users who, even presenting clinical conditions for transplantation, fail to undergo the transplant for reasons external to the disease, which are related to the expressions of the social issue, such as: lack of a companion (family member, wife, friend, neighbor), etc.) who can go with the user; impediment to leave work; unfavorable socioeconomic conditions; among others.

In the guarantee of health rights, the Ministry of Health issued Ordinance 55/1999, constituting the so-called Out-of-Home Treatment.

The antinomies of this process denote that, if, on the one hand, the GT is expressed as a way of guaranteeing access to health in the SUS, providing financial assistance to the patient and his companion (when applicable), to cover expenses with food, accommodation and tickets when undergoing treatment outside their municipality of origin; on the other hand, the reality as a Social Worker/Resident, it is denoted that this is not enough to keep the patient in HSCT.

In this sense, the daily afflictions raised some concerns, here called problematization, namely: Are the actions offered by the public health policy, GT, enough to meet the needs of a patient who is going to undergo hematopoietic stem cell transplantation

(HSCT) in Brasília together with his companion? What are the expressions of the social issue present in the daily lives of these users and how are they presented in terms of access to treatment in a comprehensive way? What are the barriers to access and permanence faced by these patients and their companions to undergo HSCT?

These initial questions allowed us to outline the problem of this research, which is: What are the challenges faced by SUS users in accessing HSCT at the interface of the Social Question?

To this end, we will present below the methodological path taken and the discussion of the fundamental categories to support the analysis of the testimonies of the research participants who narrate their singular trajectories to perform HSCT at the ICDF.

METHODOLOGICAL PROCEDURES

In this study it is understood that the methodology expresses the systematization of the processes developed in the study that is proposed, describing both the method and the instruments used to carry it out. Thus, the research method that supported this work is dialectical historical materialism, emphasizing that "it does not result from sudden operations, genius intuitions or enlightened and momentary inspirations. Rather, it is the product of a long theoretical-scientific elaboration, matured in the course of successive approximations to its object" (NETTO, 2009, p.11).

In this way, this same author points out that the method is not a set of formal rules that "apply" to an object that has been cut out for a given investigation, nor, even less, a set of rules that the subject who researches chooses, according to his will, to "frame" his object of investigation (NETTO, 2009, p.25). The choices and rules for conducting a research are built according to the reality that one wishes to investigate, without a ready-made and finished method, in a rigid way, it is possible to build methodological paths according to each occasion. Also according to this author,

> The research method that provides theoretical knowledge, starting from appearance, aims to reach the essence of the object. Reaching the essence of the object, that is: capturing its structure and dynamics, by means of analytical procedures and operating its synthesis, the researcher reproduces it on the plane of thought; Through research, made possible by the method, the researcher reproduces, in the ideal plan, the essence of the object he investigated (p.8).

By taking into account the guiding question presented at the end of the Introduction of this work, it delimited as the object of the research, the challenges faced by SUS users in accessing HSCT in the interface with the social issue.

This initial process allowed the elaboration of the common thread, that is: the challenges faced by SUS users indicated to HSCT go beyond transplantation, which hinders and weakens the right to access expressed in laws, decrees, ordinances and regulations.

The general objective, then proposed, was to identify and analyze the challenges faced by SUS users in accessing Hematopoietic Stem Cell Transplantation (HSCT) when referred to the Institute of Cardiology of the Federal District (ICDF), in view of the interfaces of the social issue.

The specific objectives were: To know the main barriers related to the expressions of the social issue in access to HSCT; To identify how patients who go to the ICDF for HSCT access and permanence take place; To analyze the processuality in the access to health of patients of Hematopoietic Stem Cell Transplantation (HSCT) as a health right**.**

In order to approach the object as a qualitative research; the latter understands movement as a constituent part of the reality that surrounds it, full of contradictions; encompassing the construction of three inseparable researches, namely: bibliographic research, documentary research and field research.

Regarding the bibliographic research, it was constituted from the conceptual categories, which are: Social Issue, Health Policy and Access. This theoretical framework guided the survey of the academic-scientific production of Theses, Dissertations, articles, as well as other bibliographic sources and existing websites on the subject.

To carry out the documentary research, primary and secondary sources were used, through Laws, Decrees, official documents, statistical sources, among others.

Regarding the field research, it considered the path to reach the essence of the object, delimiting as the *locus* of the field research the Hematology Outpatient Clinic of the Hospital das Clínicas de Goiânia HC-UFG/EBSERH, identifying as participants the patients of this Outpatient Clinic who underwent Hematopoietic Stem Cell Transplantation.

Data were collected between November and December 2018, using semi-structured interviews with a guiding script and the participant's consent signed in the informed consent. The interview was recorded by audio device and later transcribed for analysis.

In the universe of about 25 patients[6] referred for transplantation in the years 2017-2018, a sample of four (04) patients, randomly chosen, in post HSCT, in which

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[6] An estimated value of 25 patients with indication for HSCT during the period delimited as a criterion of the research is mentioned. The value is not exact because there is no systematization of records, tables or annual/semiannual surveys of the HC Hematology Service that account for the total universe of users referred for transplantation in this period, except for the records made in individual physical records. This estimate was made based on the considerations of a professional who works at this outpatient clinic.

transplantation was used as therapy to treat oncohematological diseases (Leukemias, lymphomas, Multiple Myeloma, bone marrow aplasia), of this universe, 02 female subjects and 02 male subjects were interviewed.

The inclusion criteria were for patients over 18 years of age, attended by the Hematology outpatient clinic of the HC with hematological oncological diseases and have already successfully passed the HSCT stage, at the ICDF, in a period of time between three (03) months and one year (01) after transplantation, between (2017-2018).

The exclusion criteria were: not being hematological cancer patients, being minors, having had a transplant more than one year and less than 02 months, having undergone the transplant in a unit other than the ICDF.

In this article presented here, it strictly followed all the ethical steps of the research based on Resolutions 466/12 and 510/16, being submitted and approved by the Ethics Committee of this Hospital in September 2018 under opinion No. 2,873,076, using its own resources to carry it out.

DISCUSSION

SOCIAL ISSUE AND HEALTH POLICY

In this item, we sought to bring the results of the research, together with its analysis, from the a priori conceptual categories, such as: social issue and poverty, health policy and access to health.

This organicity was defined considering the relationship that the social issue establishes with public policies, in which social policy is established as a set of actions that arises through the intervention of the State in capitalist society, as a way of confronting the class struggle, as a confrontation of the social issue, among these policies, the health policy stands out, focus of our discussion.

The starting point that we originated to understand social reality is established in the capitalist society that produces inequalities, which are related to the exploitation of workers, and the responses engendered by social classes and their segments; in its concrete relationship expressed by the process of accumulation of capital, produced and reproduced with the operation of the law of value, whose counterpart is the subsumption of labor by capital (BEHRING; BOSCHETTI, 2006).

In this sense, the class that does not own the means of production, in order to maintain its basic needs, sells its labor power to the capitalists, so that "the worker is deprived of the product of his surplus labor (surplus value); this characterizes a relationship of exploitation: the private appropriation by capital of the surplus value produced by the worker" (MONTAÑO, 2011, p.79).

The exploitation of the worker by the capitalist system does not guarantee an equivalent distribution of income over those products or commodities produced by it. In this sense, it is possible to apprehend that the relationship between capital and labor established in capitalist society is the founding arena of the disparities between the social classes that live from work and those that own the means of production. This relationship establishes a perverse configuration between profit, wealth and power, as opposed to poverty, misery and subordination.

It is in the establishment of these causal links that the social question is established, expressing,

> the set of expressions of the inequalities of mature capitalist society, which has a common root: social production is increasingly collective, work becomes more broadly social, while the appropriation of its fruits remains private, monopolized by a part of society" (IAMAMOTO, 2015, p. 27).

Thus, for this same author, the analysis of the Social Question is inseparable from the configurations assumed by work and is necessarily situated in an arena of disputes between societal projects, informed by different class interests, about conceptions and proposals for the conduct of economic and social policies (IAMAMOTO, 2004, p.10).

To this end, it is important to reiterate that the contradictions arising from the relationship between Labor and Capital that the social issue is established in the daily life of these subjects who live from work where inequalities will be more latent; established in the face of the components of resistance and rupture, therefore, impregnated by the class struggle.

Even disjointed or punctual, these ways of confronting the social issue are fought by the working class "being inequality, it is also rebellion, as it involves subjects who experience inequalities and resist and oppose them" (IAMAMOTO, 2015, p.28). This condition of conflict does not exclude subjects from conditions of poverty and vulnerability[7] – one of the main expressions manifested in the daily lives of subjects who live from work.

Poverty here is defined as "the face of the discarding of cheap labor, which is part of capitalist expansion." An expansion in which work, the source of social wealth, undergoes devastating effects of the changes that have been occurring in the accumulation process,

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[7] Vulnerability here understood as "the production of inequality is inherent to the capitalist system, by (re)producing it, it produces and reproduces vulnerabilities and social risks" (Silva; Yazbek and Giovanni, 2011, p. 50).

with the productive restructuring and the "financialization" of capital (YAZBEK, 2012, p. 293).

The consequences arising from capitalist reproduction do not leave many possibilities for those who make up a reserve army, other than "a universe marked by subordination, silent revolt, humiliation and fatigue, [...] by alienation and resistance and, above all, by strategies to better survive, despite everything" (YAZBEK, 2012, p.292).

Considering poverty and vulnerability as some expressions of the Social Question in the daily lives of the subjects, it is possible to verify that only in these conditions do the "sequelae of the social question [...] can become the object of continuous and systematic intervention by the State" (NETTO, 2011, p.29).

By bringing this fragment, the author refers to the intervention of the State in social ills through public policies, in which it executes such concessions "by seeking political legitimacy through the democratic game, it is permeable to the demands of the subaltern classes, which can make their interests and their immediate demands influence it" (NETTO, 2011).

Also according to this author, it is important to understand in this process the consensual role imprinted through social policy, in which "the bourgeois state in monopoly capitalism seeks to manage the expressions of the social question in order to meet the demands of the monopolistic order, conforming, through the adhesion it receives from categories and sectors whose demands it incorporates, variable consensus systems, but operative" (NETTO, 2011, p.30).

In this sense, social policies are constituted as developments to responses and forms of confrontation, even if in a sectorized and fragmented way, to the multifaceted expressions of the social question in capitalism.

Among these policies signaled in the relationship that is established in society between the forms of confrontation of the working class and the responses given within the State, the following stand out: making it necessary to briefly contextualize how it was instituted as a social right guaranteed in a constitutional text in Brazil.

HEALTH POLICY IN BRAZIL

Health policy in Brazil emerges as strategies of social protection pattern in the face of the unfolding of expressions of the social question at the beginning of the twentieth century, in the midst of the transition between the agro-export economy and the industrial urban economy, reflecting the advance of the division of labor, that is, the emergence of salaried labor (BRAGA; PAULA, 1986, p.41-42).

Assumed in the logic based on the absence of diseases, it has its features in public health with

> The Carlos Chagas reform, of 1923, *[which]* attempts to expand health care by the central power, constituting one of the Union's strategies to expand national power within the ongoing political crisis [...] During this period, the issues of hygiene and health of the worker were also raised, and some measures were taken that constituted the embryo of the Brazilian social security scheme, the most important being the creation of the Retirement and Pension Funds (CAPs) in 1923, known as the Elói Chaves law. The CAPs were financed by the Federal Government, the employing companies and the employees (BRAVO, 2009, p.90).

According to Bravo (2009) this was the first form of social security organization in Brazil and provided some "benefits" such as medical-curative assistance, medications, retirement for length of service, old age and disability, death pension for dependents and funeral assistance. It can be inferred in this process that the State was only responsible for limited campaigns in the face of epidemics. Social security, as in the case of CAPs, was responsible for medical care – intended only for people who contributed.

According to Braga and Paula (1986), the central alternatives sought for Health between the periods of 1930 and 1940 stand out: limited sanitary campaigns, with emphasis on actions for rural endemic areas; and from 1937 onwards, services to combat endemic diseases, such as yellow fever and malaria. Subsequently

> the health situation of the population in the period from 1945 to 1964 (with some variations identified mainly in the years 50, 56 and 63, when public health expenditures were more favorable, with an improvement in sanitary conditions), was not able to eliminate the situation of infectious and parasitic diseases and the high rates of morbidity and infant mortality, as well as general mortality (BRAVO, 2009, p.92).

These characteristics permeate the 1950s, with the creation of the Ministry of Health, and take on a more accentuated configuration with the precariousness and focus of services, in the period from 1974 to 1979. The national health policy faced a constant tension between the population and the services provided under the management of the dictatorial State – unfolding great clashes and struggles for the quality of health.

The consequences of the process corroborated the emergence of the so-called Health Reform Movement (MRS), whose banner of struggle had universal access to health care for the population as its centrality, with quality in the services provided, "managing to advance in the elaboration of proposals to strengthen the public sector in opposition to the model of privileging private producers" (BRAVO, 2009, p.203).

Thus, in the 1980s, health professionals and representatives of civil society, in the search for more effective solutions that would mitigate the problems arising from conjunctural and structural issues, constituted considerable advances for the health area and, therefore, in the lives of individuals, based on

> Conferences, seminars and mobilizations in São Paulo, dealing with the worsening of the health situation, especially preceding the 7th and 8th Health Conferences, advanced towards the proposal of a Unified Health System with popular participation and social control (FARIA; JATENE, 1995).

These mobilizations strengthened the agendas of the MRS, condensing them into the Health Reform Project, which had significant parts of its struggles expressed in the promulgation of the Federal Constitution, Social Security – guaranteed as a public policy of rights – composed of the policies of Social Assistance, Health and Social Security[8].

Thus, health in Brazil became a right of all and a duty of the State from the Federal Constitution of 1988, specifically in articles 196 to 200. The consequences of this process made it possible to build a hierarchically organized system, called the Unified Health System (SUS), regulated in the decade by the Organic Health Laws (LOS) No. 8,080/90 and No. 8,142 – both from 1990.

It is noted that these laws were fundamental in directing the operationalization of the health system, since they defined the principles and guidelines of the SUS, among them; universality, equity and integrality, participation and social control. It is worth highlighting the SUS guidelines based on Decentralization, with a single direction in each sphere of government; Comprehensive care, with priority for preventive activities, without prejudice to care services; Community participation (BRASIL, 1988).

In this period, the contradiction posed to social policies is also highlighted, resulting in disagreements with the SUS, since, contemporaneous with the achievements, there is a redirection of the role of the State, influenced by the neoliberal adjustment policy (BRAVO, 2009); bringing strong repercussions to the health policy proposal built on the principles of the Health Reform Project. These neoliberal adjustment policies have significantly reduced investments in health, falling back on different actions with a bias towards expanding privatization, stimulating private insurance, and focusing on serving vulnerable populations through the basic health package, focused on health merchandise (COSTA, 1997). This scenario refers to advances and setbacks that fall directly on the most vulnerable working class and that uses public health policy, weakening the rights achieved.

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[8] Through Social Security, Health and Social Assistance are instituted as a universal policy, but the latter will primarily serve those who need it (due to the absence of minimum social conditions for survival. Social Security, on the other hand, continues with its social security character, screening its insured by contribution criteria, linked to labor relations.

As already highlighted, the ways of facing inequality have been making advances and challenges faced within the scope of the SUS. The processuality of these rights gains materiality in the guarantee of access to quality treatment, subsidized by strategies – consolidated through policies, norms and other regulations – among them: the institution of the TFD (1999); the National Policy for Humanization in the SUS (2003); the Popular Pharmacy Program (2004); the Pact for Health (2006).

The antinomies denote that in the opposite direction of the conquered rights, neoliberal attacks on social policies unfold, with its most perverse onslaught the proposed Amendment to the Constitution No. 55, of 2016 – PEC of the ceiling on public spending, authored by the Federal Chamber of Deputies, voted and approved, becoming the fearful Constitutional Amendment No. 95, of December 15, 2016 – which we infer as one of the measures that most express the counter-reform of social policies in the perspective of the consolidation of the privatist project.

These measures consolidate the freeze on public spending by the Federal Government for 20 years, starting in 2018[9]. During this period, the resources allocated to public policies, such as health and education, tend to be the most harmed, causing incisive scrapping and dismantling of social achievements. According to Bravo *et. al.*

> With the advent of the Temer government, the acceleration and intensification of policies that contribute to the dismantling of the Brazilian State is flagrant, configuring a new phase of structural counter-reforms that attack workers' rights (BRAVO; PELAEZ; PINHEIRO, 2018, p.10).

These same authors reiterate that this picture of setbacks to Brazilian health policy is not recent in Brazil, is part of world politics and takes on different features in view of the Brazilian socio-historical particularities. Such configurations, in the current conjuncture, are thickened in the face of the conservative project assumed by the illegitimate government[10] , gaining materiality with a series of measures that go against the social rights to health, whose assumed exposure is demarcated by the privatist project, in which it has a focused character to serve vulnerable populations through the basic package for health, expansion of privatization, encouragement of private insurance, decentralization of services at the local level, elimination of the linkage of sources in relation to financing (2009, p.101).

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[9] For more information on these consequences see Bravo (2018).

[10] Temer assumed the presidency of the country after an impeachment suffered by the Dilma government, contrary to the principles of democracy that elected her. Undeniably, he represents the most reactionary, backward and conservative sectors of Brazilian society, allied with the bourgeoisie "[...] ultra-neoliberal, clearly pro-capital, which aims to solve the impasses of accumulation and favor the interests of the ruling class in the country and deepen its dependence on international capital" (BRAVO; PELAEZ; PINHEIRO, 2018, p. 12).

It is reiterated that such mismatches weaken and fragment the rights to health, including the population's access to the SUS.

RIGHT TO ACCESS TO HEALTH

Bringing the debate to the category of access within the scope of the SUS presupposes outlining the ways in which health is configured in people's daily lives. According to (FRANÇOIS, 2008) access to health is a right recognized by international organizations and by most countries. In Brazil, as already pointed out, the Federal Constitution of 1988 recognizes health as a fundamental right of the human being.

This same author also emphasizes that access to health, in addition to the proportionality between services and users, implies a dynamic relationship between the needs, aspirations and culture of the population, the demand for service and the resources available to satisfy it. Thus, "the institutional health system – Public and Private – has deficiencies that prevent care for all" (FRANÇOIS, 2008, p.140). Thus, this author explains the recommendation of the World Health Organization (WHO) that the meaning of "accessible" be adapted to each reality and each region,

> [...] this means thinking about the needs of the population not only in relation to existing institutional resources, but also in a localized way, in the communities (FRANÇOIS, 2008, p.140).

In this sense, access to health has several elements, not depending only on existing institutional resources, or on the mere provision of the service. "In Brazil, with its great distances and economic, population and distribution inequalities, the path between disease, care and cure means walking a long and difficult path" (FRANÇOIS, 2008); It is necessary to understand how these economic and social inequalities, in the interface with the social issue, affect access to health.

It is noteworthy that the supply of this service in the SUS is not enough to meet the user's demand for access to health; corroborating the notes of Travasso and Castro (2012, p.186) the "mere availability of resources does not guarantee access", there are beyond these impasses,

> [...] geographical, financial, organizational, informational, cultural barriers, among others, a characteristic expression of the offer that, in an interrelated way, act to facilitate or obstruct people's ability to use the health service (TRAVASSOS; CASTRO, 2012, p.186).

Thus, in order to guarantee access, based on comprehensiveness at all levels of care, the legal support for the TFD was established in the SUS as a possibility of access within the SUS, which even in the face of all the contradictions, the responsibility of the State in the user's health care is guaranteed.

The TFD was standardized in the 1990s by Ordinance No. 55/1999, regulating norms to endorse that the State must be responsible for referring the user to treatment outside their municipality of origin, and concomitantly, pass on

> [...] an allowance[11] to the patient, and in some cases, also to the companion, referred by medical order to health units referenced in another municipality or state of the Federation, when all means of treatment have been exhausted in the place of residence of the same, provided that there is a possibility of total or partial cure, limited to the period strictly necessary for this treatment and to the existing budgetary resources (MANUAL OF STANDARDIZATION OF THE TFD, 2015, p.03).[12]

In this sense, the TFD, through the SUS, guarantees medical treatment to patients affected by diseases that cannot be treated in the municipality of origin, when all means of care in their locality have been exhausted (BRASIL, 1999). The TFD transfers to the patient, and in some cases, to the companion, assistance for travel costs referred to other municipalities or states that are not their place of origin; having as one of the criteria for this reference the possibility of total or partial cure.

According to the TFD Manual, and Ordinance No. 55/99, the following are offered within the scope of the SUS:

> Consultations, outpatient, hospital/surgical treatment previously scheduled; Round-trip tickets for patients and, if necessary, companions in the same amount, so that they can travel to the place where the treatment will be carried out and return to their city of origin; (air, land or river transport); Allowance for food and lodging of the patient and/or companion for the duration of the treatment; Responsibility for expenses resulting from the death of the TFD user; Analysis of special situations, when the patient's physical conditions do not allow road transport (BRASIL, 1999).

It is noteworthy that the amounts referring to the aid transferred by the TFD to the user and his companion are outdated, considering that the reference of values transferred to the user/companion, established in Ordinance No. 55/99, has not undergone monetary adjustment over the years. For understanding, it is described below:

- Remuneration for air transport every 200 miles per patient/companion: R$100.00 (Individual value).

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[11] Ordinance No. 55 of 1999, which instituted the TFD, defines this financial transfer as "allowance", which is disagreed, since it goes against the perspective of rights to health in the SUS based on the universality and integrality of services in an equitable way and not as "aid".

[12] This Manual was designed by the Health Department of the State of Espírito Santo based on Ordinance No. 55/99. It was decided to use the text of this manual for the clarity of the content. Available at: https://saude.es.gov.br/Media/sesa/TFD/Manual%20TFD%202015_.pdf. Accessed on February 01, 2019.

- Remuneration for ground transportation per 50km of distance per patient/companion: R$ 3.00 (Individual value).
- Remuneration for river transport every 50km of distance per patient/companion: R$ 2.00 (Individual value).
- Allowance for food for patient and companion when there is no overnight stay away from home: R$10.00.
- Allowance for full daily allowance (food and overnight stay) for patient and companion: R$ 30.00.
- Allowance for feeding the patient without a companion when there is no overnight stay away from home: R$ 5.00.
- Allowance for full daily allowance (food and overnight stay) for unaccompanied patient: R$15.00. (BRAZIL, 1999).

For the above, the TFD alone is not able to fully guarantee the access and permanence of HSCT patients who are referred by the HC to the ICDF, [13]in which they imply the right to health and express themselves as one of the expressions of the social issue.

However, reality shows that thinking about access to health, based on the TFD policy, still requires revisiting many elements that directly interfere in the defense of rights, especially when we consider that the demands of users are plural and the difficulties are presented beyond geographical, economic and functional issues.

According to the National Cancer Institute (INCA, *online*),[14] the first 100 days after transplantation is the phase in which care is the most important, so the patient needs to be very close to the transplant unit to facilitate care in case of any symptoms (cough, fever, graft-versus-host disease, among other complications).

Considering these elements, we observed impasses and adverse challenges faced by patients and companions who need to go to Brasília to undergo HSCT. The conditions established for a successful transplant and recovery require these patients to have some obligations that are sometimes far from the social and economic reality of their families.

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[13] The cost of living in Brasilia is considered one of the highest in relation to other capitals in the country. The information is supported by the IBGE, which released the Extended National Consumer Price Index (IPCA) and the National Consumer Price Index (INPC) for the month of November 2017. Available at: http://www.curtamais.com.br/brasilia/brasilia-e-a-cidade-mais-cara-para-viver-no-brasil-segundo-ibge. Accessed on January 05, 2019.

[14] Available at: http://redome.inca.gov.br/paciente/vida-depois-do-transplante/ Accessed on December 06, 2018.

In this sense, it is identified in the daily routine – Resident Social Worker – that during the process of preparation for HSCT in the initial outpatient consultations at the ICDF, patients have the possibility of going and returning on the same day; or in some cases to stay for a few days in Brasilia, relying mainly on the support house (because the transplant has not yet been performed).

The situation worsens after the transplant, since the care is different, as previously pointed out. It is in this article that the presentation of the field research and the analysis of sensitive data are introduced, based on the testimonies of the researched subjects – explained in the final item of this work.

RESULTS

HSCT: TESTIMONIES OF A TRAJECTORY OF CHALLENGES

As previously indicated, the manifestation of the social question is expressed in its refractions in the face of capitalist social relations, with the exploitation of capital over labor being central. Thus, the subjects engender their ways of coping with social inequality. Such characteristics take on different contours in the particularities of social policies, but above all how they are assumed within each reality, as an example of the trajectory of Brazilian health policy.

Bringing these elements corroborate to think about universality and, from the singularity of the relations expressed by the subjects who experience it, the necessary mediation to think about the particularity of relations in the face of this categorical complex unfolds – in a dialectical movement.

It is worth mentioning that this text understands that particularity is the key to unveiling knowledge of the way of being social – fields of mediations – through the unveiling of social complexes, breaking with immediacy (PONTES, 2016).

Thus, considering these assumptions, an analysis of the sensitive data will be made based on the subjects' speeches, making it possible to know the social reality experienced by them in such a challenging daily life; in its determinants and conditioning factors from *the a priori categories*, with emphasis on access to health in the interface with the social issue.

As a way to enable the organicity of the interviews, we initially opted for the identification and presentation of the participants, entering into considerations about the socio-economic and family reality, ending in the notes their apprehension about Health, SUS and the process of illness – both marked by the debate on access.

Regarding the identification of the research subjects, it is presented as follows:

Table 1 - Presentation of the subjects.

Identification	Age	Sex	Municipality of residence	Schooling	Profession
Participant 1	27	M	Goiânia	Complete higher education	Environmental Engineer
Participant 2	63	F	Orizona	Complete high school	Tec. Master of Science in Nursing
Participant 3	49	F	Goiânia	Illiterate	Farmer
Participant 4	53	M	Goiânia	Complete elementary school	Production Assistant

Source: Elaborated by the researcher herself, 2019.

The age range of the participants is between 27 and 63 years old, two female and two male. Of these, only one resides in the municipality of Orizona-GO[15], the other three report currently living in Goiânia. Two of them signal the discovery of the diagnosis as a beacon for moving to the capital. As for schooling, the formations range from complete higher education, complete high school, incomplete elementary school and not literate.

In this same table 1, the profession and education of the research subjects were presented, being expressed concomitantly: Environmental Engineer, Nursing Technician, Farmer and Production Assistant; transiting through a very diversified sample when we resort to schooling, whether for illiteracy, elementary school, high school and higher education. Although, in view of the Brazilian reality, these data converge by the low level of education if compared to the process of professionalization arising from higher education, the most vulnerable conditions that these subjects are subjected to are denoted. Such information is corroborated when we present income as a social determinant that influences health, and also as a means by which people are able to provide for their basic needs, expressed in table 2:

Table 2: Social Reality.

Participants	Number of people per household	Assistance Benefit	Social security benefit	Income per household	Renda individual	Housing situation
Participant 1	User; sister	No	No	No income	No income	Rented
Participant 2	User	No	Retirement	R$ 954,00	R$ 954,00	Own
Participant 3	User; Grandson; Daughter	Bolsa Família Program	No	R$1,036.00	R$ 82,00	Rented
Participant 4	User; father; nephew; sister	No	No	R$954,00	No income	Courtesy

Source: prepared by the researcher herself, 2019.

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[15] In a survey carried out, it is noted that the distance between Orizona/GO and the capital Goiânia is 138km (IBGE/ Cidades, 2018).

Only participant 2 reported living alone, the others lived with family members, with an average of 4 people per household. With regard to individual income, subjects 1 and 4 do not have any assistance/social security benefits, as well as any other source of income; participants 2 and 3 have some form of income, either through retirement and the Bolsa Família welfare benefit. However, convergence appears in the value of the income of both participants, which move between the minimum and below them, which leads us to infer the low socioeconomic situation.

This situation corroborates the family income presented, which does not change the condition of the minimum necessary for the maintenance of the subjects, and is more acute when compared to participants 1 and 4 who depend on their families for their own maintenance.

None of the participants had any activity related to work or profession, except for participant 2, who said she crocheted, dishcloths and handicrafts to supplement her income.

These elements contribute to identifying the characteristics of the patients who underwent HSCT who participated in the research. It is noted that the absence of formal employment contract registration is part of the reality of the research subjects, contemporaneous with a reality marked by structural unemployment and such adverse health conditions that, guaranteeing their rights through social assistance and/or social security benefits, constituted in the face of so many antinomies, expressed as follows:

> It blocked the benefit then I did the expertise in the Federal Court. It was for retirement, but it doesn't come easy, the doctor there, the expert there is tiring! (Participant 4).
>
> I don't have... was denied... I appealed to the courts but I lost everything! I lost everything! And the contradiction, first by the INSS, I was denied by the medical criterion and then in the Judicial by the socioeconomic criterion... And the worst, the Social Worker expert was favorable, no one understands why the doctor and socioeconomic were favorable... Did you answer? The two requirements to be granted the benefit, but denied, go figure... It's because he earns little, right?! He earns only 30 thousand reais, and he doesn't have cancer (Participant 1).

Participant 4 and participant 1 report the attempt to access the social security/assistance benefit through the courts. Both refer to this strategy as a way to access the right to the benefit while taking care of their health conditions, since they are out of the labor market.

The multifaceted expressions of the social issue gain materiality in the daily life full of challenges to the working class, falling on the different dimensions of life that become more acute, as indicated in the following statements:

> I lost the family allowance, then I managed to do it again, it's been two months that I've been receiving R$ 82.00 reais [...] Already! I tried too hard, I've already done an expert opinion, I didn't pass, but now my daughter put it in the lawyer's hand and I'm waiting for the result (Participant 3).

Participant 3 talks about her economic condition, referring to access to the Federal Government's Bolsa Família Program (PBF) and also signals the need for judicialization of the process as a way to face social issues, with a view to accessing another welfare benefit. It is noted that the BFP constitutes his only income, having to resort to the help of the family in its maintenance.

The understanding of poverty according to (YAZBEK, 2012, p.290-291) has commonly been evaluated through income and employment indicators, "along with the enjoyment of social resources that interfere in determining the standard of living, such as health, education, transportation, housing, retirement and pensions, among others". The same author adds that the criteria, although not homogeneous and marked by the income dimension, end up converging in the definition that poor are those who, temporarily or permanently, do not have access to a minimum of goods and resources, and are therefore excluded, to different degrees, from social wealth.

It is emphasized that the ways in which poverty, as an expression of the social question, gains materiality in people's daily lives emerge, especially in the face of relationships that have work as their centrality; Factors such as unemployment and income are the most expressive, accompanied by other determinants, since poverty "is a multidimensional category, and, therefore, is not characterized only by the lack of access to goods, but is a political category that translates into the lack of rights [...]" (MARTINS, 1991, p.15).

In this sense, the population in poverty is unable to provide for their minimum needs, nor access basic citizenship rights that guarantee their dignity. In the face of this, social ills are reinforced by the neoliberal minimal State that determines the selectivity of policies and their fragmented coverage. And, even in the face of the right to health, the relationships that are imposed and constituted do not only require the absence of disease, the statements are expressed as follows:

> Oh! Health is everything in our lives, right, because sick people can't do anything, it's hard, right... Health is everything, right? We are healthy ready! (Participant 3).
>
> Oh! Health for me is everything, right? If you can't stand working in a... You won't... If it stands still, if it is a... Like me, I can't lift, keep lifting weight more than 5% of my weight because I operated on my spine as well. I've worked all my life, then two years and a little bit since I stopped (Participant 4).

Participant 3 and participant 4 converge in the statements when they refer to health as being "everything"; relating health to the capacity for autonomous life and work.

Participant1 answers this question with the following statement:

> Oh! I think it's complete well-being, right? Social, psychological, emotional well-being, so it is a set of factors that makes you... (pause), that people think that health is just a medical issue, physiological and such, but I think it's a set of factors, because like that, everything influences, right, if you think like that, if I don't have a very well-structured social life, this will influence my health, if I don't have the emotional, this social environment influences my psychology and my professional, which will influence my physique (Participant 1).

In its different forms, the subjects understand the importance of health in their lives, with some perspectives beyond the health-disease process. The definition most used to describe health is the one highlighted by the WHO (1948), which understands health as a complete state of physical, mental and social well-being, not limited only to the absence of diseases, corroborating the statement brought by participant 1.

When asked about the SUS, it is noted that there are convergences and divergences; Participant 3 expresses herself:

> SUS? SUS is a good thing, right!? because we can't afford to do an exam, the SUS gives the check, we do it, you know, so the consultations, if it was private, I wouldn't have any conditions, the treatment, you know, so the SUS is everything too, right! It's a lot (Participant 3).

The participant's statement expresses guarantees that she can access the SUS, correlating with the living conditions in the face of the services she has accessed. This understanding of the SUS based on their experiences is what gives concreteness to know the real in its multiple approximations, as follows for participant 1 and participant 2:

> The SUS is our health plan, right! Of the poor and the rich too, right?! I think it's a system, I think it's access to everyone that most people have no idea about [...] so the SUS for me, it's like I did the SUS in my personal context, it was extremely essential, relevant, very important, without the SUS I would have died a long time ago! A long time ago, because I didn't have health insurance, so if it weren't for the unified health system to try to maintain this quality of life of mine, I don't even know what it would be because the cancer treatment is very expensive, right?! (Participant 1).
>
> The unique system, ah! There are a lot of people who complain, right?! That's what I say, I can't complain, because my treatment is all through the SUS [...] I value it a lot because if it weren't for that [...]Expensive, prolonged, follow-up treatment (Participant 2).

These subjects understand the SUS in its universal aspect of the citizen's right, highlighting the access they had to cancer treatment through this system – it is denoted that the principles and guidelines of the SUS are part of the subjects' lives, whether in the appropriation and/or enforcement of these rights; At the same time, the health antinomies expressed in the previous item gain different contours in the statements.

It is worth mentioning that the Oncology policy in the SUS offers several types of services and treatments ranging from low-cost drugs to chemotherapy with more expressive values, as well as surgeries, radiotherapy, low, medium and high complexity exams such as CT scans, MRIs, biopsies, among others, representing the processuality of the principles of universality and integrality emphasized by the participants.

This appropriation of the right to health is pointed out:

> So I think that the right to health is to have access to all these benefits and these guarantees and that they are rights guaranteed by the state, right, the State in its Constitution, in its Magna Carta, says that we have to have access to health, environment, well-being and so on, so having access to this kind of thing is, I think, it's a wonderful thing (Participant 1).
>
> Having the right to health is... Good thing, right!? You have the right to health for the people who are good (Participant 3).

Both infer the right to health as a "good thing" or a "wonderful thing", which demonstrates recognition of the importance of this right, both individually and collectively. The highlight is also presented in the participant's speech1, referring to the Federal Constitution of 1988 as a guarantor of the State's responsibility in the realization of the right to health.

In this sense, participant 2 and participant 4 bring such guarantees of rights plus criticism, namely:

> This is the obligation of the SUS [...] You pay taxes and don't have... It doesn't reciprocate at all. If you need them they help very little, right?! (Participant 4).
>
> Oh, I think that's how it is, having the right to health, having better care, oh I don't know... Be entitled to more things (Participant 2).

These statements demonstrate that the participants relate the right to health to the gaps presented in the SUS. Participant 2 talks about "having better care" and participant 4 does not feel fully contemplated by the SUS health policy, stating that "it does not reciprocate at all" and "helps very little". Also in this sense, participant 2 adds:

> [..] But what is the unique system that we see on television, the poor service and everything... It needs to improve! (Participant 2).

Participant 2 talks about the SUS based on content seen on TV linked to information on the conditions of public health care. These positions are reinforced by the media in general, in which they focus more on the gaps than on the potential of the SUS. And thus, they corroborate the fact that the SUS is bad is designed in users and in the general population.

This work does not ignore the deficiencies in the face of the contradictions expressed in capitalist society that fall on the way social policies are presented, especially in the current conjuncture. However, the criticism made is that, sometimes, the ideological constructions made by the press can trigger more of a strategy to encourage the search for supplementary health plans, than the proposition that the rights to health is something constructed, requiring collective struggles and mobilizations to guarantee rights.

Regarding the guarantee of SUS services based on exams, consultations and medicines as a right to health, the participants converge:

> I was earning a little money so I started to do everything privately [...] Then I picked up and paid for some exams at Araújo Jorge (Participant 1).
>
> Sometimes it's hard for us to pay, medicines sometimes you have to buy. Now I'm getting the acyclovir, I used to buy it, then I went to the secretariat and they are giving me [...] There are some exams that I pay for, right?! (Participant 2).
>
> These exams that I brought today I couldn't do through SUS because the check was only going to come out to do it now on the day of my appointment, it was going to come out yesterday to do it and then it's 15 days to leave, it was R$ 305.00 reais that was paid to do it, but because I didn't get the check early, right?! when I went I was on top (Participant 3).
>
> I don't stay there once in the ... (pause) the train stayed there for a couple of months and in a vorto, I'd rather pay than in one... (pause). This is the budget, then the girl left it for R$ 600.00 conto, then with the funeral plan she released it, took R$ 400.00 (Participant 4).

The difficulties in accessing the exams make users bear financial resources out of their pockets to pay for them, expressing one of the barriers to the effectiveness of their treatment. Although exams and medications are health rights, all participants report paying or having already paid for them. The participants recognize the SUS as a right, valuing it, but identify antinomies when they seek private exams. Such situations, due to the risks that the health situation implies in the lives of the participants, weaken the rights, because access becomes an individual pursuit.

Regarding the referral to a specialized treatment network, the testimonies of participants 1 and 4 converge:

> The part that I had the most difficulty with was the regulation of the SUS, because usually the SUS regulates and it is the one that sends where it is going to be treated (Participant 1).
>
> He stayed there for about three months, he went hunting for the train, the train is shelved here in Goiânia, then a boy worked at SAMU then he went there and talked

> to the girl, he was pulling the train was there... He didn't even touch the train (Participant 4).

The difficulties presented by both are translated by the delay in getting a place in specialized care to carry out a cautious investigation when there was still no diagnosis to start treatment. An institutional and management barrier has been established in the SUS to ensure that people have access in a timely manner to treat malignant neoplasms. The testimony of participant 3 adds:

> Then I did all kinds of tests, I went twice to that hospital near the bus station to give me the referral and he listened to my exams and said that I had nothing! Then I said my daughter take me home, let me die at home (Participant 3).

Illness linked to the delay in discovering the diagnosis impacts the chances of improvement or cure of these users, during this time of uncertainty, they go through several paths until they get regulation[16] in a specialized unit for treatment.

These dimensions that make access unfeasible are reiterated, either in the process of discovering and identifying the disease, or after the discovery, in the face of the need to carry out necessary tests:

> The doctor said to me: oh no! You have to pay for the CT scans, I took it and said: look, paying is not something seen much in my life! I can't afford to pay! She said: look, ask! (Participant 1).
>
> Then he asked for a series of exams, right, and after he looked at the result and asked if I was able to pay for an exam, which is the bone marrow exam. (Participant 2).

Thus, the dismantling of health policies gain materiality in the daily lives of the subjects, on the one hand the professionals incorporate as something natural the payment for the performance of exams in private places; and, on the other hand, it rebounds on the life of the user himself, who is faced with decisions that cross between the disease and the financial condition – expressions of the social issue that are intensified with the neoliberal offensive, a conservative perspective that tends to blame the subject himself for his conditions.

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[16] In the State of Goiás, the main hospitals in the SUS that serve the hematology specialty are the Araújo Jorge Hospital and the Hospital das Clínicas, these have support for hospitalizations, chemotherapy and Radiotherapy at the HAJ. The vacancies made available by the units to receive newly diagnosed patients are insufficient in the face of the growing demand, leading the user to many days of waiting until they can be regulated to start treatment, going against Law No. 12,732 of 2012, which determines that patients with malignant neoplasms have the right to undergo the first treatment in the Unified Health System (SUS), within up to 60 (sixty) days from the day on which the diagnosis is made in a pathological report.

In this sense, the challenges to access begin with the indication and referral to HSCT, since when asked about the access barriers encountered for transplantation, the statements of participant 1 and participant 4 converge:

> The first aspect was the financial aspect! (pause) Right away! Right away, it was the demand that worried me the most, because I said: how am I going to stay there? (Participant 1).
>
> [...] Financial then I filed the thing, it took almost a year for them to release it... the INSS then I took the money and went to Brasília, because it took a while to get the papers (Participant 4).

The statements denote that one of the barriers and difficulties that the participants present is related to the financial condition of bearing the expenses when traveling to Brasília to prepare and perform the transplant. The weaknesses increase in the face of the slowness of the process for the benefit of the TFD:

> [...] Then there is also an issue that is very heavy, right, there are people who are not able to do the transplant and will not do it! So this is very much like this (pause), it's not that it's inhumane, but it's painful, you say: 'you don't have money' (pause) Oh, there's TFD. Oh it's all right, but the TFD pays later! The TFD should pay before, or during, it doesn't even have to be in cash, I don't know if there is a department that manages and rents, 'no, we're going to rent a net kit for you in the amount of so much and we're going to give you a value of so much food voucher in the supermarket', you understand? (Participant 1).
>
> [...] Because we could go like this with confidence, because we were trusted only in courage! Just in the courage that we were, my daughter said like this: mom, we have to trust, everything will be fine. On the day they called me at four o'clock in the afternoon, she was there at seven o'clock in the morning to do the transplant, she didn't have a penny! (Participant 3).

Both participants evidence the financial barrier as decisive in access to health, demonstrating that access to the service in a strict way is not a condition to guarantee the right, since even with the vacancy destined for HSCT, there are determinants and conditions expressed in the interface with the social issue that could prevent or hinder their access to transplantation.

This text understands that the TDF is an advance in the perspective of health rights, this strategy is timid when it comes to the difficulties experienced and reported by users, with emphasis on bureaucracy. Users only receive part of what they spend[17] after returning from treatment outside the home, so if the user does not initially have a financial reserve to cover their expenses and that of their companion, these rights become a barrier.

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[17] The reimbursement amounts are in accordance with the amounts of Ordinance No. 55/99 already mentioned in this work.

Also endorsing the conditions presented by the participants to perform the transplant, participant 1 and participant 3 converge on the point that deals with companion:

> [...] Then my sister was also working and I said: look, you have to accompany me... And so she was the one who was willing, so at the time my mother was going to accompany me but my mother was very shaken by this whole process, from the discovery to the relapse it was a very heavy train for her [...] And then my sister resigned from her job, and went to accompany me (Participant 1).
>
> It was the companion! He was the companion. It was because my daughter couldn't because she worked, and it's rented, then I have 10 siblings, my siblings none, everyone poor couldn't come, then twice I told the dotor [...] to remove my name from the list because I didn't have a companion, then I was already half, then when I talked to a brother I couldn't, The other one couldn't, then I say, until he said he could come to court, right, but we don't want that, right!? Then I said: no! If it doesn't come for love, it's because of the family (Participant 3).

For these participants, the availability of a person who could accompany them throughout the process in Brasília presented itself as a barrier to access. Participant 1 lives with his sister[18], reporting that she left her job to accompany him. It is noteworthy that in the interview it was signaled that after this process and back in Goiânia, both are unemployed – demonstrating the repercussions of this process in family life.

Participant 2 lives on rent and has a family income of just over one minimum wage[19], composed of his value from the BFP and his daughter's income, so, according to her, it was unfeasible for the family provider to leave her job to accompany her mother to the transplant.

According to Yazbek (2008), these are times when the disposable masses are growing, surplus and on the margins of rights and social protection systems in a world in which precarious wages and social insecurity are widespread, triggering poverty.

In this sense, poverty is exacerbated in the face of a significant portion of workers who have become unemployable, growing portions of workers who do not find a recognized place in society, who move on the margins of work and socially recognized forms of exchange (TELLES, 1998).

Among the participants who had companions, it is noted as follows:

> [...] my sister went with me (Participant 2).
>
> [...] My sister, only my sister, is single too, right, she has more children... (Participant 4).

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[18] See Table 2.

[19] Available in table 2.

It can be inferred that, unlike the other participants, participant 2 and participant 4 resorted to family members who do not have a job and/or other direct relationships of dependence, generated by an internal network of collaboration in the absence of support from the State.

Regarding the users' strategies to fill the gaps in the State in the provision of conditions to access health, participant 1 and participant 2 converge:

> During this period the agent organized himself, the people organized a raffle to try to raise money for me to try to pay for what? The rent in the first place, because there in social assistance they had already told me there is no support house, but the nearest support house is in Taguatinga (Participant 1).
> The girls there, a lot of people helped me, right, then I took this money and went[...] In my city, she asked and a lot of people deposited it for me and it was that she helped me too, she had my salary, right!? I put the two together (Participant 2).

These participants report in their experiences one of the strategies that contributed to them being able to go and stay for transplantation. In the face of these latent expressions of the social issue, the solidarity of the community comes into play, relatives and people close to the users try to organize themselves to make up for the lack of effective intervention of the State in this process, seeking options such as raffles and cash donations.

For Montaño (2010, p.197) these solidarity actions are expressed in the "transfer to the orbit of 'civil society' the initiative to assist it through voluntary, philanthropic and charitable practices, mutual aid or self-help". It can be inferred that there is an emphasis on the responsibility of individuals to assume the needs not met by the State, which is a reflection of the increasingly strong neoliberal attacks, "the crisis and the supposed scarcity of resources serve as a pretext for the State to withdraw its social responsibility" (MONTAÑO, 2010, p.188).

From this point on, the analysis that concerns the conditions presented by the participants about the moment when they had already gone to Brasília is established. Regarding the place of accommodation, the statements of participant 1 and participant 4 indicate:

> [...] So, I put it on the scale, I made a cost-benefit ratio so I said: no! It's much better for me to rent, rent the place near the hospital that even gives me sometimes to walk, or that the uber is the minimum price (Participant 1).
>
> [...] There is if you don't have money you have to have something, where we stay there right there are a lot of people, I paid, I got a rent [...] R$ 350.00 reais in rent[...] I paid about four months and that's it[...] It was 35 km from the hospital[...] It was because it was far away, right, there was a lot nearby, right, but it was R$ 1,200.00 per month (Participant 4).

The interviews show that, in general, the transplant recipients resorted to renting real estate, changing the barriers to access according to the economic conditions of each one.

Participants 2 and 3 used other strategies:

> There was my nephew, you know, I already stayed, I talked to him, he said he could go, he lived so far from the hospital (Participant 2).
>
> [..] I already left here knowing about the support house because I couldn't afford it, yes I couldn't afford it, then everything was arranged here for me to go to the support house, I couldn't afford to rent even there (Participant 3).

From the speeches, they demonstrate that a network of solidarity comes into play again in the face of absence, demarcating the current processes of redefinition between the roles of the State and civil society, configured from philanthropization – whether between family members or between the Third Sector. It is noteworthy that both these two participants, as well as the previous ones, converge in the fragility of the right to access due to geographical barriers.

It is worth mentioning that the institutions known as "support houses"[20] in Brasília do not have enough support to receive this patient profile, because they receive patients with the most diverse pathologies; and with collective rooms that do not meet the reality of the care that patients need after transplantation.

And, even with the geographical barriers partially resolved, his stay in Brasilia imposed other barriers, namely:

> And the support house from Taguatinga to the ICDF I couldn't take the bus, and I don't have my own drive, what would I have? Uber! Uber in Brasilia is a train like that... crazy, you jump in, it was R$15.00 reais, so from the support house in Taguatinga to the ICDF it's R$35.00 reais more or less, R$35.00 to go and R$35.00 to come back, R$70.00 reais per day, there were weeks that I went there every day, you know? (Participant 1).
>
> Then we dawned the day of the appointment then I started to look, right, then it gave R$ 60.00 reais and it went down, right, until when it gave at least R$ 35.00 for us to be able to call, because if it gave that price... There was no condition! (Participant 3).
>
> It's because I couldn't ride the bus, right? after the operation you can't ride the bus, taxi was R$100.00 conto R$110.00 only the uber that was cheaper (Participant 4).

The participants have an important difficulty in terms of access to the hospital from the place where they were staying, the cost of transportation to the ICDF demanded a high financial cost from these participants, incurring not only geographical barriers, but also economic barriers. In this sense, it is considered that;

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[20] Support house is a nomenclature used in the region to designate governmental, philanthropic, religious, or non-governmental institutions that offer accommodation, food, and transportation so that patients and companions can stay.

> The degree of real access to health depends on resources such as knowledge and information, means to travel the distance that separates from care, time to travel and funds to cover the costs that this requires (FRANÇOIS, 2008, p.140).

These resources, when they do not exist, can imbricate access to health, considering that not all users have the availability and ease of browsing the internet and cell phone applications, while considering that even with UBER values[21] lower than traditional taxis, these are still high costs for users.

When asked about the post-transplant they said:

> Then when I left the transplant it was another difficulty for me because in a few days I caught a bacteria, it's a virus that already comes out of there with it and it develops, then when I came the doctor said it's twice to come to the hospital, take the medicine, twice a day! Then I said: doctor, I can't afford to come even once (once) every day... Then she did it right away, I was hospitalized again for 24 days again, I spent 48 days inside that hospital because I couldn't afford it and I said right away, right!? And there really wasn't, then she was hospitalized... I took the medicine at 8 am and I was going to take it at 8 pm, but I spent the whole day, straight, direct, because I said I could come but I couldn't, I couldn't afford it at all! (Participant 3).

Participant 3 talks about the difficulties faced after the transplant that were established by the high risk of the patient contracting and developing bacterial, fungal, viral infections, among others, since her body is defenseless, so one of the precautions that is recommended to patients is that they avoid crowds of people; do not stay in support houses because they pose risks to transplant recipients. The understanding of post-transplant recovery is established;

> As soon as the patient is discharged from the ward, together with his family caregiver, he receives from the team a list of recommendations to be strictly followed, such as: wear a mask daily, do not touch dirt or stay in dirty places, do not drive, do not eat raw food, only drink boiled water, do not iron clothes, do not go to places where there are agglomerations – such as churches, shopping, concerts and community parties, not exposing oneself to the sun, not having sexual relations, among other medical prescriptions that end up strongly limiting the achievement of personal satisfaction and well-being, in addition to favoring situations that can generate embarrassment, discomfort or deprivation (MASTROPIETRO, SANTOS; OLIVEIRA, 2006, p.68).

The testimony of participant 3 corroborates the notes of Mastropietro *et, al.* (2006), considering that this was the only one of the participants who reported having remained in the support house after the transplant, in addition to this the statement of the same when asked about the accommodations in the support house:

> It's bunk beds, but it's very good there, right, but the transplanted ones when it's like this have their room. It's to put it like this to stay at least a month, right, while another

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[21] UBER is the name of a mobile application that relies on the services of private drivers who make trips at lower prices compared to normal taxis.

> one arrives why... Now I wasn't that lucky! Because I was right away with everyone, but God was on my side because the room was being occupied with wheelchair users, because they always put it on (Participant 3).

Participant 3 expresses the conditions presented by the place where she stayed after the transplant; characteristic of this process of philanthropization of the third sector, supported by the absence of the State, with services that equalize and level individuals, ignoring their particularities.

Considering all the difficulties presented by the interviewed participants regarding the rights to health and access to the SUS, difficulties and barriers in accessing and remaining in Brasília to perform the transplant, family and financial difficulties, it was requested by the researcher that, if they had, suggestions, additions or notes should be made in relation to the research and the performance of the transplant, Thus they answered:

> I think there... There... I can, just like there are a lot of people who don't have a place to stay and the support center I don't know if everyone will stay, right, they can stay there. And also what they complain about that is too far right, I needed ... I don't know if there was a way to have a place closer so you wouldn't spend it, right... Those who do not stay in the support house have to rent a place, if they do not have a relative (Participant 2).
>
> Yes, you can! If there was a support house closer to the hospital and had a car to take, wow! Oh that's it! There is no car, so if there was a car it would also be good, then it is very far so I said that if there was a support house near the hospital (Participant 3).
>
> But only the thing you live far away, because a support house many people stay... all kinds of people who enter go and cannot be mixed among the people or could not ride the bus (Participant 4).

These participants converge on the indication of establishing a support house or adequate place to receive HSCT patients, breaking down one of the barriers to access. It also recommends collective coping strategies that can assist the next people who will transplant, and also suggest that transportation from this support house to the ICDF be made available, in view of the difficulties faced.

Participant 1 expands his propositions:

> Access to primary care, you know, of this whole process that you go through, from being diagnosed until you start the therapeutic process, basic care is extremely necessary and important, very important, because it is in it that you will be able to identify some things and point out some paths (Participant 1).

These participants point out as a suggestion the strengthening of primary care, indicating the importance of access, diagnosis and treatment to health in a timely manner – overcoming all barriers –, and adds:

> The issue also of the remuneration of health professionals, especially frontline professionals, right because doctors will always be paid, you know? doctor always goes well paid and the others? Who are extremely poorly paid (Participant 1).

The interviews demonstrate that access to health services is a major obstacle to the guarantee of rights, falling into the search for supplementary health in the face of the life-threatening relationship that the health area conducts, especially in the particularity of patients undergoing Hematopoietic Stem Cell Transplantation (HSCT).

Regarding the complexity offered by the SUS from the performance of transplantation, it represents an advance in health, the result of struggles waged within Brazilian society. However, the offer of the service for transplantation is not the only condition for the realization of the right to access, since access is intrinsically related to geographical, financial, organizational, informational, cultural barriers, among others, a characteristic expression of the offer that, in an interrelated way, act to facilitate or obstruct people's ability to use the health service.

Thus, the realization of the right to health presupposes an articulated action in the different governmental spheres with the aim of facing the bureaucratic, institutional, cultural and conjunctural issues that permeate health policy, which present permanent challenges to users in accessing health services and inputs.

BY WAY OF CONSIDERATIONS

In view of the initial concerns, by way of considerations, it is worth bringing some notes and propositions that were constituted in the course of the work, making it possible to answer both the initial concerns and the methodological directions assumed and covered in this work. It is clear that such results obtained are far from closing the discussion; On the contrary, our intention is to trigger a debate aimed at the construction of strategies that are based on the assumptions of the realization of the rights to health.

In this sense, the present work had as its thematic centrality the right to access health services, in particularity of the right to access HSCT; thus enabling the unveiling of the real, which is assumed from successive approximations that the dialectical movement that is made with everyday life.

The thematic constellation: Social Issue, Public Health Policy, Access was the core of the conceptual foundation necessary for the understanding and analysis of the research results.

It is worth noting that capitalist relations – whose foundation is found in the relations of exploitation of capital over labor – unleash, above all, inequality. This inequality makes it possible, by unveiling its genesis, to understand both the forms of exploitation and the responses engendered by the working class.

This process, characterized by the objective manifestation of poverty and inequality, as well as its forms of confrontation, brings to light the social issue as a political issue, requiring the State to mediate the necessary to minimize the atrocities of capitalist society.

It is in this context that Social Policies are found, among them, the Brazilian Health Policy, the result of struggles and mobilizations that have in the Health Reform Movement their greatest exposure of struggles from the perspective of health as a right, guaranteed in an integral way.

These banners of struggle were partially put into effect in the 1980s, with the promulgation of the Federal Constitution of 1988, and regulated by the Organic Health Laws (LOS) – guaranteeing principles and guidelines for health, as a right of the population and a duty of the State.

However, the antinomies expressed in this societal order take on different forms in the Brazilian reality in the face of patrimonialist, patriarchal, among other characteristics, with contours that gain materiality in everyday life, transmuting the right into favor. Regarding the focus of this study, the right to access health services ends up being weakened and guaranteed in a punctual and fragmented way, especially when considering social, geographical, political, cultural, and economic barriers, among others.

This study, by inquiring the challenges faced by SUS users in accessing HSCT at the interface of the Social Question, as well as analyzing the statements of the research participants, confirms the common thread established in the course taken in this work.

It was identified that by knowing the reality experienced by HSCT patients in the health-disease process, considering the determinants and conditioning factors that were present in their daily lives, which are interrelated with the expressions of the social issue, it is noted that it is a process that makes it difficult to perform the transplant, when sometimes it makes it unfeasible.

Contemporary to this movement, it is understood that the participants facing these challenges and impasses makes them resort to individual strategies and alternatives – in the face of gravity – in facing difficulties.

These barriers to access start from the process of becoming ill in the face of the search for private exams and consultations, due to the delay that they are carried out by the SUS. However, such access challenges run through and are aggravated by the diagnosis for the performance of HSCT, since economic, social, cultural, political, and other barriers are triggered.

Travassos and Castros (2012) point out that

> [...] Access is the factor that mediates the relationship between demand and entry into the service. It refers to the characteristics of the provision of health services that facilitate or obstruct its use by potential users and expresses the capacity of the supply to produce services and respond to the health needs of the population" (TRAVASSOS; CASTRO, 2012, p.185/186).

And, even though the participants recognize and identify the guarantees, scopes and rights expressed by the SUS, it ends up imprinting individual responses to coping with the social issue, given the seriousness that the health-disease process implies and interferes with.

In this sense, some propositions emerged from this work, namely:

- Strengthen the SUS with regard to its basic principles and guidelines.
- Consolidate primary care as a way to solidify a more efficient management in the SUS in terms of referrals and regulation.
- Revisit Ordinance No. 55/90, which institutes the TFD, as a way of adapting the price list of services according to the current needs of SUS users – expressed in the ordinance as help and not aid arising as a right to health.
- It should be noted that the proximity between the locations to which patients are referred does not always guarantee access, as was clear in the case of HC Goiânia-GO x ICDF Brasília-DF.
- To institute in Brasilia, based on a collective action in a hierarchical and regionalized way actions between the different SUS management entities, a support house or place that can receive these patients in order to contemplate their particularities, because today there is no place in Brasilia to properly welcome transplant patients before and after HSCT, which would be essential to facilitate the trip and stay of the patient and his companion in Brasília during this period.

Thus, these directions are essential to contribute to the emancipation of the subjects, expansion of rights and guarantees of access in the field of health, as well as to contribute to the construction, maturation and academic consolidation from the perspective of the social sciences.

For the above, this study recognizes and values the health policy, SUS, as the result of struggles and mobilizations of health movements, especially the Health Reform Movement. However, the antinomies of this process denote that such advances are full of challenges, especially for SUS users indicated to HSCT, who are faced with their singularities and particularities not met, weakening the rights to health, especially access to services guaranteed by the SUS.

In this sense, the construction of public policies must be based on the reality and needs of the subjects who use it, built from processes of struggles and mobilizations that reiterate the forms of collective confrontation expressed in the social issue, having as a guiding thread the realization of the rights to health.

REFERENCES

1. Behring, E. R. (2009). As novas configurações do Estado e da Sociedade Civil no contexto da crise do capital. In Serviço Social: direitos sociais e competências profissionais (pp. xx-xx). Brasília: CFESS/ABEPSS.

2. Behring, E. R., & Boschetti, I. (2006). Política social: fundamentos e história. São Paulo: Cortez.

3. Brasil. (2018). Constituição da República Federativa do Brasil: texto constitucional promulgado em 5 de outubro de 1988. Brasília-DF.

4. Brasil. (1990). Lei nº 8.080, de 19 de setembro de 1990. Regulamenta o Sistema Único de Saúde (SUS). Dispõe sobre as condições de promoção e recuperação da saúde, a organização e o financiamento dos serviços correspondentes e dá outras providências. Available at: <URL>

5. Brasil. (1990). Lei n. 8.142, de 28 de dezembro de 1990. Lei complementar do Sistema Único de Saúde. Ministério da Saúde, Brasília/DF.

6. Brasil. (1997). Lei nº 9.434, de 04 de fevereiro de 1997. Dispõe sobre a remoção de órgãos, tecidos e partes do corpo humano para fins de transplante e tratamento e dá outras providências. Available at: http://www.planalto.gov.br/ccivil_03/LEIS/L9434.htm Accessed on: September 25, 2018.

7. Brasil. (1999). Portaria nº 55 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 SIA/SUS e dá outras providências. Available at: http://bvsms.saude.gov.br/bvs/saudelegis/sas/1999/prt0055_24_02_1999.html Accessed on: June 28, 2018. Brasília-DF.

8. Braga, J. C. de S., & Paula, S. de G. de. (1986). Saúde e previdência: estudos de política social (2nd ed.). São Paulo: Cebes/Hucitec.

9. Bravo, M. I. S. (2009). Política de saúde no Brasil. In A. E. Mota et al. (Eds.), Serviço Social e saúde: formação e trabalho profissional (4th ed., pp. 88-110). São Paulo: Cortez; Brasília, DF: OPAS, OMS, Ministério da Saúde.

10. Bravo, M. I. S., Pelaez, E. J., & Pinheiro, W. N. (2018). As contrarreformas na política de saúde no governo Temer. Argumentum, 10(1), 9-23.

11. Costa, N. de R. (1997). O Banco Mundial e a Política Social nos anos 90: Agenda para reforma do setor saúde no Brasil. In Política de saúde e inovação institucional: Uma agenda para os anos 90 (pp. xx-xx). Rio de Janeiro: ENSP.

12. François, A. (2008). A curva e o caminho: acesso à saúde no Brasil. São Paulo: ImageMagica.

13. Gonçalves, C. A. (2006). Direitos à saúde: um estudo sobre as práticas dos assistentes sociais das unidades de saúde de Sorocaba (Master's thesis, Pontifícia Universidade Católica de São Paulo). São Paulo.

14. Iamoto, M. V. (2015). O serviço social na contemporaneidade: trabalho e formação profissional (26th ed.). São Paulo: Cortez.

15. Secretaria de Estado da Saúde. (2015). Manual de normatização do TFD. Estado do Espirito Santo, Vitória ES. Available at: https://saude.es.gov.br/Media/sesa/TFD/Manual%20TFD%202015_.pdf Accessed on: February 1, 2019.

16. Martins, J. de S. (1991). O massacre dos inocentes: a criança sem infância no Brasil. São Paulo: Hucitec.

17. Mastropietro, A. P., Santos, M. A., & Oliveira, E. A. (2006). Sobreviventes do transplante de medula óssea: construção do cotidiano. Revista Terapia Ocupacional, 17(2), 64-71.

18. Montaño, C. (2010). Terceiro setor e questão social: crítica ao padrão emergente de intervenção social (6th ed.). São Paulo: Cortez.

19. Montaño, C. (2012). Pobreza, “questão social” e seu enfrentamento. Serviço Social e Sociedade, 110, 270-287.

20. Duriguetto, M. L. (2011). Estado, classe e movimento social (3rd ed.). São Paulo: Cortez.

21. Netto, J. P. (2011). Capitalismo monopolista e serviço social (8th ed.). São Paulo: Cortez.

22. Netto, J. P. (2009). Introdução ao método da teoria social. In Serviço Social: direitos sociais e competências profissionais. Brasília: CFESS.

23. Pasquini, R., & Coutinho, E. (2013). Fundamentos e biologia do transplante de células-tronco hematopoiéticas. In M. A. Zago, R. P. Falcão, R. Pasquini, N. Spector, D. T. Covas, & E. M. R. (Eds.), Tratado de hematologia (pp. 711-729). São Paulo: Atheneu.

24. Pontes, R. N. (2016). Mediação e Serviço Social: um estudo preliminar sobre a categoria teórica e sua apropriação pelo serviço social (8th ed., revised and expanded). São Paulo: Cortez.

25. Silva, M. O. da S. e, Yazbek, M. C., & Giovanni, G. (2011). A política social brasileira no século XXI: a prevalência dos programas de transferência de renda (5th ed.). São Paulo: Cortez.

26. Sorrentino, S. R. (1997). A saúde pede socorro. In Saúde em debate. São Paulo: Moderna.

27. Tavassos, C., & Monteiro, M. S. (2012). Determinantes e desigualdades sociais no acesso e na utilização de serviços de saúde. In L. Giovanella (Ed.), Políticas e Sistema de Saúde no Brasil (pp. xx-xx). Rio de Janeiro: Fiocruz.

28. Telles, V. da S. (1992). A cidadania inexistente: incivilidade e pobreza, um estudo sobre trabalho e família na grande São Paulo (Doctoral thesis, Department of Sociology, USP). São Paulo.

29. Yazbek, M. C. (2012). Pobreza no Brasil contemporâneo e formas de seu enfrentamento. Revista Serviço Social e Sociedade, 110, 288-322.