

Work and Illness: the Social Repercussions of the Treatment of Acute Lymphoblastic Leukemia

DOI doi: <https://doi.org/10.32635/2176-9745.RBC.2018v64n2.73>

Trabalho e Adoecimento: as Repercussões Sociais do Tratamento da Leucemia Linfoblástica Aguda

Trabajo y Adicción: las Repercusiones Sociales del Tratamiento de la Leucemia Linfoblástica Aguda

Joana Polycarpo Torres¹; Eliane Santos de Assis²

Abstract

Introduction: This is an approach on the effects of the acute lymphoblastic leukemia (ALL) treatment process, considering the impacts on the social life of individuals coming from their insertion in the world of work. **Objective:** To problematize the social repercussions of the treatment of ALL, identifying how the form of insertion in the labor market (formal or informal) impacts on the treatment process within the Brazilian Unified Health System (SUS). **Method:** This is a qualitative research with critical-reflexive analysis based on the theoretical referential of historical-dialectical materialism. The research was conducted through a semi structured interview script applied to nine adult treatment patients considered active for the labor market. **Results:** The profile of the study participants was identified based on sociodemographic data that reflect a predominance of young people in situations of financial restraint and family dependency in different areas of life. Based on the analysis of the interviews, it was possible to elucidate the worker status of the individuals during the oncological treatment process and the impacts of the precarious insertion in the labor market in the current political, economic and social conjuncture that have been shaping the fragmentation of public policies. **Conclusion:** It was possible to understand how the crescents and even the most recent changes in the sociotechnical division of labor has contributed to the widening of existing social disparities and, above all, to the extent to which such a context takes on a singular and alarming dimension in the context of cancer treatment.

Key words: Work; Health; Medical Oncology; Leukemia; Social Work.

Resumo

Introdução: Trata-se de uma abordagem sobre os impactos do processo de tratamento da leucemia linfoblástica aguda (LLA) na vida social dos indivíduos a partir de sua inserção no mundo do trabalho. **Objetivo:** Problematizar as repercussões sociais do tratamento da LLA, identificando de que maneira a inserção no mercado de trabalho (formal ou informal) impacta no processo de tratamento no âmbito do Sistema Único de Saúde (SUS). **Método:** Estudo qualitativo com análise crítico-reflexiva à luz do referencial teórico do materialismo histórico-dialético. A pesquisa se deu por meio de um roteiro de entrevista semiestruturado aplicado a nove pacientes adultos em tratamento, considerados ativos para o mercado de trabalho. **Resultados:** Foi identificado o perfil dos participantes do estudo com base em dados sociodemográficos que refletem uma predominância de jovens em situação de restrição financeira e dependência de familiares em diversos âmbitos da vida. A partir da análise das entrevistas, foram elucidados tanto a condição de trabalhador dos indivíduos durante o processo de tratamento oncológico como os impactos oriundos da precária inserção no mercado de trabalho na atual conjuntura política, econômica e social que vem conformando a fragmentação das políticas públicas. **Conclusão:** Foi possível compreender como as crescentes e, ainda, as mais recentes mudanças na divisão sociotécnica do trabalho têm contribuído para o aumento das disparidades sociais existentes e, principalmente, o quanto tal contexto toma uma dimensão singular e alarmante no âmbito do tratamento oncológico. **Palavras-chave:** Trabalho; Assistência à Saúde; Oncologia; Leucemia; Serviço Social.

Resumen

Introducción: Se trata de un enfoque sobre los efectos procedentes del proceso de tratamiento de la leucemia linfoblástica aguda (LLA), considerando los impactos en la vida social de los individuos oriundos de su inserción en el mundo del trabajo. **Objetivo:** Problematizar las repercusiones sociales del tratamiento de la LLA, identificando de qué manera la forma de inserción en el mercado de trabajo (formal o informal) impacta en el proceso de tratamiento en el ámbito del Sistema Único de Salud (SUS). **Método:** Estudio cualitativo con análisis crítico-reflexivo a la luz del referencial teórico del materialismo histórico-dialéctico. La investigación se dio por medio de un guión de entrevista semiestructurado aplicado a nueve pacientes adultos en tratamiento considerados activos para el mercado de trabajo. **Resultados:** Se identificó el perfil de los participantes del estudio en base a datos sociodemográficos que reflejan un predominio de jóvenes en situación de restricción financiera y dependencia de familiares en diversos ámbitos de la vida. A partir del análisis de las entrevistas fue posible elucidar la condición de trabajador de los individuos durante el proceso de tratamiento oncológico y los impactos oriundos de la precaria inserción en el mercado de trabajo en la actual coyuntura política, económica y social que vienen conformando la fragmentación de las políticas públicas. **Conclusión:** Fue posible comprender cómo las crecientes y, aún, los más recientes cambios en la división sociotécnica del trabajo han contribuido al aumento de las disparidades sociales existentes y, sobre todo, cuanto tal contexto toma una dimensión singular y alarmante en el contexto del tratamiento oncológico. **Palabras clave:** Trabajo; Salud; Oncología Médica; Leucemia; Servicio Social.

¹ Social Worker. Universidade Federal Fluminense (UFF). Instituto Nacional de Câncer José Alencar Gomes da Silva (INCA). Graduate Studies Program in Social Work (PPGSS), Universidade Federal do Rio de Janeiro (UFRJ). Niterói (RJ), Brazil. E-mail: joanapolycarpo@hotmail.com. Orcid ID: <https://orcid.org/0000-0002-1230-0647>

² Social Worker. Hematology Service, INCA. PPGSS, Universidade do Estado do Rio de Janeiro (UERJ). Universidade Católica (PUC-SP). Rio de Janeiro (RJ), Brazil. E-mail: eliane.s.assis@gmail.com. Orcid ID: <https://orcid.org/0000-0001-9486-5125>

Corresponding author: Joana Polycarpo Torres. Rua General Castrioto, 422 - Barreto. Niterói (RJ), Brazil. CEP 24110-256. E-mail: joanapolycarpo@hotmail.com.



INTRODUCTION

The study focuses on the theme of work and illness, problematizing the social repercussions of work's configuration in contemporary capitalist society and the impacts of treatment for acute lymphoblastic leukemia (ALL) on patients' lives. The aim was to analyze and elucidate the effects of treatment for ALL resulting from patients' position in the labor market, besides considering their economic and social status.

Our work in the Social Services Department of the Hematology Clinic at Cancer Hospital I (HCI) of the Brazilian National Cancer Institute José Alencar Gomes da Silva (INCA), under the Multidisciplinary Residency Program in Oncology, sparked reflections on the various dimensions of the world of work in relation to neoliberalism, which has led to changes, especially in the last two decades, in the social and technical division of labor, through agreements that have exacerbated already precarious work conditions, in keeping with capital's objectives in a context of structural unemployment¹.

The consequences highlight the social determination of health and cancer as an expression of the broader social issue. Cancer is a public health problem due to its significant prevalence, incidence, and magnitude, with a significant effect on access to health services. Cancer incidence is related to both genetic factors and exposure to environmental, socio-occupational, and cultural risks, permeated by dimensions of social life related to the expanded concept of health, such as income, work, housing, food, transportation, education, and leisure (Law no. 8.080 of September 19, 1990).

In addition, considering the reality of individuals during the treatment process, the difficulty with inter-sector collaboration between social policies results in the bureaucratization of social security and other social benefits (depending on formal or informal participation in the labor market), directly impacting the patients' socioeconomic status and thus their treatment adherence.

This discussion relates to the concept of health iniquity², including distinct forms of access to services and opportunities, directly linked to individuals' position in society. In this sense, health cannot be dissociated from these factors or from the intrinsic social inequalities in this society's genesis.

Acute lymphoblastic anemia has peculiar characteristics that trigger social repercussions throughout the treatment process. The disease is characterized by rapid evolution and thus the need to immediately initiate treatment after diagnostic confirmation. Treatment can last two years or more, depending on the case, with the protocol varying, either chemotherapy (the main treatment modality),

corticosteroid therapy, treatment and prophylaxis targeting the central nervous system, radiotherapy, and stem cell transplantation. The protocols require an intensive course in order to complete the treatment cycles, which necessitate frequent attendance at the unit and long hospitalization times, since the leukemic cells multiply rapidly and the disease worsens accordingly³.

All these issues make radical changes in patients' lives, such as abrupt breaks in their social, family, economic, and even cultural dynamics. The various facets of their world of work are important, since such changes materialize in their condition as workers, becoming one of the main obstacles in the treatment process, both for those whose work has been interrupted and/or those who have still not entered the labor market, considering the current context and even their young age (since ALL is often diagnosed during the transition from adolescence to adulthood). Both situations have socioeconomic impacts, especially financial ones, exacerbated by the reorganization required by treatment.

We thus call attention to the inherent relationship between the illness process and the world of work, as well as its relationship to social policies that suffer the consequences of the current context with the encroachment of measures to constrain social expenditures in a process of decentralization, targeting, and privatization of social policies and programs. Such consequences reflect the barriers to individuals' access to social policies and the related benefits, especially considering the reality of patients undergoing treatment in the public Unified National Health System (SUS).

METHOD

This was a qualitative study that aimed to problematize the social repercussions of the configuration of work in capitalist society in the context of treatment for acute lymphoblastic leukemia. The study proposes a dialogue with patients in order to grasp their specificities and their reflections on their experiences with the illness, including reflections on structural, socioeconomic, political, and cultural issues. This type of study is concerned with the deeper level of relations, processes, and phenomena⁴.

The initial study sample included a total of 24 adult patients enrolled at the Hematology Clinic of HCI/INCA from May 2014 to June 2017. The following exclusion criteria were applied: patients under 18 years of age (even if diagnosed with ALL and regardless of the treatment modality), patients in post-treatment follow-up, treatment dropout, cognitive impairment (assessed by the medical team and recorded on the patient chart), and deaths. After applying these criteria, three patients were excluded

who had evolved to death, one patient who was in post-treatment follow-up, and two that declined to participate. The final sample thus included 18 patients in treatment at the time of the study, and considered in the workforce. Of these 18, nine agreed to participate but were unable to appear on the scheduled days.

The study used a semi-structured interview script. The initial section included structured questions on demographic characteristics (age, sex, gender, color/ethnicity, children) and socioeconomic characteristics (housing status, schooling, work status, and income). It also included broad questions that encouraged participants' free thinking along the following lines: life changes due to the cancer treatment; participation (or lack thereof) in the labor market and its impacts on the ALL treatment; and social security and other social policies and their benefits. The first part of the interview script (sociodemographic questionnaire) was applied to nine patients. Of these, five opted to also participate in the second part of the interview (open questions).

The study's underlying theoretical reference was historical-dialectical materialism (contending that it is possible to intervene in a given reality), based on the Marxist method, with the understanding that "the subject (researcher) has an essentially active role, precisely to grasp not the appearance or form assigned to the object, but

its essence, its structure, and its dynamics (to grasp it as a process)"⁵⁽¹⁶⁾.

The study was submitted to the Institutional Review Board of INCA and was approved on September 20, 2017, under case review CAAE no. 72661717.5.0000.5274. Patients that chose to participate signed a free and informed consent form. Interviews were recorded and transcribed in full. Random letters of the alphabet were used to identify the participants.

RESULTS AND DISCUSSION

Tables 1 and 2 show the study participants' socioeconomic and demographic profile.

Of the sample, 78% of the participants were males and 22% females. Mean age was 36.5 years (39 in women and 35.9 in men). The majority of the sample were white (67%, self-reported), 78% were married, and 67% had children.

As for housing conditions, 56% lived with family members, 22% had their own house or apartment, 11% lived in rented housing, and 11% were living in housing lent by family or friends. As for schooling, 33.3% had complete university education, 33.3% complete secondary, 11.1% incomplete university, 11.1% complete primary, and 11.1% incomplete primary; 67% had attended public schools and 33% private schools.

Table 1. Demographic and socioeconomic characteristics of a sample of patients with acute lymphoblastic anemia in Rio de Janeiro, Brazil

Initials	Age	Sex	Gender	Color/ethnicity	Marital status	Municipality	Children	Housing status	Living with	Schooling		Profession
										Level	Public/Private	
AV	36	M	M	Brown	Married	Duque de Caxias	3	Own house	Wife and 3 children	Incomplete primary	Public	Barber
G	39	M	M	White	Single	Niterói	1	Family's home (sister)	Mother, sister, brother-in-law, and 2 nephews	Incomplete university	Private (mostly)	Glazier
P	43	M	M	Black	Single	Niterói	1	Family's home (brother)	Brother	University	Public	Administrator
R	18	M	M	Brown	Single	Campo Grande	X	Family's home (parents)	Parents and 2 siblings	Secondary	Public	X
A	19	F	F	White	Single	Rio	X	Family's home (parents)	Parents and brother	Secondary	Private	X
E	36	M	M	White	Single	Rio	X	Apartment on loan	Companion	University	Private	Administrator
T	59	F	F	White	Single	Rio	2	Rented house	Children and grandson	University	Public (mostly)	Lawyer
GL	60	M	M	White	Casado	Rio	2	Own apartment	Wife and children	Secondary	Public	Refrigerator technician
J	19	M	M	White	Single	Nova Iguaçu	1	Family's home (parents)	Parents, sister, and niece	Incomplete primary	Public	Electrician

Table 2. Income, social security status, and labor status

Initials	Personal income*	Status		Family income	Primary breadwinner	Living on this income
		Social Security	Labor			
AV	1-3 times monthly minimum wage	Worker's compensation	Informal	≤ 2 times monthly minimum wage	Sole provider	5
G	x	X	Informal	Does not know	Sister	6
P	x	X	Informal	Does not know	Brother	2
R	1-3 monthly minimum wage	Conditional cash transfer	Informal	2-4 times monthly minimum wage	Father	5
A	x	X	Never worked	> 5 times the monthly minimum wage	Mother	4
E	1-3 times monthly minimum wage	Worker's compensation	Formal	2-4 times monthly minimum wage	Companion (girlfriend)	2
T	1-3 times monthly minimum wage	X	Informal	2-4 times monthly minimum wage	Daughter	4
GL	1-3 times monthly minimum wage	Retired on pension (still working)	Formal	2-4 times monthly minimum wage	Daughter	4
J	X	X	Informal	Does not know	Father	4

* 1 monthly minimum wage = approximately US\$250.00

As for income, 44.4% had a personal income of one to three times the minimum wage (US\$250-750/month), 11.1% one minimum wage (US\$250/month), and 44.4% had no income.

The Tables provide a basis for the profile of ALL patients, considering that the study approached approximately 50% of all the patients in treatment at the Hematology Clinic during the study period. The data show a predominance of young adult patients with the disease, the majority living with family members and experiencing income constraints, indicating a degree of financial dependence.

Analysis of the data from the interviews allows measuring how exclusion from the labor market produces consequences for the individuals' lives, aggravated by the cancer treatment. Although formally employed and covered by the Social Security system, an individual who is prevented from working suffers a situation of socioeconomic constraints, as shown in the following quotes:

Everything changed after the treatment started, especially financially. Although I received a benefit [worker's compensation], I had earned a lot more while I was still working, four times the worker's compensation (A.V).

The biggest obstacle in my current difficulty was discomfort from staying with a sister and needing help. What bothers me the most today is not being

able to work. It's the anxiety of not being able to do any kind of paid work (G).

When I discovered my illness, I was still working. I'm self-employed, so I went to work when I was feeling well. And I quit working once and for all when I had to come to Rio de Janeiro. I'm from Bahia [1,630 km away], and I had to drop everything because of the treatment (P).

Despite having different profiles (as shown in Tables 1 and 2), all the patients mentioned the socioeconomic impacts of the treatment, and the quotes show how these impacts are directly related to work, not only for those who were self-supported or family breadwinners, but also for those who had not entered the work market. Table 2 shows that 67% of the participants were in the informal labor market, 22% in the formal market, and 11% had never worked. Even the latter mentioned the impacts of their family providers having to miss work because of their treatment.

The patients were clear about the heavy financial impacts of their treatment, but alongside other issues such as distance from family members, incapacity for work, financial dependence, and abandonment of future plans (at least temporarily).

Another situation that emphasizes the impacts of treatment is the need to remain close to the hospital

when the patients are subject to specific treatment protocols that can cause clinical complications requiring immediate support from the healthcare team. This situation can lead to the same discomfort as the hospitalizations themselves, making it a sacrifice by generating prolonged exclusion from one's normal social medium, besides spinoffs for the family members, especially for those who live outside the city of Rio de Janeiro or even out of state. All these repercussions challenge the healthcare team and patients in the effort to requisition the appropriate agencies to mobilize the resources and services that allow timely treatment, as in the case of the ruling on Treatment Away from Home (Resolution no. 55 of February 24, 1999).

Such impacts are experienced not only by ALL patients, but by their families as well. The data on housing status show that 56% of the participants live in family members' homes. This alone reveals the families' involvement in the treatment process, confirmed by the following quotes:

To focus on treatment of the illness is only possible by reorganizing the family, with family support. This thing of requiring support [from the family] bothers me a little, but they really back me (G).

My reorganization had to do with moving out of state and depending financially on my brother, since I can't work anymore (P).

My mother had to stop working because of my treatment. It all happened so fast. She had two jobs cleaning houses. As soon as we discovered the disease, she quit everything, the house, my brothers and sisters, and came with me. She didn't have a formal work contract. She was an informal cleaner (R).

Having to quit work was alright. I was hospitalized at the time, but my parents took care of everything for me (A).

Concerning other impacts from the financial constraints, the participants emphasized the way the specificities of ALL treatment contribute to their incapacity for work and the exacerbation of socioeconomic conditions:

For now, it's impossible for me to go back to my old profession, since I don't have the same disposition. Besides, my contact with various persons and environments is limited, due to the immunity issue, periods in chemotherapy that make me weak, and the need to stay at the hospital regularly (A.V).

Even though I'm self-employed, I can't work because of the treatment's effects. Sometimes I feel really sick from the effects of the chemotherapy, plus there are

the long hospital stays, not to mention this catheter here that prevents me from making any physical effort (P).

Now, with the treatment, things are more complicated, because there are various things that complicate singing. My lungs are no longer the same. I've gone a long time without practicing, because I don't have the same stamina that I used to. I know it'll come back, but it's complicated. This has been a difficult stage, because I don't feel safe walking outside alone. I'm afraid when I take the bus, because my legs aren't the same. I used to do everything by myself, take the bus, the subway, go to classes. So, nothing's the same. My throat's not the same, my vocal cords aren't the same, nothing's the same (A).

The quotes express the limitations for patients with ALL in their treatment process. Since ALL is an acute leukemia, cells that are still very young stop functioning properly and begin to reproduce uncontrollably⁶. The evolution is very rapid, making it crucial to begin the treatment as soon as possible. This early initiation of treatment generally means diagnostic confirmation followed by an unexpected and prolonged hospitalization, making an abrupt break from the patients' social medium. This alone means a limitation resulting from treatment of the disease, aggravated by social issues that appear next and are exacerbated in a context of illness and especially with the imminence of various forms of incapacity, ranging from incapacity for work to physical, emotional, and financial dependence.

The interviews showed that the impacts differ and that the individuals suffer the consequences of their treatment according to their economic and social status in the world of work. Informality has thus been expressed in the experience of some individuals since they first entered the labor market. When they reported having entered the labor market as children, it was implicit that the only alternative was informal work due to their young age and lack of skills, tending to interfere with their schooling. An example:

I've worked since I was 13, out of necessity (A.V). I started working very young. When I was 13 years old, I started doing odd jobs. I was still in school, but I started working out of necessity to have my own money and not depend on anyone. When I was older, I managed to get into the hotel business, and I also worked on a road-paving crew. I used to work with a formal employment contract, and then I started paying into the social security system as a self-employed worker, but later I stopped paying in. I never thought I'd need it (P).

Early entry into the work market appears in different social contexts, suggesting different fates in relation to schooling, for example. The quotes above reveal that the motivation to look for work is subsistence, while the following quotes also denote the individuals' goal of acquiring professional skills.

I began working with my father and intended to study engineering to help him with his work. But I had to quit everything because of the treatment. It was going to be impossible for me to keep up my studies, because I always have to come to the hospital, and I live far away, so it would be impossible to reconcile both (R).

I began working early. My family was strong in the construction industry, and I learned the profession in the day-to-day routine in the area of glass and in sales, organization, and management. And I traveled, lived abroad, acquired skills, and learned English. I came back [to Brazil] because of my daughter, but I kept on learning and worked in the glass industry until I was at a place where I could go it alone. So, since 2007 I can make my living without having to provide services to other companies. I began to work on a self-employed basis and made my name in the industry, with contracts and a reputation (G). Before the treatment, I was taking a private course in singing that prepared me to enroll in the technical-level course in singing and music theory at the university [UFRJ]. I was planning my professional career. I graduated from secondary school (private) in 2015 and took the university admissions exams (ENEM). My goal was to study opera singing at a public university, but I still didn't feel prepared for this course. So, I decided that I was going to prepare for it the following year (2016), focusing on the course in singing and taking the university admissions exams again and undergraduate studies in 2017 (A).

Lack of participation in the labor market poses a number of barriers to goods and services. However, early work can impact access to education and professional training, which ends up leading to the same consequences mentioned previously, when jobs are increasingly scarce in a context of structural unemployment. These individuals thus tend to remain in the informal work market. This situation in Brazil is due to changes in work management formats, social and labor legislation, and the state's role in the last two decades, representing "a new social precarization of work that involves the current flexibilization and precarization of work, renewing the historical and structural precarization of work in Brazil [...]"^{7 (55-56)}.

Before his treatment, A.V. had a profession, as a barber, as listed in Table 1. He provided services in a barber shop,

and his work could thus be classified as "less unstable". In other words, it is the kind of work with a minimum of professional knowledge and the means to work, mainly in the services sector in the vast majority of cases⁸.

A.V. reported that after he became sick it was impossible to return to his old profession. To bolster the family income (as the sole provider), he began to sell beauty products. He thus shifted from the category of "less unstable" to "an initial modality of informality", that is, "traditional informal workers in activities that require low capitalization, seeking to obtain income for individual and family consumption". These workers are alternately unemployed and absorbed by precarious forms of work, in a situation that is initially temporary and becomes permanent⁸.

This suggests how the treatment for ALL reorganized the individual's life, especially the objective conditions related to treatment adherence such as heavy expenditures with frequent commuting to the hospital, meals, and medications, where A.V and the other patients were forced to reorganize their social and family lives without being prepared for it.

Another important element is access to social policies by individuals with cancer and their families, on whom they depend.

Social policies and especially social security policy have impacted access to treatment. These policies have become increasingly restrictive and less effective in Brazil, due to the growth in the informal labor market and the bureaucratization of access to benefits. There is also a growing demand for benefits from the Social Assistance Policy, also due to the growth in deregulated work in the current political and social scenario. When asked about the Social Security and Social Assistance policies of the INSS, the patients emphasized:

I applied for worker's compensation while I was still hospitalized, and the medical examiner from the INSS came to the hospital and confirmed my incapacity for work. But they turned down my application for worker's compensation, claiming that there were "holes" in my monthly contributions, which was wrong. What's most absurd is that I can't appeal their ruling until February 2018. My life savings are running out, and because of this mistake by the INSS, I'll probably have to depend [financially] on my family, on others, because of the expenses and the fact that I can't work. I'm running out, using up all my savings (G).

I used to work with a formal employment contract, and then I started paying into the social security system as a self-employed worker, but later I stopped paying in. I never thought I'd need it. My thinking was that the INSS paid so little that I wouldn't need it [worker's compensation]. I was

contributing, thinking of my retirement, but then I let it drop. I did the figures, and being short on cash, I figured I could use the amount from the monthly contribution to earn interest on something else. I was going to pay in my whole life and get very little back in the end. Today I think INSS is really important for somebody in this situation, but INSS doesn't do its job properly, especially for someone who needs it. The amount they pay is so little, especially for somebody's who sick, if he has to support his family, buy medicines, take transportation and all. It's really hard. The feeling is that the "social arm" never reaches you. Not to mention the terrible way they treated us at the institution (P).

As for INSS, I know nothing about the subject. It was always a far-off thing for me. I know my parents are familiar with it, but the subject never crossed my mind. I always thought it was going to be a long time before I started thinking about Social Security (A). What's kept us afloat was the access to the benefit [conditional cash transfer - BPC/LOAS]. I was not even aware it existed, and when I came here [to the Social Services Department] they explained it to us, and it was really good. It not only helped me with the treatment, but my family, too, because my father is the only one working, and when he can't "bring home the bacon", I can help him. As for the Social Security contribution and INSS, I wasn't aware of them. I only heard about them when I began the treatment, but I'm not thinking about that now (R).

The quotes by patients that are already in the work market and have already started paying into the Social Security system (even though temporarily) reveal their difficulty in accessing the benefits and their dissatisfaction with the services. The younger individuals only mention the Social Security contribution as a bridge to retirement, something completely in the distant future. Such observations reflect the targeting approach adopted by such policies and reproduced in the population's reasoning. Patients who knew a little more about such policies worried about the difficulty in accessing the benefits, the services' malfunctioning, and the system's failure to meet their needs in case of necessity.

The consequences of ALL treatment are not limited to patients' current objective conditions, but also include impediments that last for at least two years and permanently alter their sociocultural lives. During treatment, patients lose contact with the routine they have developed over life and suffer the uncertainty from the treatment, with concerns in relation to the future, as noted in the following quotes:

I think it's impossible to go back to my profession, since I no longer have the same disposition. I

began contributing to Social Security hoping to set up my own business. I'd seen the advertisement announcing the Individual Micro Entrepreneur system [MEI], but I wasn't able to continue with my plans after I got sick (A.V).

I'd like to be working, but I realize I'm incapacitated. I get tired just walking up ten stairs. I can't go back to what I used to do, and the frustration is knowing my limitations. It doesn't affect me to the point of getting depressed or bitter, but it makes me anxious and irritable because I'm not producing. In order to go back to my profession, I'd have to reorganize everything, because the treatment is a new thing and I don't know how my health is going to be (G). I can't plan my professional life. I think about it, I really do. But to plan with the goal of putting things in practice, not until next year, when I'm better (R). I wouldn't be able to go back to work even if I wanted to. After the treatment is over, I'm thinking of rejoining the labor market, since I'm young and feel fit. I have all my mental faculties, but with so many unemployed people they're not going to hire a sick guy who may not be able to handle the workday. I think it's almost impossible (P).

I'm doing some exercises to try to strengthen my diaphragm, since it's a muscle and I need it to hold the long notes. It's really hard, but I'm trying. At the start of the treatment, it was impossible to do almost anything. I could only do things to keep my mind occupied, but nothing involved in my professionalism. I tried to study, and I downloaded an app with video classes, because I took the university admissions exams this year [2017], but it wasn't always possible, I wasn't always okay. But I'm trying to get reorganized little by little (A).

These quotes reveal work's central importance in the individuals' lives, represented by the patients' condition as workers and by the impacts from having to leave the labor market, even when indirectly when they depend on family members. In addition to the direct emergency financial impact, the fact that they feel "unproductive" causes frustration and highlights how work is processed in capitalist production. Thus:

In the commonsensical notion and neoliberal view, productive work and workers are profoundly permeated by the idea that the one who does the work, that produces fastest, is worthier or more competent. The central crux of apologetic views of productivity and productive work results in the idea that workers are socially remunerated or socially valued in order to remain employed (or not) according to their productivity, that is, according to their effective contribution to society⁹.

According to this logic, when experiencing limitations from the illness, especially in their ability to work, the patients felt a socially determined uselessness, since in capitalist sociability, access to the goods and services needed to maintain human life is earned by so-called “individual merit and effort”, and such access is what determines the individual’s place in society.

CONCLUSION

The study’s development allowed understanding how the growing and more recent changes in the social and technical division of labor have contributed to increasing the existing social disparities and especially the degree to which this scenario acquires a unique and alarming dimension in the context of an illness.

Exploitation of labor results in the population’s impoverishment under the aegis of informality. Structural unemployment resulting from current socioeconomic and political conditions increases informal participation in the labor market. Job stability and labor rights are replaced with “opportunities” to join the field of entrepreneurship and self-employed work.

The interviews showed that while the individuals were still fit for work, they did not appear to realize the level of their labor’s exploitation, to the extent that they incorporated the discourse of meritocracy, individuality, and productivity. In the scenario of illness, although they had still not made a complete break with such discourses, the patients felt the more abrupt effects of their precarious insertion in the work market, and as they experienced the financial, sociocultural, and family impacts, they referred (although based on common sense) to the state’s failures to meet the population’s needs.

Due to the difficulties and bureaucratization of access to Social Security and other benefits and to the treatment expenses, as well as the extent to which patients lose contact with their daily routines, requiring radical reorganization for their treatment, they are better able to measure the direct consequences of the bankruptcy of public policies and services for their treatment. These implications, in turn, pose challenges for the multidisciplinary healthcare team and reinforce the importance of in-depth discussion of these issues.

The study raised some questions that confirm the degree to which the peculiarities of acute lymphoblastic anemia contribute to exacerbating the expression of the social issue already experienced by individuals even before their illness and that trigger new manifestations resulting from the treatment process. Individual and family income is a significant factor if observed in parallel to the number of persons living on such income. All the

patients mentioned financial loss, whether due to the insufficient worker’s compensation or the fact that their income was from self-employed work. Even those who did not have a personal income before their treatment reported the financial constraints for their families due to the treatment, as with the younger patients diagnosed with ALL before entering the labor market.

As for the impacts of treatment, the study emphasized the importance of reflecting on the degree of dependence caused by this disease. Most of the interviews highlighted the fundamental role of family members during the treatment process due to clinical instability and the need for prolonged hospitalizations, requiring both support and follow-up in the hospital and solutions to practical life issues.

These elements make the healthcare work process more complex, beyond the questions discussed, due to the inefficiency of social policies in guaranteeing the means for patients’ comprehensive care. The study also provides food for thought on the lack of social policies for adults undergoing medical care. This issue is not the target of public policies in Brazil, considering the patients’ capacity for work and the fact that they are working-age individuals. The policies fail to adequately consider individuals undergoing treatment for diseases. Even the Third Sector, NGOs, and philanthropic institutions lack support for adults experiencing health problems.

The daily routine at INCA definitely reveals the impact of this process on the work of the Social Services Department in all its policies, emphasizing healthcare policy. Since the ethical and policy mission of the Social Services Department is consistent with the principles of Brazil’s Health Reform and the defense of the Unified National Health System (SUS), users’ needs should be met as a whole, with the understanding that their health treatment depends on other basic living conditions and is not limited to the institution or to access to health policy alone.

All the issues discussed in this study are exacerbated by the current political and economic context resulting from the macrosocial structure, thus bearing a direct relationship to the work performed by the Social Services Department in all its social and occupational spheres. The study thus helped understand society’s movements and contradictions, therefore raising concerns that are not completely answered in the conclusion. The study poses important problems that merit further analysis, concerning the impasses involved in the establishment of social policies, their meaning for the social services profession, and their impacts on the reality of individuals in the context of illness, especially with the impending Social Security Reform in Brazil under the bill for Constitutional Amendment (PEC) no. 287 of 2016.

CONTRIBUTIONS

Joana Polycarpo Torres collaborated in the study's conception and design, data collection, analysis, and interpretation, writing of the article, critical revision of the intellectual content, and approval of the version for publication. Eliane Santos de Assis collaborated in the study's conception and design and oriented the data analysis and interpretation and critical revision of the intellectual content.

CONFLICT OF INTEREST

None.

REFERENCES

1. Behring ER. Brasil em contra reforma: desestruturação do estado e perda de direitos. São Paulo: Cortez; 2003.
2. Barata RB. Iniquidade e saúde: a determinação social do processo saúde-doença. REVISTA USP. 2001; (51):138-145.
3. Centro Infantil Boldrini. Leucemia Linfoblástica Aguda: Entendendo a Leucemia Linfoblástica Aguda: um guia para pacientes e familiares. Leukaemia & Blood Foundation [internet]. 2013. [accessed 2018 Aug 18]. Available at: <http://www.boldrini.org.br/index.php/portfolio/lla-entendendo-leucemia-linfoblastica-aguda-guia-pacientes-familiares/>
4. Minayo MCS, organizador. Pesquisa Social. Teoria, método e criatividade. 18 ed. Petrópolis: Vozes; 2001.
5. Paulo Netto J. Introdução ao estudo do método de Marx. São Paulo: Expressão Popular; 2011.
6. Perini G. Associação Brasileira de Linfoma e Leucemia. Leucemia Linfóide Aguda – LLA [internet]. 2016. [Accessed 2018 Feb 14]. Available at: <https://www.abrale.org.br/lla/o-que-e>.
7. Druck G. A precarização social do trabalho no Brasil. In: Antunes R, organizador. Riqueza e miséria do trabalho no Brasil II. São Paulo: Boitempo; 2013, p. 55-74.
8. Antunes R. Os modos de ser da informalidade: rumo a uma nova era da precarização estrutural do trabalho? Serv. Soc. 2011;(107): 405-419.
9. Frigotto G, Ciavatta M. Educar o trabalhador cidadão produtivo ou o ser humano emancipado. Trab Educ Saude. 2003;1(1):45-60.

Recebido em 29/5/2018
Aprovado em 10/8/2018