

**Home care of patients with hematological cancer in a pandemic scenario: a new challenge***Atención domiciliar de pacientes con cáncer hematológico en un escenario de pandemia: un nuevo desafío**Cuidado domiciliar de pacientes com câncer hematológico em um cenário pandêmico: um novo desafio***Daniela Pollo<sup>1</sup>**

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**Abstract**

The aim of this study was to identify the difficulties faced and the strategies used in home management by caregivers of patients undergoing treatment for hematological malignancies, during the COVID-19 pandemic. This is a qualitative study, carried out with 20 caregivers in a reference hospital in oncology. Data were analyzed using Content Analysis, supported by Bardin's theoretical framework. Most respondents were female, married, with at least high school education and living in the Southeast region. In addition, 70.0% were spouses or children, who had taken care of the patient continuously for less than two years, but had no training in the health area. From the content analysis of the interviews, three categories emerged: difficulties related to care; difficulties related to access; and coping strategies. Ignorance of management in the face of the changes imposed by the COVID-19 pandemic in the routine care of patients with hematological neoplasia is part of the caregiver's daily life. The main coping strategies used are related to family and spiritual support. Therefore, it is necessary to develop educational strategies to improve the care provided and empower the family to solve these problems.

**Descriptors:** Neoplasms; Hematology; Caregivers; Home Nursing; Nursing.**Resumen**

El objetivo de este estudio fue identificar las dificultades enfrentadas y las estrategias utilizadas en el manejo domiciliario por parte de cuidadores de pacientes en tratamiento por neoplasias hematológicas, durante la pandemia de COVID-19. Se trata de un estudio cualitativo, realizado con 20 cuidadores de un hospital de referencia en oncología. Los datos fueron analizados utilizando el Análisis de Contenido, apoyado en el marco teórico de Bardin. La mayoría de los encuestados eran mujeres, casadas, con al menos educación secundaria y residentes en la región Sudeste. Además, 70,0% eran cónyuges o hijos, que cuidaban al paciente de manera continua desde hacía menos de dos años, pero no tenían formación en el área de la salud. Del análisis de contenido de las entrevistas surgieron tres categorías: dificultades relacionadas con el cuidado; dificultades relacionadas con el acceso; y estrategias de afrontamiento. El desconocimiento del manejo ante los cambios impuestos por la pandemia de COVID-19 en la rutina de atención de pacientes con neoplasia hematológica forma parte del cotidiano del cuidador. Las principales estrategias de afrontamiento utilizadas están relacionadas con el apoyo familiar y espiritual. Por lo tanto, es necesario desarrollar estrategias educativas para mejorar la atención brindada y empoderar a la familia para solucionar estos problemas.

**Descriptores:** Neoplasias; Hematología; Cuidadores; Assistência Domiciliária; Enfermería.**Resumo**

O objetivo deste estudo foi identificar quais são as dificuldades enfrentadas e as estratégias utilizadas no manejo domiciliar por cuidadores de pacientes em tratamento de neoplasias hematológicas, durante a pandemia por COVID-19. Trata-se de um estudo qualitativo, realizado com 20 cuidadores em um hospital referência em oncologia. Os dados foram analisados por Análise de Conteúdo, apoiado no referencial teórico de Bardin. A maioria dos entrevistados era do sexo feminino, casados, com escolaridade mínima de ensino médio e residentes na região Sudeste. Além disso, 70,0% eram cônjuges ou filhos, que cuidavam do paciente de forma contínua há menos de dois anos, mas não tinham formação na área da saúde. A partir da análise de conteúdo das entrevistas, surgiram três categorias: dificuldades relacionadas ao cuidado; dificuldades relacionadas ao acesso; e estratégias de enfrentamento. O desconhecimento do manejo diante as alterações impostas pela pandemia por COVID-19 na rotina de cuidados do paciente com neoplasia hematológica faz parte do cotidiano do cuidador. As principais estratégias de enfrentamento utilizadas são relacionadas ao apoio familiar e espiritual. Faz-se necessário, então, o desenvolvimento de estratégias educativas para melhoria da assistência prestada e do empoderamento da família na resolução desses problemas.

**Descriptores:** Neoplasias; Hematologia; Cuidadores; Assistência Domiciliar; Enfermagem.

## Introduction

Cancer has a great impact on society, due to its high mortality rate and the many challenges that patients and their families face during and after treatment. In Brazil, there were 28,515 new cases of hematological neoplasia (NH), with 11,550 cases of deaths in 2020. In the United States, the estimate is 1,806,590 new cases of cancer diagnosed in 2020 and 606,520 deaths in the same period<sup>1,2</sup>.

In a global scenario, there were 19.3 million new neoplastic occurrences and 10 million deaths in 2020, of which 58.3% occurred in Asia, 19.6% in Europe and 14.2% in America. These variations occurred according to the distribution of the different types of neoplasia. The incidence of cancer in Europe occupies 22.8%, followed by America with 20.9% of the total world population. It is estimated that 28.4 million new events will occur in 2040, with a 47% increase in cancers compared to 2020<sup>3</sup>.

NH are originated by hematopoietic cells and the most frequent are leukemias, lymphomas, multiple myeloma, plasma cell neoplasia and myelodysplastic syndrome, which represent 10% of all new cases of neoplasia, predominantly in the male population<sup>4</sup>.

Cancer treatment consists of four purposes, which can be curative, neoadjuvant, adjuvant and palliative; the choice depends on the staging, pathology and immunohistochemistry of the neoplastic cell, location of the tumor, previous diseases and physical status of the patient. Among the most common, we find chemotherapy, radiotherapy, hormone therapy, immunotherapy and surgery, which can be used alone or concomitantly<sup>5</sup>.

In NH, chemotherapy and radiotherapy are the most used. The most used chemotherapeutic agents are polyfunctional alkylants, antimetabolites, antitumor antibiotics and mitotic inhibitors; and radiotherapy are teletherapy and brachytherapy<sup>6</sup>.

These treatments cause adverse reactions called harmful and unpleasant reactions, resulting in relevant intervention to the use of antineoplastic. The most common reactions to chemotherapy are nausea, alopecia, vomiting, abdominal pain, fatigue, decreased appetite, drowsiness, constipation or diarrhea and dizziness<sup>6,7</sup>.

Due to the treatment, patients need home care, which can be supported by home care services provided by public health agencies in order to guarantee assistance. Home Care articulates the various health care points, sharing care in a horizontal network, involving primary care teams, hospitals, emergency care units and specialized outpatient clinics<sup>8,9</sup>.

In this way, it is extremely important that the patient is accompanied during his oncological treatment, whether by a family member or caregiver, and may be a health professional. This person has the role of accompanying the patient in their daily activities and providing care according to their needs, assisting in the treatment and collaborating with their well-being<sup>5</sup>.

Therefore, the caregiver's role can directly influence the patient's treatment, since these are the individuals who carry out or help with intimate hygiene, drug administration,

device care, food, financial, psychological and spiritual support<sup>10</sup>.

Home care can cause setbacks in the caregiver's life, as it requires availability of time, financial subsidy and resilience. Among the greatest difficulties encountered, we observed social isolation, deprivation of leisure, disconnection from employment activities, affective suffering, emphatic concern, stress, family conflicts, among others. Therefore, the caregiver carries a great responsibility that can lead to drastic changes in their personal life<sup>10</sup>.

Regarding the care provided, caregivers mention complications in dressing change activities, care for bedsores, handling diet and administering medication, due to lack of training on the part of health professionals, and the unavailability of division of care. There are also complaints about the precariousness of services and materials for such care, especially by those with low incomes<sup>11</sup>.

Thus, knowing the difficulties and strategies encountered by caregivers of these patients with NH, in order to gain knowledge, can support the search for improvements in care for patients and family members who go through this situation, such as training health service professionals and organization of actions that minimize the impact caused by COVID-19. The objective of this study was to identify the difficulties faced and the strategies used in home management by caregivers of patients undergoing treatment for hematological malignancies (NH) during the COVID-19 pandemic.

## Methodology

In order to meet the objectives of this research, an exploratory methodology was used, with a qualitative approach, in order to allow the investigation and analysis of experiences and experiences, with the objective of understanding the phenomena of life on the social and cultural interactions of groups and people.

The research was carried out in the Outpatient Clinics of the Chemotherapy and Radiotherapy sectors of the Hospital de Câncer de Barretos - Fundação Pio XII, a reference in cancer treatment in Brazil. Inclusion criteria were caregivers of patients with hematologic malignancy who were being treated with chemotherapy and/or radiotherapy, over 18 years of age, of both genders. Those who were not direct caregivers and people with cognitive/neurological limitations that prevented participation due to their difficulties in understanding the study were excluded.

A semi-structured interview was carried out, audio-recorded using the researcher's cell phone recorder. The semi-structured instrument was divided into two parts: the first contained questions about sociodemographic characteristics; and the second consisted of guiding questions about the difficulties and their management in the home care of patients with NH undergoing treatment. Subsequently, the interviews were transcribed in full and recorded on the REDCap platform, in order to obtain greater reliability and accuracy of the collected data, facilitating the analysis process. The questionnaire included the questions presented in Chart 1.



For data analysis, Bardin's methodological framework was used, with the Content Analysis method. This technique results in a fluctuating reading of the document, followed by approximation, understanding and analysis of the content, allowing the codification, categorization and grouping of the elements, in addition to finalizing with the unification of the data to the point of allowing the interpretation of aspects and phenomena of life social, in a concomitant interaction with the theoretical references. The method is characterized by the following

steps: 1. Pre-Analysis; 2. Exploration of the material; 3. Treatment of results: interference and interpretation.

The project was forwarded to the Research Ethics Committee (CEP) of the Hospital de Câncer de Barretos - Fundação Pio XII de Barretos-SP and approved with opinion n.º 5,059,284, ensuring that all research participants signed the Term of Free and Informed Consent (TCLE), expressing interest in participating in the study and guaranteeing their privacy and confidentiality.

**Chart 1.** Data collection instrument. Barretos, SP, Brazil, 2020

Data Collection Instrument	
1.	Age
2.	Sex
3.	Marital Status
4.	Origin
5.	Level of Education
6.	Level of kinship
7.	Follow-up time with the patient
8.	Are you or were you a healthcare worker?
9.	What difficulties have you encountered in home care for the person undergoing treatment?
10.	What strategies have you used to take care of this person during the COVID-19 pandemic?

## Results

Twenty participants were interviewed, with an average age of 46 years ( $\pm 39$  years) among women and an average age of 51 years ( $\pm 56$  years) among men, most of whom were female (65.0%), married (95.0%), with at least high school education (85.0%) and living in the Southeast

region (65.0%). In addition, 14 respondents (70.0%) were spouses or children, who had taken care of the patient continuously for less than two years (65.0%), but were not trained in the health area (90.0%). Sociodemographic profile data are described in Table 1.

**Table 1.** Sociodemographic profile of the participants. Barretos, SP, Brazil, 2022

Variables	n	%
<b>Marital status</b>		
Not married	1	5,0%
Married	19	95,0%
Divorced/Widowed	0	0,0%
<b>Education</b>		
Illiterate	0	0,0%
Elementary School	3	15,0%
High school	9	45,0%
University education	8	40,0%
<b>Caregiver</b>		
Spouse	8	40,0%
Son	6	30,0%
Mother father	3	15,0%
Hired caregiver	1	5,0%
Friend	2	10,0%
<b>Place of residence (Region)</b>		
Southeast	13	65,0%
South	0	0,0%
Midwest	5	25,0%
North	1	5,0%
North East	0	0,0%
<b>Do you work in the health field?</b>		
Yes	2	10,0%
No	18	90,0%
<b>Time of care for this patient</b>		
< 2 years	13	65,0%
> 2 years	7	35,0%

From data analysis, three categories were identified: difficulties related to care; difficulties related to access; and coping strategies, characterized below.

### Difficulties related to care

In this category, caregivers' reports on difficulties related to patient care during the pandemic were grouped. The fear of being contaminated with the SARS-CoV-2 virus, exceptionally, during peaks in the incidence of the disease, is described among the main prompts related to care.

*"During the pandemic, it was more the concern of COVID, going out, working, going back home, day-to-day concerns, using gel alcohol, washing clothes, tidying up here and after she went back to work, more concern with the take care, get home, take off your clothes and take care of this day to day" (I2).*

*"Fear of catching COVID, many times they had to cancel the trip, because there were a lot of cases in the city, so we preferred to stay at home than go out to go to a consultation or treatment, because this fear of COVID, because he is weakened and I'm epileptic, so if it catches us we're split" (I1).*

In addition, COVID-19 has changed the routine of families, which has contributed to an increase in problems in social life and aspects of mental health, previously affected by the diagnosis and treatment of cancer, as shown below.

*"So, because we always had a life like that, social life, we used to go out a lot, and because of the pandemic, we had to change radically, we just stayed at home, we stayed closed, excuse the expression, but I feel locked up in the pigsty, understand? Nothing to do. I still go out on the weekends, I go out, I have a place there, went to the ranch to fish. But she stays there isolated" (I6).*

As a result, the difficulties with home management are highlighted due to the inexperience and lack of knowledge of the caregivers with the patient, providing significant changes in their lives and being intensified by the pandemic.

*"Look at that moment, for me to tell you what was difficult, I can't tell you, because for me I think everything was difficult, all the time. So, when he got sick, we never expected it, which happened because he was a man who always worked, not staying at home, not sleeping, just working. Then he retired because he got sick. For me, it was difficult to deal with the disease, because we have to take care to see what it does, which we don't know, right! And the most drastic thing was doing this special care, which is taking care, leaving the house very clean, not letting animals near, making the food he should eat" (I20).*

*"She can't do it, after she had COVID she can't do anything anymore, nothing, everything got worse, everything" (I6).*

Among the adversities of home management, there were complaints associated with food, being one of the biggest challenges for caregivers during treatment and this without the help of trained professionals to guide this public.

*"Did you change your diet?" (researcher). There was, he couldn't, he couldn't eat food like that, neither the bland nor the general one, he couldn't eat, it was just the pasta" (I16).*

### Difficulties related to access

The lack of access to transport, professionals and financial resources led to a new set of difficulties mentioned by the interviewees. As a result of this lack of professionals, it led to increased demand for health services and reduced attendance, demonstrating weaknesses in care, resulting in difficulties for family members with the care of this patient, mainly due to the lack of guidance on the management of home care, as mentioned in the interview.

*"And what precautions did the professional have to take?" (researcher). Yeah, giving him a bath, which many times I alone and his wife had no way of doing it and many times he felt very sick, with colic, with pain in the stomach, then, as we don't know anything about medicine, then we had to be asking the nurse for help" (I1).*

At the same time, the pandemic intensified this circumstance, as there was a resizing of professionals for the COVID sectors, in addition to the high rate of leave, due to the contagion of the disease and the leave of employees in the risk group, leading to the deficit of these professionals in the health network, causing difficulties in accessing these professionals.

*"It made it a lot difficult, especially since the city is small, as the COVID had a lot of consequences, there are many people in physiotherapy together and not many people in physiotherapy, there were times when I didn't do it for a month because there was no vacancy" (I1).*

In view of the difficulties with locomotion, we can attribute it to the fact that oncological institutions are in large metropolitan centers, causing many patients to move around, therefore, there is a need for adequate transport and financial resources to pay for these trips, however, the pandemic scenario inhibited these accesses. In order to avoid the spread, many transport companies have shortened their routes and opted for cost cuts, directly affecting access to transport for these patients.

*"Yes, because we live in Tocantins, stay at other people's houses in Goiânia, and there were times when we couldn't get to the hospital, we missed the appointment and it took a while to book again, right! It was even, that's why his treatment took longer, it's because of rescheduling, it keeps rescheduling, rescheduling and rescheduling" (I3).*

*"Our biggest difficulty is being in another state, right? From there and that already enters, transportation, unfortunately, the cost of living here, which is also a little higher than what we are used to, right?" (I10).*

And given the financial conditions, we observed that this factor overloads the treatment decision and changes in the lives of these caregivers. In search of quality and free treatment, many travel or even move from their municipalities, referring to the expenses and leading to the abdication of their original jobs.

*"So, at first, we really had to pay for it, but it was like that, it was all a scare for all of us. What little we had, we have to do as soon as possible. We tried with our own resources, right? It was with our own resources that we managed. We didn't know how long*



*it would take and we were in a hurry, so what we had, we undone, we sold it and I only knew one thing, I couldn't afford the treatment, but what I could afford, I did, together with my husband. The family is helping, so what we can do, we did, so in the end there were some paid trips, but the difficulty was having a person to drive and still have to use the city hall car. We had access to the car for some trips at the end of the treatment" (I12).*

*"The difficulty was divided by the financial cost, we are weak in situation, right! So getting around is a lot and now we found a halfway house, halfway house in Matão, because we have relatives in Matão, we were there this end of the year. He was there with them, then we got this support house" (I16).*

*"The difficulty was to have access to the exams, which was very slow, difficult. The situation was difficult, financial situation, I pay privately" (I16).*

### Coping strategies

The coping strategies that caregivers sought in different ways, including family, religious and spiritual support. In the reports obtained, family support is one of the feelings that corroborate with the continuity and maintenance of treatment, demonstrated during the interviews, that this support, in addition to coming from family members, is also evidenced in the patient himself with his loved ones, therefore a relationship is formed. bond of affection between the patient and their caregiver, strengthening their bonds and supporting them along their trajectories.

*"What helps me, and what strengthens me, that he helps himself, he himself gives me strength. It was like that, he told me "My mother is incisive about this issue, my mother should be like that. Everything in life has a purpose. If it came to me, let's try to do what we can and that's it", so I embraced those words. [...]. I feel that, very strongly, he always gives me that strength and that courage, that I'm never crying, that I'm never discouraged, that I'm never looking back, that I'm looking forward, that's what we can do. [...] It was when I passed I arrived in Barretos, without knowing anything, without knowing anything, a bit disoriented, I always sought God, everything was just new and suddenly I fell into Madre Paulina [accommodation], where I say, I had the Eucharist and I had the church all to myself, for worship. This for me made me much more empowered" (I12).*

*"Look, he's a normal person, you know? He is such a person that he has everything even when he is sick. He is an excellent person. My sister gave and is giving a lot of support to us. Because she is undergoing treatment, she is being treated here. [...]. So she gives that support. He gives a lot of support and there's something else, we can't let the disease win, we have to react, we have to face it" (I16).*

All individuals have their subjectivity, which are factors surrounding the being, such as culture, religion, experiences, education, knowledge and others, in this way, the human being searches beyond himself, something or something that refers to spirituality, as a factor of support and comfort in the adversities of life. Thus, spirituality and religiosity are comprehensive points in the lives of patients and their caregivers, as they help and console during treatment.

*"I have a lot of faith, so, I know, I held the hands of God, of Our Lady and said "If he managed to get out of one, he'll make it out of this one, I have faith, I'm sure", I'm sure that today will be much*

*better. [...] I am very religious, I pray a lot with him. We talk a lot. I can support him and he can support me" (I19).*

### Discussion

The SARS-CoV-2 pandemic caused major changes in people's daily lives globally. In cancer patients, these changes were present during their treatments, in their various moments, from their diagnosis, access to professionals, transportation, financial resources, consultations, medications and the treatment itself.

Another subsequent factor of the pandemic was the delays in diagnoses, treatment and oncological follow-ups, especially during the most severe restrictions, such as physical distancing, closures of leisure areas, non-essential businesses and the use of personal protection, in order to reduce the spread. This interference may cause late diagnoses and reduced patient survival in the future<sup>12</sup>.

In addition to the implications directly generated for cancer treatment, we can also see that there were indirect results for patients and their caregivers, such as the financial impact, which had greater repercussions in low-income countries, significantly reducing family income and making it impossible to continuity of treatment, from the acquisition of medications, outpatient care, exams and transportation<sup>13</sup>.

Traveling long distances is a reality for patients, since several oncology centers are located in metropolitan regions, consequently increasing the rates of migration to these places, and that, therefore, with the need for transport and the resources to pay for these trips. Because these are aspects that are indirectly linked to the treatment, and the pandemic period modified these precedents, therefore, making access to locomotion difficult. And this intensified in underdeveloped countries and with a higher rate of contagion by COVID-19<sup>13</sup>.

Other aspects were the lack of professionals and hospital input resources, since due to the construction of sectors aimed at patients with COVID (flu and ICUs), it forced the resizing of professionals and resources and inputs for these places. In this way, international guidelines guided the rescheduling and modification of systemic treatments according to the individual assessment of risk/benefits, treatment goals, disease progression, tolerance and clinical conditions of the patient<sup>14</sup>.

Another tool that contributed to the continuity of care was the implementation of telehealth tools. This allowed for uninterrupted outpatient care, giving professionals the opportunity to evaluate their clients in real time and discuss symptoms, treatment, exams and others, and with the advantage of reducing the risk of contagion of COVID-19, through the reduction of face-to-face visits to hospitals<sup>15</sup>.

In addition to these actions, the Brazilian health system proposed some criteria that would minimize the risk of COVID-19 infection and restrict hospital appointments. Such as advancing treatments and surgeries during the peaks of the pandemic, replacing intravenous medication with oral ones, when possible, prioritizing hypofractionation in radiotherapy, reducing social contagion and expanding the





use of personal protective equipment properly and adopting remote clinical monitoring by telehealth<sup>16</sup>.

Other situations arising from the lack of knowledge about the SARS-CoV-2 pathology, is the causality of concern, intensifying negative feelings in the emotional and spiritual scope. However, to minimize these circumstances, it is recommended to follow consistent measures that promote continuity in care for these individuals, such as biosecurity measures for professionals, family members and patients. The importance of the professional's bond with the caregiver is also reported, especially in communication and encouraging the expression of feelings. In this way, these actions contribute to building a team with conviction and cooperation for the resumption of home care<sup>17</sup>.

Along with isolation and uncertainties about the follow-up of cancer treatment during the pandemic, exacerbate feelings of anxiety, fear and depression, for patients and their families. To face this emotional burden, caregivers used family and religious support as a contribution. In similar situations, the individual resorts to his spiritual beliefs and religious conceptions, to understand and assimilate the vicissitude that afflicts him, originating feelings of support, resilience, confidence and hope. It is also known that these spiritual resources potentiate the

reduction of inflammatory cytokines in the body, reducing anxiety and stress levels<sup>18</sup>.

Thus, these caregivers tended to develop the ability to reframe the adversity caused by the disease. However, the opposite can also be observed: feelings of questioning the existence and relationship with the Sacred, considering such a situation as a sin and/or divine punishment. Paying attention to these situations, the professional must take into account religiosity and spirituality as a factor that subjectifies the individual, allowing him to express his ideas and questions during the consultations, building an interpersonal, affectionate, committed and empathetic relationship, offering help and being receptive to these individuals<sup>18,19</sup>.

### Final Considerations

The results demonstrate that the lack of knowledge of management in the face of the changes imposed by the COVID-19 pandemic in the routine of care for patients with hematological neoplasia is part of the caregiver's daily life. The main coping strategies used are related to family and spiritual support. Therefore, it is necessary to develop educational strategies to improve the care provided and empower the family to solve these problems.

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