Experience of Young Adults with Cancer During the COVID-19 Pandemic: A Qualitative Study on Health Care and Psycho-Emotional Impact

Experiência de jovens adultos com câncer durante a pandemia de COVID-19: um estudo qualitativo sobre cuidados de saúde e impacto psicoemocional

Experiencia de adultos jóvenes con cáncer durante la pandemia de COVID-19: un estudio cualitativo sobre la atención sanitaria y el impacto psicoemocional

Sabrina Nathiéle da Costa Moreira<sup>1</sup>, ORCID: 0000-0002-4804-2563 Michele Cristiene Nachtigall Barboza<sup>2</sup>, ORCID: 0000-0003-1489-5813 Ruth Irmgard Bartschi Gabatz<sup>3</sup>, ORCID: 0000-0001-6075-8516 Caroline de Leon Linck<sup>4</sup>, ORCID: 0000-0001-9487-3061 Nádia Regina Rutz<sup>5</sup>, ORCID: 0009-0005-8558-1768 Patricia Affeldt Peter<sup>6</sup>, ORCID: 0009-0005-5188-5189

<sup>123456</sup> Universidade Federal de Pelotas, Brazil

Abstract: Objective: To understand the experiences of young adults with cancer during the COVID-19 pandemic and its impact on their psycho-emotional well-being. Methodology: A qualitative case study approach, with data collected through semi-structured interviews conducted with young adults who underwent cancer treatment between March 2020 and December 2021 at a chemotherapy center in southern Brazil. The data was organized using WebQDA software and analyzed thematically. Results: The study revealed that, according to the participants, there were few changes in the oncology treatment process during the COVID-19 pandemic, and these were linked to the delay in starting treatment and delays in specialist consultations. Participants expressed concerns about contracting the virus due to the low immunity caused by cancer treatment. Additionally, strict protective measures, such as isolation, significantly affected the young adults undergoing treatment. They had to suspend their activities and distance themselves from their families, leading to negative emotional impacts. Conclusions: It can be considered that young people with cancer in the pandemic context require support from health services, particularly regarding accurate information, diagnosis, and early treatment, as delays in these processes can directly affect patient survival. Providing mental health care strategies also helps to combat both cancer and COVID-19.

Keywords: nursing; COVID-19; neoplasms; young adult; psychological stress.

**Resumo:** Objetivo: Conhecer a vivência de adultos jovens com câncer durante a pandemia de COVID-19 e o impacto na sua vida psicoemocional. Metodologia: Pesquisa qualitativa, do tipo estudo de caso, cujos dados foram coletados por meio de entrevista semiestruturada,



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com adultos jovens que fizeram tratamento oncológico no período de março de 2020 a dezembro de 2021, em um serviço de quimioterapia no sul do Brasil. Os dados foram organizados no *software* WebQDA, sendo a análise do tipo temática. Resultados: Neste estudo identificou-se que na percepção dos participantes ocorreram poucas alterações no processo de tratamento oncológico durante a pandemia de COVID-19, estando vinculadas ao atraso no início do tratamento e demora das consultas especializadas. Identificou-se ainda a preocupação em contrair o vírus devido à baixa imunidade causada pelo tratamento para o câncer. Além disso, o rigor nas medidas de proteção, como o isolamento causado pela COVID-19, afetou os jovens em tratamento, pois precisaram se afastar de suas funções e ficar longe de suas famílias, o que gerou sentimentos negativos. Conclusões: Pode-se considerar que jovens com câncer no cenário pandêmico necessitam de apoio dos serviços de saúde, principalmente a fim de obterem informações corretas, diagnóstico e tratamento precoce, uma vez que o atraso neste processo pode implicar diretamente na sobrevida dos pacientes. Somado ainda na elaboração de estratégias de cuidado para fornecer a saúde mental para o enfrentamento tanto do câncer quanto da COVID-19.

Palavras-chave: enfermagem; COVID-19; neoplasias; adulto jovem; estresse psicológico.

**Resumen:** Objetivo: Comprender la experiencia de adultos jóvenes con cáncer durante la pandemia de COVID-19 y el impacto en su vida psicoemocional. Metodología: Investigación cualitativa, del tipo estudio de caso, cuyos datos fueron recolectados a través de entrevistas semiestructuradas, con adultos jóvenes que realizaron tratamiento oncológico entre marzo de 2020 y diciembre de 2021, en un servicio de quimioterapia del sur de Brasil. Los datos fueron organizados en el software WebQDA, realizándose análisis temáticos. Resultados: En este estudio se identificó que en la percepción de los participantes hubo pocos cambios en el proceso de tratamiento oncológico durante la pandemia de COVID-19, los cuales se vincularon con el retraso en el inicio del tratamiento y retrasos en las consultas al especialista. También se identificó preocupación por contraer el virus debido a la baja inmunidad provocada por el tratamiento del cáncer. Además, el rigor de las medidas de protección, como el aislamiento provocado por la COVID-19, afectó a los jóvenes en tratamiento, quienes tuvieron que ausentarse de sus funciones y alejarse de sus familias, lo que generó sentimientos negativos. Conclusiones: Se puede considerar que los jóvenes con cáncer en el escenario de pandemia necesitan apoyo de los servicios de salud, principalmente para obtener información correcta, diagnóstico y tratamiento temprano, ya que los retrasos en este proceso pueden afectar directamente la supervivencia de los pacientes. También ayuda a desarrollar estrategias de atención para brindar salud mental para combatir tanto el cáncer como la COVID-19.

Palabras clave: enfermería; COVID-19; neoplasias; adulto joven; estrés psicológico.

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Correspondence: Michele Cristiene Nachtigall Barboza. E-mail: michelecnbarboza@gmail.com

## Introduction

According to data published by the José Alencar Gomes da Silva National Cancer Institute [Instituto Nacional de Câncer - INCA], there are more than 100 types of cancers <sup>(1)</sup> which may arise from internal causes such as hormonal conditions, immune system disorders, and genetic mutations, as well as external causes associated with pollutants, solar radiation, and lifestyle habits. The latter are linked to 90 % of cancer cases. <sup>(2)</sup> It is worth noting that cancer (CA) is considered the leading public health issue worldwide, predominantly affecting individuals over the age of 65. <sup>(3)</sup> However, although less frequently, cancer also affects young adults. <sup>(4)</sup>

Young adults are defined as individuals aged between 15 and 29 years. <sup>(5)</sup> The risk of developing CA in young people is associated with high rates of genomic mutations in cells, the multiple stages of disease pathogenesis, or the inheritance of alleles predisposing to CA, compounded by external factors that may contribute to disease development. <sup>(4)</sup>

Regarding oncological treatment, its aggressiveness raises concerns, as it can impair the immune system, leading to immunosuppression and increased susceptibility to infectious diseases. <sup>(6)</sup> Therefore, improved care and precautionary measures are deemed essential, as cancer patients are at greater risk of severe respiratory complications compared to patients with other pathologies. Additionally, cancer patients may experience more rapid clinical destabilization, often requiring intensive care unit (ICU) admissions. This need for heightened care becomes even more evident in the context of a pandemic such as COVID-19. <sup>(7)</sup>

COVID-19, a respiratory infection caused by the SARS-CoV-2 virus, can progress to severe conditions, including respiratory failure, which in some cases may result in death. Transmission occurs through contact, droplets, or aerosols. <sup>(8)</sup> In response, social distancing and isolation were crucial strategies to mitigate the disease and protect public health and safety. However, these measures impacted the general population and disrupted healthcare services. <sup>(9)</sup>

A study conducted in the United States investigated the pandemic's impact on healthcare systems, revealing delays in consultations, diagnostic tests, surgeries, chemotherapy, radiotherapy, and physiotherapy, raising concerns about cancer screening, diagnosis, and treatment. <sup>(10)</sup> A similar situation was observed in Brazil, specifically in the state of Bahia, regarding radiotherapy services. A 12 % decrease in first consultation appointments was identified in 2020 compared to the same period in the year prior to the pandemic. Simultaneously, researchers noted a worsening in tumor staging, leading to an increase in secondary metastases in 2020. <sup>(11)</sup>

These delays caused anxiety and distress among individuals undergoing cancer treatment, compounded by fears of contracting COVID-19 and potentially dying from it. The study also highlighted participants' feelings of isolation, loneliness, difficulty or inability to work, financial hardships, and concerns about losing friends and family members to COVID-19. <sup>(10)</sup>

Beyond the impacts on healthcare services, young adult cancer patients were also affected by social isolation. According to a study on young adults living with cancer, they expressed a greater need for peer support and interaction, <sup>(12)</sup> which was restricted during the pandemic, amplifying negative emotions and weakening their mental health.

Receiving a cancer diagnosis can trigger a range of emotions, including fear, anxiety, insecurity, emotional and financial instability. These are further compounded by feelings related to lifestyle changes and physical alterations, potentially leading to aggression and hopelessness, especially given the life-threatening nature of the disease. <sup>(13, 14)</sup> This impact may be even more pronounced when the affected individual is young and experiencing a pandemic.

Young adults undergoing cancer treatment during the pandemic face numerous challenges, including the risk of contracting COVID-19, the reorganization of healthcare services, and mental health impacts. In this context, it is crucial to develop studies aimed at devising strategies to mitigate these consequences and promote the psychological and social well-being of this population.

Given the above, there is a need to deepen understanding of the repercussions of the pandemic on cancer patients, particularly young adults. To this end, the following research question was formulated: How did young adults with cancer experience the COVID-19 pandemic and what were the psycho-emotional impacts on their lives? Thus, this study aims to explore the experiences of young adults with cancer during the COVID-19 pandemic and its psycho-emotional impacts on their lives.

#### Method

This is a qualitative case study conducted with young adults with cancer, treated at the oncology center of a Teaching Hospital (TH) affiliated with the Unified Health System (SUS), specifically in the outpatient chemotherapy service in southern Rio Grande do Sul, Brazil. The case study aims to deeply explore a contemporary phenomenon while preserving its unitary nature within its context. <sup>(15)</sup> In this research, the focus is on the experience of young adults with cancer during the pandemic.

Six young adults who underwent treatment at the aforementioned service between March 2020 and December 2021, during the COVID-19 pandemic, participated in the study. Data collection was carried out through semi-structured interviews, which included questions about participant demographics, their experience with cancer during the COVID-19 pandemic, and potential changes in care and treatment. The following questions were asked: What changes occurred in your life due to cancer, especially during the pandemic? What feelings did you experience during the pandemic? How did the pandemic impact your treatment? These questions were developed based on prior readings that highlighted the need to expand knowledge about the impact of cancer on young adults, particularly during health crises like the COVID-19 pandemic.

The study was approved by the Research Ethics Committee for Human Subjects under CAAE: 65944322.4.0000.5337 and opinion number 5.920.267. To adhere to ethical principles, participants' anonymity was maintained by assigning them the letter I (interviewee) followed by a number (1, 2, 3...), according to the order of the interviews. Additionally, participant profiles were presented in general terms and not linked to specific statements to prevent identification.

Participants were identified through referrals from professionals working at the research site and information from the service's database, which provided details such as phone numbers and ages of potential participants. Those who met the inclusion criteria (undergoing chemotherapy at the selected service during the COVID-19 pandemic and aged between 18 and 29 years) were contacted by phone. Invitations to participate in the study were made via phone calls or in person for those still receiving treatment at the service. For individuals who did not answer phone calls, messages were sent via the WhatsApp messaging app.

The selection criteria focused on the first two years of the pandemic, considering that the first year was marked by significant uncertainty about the disease, while the second year saw the highest rates of infection and mortality. Regarding participants' age, young adults were chosen as they represent an active population engaged in various social activities (professional training, entry into the job market, and diverse leisure activities). The pandemic and its social isolation measures likely had a stronger impact on this age group, which is also not typically associated with a high prevalence of cancer.

The service initially referred 22 individuals; however, only nine met the inclusion criteria, as some were over 29 years old or had completed cancer treatment before the onset of the COVID-19 pandemic. Of these nine, three did not answer phone calls or respond to WhatsApp messages.

Thus, six individuals met all criteria and constituted the final participant group. It is acknowledged that the small sample size is a limitation of the study, restricting the generalizability of results to other contexts. However, as this is a qualitative study, the goal is not generalization but rather an in-depth exploration of participants' perspectives and emotions, with theoretical saturation being subjective in such cases.

In thematic analysis, as employed in this study, theoretical saturation cannot be predetermined since meaning is derived from interpretation. Therefore, the decision to cease data collection is subjective and cannot be fully determined prior to analysis. Consequently, data saturation is not a universally applicable concept in thematic analysis, as it depends on how thematic analysis and qualitative research are conceptualized and how data saturation itself is defined and determined. <sup>(16)</sup>

Before starting the interviews, participants were individually informed about the study's objectives, voluntary participation, and the need to sign an Informed Consent Form. Following participant invitations and acceptance, data collection commenced through semi-structured interviews. The interviews were conducted in a quiet, private, and silent location provided by the service to facilitate information gathering. It should be noted that both the study participants and the researcher wore PFF2 masks to prevent contamination and transmission of the COVID-19 virus.

The interviews lasted an average of 20 minutes and were conducted between April and June 2023. They were recorded and manually transcribed in full, with double-checking for accuracy. Transcriptions were completed in Word documents. After transcription, the data were uploaded and organized using the WebQDA software, an online platform. The use of this software enhanced the categorization and interpretation processes of qualitative data by enabling structured coding and ensuring faster and more efficient data management with systematic and transparent analysis. <sup>(17)</sup> Through this software, statements were grouped based on similarity, creating codes that were later refined and evaluated for their significance within the overall findings.

The following word cloud was generated with the 100 most frequent words, considering those with at least three characters and excluding pronouns, adverbs, adjectives, verbs, and other common words (e.g., "that," "not," "but," "he," "this," "did," "have," "one," among others) to highlight the most representative terms:

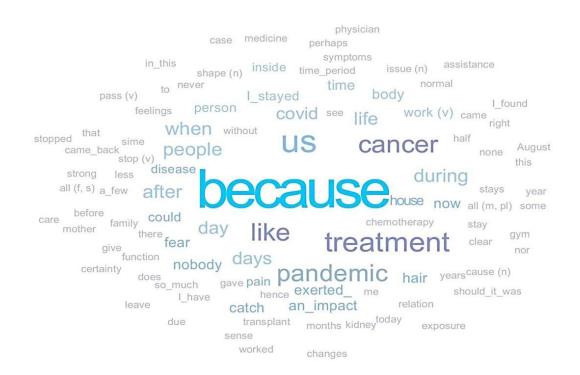


Figure 1. Word cloud of the 100 most frequent words.

Based on the figure, it is evident that the word "because" was the most cited, reflecting the questions and explanations the interviewees associated with the disease and the limitations it imposed on their lives. This served as an important guide in developing the codes that generated the categories. Some words related to the experienced period and how participants perceived their journey toward diagnosis and treatment (identified as initial codes) stand out, such as: "now", "during", "after", "time". Words associated with the disease and the pandemic, as well as the precautions participants adopted in response to cancer and the pandemic (also identified as initial codes), include: "cancer", "Covid", "disease", "impacted", "treatment", "fear", "pandemic", "changes", "family", "work". Based on these words, initial codes were created, followed by the grouping of statements to form categories.

The analysis of the collected narratives was conducted using thematic analysis, <sup>(18)</sup> which involved identifying, analyzing, and reporting themes present in the data. This process followed six steps: familiarization with the interviews (transcription and in-depth reading); generation of codes (extraction of the most frequent words, as shown in the software's word cloud); theme construction (grouping data that converged into a common theme); theme review phase (reviewing the data and categories into which they were divided); synthesis and report production phases (organization, interpretation, and discussion of themes within the established categories). Thus, based on the initial coding derived from the word cloud and following the steps outlined above, two categories were developed to present the synthesis of results: Diagnosis and treatment for cancer in association with the COVID-19 pandemic, and Perspectives and emotions experienced in the face of cancer and COVID-19.

#### Results

Regarding participant profiles, they ranged in age from 21 to 29 years, with four females and two males. In terms of occupational activities, three were university students, two were employed, and one received government assistance. Three participants lived with their parents, while the other three lived with partners. As for diagnoses, participants had various types of cancer, including breast cancer, cervical cancer, testicular cancer, synovial sarcoma, Hodgkin's lymphoma, and non-Hodgkin's lymphoma. Although data were collected during the treatment phase, participants shared experiences and emotions spanning the entire illness process.

### Diagnosis and treatment for cancer in association with the COVID-19 pandemic

This category presents participants' accounts regarding their cancer diagnosis and treatment during the pandemic. In some cases, the process was delayed due to factors such as patients' health conditions, the need for social isolation, or limited availability of medical consultations for screening. However, based on most participants' accounts, the pandemic did not alter or delay their treatment, as observed in the following statements:

My treatment was not affected during the pandemic; I didn't notice any changes while undergoing chemotherapy (I1).

No, I don't think I missed any sessions, actually. It was very smooth. My sessions were every 21 days, sometimes a bit longer, like 25 days. So, I didn't feel any difference (I2).

Everything was normal, routine exams, consultations, chemotherapy cycles all happened as scheduled; there were no complications (I3).

No, I don't recall any changes. I think everything stayed the same because it was cancer, and they couldn't afford to delay it (I6).

The above statements indicate that participants did not experience delays in their exams or treatments, with everything proceeding as planned without significant changes. Conversely, one participant reported that the pandemic delayed her diagnosis because she struggled to schedule medical appointments:

Since it was during the peak of COVID, I had to wait; sometimes it took a long time to get appointments with gynecologists. I waited; everything was reduced. I

called clinics, and some didn't answer, some said they weren't operating, and others said it would take a month to schedule. It was really difficult (I4).

I4 highlighted the challenges of scheduling specialist consultations during the pandemic, as some services were suspended at that time, making access to care more difficult. Additionally, the same participant shared that contracting COVID-19 required her to isolate, which delayed her cancer treatment.

They sent me home because I was already hospitalized at the time when I got it. So, they sent me home. I stayed in isolation for 14 days, and then my treatment, right? I had to wait to start my treatment because of COVID (I4).

I4's account illustrates how both healthcare service delays and her own health condition-contracting COVID-19-interfered with the start of her cancer treatment, as recovering from the infectious disease was prioritized. Furthermore, the pandemic context imposed certain changes on participants' lives, particularly regarding heightened hygiene and asepsis measures:

I think the pandemic mainly changed things related to asepsis and cleanliness. I think that's it - wearing masks, using alcohol sanitizer, those kinds of things (I5).

This thematic category revealed that, overall, participants did not perceive delays or changes in their diagnoses and treatments. However, in cases where delays occurred, they were attributed either to participants' health conditions requiring recovery after contracting COVID-19 or to the suspension of healthcare services at the onset of the pandemic.

# Perspectives and emotions experienced in the face of cancer and COVID-19

This category presents participants' perspectives and emotions regarding cancer, focusing on the impact of the diagnosis and treatment as well as fears related to broader disruptions beyond health, such as work and social interactions. In this context, participants experienced feelings of loneliness and fear, questioning the disease and its imposed limitations:

The first feeling is a certain loneliness, let's say. There are a thousand people around you, but no one can take it away [...] you're the one who has to feel it, this pain that's inside you; no one can save you (I2).

It ends up messing with your mental state because I've always been very active in my life - studying, working, doing my things, right? And I really liked going out too... it's complicated, right? I had to stop all my activities (I4).

I2 explained that the first feeling was loneliness, perceiving cancer as a solitary and individual experience that no one else can take away, resulting in a pain that conveys the sense that no one can save the person from this experience. I4's account highlighted questioning why she had to experience cancer despite leading an active and healthy lifestyle. She also expressed frustration at having to stop all her activities due to the diagnosis, showing a lack of understanding about why she had to go through this ordeal.

The coexistence of a cancer diagnosis with the COVID-19 pandemic had a significant psychological impact on the participants. The immunosuppression caused by chemotherapy increased the risk of infection, requiring stricter precautions and adding to the emotional burden of the participants:

Actually, I can't afford to get sick, right? So I take a lot of care, I don't go out on the street anymore, especially not around strangers. I just don't go out [...] I'm afraid of catching a cold because my immunity is low, so I can't take the risk (I1).

With low immunity, I started taking more care and taking things more seriously. So, I think regarding the pandemic, that's mostly it, especially since I'm undergoing chemotherapy and everything (I5).

Yes, I was very afraid of catching COVID because of my immunity, and how my body would respond to the treatment (I3).

It is evident that with the onset of the pandemic, participants heightened their already existing precautions, as they realized that with cancer treatment and reduced immunity, they were even more susceptible to contracting COVID-19. Out of fear of contracting COVID-19, participants stayed home more often. However, despite these measures, I1 reported contracting the disease:

Regarding the pandemic, I think it impacted everyone's life because we couldn't do anything. I caught it (referring to contracting COVID) without even leaving the house. I caught it just from delivery people who came to deliver things, even though I used hand sanitizer, wore a mask, everything —and still, I caught it [...]. I didn't leave the house; I only went out for chemo sessions and consultations. I didn't let anyone visit me, sanitized everything, shopped for groceries online - everything to avoid going out (I1).

It's account makes it clear that even with heightened hygiene measures and maintaining social distancing, the participant still contracted COVID-19. Additionally, beyond the fear of contracting COVID-19 themselves, participants also worried about their family members:

And that was on my mind one hundred percent of the time because, like, my fiancé was still working, and he worked with people, right? (I3).

I stayed home with just my mom. My mom and I wore masks so she wouldn't catch it. We didn't share utensils or anything, but of course, I was always afraid she'd catch it too (I4).

In this context of fear and uncertainty, there was even confusion between COVID-19 symptoms and cancer symptoms, as seen in I4's account:

Since I already had some symptoms 'in quotes' similar to COVID-19, sometimes I had a lot of body pain too, right? I already had the pain, and then I felt body aches, fever, and those kinds of things. So I couldn't tell what was COVID and what was cancer, right? Which pain was which (I4).

I4's account shows that symptoms of one condition can mask those of another. In other words, similar symptoms may stem from both COVID-19 and cancer, making identification more challenging. In this context, protective measures affected participants' lives. The social isolation imposed by the pandemic was also highlighted as it interfered with their lives, forcing them to stop working or interacting with family, further amplifying the vulnerability they were already experiencing due to cancer:

So I think this lack of social interaction —seeing people, hugging them, at least seeing your family. [...] and working— I'm someone who works a lot, and because I work with autistic children, I felt very guilty because I was absent, and the children needed me (I3).

I3 highlighted the impact of pandemic restrictions on her work, expressing concern not only for herself but also for the population she served —in this case, autistic children. On the other hand, I2 reported being more exposed to the virus due to the need to accompany her sick mother:

I had to live somewhat exposed, so to speak. For example, at the hospital —my mom had to undergo surgery, and my family is extremely small, so it kind of fell on me (I2).

A The need to accompany her mother during treatment increased I2's exposure, leaving her with no alternative. Additionally, it was noted that patients' families, as in the case of I6, were more concerned about the participant contracting COVID-19 than the participant themselves:

Yeah, I think my mom was more worried than I was. You know how moms are, right? They worry more about us than about themselves, even though she could also get sick —maybe even worse than me (I6).

Based on the results, it was possible to identify the impact caused by both cancer and COVID-19 on the participants' lives. They had to adjust their routines and experienced feelings of fear and loneliness.

### Discussion

Based on the results, it was observed that most participants did not perceive significant changes in cancer treatment due to COVID-19, nor in the care received from healthcare professionals. However, what intensified were the precautions adopted in care, such as asepsis.

According to participant I4, the main issue was the delay in consulting a specialist. This delay may be related to the reorganization of healthcare services during the pandemic, as one of the first measures adopted in the study's municipality was the closure of specialty outpatient clinics and the temporary suspension of specialist consultations and elective surgeries, redirecting resources to combat COVID-19 due to the high mortality rate.

Thus, it can be inferred that individuals in the initial phase, i.e., undergoing cancer screening and diagnosis, were the most negatively affected by the pandemic. The healthcare system already exhibited weaknesses prior to the pandemic, which only further exposed this problem in the country. According to a study conducted in Brazil using data from the cancer information system, there was a decline in procedures related to cancer screening, diagnostic investigation, and treatment in 2020 compared to 2019, except for chemotherapy, which maintained its volume with a slight increase in 2020. <sup>(19)</sup> However, screening tests experienced the greatest reductions, particularly from April to June 2020, the period of greatest pandemic complexity in the country.

In a study conducted in northern Brazil with data collected during the first six months of the pandemic, adequate therapeutic maintenance for patients at an oncology center was

identified. This was attributed to the adoption of preventive safety measures by the service. <sup>(20)</sup> Similarly, this study also investigated patients who were mostly undergoing ongoing cancer treatment at the institution, unlike other studies that examined specialist consultations and screening and diagnostic tests.

Likewise, a comparative study on cancer treatment before and after the pandemic identified a significant decrease in the number of patients undergoing treatment and those attended to. These declines were observed in medical consultations, particularly initial consultations and the initiation of new cycles of systemic intravenous treatments, oncological surgeries, hospitalizations for cancer-related diagnoses, and stem cell transplants. <sup>(21)</sup> In other words, the most significant and negative impact was observed among patients in the screening and treatment initiation phases.

For young adults, difficulties in screening and diagnosis can directly impact their quality of life and that of their families. The need for longer, more aggressive treatments and hospitalizations can interfere with their education and/or work processes, disrupting daily life and family income. It also isolates these young individuals from social interactions for prolonged periods, which may further affect their mental health.

From participants' accounts, it is also evident that young adults with cancer undergoing treatment experience feelings of insecurity and fear of contracting COVID-19 or other illnesses due to immunosuppression. As a result, they adopted social isolation measures to avoid contagion. In a study on social representations conducted with young people undergoing cancer treatment during the pandemic in Pernambuco, it was found that young individuals expressed fear of contracting the virus, given the compromised immunity caused by treatment. <sup>(22)</sup>

Although results do not confirm that cancer patients are more susceptible to severe infections, societies dedicated to treating these patients have highlighted an extremely vulnerable group. This group includes patients undergoing induction chemotherapy, which often involves high doses of steroids; individuals being treated for leukemia and lymphoma; those who underwent hematopoietic stem cell transplants in the past 12 months; and those receiving CAR T-cell gene therapy. <sup>(23)</sup> It is worth noting that, in addition to complications, healthcare professionals should be vigilant about the possibility of co-infections, i.e., concurrent infections by COVID-19 and other microorganisms, especially in transplant populations.

It is known that COVID-19 spreads through person-to-person contact. However, even while staying at home in isolation, some participants interacted with family members within the same household or with service providers, which generated feelings of fear and insecurity. One participant even mentioned contracting COVID-19 through service providers:

As a strategy to remain isolated, adopting changes in shopping habits —such as using delivery services and online shopping— was identified as a way to minimize exposure among study participants. During the pandemic, many people in Brazil <sup>(24)</sup> and globally <sup>(25)</sup> changed their shopping habits, opting for online platforms or delivery services. This allowed greater adherence to health protocols and became an alternative to minimize infection risk and protect health. For cancer patients who are immunosuppressed, this option proved to be not only important but necessary.

The fear of contagion, lifestyle changes, and confinement of cancer patients during the COVID-19 pandemic had a negative impact on their mental well-being, exacerbating

feelings such as stress, anxiety, depression, and loneliness. Additionally, a decline in quality of life, emotional functioning, cognitive functioning, and social functioning was identified among cancer patients during the COVID-19 period. <sup>(26, 27)</sup>

It is important to consider that oncology patients are already at risk of developing depression due to situations associated with cancer, such as fear of death. <sup>(28)</sup> This was compounded by anxieties related to the pandemic and the patients' age group. Although the pandemic is now being overcome, it is essential to invest in long-term mental health care for these individuals, as the effects of the pandemic may persist.

In this context, it is crucial to develop specific interventions for young adults undergoing cancer treatment and their families to address their psychological and social needs, <sup>(29)</sup> thereby minimizing the negative repercussions caused by COVID-19. Moreover, these strategies could foster policies aimed at mental health care for young adult oncology patients during crises, assisting in structuring the healthcare system to address pandemics and other catastrophes.

One participant shared her experience of accompanying her mother, who required hospitalization for breast cancer treatment. This demanded care, exposure to a hospital environment, and potential contamination. On the other hand, I6 reported that his greatest concern about exposure was for his mother rather than himself. The fear of contracting COVID-19 and transmitting it to the person with cancer negatively impacts the mental health of family members and their ability to support the cancer patient.

Thus, it is essential for healthcare professionals to provide support not only to the person with cancer but also to their caregiver. Considering the broader context, it is relevant to develop activities such as support groups and to expand the presence of mental health professionals in oncology services. Cancer treatment generates a range of negative emotions, and sharing ideas and thoughts could serve as a coping strategy to mitigate these challenges.

It is important to highlight that direct exposure to hospital units, the use of public transportation, and limited resources for personal protective equipment such as alcoholbased sanitizers and masks increased individuals' risk of contracting the disease. <sup>(19)</sup>. Consequently, concerns about falling ill and transmitting the virus to family, friends, or coworkers can directly affect mental health. These factors may lead to varying degrees of psychological distress, making this population vulnerable to feelings of insecurity about their own lives.

This phenomenon was also identified in a study conducted in Iran, where the failure to adhere to standard precautionary measures, such as mask-wearing and vaccination, due to negligence by companions of cancer patients, caused fear of infection and mental distress. <sup>(30)</sup> Similarly, feelings of frustration were reported by cancer patients who noticed that family members were not adopting safety measures against the virus. <sup>(31)</sup>

A COVID-19 is highly transmissible among humans. Patients presented symptoms such as fever, malaise, and cough. While pneumonia was initially the clinical hallmark of the disease that led to case detection, more recent reports have described gastrointestinal symptoms and asymptomatic infections. <sup>(32)</sup> Thus, COVID-19 symptoms such as body aches and fever were confused with cancer symptoms by one participant, as these symptoms can occur in both diseases. During the pandemic, communication barriers between patients and healthcare professionals were identified due to mask usage (making it difficult to clearly hear what was being said), <sup>(30)</sup> combined with the need to create cancer care protocols to ensure well-being and provide support during a global health crisis. <sup>(33)</sup> In this context, it is

imperative for healthcare professionals to provide support to oncology patients so they can distinguish between symptoms of cancer and COVID-19, thereby enabling appropriate treatment and care.

Additionally, the role of nursing professionals is particularly significant in this regard, as they spend most of the time with patients across all levels of healthcare services, facilitating communication and addressing doubts. Thus, training healthcare professionals to identify symptoms and ensure accurate diagnoses for cancer patients infected with COVID-19 is essential.

#### Conclusions

It was found that, from the perspective of most participants, there were no changes or delays in their treatment during the COVID-19 pandemic. However, they highlighted the fear of contracting the virus due to their low immunity caused by treatment, leading to heightened asepsis precautions. The COVID-19 pandemic intensified the social isolation already experienced by young people with cancer, limiting their social interactions and distancing them from their roles and families. Thus, the necessary distancing to avoid virus transmission, combined with the isolation resulting from cancer treatment, generated feelings that could have significant psychological consequences for these young individuals.

Data collection faced limitations due to the low number of young people undergoing treatment during this period, as most were referred to the state's main oncology center in Porto Alegre, the state capital and a specialized oncology hub. Although the results cannot be generalized to other populations, the qualitative approach addresses a specific reality and may provide important care guidelines for other contexts involving young people with cancer.

The study highlights the importance of psychological support for cancer patients and their families, especially during crises such as the COVID-19 pandemic. The fear of contamination, social isolation, and uncertainty about the future generate high levels of stress in these individuals.

To address this, it is crucial to develop specific care protocols for cancer patients during pandemics. These protocols should include clear information about COVID-19, psychological support to address emotional issues caused by the disease and the pandemic, and the expansion of multidisciplinary teams trained to meet the complex demands of this population. Implementing these protocols will help develop effective coping strategies and improve the quality of life for patients and their families.

# **Bibliographical references**

- Instituto Nacional de Câncer. O que é o câncer? [Internet]. Brasília, DF: Ministério da Saúde; 2022 [cited 2024 Mar 27]. Available from: https://www.gov.br/inca/ptbr/assuntos/cancer/o-que-e-cancer
- 2. Instituto Nacional de Câncer. O que causa o câncer? [Internet]. Brasília, DF: Ministério da Saúde; 2023 [cited 2024 Mar 27]. Available from: https://www.gov.br/inca/pt-br/assuntos/causas-e-prevencao-do-cancer/o-que-causa-o-causa-o-causa-

- 3. Cohen HJ, Wong ML. Comprehensive geriatric assessment for patients with cancer [Internet]. Waltham, MA: UpToDate; 2023 [cited 2024 Mar 27]. Available from: https://www.uptodate.com/contents/comprehensive-geriatric-assessment-for-patients-with-cancer
- 4. Kentsis A. Why do young people get cancer? Pediatr Blood Cancer [Internet]. 2020 [cited 2024 Apr 19];67(7):e28335. doi: 10.1002/pbc.28335
- 5. Brasil. Institui o Estatuto da Juventude e dispõe sobre os direitos dos jovens, os princípios e diretrizes das políticas públicas de juventude e o Sistema Nacional de Juventude SINAJUVE. Lei 12.852/2013, de 05 de agosto. Presidência da República Casa Civil, 2013. Available from: https://www.planalto.gov.br/ccivil\_03/\_ato2011-2014/2013/lei/l12852.htm
- Silva EV de S, Nascente E de P, Miguel MP, Alves CEF, Moura VMBD de. Elucidating tumor immunosurveillance and immunoediting: a comprehensive review. Ciên Anim Bras [internet]. 2021 [cited 2024 Apr 20];22:e68544. doi: 10.1590/1809-6891v22e-68544
- You B, Ravaud A, Canivet A, Ganem G, Giraud P, Guimbaud R, et al. The official French guidelines to protect patients with cancer against SARS-CoV-2 infection. Lancet Oncol [Internet]. 2020 [cited 2024 Apr 20];21(5):619–621. doi: 10.1016/S1470-2045(20)30204-7
- 8. Departamento de Assistência Hospitalar e Ambulatorial. Nota Técnica COVID-19 e Câncer [Internet]. Porto Alegre; 2020 [cited 2024 de Apr 20]. Available from: https://saude.rs.gov.br/upload/arquivos/202005/12093620-covid-e-cancer.pdf.
- Aquino EML, Silveira IH, Pescarini JM, Aquino R, Souza-Filho JA, Rocha AS, et al. Medidas de distanciamento social no controle da pandemia de COVID-19: potenciais impactos e desafios no Brasil. Ciênc Saúde Coletiva [Internet]. 2024 [cited 2024 Oct 09];25:2423-46. doi: 10.1590/1413-81232020256.1.10502020
- Greteman BB, Del Vecchio NJ, Garcia-Auguste CJ, Kahl AR, Gryzlak BM, Chrischilles EA, et al. Identifying predictors of COVID-related delays in cancer-specific medical care. Cancer Med [Internet]. 2024 [cited 2024 Apr 20];13(8):e7183. doi: 10.1002/cam4.7183
- Jesus, AS, Guedes TS, Martins. Impacto da pandemia de COVID-19 no atendimento do serviço de radioterapia em um hospital público de Salvador/BA. Revista de Ciências Médicas E Biológicas [Internet]. 2021 [cited 2024 Oct 09]; 20(3):369-374. doi: 10.9771/cmbio.v20i3.47075
- Fox RS, Armstrong GE, Gaumond JS, Vigoureux TFD, Miller CH, Sanford SD, et al. Social isolation and social connectedness among young adult cancer survivors: A systematic review. Cancer [Internet]. 2023 [cited 2024 Oct 09];129(19):2946-2965. doi: 10.1002/cncr.34934

- 13. Oliveira SSW, Vasconcelos RS, Amaral VRS, Sá KN. Spirituality in coping with pain in oncological patients: systematic review. BrJP [Internet]. 2020 [cited 2024 Apr 20];3(2):158-163. doi: 10.5935/2595-0118.20200028
- 14. Sinski KC, Lins JVA, Schneiders M, Friestino JKO, Garcia ACM, Araújo JS, et al. A corporeidade no adoecimento por câncer entre pacientes oncológicos em quimioterapia: um estudo qualitativo. Ciên Cuid Saúde [Internet]. 2024 [cited 2024 Apr 20];23:e68445. Available from: https://periodicos.uem.br/ojs/index.php/CiencCuidSaude/article/view/68445
- 15. Gil AC. Como fazer pesquisa qualitativa. 1ed. Barueri, SP: Atlas; 2021.
- Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. Qualitative Research in Sport, Exercise and Health [Internet]. 2019. [cited 2024 Aug 22];13(2):1-16. doi: 10.1080/2159676X.2019.1704846
- 17. Machado ALG, Vieira NFC. Uso do software webQDA na pesquisa qualitativa em enfermagem: relato de experiência. Rev Bras Enferm. [Internet]. 2020 [cited 2024 Apr 23];73(3):e20180411. doi: 10.1590/0034-7167-2018-0411
- Braun V, Clarke V, Hayfield N, Terry G. Análise Temática. In Liamputtong P, editor. Manual de Métodos de Pesquisa em Ciências Sociais da Saúde. Singapore: Springer; 2019, p. 843–860. doi: 10.1007/978-981-10-5251-4\_103
- Ribeiro CM, Correa F de M, Migowski A. Efeitos de curto prazo da pandemia de COVID-19 na realização de procedimentos de rastreamento, investigação diagnóstica e tratamento do câncer no Brasil: estudo descritivo, 2019-2020. Epidemiol Serv de Saúde [Internet]. 2022 [cited 2024 May 03];31(1):e2021405. doi: 10.1590/S1679-49742022000100010
- 20. Moraes D dos S, Pereira HFB do ESA, Machado M, Turner NJR, Rebello RT, da Silva LA. Influência da pandemia de COVID-19 no tratamento oncológico de pacientes com câncer de mama em um hospital referência no Amazonas. Revista Contemporânea [Internet]. 2023 [cited 2024 Aug 24];3(8):12643–12657. doi: 10.56083/RCV3N8-148
- 21. Araújo SEA, Leal A, Centrone AFY, Teich VD, Malheiro DT, Cypriano AS et al. Impact of COVID-19 pandemic on care of oncological patients: experience of a cancer center in a Latin American pandemic epicenter. Einstein [Internet]. 2021 [cited 2024 May 03];19:eAO6282. doi: 10.31744/einstein\_journal/2021AO6282
- Silva MMAS da, Accioly CC, Pedrosa APA, Azevedo SM de, Albuquerque EN, Lima TLBK, et al. Young people in oncological treatment during COVID-19: indicators of the social representation of the coronavírus. Rev Bras Saúde Mater Infant [Internet]. 2021 [cited 2024 May 03];21(Suppl 1):197–204. doi: 10.1590/1806-9304202100S100010

- 23. Silva-Rodrigues FM, Silva JK da, Felix AM da S. Coronavirus infection and nursing care for children and adolescents with cancer. Rev Bras Enferm. [Internet]. 2021 [cited 2024 May 06];74(Suppl1):e20201049. doi: 10.1590/0034-7167-2020-1049
- 24. Bracarense L dos SF, Oliveira R, Vaz L, Ribeiro M. Mudanças no comportamento em relação às compras durante a pandemia de COVID-19 e impactos sobre os padrões de deslocamentos. Revista Transporte Y Territorio [Internet]. 2022 [cited 2024 Aug 24];(27). doi: 10.34096/rtt.i27.12216
- 25. Kristofani A, Kania A, Felice A, Cynthia C, Christy J, Novita N, et al. Hubungan pertimbangan manfaat dan risiko, alat pembayaran, dan tempat berbelanja dengan perilaku konsumen menjaga protokol kesehatan. Jurnal Manajemen [Internet]. 2021 [cited 2024 Aug 24];18(2):153-170. doi : 10.25170/jm.v2i18.2884
- 26. Yera-Rodríguez K, Padrós-Blázquez F, González-Ramírez V, Sierra-Murguía A. Impacto de la COVID-19 en el distrés, ansiedad, depresión y calidad de vida en pacientes con cáncer. Psicooncología [Internet]. 2023 [cited 2024 May 04];20(2):329-344. doi: 10.5209/psic.91235
- 27. Elkefi S, Matthews AK. Disparities in the Care Disruption During COVID-19 and in its Impacts on the Mental and Physical Well-Being of Cancer Survivors. American Journal of Health Promotion [Internet]. 2024 [cited 2024 Aug 24];38(8):1188-1198. doi: 10.1177/08901171241262224
- 28. Pessanha AS, Percu BS, Leite RT, Mattos Júnior LSF, Guerrero L, Aguiar JS, et al. Efeitos gerados na saúde mental de pacientes oncológicos em meio à pandemia da COVID-19. Revista Eletrônica Acervo Científico [Internet]. 2023 [cited 2024 Oct 11];44:e12388. doi: 10.25248/reac.e12388.2023
- 29. Agua CY, Suárez SL, Gázquez D de H, Pérez EB, Sánchez BF, García MR, et al. Malestar psicológico y preocupaciones psicosociales durante la tercera ola de la pandemia en pacientes oncológicos y familiares: Un análisis exploratório. Psicooncología [Internet]. 2023 [cited 2024 May 04];20(1):11-26. doi: 10.5209/psic.87569
- Dadashzadeh A, Davoodi A, Sheikhnezhad L, Ghafourifard M, Hassankhani H, Zarrin L, et al. Challenges Faced by Cancer Patients during the COVID-19 Pandemic, a Vision for the Future: A Qualitative Study. Asian Pacific Journal of Cancer Prevention [Internet]. 2024 [cited 2024 Aug 24];25(7):2343-2349. doi: 10.31557/APJCP.2024.25.7.2343
- 31. Shay LA, Allicock M, Li A. "Every day is just kind of weighing my options". Perspectives of young adult cancer survivors dealing with the uncertainty of the COVID-19 global pandemic. J Cancer Surviv [Internet]. 2022 [cited 2024 Aug 24];16:760-770. doi: 10.1007/s11764-021-01069-9

- Thuler LCS, Melo, AC de. Sars-CoV-2/Covid-19 em pacientes com Câncer. Rev Bras Cancerolog [Internet]. 2020 [cited 2024 May 06];66(2):e-00970. doi: 10.32635/2176-9745.RBC.2020v66n2.970
- Henderson A, Xin H. Challenges Experienced by U.S. Cancer Patients during COVID-19: Implications for Future Public Health Emergency Preparedness. Universal Journal of Public Health [Internet]. 2022 [cited 2024 Aug 24];10(5):539-546. doi: 10.13189/ujph.2022.100511

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