

Care of children and adolescents undergoing cancer treatment in the COVID-19 pandemic: experience of family members

Cuidado de crianças e adolescentes em tratamento oncológico na pandemia da COVID-19: experiência de familiares

Atención de niños y adolescentes en tratamiento oncológico en la pandemia de COVID-19: experiencia de familiares

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ABSTRACT

Objective: to describe the experience of family members of children and adolescents with cancer undergoing cancer treatment, during the COVID-19 pandemic. **Method:** qualitative, exploratory and descriptive study, with 20 family members of children and adolescents undergoing cancer treatment in a pediatric oncology outpatient clinic. Semi-structured interviews were carried out in September and October 2020 and subsequent content analysis. **Results:** the experiences lived by family members in the care of children and adolescents during the pandemic reveal repercussions and ways of coping arising from concerns and insecurities related to COVID-19, changes in routine and the reorganization of therapeutic programs for the continuity of cancer treatment. **Conclusion:** both children and adolescents and their families redoubled the precautions they were used to before the pandemic. There was a need for reorganization and rescheduling of consultations, procedures and hospitalizations, but without prejudice to the planned therapy. Insecurity and anxiety were the most present feelings related to the evolution of COVID-19.

Descriptors: Oncology Nursing; COVID-19; Child Health; Adolescent Health; Family.

RESUMO

Objetivo: descrever as experiências vivenciadas por familiares de crianças e adolescentes com câncer, em tratamento oncológico, durante a pandemia da COVID-19. **Método:** estudo qualitativo, exploratório e descritivo, com 20 familiares de crianças e adolescentes em tratamento oncológico em um ambulatório de oncopediatria. Foram realizadas entrevistas semiestruturadas em setembro e outubro de 2020 e posterior análise de conteúdo. **Resultados:** as experiências vivenciadas pelos familiares no cuidado à criança e ao adolescente durante a pandemia revelam repercussões e formas de enfrentamento advindas das preocupações e inseguranças relacionadas à COVID-19, das mudanças na rotina e da reorganização das programações terapêuticas para a continuidade do tratamento oncológico. **Conclusão:** tanto as crianças e os adolescentes quanto seus familiares redobram as precauções que estavam habituados antes da pandemia. Observou-se a necessidade de reorganização e reagendamentos de consultas, procedimentos e internações, mas sem prejuízos para a terapêutica programada. A insegurança e a ansiedade foram os sentimentos mais presentes, relacionados à evolução da COVID-19.

Descritores: Enfermagem Oncológica; COVID-19; Saúde da Criança; Saúde do Adolescente; Família.

RESUMEN

Objetivo: describir las vivencias de familiares de niños y adolescentes con cáncer, en tratamiento oncológico, durante la pandemia de COVID-19. **Método:** estudio cualitativo, exploratorio y descriptivo, junto a 20 familiares de niños y adolescentes en tratamiento oncológico en un ambulatorio de oncología pediátrica. Se realizaron entrevistas semiestructuradas en septiembre y octubre y posterior análisis de contenido. **Resultados:** las experiencias vividas por los familiares en el cuidado de niños y adolescentes durante la pandemia revelan repercusiones y formas de enfrentamiento derivadas de las preocupaciones e inseguridades relacionadas con el COVID-19, los cambios de rutina y la reorganización de los programas terapéuticos para la continuidad del tratamiento oncológico. **Conclusión:** tanto los niños y los adolescentes como sus familiares redoblaron las precauciones a las que estaban acostumbrados antes de la pandemia. Hubo necesidad de reorganización y reprogramación de consultas, procedimientos y hospitalizaciones, pero sin perjuicio de la terapia prevista. La inseguridad y la ansiedad fueron los sentimientos más presentes relacionados con la evolución del COVID-19.

Descritores: Enfermería Oncológica; COVID-19; Slud Infantil; Salud del Adolescente; Familia.

INTRODUCTION

The Coronavirus Disease 19 (COVID-19), an infectious disease caused by the respiratory virus called Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2), has affected thousands of people worldwide. Its first records were identified in the city of Wuhan, China, in December 2019 and the disease spread rapidly. At the beginning of the pandemic, despite the fact that the disease caused by SARS-CoV-2 reached a greater proportion of the adult population

than that of children and adolescents, it was observed that the latter presented the asymptomatic or mild form, acting as transmission vehicles for adults; however, the occurrence of serious forms could not be ruled out².

Over time, the disease presented more and more cases with greater severity in the child and adolescent population, with new clinical manifestations that included multisystemic inflammatory syndrome, which could progress to cardiogenic shock, rendering hospitalizations in pediatric intensive care units necessary³.

In Brazil 14,638 pediatric COVID-19 cases were reported in 2020, with 1,203 deaths and a fatality rate of 8.2%, representing 0.6% of the total number of deaths due to COVID-19 in the country. Nearly 42% of the deaths occurred in children under two years of age and 43% in children and adolescents aged between 10 and 19 years old. From January to September 2021, 17,000 pediatric COVID-19 cases with 1,180 deaths were reported, reaching a fatality rate of 6.9%. Of these deaths, 37% were in children under two years of age and approximately 50% in adolescents. It is noted that 58% of the pediatric patients who died, both in 2020 and in 2021, had at least one previous condition or comorbidity⁴.

In view of the COVID-19 infection cases in children and adolescents, even if primarily presenting mild forms, at the end of 2021, vaccinations were authorized and initiated for adolescents over 12 years of age and evaluation to later expand to younger children, based on international and national studies for the use of an effective and safe vaccine for the child population⁵.

However, it is important to note that, even with the higher incidence of cases in the adult population, COVID-19 progressed in patients with comorbidities and diseases such as cancer. Cancer patients were more vulnerable to infection by the new coronavirus due to the development of complications and to evolution of the disease to more severe forms, as a result of factors such as: the systemic immunosuppression state arising from the therapies they are subjected to, mainly in oncopediatric patients undergoing myeloablative therapies, which require the administration of high doses of immunosuppressive medicines; cancer staging; and tumor aggressiveness^{3,6}.

Thus, in addition to the everyday changes faced by oncopediatric patients and their family members during the course of the pandemic, the social distancing and isolation measures adopted mainly in 2020 and 2021 are added to reduce spread of the disease.

The repercussions on the lives of these people became conflicting and were directly influenced by the health team's decision-making regarding the cancer and COVID-19 treatments, given these patients' higher contagion risk, high transmission of the new coronavirus and the need for treatment continuity, as its postponement significantly implied cancer prognosis and evolution⁶.

Therefore, given the COVID-19 pandemic scenario, it was considered relevant to identify how family members of oncopediatric patients experienced this moment. Thus, the following guiding question emerged in this study: Which were the experiences of family members of children and adolescents with cancer undergoing treatment for the disease during the COVID-19 pandemic?

Thus, this study is justified by bringing up the discussion on the repercussions of the COVID-19 pandemic on the experiences underwent by a group of family members of oncopediatric patients undergoing treatment, highlighting the need for a more attentive look by health professionals and those of the Nursing team. In addition to that, it should be considered that internal factors such as greater susceptibility to infection by the SARS-CoV2 virus and feelings of fear and anxiety, as well as external factors such as changes in the care flow and the care provided by health services and by family members can directly or indirectly influence the health-disease process of this population.

In this context, the objective of this study was to describe the experiences of family members of children and adolescents with cancer undergoing treatment for the disease during the COVID-19 pandemic.

METHOD

A qualitative, exploratory and descriptive study, carried out at the Pediatric Oncology outpatient service of a philanthropic oncological hospital located in western Paraná, Brazil, a reference for the care of children and adolescents with cancer, including border regions with Paraguay and Argentina. It is noted that development of this research met the recommendations set forth in the Consolidated Criteria for Reporting Qualitative Research (COREQ).

The participants were family members, selected for convenience and recruited through the face-to-face approach of one of the authors in the waiting room before the outpatient the child's or adolescent's appointment. 24 family members were approached, with four refusals, 20 acceptances and no withdrawals during data collection.

The inclusion criteria were as follows: being over 18 years old; self-declaring as the main caregiver; and being monitoring the child/family member undergoing cancer treatment during the COVID-19 pandemic. The exclusion criterion was having difficulty in verbal communication, a condition observed by the researcher during the initial approach, through verbal conversations in the Portuguese language, as the research scenario is located in a border region with Spanish-speaking countries.

The data were collected from September to October 2020 through semi-structured interviews, recorded with the aid of a digital voice recorder and lasting a mean of 16 minutes. Three pilot interviews were carried out and included in the study, and there was no need to implement any changes in the data collection instrument.

The interview script consisted of questions related to sociodemographic data such as age, gender, race/skin color, origin, religion, marital status, schooling, family income and work status, and the following open questions: “Which care measures has your child/family member received by the health team and by you in this pandemic period?”; “Has your child/family member continued to undergo treatment during this pandemic period?”; “Was there any change in the therapeutic schedule?”; “Did you receive guidelines or any special treatment at the health institution due to the pandemic?”; and “Are there concerns about the cancer treatment during the pandemic? How are you feeling in relation to this moment?”.

The interviews were carried out in a room adjacent to the waiting room, divided by a glass wall, allowing the participants' privacy while talking to the researcher. In most of the interviews, the patients were present and, when not, the children and adolescents remained in the waiting room, which was configured as a toy library.

It should be clarified that the content transcribed from the interviews was forwarded to the participants for validation of the information, through a message app via cell phone or email message, as agreed upon at the time of the interview.

Data content analysis followed the steps described as follows⁷: data organization and preparation; general data reading; data coding with identification of the thematic categories, consistency of the information collected and absence of new elements in the text segments, confirming data saturation; data presentation and description; and interpretation and extraction of meaning from the data.

The study was approved by the Committee of Ethics in Research with Human Beings of the institution involved. To ensure the participants' anonymity and secrecy, the following identifying code was used: P (Participant); X (A number in Arabic numerals in ascending order of participants according to data collection); F or M (Female or Male); and N (Age in years old); example: P1F32.

RESULTS

The study participants were 20 family members of six adolescents and 14 children, of which 17 were mothers, two were fathers and one was a grandmother, aged between 20 and 50 years old. The participants were characterized as follows: married and in stable unions (n=12), single (n=4), divorced and widowed (n=4); Catholics (n=12), Evangelicals (n=7) and Jehovah's Witnesses (n=1); in terms of schooling level, Complete High School (n=8), Complete Elementary School (n=6), Complete Higher Education (n=3), Incomplete Elementary School (n=2), illiterate (n=1); regarding family income, up to one minimum wage (n=10), between one and two minimum wages (n=7), more than two minimum wages (n=3); and participants who, at the data collection moment, were not working outside the house due to having to monitor the child or adolescent during the cancer treatment, as well as to the restrictive health situation arising from the COVID-19 pandemic (n=11).

The content analysis process originated three analytical categories, namely: “The care of children and adolescents undergoing cancer treatment during the COVID-19 pandemic”; “Cancer treatment during the COVID-19 pandemic”; and “Concerns and feelings in the face of the COVID-19 pandemic”.

The care of children and adolescents undergoing cancer treatment during the COVID-19 pandemic

The family members reported that the care provided to children or adolescents was intensified during this period. Resorting to protective measures, such as mask use and hygiene of hands, objects and the environment, was already part of the care actions before the pandemic; however, in this context, both the relatives and the children or adolescents began to pay more attention:

Wearing a mask, alcohol, I've always used it, since the beginning of her treatment, so she's used to it, not just during the pandemic. I always take alcohol with me, if she goes to the bathroom in the hospital, I pass the alcohol in the toilet for her to use. Alcohol and mask must never be missing (P17F27).

You can't stop wearing a mask, rubbing alcohol in your hand, so much so that my hands were peeling these days. I was getting neurotic. We stopped for a while and started to wash our hands more with soap and water. And the care measures that we should implement became a routine, like alcohol use. To take off our shoes outside the

house, the clothes that come from the hospital, I put them in the washing machine. And I use vinegar for everything to kill bacteria. Vinegar is very good for washing clothes, for cleaning the bathroom. They say it kills everything, so I put it on everything (laughs) (P5F41).

We don't leave the house and when we go out, we only come here to the hospital, from here we take our clothes off at the laundry room and put them in the washing machine and go straight to the shower. Ah! And a lot of hand hygiene (P7F30).

Cancer treatment during the COVID-19 pandemic

It was observed that, despite the changes, there was no discontinuity of the cancer treatment. The family members reported that children and adolescents attended the hospital for outpatient consultations and hospitalizations, according to the established treatment plan, but noticed some changes in the care flow and in the routines, which were understood as necessary for COVID-19 prevention:

Here inside the hospital, we saw a lot of things. Computers for the kids; they took them all away, nobody could use them. At the front (indicating the institution entrance door) they are also very careful when entering (P5F41).

The treatment continued normally, sometimes the doctor postponed an appointment. And here at the hospital it's different. The flow of people has decreased (P3M50).

During the pandemic, the appointment was canceled once because there was a COVID problem at the hospital and her doctor caught it. But she always had consultation and hospitalization (P17F27).

We chose to continue because there was some risk of enlarging the tumor. The surgery had been scheduled and was canceled because of the pandemic, so he continued with the chemotherapy so as not to enlarge the tumor (P19F30).

Concerns and feelings in the face of the COVID-19 pandemic

As it is a new disease and there are many uncertainties regarding COVID-19 evolution and treatment, the family members reported times when they felt fear and insecurity in the face of the pandemic situation, especially in view of the need for continuity and maintenance of the cancer treatment, as well as the concerns expressed by the children or adolescents:

We feel more fear in this period. We're more concerned, because whether we like it or not, it's a risk group, and we're afraid that she'll get it (P6F27).

During this period, the normal treatment continued, but it was scary. He says he's afraid to catch it. He says like this: Mom, if I get the coronavirus, it's over! And if he sees something wrong, he scolds others, for example, if he sees that a person hasn't washed his hands, no matter who he is, he speaks up. He's very careful (P7F30).

I came, 6 months ago. We stayed so as not to go back and forth, even because the border closed and to reduce the risk of catching the coronavirus. Anxiety and fear increased a little, because in the last chemotherapies he was more anxious to finish soon, to go home (P2F40).

He became very anxious, so much so that he undergoes treatment, he had to see a psychiatrist. But the pandemic, it really got to him. Because he has no contact with anyone, only with us at home. He was a little afraid of catching the virus and if I leave the house, he becomes desperate, for fear of me (P1F36).

DISCUSSION

From confirmation of the cancer diagnosis in children and adolescents, the daily changes for the patients are inevitable and are related to the recurrent need for hospitalizations and, consequently, to distancing from family members, friends and school, changes in diet, frequent uncomfortable procedures, and the therapies to which they are subjected. In this way, care and monitoring of children and adolescents become more rigorous and are redoubled in the activities of daily living⁸.

In this study, it was observed that the care measures provided by family members corroborated those recommended for preventing and controlling COVID-19 spread. Among these protective measures, the following stand out: social isolation; restriction of meetings with people outside the home; mask use; hygiene of hands and clothes; as well as leaving the house only to attend a health service, when necessary^{2,9,10}.

As for treatment continuity, changes in service flows, reduction in the number of visits, cancellation of elective surgical procedures and structural reorganization of institutions were some of the recommendations indicated by the Brazilian health agencies, in order to reduce the population's exposure to the virus and provide more possibilities for hospital beds for COVID-19 suspected or confirmed patients¹⁰, a reality faced across the country since the beginning of the pandemic.

These measures to restrict movement of people and rationalize resources, in addition to the delay in initiating vaccination during the pandemic, resulted in barriers for patients to access the health services, mainly for children with complex health conditions that require specific care, increasing the vulnerability of this population segment due to the difficulties providing health care and the impact on the routine with the changes resulting from the pandemic¹¹.

In this sense, with the objective of evaluating the effect of the COVID-19 pandemic on the treatment of childhood cancer worldwide, a cross-sectional study with 311 professionals who worked in pediatric oncological care in 79 countries identified that: there was a temporary closure of services, both for the continuity of oncological care and for the diagnosis of new cases; 34% of the services reported an increase in treatment abandonment by the patients; 72% of the institutions reduced the performance of surgical procedures; 60% had shortage of blood products; 57% reported that there was a change in the chemotherapy treatment; and 28% reported radiotherapy interruption¹².

In addition to that, the study evidenced that treatment abandonment, unavailability of chemotherapy drugs and radiotherapy interruption were more frequent in low- and middle-income countries, denoting that the COVID-19 pandemic has considerably affected Pediatric Oncology services worldwide, causing substantial interruptions in the diagnosis and treatment of childhood cancer¹².

Patients with chronic conditions and special health-related needs are susceptible to infection and require ongoing care, specialist medical consultations, and hospitalizations for testing and treatment². Thus, after the initial period of the pandemic, the concern of the professionals working in this area contributed to the publication of international consensus and recommendations supporting continuity of care and assistance in the diagnosis, treatment and support of children and adolescents with cancer¹³.

Another concern of professionals, associations and societies devoted to pediatric cancer treatments is the alert for conditions that increase the possibility of concomitant infections between COVID-19 and other microorganisms, such as children undergoing chemotherapy in the induction phase, with high doses of steroids; patients diagnosed with lymphomas and leukemias, which present high rates in children and adolescents; and people undergoing transplants, such as hematopoietic stem cells¹⁴.

In addition to the difficulties related to the daily changes for cancer treatment, the family members reported their concern about maintaining monitoring of their children in the face of the restrictions imposed by the pandemic and the uncertainties arising from COVID-19. Feelings such as anxiety, fear and insecurity in the face of the new disease were also observed in 321 families, where it was identified that the caregivers expressed exceptional resilience, highlighting the similarities between caring for a child with cancer and adopting prophylactic measures against COVID-19. However, there are reports of delayed or canceled exams and appointments and financial difficulties for basic needs, which are associated with interruptions in everyday life, increased anxiety and impaired sleep, as well as barriers in accessing social support¹³.

Given the ongoing nature of the COVID-19 pandemic, parents and caregivers of English children with cancer reported concern about infection by the virus, so that they became more vigilant about respiratory and cancer-related symptoms. They also mentioned that the hospital is no longer considered a safe place; the fear of becoming infected with the disease and transmitting it to their children; the fear that cancer treatment is no longer ideal due to reorganization of the health services; and the anguish and anxiety related to the psychological, social and economic impacts induced by isolation and the restrictions imposed with the lockdown measures¹⁵.

Another relevant issue is that, despite the lower risk of infection and severe forms of COVID-19 among children and adolescents, there was greater concern in the childhood cancer context, expressed in recommendations that highlighted the importance of guidelines on changes in the treatment process and potential risks for this population group, which should be made available in a clear and appropriate way, considering their age and the information requested by them¹⁶. Such care is due to the fact that family members and patients search the Internet for information related to health conditions and cancer and COVID-19 diagnoses, with the intention of answering their doubts and insecurities; however, the information quality and sources can reflect on the increase in concerns and, consequently, on the care offered to these patients¹⁷.

In this way, the increase in the level of stress and feelings of fear, anxiety and insecurity are understandable in view of the abrupt changes that children and adolescents have been exposed to with the pandemic and, therefore, the importance of guidelines for parents and family members about care that seeks to minimize the effects of these anxieties and distress manifested by the children, which can be expressed in abnormal behaviors, discomfort, concerns, sleep disorders and loss of appetite, among others².

However, the vulnerability inherent to the illness of a child or adolescent due to a malignant disease was more pronounced in the pandemic context, in the face of restrictive measures in social coexistence and home-based care³.

However, the search for care measures to minimize the obstacles faced by the patients should be extended to the family members who have experienced concerns and disturbances related to changes in health services, financial and emotional problems during the pandemic, demanding attention from health professionals to better serve them with their children, with clarifications and reliable information about COVID-19, given the constant struggle faced by parents and family members and the conditions and infectious risk that these oncopediatric patients are prone to since the cancer diagnosis^{13,14}.

Study limitations

The limitations faced during the research are related to the difficulties accessing the research field during the data collection period due to the health situation faced in the COVID-19 pandemic context, with suspensions of academic activities at the institution, in addition to the reduction in the number of consultations scheduled at the Pediatric Oncology outpatient service, reducing the number of patients and family members for recruitment of the participants.

CONCLUSION

In view of the above, it was observed that the experiences and transformations experienced by the family members in the care of children and adolescents, as well as the sequence in the cancer treatment, brought about repercussions and different ways of coping.

As for the care measures, both children and adolescents and their family members redoubled the precautions they were used to before the pandemic. In relation to the cancer treatment, in some cases there was a need to reorganize and reschedule consultations, procedures and hospitalizations, although without prejudice to the planned therapy. Regarding the concerns expressed by the family members, fear, insecurity and anxiety were the most common feelings, which were related to the COVID-19 evolution, which at the time was still being studied by the global scientific community, the uncertainties of the pandemic scenario and its repercussions for patients undergoing cancer treatment.

It is noted that the data from this research can contribute to reflections related to health care using therapeutic strategies, supported by scientific knowledge to substantiate the Nursing Process and care, considering the impact of the pandemic on the lives of patients and family members who face childhood cancer.

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Author Contributions

Conceptualization, L.A.G.P.S. and N.N.A.M.; methodology, L.A.G.P.S. and N.N.A.M.; formal analysis, L.A.G.P.S., N.N.A.M. and L.P.K.; investigation L.A.G.P.S. and B.I.O.; validation, L.A.G.P.S. and N.N.A.M. resources, L.A.G.P.S.; data curation, L.A.G.P.S.; manuscript writing, L.A.G.P.S.; writing—review and editing, L.A.G.P.S., B.I.O., N.N.A.M. and L.P.K.; supervision, N.N.A.M.; project administration, E.R.C.M. N.N.A.M. and L.A.G.P.S. All authors have read and agreed to the published version of the manuscript.