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FAMILIES OF CHILDREN WITH CANCER IN PEDIATRIC ONCOLOGY EMERGENCY SERVICES: UNVEILING MEANINGS

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ABSTRACT

Objective: to understand the meanings attributed by family members of children with cancer to Oncology emergencies.
Method: a descriptive study with a qualitative approach carried out with 18 family members of children undergoing Oncology emergencies at an institution in Rio de Janeiro-RJ, Brazil. The data were collected through semi-structured interviews, between February and September 2021, analyzed using thematic-categorical analysis and interpreted in the light of Symbolic Interactionism.
Results: two categories emerged from the analysis, namely: meanings attributed by family members attribute to Oncology emergencies and family dynamics; and interaction with health professionals in the Pediatric Oncology Emergency sector.
Conclusion: the findings mark intense changes of a social, emotional, economic and psychological nature in family dynamics and point to the value of interactive processes with professionals, which can contribute to the advancement of family-centered care.

DESCRIPTORS: Nursing. Child. Emergencies. Oncology. Family.

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A FAMÍLIA DA CRIANÇA COM CÂNCER EM EMERGÊNCIA ONCOLÓGICA PEDIÁTRICA: REVELANDO SIGNIFICADOS

RESUMO

Objetivo: compreender os significados que os familiares de crianças com câncer atribuem às emergências oncológicas.
Método: estudo descritivo com abordagem qualitativa realizado em uma instituição no Rio de Janeiro-RJ, Brasil, com 18 familiares de crianças em emergência oncológica. Os dados foram coletados por entrevista semiestruturada, entre fevereiro e setembro de 2021, analisados através da análise temático-categorial e interpretados à luz do Interacionismo Simbólico.
Resultados: a partir da análise, duas categorias emergiram: significados que familiares atribuem às emergências oncológicas e a dinâmica familiar; e interação com os profissionais de saúde na emergência oncológica pediátrica.
Conclusão: os achados demarcam intensas alterações na dinâmica familiar de natureza social, emocional, econômica e psicológica e apontam para o valor dos processos interativos com os profissionais, podendo contribuir para o avanço de cuidados que sejam centrados na família.

DESCRITORES: Enfermagem. Criança. Emergências. Oncologia. Família.

FAMILIAS DE NIÑOS CON CÁNCER EN SERVICIOS DE EMERGENCIA ONCOLÓGICA PEDIÁTRICA: REVELANDO SIGNIFICADOS

RESUMEN

Objetivo: comprender los significados que los familiares de niños con cáncer atribuyen a las emergencias oncológicas.
Método: estudio descriptivo de enfoque cualitativo realizado en una institución de Río de Janeiro-RJ, Brasil, con 18 familiares de niños en situaciones de emergencia oncológica. Los datos se recolectaron por medio de entrevistas semiestructurada entre febrero y septiembre de 2021, y fueron analizados por medio de análisis temático-categórico e interpretados sobre la base del Interaccionismo Simbólico.
Resultados: surgieron dos categorías a partir del análisis, a saber: significados que atribuyen los familiares a las emergencias oncológicas y a la dinámica familiar; e interacción con los profesionales de la salud en los servicios de Emergencia Oncológica Pediátrica.
Conclusión: los hallazgos demarcan profundas alteraciones de naturaleza social, emocional, económica y psicológica en la dinámica familiar y señalan el valor de los procesos interactivos con los profesionales, con la posibilidad de contribuir al avance de medidas de atención centradas en la familia.

DESCRIPTORES: Enfermería. Niño. Emergencias. Oncología. Familia.

INTRODUCTION

Cancer is a disease that has within its framework a disorderly growth of cells, whose genetic material undergoes continuous changes, generating failures in their structural process. This pathology is classified as one of the main causes of death due to non-communicable diseases in the world. Despite significant advances in technological evolution in the Oncology area, there is still a challenging path ahead regarding this therapeutic reality[1].

In Brazil, the estimates project 704,000 new cancer cases for the 2023-2025 period. Specifically regarding cancer in children and adolescents, which affects the age group from 0 to 19 years old, the estimate for each years of the same triennium is 7,930 cases. Given this panorama, it is worth noting the latent importance of studies and surveys targeted at this population group[2].

Cancer in children and adolescents is of a predominantly embryonic nature and mainly affects cells of the circulatory system and of supporting tissues. The most frequent types of cancer are the following: leukemia, myeloproliferative and myelodysplastic diseases, lymphomas, reticuloendothelial neoplasms, Central Nervous System (CNS) tumors, intracranial and intraspinal neoplasms, neuroblastomas, retinoblastomas, renal tumors, hepatic tumors, malignant bone tumors, soft tissue sarcomas, germ cell neoplasms, trophoblastic neoplasms and carcinomas[3].

Onset of a disease like cancer in the family environment represents a moment of sorrow in all its members. The dynamics between family members change and feelings such as fear and anxiety start to be part of this path, especially in the face of health complications and problems that can happen suddenly, requiring the family to seek immediate care[4].

This term refers to acute conditions and complications that occur suddenly, related to the course of the cancer disease or to its treatment, which require rapid evaluation, intervention and treatment given the higher risk of morbidities, sequelae, intense suffering or death[5].

Thus, it is acknowledged that cancer causes countless acute emergency situations along the therapeutic path due to severity of the disease and its specificities, which sometimes generate complications with diversified and systemic signs and symptoms, requiring expertise from nurses to skillfully recognize, manage and intervene[6–7].

Pediatric Oncology emergencies present themselves as a difficult moment for a child and his/her family, as they impose an abrupt change in life routine and dynamics. The literature reveals that the everyday life of the family of a child with cancer is altered; their affective relationships are distanced and, throughout, the oncological therapeutic path, the family context suffers from the coping situations imposed by the disease[8].

The transformations in the everyday life of the entire family aim at constituting an unveiling moment, culminating in negative forecasts that culturally surround cancer. Immersed in expectations and turbulence, the families need to use strategies that can support the changes resulting from the malignant neoplastic disease in their child[9].

The repercussions of cancer among the relatives differ according to each family, but they always result in changes in the way of life of this social group. The singular interactions between their members, the socioeconomic conditions and a succession of factors interfere in the families' routine practices[10–11].

This fact reveals the need for the Nursing team to be prepared to receive and care with expertise children with cancer and their family members in the context of an Oncology emergency, where feelings of fear, anxiety and lack of knowledge about the outcome of the circumstance are stressors that can bring about implications for family dynamics[12].

Scientifically grounding measures that subsidize care with expertise and quality in emergency care for people with a chronic disease and their families can exert a positive impact on the quality of life of these individuals, including children with cancer[13]. Thus, the questions are as follows: Which meanings do family members of children with cancer attribute to Oncology emergencies? How do they perceive their interaction with health professionals in the Pediatric Oncology Emergency sector?

The relevance of this study lies in the possibility of knowing, based on the meanings attributed to Oncology emergencies by family members of children with cancer, how the family thinks and organizes itself in the face of this fact, which can point to strategies to advance family-centered care. Therefore, the objective of this study was to understand the meaning attributed by family members of children with cancer to Oncology emergencies.

METHOD

A descriptive study with a qualitative approach carried out in a Pediatric Oncology Emergency Service of a reference institution in the assistance to cancer patients, located in the municipality of Rio de Janeiro, Brazil.

The research participants were 18 family members of children with cancer aged up to 12 years old, seen in the Pediatric Oncology Emergency sector. They met the following inclusion criteria: being a family member of a child with cancer; having the child as a patient enrolled in the care institution; and having attended at least one of the child's appointments in the Pediatric Emergency sector. The exclusion criteria were as follows: underage family member (under 18 years old); family member (physically or emotionally) not capable of agree to the interview (signaled by the sector's service team); and being a family member of a child over 12 years of age.

The semi-structured interviews were carried out individually between February and September 2021, being recorded in a digital file and later transcribed. A script was followed containing closed questions that allowed characterizing the participants as well as open questions to reach the objectives, namely: Tell us about you and your child in relation to the need to come to the Pediatric Oncology Emergency sector (decision-making, feelings, coping situations, family dynamics). What do you think about the care of your child and your family when facing Oncology emergencies?

The lead author was in charge of recruiting the participants and conducting the interviews. During collection of the interviews, it was possible to provide certain distance for the family member to speak at more ease, although remaining within the child's sight. This is because, in general, family members avoid talking about severity of the disease around their child and, thus, the care team provided playful and dialogic distraction for the child, in a respectful manner. It is also noted that all the care measures recommended due to the COVID-19 pandemic were met.

There were no withdrawals and all the family members approached took part in the study. Sampling was for convenience and the collection procedure was ended based on the data saturation criterion[14].

Data analysis followed the Thematic-Categorical Analysis stages. The stages are first developed with choice of the documents or definition of the analysis *corpus*, formulation of the objectives and elaboration of the indicators that support the final interpretation. Subsequently, the exploration of the material or coding process, through which the unprocessed data are systematically transformed and aggregated into units, which allow for an exact description of the characteristics pertinent to the content expressed in the text[15].

After transcribing the interviews, an initial floating reading was performed, which generated units in common in the testimonies. The thematic content of each statement was identified, clipped and transferred to a new file, in which there was the possibility of preparing the thematic units and identifying their recurrence in the respondents' testimonies, called "units of meaning", followed by the "registration units", quantifying recurrence in the analysis *corpus*[15].

The data collected were interpreted in the light of Symbolic Interactionism (SI). Based on this theoretical framework, it is understood that reality is symbolic, being constructed through interactive processes between subjects, who act based on the meanings that things have for them, that is, it is the meanings that guide and modulate the actions and interactions between subjects in social life[16]. For this reason, as the study object involves the symbolic context of the meanings that relatives of children with cancer attribute to Oncology emergencies, it was decided to use this theoretical framework for considering it pertinent to the epistemology of the study.

The research was approved by the Research Ethics Committees (*Comitês de* Ética *em Pesquisa*, CEPs) of the proposing and coparticipating institutions. In order to conduct the interviews, both the participants and the researcher signed the Free and Informed Consent Form (FICF). To ensure data confidentiality, all interviews and references to the speech excerpts were presented in the text using alphanumeric codes where "F" represents family member, followed by Arabic numbers, referring to the order in which these participants were included in the study (F1, F2....F18).

RESULTS

Among all 18 participating family members, 15 were mothers, two were fathers and there was a maternal aunt, with their age varying between 19 and 51 years old and a mean of 33. As for schooling, three family members had Complete Elementary School, 11 indicated Complete High School and four had attended Higher Education. It is noted that half of the participating family members reported monthly family incomes of up to one minimum wage (R$ 1,100.00) and that 12 families consist of more than four people living in the same household.

Regarding the age of the children to whom they were companions in the Pediatric Oncology Emergency sector, it varied between 1 and 12 years old, with a mean of six years old. Only one participant was a companion to a child undergoing treatment for leukemia (hematological tumor), with the remaining 17 family members accompanying children who were being treated for solid tumors. This was due to the fact that the research locus is a tertiary-level hospital specialized in Pediatric Oncology that is a reference in solid and rare tumors.

The following categories emerged from the analysis:

Meanings attributed by family members to Oncology emergencies and to family dynamics

This first category presents the reader with units of meaning referring to the family life dynamics in the symbolic context of cancer and the need to seek emergency care. The results denote constant surveillance by the family caregiver, who is mainly the mother, but also agreements and adjustments of the entire family focused on the care of the child who is undergoing cancer treatment:

It quite changed my routine, [...] *I don't sleep straight hours anymore. I wake up any time and look at her to know that she's fine, like yesterday that I was attentive all the time* (F2).

The change was more noticeable after the first surgery, I had to talk to my younger girls [...]. *We ended up setting up a fence around this child to take care of him. All the family focused, all the attention for him* [...]. *I told them to be more careful, calm, tranquility, patience* (F8).

The families report significant changes in the life routine after the childhood cancer diagnosis, also related to Oncology emergencies. The coping situations arising from the therapeutic path undergone by these families are of an emotional, social and economic nature.

As soon as we started his treatment, we decided to live nearby. Changing address, in financial terms, affected a lot [...]. *Today we commit almost eighty, ninety percent of the salary, but for him, if it was necessary up to one hundred percent or more, we'd find a way* (F10).

I receive a lot of food and money donations. It's this money that we use to bring her here, to buy something, because she's on a diet. So I spend a lot on tickets then (F5).

I don't do anything at home [...] *I cook at the most, wash dishes and put clothes in the washing machine and that's it* [...]*. I only take care of* [child's name]*, my life is hers, right!? I feel bad, even more when they say that she needs to be hospitalized* (F12).

You end up being unable to create a routine because you don't know what you can expect. One hour we're home very well and out of nowhere something happens and you have to run with him. Life has totally changed (F18).

Cancer treatment imposes some limitations on children's everyday interactions, which is reflected in academic and playful development, as described in the statements below:

The change was at his school. He was in third grade, starting to read alone and went back a little. Now he doesn't want to write, doesn't want paper, doesn't want to paint (F8).

[Child's name] *didn't live like that, he used to play, run, go out to the street. Nowadays, he has a more regimented life, he doesn't go out, he doesn't play* (F14).

In addition to the evident changes in the everyday life of these families, it was possible to perceive certain difficulty for some family members in using the term "cancer", which is due to the socially constructed meaning, as the terms generally used were the following: "this thing" and "this disease".

After I discovered this thing about her, about this disease, I don't sleep straight hours anymore (F2). [...] *but then came the situation, his health problem* (F10).

Down here I don't know anything and I still haven't learned how to take the bus and, because he has this little problem, in crowds, in the subway, these things... (F3).

The parental perception of burden is something explicit in the study participants' statements and the Oncology emergency ends up exacerbating each exhausting day marked by care and responsibilities.

So it's all me and at home too, I feel overloaded, I forget things, I forget what I was going to do or where I left something and it's everything up to me. Today she's going to be hospitalized, it's me for everything (F5).

So, I no longer have a social life with anyone else, because if I got sick there'd be no one else to come and take care of her. His father is absent, then there's no way, just me (F16).

Interaction with health professionals in the Pediatric Oncology Emergency sector

This second category reveals the family members' meanings in the Pediatric Oncology emergency resulting from the health professionals' assistance/actions, also including Nursing care and reception. The results denote that certain interaction for the care of the child and the family is perceived, mediated by love and attention, as highlighted in the statements below:

Look... when we discover a disease like this and are treated by people who love what they do... It's just what I say: There's care for love and there's care for the profession, and I see love there (F1).

Here, there's attention all the time, because there are places that leave you there, let go, it's over. You don't have to study for money. In such a profession you need to study out of love (F6).

I've always had a very differentiated service here. If I talk to a nurse, she pays attention to me as a mother, and she'll ask me things and won't direct them to my husband. Because I'm still the mother of [child's name]*, regardless of being a person with a disability and I've always been treated very well* (F13).

In the multiple symbolic interactions, the family of a child undergoing cancer treatment seeks to trust the team, especially when they have the perception of the technical-scientific knowledge of the professionals who work in the care of their child.

Then I think that you study for that. I try to trust. It's no use for me to tell you, 'I don't want, don't take blood out of my daughter'. Then... if you're here, you studied for this, to take care of my daughter (F12).

Even in the Oncology emergency context, both family members and professionals recognize each other for the time and frequency of the consultations, creating bonds outside the hospital.

It's because some of them (health professionals) are more like friends, we exchange phone numbers and talk more (F12).

DISCUSSION

The results of this research denote that family members of children with cancer have socioeconomic and emotional vulnerabilities that need to be considered in the assistance provided, which can be especially challenging in a context of Pediatric Oncology emergencies.

The diagnosis of cancer in childhood significantly interferes with the dynamic balance of the family, requiring adaptations in the family dynamics with redefinition of roles, changes in the everyday routine and expansion of the support network to meet the biopsychosocial, economic and spiritual needs of the family[17]. Thus, it is acknowledged that cancer in childhood conditions the symbolic nature of the social life of children and their families, influencing their behaviors, actions and interactions in coping with the disease[16].

In this logic, a study[18] that analyzed the impact of the cancer diagnosis on 12 children aged between six and 12 years old and on their parents identified that more than half of the families had psychosocial risk factors at the clinical level (58.3%), with family problems and problems with the child as the conditions that place the family of a child with cancer in a situation of greater vulnerability with regard to the recent diagnosis.

Another study[19] carried out with 27 families revealed that the impact of the cancer diagnosis undermines the entire psychological structure of the parents, who start to demand themselves in relation to the care of the child, due to the fear of death being very present. Parents feel despair, fear and uncertainty about everything that can happen to the child. This result corroborates the findings of this study with regard to the high demand for the care of children undergoing cancer treatment.

This high demand in the care of a child with cancer reveals the parents' intention to provide everything necessary to mitigate the child's suffering. In the light of Symbolic Interactionism[16], such action reveals certain ethical and human conscience in the parents, who reflect, think and interpret their child's reactions in the symbolic interactions of care.

Regarding the uncertainties that permeate the treatment of children with cancer, a study[20] carried out with 119 relatives of children undergoing cancer treatment revealed that the uncertainty levels in the parents of pediatric cancer patients present statistically significant differences between the treatment phases, with a higher uncertainty level at the beginning (87.77 ± 13.43) and during the course (83.33 ± 15.10) of the treatment than in the post-treatment phase (75.35 ± 12.82). In all stages, the Nursing care demands were related to infection control, diet, activities of daily living and prognosis. There is a correlation with this study in regards to Oncology emergencies as complications in the course of the disease and treatment that can increase uncertainty in parents, affecting the family life dynamics.

In this study, the participating mothers reported being the main responsible for the home care provided to the children and that they remained overloaded for accompanying them in emergencies and successive hospitalizations. The literature[21] reinforces this result when analyzing six mothers of children with cancer, highlighting that the maternal burden experienced in the care of hospitalized children with cancer is the result of the accumulation of stressors resulting from care itself and the children's disease condition, especially due to the cancer diagnosis.

The mothers' burden can be classified as physical, financial, information-related and emotional. As for the physical burden, they manifested physical fatigue related to the routine of caring for the child during hospitalization and, at home, to the demands of household chores and caring for other family members; the financial burden arising from dependence on other family members, due to job abandonment; the information-related burden on how to take care of the children, increasing the anguish and leaving them confused; and the emotional burden resulting from all the other overloads and stressors, as well as how to deal with some professionals' lack of understanding and with people's stigmas in relation to cancer[21].

The results of this research highlight the socioeconomic effects that childhood cancer, treatment and Oncology emergencies can exert on the families' financial dynamics. Limitations for commuting, compromise of the family income and scarce resources to handle the therapeutic path were evident in the testimonies and correlate with the participants' characterization. In turn, this is supported by the findings of a study carried out with 55 parents/guardians of children or adolescents with solid tumors, which highlighted a reduction in family income and impoverishment of families after diagnostic confirmation. It is important to highlight that social programs and benefits have limitations because they are centered on the income criterion for eligibility and offer focused actions that fail to reach the multidimensional perspective of the needs of these families[11].

The results of this study reveal that cancer treatment imposes changes in the child's lifestyle, as well as new meanings in family relationships. In other words, cancer treatment demands new social arrangements from children and their families, which reverberate in their behavioral actions in view of the symbolic interpretations they develop about the disease and its treatment. During this period, meanings are manipulated and modified through an interpretive process, producing new meanings regarding care[16].

It is known that childhood cancer generates a series of psychosocial and developmental impacts at the individual, family and community levels[22]. For the child, the recurrent hospitalizations and the loss of school days, of collective spaces for playing and of interactions bring about harms to social, psychological and educational development, which needs to be the target of policies and programs that help socialization, even during the cancer treatment[23].

In addition, it is worth highlighting the parents' efforts to share their attention with other children, allowing engagement in the care of the sick child. Regarding the above, a study revealed that siblings of children undergoing cancer therapy had worse family relationship scores when compared to the score of their sick brother or sister. The same study warns about the possible presence of depressive symptoms in siblings of children undergoing cancer therapy[24].

In another study[25], it was identified that single parents reported less ability to meet the basic needs of their children with cancer after the diagnosis, a fact that is also repeated in their efforts to meet the emotional needs of their other children after the cancer diagnosis.

The impact, concerns and fear related to diagnosis of the disease are observed in the testimonies and perceived when the participants avoid using the word "cancer", using other terms to refer to the disease. This fact is evidenced in a study[26], where it was observed that mothers, as well as other family members, meant the word "cancer" as a bad word and as the worst of diseases, evoking negative feelings such as sadness, fear, affliction, faith, impact, hope, questions, death, pain, despair and suffering.

However, it is possible that the interactive processes established between family members and health professionals, as well as between family members who experience childhood cancer, help the participants of this research to attribute new meanings to the disease and its treatment, not associating it with a death sentence, as it is from the interactive process between human beings that meanings are elaborated and can be modified[16].

As for the interaction with health professionals in the Pediatric Oncology Emergency service, the family members reported feeling welcomed and respected and that they trusted the care provided by the health team, with emphasis on participants for the humanized and holistic care by the Nursing team. These meanings regarding professional care for children with cancer draw the attention to the quality of the interactions established between family members and health professionals, given that they are not inherent to the object in question nor do they arise from psychological elements of the person, but from the interactive process between people, through interpretation, from which they are used and revised as instruments to guide and shape actions[16].

The scenario of pediatric emergencies presents itself as a difficult environment for children and their families. The Nursing team has the role of welcoming and providing all the necessary information to clarify the family about the actions and interventions implemented in emergency care. Providing information and clarifications that can assist a family members in the search for emergency care facilitates and provides a positive sense of security, bringing the family closer to urgent care resources that can alleviate the stressful situation they are experiencing[27].

Childhood cancer impacts family dynamics, causing changes due to stressful situations related to cancer and emergencies resulting from treatment. Thus, there is a need for effective communication between professionals and family members of children undergoing cancer treatment, with a view to welcoming and supporting them[28].

With regard to the elements inherent to the quality of the interactions highlighted by the participants in this research, such as love, attention, bonding and trust, the literature[28] corroborates this study by highlighting that nurses who provide care have the advantage of being able to understand the family and the child with cancer as unique beings, as well as to capture and identify their feelings and emotions, recognizing their uniqueness and totality. In this context, empathetic listening, strengthening bonds and valuing family beliefs are strategies that nurses should use to promote good interaction with the families[29].

Nurses play a key role in Pediatric Oncology emergencies, as they identify the needs of each patient/family and, together with the multidisciplinary team, are able to propose interventions and adaptations. Thus, nurses' investment in the affective interaction with children and their families, manifested by a gentle voice, tender look, use of welcoming verbal expressions, empathy, positive reinforcement and sympathetic gestures, reduce the distance and can be considered strategies to ease the interactions for the care relationships[28].

In synthesis, the meanings that were evidenced in this study point to Oncology emergencies beyond children's clinical disorders. The clinical complications that drive the search for emergency care are closely associated with other problems in the family dynamics, which are still little considered in the care practice, such as lack of financial resources, changes in family dynamics, impairment of children's development at school and at home and in socialization, constant surveillance by the main caregiver for sudden complications and consequent parental burden. The interactions with professionals were identified as significant for the perception of zealous and reliable care for the child.

The study limitations were related to the reduced number of institutions specialized in Oncology in the municipality of Rio de Janeiro, within the scope of the Unified Health System, with Pediatric Oncology Emergency services, making it possible to carry out the study only in a single unit. Another important limitation was the need to adapt data collection to the COVID-19 pandemic period, which reduced access to other family members, only allowing collection from the accompanying family member.

CONCLUSION

Based on the results, it is understood that the family members of children with cancer signify Oncology emergencies from the family reality in socioeconomic and emotional terms and from the interactions with health professionals. In this regard, the findings of this study reveal a context marked by uncertainties, changes in family dynamics, maternal burden and family care demands of a social, emotional, economic and psychological nature.

In addition, it was understood that the interactions with the health professionals from the Oncology Emergency unit enabled the elaboration of meanings that allow for the perception of humanized professional assistance, based on affective bonds and technical-professional trust for the care of the child.

The results presented enable advances in the Family Nursing and Pediatric Oncology Nursing context by allowing understanding the impacts of childhood cancer on family organization in the face of Oncology emergencies, as well as by pointing to the development of new research studies on the topic anchored in the perspective of advancing family-centered care strategies.

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NOTES

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CONTRIBUTION OF AUTHORITY

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CONFLICT OF INTEREST

There is no conflict of interest.

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