



PERCEPTIONS AND EXPERIENCES OF THE NURSING TEAM BEFORE THE PEDIATRIC PATIENT IN PALLIATIVE CARE

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ABSTRACT

Introduction: the proposal of Palliative Care is implemented for patients in situations of vulnerability to a serious, limiting disease that can inevitably lead to terminality. **Objective:** to know the perceptions and experiences of nursing professionals regarding the care of children in palliative care in pediatric units. **Methodology:** exploratory descriptive qualitative study conducted in pediatric units of a large university hospital in southern Brazil. Data were obtained through semi-structured interviews with nine participants, nurses and nursing technicians. Thematic content analysis was performed. **Results:** from the thematic analysis, four themes emerged: Child in palliative care: nursing view; Family-centered care; Experiences, feelings and perceptions of the nursing team; and Nursing team coping: challenges for care. The establishment of the principles of pediatric palliative care is fundamental to support qualified care. Nursing professionals reveal the need to be included in multidisciplinary meetings held to decide on conduct towards the patient, and feel the need for psychological support. **Final considerations:** the understanding that the philosophy of Palliative Care needs to be extended to an integrated network of care and respect for end-of-life decisions was revealed.

Keywords: Palliative care. Pediatric nursing. Nursing care. Nursing team.

INTRODUCTION

Palliative Care is an expression used for a set of actions aimed at protecting patients without therapeutic possibilities of cure. This terminology indicates a new perspective: of caring, in addition to healing. Palliation means the relief of suffering of the Being. In pediatric nursing, palliative action is understood as any therapeutic measure without curative intent aimed at reducing the negative consequences of the disease on the wellbeing of the child and the family as a whole⁽¹⁾.

Modern palliative care emerged in the late 1950s. The most recent revision of its concept refers to the improvement of the quality of life of patients and their families when they face life threatening conditions through the prevention and relief of suffering with diagnoses and early interventions, pain relief and physical,

psychosocial and spiritual symptoms⁽²⁻³⁾. It does not mean terminality, but is indicated in all situations of incurable diseases or health problems that threaten life.

The aim of this type of care is to relieve stressful symptoms, such as pain, promote the most active life possible and face death as a natural process of human existence, thereby rejecting the idea of "not having anything else to do"⁽¹⁾. This expands the field of action of health team professionals as it also includes spirituality among the dimensions of human beings to be considered. It also recommends the inclusion of family in care, even after the patient's death, during the mourning period⁽⁴⁾.

From the Palliative Care perspective, follow-up should start from the moment of diagnosis of an incurable disease or an unfavorable prognosis, even if the patient is still receiving curative treatment, since they are not

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excluding⁽⁵⁾. The application of Palliative Care in children is recommended in six different situations: when receiving long term treatment; in uncertainty or failure of cure; severe neurological damage; when there is no hope of improvement; newborns with limited life expectancy; and families of children who suffered trauma, sudden death of a newborn or infant⁽⁶⁾. It includes providing dignified survival and a quiet death. Thus, health professionals are referred to as the support pillar of children and their families⁽⁷⁾; which implies putting themselves in the other's shoes and showing feelings of esteem and concern for their wellbeing. This helps to develop in parents the trust that their child is being cared for in their fullness⁽⁸⁾.

The family's presence is essential for the team, because they are children's spokes person, translate their feelings, attitudes and sociocultural behaviors internalized in the life world of the child. However, the family needs effective communication, solidarity, emotional involvement, and compassion for their needs⁽⁹⁾. In this perspective, this is a considerable challenge for nursing, as they seek to assume the responsibility of rescuing the self-esteem, comfort and individuality of the patient, and the family's central role in care^(10, 11).

The experiences in pediatric hospitalization impose challenges to the care team related to the approach to children in palliative care and their family, and to the need for knowledge that supports care strategies. In parallel, scientific production in this care context is scarce. In view of these considerations, the following question was established as the guiding thread of this study: what are the experiences and perceptions of nursing professionals towards children in palliative care? The objective was to know the perceptions and experiences of nursing professionals regarding children in palliative care in pediatric units.

METHODOLOGY

This is a descriptive exploratory qualitative study. It was conducted in two pediatric inpatient units of a university hospital in southern Brazil. Nursing care includes the shared hospital room (Sistema de Permanência

Conjunta) as a strategy for comprehensive childcare. It serves children aged up to 12 years with clinical and surgical problems, among which respiratory, neurological, gastrointestinal, urinary and metabolic disorders stand out; as well as children in the pre- and postoperative period of liver transplantation.

The study period was between March and November 2017. Data were obtained by one of the researchers through semi-structured interviews conducted with nursing professionals. An instrument with the following guiding question was used: How do you feel when caring for children in palliative care and how has your experience been in the daily care of these children and their families? The interviews were conducted in the units under study, scheduled according to participants' availability, audio recorded and transcribed to a Microsoft Word 2010 file for further analysis.

For the selection of participants, the following inclusion criteria were adopted: being a nurse or nursing technician and offering care to children in palliative care in pediatric inpatient units. The exclusion criteria were: being a nurse or nursing technician on sick leave, vacation or any other type of leave from work activities that would make the participation of the professional in data collection impossible.

Nine professionals (five nurses and four nursing technicians) with between six months and ten years of experience in care for children in palliative care participated in the study. The end of data collection occurred when reaching data saturation, with enough material to know the object under investigation⁽¹²⁾.

Data analysis and interpretation were performed through Thematic Content Analysis. According to Minayo⁽¹³⁾, this type of analysis unfolds in three steps: (a) pre- analysis; (b) exploration of the material or coding; (c) treatment of the results obtained/interpretation. In the first step, the units of meaning were defined; in the second, the study themes were constructed by grouping the units of meaning; and in the third step, trends and other characteristics of the analysis were searched for the formation of the characterized themes, that is, the units around which a conclusion could be drawn. Afterwards, reflections and dialogue with literature were performed.

This study was approved by the Research Ethics Committee of the institution under number CAEE 68426817900005327. The precepts and guidelines for research with human beings were respected. Participants signed the Informed Consent form. To guarantee anonymity, the statements were identified by the letter 'P' of participant followed by the sequential number of the order in which interviews were conducted.

RESULTS AND DISCUSSION

By interpretation of the nuclei of meaning derived from the pre-analysis and exploration of materials obtained in the interviews, were found meanings that gave rise to four themes: Child in palliative care: nursing view; Family-centered care; Experiences, feelings and perceptions of the nursing team; and Nursing team coping: challenges for care.

Child in palliative care: nursing view

From the perspective of interdisciplinary work, in the establishment of the philosophy of Palliative Care, end-of-life and mourning care, most obstacles can be overcome by training the teams with continuing education strategies⁽¹⁴⁾. The team must promote coordination and continuity of care⁽¹⁵⁾.

In the units under study, there is no clear evidence that the principles guiding palliative care actions are established in the daily work of the care team. Participants mentioned a medical team that provides specific care for some patients.

In pediatrics as a whole, it is a new term. Routines are being established, but there is no one hundred percent established protocol. There is a group in the ICU [pediatric] centered on some doctors, but it is not a multidisciplinary team, it is multi if there is a specific situation in the units [...] But there is no systematization, this team comes by a consultancy request so, there is no flow, an established protocol (P1).

In fact, when there is a palliative patient, it takes a long time to start a conduct for the whole team. Because generally, the care team is different from the palliative care team, and the care team is in more direct contact with the family, sometimes, they do not accept the conduct of the palliative

care team very much (P3).

There are still gaps in the processes of education and training of professionals to work in palliative and end-of-life care in the field of pediatrics⁽¹⁶⁾. The interdisciplinary approach by a palliative care specialized team is clearly an advantage, considering the complex needs of children referred to palliative care. It is unfounded to expect professionals, in isolation, to be able to adequately resolve all needs of children and their families⁽¹⁷⁾.

In palliative care, pain control becomes a requested and exercised care action with the utmost consideration to the dignity of the Being⁽⁵⁾. Professionals describe pain management as one of the care actions inherent to the profile of children in palliative care:

Pain control, the most appropriate medication for altered vital signs of pain, right to rest, decrease the [frequency of measuring] vital signs (P5).

Along with pain care, hygiene, comfort and privacy provided to patients and their families were also mentioned. The decrease in frequency of measuring vital signs as a way to avoid manipulation and generate less discomfort for the child is a resource added to qualify the best possible feelings of wellbeing for the child.

Then, the nursing prescription has vital signs, which are measured once a shift, plus hygiene care, comfort (P6).

Nursing care, vital signs, comfort care. Sometimes, a few care actions are reduced, such as the measuring of vital signs to avoid much manipulation of the patient if he is palliative, to avoid further stress! (P7).

In the sphere of palliative care, the threshold between what needs to be done and what can be postponed is very subtle. This condition induces nursing professionals to deep reflections, but results in unique learning: it is essential that decisions, in their entirety, are conducted as a team, with care not to postpone the child's suffering⁽¹⁾. There is vital concern about the privacy given to children and their family members, who are often in considerable confusion and pain. In this sense, professionals report the effort to keep children in palliative care away from the eyes of the nursing team and bring them closer to the family.

The issue of privacy, that the family may visit without so many limitations (P1).

For some, a bed screen was placed, while others were put in private beds to stay with fewer patients. Most who stay there in the ward, we try to place more at the ends, preferably by the window, so as not to be more exposed, because people end up knowing and they become the target, draw attention, come the questions (P9).

And the special look at the family too, of being able to provide an individualized environment for that family, so they can have an environment where only the family could remain, so the child would be a little more comfortable too, close to family members without that flow of other patients. This type of care, basically, that looks like, as much as possible, a cozy, familiar environment, in short (P4).

Communication actions to support children and their families, such as asking about their needs or what can be done to help them in that moment, show a deep respect for the real needs of those experiencing finitude.⁽⁸⁾ Expressions of genuine respect for compassionate actions are recognized by professionals.

[...] Things that relieved the patient, like: "I want to lick some ice" or "I would like such a diet", "if I can eat such a thing" then, were allowed. Use of oxygen for comfort (not therapeutic, but for comfort), 24-hour companion, visits allowed so they could somehow say goodbye (P5).

According to professionals' understanding, offering palliative care means adding quality of life to the remaining days of children and not more days to their life⁽⁷⁾. This is why the nursing team is so fundamental: quality palliative care depends on the contribution of these professionals, who are permanently at the child's side, by allowing open communication channels with and between the team and the family⁽¹⁸⁾.

Family-centered care

Nursing professionals believe that patient care actions are performed properly, although they expressed the need to expand family care. They notice that family members often do not understand children's situation fully and/or have difficulty with accepting palliative care.

Whenever a patient is in palliative care, the care team ends up feeling unsure and moves away

from the patient [...] the families receive very little assistance. The main caregiver, very little is said to him compared to what should be said, and to explain and be there to listen to the family (P3).

Confusion for the family: when it becomes palliative care, some things are not done anymore: ICU is not called, QRT [quick response team] is not initiated, and the family wants this until it becomes really palliative care. The family's understanding is that they are a palliative patient who is expected to be "shut down" (P9).

This dubious behavior of the family is completely understandable. In this perspective, when the family is provided with support, they feel empowered and encouraged to care for the sick child. On the other hand, when there is lack of embracement by the team, family members feel overwhelmed and lonely in the battle for the child's life⁽¹⁹⁾.

Communication is essential in the adoption of a family-centered care model⁽⁹⁾. In this regard, the team mentioned the difficulty in talking with the family and with/among all members of the care team itself for the establishment of a care plan.

For us, it is palliative care for a long time, but until the team sits down with the family and says: "Look, this child will be in palliative care from today". This takes a while. It is like "He/She will be in palliative, will initiate palliative care", but until this is established, it takes time (P9).

For the family [...] it takes a long time to decide if the patient will only remain in comfort and pain relief and nothing else will be done, like an invasive procedure or some other procedure that will only increase the suffering and prolong the survival time (P3).

These statements and perceptions of professionals may be linked to the fact that they do not participate in discussions and the decision-making process regarding the adoption of palliative care for their patients, and the same occurs with the family⁽⁸⁾. In a consultancy model, this problem can be frequent if there is no space for interdisciplinary work, given the need to work with unprepared teams to deal with such a philosophy, who, initially, may offer resistance to some behaviors and require time to elaborate the concepts⁽¹⁵⁾.

Care for human beings presupposes a vision of the unity of Being, in which the different

aspects of human existence are interconnected⁽⁹⁾. Uncertainties regarding the prognosis of the disease, divergent views on the objectives of treatment, and a lack of consensus on what constitutes a good result can create ethical dilemmas and contribute to possible conflict with families and between members of the interdisciplinary team. Therefore, in order to provide comprehensive care, the team must work in sync, share knowledge, actions and sensitivities⁽²⁰⁾. Thus, when all professional caregivers are involved in decisions about their patients, with an open communication channel to express doubts, anxieties and suggestions, the feelings of incomprehension and strangeness disappear to give place to the serenity of compassionate care for each patient/family, which is appropriate to their time and life situation⁽²¹⁾.

Experiences, feelings and perceptions of the nursing team

Nursing professionals express different feelings and perceptions: empathy, compassion, love, donation, involvement, gratification, impotence, malaise and discomfort when caring for a child in palliative care.

There was a patient who died with us and was very fond of samba. Whenever I was going to do any procedure, I used to sing Zeca Pagodinho for her. It was a way of dealing with it, because it is very painful. It is the functioning of a defense mechanism, in a certain way. So, I have a feeling of donation. If that moment requires that I sing for the patient, I sing. And children play. Anyway, this is the feeling, it is a donation, it is what I can do (P5).

I see it a great challenge, I feel very empathic in these situations and I feel that sometimes, in day-to-day rush, it is not possible to give the attention needed. Sometimes I feel in debt, "what else could I have done?" Empathy, compassion, are feelings that one must have (P1).

Feelings of empathy, compassion and affection are constituent elements of daily nursing practice in pediatric palliative care. These professionals denote reciprocity to the longings, pains and psychological and spiritual suffering of those experiencing the existential processes to the fullest, whether is the child in palliative care or his/her family⁽²²⁾. Despite not

having had a similar experience, such as the loss of a child, they are able to see the extent of the pain due to the fact of having shared this experience with the family⁽²¹⁾. Professionals who care for children on the verge of death, are presence and support to the family and provide care with delicacy and ethics. However, this may require that they use personal coping strategies to deal with these situations^(22, 23).

Living with children with chronic and complex diseases who need long periods of hospitalization allows the development of a close relationship between nursing professionals, the child and their families. This generates a range of feelings in the team towards children and their families.

I have this feeling ... they spend so much time with us, that one has love, empathy for the families, it is different, like, to face it. We grow up together with that family, each family is a family! The mourning is elaborated together with the family (P2).

And then, to accept that a two-year-old child whose parents fought horribly to get pregnant, passed away, is very hard, is very complicated for people. Even more here in pediatrics, as we get very involved with families and patients, not least because they are patients with chronic disease (P5).

The close interaction establishes unique bonds of affection permeated by learning experiences that promote a peculiar personal development. Paradoxically, situations of suffering can trigger coping processes, especially when professionals share different existential processes in the trajectory experienced before the fragility of the human condition^(9,22).

On the other hand, the difficulty of professionals with coping in the face of children in palliative care was also observed. They described feelings of malaise, discomfort, helplessness and the desire to keep the patient alive. These difficulties are directly related to the prospect of the child's death.

Very bad. Knowing that the child will die and there will be nothing you can do, only give him comfort. You won't be able to do anything else. Not being able to do anything, feeling of incapacity (P8).

Then you feel kind of, maybe, kind of helpless.

There is nothing you can do for this child and you think about the family too, how come you will not do anything. What if she stops and then you think “But is that it? What if I did something, would it change the picture?”. You try to put yourself in the place, it is difficult, sometimes, a patient, when there is nothing you can do, dies in front of you! (P7).

Professionals associate palliative care directly with death. There is a clear difficulty in dealing with the child’s terminality and the family’s suffering associated with the dying process.

I feel uncomfortable before the family member, it is the jewel he is losing, the son’s preciousness (P6).

I think the team might not accept it, they are afraid. Nobody wants the patient to die. So, maybe it’s kind of a denial of death, not accepting it. Even if they have nothing to do, no one wants the patient to die in their shift to avoid going through the family’s suffering (P7).

I don’t like palliative patients. I know that many are there and will go. Knowing they can go any second, at any time, makes me panic (P9).

This difficulty occurs mainly in the death process of patients with whom the professional became more involved. The weight of mourning is proportional to the memory of the special moments experienced in day-to-day hospitalization of that child. Thus, the need to find coping mechanisms that make it possible to maintain serenity for providing proper care to children and their families in the final moments. For many professionals, the principle generating this serenity, despite grief, is the perception of the atrocious suffering experienced by the child and the awareness of the time to alleviate it through comfort measures⁽²¹⁾.

Nursing team coping: challenges for care

When participants were asked about the preparation of the team to care for children in palliative care, in general, they reported unpreparedness.

I think the team is not trained for this. I think we are not prepared to deal with palliative (care) (P9).

No, I don’t think so. As I said, it is such a complex situation, and we have few qualifications in this area, few reference professionals in this area, too (P1).

It is not fully [prepared], because now there are more and more patients who are palliative, that we didn’t have before. They are chronic patients who end up being palliative for not having what to do. [...] Sometimes, the patient is palliative, but if there is a drop in saturation, you will check. It’s kind of complicated! If it’s palliative care, you shouldn’t. But how are you going to let the child turn purple? I think the team is not well prepared (P7).

The excerpts above reveal that confusing concepts still exist. Professionals demonstrate they have not appropriated from the fact that adopting palliative care does not mean the implementation of a bundle of recommended conducts, for example, the order not to resuscitate. In the imagination of some professionals, implementing palliative care necessarily means end-of-life care, which includes the order not to resuscitate, the suspension of all curative treatments (such as the use of antibiotics, oxygen administration), and analgesic care in the final minutes of life.

However, palliative care is more comprehensive and means the implementation of principles in the care plan of each patient that are pertinent to the moment they are living with the aim to ensure better quality to their remaining life. The adoption of this care is individualized and defined jointly in a consensual way between the interdisciplinary team and the family⁽⁸⁾.

In parallel with the team’s verbalization regarding their unpreparedness to administer care to children in palliative care, professionals mentioned a vertical work between teams, in which information is only passed on to the nursing team, and this happens mainly with nursing technicians.

The nurse often participates, sometimes not, but not the technician. If we don’t inform and don’t give details, it’s kind of vague, like, “what’s going on?” (P2).

In nursing, not everyone participates, perhaps including the nursing technician together, so not only the nurse goes (P7).

Interdisciplinary work horizontalizes work relationships, facilitates the construction of effective communication and the dialogue between teams, benefiting children and their family, who started to be fully assisted by all professionals⁽¹⁸⁾. Participating in conduct

decision meetings can meet this demand⁽²¹⁾. However, there are gaps from a psychological point of view, and professionals often do not know how to deal with their emotions before children with no possibility of cure or in a terminal phase.

In some cases, you have to change an employee of the shift. Because some have the emotional structure to work with that and others don't [...] it depends a lot on [...] if there is an employee with a child the same age, then you end up changing them, because it affects them a lot (P3).

Work is often performed in the form of task fulfillment, showing the lack of knowledge of the purpose of the actions requested. In this sense, nursing technicians report they do not have access to discussions, guidelines and decisions about palliative care for their patients.

Of course, they [Nursing Technicians] do not check the medical record so much [...] they do not understand very much the reason, the matter of the disease, why it happened, what happened. It goes like this: "Yes and it is done. The information has arrived, it is a fact" (P7).

The valorization of communication, participation in meetings where they can share and learn from each other the best ways to face and resolve the situations experienced^(22, 23), and actions from the perspective of continuing education instrumentalize professionals^(14, 18). Furthermore, they offer subsidies for the development of care, and combine ethical and moral values and scientific knowledge with the daily care practice.

FINAL CONSIDERATIONS

This study enabled the identification of an association between daily care, pain relief, comfort and promotion of privacy for children in palliative care and their families. Gaps in the

processes of continuing education and preparation of professionals to act in the face of this existential facticity were also revealed. Thus, the Palliative Care philosophy needs to be expanded to an integrated network of care and respect for end-of-life decisions in an interdisciplinary perspective. It is vital to take a careful look at nursing professionals in order to favor their empowerment for the exercise of ethical and sensitive care required by these patients at this existential moment.

Since establishing the principles of pediatric palliative care is fundamental, recognizing the gaps in the education and training processes of professionals to work in palliative care and end-of-life care enables the identification of possible strategies.

The participation of nursing professionals in interdisciplinary discussions is essential for decision making regarding the best conduct with children in palliative care and their families. However, psychological support is necessary considering the complexity of situations experienced in daily care in a unique way, when professionals are faced with the fragility of the human condition.

Dealing with human suffering, especially when it comes to children in palliative care and their families, is not an easy nor spontaneous task. It often requires self-denial and a compassionate and empathic look from all those who live in these unique spaces of pain and the most diverse vicissitudes. In view of the understanding achieved, is proposed an articulation of knowledge and practices for the construction of knowledge and applicability of the Palliative Care philosophy in Pediatric Nursing by overcoming the disease orientation and curative aspects and revitalizing the art of caring.

PERCEPÇÕES E VIVÊNCIAS DA EQUIPE DE ENFERMAGEM FRENTE AO PACIENTE PEDIÁTRICO EM CUIDADOS PALIATIVOS

RESUMO

Introdução: a proposta dos Cuidados Paliativos é implementada para pacientes em situações de vulnerabilidade ante uma doença grave, limitante e que pode, inevitavelmente, se encaminhar para a terminalidade. **Objetivo:** conhecer as percepções e vivências dos profissionais de enfermagem frente ao cuidado à criança em cuidados paliativos em unidades pediátricas. **Metodologia:** estudo qualitativo, exploratório e descritivo, realizado em unidades pediátricas de um hospital universitário de grande porte do Sul do Brasil. Os dados foram obtidos mediante entrevistas semiestruturadas com nove participantes, enfermeiros e técnicos de enfermagem, submetidas à análise de conteúdo temática. **Resultados:** a partir da análise temática emergiram quatro temas: Criança em cuidados paliativos: olhar da

enfermagem; Cuidado centrado na família; Vivências, sentimentos e percepções da equipe de enfermagem; e Enfrentamento da equipe de enfermagem: desafios para o cuidado. O estabelecimento dos princípios de cuidados paliativos pediátricos é fundamental para subsidiar o cuidado qualificado. Os profissionais de enfermagem revelam a necessidade de serem incluídos nas reuniões multidisciplinares realizadas para decidir condutas em relação ao paciente e sentem necessidade de apoio psicológico. **Considerações finais:** desvela-se a compreensão de que a filosofia de Cuidados Paliativos precisa ser ampliada para uma rede integrada de atenção e respeito às decisões para o final da vida.

Palavras-chave: Cuidados paliativos. Enfermagem pediátrica. Cuidados de enfermagem. Equipe de enfermagem.

PERCEPCIONES Y EXPERIENCIAS DEL EQUIPO DE ENFERMERÍA HACIA EL PACIENTE PEDIÁTRICO EN CUIDADOS PALIATIVOS

RESUMEN

Introducción: la propuesta de los Cuidados Paliativos es implementada para pacientes en situaciones de vulnerabilidad ante una enfermedad grave, limitante y que puede, inevitablemente, encaminarse para el fallecimiento. **Objetivo:** conocer las percepciones y experiencias de los profesionales de enfermería ante al cuidado al niño en cuidados paliativos en unidades pediátricas. **Metodología:** estudio cualitativo, exploratorio y descriptivo, realizado en unidades pediátricas de un hospital universitario de gran tamaño del Sur de Brasil. Los datos fueron obtenidos mediante entrevistas semiestructuradas con nueve participantes, enfermeros y técnicos de enfermería, sometidas al análisis de contenido temático. **Resultados:** a partir del análisis temático surgieron cuatro temas: Niño en cuidados paliativos: percepción de la enfermería; Cuidado centrado en la familia; Experiencias, sentimientos y percepciones del equipo de enfermería; y Enfrentamiento del equipo de enfermería: desafíos para el cuidado. El establecimiento de los principios de cuidados paliativos pediátricos es fundamental para fomentar el cuidado calificado. Los profesionales de enfermería revelan la necesidad de ser incluidos en las reuniones multidisciplinares realizadas para decidir conductas en relación al paciente y sienten la necesidad de apoyo psicológico. **Consideraciones finales:** se demuestra que la filosofía de Cuidados Paliativos necesita ser ampliada para una red integradora de atención y respeto a las decisiones para el final de la vida.

Palabras clave: Cuidados paliativos. Enfermería pediátrica. Atención de enfermería. Equipo de enfermería.

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