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## Reflections of nursing professionals on palliative care

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### Abstract

Palliative care aims to provide quality of life for patients and family, seeking to alleviate problems and symptoms, focusing on relieving suffering. The nursing team extensively participates in this care, which can emotionally overload the professional. Hence, this descriptive, qualitative, and exploratory study sought to clarify the feelings of nursing professionals working in palliative care. Data was collected by a semi-structured script applied to ten nursing professionals from the palliative care sector of a hospital. Emotional overload and difficulties in addressing certain feelings were observed in the interviewees. Results show a lack of strategies to mitigate these overloads in the work environment and the lack of palliative care in the health curricula. Some of the feelings described were difficult to manage, especially by less experienced professionals.

**Keywords:** Palliative care. Emotions. Nursing, team. Nursing care.

### Resumo

#### Reflexões de profissionais da enfermagem sobre cuidados paliativos

Os cuidados paliativos visam proporcionar qualidade de vida ao paciente e à família, buscando atenuar problemas e sintomas, com foco em aliviar sofrimento. A equipe de enfermagem participa amplamente destes cuidados, que podem sobrecarregar emocionalmente o profissional. Portanto, este estudo buscou esclarecer os sentimentos de profissionais da enfermagem que atuam nesta área. Trata-se de estudo descritivo, qualitativo e de caráter exploratório, utilizando roteiro semiestruturado como instrumento de coleta de dados. Participaram do estudo dez profissionais da equipe de enfermagem do setor de cuidados paliativos de um hospital. Observou-se sobrecarga emocional nos entrevistados e dificuldades em lidar com alguns sentimentos. Percebeu-se a carência de estratégias que amenizem estas sobrecargas no ambiente de trabalho e da abordagem da paliatividade nos currículos de saúde. Alguns sentimentos descritos pelos entrevistados foram difíceis de administrar, principalmente por profissionais menos experientes.

**Palavras-chave:** Cuidados paliativos. Emoções. Equipe de enfermagem. Cuidados de enfermagem.

### Resumen

#### Reflexiones de profesionales de enfermería sobre cuidados paliativos

Los cuidados paliativos tienen como objetivo proporcionar calidad de vida al paciente y a su familia, tratando de atenuar los problemas y síntomas, centrándose en aliviar el sufrimiento. El equipo de enfermería participa ampliamente en estos cuidados, lo que puede sobrecargar emocionalmente al profesional. Por lo tanto, este estudio buscó aclarar los sentimientos de los profesionales de enfermería que actúan en este ámbito. Se trata de un estudio descriptivo, cualitativo y de carácter exploratorio, que utiliza un guion semiestructurado como instrumento para recopilar los datos. Participaron en el estudio diez profesionales del equipo de enfermería del sector de cuidados paliativos de un hospital. Se observó una sobrecarga emocional en los entrevistados y dificultades para enfrentar algunos sentimientos. Se percibió la falta de estrategias que amenicen estas sobrecargas en el entorno laboral, así como de un abordaje de los cuidados paliativos en los currículos de los cursos de salud. Algunos de los sentimientos descritos por los entrevistados fueron difíciles de gestionar, especialmente por parte de los profesionales con menos experiencia.

**Palabras clave:** Cuidados paliativos. Emociones. Grupo de enfermería. Atención de enfermería.

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The increase in life expectancy and the incidence of chronic diseases such as cancer is responsible for a large part of deaths worldwide. Data from the 2020 Global Cancer Statistics show that 19.3 million new cases and almost 10 million deaths from this pathology occurred in that year<sup>1</sup>. Since it is chronic-degenerative, cancer evolves slowly in some cases and quickly in others, constituting the second leading cause of death in Brazil, only behind cardiovascular diseases<sup>2</sup>.

Factors inherent to cancer, such as pain, suffering, and death, highlight the importance of the quality of care provided to patients in terms of their physical, psychological, social, and spiritual needs<sup>3</sup>. It is estimated that around 20 million people need palliative care at the end of life worldwide. However, there is still a lack of well-qualified professionals to deal with this demand, which has become one of the major issues in public health.

The practice of care is intrinsic to the human condition, essential both in the course of life and at the moment of death. Over time, this practice underwent transformations regarding the physical space of care (previously exercised at home, now in hospitals) and, thus, its knowledge (from empirical to scientific)<sup>4</sup>. In this perspective, "palliative care" is an assistance which aims to provide quality of life for patients and their families, seeking to reduce problems and symptoms with treatments to alleviate suffering. Therefore, humanized, comprehensive, and individual care not only for patients but also for their family members in a period of mourning, is essential, so that it is experienced and accompanied by professionals<sup>5</sup>.

Palliative care promotes quality of life for patients affected by a disease that fails to respond to treatment, that is, without therapeutic possibilities. This approach seeks to provide well-being to patients and their families, preventing and relieving suffering by identifying, evaluating, and treating pain and other physical, psychosocial, and spiritual problems<sup>6</sup>. To mitigate symptoms related to the patient's clinical condition, palliative care is presented as a fundamental element to expand care and improve its quality without violating the rights and goals of the patient whose autonomy, values, and desires must be considered in the planning and implementation of care<sup>7</sup>.

In this sense, at times death can be faced as the only possibility to alleviate the patient's suffering, although the daily life of professionals working in palliative care is permeated by feelings and reactions caused by the difficulties in dealing with death. The main characteristics of these feelings are analyzed negatively and permeated by sadness, pain, and suffering<sup>8</sup>.

The study of palliative care in patients without therapeutic possibilities is necessary due to the importance of humanized care, especially that aimed at the patient at the end of life, seeking to relieve their pain and other physical symptoms, control psychosocial issues, and assist in the understanding of death. Thus, this research aimed to clarify the reflections of nursing professionals about feelings related to the work they perform with patients in the final stage of life in an oncology palliative care clinic.

## Methods

This is a descriptive exploratory study with a qualitative approach. Descriptive research aims to outline aspects of the object, population or phenomenon analyzed using standardized data collection techniques to characterize a particular group; survey opinions, attitudes, and beliefs of the study population; and assess possible associations between variables. Depending on its objectives, descriptive research is similar to exploratory research, which seeks a new vision of the problems. The exploratory nature of this study includes a bibliographic and documentary survey, non-standardized interviews, and a case study<sup>9</sup>.

In qualitative research, subject and environment have an objective and inseparable bond. During field research, this interaction should not be intentionally manipulated by the researcher, who inductively conducts the study, maintaining direct contact with the space and the object of study. Qualitative research values quality, not quantity, and its sample is usually small<sup>10</sup>.

This study was conducted in a large hospital, a reference in oncology, nephrology, neurology, and transplants, located in the city of Belém, Pará, Brazil. This institution offers chemotherapy, radiotherapy, and tumor extraction treatments, performs biopsies, and houses two palliative

care clinics assisted by a multidisciplinary team. Its Oncology Palliative Care Clinic (CCPO), the research site, is subdivided into CCPO1 and CCPO2, with 37 beds in total, caring for patients with very advanced cancer. About 52 professionals work at CCPO, distributed in morning, afternoon, and evening shifts.

Professionals who worked in the nursing team of the CCPO for more than a year, agreed to participate in the research and signed an informed consent form (ICF) were included in the study. All participants were informed and assured that the data would be kept completely confidential after the research, preserving their identity by pseudonyms coding, as provided for in Resolution 466/2012 of the National Health Council (CNS)<sup>11</sup>. They were also informed that they could choose to withdraw from the study or disallow the use of their information at any time.

Those who agreed to contribute to this research signed the ICF in two copies, and research started after all questions had been answered. Data were kept confidential, guaranteed by professional secrecy. The sample included ten nurses and nursing technicians of both sexes who work at the CCPO in the morning and/or afternoon.

Data were collected by a semi-structured script composed of questions about the characterization of respondents and six open questions (Chart 1). Interviews were conducted in a room intended for professionals to individually rest for approximately 10 minutes – the time provided for each interview. For a reliable analysis, the interviews were audio recorded and later fully transcribed. The researchers previously contacted those responsible for the sector of the hospital institution to request a suitable room for the interviews.

**Chart 1.** Research data collection instrument

| Characterization of the interviewees:                                                                                                            |       |
|--------------------------------------------------------------------------------------------------------------------------------------------------|-------|
| Age (in years):                                                                                                                                  | _____ |
| Religion: ( ) Catholic ( ) Evangelical ( ) Spiritist ( ) Other:                                                                                  | _____ |
| Professional training: ( ) Nurse ( ) Nursing technician ( ) Nursing assistant                                                                    |       |
| Professional training time (in months):                                                                                                          | _____ |
| Area of specialization (if any):                                                                                                                 | _____ |
| Master's area (if any):                                                                                                                          | _____ |
| PhD area (if any):                                                                                                                               | _____ |
| Time working at the institution (in months):                                                                                                     | _____ |
| Time working in oncology (in months):                                                                                                            | _____ |
| Working hours: ( ) 6h daily ( ) 8h daily ( ) 12x36 ( ) Day ( ) Night                                                                             |       |
| Works in another institution: ( ) Yes ( ) No                                                                                                     |       |
| Interview:                                                                                                                                       |       |
| 1. What led you to work in oncology or palliative care?                                                                                          |       |
| 2. What do you know about palliative care for terminally ill patients? Describe such care.                                                       |       |
| 3. What aspects do you most observe in patients under palliative care so that nursing care can be provided in the best possible way?             |       |
| 4. Could you summarize your feelings when caring for a patient without therapeutic possibilities?                                                |       |
| 5. In your opinion, how can we work with the feelings faced regarding death in cases in which there are no longer any therapeutic possibilities? |       |
| 6. Does the institution in which you work offer any kind of emotional support for employees?                                                     |       |

To better evaluate and discuss the data obtained, the elements found in interviewees' narratives were listed in six categories of analysis which emerged later and were systematically organized according to the content. Respondents' answers were associated with a theoretical framework so that their content could be examined in a scientifically reliable way. Moreover, to ensure anonymity and the ethical precepts of the research, the researchers identified the interviewees by pseudonyms (Peace, Gratitude, Solidarity, Faith, Life, Hope, Trust, Compassion, Affection, and Humanization) related to feelings and actions observed in the professionals working in palliative care.

The information collected was analyzed in a sequence of procedures that involved the reduction, categorization, and interpretation of data. A report was subsequently written<sup>12</sup>. In this research, data reduction meant simplifying the content collected to facilitate the selection of the most relevant information. The second procedure, categorization, aimed to organize the research data to support its discussion and reveal knowledge implicit to them. During interpretation, the researchers added their critical views, seeking to go beyond what was already known to culminate in the study findings in later surveys. The writing of the report complied with the requirements of scientific research: clarity, precision, conciseness, and objectivity.

This study followed the guidelines of Resolution CNS 466/2012<sup>11</sup> and was approved by a Research Ethics Committee. The ethical and scientific precepts regarding integrity, dignity, and autonomy were assured to participants, who could choose to remain in the study or not. Moreover, participants were made aware of the seriousness of the research, its non-profit goals, and the guaranteed professional secrecy. According to CNS Resolution 466/2012<sup>11</sup>, interviewees were also informed of the risks of this investigation. The researchers explained that these, even though they were minimal and predictable, were avoided, emphasizing the social relevance of the research and the advantages for the participants.

## Results

The research had 10 participants from the CCPO nursing team: four nurses specialized in internal medicine, cardiology, family health, and oncology;

and six nursing technicians of both sexes. In total, there were eight female and two male participants. The ages of these professionals ranged between 31 and 56 years old; their minimum and maximum training time were four and 20 years, and their experience in oncology or palliative care ranged from three to 13 years. Respondents had worked at the institution for a minimum of four and a maximum of 15 years, and six of them worked in no other institutions. Regarding religion, five professionals claimed to be Catholic; four, Evangelical; and one declared not to profess any religion but claimed to believe in Jesus Christ. We show the six analysis categories obtained in the study below.

### Category 1: professionals' perception of their work

*"It was more about a selection process opening up. Then, I started to work, but it was not by choice or for an interest or simply because I wanted to work with oncology or palliative care" (Solidarity).*

*"Well, this is my first job and I didn't have much choice" (Confidence).*

*"Actually, I've always really liked the field of oncology or palliative care, and there was a special situation in my family: my grandmother had cancer and I was very surprised by the things that happened and what she had. She underwent treatment in São Paulo and it was a very revolutionary phase; something very different, and then I fell in love with it" (Peace).*

*"Actually, since college I already related to cancer patients and, in fact, oncology always encourages us. The unknown is very present, so it is this challenge of trying to understand this disease and care process that has always motivated me to work with oncology or palliative care; the discovery of these new things" (Hope).*

### Category 2: professionals' knowledge about palliative care

*"It's comfort, especially the issue of pain control and the matter of listening; it is part of the care also trying, along with other professionals, the issues of patient autonomy, hygiene care,*

when necessary; for example, in wound care, which, many times, you will not solve, cure, heal that wound, but you will give a quality of life with odor control; when you control the odor, you restore dignity to the patient" (Peace).

"Palliative cancer care, in itself, can alleviate a symptom of pain, a respiratory discomfort. It's you alleviating a psychological pain, a symptom of depression; it's you welcoming the patient and their family member; welcoming the people who are around that patient because, in most of these cases, the whole family gets sick. Thus, palliative care, as I understand it, is minimizing the suffering of patients and the family members involved and ensure that they have a comfortable end of life" (Solidarity).

"Palliative care is not aimed at prolonging suffering or anticipating death, it just sees death as a factor that we cannot change as the disease progresses, and it tries to alleviate signs and symptoms. It is related to the progression of the disease, such as pain, nausea, weakness, and spiritual and emotional despair. One of the main focuses of palliative care is pain control, which is related to several factors" (Hope).

### Category 3: patient characteristics and possible care difficulties

"What we observe the most is pain, which is the most present in all of them and is one of the main focuses of palliative care. There is also one of the most essential aspects, the issue of hygiene and comfort, which is closely linked to nursing; the issue of dressings and of making patients maintain that self-esteem, even in the pre-death process, in the sense that what you can give them is a good bath, a good care, a good smell, as much as possible, and pain control" (Hope).

"They really need attention, conversation, they need love, they need affection, and they need to be treated with humanization; humanization in the area of palliative care is sometimes more significant than the medication itself" (Confidence).

"Patients in palliative care are practically 100% treated by nursing; most of them are bedridden in intensive care at our institution; they don't go to the an intensive care clinic, so they are sedated in the clinic.

This patient arrives for us in bed, restricted to bed, and all activities are under the responsibility of nursing, from simple diaper changes, change of positions, feeding; everything is ours and under our responsibility; symptom control, control of exudates, odor, wounds, pain, wound-related pain, use of medications related to this patient's pain due to cancer" (Humanization).

### Category 4: feelings related to professional performance in palliative care

"I suffer a lot when I see a patient die young, when I see a family member suffer for a loved one. I put myself in the other person's shoes a lot, so it still moves me – it shouldn't move me, and it ends up hurting, but it still moves me a lot" (Solidarity).

"Actually, I believe in many cures, not just for the body; I also believe in healing when the person is able to understand death as a process of life. What I don't like is people dying in suffering, but when the patient shows signs of life, is well medicated and with symptom control, odor control if they have wounds, I feel good about providing this care" (Peace).

"Look, over time we get a little tougher but it's not easy. We take care of them. So, I have some time in it and I end up not getting too involved, because I can suffer and cry a lot, and it's not nice; it is good for them that we give them strength at this moment" (Gratitude).

"Our training does not prepare us to accompany a person when they are dying; we are not prepared to talk about death in the family. Religion doesn't prepare us for this either, so logically, as professionals, we're going to be more fragile in that sense. I think it's still much more of an individual search" (Humanization).

### Category 5: strategies used by professionals to elaborate feelings

"We pay extra attention. We have to be very patient with patients and companions – let's say those who get nervous and cry easily –, but we don't serve as a technician in taking care of them.; We talk so we can ease the pain they are feeling in this moment of illness" (Gratitude).



*"I usually leave it at work; I don't take [the feelings] with me so it doesn't interfere with our day to day, our professionalism. Because it can interfere with your psyche and make you really have no reason to work; if you give yourself too much into the feeling of pain, you lose that patient and you may have problems and disorders, which even make your day-to-day work difficult" (Life).*

*"We have group therapy, a weekly team meeting; it's the moment when all the teams get together: neurologist, doctor, psychologist, nursing technician, dentist, everyone. It is the moment when the team meets to discuss the cases of patients or a specific patient and also to verbalize, discuss, and vent about what they are feeling, about their anxieties, their fears, about their frustrations [in] that patient's case [in which] you did not expect such a situation. So, I see that as a way of softening this side, the sentimental part, which is part of oncology and, unfortunately, there is no way for us to get rid of it; so, I see that the only effective way today is team meetings, which take time and have a very good result for all team members" (Solidarity).*

### Category 6: emotional difficulties encountered by professionals

*"So, you need to have a very good emotional balance to deal with this suffering, to deal with pain, to deal with death and for you to see it not as a failure but as something natural in the life process" (Hope).*

*"If the hospital offers it, I haven't seen anything yet. The only support I told you was from the CCPO team meeting; the clinic itself has this moment once a week but the hospital does not offer a form of support for us; I still haven't seen it clearly; if the hospital has it, it needs to be better worked on, better publicized, better offered to the whole team" (Solidarity).*

*"Yes, it does: we have the Servant Assistance Working Group [GTAS], which has a psychologist and a doctor. And the hospital also offers therapy for professionals. In fact, I have already sought care several times for other situations not related to the hospital, but there is, yes. It is a support, and here at the hospital we have very good professionals" (Hope).*

*"We used to have a meeting once a week to talk about our doubts, our feelings, about what is afflicting us at that moment and they were always mentioned; each one expressed their doubts, their feelings, their fears; it was very productive" (Peace).*

### Discussion

In this study, the sample was segmented between participants who chose oncology or palliative care and those who did not intend to work in the area but who perhaps needed to specialize in the area to obtain more knowledge and better assist their patients. Corroborating other research<sup>13</sup>, this result indicates that curricular changes are needed in professional training to include and deepen the approach of oncology and palliative care. Additionally, one must address the professionals' own knowledge, to seek more training in these areas since the demand for cancer services increases every year<sup>13,14</sup>.

During the analysis of the answers obtained, we found that most interviewees started their work in oncology or palliative care due to the need to work after completing their training. Coincidentally, admission was made possible by the institution. The other interviewees, however, expressed an affinity for the area due to an interest in delving into it or because they felt motivated by a family history of cancer.

All interviewees were concerned about patients' comfort regarding physical, psychological, and/or spiritual pain. This shows that professionals' knowledge directs them to perform quality and comprehensive care in practice since, concerning the perception of palliative care, all showed knowledge corresponding to that found in the current literature for the principles pertaining to the theme. Guidelines such as minimizing pain and other symptoms, not accelerating death, paying attention to psychological and spiritual aspects of patients, and offering support to the patient and family are some of the aspects recommended by the World Health Organization<sup>15</sup>. Palliative care in nursing focuses on the comprehensive care of the patient, preventing and controlling symptoms of the disease, in addition to involving everyone around them, such as family, caregivers,

friends, and even the multidisciplinary team, as this care aims to alleviate physical, psychological, and spiritual pain<sup>16</sup>.

Respondents have similar views regarding palliative care patients at the clinic in which they work. Although each patient affected by cancer has their specificity, in general, they all have the same aspects to be addressed<sup>15</sup>. The aspects most cited by professionals were pain, personal hygiene, dressings, and emotional and/or psycho-spiritual support.

The health team must offer the patient the necessary care to relieve symptoms and integrate multidisciplinary approaches to cover biopsychosocial and spiritual aspects, including support for the family concerning grief<sup>15,17</sup>. It is, therefore, necessary to know the management of cancer treatment and complications, as well as the evolution of the disease<sup>17</sup>.

In view of the answers obtained, we can see the diversity of feelings reported by interviewees. Solidarity proved to be empathic, and Peace, based on her beliefs, explains the feeling of well-being acquired by the patient's acceptance of death and the alleviation of suffering due to the care provided. We found, in Gratitude and Humanization's answers, professionals' emotional charge and their way of dealing with their feelings according to their specificity since they highlighted that, with several years of experience and work routine, they learned not to get so deeply involved to the point of harming both the care and themselves in the emotional aspect with the palliative care patient.

We also observed a feeling of unpreparedness, in academic training, to deal with situations inherent to the daily life of palliative care clinic. The nursing team working in the oncology or palliative area is constantly exposed to high emotional commitment due to their presence in much of the care, always witnessing the pain, death, and suffering of others<sup>18</sup>. Furthermore, even though they know that death is part of the natural cycle of life, these professionals feel unprepared to deal with this inevitable event. Most professionals attribute feelings such as work failure and care failures to death since nursing is the area that accompanies the individual for the longest time, from birth to death<sup>8</sup>.

Few studies address the feelings of nursing professionals in their experience with death,

such as compassion, guilt, indifference, denial, emotional involvement, and empathy<sup>19</sup>. Therefore, it is important that professionals explored the theme of so they can feel more prepared to act in the care of patients and their families<sup>13</sup>. Humanization must integrate nursing care in palliative care and this team understands that providing comfort and attention in care humanizes the work environment<sup>20</sup>.

Most interviewees were concerned with providing comfort to the patient as the main objective of palliative care, which is observed Gratitude's answers. However, the humanization of this type of assistance goes beyond the mechanical care to provide comfort, that is, there is a need to alleviate feelings related to the need for attention, affection, and love, as well as those of a spiritual nature<sup>21</sup>.

Thus, the varied feelings acquired daily can be improved either individually or collectively<sup>22</sup>. When questioning how each participant in this research managed their feelings, most say that, over time, they manage to separate their professional from their personal lives. Other interviewees mention a team meeting – focused on externalizing emotions, exposing doubts, opinions, and positions – as a strategy to work with them, as shown in Peace and Solidarity's answers.

Humanized care depends on several internal and external factors, most of which include the individual to be cared for – who needs special attention in their uniqueness<sup>21,23</sup>. Nursing has a fundamental role in humanization since the professionals who are part of it spend most of their time with patients and must act holistically in meeting their needs, treating them with solidarity, affection, and respect<sup>23</sup>.

Building a comfortable environment for the patient is not dissociated from the spiritual aspect and, by understanding the patient's need regarding this perspective, one can develop better palliative care<sup>21,24</sup>. The need to work on spiritual aspects is clear in most patients, linked or not to religiosity, providing comfort that embraces the patients in their entirety, ensuring humanized care in its different dimensions<sup>24</sup>.

Care generates strong feelings between patients and professionals, and both agents feel the loss of the person receiving care,



which requires professionals to know how to deal with these emotions to avoid disorders in their lives<sup>22</sup>. According to Hope's answers, nursing team professionals can face death in the work environment by knowledge and acceptance of finitude as a natural process of life. Some professionals, such as Solidarity, report receiving no emotional support at the institution in which they work, whereas others claim to be supported by GTAS.

Health teams must be in good mental health so they can develop their work in the best possible way in the care of patients and families. They see GTAS as the institution providing this emotional support. However, other interviewees claim the hospital failed to directly offer this support. As Peace's answers show, it is the multidisciplinary team which supports these professionals. Therefore, having a space in which professionals share their feelings and are psychologically supported can improve the quality of work and their satisfaction with it since they currently feel the absence of this support<sup>22,25</sup>.

Health professionals face challenges in their work environment that hamper the decision to apply palliative care to the patient, as well as their communication with family members<sup>16</sup>. The professional's greatest difficulty is the interruption of their relationship with patients, especially at the time of their death, and the impossibility of relieving their pain and suffering<sup>19</sup>.

Death must be treated as an inherent part of the profession. Thus, addressing these feelings

facilitates its confrontation. Feelings of loss, absence, and sadness, even if repressed, surfaced in professionals' minds as a need for survival and a reaction to fear linked to the end of life, triggering emotions that need to be elaborated in daily life<sup>25,26</sup>. Therefore, one must develop a space in which the various emotional issues of the health team can be welcomed and supported in psychology. Interventions that include psychosocial projects need to be included in professionals' routines and shifts to minimize problems related to feelings occurring in the work environment<sup>27</sup>.

## Final considerations

For most respondents, working in oncology or in palliative care clinic was not a matter of choice or of having acquired the necessary knowledge during training. This scenario showed the lack of addressing these issues in educational institutions and the need to better qualify health professionals in these areas. Therefore, the feelings the study participants described, resulting from palliative care practice, were more difficult to be managed by some, especially those with less experience, which also affects the humanization of care. However, realizing the importance of professional development and patient well-being, many sought to specialize in the subject and acquire experience in the work environment to humanize care and improve its quality.

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