

# Palliative care: dignity, frailty, and functionality in comfort feeding

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## Abstract

This study examined the relationship between dignity, frailty, and functionality in palliative care patients prescribed for comfort feeding. A cross-sectional, exploratory, and quantitative study was conducted with 20 hospitalized patients undergoing comfort feeding. Data collection included the application of the Brazilian version of the Patient Dignity Inventory, medical records data, and the use of the Palliative Performance Scale and the Clinical Frailty Scale, both adapted to Brazilian Portuguese. The results indicate that when symptoms are controlled, the perception of dignity protection increases; conversely, greater symptom burden and increased dependence lead to elevated existential suffering and diminished perception of dignity. The assessment of frailty, functionality, and dignity preservation can support the planning of care focused on patients' biographical aspects, with comfort feeding being crucial in this process.

**Keywords:** Palliative care. Frailty. Functional status. Diet. Patient Comfort. Respect.

## Resumo

### Cuidados paliativos: dignidade, fragilidade e funcionalidade na alimentação de conforto

Este estudo examinou a interação entre dignidade, fragilidade e funcionalidade em pacientes sob cuidados paliativos que recebem alimentação de conforto. Realizou-se um estudo transversal, exploratório e quantitativo em 20 pacientes hospitalizados sob essa prescrição alimentar. A coleta de dados envolveu a aplicação do Inventário de Dignidade do Paciente na versão brasileira, informações extraídas dos prontuários e a utilização das escalas *Palliative Performance Scale* e *Clinical Frailty Scale*, adaptadas para o português. Os resultados indicam que, com os sintomas sob controle, a percepção de proteção da dignidade se eleva. Por outro lado, um aumento dos sintomas e da dependência resulta em maior sofrimento existencial e diminuição da percepção de dignidade. Avaliar a fragilidade, a funcionalidade e a preservação da dignidade é crucial para planejar cuidados centrados na biografia do paciente, sendo a alimentação de conforto um componente fundamental desse processo.

**Palavras-chave:** Cuidados paliativos. Fragilidade. Estado funcional. Dieta. Conforto do paciente. Respeito.

## Resumen

### Cuidados paliativos: dignidad, fragilidad y funcionalidad en la alimentación de confort

Este estudio analizó la relación entre dignidad, fragilidad y funcionalidad en pacientes en cuidados paliativos con prescripción de alimentación de confort. Se realizó un estudio transversal, exploratorio y cuantitativo con 20 pacientes hospitalizados con prescripción de alimentación de confort. La recolección de datos incluyó la aplicación de la versión brasileña del Inventario de Dignidad del Paciente, datos de la historia clínica y la aplicación de las escalas *Palliative Performance Scale* y *Clinical Frailty Scale* adaptadas al portugués. Los resultados muestran que, cuando los síntomas están controlados, hay una mayor percepción de protección de la dignidad. Si aumentan los síntomas y la dependencia, empeora el sufrimiento existencial y reduce la percepción de la dignidad. La evaluación de la fragilidad, funcionalidad y percepción de preservación de la dignidad contribuye a planificar los cuidados centrados en la vida del paciente, siendo la alimentación de confort un elemento esencial de este proceso.

**Palabras clave:** Cuidados paliativos. Fragilidad. Estado funcional. Dieta. Comodidad del Paciente. Respeto.

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Patients in all age groups and with any chronic and life-threatening disease—especially in the end-of-life stage—can benefit from palliative care<sup>1</sup>, regardless of the service context. Such care can be offered from a multidisciplinary, interdisciplinary and transdisciplinary perspective, always considering the importance of the patient's background and context. Excellence in care—which includes maintaining quality of life and preserving human dignity<sup>2</sup>—is essential for the professionals who care for these patients and their families.

The preservation of dignity, beyond a concept, is an essential pillar that guides professionals, patients and families in defining objectives for health care and basic conditions for end-of-life care<sup>3</sup>. The ability to eat, move and perform daily activities is fundamental for patient quality of life. However, as frailty increases and functionality deteriorates due to disease progression, in addition to the psychosocial impact of eating, the perceived dignity can be affected in the end-of-life context.

In palliative care, the preservation of dignity is directly related to the quality of the service and the sensitivity of the support network that provides care<sup>4</sup>. When discussing comfort feeding as a strategy to maintain dignity, it is salutary to be available to customize care, meeting the individual needs and experiences of patients and families and exploring possibilities to ensure patient autonomy, dignity and protagonism in this aspect.

Throughout the course of the disease process and the progression of chronic conditions, there may arise the need for hospitalization. At this time, the health care team should focus on important points to preserve patient dignity, including the control of symptoms, hygiene, feeding and service quality in the hospital, aiming to promote patient comfort. Comfort feeding has the power to preserve dignity, as it enables patients—even with functional limitations and frailty—to incorporate personal elements, choosing to eat in their most comfortable and appropriate manner.

The food-related comfort possibilities notably includes the important understanding

of the patient's relationship with the act of eating. That is because, in addition to supplying calories and nutrients, food serves as a form of personal expression, enabling patients to express their preferences and autonomy, in addition to reinforcing bonds, expressing their emotional state and promoting well-being<sup>5</sup>. Thus, nutritional interventions, which previously sought to reestablish frailty and functionality indicators, now focus on patient comfort, prescribing proportional conducts adapted to each stage of the palliative care process.

The expression “comfort feeding only” was initially proposed by Palecek and collaborators<sup>6</sup> for individuals with advanced stage dementia. However, this approach has been extended to palliative care patients with other debilitating conditions. Being able to feed orally, they have no benefit from artificial nutrition methods such as enteral or parenteral nutrition<sup>7</sup>.

Relevantly, end-of-life nutritional care has different objectives, focusing mainly on ensuring patient comfort and well-being<sup>8</sup>. Thus, studying how dignity is perceived in the context of feeding can support more efficient care. That is because care, as an active intervention, has the power to preserve or even strengthen the dignity of end-of-life patients<sup>9</sup>, despite functional losses and frailty, which, at first, could hinder this perceived dignity.

This study aims to correlate functionality and frailty state with perceived dignity in patients prescribed comfort feeding during palliative care hospitalization.

## Method

This is a cross-sectional and exploratory study, with a quantitative approach, aiming to correlate functional aspects with perceived dignity preservation in palliative care patients under prescribed comfort feeding.

The study included 20 patients, aged 18 years or older, of both sexes, admitted to palliative care in a private hospital in Santa Catarina, with a prescription of “comfort feeding.” The sample was intentionally selected<sup>10</sup>, as the characteristics of

this population could provide fruitful information for the research.

Data collection was conducted between August 2021 and April 2022, using the Brazilian Portuguese version of the Patient Dignity Inventory (PDI-Br), translated from the original Patient Dignity Inventory (PDI). On this occasion, we also collected data from the patients' medical records, including age, sex, diagnosis, time since diagnosis, duration of hospitalization and period in palliative care. In addition, we obtained sociodemographic information, such as city of origin, income, religion, education and profession, and applied the Palliative Performance Scale (PPS) and Clinical Frailty Scale (CFS), adapted to Portuguese.

The Palliative Performance Scale (PPS)<sup>11,12</sup> is a scale developed to assess the performance of patients in palliative care, whether during outpatient follow-up, hospitalization or home care, based on the stage of disease evolution. It is an important tool for decision-making, diagnostic evaluation and prognostic evaluation. Scores range from 100% to 0%, where 100% indicates a patient able to perform their daily activities, such as walking, working or practicing hobbies, taking care of oneself, eating and maintaining the level of consciousness, in an integral way, while 0% corresponds to a deceased patient.

The Clinical Frailty Scale (CFS)<sup>13</sup> is an ordinal scale used to assess the frailty of patients. It consists of nine score levels, analyzed holistically by the health care professional, based on the individual's clinical findings and functional capacity. Scores range from 1 to 9, where 1 indicates a very active patient and 9 indicates a terminally ill patient.

Patient Dignity Inventory (PDI) is an inventory originally developed by Chochinov and collaborators<sup>9</sup> to understand the multiple factors that influence the perceived loss of dignity of end-of-life patients. This instrument is a valid and consistent screening tool used in palliative care to provide a more accurate view of patient experience, enabling them to expose and discuss specific points that may be causing suffering<sup>14</sup>. The Brazilian version of the inventory maintains

the original proposal, contributing to a better understanding of the variables that affect the sense of dignity and to the improvement of care for this population<sup>15</sup>.

The inventory consists of 25 items, divided into three domains, with the objective of identifying problems associated with loss of dignity: "Presence of symptoms" (PS), which addresses the recognition of disease progression-related discomfort or distress, including suffering due to unawareness of the state of health, treatment or process of death; "Dependence" (D), which reflects the patient perception of the maintenance of cognitive and functional acuity to perform daily activities; and "Existential suffering" (ES), which refers to questions about the meaning of life and the social roles played by the patient<sup>3,14</sup>.

The 25 inventory items represent specific situations, such as the inability to perform daily activities (such as bathing or dressing), the presence of stressful physical symptoms (such as pain, shortness of breath or nausea) and the feeling of lack of control over one's life. For each situation, the patient should indicate the degree to which it represents a problem or concern in the last days, marking one of the options with a corresponding score: 1) it is not a problem; 2) a small problem; 3) a problem; 4) a large problem; 5) a huge problem. The sum of the scores results in a total score and in scores for each domain: "Presence of symptoms" (PS), "Dependence" (D) and "Existential suffering" (ES). These scores were correlated with sociodemographic characteristics and with the scores of the PPS and CFS scales.

The sample selection criteria in relation to the scales were: patients with CFS score below 7 and PPS score above 30%. This score range was chosen to include only those patients with sufficient level of consciousness and functionality to answer the PDI-Br.

Data analysis used the SPSS 22.0 program, presenting the results in minimum and maximum values, mean and standard deviation. The correlations between the variables were evaluated by Spearman's test, considering values with  $p < 0.05$  to be significant.

## Results

The study included 20 palliative care patients from a hospital ward in Santa Catarina. Of these patients, 11 (55%) were women. Regarding marital status, 12 (60%) were married, 3 (15%) were single, and 5 (25%) were widowed. Length of stay ranged from 2 to 21 days, with an average of 8.6 days of stay. The participants had varying educational levels: 1 had a postgraduate degree, 8 (40%) had completed higher education, 3 (15%) had completed high school, 1 had completed

a vocational course, 4 (20%) had completed elementary school, and 3 (15%) had incomplete elementary education. Regarding religion, 12 were Catholics, 4 Lutherans, 3 evangelicals and 1 had no specific religion.

The participants' diagnosis mainly included oncological disease, with 16 cases, in addition to conditions such as cardiovascular disease, chronic obstructive pulmonary disease (COPD) and renal failure. During the study, 17 participants (85%) died in the hospital ward. Table 1 details the participants' sociodemographic and clinical data.

**Table 1.** Correlation of the participants' general characteristics (n=20)

	Minimum	Maximum	Mean	Standard deviation
Age (years)	31	94	61.9	18.7
Monthly Income (reais)	1,100	10,000	4,735.00	2,604.51
Length of hospital stay (days)	2	21	8.6	5.1
Diagnosis time (months)	8	240	57.8	56.8
Time in PC (weeks)	1	40	7.3	9.3
PPS Score (%)	40	60	44.5	6.9
CFS Score	3	7	5.7	1.1

Source: the researchers (2022).

It can be observed that, despite varying levels, all participants presented some degree of frailty, with scores ranging between 3 and 7, and performance ranging between 40% and 60%. As described in the methods section,

these participants had functional impairment, requiring some type of support to perform daily activities.

Table 2 presents the results of the raw scores for the domains of the Patient Dignity Inventory.

**Table 2.** Raw scores for the domains of the Patient Dignity Inventory (PDI-Br) of the participants (n=20)

	Minimum	Maximum	Mean	Standard deviation
Presence of Symptoms	16	52	35.1	10.1
Dependence	5	25	16.0	5.9
Existential Suffering	8	26	15.0	5.5

Source: the researchers (2022).

Table 3 presents the correlations between the variables collected from the participants.

The results presented in Table 3 indicate a positive and significant correlation between age

and Time of diagnosis ( $r=0.604$ ;  $p<0.01$ ), as well as the CFS Score ( $r=0.732$ ;  $p<0.01$ ). On the other hand, age showed a negative correlation with Time in palliative care ( $r=-0.483$ ;  $p<0.05$ ), with the PPS

Score ( $r=-0.576$ ;  $p<0.01$ ), and with the Presence of Symptoms ( $r=-0.464$ ;  $p<0.05$ ) and Existential Suffering ( $r=-0.456$ ;  $p<0.05$ ) domains of the Patient Dignity Inventory.

**Table 3.** Correlation of the general characteristics of the participants

	Age	Length of hospital stay (in days)	Time since diagnosis (in months)	Time in PC (in weeks)	PPS Score	CFS Score	Presence of Symptoms (D1)	Dependence (D2)	Existential Suffering (D3)
Length of hospital stay (in days)	0,021								
Diagnosis time (months)	0.604**	-0.193							
Time in PC (in weeks)	-0.483*	-0.286	-0.128						
PPS Score	-0.576**	0.260	-0.595**	0.123					
CFS Score	0.732**	0.017	0.630**	-0.386	-0.521*				
Presence of Symptoms (D1)	-0.464*	-0.027	-0.083	0.348	0.301	-0.568**			
Dependence (D2)	-0.136	0.077	0.132	0.093	0.084	-0.238	0.743**		
Existential Suffering (D3)	-0.456*	-0.517*	-0.006	0.567**	-0.061	-0.574**	0.632**	0.482*	
Total	-0.384	-0.110	0.014	0.282	0.160	-0.496*	0.937**	0.880**	0.736**

\* Significant correlation at  $p<0.05$ ; \*\* Significant correlation at  $p<0.01$  (Spearman's correlation, two-sided). The presence of the negative sign in front of the value corresponds to negative correlations. "Monthly income" did not correlate with any variable, and is not shown in the table. Source: the researchers (2022).

In the analyzed sample, the time since diagnosis correlated positively with the CFS Score ( $r=0.630$ ;  $p<0.01$ ) and negatively with the PPS Score ( $r=-0.595$ ;  $p<0.01$ ). In addition, the CFS Score and PPS Score showed a negative correlation with each other ( $r=-0.521$ ;  $p<0.05$ ). When analyzing the relation between the CFS scale score and the Patient Dignity Inventory, we observed a negative correlation with the total score of the inventory ( $r=-0.496$ ;  $p<0.05$ ) and with the domains Presence of symptoms ( $r=-0.568$ ;  $p<0.01$ ) and Existential suffering ( $r=-0.574$ ;  $p<0.01$ ). No significant correlations were found between the PPS Score and the Patient Dignity Inventory scores.

When analyzing the length of hospital stay in relation to the Patient Dignity Inventory, we observed a negative correlation with the

Existential suffering domain (D3) ( $r=-0.517$ ;  $p<0.05$ ). On the other hand, when examining the relation between the Existential suffering domain (D3) and the time in palliative care, we found a positive correlation ( $r=0.567$ ;  $p<0.01$ ), suggesting that existential suffering tends to increase with time in palliative care.

In the study in question, when investigating the other domains of the Patient Dignity Inventory, there is a positive correlation between Presence of symptoms (D1) and Existential suffering (D3) ( $r=0.632$ ;  $p<0.01$ ), as well as a positive correlation between Dependence (D2) and Existential suffering (D3) ( $r=0.482$ ;  $p<0.05$ ). These results show that existential suffering tends to worsen as the presence of symptoms and dependence increase.



## Discussion

Comfort feeding plays a crucial role in the care of palliative care patients. However, it is essential to consider other factors to promote the best possible support to this population, showing the complexity involved. The promotion of comfort should consider the specific needs at each stage of the disease, including adjustments in functionality and increased frailty of the patient.

The data show a positive correlation between age and time since diagnosis, while presenting a negative correlation between age, time in palliative care, and frailty scores in the Presence of Symptoms and Existential Suffering domains of the inventory. Although these results are consistent with a benchmark study in the area<sup>4</sup>, they differ from more recent research<sup>16</sup>, which, when examining a sample of 83 patients, found that younger individuals reported lower scores for distress associated with loss of dignity.

It is essential to note that age alone does not define a worse prognosis. However, it is pertinent to consider that older adults often have multiple comorbidities<sup>1</sup>. Therefore, the implementation of palliative care is essential from the moment of diagnosis, providing patient monitoring for a longer period and preserved quality of life throughout the process<sup>2</sup>. In addition, it is crucial that the symptoms and aspects of existential suffering are addressed in holistically and multidisciplinary.

Regardless of the baseline condition, lost functionality and increased dependence on other persons for daily activities are associated with an unfavorable prognosis<sup>1</sup>. The present study observed that both functional deterioration and frailty correlate with a longer time since diagnosis. Therefore, health care planning for these patients should include a continuous functional assessment, guiding the team to adopt measures to prevent discomfort, such as the use of pads to avoid pressure injuries, the reduction of risk factors for delirium, the adaptation of diet consistency, the prescription or adaptation of motor and respiratory physical therapy, and the management of possible frustrations and anxieties, among other interventions.

Even with all participants under exclusive prescription of comfort feeding, we observed significant reports in the three domains of the Patient Dignity Inventory, showing the complexity involved in providing comfort to patients under palliative care. The promotion of comfort should be based not only on diet, but also on the assessment of specific needs at each stage of the disease, taking into consideration changes in functionality, increased frailty and variations in the overall performance of patients.

The results of this study show the difficulties faced by the participants, as: the better the physical robustness and control of symptoms, the greater the perceived protection of dignity. This finding is consistent with the literature, which indicates that the feeling of reduced dignity is influenced by the disease experience and directly proportional to the degree of physical suffering and limitations or losses resulting from disease progression<sup>4,17</sup>. A rigorous nutritional approach, focused on caloric and nutrient goals, can result in uncomfortable symptoms or require alternative feeding methods, such as enteral or parenteral methods, which can also cause discomforts, symptoms and risks, thus increasing the score for the Presence of symptoms domain. From this perspective, existential suffering is also justified, as it can be impacted by the feeding method or by an approach that contradicts the patient's will.

By prioritizing symptom control and functionality maintenance within the patient's capabilities, palliative care has the intrinsic objective of preserving relief. Such initiative enables the support of patients and their families at different stages of the disease, providing comprehensive care and preserving dignity<sup>18</sup>. As for the nutritional care aspect, comfort feeding is viable in contexts such as offering foods that are easy to ingest, which aid in chewing and swallowing and promote relief from distressing gastrointestinal symptoms, ensuring that all symptoms are adequately treated<sup>8</sup>.

During hospital stay, several factors involved in existential suffering can be addressed through contact with providers, management of communication or other interventions aimed at

improving care. The research data of this study, by showing a negative correlation between length of hospital stay and the Existential Suffering domain, indicate the relevance of the relation between the health care provided by the institution and the maintenance of the well-being and quality of life of patients under palliative care. A study with end-of-life patients<sup>4</sup> found that inpatients felt a break in dignity due to the lost autonomy and independence, suggesting that hospitals can play an important role in preserving or deteriorating the patient perceived dignity.

It is important to note the positive correlation between the existential suffering domain and time in palliative care. This finding fosters in-depth reflection by health care providers on this dimension of suffering, because, although physical suffering is a priority and constitutes the initial focus of the team's intervention, the impact of existential suffering cannot be neglected. According to a study with cancer patients in end-of-life stage<sup>4</sup>, those with a greater perception of violation of dignity reported a more intense feeling of lost desire to live and a greater desire to die, compared to patients who did not feel their dignity compromised. Thus, the erosion of dignity can trigger suffering and feelings of hopelessness, which are central points that require consideration in the care of existential issues.

In this aspect, feeding—with its multidimensional nature—assumes an existential character in the patient's experience, as it gives meanings, significances and affections to their eating routines and to the adaptation of the nutritional therapy to their specific needs. This understanding is extremely valuable for health care professionals, as the recognition of suffering in its various facets—physical, emotional, spiritual and other personal dimensions—contributes to the definition of objectives and approaches in the end-of-life care process.

Due to worsened health condition, patients may face challenges in maintaining a sense of essence or self-esteem, in addition to questioning whether their previous social roles still deserve to be valued<sup>3</sup>. Thus, it is essential that existential

issues are also addressed seriously and that there may be opportunities for the patient, together with the team, to process these distressing aspects related to the pursuit of meaning for their life experience.

As for feeding in this context, professionals should consider the objectives of care and protect the patient from situations that cause discomfort, such as obstinate interventions, to prevent them from becoming a variable of degradation of dignity<sup>19</sup>. As the end of life approaches, the palliative care team should intensify the focus on managing suffering, as people who receive unsatisfactory end-of-life care may experience perturbations that, in turn, may increase the feeling of lost dignity<sup>4,17</sup>.

Noting that existential suffering is aggravated by the increased presence of symptoms of dependence, the results corroborate the premise that the perceived dignity is related to the ability to manage physical and psychological conditions. Thus, as the disease progresses, factors such as physical changes, feeling of being a burden to others, need for help with daily activities, pain and required hospitalization are directly associated with the feeling of lost dignity<sup>4</sup>.

Loss of control and autonomy are central issues in the patient's experience of perceiving dignity, showing the need to consider and implement measures that promote and preserve these aspects<sup>3</sup>. This situates the patient in a protagonist position. The ability to decide what to eat can reinforce the sense of control, representing an exercise of autonomy and a means of preserving dignity as the patient realizes that their will is respected by the institution and professionals.

The concept of dignity provides a broad framework and a moral compass for care, guiding patients, families and health care professionals in defining goals and making decisions about fundamental therapies for end-of-life care<sup>17</sup>. It is essential to adopt strategies to affirm patient control and autonomy to preserve their dignity and that are based on their involvement in care planning and treatment decision-making, if so they wish<sup>3</sup>. Comfort feeding is one of these strategies.

Chochinov and collaborators proposed Dignity Therapy<sup>20-22</sup>, an intervention geared toward patients under palliative care, in order to promote a dignified end-of-life experience, considering a multigenerational impact for patients and families.

A limitation of this study was the impossibility of evaluating a control group without prescription of comfort feeding and reflecting on the comparison between groups. The present study reinforces the insight that, despite discussions on the notion of dignity near the end of life, there is still a lack of empirical information and a limited variability of available research on the issue<sup>17</sup>.

## Final considerations

Functionality and frailty are related to the perceived preservation of dignity, as evaluating these aspects is essential to define conducts that consider the multidimensional condition of patients in palliative care. In this regard, feeding, whether orally or alternatively, when not aligned with comfort objectives, can negatively impact the perception of dignity. On the other hand, the fact that the study participants are under exclusive prescription of comfort feeding does not necessarily imply worse frailty or functionality scores, which is a relevant concern for health care professionals and family members.

Based on the results, dignity can be seen as a central element that drives actions directed to end-of-life patients, considering personal and proportional aspects. In this context, feeding

emerges as a favorable field for the exercise of patient protagonism. As these are patients who have been prescribed comfort feeding, it is understood that this nutritional support method is directly associated with increased perception of preserved dignity. That occurs because it is associated with less physical suffering (avoiding alternative feeding methods and unpalatable or bulky diets), better control of symptoms (such as nausea, vomiting and constipation), respect for patient autonomy, a greater sense of control (ability to choose what, when and how much to eat) and consideration of emotional factors (meanings and feelings related to the feeding experience).

Despite the small sample size, it is necessary to recognize that this study involved terminal and end-of-life patients. The difficulty in conducting studies with this population is notorious, since most participants died during the research, which makes the research process even more challenging.

Insight into the aspects involving dignity at the end of life provides society with the opportunity to adopt a more attentive and sensitive view of those who get sick, as well as to obtain structure to meet needs not always recognized as relevant in the general context.

This study is in line with pioneering studies on preserving the dignity of patients under palliative care. Despite the challenges posed by research with this population, further studies exploring the various aspects of palliative care are essential for the advancement of knowledge and to ensure that care is permanent and that the dignity of human life is preserved until the last moment.

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#### Contribution of the authors (CRediT)

Marcia Caetano da Costa contributed in the design and delineation of the study, data collection, analysis and interpretation, writing of the manuscript and approval of the final version. Maria Eliana Madalozzo Schieferdecker was responsible for the critical review of the intellectual content and approval of the final version. Mariele Rodrigues Correa worked in the critical review of the intellectual content and approval of the final version. Marianna Rodrigues Beltrão participated in data analysis and interpretation. Carla Corradi-Perini was responsible for supervision, writing, data interpretation, critical review of intellectual content and approval of the final version. All authors declare themselves responsible for the integrity and accuracy of the content of this article, as well as approve its final version for publication.

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