

# Palliative care in stroke: a nutritional look

# Cuidado paliativo em acidente vascular cerebral: um olhar nutricional Cuidado paliativo en accidente cerebrovascular: una perspectiva nutricional

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This is a theoretical-reflective study carried out in 2020. It was based on the analysis of books, documents and scientific articles obtained in databases, with the aim of elaborating reflections on nutritional approaches in the palliative care of patients affected by strokes. The guiding question was: What are the contributions of the nutritional approach for patients affected by strokes in palliative care? 15 references were considered, most of them international. The reflective axes were: Palliative care in stroke; Nutritional approaches in palliative care; and Nutritional approaches in palliative care in stroke. In addition to specific palliative guidelines and professional training, combating prognostic inaccuracies after the event is essential. Although nutritional interventions are of varying importance in the palliative approach of this patient, they must always respect the autonomy of the patient and their family. Stroke is a great cause of death and functional disability worldwide. The provision of palliative care as part of continuous care and integrated into the Unified Health System has recently been standardized and the issue of nutrition in a palliative situation needs a greater national approach.

**Descriptors:** Diet therapy; Stroke; Palliative care.

Trata-se de um estudo teórico-reflexivo a partir da análise de livros, documentos e artigos científicos obtidos em bases de dados, realizado em 2020, com o objetivo elaborar reflexões sobre abordagens nutricionais no cuidado paliativo de pacientes acometidos por acidente vascular cerebral. A questão norteadora foi: *Quais as contribuições da abordagem nutricional para pacientes acometidos por acidente vascular cerebral em cuidados paliativos?* Foram considerados 15 referencias, na sua maioria internacionais. Os eixos reflexivos foram: *Cuidados paliativos em acidente vascular cerebral; Abordagens nutricionais em cuidados paliativos; e Abordagens nutricionais em cuidados paliativos no acidente vascular cerebral.* Além de diretrizes paliativas específicas e capacitação profissional, é imprescindível o combate à imprecisão prognóstica após o evento. Embora as intervenções nutricionais sejam de importância variada na abordagem paliativa deste paciente, devem sempre respeitar a autonomia do paciente e de sua família. O acidente vascular cerebral é importante causa de óbito e incapacidade funcional em todo o mundo. A oferta de cuidados paliativos como parte da atenção continua e integrada no Sistema Único de Saúde foi recentemente normatizada e, a questão da nutrição em situação paliativa necessita de maior abordagem nacional. **Descritores:** Dietoterapia; Acidente Vascular Cerebral; Cuidados paliativos.

Se trata de un estudio teórico-reflexivo basado en el análisis de libros, documentos y artículos científicos obtenidos de bases de datos, realizado en el año 2020, con el objetivo de desarrollar reflexiones sobre los enfoques nutricionales en el cuidado paliativo de pacientes que sufrieron accidentes cerebrovasculares. La pregunta guía fue: ¿Cuáles son las aportaciones del enfoque nutricional para los pacientes que sufrieron accidentes cerebrovasculares en cuidados paliativos? Se consideraron quince referencias, la mayoría de ellas internacionales. Los ejes de reflexión fueron: Cuidados paliativos en accidente cerebrovascular; Enfoques nutricionales en cuidados paliativos; y, Enfoques nutricionales en los cuidados paliativos en accidente cerebrovascular. Además de las directrices paliativas específicas y de la formación de los profesionales, es fundamental combatir la imprecisión pronóstica a posteriori. Aunque las intervenciones nutricionales tienen una importancia variada en el enfoque paliativo de este paciente, deben respetar siempre la autonomía del paciente y de su familia. Accidentes cerebrovasculares son una importante causa de muerte y discapacidad funcional en todo el mundo. La oferta de cuidados paliativos como parte de la atención continua e integrada en el Sistema Único de Salud se ha regulado recientemente y la cuestión de la nutrición en situación paliativa necesita un mayor enfoque nacional.

**Descriptores**: Dietoterapia; Accidente Cerebrovascular; Cuidados paliativos.

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# INTRODUCTION

stroke is a neurological deficit of vascular origin, usually focal, of sudden onset or with rapid evolution, lasting more than 24 hours, or less, but leading to death; it is considered an important public health problem in the whole Western world. Neurological damage results from the loss of blood supply due to spasm, clot or blood vessel rupture, and there may be loss of consciousness, paralysis and other changes, depending on the location and extent of brain damage<sup>1</sup>.

In general, strokes are generally classified by the pathological aspect it determines, and may be ischemic or hemorrhagic. An ischemic stroke is caused by obstruction or reduced blood flow in the cerebral artery, causing a lack of circulation in its vascular territory. A hemorrhagic stroke is caused by spontaneous (non-traumatic) rupture of a vessel, with blood leaking into the brain (intracerebral hemorrhage), to the ventricular system (intraventricular hemorrhage) and/or subarachnoid space (subarachnoid hemorrhage)<sup>1</sup>.

According to the World Health Organization (WHO), by 2030, strokes will continue to be the second leading cause of death in the world, accounting for 12.2% of deaths predicted for that year, and with no prospect of improvement. The situation in Brazil does not seem to be very different, where cardio and cerebrovascular diseases are the main causes of death in the country<sup>2</sup>.

Despite numerous and relevant scientific advances, the prognosis for individuals who suffer from strokes is also very worrying. Between 35 and 52% of those affected by hemorrhagic strokes die within 30 days. Approximately 50% of deaths occur in the first 48 hours, and the rest are often associated with complications of the condition (aspiration pneumonia and sepsis)<sup>3</sup>.

Even with the bad scenario for patients who suffered a stroke, individualized prognostic studies have clinical, emotional and social relevance for the patients, their families and health service professionals. These studies are especially important to determine the level of care, conduct and care protocols for each patient, based mainly on the estimate of the initial severity of the stroke. Lowering the level of consciousness, incontinence and/or hemiplegia are also considered important indicators of morbidity and mortality<sup>4,5</sup>. But, obviously, the prognosis for survival and disability should always be individualized.

For some situations, prioritizing comfort and treatment of the patient's symptoms, their family, friends and the health teams themselves, instead of curative or adaptive processes will be the best indication. This is the context in which palliative care is used, a relatively innovative form of assistance in the health area, despite its origins that date back, at least, to the end of the 1950s, in England<sup>6</sup>. Such an approach uses a multiprofessional structure, which is increasingly frequent in hospital settings, specialized clinics and in primary care. This field of work seems to be expanding rapidly, not only due to the aging of the population, but also due to the greater success of curative therapies or that allow a better quality of life in patients with chronic diseases, which were once quickly fatal<sup>5</sup>.

In 2018, the palliative approach made significant progress as a public health policy in Brazil. The Ministry of Health published a resolution that regulated the provision of palliative care as part of the continuous care integrated within the scope of the Unified Health System (SUS), and should therefore be offered anywhere in the health care network, from primary care to hospital care. SUS already offered a palliative approach, but there were no regulations defined for the recognition and organization of the offer, and it is now possible to define guidelines and improve activity. According to the resolution, palliative care is guaranteed to every person affected by a life-threatening illness, whether acute or chronic, from the diagnosis of this condition<sup>7</sup>.

Considering the epidemiological importance of strokes, its respective therapeutic and/or palliative approaches, in addition to the multiprofessional nature of the relevant public

health policy, the aim of this study was to elaborate reflections on nutritional approaches in the palliative care of patients affected by strokes.

# **METHOD**

This is a theoretical-reflective study carried out in 2020, through the reading of books, scientific articles and documents guiding palliative and nutritional approaches. The guiding question was: What are the contributions of the nutritional approach for patients affected by strokes in palliative care?

The survey of scientific articles sought clinical-nutritional guidelines for patients affected by stroke in palliative care, in the databases LILACS, Scielo, BVS and PUBMED. Initially, combinations with simultaneous participation of descriptors were used, creating groups 1, 2 and 3, one of each group by search, according to the bases searched and using the Boolean operator "AND". For group 1, the descriptors were used: "Acidente Vascular Cerebral", "Acidente Vascular Encefálico", "Derrame" and "Stroke". For group 2, it was used: "Cuidados Paliativos" and "Palliative care". Group 3 had the descriptors: "Terapia nutricional", "Dietoterapia", "Nutrição artificial", "Cuidado nutricional" and "Nutritional therapy", "Dietotherapy", "Artificial nutrition" and "Nutritional care".

Then, new searches in the databases mentioned were made using simultaneous combinations of descriptors from only two of the groups presented. The preliminary evaluation of the articles involved the analysis of their titles and abstracts.

# **RESULTS**

Fifteen references were considered for the study, and they were divided into three thematic areas, namely: *Palliative care in stroke*; *Nutritional approaches in palliative care*; and *Nutritional approaches in palliative care in stroke*.

# **DISCUSSION**

According to the WHO, palliative care is an approach that seeks to promote quality of life through the prevention and relief of suffering of patients and their families who face life-threatening diseases<sup>8</sup>. This approach considers guiding the prevention and treatment of symptoms, care aimed at the patient and family, autonomy and independence, work in multiprofessional teams, communication and psychosocial and spiritual intervention<sup>5,8</sup>.

Palliative care in oncology seems to be more debated than in other clinical settings. However, palliative care has been increasingly used in other situations, such as the assistance of degenerative neurological diseases, advanced heart and lung diseases, Acquired Immunodeficiency Syndrome, among others.

In addition, palliative care can also be organized in health services, public or private, in different locations, reaching the cultural diversity of peoples and different religions, in addition to serving the adult/elderly or pediatric public, both male and female. The great flexibility of palliative care applications may occur because, instead of protocols, such care is based on principles, as can be seen in Table 1.

# Table 1. Palliative Care Guidelines. Geneva, 20028.

- 1 Provide relief from pain and other distressing symptom.
- 2 Affirm life and regards dying as a normal process.
- 3 Intend to neither hasten nor postpone death.
- 4 Integrate the psychological and spiritual aspects of patient care.
- 5 Offer a support system to help patients live as actively as possible until death.
- 6 Offer a support system to help the family cope during the patients' illness and in their own mourning.
- A team approach to address the needs of patients and their families, including mourning counseling, if indicated
- 8 Enhance quality of life, and may also positively influence the course of illness.
  - It is indicated as early as possible, in conjunction with other therapies that are intended to prolong life, such
- 9 as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

#### Palliative care in stroke

The importance of studying the palliative approach, particularly in stroke survivors, is due to the epidemiological appeal of the topic and the specific attributes of the care to be used in these patients. The stroke pathophysiology itself, such as the sudden onset of a severe functional impairment, with a lowering of the state of consciousness, loss of decision-making capacity and uncertainty in the prognosis, produces a great functional dependence in an abrupt way for the patient, leading to the immediate search for urgent/emergency and hospital care. This is quite different from the relatively slow evolution of diseases, such as, for example, cancer or neurodegenerative diseases, which monitoring is preferably outpatient<sup>5</sup>.

Abrupt changes in the clinical status of the stroke patient bring rapid changes in behavior and make clinical follow-up quite dynamic, especially in the acute setting. Even if some reversibility is possible and there is still a situation that is still relatively unstable from a clinical point of view, after the stroke, part of the patients should be referred to the palliative care team. This indication is relatively common in clinical practice, and occurs, among other factors, due to the predictability of the damage, to the patient's functional disability at the time of the assessment and preparation of the clinical and functional diagnoses<sup>4, 5</sup>.

If, on the one hand, the recommendation for palliative care in stroke may seem premature when it occurs since the diagnosis, on the other hand, it may allow more time for the team and family to act, to promote maximum comfort to the patient. In addition to eventual functional adaptation of the patient, longer-term palliative care may allow more time for the patient and his family to accept the condition, and greater capacity for the patient's voluntary response to discomfort, promoting an improvement in the palliative care service for the patient, family and health team.

# Nutritional approaches in palliative care

In the scope of palliative care, nutritional care can play a fundamental role in the well-being, comfort and quality of life of the patient and/or family, since the evolution of the underlying disease, symptoms and treatment can affect their feeding way, appetite, consumption and food pleasure. Thus, the nutritional, caloric, protein and water needs must be established observing the patient's acceptance, tolerance and symptoms, aiming at promoting comfort and quality of life, and not ensuring adequate nutrient intake. In this sense, it may be essential to avoid, in some cases, more invasive and unnecessary nutritional interventions, such as the introduction of enteral or parenteral nutritional therapy. It is necessary to evaluate in depth the indication of support and nutritional therapy in each case<sup>4, 5,6,9,10</sup>.

Another important and controversial issue is the determination of the appropriate time and route of administration for the patient's artificial nutrition. Oral feeding, despite being the most natural and desirable method, is hampered by the patient's inability to chew and swallow as a result of motor and cognitive losses.

Parenteral feeding has a very limited application in the palliative approach, as it involves, above all, a greater infectious risk, higher cost and requires rigorous technical training

to handle this type of food, being associated with conditions where its use is of short duration. The use of tube feeding, however, allows for adequate nutrition, and is not compromised by reduced appetite, dysphagia or inability of the patient to eat, thus being able to improve physical recovery, reducing risks of bronchoaspiration.

Undoubtedly, the choice of this feeding route is much less comfortable than oral feeding, but it is the one that allows the maintenance of life for a longer time, until a better stability of the patient's condition, being of less indigestible cost and therefore of greater employability than the parenteral route.

Tube feeding, normally used during hospitalization, can be of the naso or oroenteral type, or gastro or percutaneous endoscopic jejunostomy. The latter may not be appropriate for patients who present rapid and progressive deterioration of their clinical condition, in association with an incurable disease. This would characterize futile treatment. Thus, the use of a naso or oroenteral tube in a period of clinical instability can result in a similar outcome, being a simpler procedure. Feeding through gastro or jejunostomy would be more interesting if the stability of the clinical condition was greater and the expected use of the probe was greater than 3-4 weeks, since these are less uncomfortable than the naso or oroenteral tube.

# Nutritional approaches in palliative care in stroke

In general, when the patient is in palliative care due to a stroke, their autonomous decision-making ability has been impaired. Although it seems paradoxical, at this point the nutritional approach must focus on dialogue. It is essential that the palliative care team interact with each other and, especially, with the patient's family to determine the nutritional care to be employed. It is also necessary to maintain absolute respect for the principles of autonomy of the patient and his family, and principles of beneficence and non-maleficence<sup>9</sup>.

It is expected that the use of nutritional therapies in terminal situations does not have a strong impact on the reversibility of the patient's general clinical condition and has little influence on the quality of life of patients with a total decrease in the level of consciousness. However, according to the "disability paradox", some patients are able to adapt to a high degree of disability, maintaining an acceptable quality of life<sup>12</sup>.

Thus, for this group of stroke survivors, support and eventual nutritional therapy will be essential for maintaining life. Thus, it remains for the nutritionist/palliative care team, in these cases where it is impossible to feed orally, discuss with the team and the family and improve the quality of life of this patient as much as possible using artificial enteral or parenteral feeding<sup>5,9</sup>.

Obviously, the initial approaches to the organization of palliative care, as proposed by the Ministry of Health<sup>7</sup>, and especially for stroke victims, occur in a hospital environment<sup>5</sup>. In cases of dehospitalization, however, with prolonged use of enteral/parenteral nutrition for comatose patients due to stroke, the nutritionist/palliative care team should guide various precautions in preparing, portioning and administering the food to be offered by the caregiver to the patient<sup>9</sup>. These are common care also for other clinical situations, the outcome of which is enteral/parenteral feeding. In these cases, an outpatient or home care routine must be structured for the proper monitoring of the patient.

In turn, much is still discussed about the applicability of artificial feeding, regardless of the route, in patients under palliative care<sup>9,11</sup>. This is a broad topic and still under intense debate, which permeates the limits between what is palliative care, therapeutic effort and futile treatment, and between orthothanasia and euthanasia<sup>11,13</sup>.

Life-ending decisions related to food and hydration seem to be the ones that cause the greatest anxiety in the family and conflict with professionals. Despite the scarce literature on the subject<sup>5</sup>, it is estimated that half of the deaths of stroke patients in palliative care seem to be caused by the removal of life support interventions, such as respirators and artificial feeding<sup>14</sup>.

Issues related to food and hydration are topics discussed in a consultation specialized in palliative care<sup>14</sup>. A study<sup>15</sup> proved that families are very concerned about the food that will be offered to stroke victims. Concerns about hydration and diet were reported by 45.7% of relatives of stroke victims in palliative care. In addition, the study showed that nutrition by a naso or orenteric tube was suspended or never used for 96.8% of stroke victims who were referred for palliative care, and intravenous fluids were interrupted in 87.2% of patients. Most of the study participants were treated only with drugs such as morphine (93.6%) and scopolamine (81.9%)<sup>15</sup>.

The interruption of an artificial feeding and/or hydration of the patient, in these conditions, may not be the great immediate determinant of the patient's death, since the body's energy reserves can be used well before the interruption of the functioning of vital organs. However, the theme seems far from having a consensual outcome.

The truth is that decision-making in immediate contexts is contraindicated<sup>11</sup>, this being the case, there may be some prognostic inaccuracy for stroke patients<sup>15</sup>. In addition, in the national context, it is also considered essential to stipulate more specific palliative guidelines for stroke and the training of professionals trained for this emerging demand<sup>5</sup>.

# **CONCLUSION**

Bearing in mind the importance of formulating protocols involving palliative care in SUS or private health services, the need for specific guidelines on palliative care for stroke patients, their families and the caregiving team is emphasized. The interaction of so many involved in the care process centered on the patient due to stroke is able to, above all, provide comfort and quality of life to all these entities.

Palliative procedures are mainly guided by the prognosis of each patient. This makes it essential to seek the maximum precision of this prediction. The nutritional approach in palliative care, in particular, of the patient affected by the stroke, must respect the decisions of the patient, their family, clinical team, as well as the bioethical principles of autonomy, beneficence and non-maleficence. Thus, nutritional interventions can have very varied importance depending on the patient's clinical condition and the objective proposed in the palliative approach.

As a limitation of this study, there is a reduced availability of practical works on the theme, revealing little experience, attention or number of palliative care teams specialized in stroke patients. This led the study to consider mostly foreign works, and thus may not accurately portray the Brazilian reality.

On the other hand, the work proposes some demands on the training of teams, since education for palliative care and family awareness of the patient's nutritional aspects, should be part of palliative care. The scarcity of Brazilian references may also reveal the national need to form more teams specialized in palliative care. In addition to all this, the work points out possibilities for the participation of nutritionists in specialized multidisciplinary teams.

Due to the nature of the topic addressed, there is still a need for further studies on the feeding of patients in palliative care, not only in the oncology area, but also in the various situations that encompass the palliative theme.

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# **CONTRIBUTIONS**

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