

CUIDADO É FUNDAMENTAL

Escola de Enfermagem Alfredo Pinto – UNIRIO

INTEGRATIVE LITERATURE REVIEW

DOI: 10.9789/2175-5361.rpcfo.v17.13743

PALLIATIVE CARE FOR PATIENTS AFTER SURGICAL RESECTION FOR HIGH-GRADE CENTRAL NERVOUS SYSTEM TUMORS

Cuidados paliativos para pacientes após ressecção cirúrgica de tumores de alto grau do sistema nervoso central

Cuidados paliativos para pacientes después de la resección quirúrgica de tumores de alto grado del sistema nervioso central

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RESUMO:

Objetivo: analisar os cuidados paliativos após ressecção cirúrgica em pacientes com tumores de alto grau do sistema nervoso central. **Método:** revisão integrativa da literatura realizada nas bases de dados MEDLINE via PubMed, Scopus e Web of Science, sem restrições de idioma ou ano de publicação. **Resultados:** a análise identificou temas relevantes, como a necessidade de neurocirurgia, alívio de sintomas, subdivisões de cuidado e envolvimento multiprofissional. Destaca-se o impacto positivo dos cuidados paliativos na qualidade de vida dos pacientes e no curso da doença, desde o diagnóstico até o final da vida. **Conclusão:** cuidados paliativos precoces e bem executados reduzem internações desnecessárias, promovem

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Received: 2025/01/16. **Accepted:** 2025/04/28

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How to cite this article: Puntel CF, Ricardo YAR, Pretto KP, Conceição WRBG, Haack CM, Rosa BD, Silva DTR. Palliative care for patients after surgical resection for high-grade central nervous system tumors. R Pesq Cuid Fundam (Online). [Internet]. 2025 [cited year month day];17:e13743. Available from: <https://doi.org/10.9789/2175-5361.rpcfo.v17.13743>.



suporte físico, psicológico, social e espiritual, e beneficiam pacientes e familiares. Recomenda-se a implementação de políticas públicas e programas de treinamento para ampliar o acesso a este cuidado essencial.

DESCRITORES: Cuidados paliativos; Tumores do sistema nervoso central; Oncologia; Cirurgia.

ABSTRACT:

Objective: to analyze palliative care following surgical resection in patients with high-grade central nervous system tumors.

Methods: integrative literature review conducted in the MEDLINE database via PubMed, Scopus, and Web of Science, with no restrictions on language or year of publication. **Results:** key themes identified include neurosurgical needs, symptom relief, care subdivisions, and multiprofessional involvement. The positive impact of palliative care on patient quality of life and disease progression, from diagnosis to end-of-life, was highlighted. **Conclusion:** early and well-implemented palliative care reduces unnecessary hospital admissions, provides physical, psychological, social, and spiritual support, and benefits both patients and families. The implementation of public policies and training programs is recommended to improve access to this essential care.

DESCRIPTORS: Palliative care; Central nervous system tumors; Oncology; Surgery.

RESUMEN:

Objetivo: analizar los cuidados paliativos después de la resección quirúrgica en pacientes con tumores de alto grado del sistema nervioso central. **Métodos:** revisión integrativa de la literatura realizada en las bases de datos MEDLINE vía PubMed, Scopus y Web of Science, sin restricciones de idioma ni año de publicación. **Resultados:** se identificaron temas clave como necesidades neuroquirúrgicas, alivio de síntomas, subdivisiones de cuidado y participación multiprofesional. Se destacó el impacto positivo de los cuidados paliativos en la calidad de vida de los pacientes y en el progreso de la enfermedad, desde el diagnóstico hasta el final de la vida. **Conclusión:** los cuidados paliativos precoces y bien implementados reducen hospitalizaciones innecesarias, brindan apoyo físico, psicológico, social y espiritual, y benefician tanto a pacientes como a familias. Se recomienda implementar políticas públicas y programas de formación para ampliar el acceso a este cuidado esencial.

DESCRIPTORES: Cuidados paliativos; Tumores del sistema nervioso central; Oncología; Cirugía.

INTRODUCTION

Palliative care, in essence, is treatment that focuses on the person rather than the disease. This care involves multidisciplinary interventions that aim to relieve pain and other symptoms associated with advanced or even chronic diseases, always seeking to improve the quality of life of the patient and, consequently, their family.¹

Cancer is one of the leading causes of death worldwide, killing approximately 9.7 million people in 2022. According to the WHO, there are 20 million new cases per year, with a higher prevalence in developed countries. Cancers arising from the central nervous system (CNS) rank 19th worldwide in incidence, with approximately 320,000 new cases documented in 2022. However, they rank 12th worldwide in terms of mortality, totaling approximately 250,000 deaths in 2022.²

The CNS is basically composed of the brain and spinal cord, histologically formed by two layers, the cortex and medulla, with two main cell groups, the main cells called neurons and glial cells, which have various neuronal support functions (dendrite, soma, and axon). Thus, CNS neoplasms

are heterogeneous, malignant or not, and have several subtypes of classification according to the cell affected and the region, with some having a higher incidence depending on age, developing the pathology in different ways, with different signs, symptoms, and prognoses.³

The most commonly used treatment for primary brain tumors is surgery, with maximum tumor resection being accepted in the literature, provided that it does not affect the patient's neurological functions, as well as radiotherapy combined with chemotherapy, which has been shown to be the most effective treatment.⁴ Basic palliative care encompasses a range of essential support provided by healthcare professionals in various settings, such as hospitals, clinics, and even at home. This approach aims to relieve symptoms related to serious illnesses, while also providing emotional and spiritual support to both the patient and their family.⁵

Doctors, nurses, psychologists, and social workers, among other healthcare professionals, play an integrated role in ensuring the patient's comfort and well-being. General practitioners, although not specialized in palliative care, play a

crucial role in identifying and treating common symptoms in patients with serious illnesses, as well as providing emotional support and relevant information.⁶

As such, specialized palliative care relies on a trained interdisciplinary team, and professionals play a crucial role in the management of patients with advanced diseases. At its core, palliative care refers to the treatment of the person and not the disease, focusing not only on the control of physical symptoms but also on the individualization of that patient's case, ensuring that the patient's preferences and values are respected in all decisions made during the progression of the specific disease, thus promoting patient-centered care and dignity until the end of life. Therefore, this review proposes to correlate the importance of the discussion on palliative care in high-grade brain tumor resections, highlighting the importance of the division of care and multidisciplinary teams. This brings about an improvement in quality of life and influences the course of the disease in the patient.⁷

METHOD

This article was developed through an integrative review of the current literature. Regarding eligibility criteria, studies addressing palliative care for patients after surgical resection of high-grade central nervous system tumors were included. The following types of publications were excluded: (i) case reports; (ii) letters; (iii) abstracts and short texts; (iv) opinion reports; (v) protocols; (vi) summaries; (vii) full texts unavailable even after contacting the corresponding author; and (viii) literature in languages other than English, Portuguese, and Spanish.

The integrative review was conducted by analyzing articles from the MEDLINE databases via PubMed, Scopus, and Web of Science. The analyses were performed without language or publication year limitations. The literature search and selection took place between March and July 2024. In the first phase, titles and abstracts of all types were selected. In the second phase, the authors read the full texts of the preselected literature and excluded those that did not

Although this review followed a rigorous method, it is possible that relevant studies were not identified. This risk was minimized by the constant and updated search of the available scientific literature. Around the world, there are people looking for resources and ways to minimize suffering in the face of a cancer diagnosis, and patients with high-grade central nervous system tumors are no different. Thus, palliative care is an accepted and widely used tool; however, there are still limitations and a lack of use of interventions that could alleviate the suffering and pain of these patients.

RESULTS AND DISCUSSIONS

Patients with high-grade CNS cancer in palliative care

Although cancer is one of the leading causes of death worldwide, only about 14% of patients with this diagnosis receive palliative care to reduce suffering and improve their quality of life. One of the biggest problems is the lack of knowledge among healthcare professionals about palliative care. Even so, palliative care continues to develop rapidly around the world, demonstrating the need for interdisciplinary work by various professionals in the care of these patients, improving the quality of life of patients and their families, as well as reducing healthcare costs, especially in patients with high-grade tumors in the central nervous system, considering the specificities and complexity of these cases.

The most complex types of CNS tumors are meningiomas and glioblastomas, the latter being considered the most common and aggressive primary malignant brain tumor, ranging from grade I to IV, not responding well to chemoradiation and its counterparts, with neurosurgery being the most appropriate treatment. However, due to its aggressiveness, the survival rate is 50% in one year and 15% in five years, and these patients are the ones who most need palliative care or end-of-life care.⁹

Palliative care must be personalized for each individual and each type of cancer, requiring detailed knowledge by the professionals involved for the best management of complications and symptoms arising from cancer. Although palliative care is often confused with end-of-life care, which has a negative and passive connotation, this care should be active, aiming at the physical, psychological, and emotional well-being of the patient in the face of the incurability of the disease, adopting dynamic therapeutic approaches. Considering the poor prognosis/low survival expectancy of high-grade gliomas, palliative care is necessary for these patients in order to improve their quality of life.¹⁰

Patients with high-grade CNS cancer in palliative care generally have a poor prognosis due to the aggressiveness of the tumors, with low survival expectations. These patients suffer from neurological and psychological problems arising from the disease, such as seizures, acute headaches, fatigue, and psychological problems such as depression. Such symptoms affect not only the patient but also their family members, as it is usually a fatal diagnosis. At this threshold, the early introduction of palliative care is required in order to alleviate suffering and pain and bring comfort to the patient and their family.³

Comprehensive patient care has a major impact on the individual's therapeutic process. However, with the hegemony of the biomedical model prevailing in the West, the treatment of the disease is still seen as paramount, regardless of the cost to the patient. This makes it necessary to develop new interventions that value all dimensions of care, enabling technical, attentive, and humanized care, minimizing the pain and suffering of the patient and their family.¹¹

Impact of disease and pharmacological treatments on the quality of life of patients with high-grade CNS cancer

According to the 2012 provisional clinical opinion (PCO) of the American Society of Clinical Oncology, palliative treatment should be carried out from the onset of symptoms, in conjunction with traditional treatment, when dealing with high-grade tumors, i.e., those that are metastatic with a poor prognosis.^{7,12} In relation to CNS cancers, the most commonly malignant ones, such as glioblastoma, become incapacitating and significantly reduce quality of life.

Quality of life can be defined as a subjective feeling, determined by the needs, beliefs, values, and attitudes that are modulated by the context in which the individual is inserted.¹³ To assess the quality of life of subjects, criteria focused on the current functional level and their ideal functional level are used, defined based on physical and emotional reasons. Thus, each individual undergoing treatment has a different response, based on criteria such as age, support network, lifestyle, and type of treatment.¹⁴

In cancer treatment, in particular, there is a significant impact on psychological, social, and biological issues, which interfere significantly. The discovery of the diagnosis is a difficult process and requires acceptance by the individual in order to proceed with treatment more effectively. Symptoms such as anxiety and depression are often seen in this scenario, especially when dealing with recurrences or due to fear of them.¹⁵

In patients with CNS tumors who have undergone resection surgery, the impact on quality of life is strongly related to age, symptom burden, histological grade of the tumor, its size, and extent of resection, which can lead to possible sequelae.¹⁶ In addition, many patients may require other therapies such as chemotherapy, radiotherapy, or immunotherapy before or after surgery to complete their treatment. The pain and side effects associated with this process, which depend on the type of treatment used and its combination, are important factors that impact patients' daily lives, affecting their autonomy and, consequently, their physical and mental well-being. The most frequently reported side effects, especially in chemotherapy, are fatigue, loss of appetite, difficulty sleeping, constipation,

pain, weight gain or loss, nausea, and vomiting, which greatly exacerbate the damage associated with the disease.^{13, 15}

In addition, contributing to the path to recovery, social relationships in this context generally change, with family members becoming closer as a support network, which can provide greater security for the patient. At the same time, after surgical resections and radiotherapy treatment, scars may be visible that can significantly interfere with the patient's self-image, affecting their social interaction as well as their relationship with themselves. Some coping characteristics based on religious beliefs are being directly related to an increase in the quality of life of cancer patients, highlighting the importance of a holistic view of the situation by the professionals involved.^{15, 17}

In addition to the psychosocial aspects mentioned above, low economic status negatively affects the quality of life of patients undergoing treatment for CNS tumors, as evidenced in patients with meningioma, both because of the impact on treatment and on their own health care.¹⁶

To this end, it is necessary to provide symptom control measures, listening to the patient and always observing them holistically, relying on a multidisciplinary team to provide care focused on improving quality of life.

Neurosurgery and pre- and post-surgical treatments: the gold standard for the treatment of high-grade CNS cancer resection

According to the European Society for Medical Oncology¹⁸, molecular markers are used to identify high-grade CNS neoplasms, and imaging is also extremely important, with magnetic resonance imaging (MRI) being the best method for staging. When a high-grade tumor is diagnosed in the CNS, confirmed by MRI of the tumor, the first indication is surgical resection, and if, due to compromise, it is not the best option, biopsy or subtotal resection should be chosen, simultaneously assessing whether the same organ still requires adjuvant treatments appropriate to the level of risk.

Since resection surgery is the standard treatment, it is necessary to consider pre- and postoperative factors that influence the patient's prognosis. Initially, it should be noted that cancer patients are generally frail, according to FRAIL Scale tests, which characterize them by low physiological reserves and decline in general health. This occurs due to several factors, such as the use of medications for treatment, immune dysfunction, and the metabolism of the tumor itself, among others.¹⁹

Therefore, preoperative care such as cognitive stimulation activities, improved sleep quality, early mobilization, adequate

nutrition, and hydration have proven to be effective in the postoperative period, as they have reduced the rates of delirium, one of the main postoperative complications, which is even more prevalent in patients with a high degree of frailty.¹⁹

However, even in high-grade tumors, there are cases in which resection is not performed. The two main conditions that contraindicate surgery are the high degree of complexity of the tumor, such as skull base or optic nerve sheath meningiomas,²⁰ or patients who, due to the low risk of their tumor, do not receive any type of treatment, only screening. This occurred in approximately 30% of CNS tumor cases identified in the United States between 2004 and 2015. This highlights the importance of patient management for palliative care and the importance of continuing to monitor the clinical condition.²¹

In addition to recommendations tailored to each patient and their tumor, social factors directly impact pre- and postoperative treatment for CNS tumor resection. It has become clear that social and racial minorities have limited access to treatment from the outset, with lower rates of referral for surgical treatment. Furthermore, the postoperative period is affected as they are referred less frequently to palliative care and assistance services. This highlights the disparity in care for cases and possible prognostic outcomes among patients.¹²

Palliative care: basic and specialized in patients after resection of high-grade CNS tumors

Knowledge of the patient's characteristics and individualization of their treatment are essential for good treatment adherence and consequent positive results.²² To this end, considering the trajectory experienced from diagnosis to the end of life, the individual will come into contact with various professionals, receiving from each one certain guidelines related to the degree of monitoring and progression of the disease. Palliative care for patients undergoing surgical resection for the removal of high-grade CNS tumors is complex and varied, and is divided into two classes: basic—provided by any healthcare provider, usually general practitioners, nurses, and social workers, who follow the patient longitudinally—and specialized—provided by oncologists and neurosurgeons. Thus, it is essential to understand the particularities of disease progression in each individual in order to promote efficient holistic care.²³

Basic palliative care plays a crucial role from the first contact with health services, marking the beginning of treatment for patients facing serious illnesses. By promptly identifying and treating key symptoms, this type of care provides immediate relief to the patient, significantly improving their quality of life.¹⁰ In addition, basic palliative care is often the first to

provide information about the diagnosis and initiate palliative care, establishing a solid foundation for future treatment.

It is through this initial care that adults who may be approaching the end of their lives are identified, as well as their caregivers and other people important to them. Therefore, well-done basic palliative care, in all types of cancer, but especially for patients with high-grade CNS tumors after surgical resection, not only alleviates the patient's suffering but also establishes an essential foundation for more individualized and personalized care approaches in the future, as presented by the WHO.²

Well-performed specialized palliative care offers an individualized approach that takes into account the social determinants of the health-disease process, providing personalized care tailored to the specific needs of each patient.²³ This includes the implementation of surgeries and methodologies specific to the patient's situation, as well as personalized drug dosages, taking into account the characteristics of the patient and the central nervous system tumor they present. In addition, specialized palliative care develops treatment plans that consider the individual's beliefs, interpersonal relationships, family support, and family routine, suggesting personalized activities and dynamics that promote greater adherence to treatment.²²

This approach, in turn, leads to more promising results, improved quality of life, and increased patient survival. In summary, specialized palliative care offers holistic and personalized care that aims not only to alleviate the patient's suffering but also to promote a significant improvement in their quality of life and overall well-being.²⁴

Therefore, palliative care presents a holistic approach that aims to address three types of palliative care: physical—focusing on the treatment of physical symptoms, pain, and suffering of patients; psychological—which acts to relieve the individual's mental stress, depression, and grief, for example; and social—aimed at understanding and ensuring active social interaction and respect for family and community issues.¹ Thus, patients approaching the end of life can count on professionals prepared to provide emotional support, counseling, and guidance on practical issues, as well as assist patients in activities of daily living, engage in good communication, information sharing, and shared decision-making, facilitate access to rehabilitation equipment and services, and offer support while respecting cultural diversity.²⁵

Thus, in a palliative care context, palliative care for patients undergoing surgical resection of high-grade central nervous system tumors requires longitudinal attention, accompanying the individual from diagnosis, through comfortable and

safe pre- and post-surgical periods, to end-of-life care when necessary. Therefore, primary palliative care plays a fundamental role as a starting point, providing basic and essential support for both patients and their families, while specialized palliative care is important for more complex and challenging cases, ensuring personalized, high-quality care. The integration between these different levels of care is crucial to ensure the well-being and dignity of patients facing serious and advanced illnesses. In short, a collaborative and integrated approach between these modes of care is essential to provide comprehensive and compassionate support to patients and their families during difficult times in their lives.

Management of specific symptoms and forms of relief through palliative care in patients after CNS tumor resection

Cancer patients often face a complex and debilitating set of physical and psychosocial symptoms.²³ Effective management of these symptoms is crucial, as it aims to alleviate or even eliminate pain, dyspnea, nausea, vomiting, and fatigue, providing maximum comfort within the context of care and available resources. In the case of patients with central nervous system tumors undergoing surgical resection, the symptoms and their management in the pre- and postoperative periods are essential to maximize the individual's quality of life.

When analyzing the symptoms manifested in patients with high-grade central nervous system brain tumors, it is noted that severe headache is an aggravating factor, given that it requires attention when it occurs constantly. Medications such as paracetamol, opioids, and dexamethasone are primarily used to relieve headaches, while anti-inflammatory steroids are strongly contraindicated due to poor prognosis.²⁷

Behavioral signs such as agitation and changes in mental status are indicative of symptomatic clinical manifestations in these patients. These symptoms are alarming and indicate the need for care and attention, as they can further affect the patient's clinical condition, so rapid intervention is recommended. In cases of delirium, neuroleptics and alpha-agonists are commonly used for relief, however, there are still few options for this intervention.²⁷

Another common symptom is brain compression that occurs in the central nervous system due to the brain tumor, causing dysfunctions and changes in communication, mood, personality, and appetite. For symptomatic relief, speech therapy is necessary to improve communication and swallowing. Regarding mood swings, the best techniques for alleviating these changes are integrative approaches and primarily non-pharmacological options. However, if necessary, antidepressant medications are used.

Generalized physiological issues that are very common in cancer patients, such as pain, fatigue, hunger, and dehydration, also deserve attention and specialized care, aiming to improve the quality of life of patients, family members, and caregivers, as this promotes a lighter and more effective treatment.²⁶

In addition to these symptoms, 30-50% of patients experience seizures, which cause cognitive and behavioral dysfunction and can successively aggravate the other symptoms. To improve the symptoms of this condition, antiepileptic drugs are used to regulate and control the condition.²⁷

Therefore, palliative care and adequate symptom management are necessary, especially after surgical resection of high-grade brain tumors, given how affected patients are by radiation, the effects of chemotherapy, and the sequelae left by the disease, highlighting the importance of making this care available to patients and companions in a personalized manner.

Professionals involved in palliative care for patients after CNS tumor resection

A multidisciplinary team is essential in palliative care to provide more effective care that addresses all aspects of the patient's life, not only from the pathological perspective of what led them to need this care, but also in terms of the impact of the diagnosis and treatment, which have physical, spiritual, social, and emotional repercussions.

The composition of the multidisciplinary team, especially in oncology, should ideally include a physician, nursing team, psychologist, social worker, physical therapist, nutritionist, and dentist from the time of diagnosis, covering not only the patient but also their family members.^{29,30} The focus is on a team that is prepared and specialized in palliative care to ensure a better quality of care. Within this team, each professional provides

care focused on their area of expertise, paying attention to the specificities of the patients in question.

Within the multidisciplinary team, the physician, whose training focuses on the diagnosis and treatment of diseases, must review their concepts and limitations in view of the patient's needs. They play a key role in the early diagnosis of pathologies and their prognosis, in addition to acting on these concepts by providing feedback to other professionals.³¹

Nursing professionals, nurses, or nursing technicians make up the majority of the healthcare workforce, playing a fundamental role in the provision of primary palliative care. Because they are in direct contact with the patient more frequently, especially during hospitalization, they are

responsible for conducting various vital conversations about advance care planning and transitions, as well as assessing signs and symptoms³¹ and providing guidance to patients and their families. In addition, based on the nurse's assessment of the patient's clinical condition and its repercussions, nursing diagnoses are listed that support the prescription of individual care.

In general, in oncology, cancer and the recommended treatments significantly impact patients' physical capacity, psychological well-being, and social life. This can influence nutritional status, since cachexia and anorexia are believed to be the cause of 20% to 30% of patient deaths. Therefore, nutritionists must monitor the patient's nutritional status, in partnership with the nursing team, observing the need for nutritional treatment, which aims to preserve oral nutrition, stimulating eating and reducing discomfort and the need for alternatives and nutritional supplementation.

^{33,34} In addition, the physical therapist acts in the prevention, treatment, and dysfunction at any time during the palliative process, which can be caused by various types of treatment, to reduce the debilitating physical/emotional process, to stimulate the patient's autonomy by discouraging immobility, in an attempt to strengthen muscle and elasticity within each individual's capabilities.³⁵ They also work to relieve pain, which in some cases becomes incapacitating, through the use of manual, physical, and orthotic resources that minimize the symptomatic perception of pain.³⁶

Through their work with patients, psychologists use their technical knowledge of psychology, through listening, to assist patients from the moment they receive their diagnosis, through treatment and care development, with care aspects that may include the stages of grief described by Kübler-Ross as denial and isolation, anger, bargaining, depression, and acceptance of their condition.³⁶ This contributes to the understanding of the psychological factors involved, bringing the other members of the multidisciplinary team closer to a more effective prescription and approach to care.

In addition to the technical and higher-level professionals who should be involved, it is important for the team to provide opportunities and encourage contact with people who may be connected to the patient's beliefs and thus, according to their wishes, can bring them some comfort in the process.³⁰

Contributions to practice

It is clear that the integrative approach to palliative care plays a fundamental role in improving the quality of life of patients undergoing surgical resection of high-grade central nervous system tumors. A comprehensive analysis of pre- and postoperative factors, considering treatment from a complex

perspective, highlights the importance of individualized care for each patient. In addition, collaboration among healthcare professionals in the multidisciplinary team is crucial to ensure holistic and effective follow-up throughout the patient's journey.

Early and well-executed implementation of palliative care has proven to be essential in reducing complications arising from physical, psychological, social, and spiritual symptoms, which, together with the participation of a trained team, contributes significantly to the overall well-being of patients undergoing surgical resection of central nervous system tumors and their families and caregivers. Early identification of patients who may benefit from palliative care, together with the provision of clear information and emotional support from the time of diagnosis, establishes a solid foundation for future treatment and shared decision-making.

The low implementation of palliative care by healthcare professionals highlights the need for effective policies and continuing education programs to ensure equitable access to these essential services. Collaboration between different specialties, such as neurologists, oncologists, and social workers, is crucial to ensure a comprehensive and individualized approach for each patient, respecting their preferences and values throughout the treatment process, especially considering cases of patients with central nervous system tumors that have complexities and specificities characteristic of the sensitive and fundamental region affected.

FINAL CONSIDERATIONS

Given the complexity of high-grade central nervous system tumors, the effective integration of palliative care from the beginning of treatment to the end of life is essential to provide symptom relief, improve quality of life, and positively influence the course of the disease. Attention to patients' physical, emotional, and spiritual needs, combined with open and empathetic communication, contributes to patient-centered care and dignity. Ultimately, the central conclusion of this study highlights that the implementation of comprehensive palliative care is critical to ensuring that patients undergoing surgical resection of high-grade central nervous system tumors have a better quality of life and well-being throughout their treatment journey.

ACKNOWLEDGEMENTS

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