Profile of patients with brain tumors and the role of nursing care

Perfil dos pacientes com tumores cerebrais e o papel do enfermeiro

Perfil de pacientes con tumores cerebrales y el papel de la enfermería

Kênia Cristina Soares Fonseca de Magalhães[I], Josiane Pinto Moreira Vaz[II],
Pollyana Anicio Magalhaes Gontijo[I], Gervásio Teles Cardoso de Carvalho[I], Paulo Pereira Christo[I],
Renata Toscano Simões[I], Karla Rona da Silva[I]

[I] *Santa Casa de Belo Horizonte, Institute of Education and Research. Belo Horizonte, Minas Gerais, Brazil.*
[II] *Instituto Metodista Izabela Hendrix. Belo Horizonte, Minas Gerais, Brazil.*

ABSTRACT

Objective: to describe the profile of 200 patients with central nervous system tumors (CNST), and the role of the nursing care. **Method:** prospective, quantitative and descriptive analysis of medical records of 200 patients with TSNC. **Results:** a total of 61% of our patients had benign CNST and 39% had malignant tumors. The extent of patient dependence, according to the Karnofsky Performance Status scale, was significantly greater for patients with malignant CNST ($p < .05$), indicating that these patients needed more support with their activities of daily living. **Conclusion:** patients with CNST need specialized care, with specific guidance regarding their disease and aspects of daily living after treatment. Thus, the nurse can function as a key element for the effectiveness of care provided to patients and family members with the aim of enhancing the quality of life of all those affected, directly or indirectly, by the disease.
Key words: Brain Neoplasms; Nurse's Role; Nursing Care; Karnofsky Performance Status; Oncology Nursing

RESUMO

Objetivo: descrever o perfil de 200 pacientes com tumores no sistema nervoso central (TSNC) e o papel do cuidado em enfermagem. **Método:** análise prospectiva, quantitativa e descritiva de prontuários de 200 pacientes com TSNC. **Resultados:** 61% dos pacientes possuíam TSNC benignos e 39% tumores malignos. O grau de dependência do paciente de acordo com a Escala de Karnofsky foi significativamente maior para pacientes com tumores malignos (P < 0,05), indicando que estes precisam de maior esforço e, consequentemente, apoio em suas atividades diárias. **Conclusão:** Pacientes com TSNC necessitam de cuidados especializados, com orientações específicas a respeito de sua doença e aos aspectos da sua vida diária após o tratamento. Assim, o enfermeiro pode ser um elemento-chave para a eficácia dos cuidados prestados aos pacientes e familiares com o objetivo de melhorar a qualidade de vida de todas as pessoas afetadas, direta ou indiretamente, pela doença.
Descritores: Neoplasias Encefálicas; Papel do Profissional de Enfermagem; Cuidados de Enfermagem; Avaliação de Estado de Karnofsky; Enfermagem Oncológica.

RESUMEN

Objetivo: describir el perfil de los 200 pacientes con tumores del sistema nervioso central (TSNC) y el papel de la enfermería. **Método:** análisis prospectivo, cuantitativo y descriptivo de los registros médicos de 200 pacientes con TSNC. **Resultados:** 61% de los pacientes tenían TSNC benignos y 39% tumores malignos. El grado de la dependencia de los pacientes según la Escala de Karnofsky fue significativamente mayor en los pacientes con tumores malignos (P < 0,05), lo que indica que estos pacientes necesitan más apoyo en las actividades diarias. **Conclusión:** los pacientes con tumores cerebrales requieren atención especializada, con directrices específicas sobre su enfermedad y aspectos de la vida diaria después del tratamiento. Por lo

tanto, los enfermeros pueden ser un elemento clave para la eficacia de la atención prestada a los pacientes y sus familias con el objetivo de mejorar la calidad de vida de las personas afectadas por la enfermedad.

Palabras clave: Neoplasias Encefálicas; Rol de la Enfermería; Atención de Enfermería; Estado de Ejecución de Karnofsky; Enfermeria Oncologica.

CORRESPONDING AUTHOR   **Renata Toscano Simões**   E-mail: simoesrt@yahoo.com.br

INTRODUCTION

Central nervous system tumors (CNST) are a major challenge, as they are composed of a single class of tumors considered to be the most difficult to treat; this aspect is related to several factors (anatomical protective blood-brain barrier (BBB), the absence of a lymphatic drainage system, and the fact that they develop into a highly immunosuppressive environment, mainly due to the low tumor infiltration by regulatory T cells, facilitating the rapid proliferation of tumor cells)[1].

The World Health Organization forecast 27 million new cases of cancer worldwide (in general) for the year 2030, and 17 million deaths from the disease. Developing countries will be most affected, among them Brazil. When considering only central nervous system (CNS) cancers, this represents 1.9% of all malignancies in the world. Among the more frequent tumors, CNST are the fourteenth most common in men (close to 4,960 new cases in Brazil in 2014) and the fifteenth most common in women (nearly 4,130 new cases in Brazil, in 2014). This type of cancer attacks individuals at an average age of 45: mostly men, but also a considerable number of children[2].

CNST are classified as malignant or benign, with malignant tumors characterized by their invasiveness, with an impact on quality of life, greater dependence for personal care and, ultimately, a shorter survival time[3]. The cornerstones of CNST treatment are: surgical tumor resection, chemotherapy, and radiotherapy. Because these are very aggressive treatment modalities, they can lead to impairments, loss of independence, and/or some form of disability, such as paraparesis, impaired ambulation, and, in cases of extensive radiation therapy, severe toxicity[4].

To assess the extent of patient dependence when performing activities of daily living, the Karnofsky Performance Status scale (KPS) and the Glasgow Coma Scale (GCS) are used. These scales measure the patient's degree of disabilities or functional impairment, and are widely used in neurosurgical practice. The lower the scores, the poorer the likelihood of recovery or return to normal activities, impacting the quality of life[5-6]. Low KPS and GCS scores typically result in a greater need for, and/or dependence on, nursing care.

Nursing care follows the guidelines of the Nursing Care Systematization program (*Sistematização da Assistência de Enfermagem* - SAE), through the Nursing Process (NP), which was implemented in Brazil by Wanda Aguiar Horta beginning in the 1970s, which can be understood as a practical application of nursing theory to patient care. The NP consists of five steps: assessment, nursing diagnosis, planning, implementation of nursing care, and evaluation[7-8]. This framework is used by the nurse as a method of care optimization that facilitates cross-disciplinary communication[9]. The SAE is crucial for the coordination of care for patients with CNST, as it provides nurses with adequate tools for a holistic and patient-focused approach.

There is no dispute that the CNS is the key element for maintaining critical functions related to human independence and autonomy, which may be compromised when affected by a tumor[10]. Therefore, caring for and understanding patients with CNST is paramount to promoting their autonomy, trust, acceptance of treatment, and rehabilitation, while respecting their limitations, values, and beliefs. In this sense, cross-disciplinary interventions are needed to minimize impairments and improve the patients' quality of life. The role the nurse plays in this dynamic is important because these professionals are in a position to care for patients in an active and individualized manner, and to help them achieve those goals. The aim of our study was to evaluate the profile of patients with CNST admitted to the *Santa Casa de Belo Horizonte* Hospital (SCBH), and to examine the role of the nurse in the care for those patients.

METHOD

The current prospective, quantitative, analytical study was conducted during the period of August of 2011 to April of 2015. Two hundred CNST patients (ranging from 1 to 80 years old) admitted to the SCBH Neurosurgery unit were investigated. The study project was approved by the SCBH Research Ethics Committee (registry n°. 019/2010), in compliance with the Brazilian legislation regarding the guidelines and standards regulating research involving human beings, National Health Council Resolution No. 196/96 (repealed in 2012)[11], giving way to the current Resolution nº. 466/12[12].

The study was developed in four stages:

a. Informed consent: The study subjects (and/or their legal guardians) were informed of the data collection method and provided their written informed consent;

b. Data collection: Patient medical charts were used to obtain quantitative data, and thus determine the profile of each patient. We collected data regarding patient gender, age, race, use of medications, underlying disease, signs and symptoms, and scores on the KPS and GCS;

c. Review of the literature: We accessed the BVS (*Biblioteca Virtual da Saúde*) website to search for journals in the following databases: SciELO (Scientific Electronic Library Online), PubMed (National Library of Medicine of the National Institutes of Health), LILACS (*Literature Latino-Americana e do Caribe em Ciências da Saúde*), and BIREME (*Biblioteca Regional de Medicina*). We searched for articles using the following search terms: Brain Neoplasms, Nurse's Role, Nursing Care, Karnofsky Performance Status. Articles that were not relevant to the subject under study were excluded.

We included the full-text articles that addressed the proposed themes. In total, 89 articles were selected. After careful reading, 24 articles were appraised;

d. Data analysis: All statistical analyses were performed with the aid of the GraphPad Prism software, version 5.0. Demographics and clinical data were analyzed using the t-test, X^2 test, odds ratio (OR), and relative risk (RR). Values of $p < .05$ were considered statistically significant. Standard deviations (SD) of means were represented between brackets.

RESULTS

General Characteristics of the Patients

From the review of 200 medical charts encompassing a period of nearly two years, we found that 61% (122/200) of patients had benign CNST, while 39% (78/200) developed malignant CNST ($p < 0.0001$; OR: 2.446, RR: 1.564). Significant differences were also noted in the age of patients: the mean age of patients with benign tumors was 44 ± 18.4 years, while the mean for those with malignant tumors was 52.9 ± 15.4 years ($p = 0.0005$). When analyzing tumor classification by sex, we noted a higher frequency of CNST in female patients - both benign (60.7%, 74/122) and malignant tumors (64.1%, 50/78). However, the difference was not significant ($p > 0.05$).

Regarding ethnicity, 29.5% (23/78) of the patients with malignant CNST were of Caucasian descent, and 70.5% (55/78) were of African descent. In the group of benign CNST, 40.2% (49/122) of patients were white, and 59.8% (73/122) were black. However, these differences were not statistically significant.

Clinical data

All of the clinical data, frequencies, and absolute numbers are shown in Table 1.

The most commonly used medications in both groups were anticonvulsants associated with glucocorticoids, with statistical significance. In the benign CNST group, the frequency of this drug therapy was 54% (66/122), and in the malignant CNST group, 63% (49/78) ($p = 0.0054$; OR = 0.44; RR = 0.70).

The analysis of comorbidities showed that 44% (54 of 122) of benign CNST patients had systemic arterial hypertension (SAH) associated with diabetes mellitus (DM), with a frequency of 20% (24 of 122) for SAH alone. Hypertension was also the single most frequent comorbid condition in patients with malignant CNST (45%, 35/78) ($p = 0.0002$; OR = 0.30; RR = 0.52). The

other patients were evenly distributed among other comorbidities, such as stroke, acute myocardial infarction, other tumor types, and epilepsy, as well as previously healthy patients.

Headache was the most frequent symptom in both groups, with statistical significance ($p = 0.0292$; OR: 0.5244; RR: 0.7819), manifested by 48.4% (59/122) in the benign CNST group and by 64% (50 of 78) in the malignant CNST group.

There was a significant difference in KPS scores between the groups, with a mean of 92.2% (12.6%) - able to perform normal activity - for patients with benign CNST, and 82% (14.7%) - normal activity with effort - for those with malignant CNST ($p < 0.0001$). The mean GCS scores were 14.8 (0.5) and 14.3 (1.2), respectively ($p = 0.0013$).

We found that 10% (13 of 122) of the patients with benign tumors had a family history of cancer, as compared to 18.2% (14 of 78) of those with malignant tumors. This difference, however, was not statistically significant.

Table 1 - Frequency of the clinical characteristics assessed of patients with malignant and benign CNST

Clinical Data	CNST		p value (OR/RR)
	Benign n (%)	Malignant n (%)	
Sex			
Female	74 (60.7)	50 (64.1)	0.4
Male	48 (39.3)	28 (35.9)	
Total	122 (61)	78 (39)	
Mean age (years)	44.0 (18.4)	52.9 (15.4)	0.0005
Skin color			
White	49 (40.2)	23 (29.5)	0.09
Brown	48 (39.3)	29 (37.2)	
Black	25 (20.5)	26 (33.3)	
Total	122 (61)	78 (39)	
Use of medication*			
Yes	66 (54)	49 (63)	0.0054 (OR: 0.44 / RR: 0.70)
No	56 (46)	29 (37)	
Total	122	78	
SAH			
Yes	24 (20)	35 (45)	0.0002 (OR: 0.30 / RR: 0.52)
No	98 (80)	43 (55)	
Total	122	78	
Headache			
Yes	59 (48.4)	50 (64)	0.0292 (OR: 0.5244 / RR: 0.7819)
No	63 (51.6)	28 (36)	
Total	122	78	
KPS	92.2 (12.6)	82 (14.7)	< 0.0001
GCS	14.8 (0.5)	14.3 (1.2)	0.0013

Notes: * Anticonvulsants and glucocorticoids; Abbreviations: CNST: central nervous system tumors; KPS: Karnofsky Performance Status Scale; GCS: Glasgow Coma Scale; SAH: systemic arterial hypertension alone; OR: odds ratio; RR: relative risk.

The mean survival time of patients with malignant tumors was seven months. For benign CNST, it was not possible to estimate survival time, since these patients typically respond well to the surgical treatment and do not always die as a consequence of the benign tumors.

DISCUSSION

Sample demographics

The predominant type of tumor in our study was benign CNST. This is corroborated by the literature, which shows that low-grade gliomas, meningiomas and neurinomas are the most frequent types of CNST[2].

We observed a higher frequency of women with cancerous or non-cancerous tumors. This finding diverges from the literature, according to which malignant CNST are more common in men[3]. Our results could have been influenced by cultural factors, given that women in the Brazilian context seek medical attention more often than men - a fact corroborated by the literature which shows that the presence of men in health care units is less frequent than that of women[13]. Furthermore, other authors have related this picture to the socialization process of men, in which caring for oneself is not viewed as masculine behavior. In fact, a study conducted in the city of São Paulo showed that the attendance of men in health care units was lower than that of women[14-15].

The average age at tumor diagnosis in our study was 44 years, which is in agreement with the literature data reporting greater prevalence around 45 years of age, for both sexes[2]. However, in our study the mean age of patients with benign tumors was significantly lower than that of patients with malignant tumors, which could contribute to poorer prognosis after surgical treatment[16].

Malignant CNST were more common in brown-skinned individuals, while benign tumors were more frequent among white patients, albeit without statistical significance. However, given the high proportion of racial admixture in our population, more specific studies using ancestry markers should be conducted to allow more accurate conclusions regarding ethnicity.

The use of medication has been described in several studies as a strategy to minimize injury to the brain and improve the patient's clinical status prior to neurological surgery[17-20]. Among the various drugs that have been used for medical treatment, the most frequent in our sample were anticonvulsants in conjunction with glucocorticoids. These two drugs are also cited in the literature as the most widely used. Anticonvulsants attenuate the effects of brain injury in patients with CNST, thereby preventing seizures[21]. Glucocorticoids are used to suppress the immune response by modulating cell proliferation[22]. As a result, they can prevent or reduce tumor growth, thus allowing a safer surgical procedure and more time for operative preparation and planning.

The most frequent comorbidity among our patients with benign CNST was SAH, followed by DM. In the group of patients with malignant CNST, SAH was individually the most frequent. Despite this result, data on comorbidities are still unclear in the literature, since the present study was the first to take preexisting diseases into account.

By contrast, the main signs and symptoms of CNST have been well established. Headache is prominent both in benign and malignant tumors, with a higher prevalence in the latter. Other complaints were seizures for benign CNST and confusion for malignant tumors[23]. In line with the literature, our study showed that headaches were significantly more frequent among patients with CNST.

The median survival of the patients was approximately 14.6 months[24]. This is not in agreement with our findings, which indicated a survival time of seven months. However, such short survival time may be due to the fact that most of our patients with malignant CNST (82%) had high-grade tumors, namely, glioblastoma multiformes, a highly invasive type of tumor. A similar result was documented in a study developed by the neurology service of the *Hospital dos Servidores do Estado do Rio de Janeiro*, Brazil, in which a retrospective review of the medical records of surgical patients with glioblastoma multiformes showed a mean survival of 7.7 months[16].

It is not possible to estimate survival in the case of benign tumors, since these tumors are treated surgically and, in contrast to malignant tumors, do not recur, allowing for disease remission[2].

Role of the nurse

In oncological disease, nursing assistance is conducted according to the manifestations of the patient, with a holistic and individualized understanding of each patient. Our data led us to realize that the extent of patient dependence is a paramount factor in defining the competencies of the nurse. We found a significant difference ($p = 0.0001$) in mean KPS between patients with benign (92.2% [12.6%]) and malignant (82% [14.7%]) CNST. In spite of this difference, both results indicate a better prognosis to our patients, since the literature reports that patients with KPS > 70% have longer survival and can achieve better quality of life[16]. With increased survival, the competencies of the nursing team assume even greater relevance, because it is their provision of care that will insure enhanced quality of life for these patients.

Competency in nursing is understood as the assessment, planning, and implementation of care in the assistance of patients[25]. The nurse needs to know how to direct the team to the best course of action for the maintenance of health of CNST patients, relying on ongoing observation and attention to the patients singularities.

It is worth stressing that from the KPS scores the nurse can articulate assistance and management actions with the provision of education and guidance to all of the involved parties. These initiatives are based on strategies of prevention and health promotion aimed at furthering self-care and the social reintegration of patients and families.

These considerations lead us to understand that the essence of the nursing profession lies in the act of providing care and coordinating social educational practices with the ongoing aim of improving quality of life.

In order to refine the assistance provided by the nurse, consistent reasoning is imperative to support decision-making concerning the health of cancer patients. In view of this, the SAE becomes a crucial tool for the nurse to assist these individuals in

a holistic manner[9]. Furthermore, considering the symptoms of our patients with CNST, it becomes clear that physical examinations performed by nurses are important for revealing the comorbidities resulting from the underlying disease and, drawing on the excellence of evaluation, to develop a SAE-based patient care plan to guide the nursing team in the provision of care to mitigate the suffering of patients and families.

Experts state that delivering quality care to patients with CNST is a challenge to the nurse, because in addition to providing health assistance they have to engage in management and administrative functions that often burden these professionals[25]. Such aspect was not examined in our study, but an analysis a posteriori might be practicable.

On further reflection, we understand that the nurse should be an inspiring leader of the team and establish goals to enhance assistance and excellence in care, emphasizing the strategies of tailored care and health education.

The nurse has to act as a key element in the health care team, guiding and evaluating the quality of the assistance provided to CNST patients, so that this assistance can be conducted in a holistic manner to meet all the basic human needs of these patients.

In addition to delivering quality care and exercising leadership, the nurse must also be an educator. This education process must be continuous in order to provide openness to learn from each other, with the possibility of a shared construction of knowledge resulting in natural forms of care to each individual[26]. Through education, the nurse can address health issues with the team, the patient, and the family or caregiver, solve doubts, and also develop prevention, health promotion, and rehabilitation initiatives. Therefore, the nurse is a fundamental support in the realm of health education, as he or she imparts knowledge to the public with a view to enhancing the awareness of patients, families, and the nursing team regarding the particularities of the brain tumor[27].

In view of the profile of our patients and the changes imposed by the disease on their daily routine and that of their families, it is clear that all of those involved in this context need the nurse's support and guidance. The nurse is responsible for instructing all the parties involved in the treatment of the disease by giving clear and objective information based on the planning of care. By doing this, the nurse will alleviate their anxiety, offering reassurance and making it possible for their family life at home to be as comfortable as possible after hospital discharge.

Encouraging the involved individuals to verbalize their feelings and thoughts is essential, as is the nurse recognizing the need for the intervention of a multi-professional team to achieve excellence of care.

In summary, the nurse must assess the complexity of assistance required by patients with CNST and have the competency and refined sensitivity to develop adequate assistance to enhance the quality of life of patients and families.

Therefore, it is essential for the nurse to master the necessary technical-scientific knowledge and have a clinical eye to develop nursing assistance, allowing CNST patients to have quality care and a less traumatic treatment.

Nevertheless, further studies focusing on nursing assistance are warranted to enable a better understanding of the dynamic of the assistance to these patients in clinical practice, as well as the weaknesses and potentials that could contribute to improved quality of life for all.

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