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Effect of instructional guidelines on brain tumors patients' pain and fatigue levels

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Abstract---One of the most prevalent and severe side effects for patients with brain tumors is pain and fatigue. The aim was to determine the effect of instructional guidelines on brain tumor patients' pain and fatigue levels. Subjects and method: Design: A quasi-experimental research design was used to achieve the aim of this study. Setting: the research was conducted in the neurosurgery department at Beni-Suef University Hospital. Subjects: A purposive sample of 50 adult patients was included. Three tools were used: Tool (I) a structured interview questionnaire (II) a numerical pain rating scale, and (III) a Fatigue assessment scale. Results: The current study revealed that there was a highly statistically significant difference between pain mean scores pre and post-instructional guidelines implementation at (P= <0.05). Also, the study showed that there was a highly statistically significant difference between anxiety scores pre and post-instructional guidelines implementation with (P=<0.001). Conclusion: The instructional guidelines implementation had a positive effect on reducing pain and fatigue levels among patients with brain tumors. Recommendations: The instructional guidelines implementation regarding brain tumors should be provided and discussed in the rehabilitation programs.

Keywords---fatigue level, instructional guidelines, pain level, patients with brain tumors.

Introduction

Malignant brain tumors (BT) are horrible illnesses that, in addition to having a dismal prognosis, can have a major influence on a person's capacity for function and quality of life. It is expected that 23,180 new cases of primary malignant BT will be found in the USA. Primary malignant BT includes include cancers of the

brain, central nervous system, pituitary, and nose. The most common treatments for BT include chemotherapy, radiation therapy, and partial or complete surgical resection. In the USA, the 5-year survival rate following BT diagnosis is 34.2% overall (Valko. et al., 2018).

Central nervous system (CNS) tumors, which account for 40% to 60% of all CNS primary tumors and are most common in adults, are produced by glial cells. Neurological problems brought on by glioblastomas include ataxia, changed behavior, vertigo, motor deficits, visual impairment (blurred vision, diplopia), epilepsy, recurrent syncope, and, in more severe cases, excessive sleepiness and coma. The literature indicates the 10- to 24-month survival rate for patients with glioblastoma multiforme. Radiotherapy, chemotherapy, and surgery are the standard order of treatment (Lakhan & Harle, 2019).

Even while benign tumors are more prevalent and are generally regarded to be more treatable than malignant tumors, any intervention for a brain tumor can be invasive. Brain tumors can be treated through observation, surgery, chemotherapy, and radiotherapy. When deciding on a treatment plan, it is important to take into account the characteristics and location of the tumor as well as the patient's condition and preferences (McCarty et al., 2017). The risks of therapies do exist, though. Exhaustion and encephalopathy are potential side effects of chemotherapy and radiation therapies. It is well-recognized that people with brain tumors can experience a wide range of health problems, including venous thromboembolic illness, the syndrome of inappropriate antidiuretic hormone (SIADH), dysphagia, and seizures. In addition to psychological symptoms like depression, tiredness, mood swings, personality problems, headaches, irregular sleep patterns, and cognitive difficulties have been noted. (Berger et al., 2018).

It is commonly accepted that one of the most common and disturbing side effects of cancer and its treatment is weariness. The clinical symptom of fatigue, which can also include generalized weakness, poor mental focus, insomnia or hypersomnia, and emotional alteration before and after treatment, has a substantial negative influence on the quality of life of cancer patients worldwide. It seems that physiological, biochemical, and psychological problems are at work, even though the exact cause of the connection between cancer and weariness is not yet known. Due to the complexity of the problem, many management techniques for cancer-related fatigue have been investigated (Armstrong & Gilbert, 2018). Dysregulation of inflammatory cytokines, anomalies in the serotonergic system of the central nervous system (CNS), and changes to the hypothalamic regulator circuit are a few examples of physiopathological reasons for fatigue (Horneber et al., 2017). Additionally, variations in circadian rhythms, sleep-wake cycles, and gene polymorphisms of regulatory proteins are involved in oxidative phosphorylation, B-cell signaling, the generation of pro-inflammatory cytokines, and catecholamine metabolism (Raaf et al., 2018).

Cancer patients' quality of life may be significantly impacted by cancer-related pain, which can be both physical and mental in origin. As a dose-limiting side effect of antineoplastic drug dosing regimens, the pain brought on by brain tumors can affect neural structures, a bone from cancer that has metastasized to

the bones, and discomfort from injured peripheral nerves. It's interesting to note that different factors might have an impact on both patients' and doctors' perceptions of cancer pain. In the end, the pain brought on by brain tumors can present serious problems, including concerns with diagnosis, therapy, and psychosocial problems. If a brain tumor is pressing on pain-sensitive regions of the brain, it may result in headaches. Blood vessels and nerves are located in these regions. Certain treatments such as radiotherapy, chemotherapy, and surgery can also cause headaches at first (Armstrong& Gilbert, 2018).

In postoperative patients around the world, pain is one of the most prevalent complaints. Although there are medications and anesthetic treatments available, postoperative discomfort is frequent. Around 41% of postoperative patients suffered moderate to severe pain despite the use of sedatives (Kaur et al., 2019). 300 patients were included in the comprehensive survey, and 86% reported postoperative pain, with 75% reporting moderate to severe pain right away. Even though about 88% of patients were prescribed painkillers, side effects were reported by 80% of them, and 39% of them still experienced moderate to severe pain thereafter (Gan et al., 2017).

Furthermore, acute postoperative pain is frequently not adequately managed. Poor postoperative pain control may raise the chance of patients experiencing physiological pain reactions that have negative effects on the body after surgery or, in some sensitive individuals, developing chronic pain issues. For instance, 74% of 300 surgery patients reported continuing excruciating pain after being released from the hospital (Kaur et al., 2019). There isn't a tried-and-true gold standard for treating fatigue because of its complex etiology and the lack of knowledge of the underlying mechanisms. However, it has been found that several pharmacological and non-pharmacological approaches can assist in reducing the fatigue brought on by cancer. The non-pharmacological strategies that are used the most frequently are physical activity (exercise), psychological interventions, including educational interventions, regulation of work and rest hours, and relaxation and focus techniques. (Bower, 2014).

Cancer-related fatigue (CRF) is described as "an unpleasant, persistent, subjective feeling of physical, emotional, and/or cognitive tiredness or exhaustion associated with cancer or cancer therapy that is not proportional to recent activity and interferes with normal functioning." The so-called "healthy" or "normal" fatigue is fundamentally different from CRF since it is frequently more acute, distressing, and unlikely to be relieved by rest. More than 80% of BT patients, according to research, claim to have felt weary throughout their therapy (Armstrong & Gilbert, 2018). According to an expert neurological assessment, nurses play a crucial role in the care of adult patients with brain tumors at different stages of intervention and are essential to the patient's overall result. They also play a key role in the health education of these patients. For the best nursing intervention and education to benefit the patient's health, the nurse must have a complete awareness of their needs (White et al.,2017).

Significance of the study

In a prospective cohort study, individuals with brain tumors reported pain and exhaustion in 55% of cases (McCarty et al., 2017). Patient education encompasses all instructional initiatives designed to improve patients' hygiene habits and health. The main objective of this treatment is to maintain or improve the patient's health, or in some cases, to stop further deterioration. Patients who are knowledgeable and educated can actively participate in their care, improve outcomes, identify errors quickly, and reduce the length of their hospital stays. The medical aspect of health education includes advice on health and well-being, as well as preventative measures. According to studies, the first stage in effective health education is understanding the numerous crucial needs of patients (Pachman et al., 2018).

Along with counseling and support groups, psychosocial interventions that have been shown to have a significant favorable effect on patients include cognitive-behavioral therapy and educational therapy. Educational recommendations also cover a broad understanding of fatigue in addition to presenting fresh concepts about energy conservation, self-care, and conflict resolution techniques. Energy conservation is defined as specific planning aimed at enhancing a patient's ability to manage fatigue during the day and preventing a patient's ability to maintain the level of energy required to complete a task from declining (White et al., 2017). So, this study was conducted to evaluate the effect of the nurse-led intervention on headache pain, anxiety, and fatigue level amongpatients with brain tumors.

Aim of the study

To determine the effect of instructional guidelines on brain tumors patients' pain and fatigue levels through:

- Assessing pain level among patients with brain tumors.
- Assessing fatigue level among patients with brain tumors.
- Designing and implementing instructional guidelines based on the patient's needs.
- Evaluating patients' pain and fatigue levels among patients with brain tumors after instructional guidelines implementation.

Research hypothesis

- H1- Patients with brain tumors who received instructional guidelines are expected to experience low pain levels post-implementation than pre-instructional guidelines implementation.
- H2- Patients with brain tumors who received instructional guidelines are expected to experience low fatigue levels post-implementation than instructional guidelines implementation.

Subjects and Method

Research design

A quasi-experimental research design was used to achieve the aim of this study

Setting

The research was done in the neurosurgery division at Beni-Suef University Hospital in Egypt. This location was chosen for the study because it serves the largest geographic area of the population and has a high prevalence of patients.

Subjects

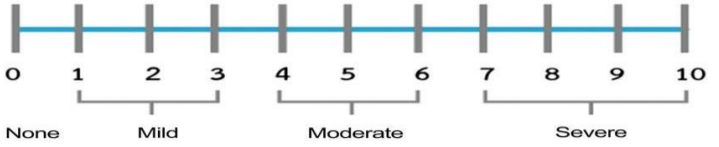
Sample size calculation

The sample size was determined based on the power analysis's 0.95(=1-0.95=0.5) alpha level of significance. The significance level was set at 0.05 (one-sided), while the strong significance level was set at 0.001. The effect size was considerable (0.5). 50 patients were included as part of a purposeful sample from a population who had received care in the aforementioned environment within the previous six months and who matched the inclusion criteria. Adult patients who visited the aforementioned location were completely oriented, ranged in age from 20 to 60, and agreed to participate in the study met the inclusion criteria. Their ages ranged from 18 to 60. Before leaving the neurosurgery department, the patients received follow-up care for a month. Disoriented patients and uncooperative patients were among the exclusion criteria.

Data collection tools

Three tools were used to collect the data for the study as the following:

- The tool I: A structured interview questionnaire was developed by the researchers after reviewing the related literature and research studies (Pachman et al., 2018, (NCCN Clinical Practice Guidelines in Oncology, 2019 and Yennurajalingam & Bruera, 2019); it included two parts:
- Part (1): It included personal data of patients such as age, educational level, occupation, and residence.
- Part (2): It included past and medical data-related items such as previous neurological problems (More than one), presence of chronic illness, previous neurosurgery treatment received, type of tumor, and family history
- Tool (II):- Numeric Pain Rating Scale (NRS) adopted from McCaffery, (1999), used to assess pain intensity, the patient is asked to choose the numerical value on a segmented scale that best depicts their level of pain. The scale has 11 points, with 0 denoting "no pain" and 10 denoting "unbearable pain." In a one-on-one interview conducted with researchers before and after the manipulation, it was used twice.



- Tool (III):- Fatigue assessment scale: This measure, a 10-item rating scale that was independently created, was adapted from Kleijn et al. (2011), which assesses an individual's level of fatigue during different activities throughout a week in terms of their physical, social, psychological, and spiritual domains and how that level of fatigue relates to the time of day. Scores could range from 0 (no fatigue) to 10 with a total score range of 0 to 100. (worst possible). The following numbers represent different levels of fatigue: 0, 1, 9, 10, 31, 60, 61, 80, and 81, respectively. The overall score's Cronbach's alpha of 0.81 indicates strong reliability for the scale.

Validity of the tools

Five experts, including two professors in the field of psychiatric nursing and three professors in medical-surgical nursing, evaluated the tools' content validity, clarity, comprehensiveness, appropriateness, and relevance. To ensure that the sentences were clear and the content was suitable, changes were made following the panel's verdict.

Reliability of the tools

State-Trait Anxiety Inventory reliability is considered good with Cronbach's alpha of 0.87 for the total score. The Numeric Pain Rating Scale reliability was (r = 0.94). A structured interview questionnaire reliability was (r = 0.93).

Ethical considerations

The Beni-Suef Faculty of Nursing's administrative approval was required before the study could be conducted. The study's goal was explained to the medical and nursing directors of the chosen settings, and their consent was obtained. To secure the patients' cooperation, written consent was acquired from them. This letter asking for permission to gather data highlighted the study's purpose as well as the anticipated results from its implementation. The study's goal was disclosed to the patients. The trial was voluntary, and patients were free to decline to participate, the researchers told them. Patients were free to leave the study whenever they wanted, without giving any reason.

A pilot study

A pilot study was conducted on 10% (5 patients) of the total sample to test the clarity and feasibility of the research process. No modifications were carried out to develop the final form of the tools. Patients who were in the pilot were included in the research study.

Fieldwork

The actual study was divided into three phases:

Assessment phase

50 patients participated in the study. Patients who visited previously chosen locations twice a week from 9 am to 1 pm on the morning shift were the subjects of data collection (Sunday and Tuesday). From March 2021 through the end of September 2021, data were collected for 6 months. Each interview questionnaire was finished in about 40 to 50 minutes.

Implementing Phase

In the waiting room present in the previously chosen settings, the researchers met patients one-on-one and introduced themselves before outlining the purpose of the study. To assist the patients in filling out their responses with the tools, the researchers conducted face-to-face interviews and read the questions and potential answers to them. After choosing the patients who met the criteria for inclusion, the purpose and significance of the research project were discussed. After evaluating the pertinent literature based on the evaluation of the actual needs of the examined patients, the streamlined booklet was utilized as a supportive material and distributed to adult patients in the Arabic language to cover every aspect relating to brain tumors. Various instructional techniques, including lectures, dialogues, images, and posters. The standards for teaching about brain tumors were created and put into place by the researchers. Lectures, posters, educational movies, scenarios, and role-plays were used to implement it. Patients received an informational pamphlet about brain tumors from the researchers that were written in plain Arabic and included illustrations.

The subject material was divided into 4 sessions, each lasting between 20 and 30 minutes. For each one, the total time was two hours. The nurse-led intervention for brain tumors was introduced at the start of the first session, and each one thereafter began with a recap of the session's input. The instructional guidelines included brain tumors as follows:

- Brain anatomy
- Diagnostic procedures and how to be prepared for it
- Benefits of surgical management, systemic and neurosurgical postoperativecomplications after brain tumors surgery
- Reducing and preventing postoperative complications through medical therapy after surgery
- How to deal with seizures
- Nutrition
- Weight control
- Rest
- Physical activity and exercises
- Smoking cessation
- Care of wound site

- Stress reduction
- Effective communication
- Chemotherapy and radiotherapy
- Routine follow up

Evaluation Phase

occurred after one month, each patient was re-interviewed to assess their pain and fatigue level. Reassessment of the adult patient was done using the same tool (II and III).

Administrative design

Administrative permission was obtained through an issued letter from the Dean of the Faculty of Nursing, Beni-Suef University to the Directors of the Neurosurgery Department to achieve this study.

Statistical analysis

SPSS for Windows, version 20, was used for both data entry and statistical analysis. Descriptive statistics were used to represent frequencies and percentages for qualitative variables and means and SDs for quantitative variables. The t-test for differences between the two means was applied. Comparing qualitative factors was done using the Chi-square (x2) test. Pearson's correlation coefficient test () was employed. A P-value of 0.05 was used to determine statistical significance.

Results

Table 1 demonstrates that 64% of the patients in the study were between the ages of 40 and 60. 68% of the sample's participants were male, 42% had a secondary education, 70% were employed, and 64% lived in metropolitan areas.

Table 2: Displayed that (88%) of the patients under study had neurological issues in the past, (54%) of the patients under study had a chronic illness, (58%) of the cancer patients under study had chemotherapy administered to them, and (100%) of the patients under study had received anticonvulsant medication, analgesics, and antibiotics. 86 percent of them received steroids. Less than two-thirds (64%) of the investigated patients did not have a family history of cancer, and 68% of the patients had benign brain tumors.

Figure (1) showed that 78% of the patients who participated in the study said that their primary source of knowledge concerning brain tumors came from their doctors.

A statistically significant change was seen among the patients in the study one month after the implementation of the instructional instructions, as shown in Table 3 (P <0.001).

Table (4): Frequency and percentage distribution of tiredness levels were shown for the examined patients before and after the application of the instructional guidelines. It was found that there was an improvement in fatigue levels among patients who had lower fatigue level scores (p 0.001).

Table 5 shows that after one month of implementing the instructional instructions, there was a highly statistically significant (P0.000) drop in fatigue index and a statistically significant difference among the patients.

Table 1
Frequency and percentage distribution of the studied patients regarding their data (n=50)

Items	No.	%
Adult patients ' age in years		
21< 30 years	3	6
30< 40 years	15	30
40 - 60 years	32	64
Gender		
Male	34	68
Female	16	32
Education level		
Illiterate	6	12
Read and write	3	6
Secondary education	21	42
Higher education	20	40
Occupation		
Working	35	70
Not working	15	30
Residence		
- Rural	18	36
- Urban	32	64

Table 2
Frequency and percentage distribution of the studied patients regarding their past and medical data (n=50)

Item	No.	%
Previous neurological problems:		
- Yes	44	88
- No	6	12

Presence of chronic illness		
- Yes	27	54
- No	23	46
Previous neurosurgery		
- Yes	0	0
- No	50	100
Treatment received		
Radiotherapy	23	46
Chemotherapy	29	58
Anticonvulsants medication	50	100
Analgesics medication	50	100
Antibiotics	50	100
Steroids	43	86
Type of tumor		
- Benign	34	68
- Malignant	16	32
Having afamily history of cancer		
N0	32	64
Yes	18	36

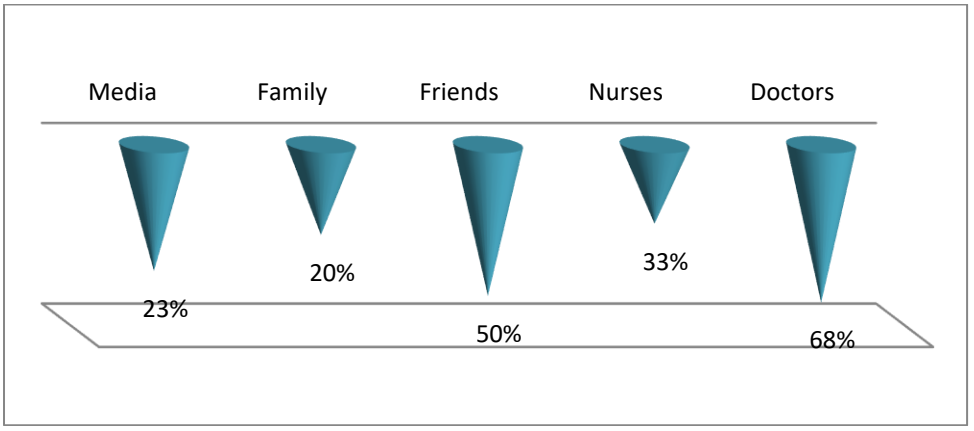


Figure 1. Percentage distribution of the studied adult patients about their source of knowledge regarding brain tumor

Table 3
Differences between patients' pain mean scores pre and post-one month of instructional guidelines implementation regarding brain tumors (n=50)

Items	Pre instructional guidelines	Post- instructional guidelines	P- value
Pain score	6.76 ± 2.53	2.22 ± 2.11	0.138 (<0.000*)

*highly Significance at 0.0001 levels

Table 4
Frequency and percentage distribution of fatigue level of the studied patients' pre and post-instructional guidelines implementation (n=50)

Fatigue level	Pre-instructional guidelines implementation		Post- instructional guidelines implementation		T	P-value
	No	%	No	%		
No fatigue (0)	0	0.0	4	8.0	16.044	<0.001*
Very little (1-9)	0	0.0	12	20		
Mild (10-30)	0	0.0	21	42.0		
Moderate (3- 60)	21	42	15	30		
Severe (61-80)	16	32	0	0.0		
Worst (81-100)	13	26	0	0.0		

Table 5
Differences between patients' fatigue mean scores pre and post-one month of instructional guidelines implementation regarding brain tumors (n=50)

Items	Pre instructional guidelines	Post- instructional guidelines	P- value
Fatigue score	27.87+ 4.01	15.03+ 1.22	0.125 (0.001*)

*highly Significance at 0.001 levels

Discussion

It is believed that pain and fatigue are the most common symptoms for people with brain tumors from the time of diagnosis until death. Physical, emotional, and/or cognitive tiredness are said to be the cause of these symptoms, which are characterized as an unpleasant, persistent, and unreasonable feeling that makes it difficult to go about everyday activities (Bower, 2014). More than three-fifths of the whole sample, or people in their 40s to 60s, were men, according to the findings of the present study. These findings are analogous to those of a study by Bin-Madhi, (2017) "Brain tumor excision guided by neuronavigation: Practical application and outcomes," That study discovered that men were more likely than women to have brain tumors, with a mean age of 47 years old.

According to the study's findings, the majority of the individuals in the current study had past neurological issues. According to Krucik (2018) and Urden et al. (2016), the more frequent clinical symptoms of brain tumors are headache, drowsiness, and visual abnormalities, altered levels of awareness, seizures, and motor dysfunction. The study's findings revealed that more than half of the individuals who were evaluated had chronic illnesses. This finding is similar to that of Edlinger et al. (2016), who investigated "Blood Pressure and Other Metabolic Syndrome Factors and Risk of Brain Tumor," discovering that hypertension affected half of the study sample's participants. As a result, those who have high blood pressure may be more susceptible to developing brain tumors. Additionally, Tong et al. (2018) found a similar result in their research on

"Diabetes mellitus and risk of brain cancers," which discovered that women with diabetes had a 24% higher risk of brain tumors.

The study's conclusions state that all of the patients assessed were given anticonvulsant medication, analgesics, and antibiotics and that more than half of them also received chemotherapy. Most of them had steroid injections. White et al., (2017) state that patients with brain tumors need a variety of medical treatments. To avoid the possibility of seizures, anticonvulsant medications are frequently given. Typically, infections are treated with medicines. Steroids are routinely given to reduce cerebral edema after intracranial surgery, while analgesics are frequently given to alleviate pain.

According to the family history of the patients, less than two-thirds of the study participants had no history of cancer in their families. It suggested to the researchers that it was possible for the patients who were the subject of the study to also have cancer. The results of the study showed that more than 75% of the survey respondents reported that their primary source of knowledge regarding brain tumors was doctors. This demonstrates, from the researchers' perspective, that patients are effectively advised when seeking therapies and assistance for these chronic diseases. After one month of implementing the instructional guidelines, there was a very statistically significant drop in the study subjects' pain levels, along with a statistically significant difference among the patients. Researchers claim that this result illustrates the positive effects of implementing instructional guidelines that are tailored to patients' requirements and provide them with the knowledge they require to maintain their health and minimize their discomfort.

The results of the study showed that following a month of brain tumor therapy using instructional guidelines, patients' average fatigue scores were statistically considerably reduced. These results were backed by the investigation's objective and hunch. These results support Parth et alresearch .'s from 2020 on "Rehabilitation of Patients with Primary Brain Tumors," which discovered a decrease in fatigue after the rehabilitation program. The researchers claim that the guidelines for education about brain tumors were successfully put into practice. According to Piper and Stewart's (2009) research, an effective health education program will result in long-lasting improvements that corroborate their findings by demonstrating improved awareness of certain medical and health-related issues. Effective health education will lead to short- and long-term behavioral adjustments that reduce risky behavior and diminish or even eliminate several postoperative issues. These behavioral modifications may be documented by evaluator observations and learner comments.

Conclusions

Based on the results and hypotheses of the present study, the study findings concluded that the results support the research hypothesis in implementing instructional guidelines had a positive effect on reducing pain and fatigue levels among patients with brain tumors.

Recommendations

Based on the current study results, the following recommendations are proposed:

- The instructional guidelines implementation regarding brain tumors should be provided and discussed in the rehabilitation programs.
- Giving patients colorful booklets and brochures to help them learn more and feel less pain and fatigue
- For the study to be generalized, a broader sample of patients in varied settings must be used in replication.

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