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Investigation of symptoms severity, symptoms clustering and status of interference in the life of patients with primary brain tumors

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Abtract

Aim: The objective of this research is to determine the symptom severity of the patients with primary brain tumors, their symptom clusters as well as interference levels in their lives.
Methods: It is a descriptive study. Its sample consists of 114 patients with primary brain tumors. In the research, the approval was taken from the ethics committee and written permission was taken from the inventory owner as well as the institution and patients. Data were collected through MD Anderson Symptom Inventory-Brain Tumor Turkish Form (MDASI-BT^{Tr}). Items of the inventory are evaluated between 0 and 10 in the form of a likert-type scale. Data were analysed via mean values, number, percentage and cluster analysis.
Results: The most severe symptoms of patients are sadness (4.86±3.48), distress (upset) (3.55±3.58), irritability (3.38±3.62). Symptoms mostly affect the mood (5.27±3.39), work (4.79±3.48) and general activity (4.51± 3.49). Symptoms constituted five clusters (gastrointestinal, affective and treatment-related, generalized, focal neurologic, cognitive symptoms) in patients with primary brain tumor.
Conclusion: Symptom severity and interference level of primary brain tumor patients are mild and moderate. This result can be explained by the fact that patients with severe neurologic symptoms were not included in the sample as well as by the effect of medication. Thus, nurses should develop new forms in order to evaluate the patients who cannot express their symptoms. Especially when a symptom included in one of the clusters was detected in the care activities, nurses should launch interventions to prevent the others.

Key Words: Nursing, Primary Brain Tumors, Symptom Severity, Symptom Clusters, MDA-BTSE-Tr
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Introduction

Primary brain tumors (PBT) are tumors that originated from cells and structures in the brain (1). PBT constitutes 14.0 per hundred thousand of all cancer patients (2). In Turkey, brain tumors are observed in men by 3.99 % and in women by 3.77 % among all cancer cases (3).

Patients with PBT experience many symptoms peculiar to the disease, general symptoms of the cancer and the symptoms developing with the treatment altogether (4). Symptoms seen in patients with PBT differ by the site of the tumor (5), its type and size as each part of the brain has a different function (6,7,8). Symptom is a subjective experience reflecting the change in demographic, cognitive, affective and biopsychosocial functions of the individual (9). Symptom experience includes the frequency and severity of symptoms, perception of the individual about symptom, its meaning for the individual and the individual's response (7, 10).

In PBT, neurologic symptoms are constituted by four basic mechanisms: a) brain parenchyma invasion, b) brain compression, c) inhibition of cerebrospinal fluid circulation, d) increase in intracranial pressure and herniation. In patient with PBT, firstly focal symptoms emerge depending on the location of the tumor

through the invasion and compression mechanisms. In supratentorial tumors, cognitive changes concerning the memory and learning skill are seen, in particular, in addition to motor weakness, sensorial disorders, troubles in visual and spatial perception, speaking, smelling, and hearing defects. In infratentorial (cerebellum and brain stem) tumors, however, such focal symptoms as balance and coordination disorders, hearing, speaking and swallowing problems are common (5). Furthermore, in hypothalamic tumors and the secretory tumors originating from the pituitary gland, gigantism can be observed in children and acromegaly can be observed in adults due to uncontrolled secretion of growth hormone. While diabetes insipidus can be seen in the deficiency of the antidiuretic hormone, Syndrome of Inappropriate Antidiuretic Hormone Secretion (SIDAH) in the excess of this hormone. Besides, additional symptoms can also be seen depending on the change in the other hormones (11). In patients with PBT, general symptoms develop with the mass effect of tumor, brain edema, cerebrospinal fluid obstruction, ICP increase and herniation development (7). The most frequently encountered general symptoms are headache, changes in mental status, seizure (12,13,14), nausea, vomiting, papillae edema, advanced pupil and consciousness changes (15). Personality disorders and cognitive dysfunctions can be detected in the mental assessment (1,14). Concentration disorder, memory problems, incompetence in language skill, disorder in cognitive control, confusion or disorientation may arise (1,14). It must be taken into consideration that each one of these symptoms can result from tumor, seizure, surgical operation, chemotherapy, radiotherapy, corticosteroid and antiepileptic drugs (14). While focal symptoms are typically seen at the primary phases of the disease, general symptoms are added into the clinical table depending on the growth of the tumor at the advanced stages (14).

It is known that symptoms co-exist and affect the development of other symptoms (7,10). This situation is identified as symptom group, symptom combinations and symptom cluster, in general (16,17,18). Symptom cluster refers to the co-existence of two/three or more simultaneous symptoms and their relationships (16,18,19). Symptoms with different etiologies can be classified into the same group. The power and duration of the relationship between the symptoms constituting the symptom cluster have not been clarified in the literature yet (7). On average, 12-13 symptoms can be seen in patients with solid tumors (7,20). In patients with PBT, one or more symptoms can exist together depending on the development of the tumor (20). Studies conducted on the symptoms of PBT patients revealed that these patients frequently suffer from such neurologic indications as seizure, cognitive disorders and weakness in one side of the body (7). It is thought that symptom clustering results from cancer or cytokines which are liberated in the cellular response given to the cancer therapy and it can be the indicator of a broader pathophysiological syndrome (7).

Symptoms affect “functional, cognitive, social and affective statuses” of patients and in turn, their life qualities are affected (21). Symptom clusters reduce treatment tolerance of individual and the lack of an effective treatment deteriorates the disease (7). This vicious cycle affects functional and affective statuses and in turn, life quality of the patient/family severely (17,22). Clinically, this situation makes patient care and symptom control

more difficult (17) and indicates how important the multiple symptom formation is (7). Since 1958, many researches have reported the symptoms of patients with PBT and they were evaluated in a systemic examination (7). In our country, symptom ratios of patients with brain tumors were studied on (23) while independence level of consultancy provided to the patients with PBT and its impact on some symptoms were examined in the field of nursing (24,25). Neurologic symptoms seen in PBT patients are considerably different from those seen in other cancer patients and they are more severe (10). The studies conducted so far indicated the importance of symptom evaluation and control in PBT patients with severe and poorly-controlled symptoms (7). Symptoms were generally examined through questionnaires and follow-up forms in patients with brain tumors. Besides, the impact of brain tumor on the life of the patient was typically evaluated through Karnofsky Performance Scale. ***In this study, the objective was to examine the*** severity of symptoms, interference levels of patients and symptom clusters via the measurement tool developed specially for PBT patients. These results will provide data to the nurses about the symptoms seen in PBT patients, their interference levels and symptom clusters and will lead to better identification of patients and in turn, to a more well-planned care.

Purpose and Research Questions

In this research, it was aimed at examining the symptoms that the patients suffer from through a symptom inventory peculiar to the PBT patients. Thus, answers were sought to the following questions:

1. How severe are the symptoms seen in PBT patients?
2. How is the life of a PBT patient affected by the symptoms?
3. What are the symptoms clusters seen in PBT patients?

Materials and Methods

Design

The study was a descriptive study. Besides, a cluster analysis was conducted in this study. Research was carried out in the Neurosurgery clinics and Radiotherapy/Chemotherapy polyclinics of two university hospitals found in İzmir, a province in the west of Turkey.

Sampling

The research sample consisted of 144 patients with primary brain tumor. All adult patients (>18) who were diagnosed with primary brain tumor (new diagnosis and recurrence) and were on treatment (surgery, chemotherapy and radiotherapy) were included in the research sample. Data about the inclusion criteria, exclusion criteria and the sampling losses are displayed in Figure 1.

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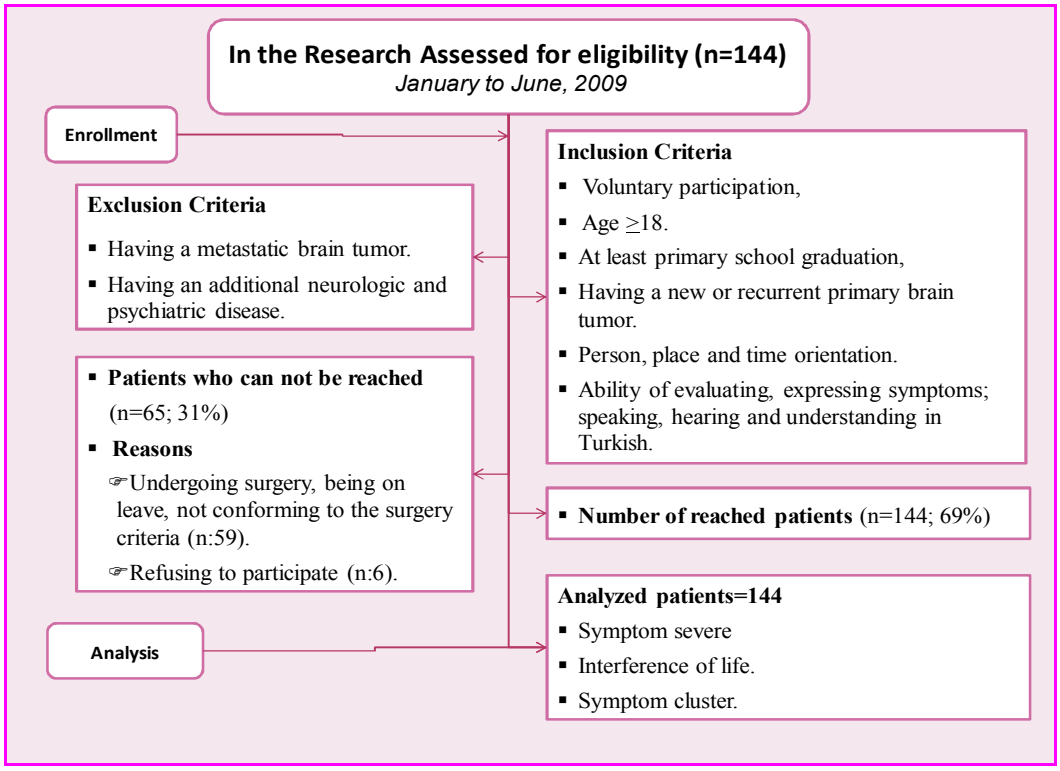

Figure1. Flow diagram of Sample

Procedure and Instruments

Research data were collected by the researcher between January and June 2009. Researcher collected these data by going to clinic or polyclinic at least two times a week and made face-to-face interviews with patients for 10-30 minutes on average. Other information about the patients (protocol number, used drugs, radiotherapy, chemotherapy and surgical treatment history) were taken from the medical records. Data collection tools used in the research are given below.

Patient Demographic Questionnaire: This form consists of questions concerning the sociodemographic characteristics, disease and treatment.

MD Anderson Symptom Inventory-Brain Tumor Turkish (MDASI-BT^{Tr}) Form: MD Anderson Symptom Inventory-Brain Tumor Module (MDASI-BT) was developed by Armstrong, Mendoza, Gring, Coco, Cohen, Eriksen, Hsu, Gilbert and Cleeland. Content validity of this inventory was published in 2005 while its reliability and validity results were published in 2006 (10,21). Reliability and validity tests for MDASI-BT^{Tr} form of the inventory were carried out by Baksi and Dicle (2010). Internal consistency reliability coefficient of the inventory was found as 0.90 while item-total score correlation coefficients varied between 0.21 and 0.69. Model fit indeces of confirmatory factor analysis indicated that the inventory has a similar structure to the original inventory. When examined according to Karnofsky Performance Scale, it was observed that inventory was distinguishing. MDASI-BT^{Tr} contains two sections, seven sub-dimensions and 28 items in total and items are evaluated in the likert form between 0 and 10 (10). First section of the inventory is related to the "symptoms" while second section of the inventory is related to the "state of interference of the life of the

individual". Symptom section of the inventory consists of six sub-dimensions including affective symptoms (fatigue, sleep disorder, anxiety, distress, bad temper/anger), cognitive symptoms (difficulty of remembering, difficulty of understanding, speaking disorder, concentration problem), focal neurological disorders (pain, numbness/lack of energy/tingling, weakness in one side of the body, seizure), therapy evaluation symptoms (lack of appetite, sleepiness and dry mouth), general symptoms (shortness of breath, visual impairment, change in appearance, defecation problems) and gastrointestinal system symptoms (GİS) (nausea, vomiting) (10). 13 items of the symptoms found in the inventory include main symptoms of cancer (pain, fatigue, nausea, disturbed sleep, distressed, shortness of breath, remembering things, lack of appetite, drowsy, dry mouth, sadness, vomiting, numbness or tingling) while nine items include the symptoms of PBT *[weakness on one side of the body, difficulty in understanding, difficulty in speaking, seizures, difficulty in concentrating, vision, change in appearance, defecation problems (diarrhea or constipation), irritability]*. The second section indicating the state of interference of symptoms in the life of patients contains six items [general activity, mood, work (including work around the house), relations with other people, walking, enjoyment of life) (10,27). In the inventory, symptom severity can be evaluated as moderate (5-6) or severe (7-10) (10).

Karnofsky Performance Status (KPS) Scale: It is commonly used in clinic oncology to determine functional status (28). With KPS, functional status of an individual indicates function loss from 100 (normal function) to 0 (death) by decrements of 10 points. This scale can be evaluated by categorizing in three sections as A, B, C (29). A cutting point was created by assessing those with a KPS score of 90 and above as good performance (n=74) and those with a KPS score of 80 and below as bad performance (n=70). Here, the fundamental approach is to base it on the assumption that function loss increases as the symptom severity increases.

Ethical considerations

In the research, approval was taken from the ethical committee of the higher education institution (B. 30.2.DEÜ.0.Y3.02.05/1422-05.12.2008) and permission was taken from the institutions where the research would be conducted and the owner of the inventory. Objective of the research was explained to the patients and their written permissions were taken.

Statistical Analysis

Research data were analyzed in the computer environment through a statistical software program. Sociodemographic/clinic characteristics of PBT patients, symptom severity and state of interference of the individual were evaluated through arithmetic mean, number and percentage. Symptom clusters were analyzed through ***cluster analysis***. In the cluster analysis, Pearson Correlation coefficient and distances (1-r) were determined among symptoms. According to these distances, clustering was performed through "Average Linkage" clustering method. All symptoms were analyzed for cluster analysis, combination of two or more symptoms was sought and correlation level of 0.25 and over was taken as basis.

Results

Patient Characteristics

Distribution of PBT patients constituting the sample by their socio-demographic and clinic characteristics are given in Table 2.

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Age average of the patients included in the sample was 47.1±13.9 and 57.6 % of them were female. 41.7 % of the patients were in the preoperative period while 45.1 % of them were in the postoperative period. In total, 54.2 % of the participants received steroid therapy (Table 1).

Table1. Examination of PBT Patients' Distribution by Their Socio-demographic and Clinic Characteristics (n=144)

Age (years)	$\bar{x}$ **SD**	**Median**	**Range**
	47.1 ± 13.9	59.0	18-77
Sex		**Number**	**Percentage (%)**
Female		83	57.6
Male		61	42.4
Marital Status			
Single		35	24.3
Married		109	75.7
Education level			
Primary school		90	62.5
Middle school		10	6.9
High school		27	18.8
University		17	11.8
Work status			
Working at		43	29.9
Not working because of PBT		13	9.0
Retired		17	11.8
Not working		71	49.3
Current treatment			
Planning surgery (preoperative)		60	41.7
Undergone surgery (postoperative)		65	45.1
Chemotherapy		2	1.4
Radiation		14	9.7
Admission for control		3	2.1
Concurrent medications			
Steroids		44	30.6
Anticonvulsants		20	13.9
Steroids+Anticonvulsants		34	23.6
No drug treatment		40	27.8
Others		6	4.2
Total		**144**	**100**

Symptom Severity

Symptom severities and interference levels of the patients with PBT are given in Table 2. Averages of items about symptom and interference status were ranked from the highest to the lowest. Besides, symptom severity and interference ratios of patients were grouped into moderate (5-6) and severe (7-10). When symptoms seen in patients with PBT were evaluated between 0 and 10, symptoms with the highest averages were sadness (4.86 ± 3.48), distress (upset) (3.55 ± 3.58), irritability (3.38 ± 3.62), dry mouth (3.38 ± 3.46), fatigue (3.33 ± 3.04), sleep disorder (3.16 ± 3.71) and visual impairment (3.08 ± 3.34) while seizures (0.37 ±1.60), vomiting (0.53 ± 1.99) and shortness of breath (0.92 ± 2.26) had the lowest averages. When symptoms included in the inventory were evaluated by frequency percentages, it was detected that sadness (77.8 %), fatigue (67.4 %), dry mouth (59.7 %), pain (58.3 %), distress (upset) (57.6 %), visual impairment (54.2 %), irritability (52.8 %) were seen more frequently than the other symptoms. When percentages of the symptoms with symptom severity higher than 4 (5-6) were considered, it was found out that sadness (26.4 %), pain (24.3 %) and fatigue (22.2 %) were more common. On the other hand, when symptoms with symptom severity more than 6 were taken into consideration, it was seen that sadness (34.6), dry mouth (27.0), sleep disorder (26.3) and distress (upset) (26.3) had higher frequency ratios.

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Table 2. Symptom Severity and Interference Status of Patients with Primary Brain Tumor (n=144)

Part I Symptoms	Mean (SD*)	Min† - Max‡.	Presence of symptoms 1-10 rating (%)	Moderate§ 5-6 rating (%)	Severe†† 7-10 rating (%)
Sadness	4.86 (3.48)	0-10	77.8	26.4	34.6
Distress (upset)	3.55 (3.58)	0-10	57.6	18.8	26.3
Irritability	3.38 (3.62)	0-10	52.8	18.8	24.3
Dry mouth	3.38 (3.46)	0-10	59.7	9.7	27.0
Fatigue (tiredness)	3.33 (3.04)	0-10	67.4	22.2	19.0
Sleep disorder	3.16 (3.71)	0-10	49.3	11.8	26.3
Vision	3.08 (3.34)	0-10	54.2	16.0	22.9
Sleepiness	2.82 (3.32)	0-10	48.6	14.6	19.5
Pain	2.64 (2.78)	0-10	58.3	24.3	8.4
Numbness or tingling	1.96 (2.76)	0-10	41.0	9.7	9.8
Remembering things	1.85 (2.68)	0-10	39.6	13.2	8.4
Weakness	1.74 (3.00)	0-10	30.6	8.3	11.9
Lack of appetite	1.65 (2.93)	0-10	29.9	6.9	11.9
Defecation problem	1.60 (2.96)	0-10	29.2	4.9	13.3
Nausea	1.53 (2.70)	0-10	31.2	9.0	7.7
Change in appearance	1.50 (3.00)	0-10	31.2	9.0	7.7
Difficulty in understanding	1.10 (2.28)	0-10	23.6	8.4	4.9
Difficulty in concentrating	1.07 (2.34)	0-10	22.2	4.9	7.0
Difficulty in speaking	1.01 (2.13)	0-10	22.9	7.6	3.5
Shortness of breath	0.92 (2.26)	0-10	17.4	6.2	6.3
Vomiting	0.53 (1.99)	0-10	9.0	0.7	4.2
Seizures	0.37 (1.60)	0-10	6.2	0.7	3.5
Part II Interference Status	**Mean (SD)**	**Min-Max.**	**Presence of symptoms 1–10 (%)**	**Moderate (5-6) (%)**	**Severe (7-10) (%)**
Mood	5.27 (3.39)	0-10	80.6	28.5	40.2
Work *(including work around the house)*	4.79 (3.74)	0-10	68.1	16.0	43.7
General activity	4.51 (3.49)	0-10	79.8	16.7	39.6
Walking	4.51 (3.61)	0-10	69.4	19.5	36.1
Enjoyment of life	2.95 (3.67)	0-10	45.1	13.9	23.6
Relations with other people	1.63 (2.92)	0-10	26.4	9.7	11.9

**SD: Standard Deviation, † Min: Minimum, ‡ Max: Maximum,*
§Moderate; Symptom severity and interference status vary between 5-6 when evaluated according to the Numerical Rating Scale between 0 and 10.
††Severe; Symptom severity and interference status vary between 7-10 when evaluated according to the Numerical Rating Scale between 0 and 10.

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Comparison Between Symptom Severity and Karnofsky Performance Level

A cutting point was created by evaluating those with a KPS score of 90 and above as good performance (n=74) and those with a KPS score of 80 and below as bad performance (n=70). It was determined that there was not a highly significant difference between patients displaying good and bad performances in terms of main symptom severity (4.60 against 1.99, P<.001) and interference average (5.5 against 2.5, P<.001).

Interference Status of Patients

When interference status and level of patients with PBT were evaluated between 0 and 10, the highest interference levels were obtained in mood (5.27 ± 3.39), work (including work around the house) (4.79 ± 3.48) and general activity (4.51 ± 3.49). 80.6 % of the patients with PBT were interfered in terms of mood while 79.8 % of the participants experienced interference in the general activities. Likewise, 43.7% of the patients experienced interference in working environment at the severity of 7-10 (Table 2).

Symptom Cluster Analysis

Symptoms constituted five clusters in patients with PBT. The first cluster included gastrointestinal symptoms (nausea, vomiting), the second cluster included affective and treatment-related (fatigue (tiredness), sleepiness, lack of appetite, dry mouth, sleep disorder, distress (upset), defecation problem, sadness and irritability), the third cluster included general symptoms (change in appearance, shortness of breath, pain), the fourth cluster included focal neurologic symptoms (weakness on one side of the body, numbness or tingling) and the fifth cluster mostly included cognitive symptoms (remembering things, difficulty in understanding, difficulty in concentrating, difficulty in speaking and seizures). Symptom clusters of PBT patients are given in Figure 2.

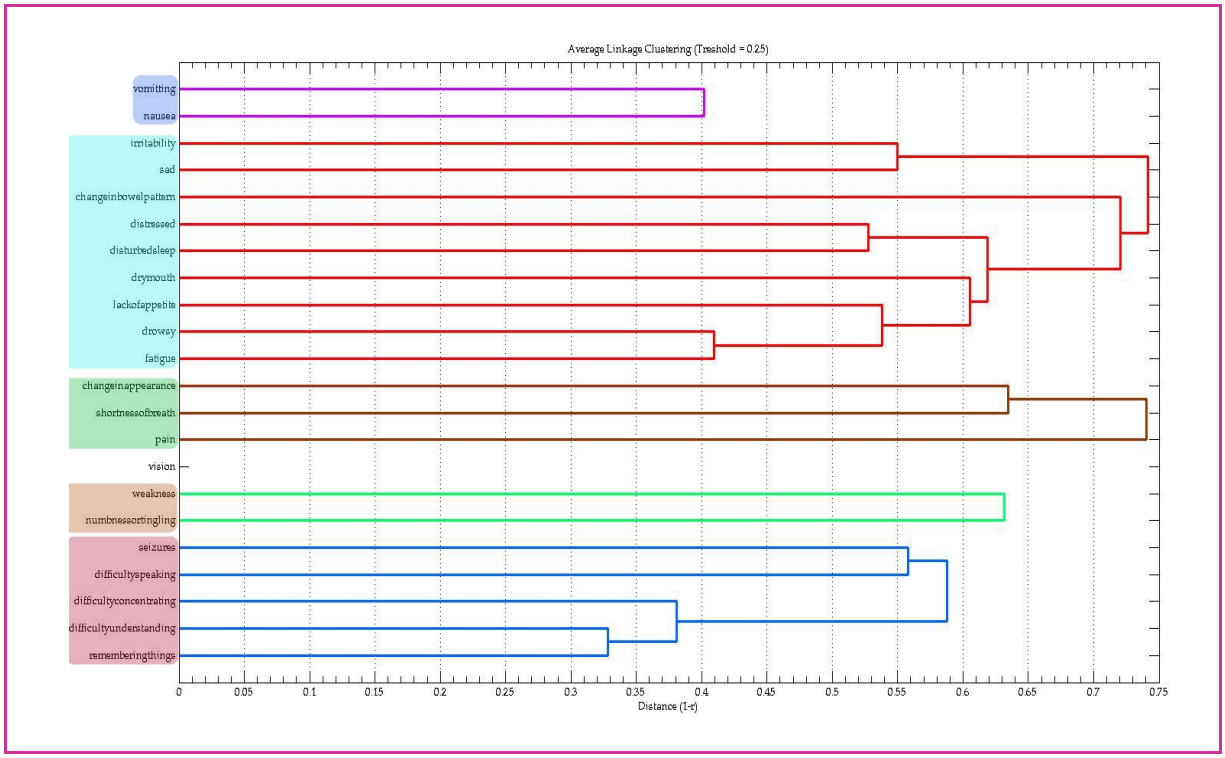

Figure 2. Examination of Symptom Clusters in Patients with Primary Brain Tumor (n=144)

Discussion

Age average of PBT patients included in the research sample is 47.1±13.9 (Table 2). It is known that the age average of diagnosis in PBT patients is 57 (30). In the literature review concerning the epidemiology of PBT patients, it was determined that age average was 54 at the onset of the disease (31). Age distribution varies according to the location of the tumor as well as its histological type (31). For instance, oligodendroglioma is seen in the age group of 35-44 while astrocytoma and glioblastoma are seen in the age group of 65-74 (31). In the research sample, there were more female participants than male participants (Table 1). It has been reported that PBT is seen more commonly among men when compared to women except for some types of it (meningioma) (30,31).

According to the results of the study where symptoms seen in PBT patients were evaluated between 0 and 10, it was found out that averages of all symptoms were lower than 5 while their minimum and maximum values varied between 0 and 10. In terms of symptom severity, symptoms with the highest averages were sadness (4.86 ± 3.48), distress (upset) (3.55 ± 3.58), irritability (3.38 ± 3.62), dry mouth (3.38 ± 3.46), fatigue (3.33 ± 3.04), sleep disorder (3.16 ± 3.71) and visual impairment (3.08 ± 3.34) while seizures (0.37 ±1.60), vomiting (0.53 ± 1.99) and shortness of breath (0.92 ± 2.26) had the lowest averages (Table 2). However, when symptoms were evaluated between 0 and 10 in a research conducted by Armstrong et al. (2006) on 201 patients with PBT, symptoms with the highest averages were found as fatigue (3.79 ± 3.17), drowsiness (3.24 ± 3.05), sleepiness (2.99 ± 3.00), sleep disorder (2.82 ± 3.23), memory weakness (2.51 ± 2.81), distress (2.39 ± 2.83) and dry mouth (2.16 ± 2.83), while symptoms with the lowest averages were seizure (0.35 ± 1.46), vomiting (0.37 ± 1.59) and shortness of breath (0.69 ± 1.46) (10). These results are in parallel with the results of the present study. Only the symptoms of distress (1.72) and visual impairment (1.46) had lower averages in the research conducted by Armstrong et al. (2006). In the present study, distress, sadness and irritability were found out to be the symptoms with the highest averages. If necessary to explain, about ¾ of the patients experienced distress while more than half of the patients experienced sadness and irritability. This difference between our study and the research conducted by Armstrong et al. (2006) brings two important points to mind. One of these factors is the fact that these patients, after being diagnosed, could not talk with their families obviously, they did not prefer talking about this issue as a cultural attitude, the issue was avoided with such expressions as “I will recover, there will be nothing left after the operation etc.” instead of allowing the patients express their emotions and the patients could not find opportunity to express themselves. The second one is that Neurosurgery clinics generally have a heavy work load. Nurses providing care to these patients deal with 12-16 patients a day on average and they have an excessive work load. These nurses also have to deal with new patients hospitalized in the emergency clinic as well as the early postoperative patients following emergency operation. These factors make us conclude that nurses cannot allocate sufficient time for these patients and their families (22). Besides, there is certain need of training in order to make the time spent with the patient more efficient. The

average of the symptom of visual impairment was higher in this research and this finding may be attributed to the fact that patients ignore findings, they are late in applying to a doctor and some of them firstly go to eye polyclinics. This is of importance as it shows that preventive care should be emphasized in the general community trainings to raise awareness. Another important point is the examination of the type and location of the tumor. The average of the symptom of memory problems was lower than the literature and this may have resulted from the fact that patients with difficulties in evaluating and expressing the symptoms were excluded from the sample.

When symptoms were evaluated by frequency percentages in this study, it was detected that sadness (77.8 %), fatigue (67.4 %), dry mouth (59.7 %), pain (58.3 %), distress (upset) (57.6 %), visual impairment (54.2 %), irritability (52.8 %) were seen more frequently than the other symptoms. When percentages of the symptoms with symptom severity higher than 4 were considered, it was found out that sadness (26.4 %), pain (24.3 %) and fatigue (22.2 %) were more common. On the other hand, when symptoms with symptom severity more than 6 were taken into consideration, it was seen that sadness (34.6), dry mouth (27.0), sleep disorder (26.3) and distress (upset) (26.3) had higher frequency ratios (Table 2). When percentages of the symptoms with symptom severity higher than 4 were considered in the study conducted by Armstrong et al. (2006) by using the same scale, it was found out that fatigue (40.0), drowsiness (24.3) and sleepiness (22.2 %) were more common. On the other hand, when symptoms with symptom severity more than 6 were taken into consideration, it was seen that fatigue (23.0), sleepiness (19.0), drowsiness (18.0) had higher frequency ratios than the other symptoms (Table 3). At the end of the study conducted to determine neurological disorders in patients with brain tumors (n: 51), the most common symptoms were determined as cognitive disorders (80 %), weakness (78 %), perceptual, visual disorders (53 %), hearing loss (38 %), intestinal and urinary disorders (37 %). The least common symptoms were, however, cranial nerve palsy, dysarthria, dysphagia, aphasia, ataxia and diplopia (32). In the study conducted by Yeh et al. (1999) on 65 patients with supratentorial malign glioma, the most common symptoms of patients were found as headache, nausea, vomiting (69 %), lack of energy in extremities (55 %), visual impairment (22 %), speaking difficulty (22 %), seizure (18 %) and mental changes (17 %). However, in the research carried out by Chang et al. (2005) on 565 patients who were newly diagnosed with malign glioma, the most common symptoms were cognitive changes, headache, memory loss, nausea-vomiting, speech disorders, personality disorders, motor dysfunctions and seizure. In a case control study conducted to determine clinical characteristics of PBT patients, 10.2 5 of the patients reported headache, 8.7 % reported motor loss, 4.4 % reported new-onset epilepsia, 3.1 % reported confussion, 2.7 % reported weakness and 1 % reported visual impairment (35,36). Symptoms have been defined with different tools in the literature and different symptoms were evaluated. However, symptoms revealed at the end of the study show parallelism with the symptoms detected in the literature. While it was reported that cognitive, visual and perceptual symptoms were commonly seen in the literature (32), affective symptoms are prominent in the results of the present study. In the study conducted by Fox et al. (2007) on 73 patients with

high grade glioma, 95 % depression, 96 % fatigue, 100 % sleep disorders, 58 % pain and 79 % cognitive problems were observed. Although it was expected that the symptom of seizure would have a higher frequency ratio among PBT patients, it had the lowest ratio and less than 10 % of the patients experienced it (Table 2). Seizures are important for PBT patients and thus, should be measured. In addition to tumor histology, seizure also depends on the location of the tumor and it is largely seen in early-stage tumors (1,14). Low frequency of the symptom of seizure may have resulted from the fact that patients included in the research sample constituted a heterogeneous group in terms of tumor type, stage and treatment. In terms of treatment, the ratio of patients who were not on treatment was around ¼. It is thought that the corticosteroid and anticonvulsant treatment and surgical decompression are effective in this finding.

Results of this study reveal that symptoms affect the lives of patients negatively (general activity, mood, work (including work in the house), relations with other people, walking, and enjoyment of life) (Table 2). It was determined in the research that there were significant differences between patients displaying good and bad performances in terms of main symptom severity (4.60 against 1.99, P<.001) and interference average (5.5 against 2.5, P<.001). In the literature, it has been reported that symptoms affect "functional, cognitive, social, affective statuses of patients and thus, their life qualities" (21). Likewise, it was seen in the study conducted by Armstrong et al. (2006) on 201 patients with primary brain tumors that functionality reduced as the symptoms deteriorated. When the relationship between life quality and functional status were examined in the study conducted by Fox et al. (2007) on 73 patients with high grade glioma, it was reported that life quality and functional status deteriorated as the symptoms worsened.

Symptoms constituted five clusters in the patients with PBT (Figure 2). The first cluster included gastrointestinal symptoms (nausea, vomiting), the second cluster included affective and treatment-related (fatigue (tiredness), sleepiness, lack of appetite, dry mouth, sleep disorder, distress (upset), defecation problem, sadness and irritability), the third cluster included general symptoms (change in appearance, shortness of breath, pain), the fourth cluster included focal neurologic symptoms (weakness on one side of the body, numbness or tingling) and the fifth cluster mostly included cognitive symptoms (remembering things, difficulty in understanding, difficulty in concentrating, difficulty in speaking and seizures). Studies conducted so far on the symptoms of PBT patients revealed that patients frequently experienced such neurological symptoms as seizure, cognitive disorders and weakness on one side of the body together (7). The present study also indicated that focal neurological disorders and cognitive symptoms co-existed in patients. Gleason et al. (2007) created two symptom clusters and one symptom couple through factor analysis, cluster analysis and Pearson Correlation method prior to and following the radiotherapy in their study carried out on patients who were newly diagnosed with brain tumor. These two clusters were named as "language" and "mood" clusters. Language cluster consisted of such symptoms as difficulty in reading, writing and expressing while mood cluster included the symptoms of sadness, irritability and depression. Concentration difficulty and fatigue constituted the symptom couple. On the other hand, two

clusters were determined by Fox et al. (2007) in order to identify life quality and functional status. The first cluster included depression, fatigue, sleep disorder, cognitive disorders and life quality while the second cluster included depression, fatigue, sleep disorder, cognitive disorder, pain and functional status. As the tools used in the individual studies were different, the emerging clusters did not contain the same symptoms. When the literature is examined, it is clear that there is a limited number of studies on symptom clustering in PBT patients (7). There is no study concerning the other clusters in the literature, as well. However, the symptom clusters obtained in this research show parallelism with the symptom clusters obtained at the end of the reliability and validity study conducted by Armstrong et al. (2006) on 201 PBT patients by using the same scale. Determining how the symptoms are clustered in PBT patients will provide scientific data in treatment, care and follow-up of patients.

In conclusion, symptom severity and interference level of primary brain tumor patients were found out to be moderate and severe. In PBT patients, the most severe and frequent symptoms were affective symptoms. As to the symptom clusters, affective-treatment related, focal neurological and cognitive symptoms stood out. Nurses providing care to these patients should primarily apply the interventions related to the most severe symptoms and launch the associated interventions when one symptom of a cluster is diagnosed. This nursing approach will facilitate the patient compliance to the treatment, contribute to the improvement of functional, cognitive, social and affective statuses, reduce the interference levels of patients' lives and will enhance the quality of life.

Limitations

In the research, averages related to the symptoms and interference statuses were found out to be low. There are two reasons to explain this situation. The first one is that treatment was started immediately in patients included in the sample and sample consisted of a mixed patient group including preoperative and postoperative patients. The second reason is possibly that patients who could not establish written and oral communication and suffered from such clinical problems as speech difficulty and consciousness problem were excluded from the sample as their symptom severities could not be evaluated accurately and precisely.

Recommendations

A tool is needed for nurses to evaluate the symptoms in the patient group whose data could not be collected due to the reasons mentioned in the limitations. Symptom clustering studies on PBT patients are limited and the increase of these studies will provide us with a better understanding of symptom clusters. There is also need for studies which identify longitudinal symptom severity and incidence and analyze its relationship with prognosis.

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