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Original Article

Evaluation of Early and Late Stage Stress Burden Among Caregivers of Patients Undergoing Neurooncological and Neurovascular Surgery

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ABSTRACT

Objective: Caregiving to neurosurgical patients is the demanding task load to caregiver some physical, psychological, social and economic issues. We focused on neurooncological and neurovascular patients and aimed to investigate stress burden of caregivers and to identify factors contributing to it for this group of patients.

Methods: 20 subarachnoid hemorrhage, 20 malignant tumor and their caregivers were included. Patients' neurophysical condition were evaluated using Barthel index. Caregivers' physical, psychological burden was measured by "Caregiver Strain Index". Both of index were completed during preoperative period and at 3rd month postoperativel. The probable predictor factors for caregivers on stress burden of caregiver was investigated.

Results: For oncological and vascular patient groups, preoperative Barthel index scores were 15.45 (±4.04) and 12.6 (±5.9) respectively. Barthel index scores showed improvement of their clinical condition in vascular group as a difference at 3th months. Caregiver Strain Index scores were similar in both caregiver groups preoperatively (5.3 and 5.1 respectively; p=0.87). However, when both groups are compared, Caregiver Strain Index scores at 3rd month postoperatively showed a significantly higher stress burden for caregivers of oncological patients (p=0.01).

Conclusion: During hospital stay, both groups had similar dependency levels and their caregivers also showed similar stress burden. Reducing dependency level of oncological patients and clinical improvement of vascular patients resulted in a clear difference between the stress levels of caregivers. An organized education plan with a holistic approach may reduce caregiver's physical, psychological and social burden and improve patient's activities of daily living and surgical outcome.

INTRODUCTION

With advancements in treatment methods and prolonged life expectancy, there has been a corresponding rise in the number of patients requiring daily care. In many developed nations, patient care can be delivered in specialized centers, while in developing countries, direct care is often provided by family members. This demanding responsibility also introduces challenges, including impacts on the caregiver's role in their social life.

The daily care needs of patients undergoing surgery vary and are closely related to the nature of the illness or the specific procedure performed. Patients typically require ongoing care and support even after discharge. For neurosurgical patients, potential neurological deficits often make daily care more complex and demanding. Postoperative follow-up reveals that pain is the most frequently reported issue among patients, whereas neurosurgical patients predominantly report difficulties in performing self-care activities. Such self-care limitations impose a significant burden on both patients and caregivers, adding an additional layer of stress to existing challenges. According to a study by Subasi et al.,[1] among patients requiring assistance with activities of daily living, 81.7% received care from family members at home.

The caregiver's load encompasses all the physical, psychological, social, and economic challenges that caregivers face. The term "load" is challenging for researchers to standardize. Additionally, cross-cultural differences limit the adaptability of such studies to specific societies. A study by Stone et al.[2] found that in the United States, wives and husbands represent 23% and 13% of the caregiver population, respectively. Another study investigating caregivers' challenges in Türkiye reported that 78% of informal caregivers were women, with 34% providing care for their husbands.[3]

Montgomery et al.[4] proposed categorizing caregiver burden into objective and subjective burdens. Objective burden is defined by the caregiver's effort, time, and financial costs associated with providing care. Subjective burden, on the other hand, reflects the emotional impact on the caregiver who experiences these objective challenges. This type of burden includes affective changes such as distress, grief, guilt, anger, fatigue, and depression. Over time, such burden may lead to a decline in caregivers' quality of life and reduce their overall functionality. The impact of this burden can vary significantly between individuals and across cultures.

Our study focuses on two primary groups of patients commonly encountered in neurosurgical practice: neuro-oncological and neurovascular patients. We aim to examine the stress burden on caregivers of these patient groups and to identify factors that contribute to this burden.

MATERIALS AND METHODS

Ethics approval for the study was obtained from the Local Ethics Committee, and the study adhered to the principles of the Helsinki Declaration. Informed consent was obtained from each participant. Two patient groups and their caregivers were selected, which differed significantly in terms of natural disease course and pathological characteristics. The study included 20 patients who underwent surgery for malignant intracranial lesions and 20 patients operated on for subarachnoid hemorrhage due to a ruptured cerebral aneurysm in 2012, along with their caregivers. Age, gender, and educational level were recorded for each participant.

Patients' physical capacity and limitations in activities of daily living were assessed using the Barthel Index. The Barthel Index is a widely recognized tool for evaluating the physical disability of neurological patients by examining 10 aspects of daily living activities (scored between 0-20). A score of 12 or above generally indicates minimal dependency or independence, while a score of 0-12 is considered dependent. In our study, the Barthel Index was applied during the hospital stay prior to surgery and again at the 3rd postoperative month.[5]

Caregivers' demographic data, including age, gender, educational level, and income level, were recorded. The caregivers' physical and psychological burden was assessed using the "Caregiver Strain Index." This index was developed and validated by Robinson in 1983 and later translated into Turkish, with validity and reliability confirmed by Ugur and Fadilloglu in 2006. The tool consists of 13 questions, with scores of 7 or higher indicating a high level of stress.[6,7] The Caregiver Strain Index was completed in the hospital through personal interviews during the preoperative period and via telephone interviews at the 3rd postoperative month.

The impact of demographic data, educational level, and the level of independence of both patients and caregivers on the caregiver's stress burden was examined. Normality of the numerical variables was assessed using the Shapiro-Wilk test, and the Student's t-test was applied only when normal distribution was confirmed. The Chi-squared test was used for categorical variables, while Pearson's correlation test was applied for evaluating relationships between numerical variables. Student's t-test was used for comparisons involving normally distributed numerical variables. Statistical analysis was conducted using IBM SPSS Statistics for Windows, Version 22.0 (Armonk, NY: IBM Corp.).

RESULTS

A total of 40 patients (20 patients operated on due to neuro-oncological diseases and 20 due to neurovascular diseases) and their caregivers were included in the study. Demographic data of the patients and their caregivers, along with the results of the applied questionnaires, are summarized in Table 1 and Table 2. The oncological group consisted of 16 females and 4 males, with a median patient age of 47.3±15.2 years (range 16-77). In this group, 17 caregivers were female and 3 were male, with a median caregiver age of 40.2±11.1 years (range 22-68). The vascular group included 9 females and 11 males, with a median patient age of 53±13.7 years (range 22-74). For vascular patients, 16 caregivers were female and 4 were male, with a median caregiver age of 39±14.4 years (range 19-72). Patients in both groups were comparable in terms of age and gender, with most patients in both groups being in middle adulthood. The gender distribution between patient groups was statistically significant, with a predominance of females in the oncological group, while gender was evenly distributed in the vascular group (p=0.02). Since studies indicate minimal or no gender differences for malignant brain tumors, this discrepancy was considered an asymmetrical patient distribution for a group of 20 consecutive patients. Both caregiver groups showed a significant pre-

Table 1. Demographical data of patients and caregivers, patient's clinical condition and caregiver's stress burden

	Patient n (%)		Caregiver n (%)	
Factor	**Oncological**	**Vascular**	**Oncological**	**Vascular**
Gender				
Male	4 (20)	11 (55)	3 (15)	4 (20)
Female	16 (80)	9 (45)	17 (85)	16 (80)
Age	47.3 (±15.2)	53 (±13.7)	40.2 (±11.1)	39 (±14.4)
Marital status				
Married	20 (100)	20 (100)	20 (100)	20 (100)
Single	-	-	-	-
Education				
Illiterate	3 (15)	-	-	-
Eementary school	11 (55)	14 (70)	15 (75)	14 (70)
Middle school	2 (10)	1 (5)	3 (15)	2 (10)
High school	-	-	-	-
College	4 (20)	5 (25)	2 (10)	4 (20)
Barthel index				
Preoperatively	15.5 (±4)	12.6 (±5.9)	-	-
Postoperatively	13.4 (±6.5)	16.3 (±6.5)	-	-
Caregiver strain index				
Preoperatively	-	-	5.3 (±2.9)	5.1 (±3.2)
Postoperatively	-	-	6.6 (±3.8)	3.5 (±3.1)

Table 2. The effects of caregivers' demographical features on strain index

	Oncological group (p value)	Vascular group (p value)
Gender	0.56	0.62
Age	0.34	0.78
Level of education	0.81	0.71
Level of income	0.25	0.38

dominance of females (85% and 82%, respectively). Caregiver groups were younger than patient groups and were similar in age and gender distribution. The effects of gender and age on the stress burden for caregivers were not statistically significant (p=0.56 and p=0.34 for the oncological group, and p=0.62 and p=0.78 for the neurovascular group, respectively).

The education levels of patients were low in both the oncological and vascular groups, with most patients being elementary school graduates (65% and 75%, respectively). Similarly, 70% of the caregivers were also elementary school graduates. The level of education had no statistically significant effect on the stress burden for caregivers (p=0.81 for the oncological group and p=0.71 for the neurovascular group, respectively).

According to the income levels of caregivers, 70% of the oncological group and 80% of the vascular group were below the poverty line defined by the Turkish Statistical Institute. Both caregiver groups showed no significant differences in terms of educational level and income (p=0.29 and p=0.8, respectively). Income level had no impact on the stress burden in either group (p=0.25 for the oncological group and p=0.38 for the vascular group).

For the oncological and vascular patient groups, preoperative Barthel Index scores were 15.45 (±4.04) and 12.6 (±5.9), respectively. Although both groups did not differ statistically, the oncological group showed slightly better outcomes in activities of daily living (Table 3). At the 3rd postoperative month, Barthel Index scores decreased for the oncological group (13.4±6.5), while vascular patients had higher scores than in the early postoperative period (16.3±6.5), indicating an improvement in their clinical condition (p=0.02).

Preoperatively, Caregiver Strain Index scores were similar for caregivers of both oncological and vascular patients (5.3 and 5.1, respectively; p=0.87). However, the stress burden for caregivers of oncological patients increased significantly (6.6±3.8, p=0.05), whereas caregivers of vascular patients experienced a reduction in stress burden during the postoperative period (3.5±3.1; p=0.01). When comparing both groups, Caregiver Strain Index scores at the 3rd postoperative month indicated a significantly higher stress burden for caregivers of oncological patients (p=0.01).

Table 3. Changes in patients' clinical condition and caregivers' strain index preoperatively and at 3rd month postoperatively

	Preoperative period	Postoperative period	P value
Patients' Barthel index			
Oncological	15.5 (±4)	13.4 (±6.5)	0.11
Vascular	12.6 (±5.9)	16.3 (±6.5)	0.02*
Caregivers' Strain index			
Oncological	5.3 (±2.9)	6.6 (±3.8)	0.05*
Vascular	5.1 (±3.2)	3.5 (±3.1)	0.01*

*Student's t-test was applied for comparisons involving normally distributed numerical variables.

DISCUSSION

The factors affecting caregivers' stress burden and quality of life can be categorized in three distinct ways: 1) caregiver-related, 2) patient- and disease-related, and 3) care-related. Caregiver-related factors include the caregiver's gender, age, economic status, and occupation. Patient- and disease-related factors encompass disease severity, patient age, and the relationship between the patient and the caregiver. Care-related factors refer to the duration, location, and intensity of care. Demographic factors, caregiver age, and level of education have each been shown to influence caregivers' stress levels independently.

In terms of gender, caregiving is primarily provided by women.[2,3] In societies where fewer women participate in the workforce, as is the case in our country, caregiving is perceived as a regular part of women's daily routine and is often viewed as a simple task. In cultures where paternalistic traditions shape daily life, caregiving is predominantly undertaken by mothers, and patient care is seen as a natural extension of this role. Studies indicate that this responsibility imposes a higher stress burden on women than on men. Men, on the other hand, often view caregiving as an excessive workload, with low expectations placed on themselves and other family members. Altun et al. reported that 78% of all caregivers in Türkiye are female.[3] In a study involving caregivers of brain tumor patients, Keir et al. highlighted the predominance of women.[8] Consistent with the literature, our study also revealed a female predominance among caregivers.[3,8-11] Although women tend to experience slightly higher stress levels than men, gender and age differences among caregivers appear to have a limited association with stress burden.[9-12] Interestingly, the study by Keir et al.[8] reported higher stress levels in men than in women. A widely accepted view regarding gender is that younger caregivers are more susceptible to stress.[8,10,12-14] Social isolation may contribute more to the stress burden of younger caregivers compared to older individuals. Our study showed no effect of gender or age on stress levels.

Caregivers must adapt to potential new challenges and be capable of finding solutions. The ability to provide effective and rapid solutions not only decreases the mortality and morbidity associated with the disease but also reduces the caregiver's stress burden. A higher level of education may enable caregivers to respond to unexpected situations more accurately and swiftly. Education level contributes not only to problem-solving abilities but also to the capacity to understand and assess the patient's subjective complaints. The inability to recognize such signs and symptoms is a factor that increases the caregiver's stress burden. In our study, caregivers demonstrated a low level of education. For both patients and caregivers, 80% were either illiterate or had only elementary or middle school education. Although statistical data indicate no effect of education level on stress burden, the small sample size limits a definitive interpretation.

The course of the disease plays a significant role in the socio-psychological adaptation of caregivers. Consequently, high-grade disease, poor prognosis, and prolonged disease duration are known to have negative effects. Given that these factors are present in oncological patient groups, particularly in patients with high-grade cerebral neoplasms, it is anticipated that caregivers are directly impacted by them.[8,15,16] Compared to other illnesses, cancer is regarded as a distinct and unique stressor for both the patient and the caregiver. Beyond its physical consequences, the term "cancer" itself imposes psychological pressure.[8,17] Furthermore, it has been shown that the psychological trauma experienced by the caregiver may lead to increased morbidity or mortality in the patient.

Neurovascular diseases (in our study, cerebral aneurysmal hemorrhage) manifest acutely, with significant morbidity and mortality observed upon hospital admission. Patients' clinical conditions usually improve following discharge or during physiotherapy and rehabilitation. Due to these characteristics, patients with neurovascular diseases differ from those in the neuro-oncological patient group.

Our study focuses on the effect of disease type on the caregiver's stress burden, thus including two distinct patient groups. It was clearly demonstrated that neurovascular patients showed significant improvements in neurological status and dependency levels compared to their condition during hospitalization. Conversely, though not statistically significant, oncological patients showed a decline in clinical condition. During hospitalization, both groups exhibited similar levels of dependency, and their caregivers experienced comparable stress burdens. Our study supported the notion that caregivers of demographically similar patients are expected to have similar initial stress responses to analogous clinical conditions. However, the reduction in dependency among oncological patients and the clinical improvement of vascular patients led to a noticeable difference in caregiver stress levels.

Conclusion

Providing care is a demanding and intense task that disrupts the caregiver's personal life and daily routine. Due to the sociocultural structure of society, caregivers may have limited access to professional support and may be compelled to provide care, which has physical and psychological consequences. Another issue is the lack of adequate information and standardized discharge procedures. Informing the caregiver about potential problems after discharge is crucial for developing coping strategies. A well-structured educational plan with a holistic approach can reduce the physical, psychological, and social burdens on caregivers, thereby improving the patient's daily living activities and surgical outcomes.

Ethics Committee Approval

The study was approved by the Başakşehir Çam and Sakura City Hospital Ethics Committee (Date: 27.01.2024, Decision No: 2024-KAEK-11).

Informed Consent

Retrospective study.

Peer-review

Externally peer-reviewed.

Authorship Contributions

Concept: O.H., G.H., S.S., Ö.B.H., B.C.K., E.A., B.T.; Design: O.H., G.H., S.S., Ö.B.H., B.C.K., E.A., B.T.; Supervision: O.H., G.H., S.S., Ö.B.H., B.C.K., E.A., B.T.; Materials: O.H.; Data collection &/or processing: G.H., S.S.; Analysis and/or interpretation: O.H., G.H., S.S., Ö.B.H., B.C.K., E.A., B.T.; Literature search: O.H., B.T.; Writing: O.H., B.T.; Critical review: B.C.K., Ö.B.H, E.A, B.T.

Conflict of Interest

None declared.

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Nöroonkolojik ve Nörovasküler Hastalıklar Nedeniyle Cerrahi Geçiren Hastalara Bakım Verenlerde Erken ve Geç Dönemde Stres Yükünün Değerlendirilmesi

Amaç: Nöroşirürji hastalarına bakım vermek, bakım veren kişilere sosyal, fiziksel, psikolojik ve ekonomik anlamlarda yük bindiren tüketici bir görevdir. Bu çalışmada, nöroonkolojik ve nörovasküler nedenlerle cerrahiye alınan hastalar ele alınarak bu hastalara bakım verenlerin stres yükü değerlendirildi ve stres yükünü etkileyen faktörler araştırıldı.

Gereç ve Yöntem: 20 subaraknoid kanama, 20 malign tümör hastası ve onlara bakım verenler çalışmaya dahil edildi. Hastaların nöropsikolojik durumları Barthel indeksi ile değerlendirildi. Bakım verenin fiziksel, psikolojik yükü ise "bakım verenin stres indeksi" ile ölçüldü. Her iki indeks de operasyon öncesi dönemde ve operasyon sonrası 3. ayda iki kez kayıtlandı. Bakım verenin stres yükünü etkileyen muhtemel faktörler araştırıldı.

Bulgular: Onkolojik ve vasküler hasta grupları için preoperatif Barthel indeksi skorları sırasıyla 15.45 (±4.04) ve 12.6 (±5.9) idi. Barthel indeks skorları vasküler hasta grubunda 3. ayda belirgin düzelme gösteriyordu. Bakım verenin stres indeksi skorları preoperatif dönemde her iki grupta da benzerdi (sırasıyla, 5.3 ve 5.1; p=0.87). Bununla beraber,her iki grup karşılaştırıldığında, Bakım verenin stres indeksi 3. ayda, onkolojik hastalara bakım verenlerde belirgin şekilde daha yüksek stres yükü olduğunu gösteriyordu (p=0.01).

Sonuç: Hastanede yatış süresince her iki grup aynı düzeyde bağımlılık gösteriyordu ve bakım verenlerde de stres yükü benzerdi. Onkolojik hastalarda bağımlılığın artması ve vasküler hastalarda klinik düzelmenin gözlenmesi ile bakım verenlerde stres yükü belirgin farklılık göstermekteydi. İyi bir eğitim planlaması ve bütünlükçü bir yaklaşım ile bakım verenin fiziksel, psikolojik ve sosyal yükü azaltılabilir ve bu durum hastanın gündelik yaşam aktivitelerine katılımını artırabilir ve cerrahi sonuçları iyileştirebilir.

Anahtar Sözcükler: Bakım veren; nöroşirurji; stres yükü.