Evaluation of Caregiver Burden of Family Members Providing Support for the Care of Patients Undergoing Brain Surgery at the Hospital

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Abstract

AIM: The brain regulates various functions which control and coordinate the body. As brain surgeries influence the structures that regulate body functions, they can cause serious complications in patients, such as disability or death. This study aimed to determine the caregiver burden of family members providing support for the care of patients who had undergone brain surgery.

METHOD: The descriptive study was done with family members of 102 patients who had surgery at the neurosurgery department of a university hospital in Turkey. Data were collected using the descriptive features form for the patients, descriptive features form for the care providing family members, Zarit Care Load Scale adjusted for the clinic, and Barthel daily living activities index.

RESULTS: The results of the study revealed that patients undergoing neurosurgery were dependent to an extreme level and that care providing family members had mild or moderate level of care load. A statistically significant difference was found between the averages of family members and their age, sex, marital status, education level, monthly income level, and working status (p < .05).

CONCLUSION: As the level of dependency of the patients undergoing neurosurgery increased, the load of the family members providing care also increased. It would be beneficial to evaluate the support sources owned by care providing family members for taking care of patients and to direct them to people and institutions from where they could get assistance.

Keywords: Family, neurosurgery, patient care, perioperative nursing

INTRODUCTION

As the skull occupies a limited area and is close to vital centers, after neurosurgery patients can develop increased intracranial pressure, cardiac arrhythmia, air embolism, loss of hearing and difficulty in swallowing owing to the cranial nerves being influenced, loss of memory, paralysis, loss of senses such as blindness, speech disorders, mental confusion, and other complications in the postoperative period. Furthermore, in the postoperative period, medical dressings and drains in the surgical area trigger infections, and the patients become dependent for carrying out their daily living activities because of pain and tiredness. This also increases their need for family members to accompany them to the hospital and also increases the burden of care providers (İlçe et al., 2010; Moieni et al., 2014).

However, this situation restricts the daily activities and social lives of the family members providing care to the patient, the time they can allocate to other family members gets reduced, and can cause economic difficulties (İzgü, 2015). Caregiver burden is related to the degree of dependency of the patients for their daily living activities. As the degree of dependency and the time required for patient care increase, the load of the care provider also increases.

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As the caregiver burden increases, the quality of life of the caregiving family members worsens. Family members who are caregivers end up neglecting both their health and the health of the patients to whom they provide care. Caregivers feel restricted and desperate, they cannot meet their own requirements, and their satisfaction gets reduced. Patient care by a care provider whose life quality has reduced, can also be negatively influenced. When a caregiver does not have the mental and physical strength to deal with the problems arising as a result of the treatment being applied, their burden of care increases and quality of life get reduced (Aşiret Duru & Kapucu, 2012). A review of the literature shows that even though there are only a few studies related to the load of care providers, most of them are related to older people and those who provide care to patients with chronic diseases (Aşiret Duru & Kapucu, 2012; Atagün et al., 2011; Çıtlık et al., 2014; Kankaya et al., 2016). Therefore, we conducted this study in the postoperative period with relatives of patients who had undergone surgery for intracranial mass, subarachnoid hemorrhage, cerebral aneurysm rupture, and brain tumor. Once the caregiver burden of the family members providing support for the care of patients undergoing brain surgery at the hospital can be determined, the awareness of the surgical nurses about the load of care providers will increase, and the quality of care will improve, facilitating support for family members. This study aimed to evaluate the caregiver burden of family members providing support for the care of patients undergoing brain surgery at the hospital.

Research Questions

1. Do the caregiver family members of neurosurgery patients have burden of care?
2. Is there a relation between the dependency levels of patients after neurosurgery and the burden of care of caregiver family members?
3. Is there a relation between sociodemographic features of caregiver family members of neurosurgery patients and their burden of care?

Method

Study Design
This was a descriptive study.

Sample
The study was conducted between August 2016 and February 2017 at the neurosurgery department of a university hospital in Turkey. To determine the sample size of the study, a statistical analysis was performed with 90% power analysis using the Open Source Epidemiologic Statistics for Public Health program Version 3.01 (Dean et al., 2013), and family members of 102 patients were included.

This study was carried out with family members who were over the age of 18 and who had spent 48 hours as caregivers after brain surgery of their patients.

Data Collection Tools

Data were collected using the descriptive features form for the patients, the descriptive features form for the care providing family members, Zarit Care Load Scale adjusted for the clinic, and Barthel daily living activities index.

Descriptive Features Form for Patients: This form, prepared by the researcher, includes 10 questions for determining the features of the patient (such as age, sex, and so on) for whom the care provider is responsible (Bayram, 2014; Kaya et al., 2014; Özer et al., 2012).

Descriptive Features Form for Care Providing Family Members: This form includes 19 questions and 2 sections. In the first section, there are 11 questions including sociodemographic features of the family members of patients (such as age, sex, and so on). In the second section, there are 8 questions including information about the family members of patients regarding their care provision (such as the time spent on patient care, time spent on going to the hospital and coming back).

Zarit Care Load Scale that is Adapted for the Clinic (ZBI-TR): The Care Load Scale was developed by Zarit et al., in 1980. It is a scale used to determine the stress lived through by those providing care to people in need or to elderly people (Zarit et al., 1980). The Care Load Scale was adapted to Turkish by Özer et al. (2012), and validity and reliability studies have been conducted. The scale is a Likert-type scale with scores from “0” to “4”, such as never (0), seldom (1), sometimes (2), often (3), or almost always (4). The studies in the scale are generally related to social and emotional areas. The total score is obtained by adding all the studies. The total score can vary from 0 to 88. The higher the total score, the higher the load. If the load is between 0 and 20 points, it implies little or no load; between 21 and 41, moderate
or intermediate level of load; and between 41 and 60, high level of load. The range of 61 to 88 is rated as excessive load. The Cronbach alpha coefficient of the Zarit care burden scale was .82. In this study, the cronbach alpha value was found to be .80.

**Barthel Daily Living Activities Index (BDLAI):** This index, which was developed by Mahoney & Barthel in year 1965, has been used to determine the level of independence of daily living activities of individuals. The validity and reliability of the scale was verified by Kucukdeveci et al. (2000). The scale includes articles evaluating nutrition, passing from the wheelchair to the bed and back, self-care, bath, walking, going up and down the stairs, dressing, and bladder and bowel continence. Scores from the scale can range from “0” (lowest) to “100” (highest), with 0–20 points defining complete dependence, 21–61 advanced level of dependence, 62–90 intermediate level of dependence, and 91–100 points independence. The Cronbach alpha coefficient of the Barthel daily living activities index was .88. In this study, the cronbach alpha value was found to be .82.

**Statistical Analysis**

The data were analyzed with the Statistical Package for the Social Sciences version 18.0 (SPSS Inc., Chicago, IL, USA) software program. The Kolmogorov-Smirnov test was applied to determine whether the data were normally distributed. Statistical methods used included percentage, mean, Mann-Whitney U test, Kruskal-Wallis variance analysis, Spearman correlation analysis, and linear regression analysis.

**Ethical Considerations**

Ethical counsel permit (29.07.2016 Issue: 24237859-450) was obtained from the presidency of Karadeniz Technical University Medical Faculty Scientific Research Board ethical counsel for scientific research, and institutional permit was obtained from the hospitals. In addition, informed consent was obtained from each patient and caregiver family members. All the participants were informed that participation was voluntary and that all their information would be kept confidential.

**Results**

Of the patients in the study, 66.7% were 55 years or older, 63.7% were men, and 74.5% were married. A total of 71.6% of the patients were elementary school graduates, 76.5% had intermediate income levels, 78.4% of them did not work, and all of them had social security. Neurosurgery was performed for an intracranial tumor in 63.8% of the patients, 50% had at least 1 disease other than the disease for which they had surgery, and they stayed in the hospital for 8.0 ± 9.1 days on the average.

Of the care providers, 40.2% were between 19 and 36 years of age, 68.6% were women, and 80.4% were married. Nearly half the patient’s relatives who participated in the study were primary school graduates, living in the city center, and 75% were in a nuclear family structure. A total of 83.3% of the caregivers had an intermediate level of income, 63.7% of them did not work, and all of them had social security. Of the caregivers who were family members, 91.2% were first-degree relatives of the patient, and 27.5% had a chronic disease.

Approximately, 50% of the caregivers had been caring for their patients for <30 days, 73.5% continuously stayed with the patient, and 64.7% were involved in patient care for 8–16 hours a day. It was determined that 28.4% of the caregivers had at least 1 person they were liable to look after at home, and 86.2% were liable to look after their children. A total of 55.9% of the caregivers were supported by other family members during the time they stayed in the hospital with the patient, and the most frequently received support was physical support (93.0%). Of the caregivers, 94.1% gave physical support to the patient, 58.8% lived through problems during the time they stayed at the hospital, and the most frequently experienced problem was related to sleeping (73.3%).

The total BDLAI score average of patients who were receiving care was 34.8 ± 31.8, and the ZBI-TR score average of the caregivers was 27.3 ± 12.8 (Table 1).

The total ZBI-TR score averages of family members providing care to patients undergoing brain surgery at the hospital were 36.2 ± 11.0 for those aged 55 or more, 29.4 ± 13.7 for women, 29.2 ± 12.4 for the

| Table 1: BDLAI Score Averages of Patients Undergoing Brain Surgery and ZBI-TR Score Averages of Care Providing Family Members (n = 102) |
|---|---|---|
| Scale types | n | Mean ± SD | Medium (min-max) |
| BDLAI | 102 | 34.8 ± 31.8 | 30.0 (0–100) |
| ZBI-TR | 102 | 27.3 ± 12.8 | 26.0 (2–56) |

Note: BDLAI = Barthel daily living activities index; ZBI-TR = Zarit Care Load Scale that is adapted for the clinic; n = Sample size; SD = Standard deviation.
married ones, 30.9 ± 12.5 for elementary school graduates, 32.5 ± 14.4 for those living in villages, 33.6 ± 12.1 for those having low monthly income levels, 29.9 ± 13.1 for those having extended families, 30.2 ± 12.9 for those not working, 27.4 ± 13.0 for those being first-degree relatives, and 27.5 ± 12.4 for those not having health problems. There was a statistically significant difference between the total ZBI-TR score averages in terms of age, sex, marital status, education status, monthly income level, and working status (p < .05) (Table 2). Therefore, it was determined that increased age, female sex, being married, low education level, and low monthly income increased the burden of care.

**Table 2**
Comparison of Sociodemographic Features of the Family Members Providing Care to Patients Undergoing Brain Surgery at the Hospital and ZBI-TR Score Averages (n = 102)

| Sociodemographic features                  | n (%)  | Mean ± SD   | Statistical analysis |
|--------------------------------------------|--------|-------------|----------------------|
| **Age (years)**                            |        |             |                      |
| 19–36                                      | 41 (40.2) | 20.8 ± 10.0 | KW = 22.131          |
| 37–54                                      | 36 (35.3) | 28.5 ± 12.9 | p = .000             |
| 55 and older                               | 25 (24.5) | 36.2 ± 11.0 |                      |
| **Sex**                                    |        |             |                      |
| Female                                     | 70 (68.6) | 29.4 ± 13.7 | Z = −2.387           |
| Male                                       | 32 (31.4) | 22.8 ± 9.2  | p = .017             |
| **Marital status**                         |        |             |                      |
| Married                                    | 82 (80.4) | 29.2 ± 12.4 | Z = −2.866           |
| Single                                     | 20 (19.6) | 19.5 ± 11.4 | p = .004             |
| **Education status**                       |        |             |                      |
| Elementary school                          | 58 (56.8) | 30.9 ± 12.5 | KW = 12.518          |
| High school                                | 22 (21.6) | 24.9 ± 13.1 | p = .002             |
| High school/University                     | 22 (21.6) | 20.1 ± 9.7  |                      |
| **Place of living**                        |        |             |                      |
| City                                       | 60 (58.9) | 27.1 ± 12.3 | KW = 1.377           |
| District                                   | 34 (33.3) | 26.5 ± 13.4 | p = .502             |
| Village                                    | 8 (7.8)  | 32.5 ± 14.4 |                      |
| **Monthly income level**                   |        |             |                      |
| Good                                       | 7 (6.9) | 13.2 ± 10.4  | KW = 9.287           |
| Intermediate                               | 85 (83.3) | 27.7 ± 12.3 | p = .010             |
| Low                                        | 10 (9.8) | 33.6 ± 12.1  |                      |
| **Family type**                            |        |             |                      |
| Nuclear                                    | 77 (75.5) | 26.4 ± 12.7 | Z = −1.005           |
| Wide                                       | 25 (24.5) | 29.9 ± 13.1 | p = .315             |
| **Working status**                         |        |             |                      |
| Working                                    | 37 (36.3) | 22.3 ± 11.1 | Z = −2.924           |
| Not working                                | 65 (63.7) | 30.2 ± 12.9 | p = .003             |
| **Degree of closeness to the patient**     |        |             |                      |
| First degree relative                      | 93 (91.2) | 27.4 ± 13.0 | Z = −1.189           |
| Second degree relative                     | 9 (8.8)  | 26.5 ± 11.3 | p = .850             |
| **Situation of having a health problem**   |        |             |                      |
| Yes                                        | 28 (27.5) | 26.6 ± 13.9 | Z = −.398            |
| No                                         | 74 (72.5) | 27.5 ± 12.4 | p = .681             |

Note. ZBI-TR = Zarit Care Load Scale that is adapted for the clinic; n = Sample size; SD = Standard deviation.
### Table 3
Comparison of Care Provision Features of Family Members Providing Care to Patients Undergoing Brain Surgery at the Hospital and ZBI-TR Score Averages (n = 102)

| Features related to the care provision period | n (%) | ZBI-TR Mean ± SD | Statistical analysis |
|-----------------------------------------------|-------|------------------|----------------------|
| **Period of dealing with patient care**       |       |                  |                      |
| Less than 30 days                             | 48 (47.1) | 24.3 ± 11.4 | KW = 9.387 |
| Between 31 and 180 days                       | 19 (18.6)  | 25.0 ± 10.8 |                      |
| More than 181 days                            | 35 (34.3)  | 32.7 ± 14.1 | *p = .009*          |
| **Frequency of staying at the hospital**      |       |                  |                      |
| Continuous                                    | 75 (73.5)  | 26.0 ± 13.0 | Z = −1.705          |
| Sometimes                                     | 27 (26.5)  | 30.8 ± 11.6 | *p = .088*          |
| **Period of providing care to the patient**   |       |                  |                      |
| Less than 8 hours                             | 13 (12.7)   | 17.9 ± 14.8 | KW = 6.73           |
| Between 8 and 16 hours                        | 66 (64.7)   | 28.5 ± 12.1 | *p = .035*          |
| More than 17 hours                            | 23 (22.6)   | 29.0 ± 11.8 |                      |
| **Existence of people being liable to take care of at home** | | | |
| Yes                                          | 29 (28.4)   | 29.7 ± 12.4 | Z = −1.248          |
| No                                           | 73 (71.6)   | 26.3 ± 12.9 | *p = .212*          |
| **People being liable to take care of at home (n = 29)** | | | |
| Mother-Father                                 |       |                  |                      |
| Yes                                          | 6 (20.7)    | 30.7 ± 14.7 | Z = −.081           |
| No                                           | 23 (79.3)   | 29.5 ± 12.1 | *p = .937*          |
| Child                                        |       |                  |                      |
| Yes                                          | 25 (86.2)   | 28.7 ± 12.0 | Z = −1.048          |
| No                                           | 4 (13.8)    | 36.5 ± 15.0 | *p = .310*          |
| **Existence of other family members providing support for the care** | | | |
| Yes                                          | 57 (55.9)   | 25.2 ± 13.0 | Z = −1.738          |
| No                                           | 45 (44.1)   | 30.0 ± 12.2 | *p = .082*          |
| **Type of support provided to the patient by other family members giving support for the care (n = 57)** | | | |
| Psychological support                         |       |                  |                      |
| Yes                                          | 48 (84.2)   | 26.1 ± 13.3 | Z = −1.228          |
| No                                           | 9 (15.8)    | 20.9 ± 11.5 | *p = .219*          |
| Physical support                              |       |                  |                      |
| Yes                                          | 53 (93.0)   | 25.2 ± 13.1 | Z = −0.047          |
| No                                           | 4 (7.0)     | 25.8 ± 13.6 | *p = .964*          |
| Financial support                             |       |                  |                      |
| Yes                                          | 39 (68.4)   | 26.4 ± 14.1 | Z = −1.049          |
| No                                           | 18 (31.6)   | 22.7 ± 10.2 | *p = .294*          |
The total ZBI-TR score averages of the caregivers was 32.7 ± 14.1 for those involved for more than 181 days, 30.8 ± 11.6 for those staying at the hospital sometimes, 29.0 ± 11.8 for those providing care for >17 hours, 29.7 ± 12.4 for those having someone to look after at home, 30.7 ± 14.7 for those having to look after their parents at home, 36.5 ± 15.0 for those having to look after their children at home, and 30.0 ± 12.2 for those not having other family members providing care support (Table 3).
The total ZBI-TR score averages of other family members providing support for the care of patients undergoing brain surgery was $26.1 \pm 13.3$ for psychological support to the patient, $25.8 \pm 13.6$ for physical support to the patient, and $26.4 \pm 14.1$ for financial support to the patient. The total ZBI-TR score average was $28.3 \pm 12.4$ for family members providing physical support to the patient, $28.7 \pm 12.6$ for those providing financial support, and $27.3 \pm 12.6$ for those providing psychological support (Table 3).

The total ZBI-TR score average of caregivers living through problems at the hospital was determined to be $29.1 \pm 13.6$. Regarding the problems experienced at the hospital, the total ZBI-TR score averages were found out to be $29.8 \pm 14.2$ relating to sleep, $33.4 \pm 12.1$ relating to food, $34.0 \pm 13.5$ relating to worship, $33.2 \pm 13.0$ relating to transportation, and $29.7 \pm 16.4$ relating to hygiene (Table 3).

There was a statistically significant difference between the period of being involved with patient care; the period of providing care to the patient; the existence of physical support for the family members providing care to the patient; problems related to food, worship, and transportation faced by the caregivers providing patient care at the hospital and the total ZBI-TR score averages ($p < .05$ (Table 3). It was determined that the problems experienced by caregivers during their stay at the hospital increased their care burden. There was a significant negative relationship between the ZBI-TR score averages of family members providing care to the patients and BDLAI score averages of the patients ($r = -.288$). Accordingly, as BDLAI score averages increased, the total ZBI-TR score average decreased (Table 4).

**Discussion**

The care burden of the family members of the patients participating in the study was found to be mild and moderate. Various studies conducted with different surgical patient groups show that the care burden of family caregivers is moderate (Bayram, 2014; Dalgıç, 2015). In other studies, the patients’ relatives were reported to experience excessive burden (Crespo-Burillo et al., 2018; Kaynar Öztürk & Yural, 2018). In the postoperative period, neurosurgical patients restrict their activities for a certain period and need long-term care, requiring the participation and support of family members in hospital care. It is thought that neurosurgical patients’ dependence on others increases the care burden of family members.

A statistically significant difference was observed between the ZBI-TR mean scores of the family caregivers depending on their age, sex, marital status, education level, monthly income level, and employment status. Similar studies have reported that sex, marital status, educational status, health insurance, and economic status have a significant effect on care burden (Aoun et al., 2015; Moieni et al., 2014; Selen & Kav, 2014). Being a woman, being married, having a low income, and being employed are the factors that increase the burden of the caregivers.

This study revealed that the care burden of first-degree relatives was higher than that of others, and no severe care burden was found in second-degree relatives. The care burden of the patients’ relatives was evaluated by Yilmaz for patients with colon cancer and by Moieni for patients undergoing coronary artery bypass grafting, and the results were found to be similar to those of this study (Moieni et al., 2014; Yılmaz, 2016). As individuals who have a strong social relationship with the patient, in addition to their physical blood ties, also undertake the responsibility of providing care to the patient, having an increasing care burden can be thought of as a normal situation.

There was a statistically significant difference between the duration of providing care to the patient and the mean the ZBI-TR scores. It was seen that as the duration of care for the patients increased, the burden of the caregiver increased. This study results are in agreement with the literature in this aspect (Eğilli & Sunal, 2017; Pinquart & Sörensen, 2007; Şahin et al., 2009). It is thought that the duration of caregiving is among the factors affecting the burden of care; and as the duration of care increases, the burden and burnout level of the caregiver increase. In contrast to this study, another study revealed that the burden of the caregivers was lower in the first 1 or 2 years after liver transplantation (Çıtlık Sarıtaş et al., 2014). The fact that the perception of burden of the caregivers who have a care period of 1 to 2 years is less than that of those who care for less than 1 year can be attributed to the patients’ improved health over time and being more effective in performing activities of daily living.

This study demonstrated that caregivers who stay with patients who have had neurosurgery constantly felt more burden of care than occasional caregivers.
which is similar to other relevant studies (Malak & Dicle, 2008; Yilmaz, 2016). As time goes by, people who provide continuous care consider this a task, get used to it, and make it 1 of their daily life activities; whereas occasional caregivers are believed to have higher care burdens as they consider caring an obligation. In a study with oncology patients and their caregivers by Öner (Öner, 2012), those who gave continuous care to patients were reported to perceive more care burden. The fact that family caregivers constantly stay with the patient, cannot spare time for themselves, have their social life interrupted, and have difficulties in maintaining their self-care causes them to perceive caregiving as a stressful situation (Lang et al., 1999). Because of stressors resulting from being with the patient all the time, it is thought that family caregivers have more care burden.

The care burden of family members who gave physical support to the patient was found to be high in this study. In different studies, similar results were obtained (Bayram, 2014; Özdemir et al., 2009). This situation may suggest that neurosurgical patients become dependent on others for their daily life activities in the postoperative period and that family caregivers need more physical support.

Family caregivers of neurosurgery patients had problems with food, worship, and transportation during their stay at the hospital; and therefore, their mean ZBI-TR scores were found to be high. Relevant studies in the literature report similar results (Bayram, 2014; Özdemir et al., 2009). The reason for this is thought to be that the majority of family caregivers come from outside the province and thus stay with the patient constantly, the hospital does not provide food for them, the space allocated to them is physically insufficient, and the symptoms experienced by the patients are severe.

In this study, it was found that if family caregivers were also obliged to take care of their parents at home, their care burden increased. Similar results were found in different studies (Ateş & Bilgili, 2013; Bayram, 2014). According to this result, family caregivers cannot fulfill their roles at home during their hospital stay, which is thought to increase the perception of burden of care as their family life is interrupted.

Increasing dependency level of the patients in daily living activities increased the level of care burden felt by the family caregiver. As the Barthel Daily Living Activities Index scores increased, the independence of the person increased, and the care burden on the caregiver decreased. As a result of regression analysis on the basis of the statistically significant relationship between the 2 scales, it was seen that the dependence levels of the patients, measured by BGYAI, had a statistically significant effect on the caregivers’ feeling of the burden of care. As the dependency levels of the patients increased, the care burden also increased. There are studies in the literature with similar results (Crespo-Burrillo et al., 2018; Kaya et al., 2007; Malak & Dicle, 2008).

Study Limitations
A limitation of this study is that it was conducted at the neurosurgery clinic of a university hospital with the family members of patients undergoing brain surgery who agreed to participate in the study; so the results cannot be generalized for the family members of all patients undergoing brain surgery.

Conclusion and Recommendations
This study determined that patients undergoing brain surgery were dependent at an advanced level and that family members providing care felt a mild to moderate degree of load, and that as the dependency level of the patients increased, the load of care providing family members also increased. Furthermore, it was found that sociodemographic and care provision features of the family members providing care to the patient at the hospital played a part on the load of care. As per the results of this study, recommend that support be given to the nurses to undertake their responsibilities effectively with the aim of supporting care providing family members; the nurses must communicate with the care providers and specify their needs, and the patients and their relatives should be informed that patients undergoing brain surgery are dependent at an advanced level.

Ethics Committee Approval: Ethics committee approval was received for this study from the ethics committee of Karadeniz Technical University (29.07.2016 Issue: 24237859-450).

Informed Consent: Written informed consent was obtained from all the patients who participated in this study.

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