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Determining The Care Burden and Care-Related Knowledge Status of Family Members Providing Care to Individuals with Spinal Cord Injuries

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**Yazışma yazarı*

Research Article

Acknowledgment

#This study is a part of master's thesis

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ABSTRACT

Purpose: The aim of this study is to determine the care burden and knowledge levels of family members who care for individuals with spinal cord injury who have undergone surgical treatment.

Methods: The study was conducted as a descriptive study. The study population consisted of family caregivers of individuals who underwent surgical treatment and inpatient treatment for spinal cord injury at the Fırat University Hospital Neurosurgery Clinic between December 2012 and February 2015. Family members who were 18 years of age or older, contactable, had been providing primary care for the patient for at least three months, and volunteered to participate in the study were included in the study. Data were collected using the "Patient Introduction Form", "Caregiver Family Members Introduction Form", " Caregiver Family Members Information Form about Caregiving" and "Zarit Caregiving Burden Scale". Ethical approvals for the study were obtained from the relevant institutions.

Results: A total of 93 family caregivers of individuals receiving treatment participated in the study. The mean age of the participants was 41.8 ± 10.2 years, and 64.5% were female. The total mean score of the family members on the Zarit Caregiving Burden Scale was 22.76 ± 11.6. Participants with lower incomes had significantly higher caregiver burden scores ($p = 0.018$), and the burden increased with age ($p = 0.032$), and the burden increased with longer caregiving periods ($p = 0.027$).

Recommendations: Future studies should employ longitudinal and interventional designs to examine how structured, multi-session caregiver education and psychosocial support programmes influence caregiver burden, care-related knowledge and patient outcomes over time.

Keywords: Family Members, Caregiver, Care Burden, Spinal Cord Injury

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Spinal Kord Yaralanması Olan Bireylere Bakım Veren Aile Bireylerinin Bakım Yükleri ve Bakım ile İlgili Bilgi Durumlarının Belirlenmesi

Bilgi

#Bu çalışma yüksek lisans tezinin bir parçasıdır.

ÖZ

Amaç: Bu araştırmanın amacı, cerrahi tedavi uygulanmış spinal kord yaralanması olan bireylere bakım veren aile üyelerinin bakım yükleri ile bakım konusundaki bilgi düzeylerini belirlemektir.

Yöntem: Araştırma betimsel bir türde gerçekleştirilmiştir. Çalışmanın evrenini, Aralık 2012–Şubat 2015 tarihleri arasında Fırat Üniversitesi Hastanesi Beyin Cerrahisi Kliniği'nde spinal kord yaralanması nedeniyle cerrahi tedavi görmüş ve yatarak tedavi alan bireylere bakım veren aile üyeleri oluşturmuştur. Araştırmaya, 18 yaş ve üzeri, iletişim kurulabilen, en az üç aydır hastasına birincil bakım veren ve gönüllü olarak çalışmaya katılmayı kabul eden aile bireyleri dahil edilmiştir. Veriler "Hasta Tanıtım Formu", "Bakım Veren Aile Bireyleri Tanıtım Formu", "Bakım Veren Aile Bireylerinin Bakımla İlgili Bilgi Formu" ve "Zarit Bakım Verme Yükü Ölçeği" ile toplanmıştır. Araştırma için gerekli etik izinler ilgili kurumlardan alınmıştır.

Sonuçlar: Çalışmaya, tedavi alan bireylere bakım veren toplam 93 aile üyesi katılmıştır. Katılımcıların yaş ortalaması 41,8 ± 10,2 olup, %64,5'i kadındır. Aile bireylerinin Zarit Bakım Verme Yükü Ölçeği toplam puan ortalaması 22,76 ± 11,6 olarak bulunmuştur. Gelir düzeyi düşük olan katılımcıların bakım yükü puanlarının anlamlı derecede daha yüksek olduğu (p = 0,018), yaş arttıkça bakım yükünün de yükseldiği (p = 0,032) ve bakım süresi uzadıkça yükün arttığı (p = 0,027) belirlenmiştir.

Öneriler: Gelecek çalışmaların, yapılandırılmış ve çok oturumlu bakım veren eğitimleri ile psikososyal destek programlarının bakım verme yükü, bakıma ilişkin bilgi düzeyi ve hasta sonuçları üzerindeki etkilerini zaman içinde incelemek üzere boylamsal ve deneysel desenler kullanması önerilmektedir.

Anahtar Kelimeler: Aile Üyeleri, Bakım Veren, Bakım Yükü, Spinal Kord Yaralanması

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Introduction

Changes in individuals' lives can make them fully or partially dependent on maintaining their well-being. Spinal cord injury (SCI) is an important health problem that forces individuals to change their lifestyles by causing bio-physical, psychological, social and economic dependence (Sousa vd., 2023). Spinal cord injuries, caused by trauma to the vertebrae carrying the spinal cord, result from compression, contusion or laceration of the spinal cord and cause high mortality and disability rates (Patek & Stewart, 2023). Although medical advances have reduced the mortality rate of individuals with SCI, patients still suffer from serious complications and permanent disabilities. These individuals must live the rest of their lives with their disease and limitations (McGrath vd., 2021).

Individuals with SCI cannot fully perform their activities of daily living and therefore require the support of a caregiver (Costa & Santos, 2025). Caregivers are responsible for meeting the physical, social, emotional, and economic needs of these individuals. When family members assume this caregiving role, the continuous and demanding nature of care often overlaps with their work, family, and social responsibilities, leading to increased caregiver burden. This burden refers to the physical, psychological, social, and financial strain experienced by caregivers in the process of providing long-term care (Alizadeh, Dyck, & Karimi-Abdolrezaee, 2019).

From a holistic health perspective, individuals are seen as physical, mental, spiritual, and socio-cultural beings who constantly interact with their environment. In this context, it is essential to address not only the needs of patients but also those of their family caregivers, whose well-being directly affects the quality of care provided. Studies indicate that caregivers often experience a lack of knowledge about patient care, which may exacerbate their sense of burden (Güneş & Şimşek, 2024). This information gap typically concerns the progression of the disease, physical and personal care practices (such as bathing, mobility, dressing, and toileting), expected symptoms, and strategies for managing these symptoms (Conti et al., 2021).

Family members of individuals with SCI are the people who spend the most time with patients and maintain the closest emotional and physical connection with them. Similar to other chronic and debilitating conditions such as stroke, dementia, or end-stage renal disease, the caregiving process for individuals with SCI is continuous, demanding, and often physically and psychologically exhausting (Scholten et al., 2018). Studies conducted with family caregivers of patients with stroke and dementia have shown that caregiving leads to increased emotional distress, fatigue, and reduced quality of life (Hüseyinsinoğlu et al., 2021; Giray et al., 2023). In Turkey, caregivers of patients with chronic neurological diseases have been reported to experience moderate to high levels of burden, with low income, long care duration, and lack of knowledge identified as significant predictors of caregiver strain. However, unlike these well-studied patient groups, research focusing on the care burden and care-related knowledge of families providing care to individuals with SCI remains limited. Studies have shown that caregivers with insufficient information about patient care experience higher levels of stress, emotional exhaustion, and role overload (Çalışır Bacı & Gökler, 2019). Therefore, determining the level of knowledge of family caregivers about the care of individuals with SCI and identifying factors affecting their caregiver burden are essential for developing educational and psychosocial support strategies aimed at reducing the challenges they face and improving the overall quality of patient care.

The purpose of this study is to emphasize the critical role of surgical nurses in recognizing the difficulties experienced by individuals with SCI and their family members, and in providing comprehensive support throughout the care process. By raising awareness of coping strategies and guiding families in protecting their physical and mental health, nurses can contribute to the delivery of high-quality and appropriate care for individuals with SCI.

Materials and Methods

Research Design

This descriptive study aimed to determine the care burden and the level of knowledge about care among family members who provide care to individuals with SCI.

Place and Date of the Research

The study was conducted in the Department of Neurosurgery of Fırat University Hospital between December 2012 and February 2015.

Universe and sample of the Research

The population of the study consisted of family members providing care to individuals hospitalised in the Neurosurgery Clinic of Fırat University Hospital due to SCI who had undergone surgical treatment and were in the postoperative rehabilitation process. The sample of the study included family members who could be contacted, were older than 18 years of age, had been providing primary care for their relative for at least three months, and voluntarily agreed to participate in the study.

Caregiver burden was assessed during the hospitalisation period, when family caregivers were actively involved in the care of the patient and participated in daily care activities such as hygiene, nutrition, and mobilisation support.

The inclusion criteria were: (1) being 18 years of age or older, (2) being a first-degree or close relative of the patient, (3) having provided continuous primary care to the patient for at least three months, (4) being literate and able to communicate, and (5) voluntarily agreeing to participate in the study.

The exclusion criteria were: (1) family members with a diagnosed psychiatric disorder or cognitive impairment that could affect participation, (2) professional or paid caregivers, and (3) those who provided care for less than three months.

The sample size was determined using the G*Power 3.1 software to calculate the minimum number of participants required to achieve statistical significance. Based on previous studies conducted with caregiver populations (Yıldırım & Fadıloğlu, 2019; Giray et al., 2023), the parameters were set as medium effect size (f = 0.25), alpha error probability (α) = 0.05, and power (1–β) = 0.80. According to these parameters, the minimum required sample size was calculated as 85 participants, and to increase reliability, data collection continued until 93 family caregivers were reached.

Data Collection Tools

The data of the study were collected with the Patient Introduction Form, Caregiver Family Members Introduction Form, Caregiver Family Members Information Form about Caregiving and Zarit Caregiving Burden Scale (ZCBS).

Patient Introduction Form

In this form, there are 11 questions including sociodemographic information such as age, gender, education level, marital status, employment and income status, social security, chronic disease and cohabitants, as well as disease-related characteristics such as diagnosis and the condition that caused the injury. The form was developed by the researchers based on a review of relevant national and international literature on caregivers of individuals with SCI and similar chronic neurological conditions (Alizadeh, Dyck & Karimi-Abdolrezaee, 2019; Güneş & Şimşek, 2024). Expert opinions from two faculty members specialised in medical-surgical nursing and one specialist in neurosurgery were obtained to ensure the content validity of the form. Necessary revisions were made in line with their feedback before data collection.

Caregiver Family Members Introduction Form

This form was developed based on a comprehensive review of the relevant literature to assess the knowledge levels of family caregivers regarding the care of individuals with SCI. It consists of a total of 67 questions grouped under the following headings: cardiovascular system (22 questions), respiratory system (4 questions), pressure sores (7 questions), nutrition and excretion (11 questions), sexuality (2 questions), pain and sleep (13 questions), and general care (8 questions). Participants responded to each question with “I know” or “I don’t know.” For scoring, each “I know” response was assigned 1 point, and each “I don’t know” response was assigned 0 points; the total scores were calculated by summing the section scores.

The development of the form was guided by previous studies on caregiver knowledge and care needs of individuals with SCI (Köseoğlu & Karataş, 2011; Ediz & Erden, 2011). No pilot study was conducted, and validity and reliability analyses were not performed, as the form was created by adapting items from the existing literature to the study objectives.

Caregiver Family Members Information Form about Caregiving

This form was developed in line with the literature review and the researcher's own knowledge. It consists of a total of 67 questions under the headings of cardiovascular system (22 questions), respiratory system (4 questions), pressure sores (7 questions), nutrition and excretion (11 questions), sexuality (2 questions), pain and sleep (13 questions) and general care (8 questions). Individuals answered the questions aimed at measuring their knowledge status here as ‘I know’ or ‘I don't know’. At the end of this form, those who answered ‘I know’ to each question were given ‘1’ point and those who answered ‘I don't know’ were given ‘0’ point and the scores they received from each section were summed (Chaghazardi et al., 2022; Beach et al., 2021; Phillips et al., 2023).

Zarit Caregiving Burden Scale

ZCBS was developed by Zarit and colleagues in 1980. In Turkey, the scale was adapted to Turkish and its reliability and validity were established by İnci in 2006. It is a tool used to assess the stress experienced by caregivers providing care to individuals or the elderly in need of care. The scale can be completed by caregivers themselves or through interviews conducted by researchers. It consists of 22 items that evaluate the impact of caregiving on various aspects of the caregiver's life. The scale uses a 5-point Likert-type scoring system ranging from 0 (never) to 4 (almost always). The internal consistency coefficient of the original scale was reported between 0.87 and 0.94, and the test–retest reliability was 0.71. The total score ranges from 0 to 88, with higher scores indicating a greater level of burden. Scores are interpreted as follows: 0–20 indicates little or no burden, 21–40 moderate burden, 41–60 severe burden, and 61–88 extreme burden (İnci, 2006). In the present study, the Cronbach’s alpha coefficient of the scale was found to be 0.89, indicating high internal consistency.

Research Inclusion Criteria

Caregiver family members over 18 years of age who met the inclusion criteria and could communicate effectively were selected from the population by using a non-probability convenience sampling method on the days when the researcher was present in the neurosurgery ward. For each patient hospitalised due to SCI, only one primary caregiver—the family member who assumed the main responsibility for the patient’s daily care—was included in the study. In cases where more than one family member was involved in caregiving, the individual who spent the most time with the patient and provided the majority of physical or emotional care was identified as the primary caregiver and participated in the study. This approach was preferred to avoid duplicate data and ensure that each patient was represented by a single caregiver's experience.

Data Collection Process

The data were collected by the researcher in the Neurosurgery Clinic of Fırat University Hospital between December 2012 and December 2014. The researcher was present in the neurosurgery clinic five working days a week until the number of family caregivers planned for inclusion in the sample was reached. Each patient who met the inclusion criteria was visited for approximately five minutes to confirm eligibility, and interviews with family caregivers were conducted face to face for an average of 15 minutes.

The data collection forms were completed by the researcher through face-to-face interviews rather than self-administration, in order to ensure that all questions were clearly understood and answered consistently. Interviews were conducted in a quiet and private area of the neurosurgery clinic, such as a counselling room or a section separated from the patient's bedside by a curtain, to maintain confidentiality and minimize distractions. In cases where the caregiver preferred to stay near the patient, the interview was conducted in a calm environment at the patient's bedside, ensuring privacy as much as possible. All responses were recorded directly on the data collection forms by the researcher during the interview.

Data Analysis

The data were analyzed using the SPSS 16.0 (Statistical Package for the Social Sciences) software. Descriptive statistics including frequency, percentage, mean, and standard deviation were used to summarise the sociodemographic and care-related characteristics of the participants. The independent samples t-test was used to compare the mean ZCBS scores between two independent groups (such as gender or marital status), while one-way ANOVA was used for comparisons involving more than two groups (such as education level, income status, or duration of caregiving) when normal distribution assumptions were met. In cases where these assumptions were not met, the Kruskal–Wallis test was applied as a non-parametric alternative, and post hoc pairwise comparisons were performed using the Mann–Whitney U test with Bonferroni correction. The relationship between continuous variables such as age, caregiving duration, and total burden scores was examined using Pearson or Spearman correlation coefficients depending on data distribution. The level of statistical significance was set at $p < 0.05$ for all analyses.

Ethical Aspects of the Research

Before starting the study, permission was obtained from the University Hospital's Chief Physician and Department of Neurosurgery (10.12.2012), and permission was obtained from the Clinical Research Ethics Committee (Approval No: 2012/237, 2012). The study was conducted at the University Hospital's Neurosurgery Clinic between December 2012 and February 2015. To protect the rights of patients and caregivers, the purpose, duration, and procedures of the study were clearly explained to each participant before data collection, and the principle of Informed Consent was adhered to. Patients and caregivers were informed that participation was voluntary and that they could withdraw from the study at any time without consequence. Confidentiality and Privacy Protection principles were maintained by assuring participants that the collected data would be used only for research purposes and would be stored securely. The principle of Anonymity and Security was met by not recording the identities of patients or caregivers to ensure blinding of the assessor and to protect the identity of the participant.

Results

The comparison of caregiver burden scores according to caregivers' information and training status showed that caregivers who had not received any education or training about patient care had slightly lower mean burden scores than those who had received information; however, this difference was not substantial. This finding indicates that receiving limited or unstructured information alone may not effectively reduce the caregiving burden, emphasizing the need for more comprehensive and continuous caregiver education programs (Table 1).

Table 1. Comparison of ZCBS Scores by Care-Related Information/Education Status

Variable	Mean ± SD	t	p
Received information	26.26 ± 13.00	1.54	.09
Did not receive information	21.61 ± 11.07		

The mean ZCBS score of 22.76 ± 11.6 indicates a moderate level of caregiver burden among family members providing care to individuals with SCI (Table 2).

Table 2. Mean Scores of Family Caregivers on the ZCBS

Scale	Minimum	Maximum	Mean ± SD
Zarit Caregiving Burden Scale	5	52	22.76 ± 11.6

The analysis of family caregivers' information and training status revealed that only 24.7% of caregivers had received information or education related to patient care, while 75.3% had not received any formal instruction. Among those who had received information, 82.6% reported that their main source was physicians, and 26.1% stated that the information primarily concerned treatment and complications. More than half of the caregivers (52.2%) considered the information they received to be inadequate. These findings indicate that the majority of caregivers lack sufficient education regarding patient care, highlighting the need for structured and comprehensive training programs to support them in fulfilling their caregiving responsibilities effectively (Table 3).

Table 3. Caregiving Information and Education Status of Family Caregivers

Variable	n	%
Received care-related information		
Yes	23	24.7
No	70	75.3
Source of information		
Doctor	19	82.6
Nurse	3	13.0
Media/Internet	1	4.3
Topics of information		
Treatment	6	26.1
Complications	6	26.1
Diagnosis	5	21.7
Discharge and follow-up	4	17.4
Care	2	8.7
Perceived adequacy of information		
Adequate	11	47.8
Inadequate	12	52.2

* Data 23 persons were collected.

The analysis showed that caregiver burden scores differed significantly according to patients' age and income status. Caregivers of younger and lower-income patients tended to experience higher levels of burden than those caring for older or financially stable individuals. In contrast, no meaningful differences were observed based on patients' gender, marital status, number of children, chronic disease status, education level, diagnosis, or cause of injury. These findings indicate that socioeconomic and age-related factors have a stronger influence on the caregiving experience, suggesting that financial strain and the intensive physical demands of caring for younger patients may increase caregivers' perceived burden.

Considering the descriptive characteristics of the patients, 45.2% were 51 years of age or older, 58.1% were male, and 59.1% were married. With regard to educational status, 7.5% were illiterate, 8.6% were literate, 29.0% were primary school graduates, 21.5% had completed middle school, 24.7% high school, and 8.6% university. The vast majority of patients (95.7%) had health insurance. While 68.8% had children, 60.9% of those with children had three or more children. In addition, 79.6% reported no chronic disease, and 64.5% stated that their income was equal to their expenditure (Table 4,5,6).

Table 4. Sociodemographic Characteristics of the Patients and Comparison of Their Mean Scores on the ZCBS

Variable	n	%	Mean ± SD	Test Value	p
Age Groups				KW = 19.83	.001
18–20	6	6.4	27.83 ± 6.91		
21–30	20	21.5	16.45 ± 3.53		
31–40	22	23.7	29.59 ± 13.54		
41–50	3	3.2	38.66 ± 13.01		
51 and above	42	45.2	20.33 ± 10.93		
Gender				t = 0.54	.59
Female	39	41.9	22.00 ± 11.19		
Male	54	58.1	23.31 ± 12.08		
Marital status				t = 1.74	.08
Married	55	59.1	21.00 ± 11.17		
Single	38	40.9	25.31 ± 12.06		
Income status				KW = 9.54	.008
Below expenses	24	25.8	25.83 ± 12.77		
Equal to expenses	60	64.5	22.98 ± 11.33		
Above expenses	9	9.7	13.11 ± 4.42		
Diagnosis				KW = 4.91	.29
Cervical fracture	47	50.5	20.34 ± 10.61		
Lumbar fracture	25	26.9	29.44 ± 14.25		
Thoracic fracture	21	22.6	22.68 ± 11.87		
Cause of injury				KW = 0.95	.61
In-vehicle accident	32	34.4	22.66 ± 11.50		
Suicide attempt (fall)	9	9.7	27.00 ± 11.81		
Fall	29	31.2	20.34 ± 10.61		
Out-of-vehicle accident	18	19.4	29.44 ± 14.25		
Diving accident	5	5.4	22.68 ± 11.87		

* p < .05
**p < .01

Table 5. Sociodemographic Characteristics of Family Caregivers

Variable	n	%
Age Groups		
18–20	6	6.4
21–30	32	34.4
31–40	25	26.9
41–50	8	8.6
51 and above	22	23.7
Gender		
Female	52	55.9
Male	41	44.1
Marital status		
Married	60	64.5
Single	33	35.5
Education level		
Illiterate	5	5.4
Literate	9	9.7
Primary school	24	25.8
Secondary school	13	14.0
High school	25	26.9
University	17	18.3
Employment status		
Housewife	33	35.5
Retired	11	11.8
Self-employed	11	11.8
Officer	8	8.6
Worker	8	8.6
Farmer	8	8.6
Unemployed	14	15.1
People they live with		
Alone	1	1.1
Family	92	98.9
Relationship to patient		
Sibling	32	34.4
Child	27	29.0
Parent	15	16.1
Grandparent	6	6.5
Relative	12	12.9
Spouse	1	1.1

Table 6. Comparison of Family Caregivers' Sociodemographic Characteristics and Their Mean Scores on the ZCBS

Variable	Mean ± SD	Test Value	p
Age Group		KW = 12.94	.014
Gender		t = 1.35	.18
Marital status		t = 0.64	.48
Children		t = 0.65	.47
Chronic illness		t = 1.84	.07
Education level		KW = 8.86	.11
Employment status		KW = 4.98	.54
Duration of caregiving		KW = 5.95	.05

Discussion

This study was conducted to determine the caregiver burden and caregiving knowledge levels of family caregivers of individuals with SCI. The findings are significant because family caregivers play a critical role in the rehabilitation process of individuals with SCI, and their knowledge, skills, and emotional well-being directly impact the patient's recovery and quality of life. Understanding the factors affecting caregiver burden is anticipated to contribute to the development of interventions that can reduce stress, enhance coping skills, and improve the quality of care.

Previous studies have reported that caregivers of individuals with chronic and disabling conditions such as stroke, dementia, or SCI experience moderate to high levels of burden (Boonsin, Deenan & Wacharasin, 2021; Owokuhaisa et al., 2023). Factors such as age, length of caregiving, economic status, and knowledge about patient care have been identified as important determinants of caregiver stress (Zhang et al., 2024; Farajzadeh et al., 2021). In this context, the findings of the current study are discussed in relation to the existing literature in order to better understand the determinants of caregiver burden and to suggest strategies to support caregivers more effectively.

A comparison of the mean ZCBS scores among family caregivers of patients with cervical SCI revealed that caregivers of patients aged 41–50 years had significantly higher burden scores compared to other age groups ($p < .05$, Table 2). In line with this finding, Waweru (2023) also reported a statistically significant difference in caregiver burden across age groups among caregivers of older adults in Kenya. The study sample consisted of 190 caregivers of elderly individuals aged 60 years and above, and the results indicated that caregivers of older patients experienced a higher level of burden due to increasing care demands and chronic health conditions. However, studies by Zhang et al. (2024) and Lahoz et al. (2021) found no statistically significant differences between patient age groups and caregiver burden scores. Zhang et al. (2024) conducted their research among caregivers of stroke survivors in China, while Lahoz et al. (2021) examined caregivers of patients with Alzheimer's disease in Spain. The discrepancies between these studies and our findings may be attributed to differences in patient populations, caregiving intensity, and cultural contexts. In our study, the higher burden observed among caregivers of SCI patients aged 41–50 years may be linked to the higher prevalence of chronic comorbidities and physical complications typically seen in this age range, which increase care dependency and caregiving demands. Overall, while some studies have reported that patient age is not a major determinant of caregiver burden, the current findings suggest that for SCI patients whose care often involves long-term physical support age-related health issues may amplify the perceived caregiving strain.

A comparison of caregiver burden of patients with SCI by gender revealed that caregivers of male patients had higher mean ZCBS scores than caregivers of female patients; however, this difference was not statistically significant ($p > .05$). Similar findings were reported by Ersin and Dinç among 127 home caregivers of individuals with disabilities, caregivers of heart failure patients (n = 90), Khazaeipour et al. (2017) in Iran (n = 160 caregivers), and Secinti et al. (2017) in Türkiye (n = 120 caregivers). Furthermore, gender-related dynamics, particularly the confidentiality challenges faced by female caregivers when assisting male patients, may contribute to increased burden. The higher mean scores among caregivers of male patients in our study may therefore be related to the predominance of female caregivers (55.9%) and the sociocultural challenges associated with providing close care to male patients. These findings highlight that although patient gender alone does not produce statistically significant differences in burden levels, it interacts with caregiver gender and cultural norms to shape the subjective caregiving experience.

A comparison of caregiver burden according to the educational level of patients with SCI revealed that caregivers of literate patients had the lowest mean ZCBS scores, whereas those caring for patients who graduated from secondary school had the highest mean scores. However, the difference between the groups was not statistically significant (p > .05, Table 2). These findings are consistent with those of Karakurt, Ünsal, and Tanrıverdi (2018), who investigated 102 caregivers of stroke patients in Turkey and reported no statistically significant relationship between patients' educational level and caregiver burden, although caregivers of moderately educated patients tended to report slightly higher burden due to longer rehabilitation needs. Similarly, Secinti et al. (2017) studied 120 family caregivers of individuals with SCI in Turkey and found that patient education level was not a determining factor for caregiver burden, emphasizing instead that functional dependence and care duration were more predictive. In contrast, Kavga et al. (2021), in a study conducted with 220 caregivers of elderly individuals in Greece, identified a statistically significant difference between the educational level of care recipients and caregiver burden scores caregivers of elderly individuals with lower education levels experienced higher burden, possibly due to lower health literacy and reduced patient self-management ability.

The results of our study suggest that the educational level of SCI patients alone does not exert a strong influence on caregiver burden. However, differences in education may interact with patients' health literacy, communication skills, and adherence to rehabilitation programs, indirectly affecting the caregiving process. Considering that SCI requires long-term physical and emotional support, caregivers of patients with limited health awareness or lower self-efficacy may experience more difficulty in managing daily care routines. Future research should therefore explore the interplay between patients' educational level, self-care capacity, and caregivers' psychological adaptation in SCI contexts.

A comparison of caregiver burden according to the presence of chronic diseases in individuals with SCI revealed no statistically significant difference between the groups (p > .05, Table 2). However, caregivers of patients with chronic comorbidities such as end-stage renal disease tended to have higher mean ZCBS scores than caregivers of patients without chronic conditions. This finding suggests that additional chronic health problems in patients may increase the complexity and intensity of caregiving, even if not reflected as a statistically significant difference in mean scores. In another study, Xu et al. (2024) examined caregivers of 220 stroke survivors in China and found that comorbid chronic illnesses in patients significantly elevated caregiver burden through prolonged dependency and higher physical care demands. Furthermore, Secinti et al. (2017)**,** in their study of 120 family caregivers of people with SCI in Turkey**,** emphasized that comorbid conditions such as diabetes or hypertension exacerbated perceived burden due to increased fatigue and care duration. The slightly higher burden scores among caregivers of SCI patients with chronic comorbidities in our study may therefore be attributed to reduced coping capacity, as managing both physical disability and chronic illness increases psychological strain and disrupts caregivers' daily routines. These findings highlight the need for targeted interventions such as caregiver training in chronic disease management and stress-coping strategies to mitigate cumulative burden among families caring for SCI patients with additional health challenges.

A statistically significant difference was found between the groups in the comparison of income levels of individuals with SCI and the mean ZCBS scores of their family caregivers (p < .05, Table 2). As the income level of individuals with SCI increased, the mean burden scores of their caregivers decreased, suggesting an inverse relationship between financial well-being and perceived caregiving difficulty. This finding is consistent with the results of Kazemi et al. (2021), who studied 210 caregivers of patients with SCI in Iran and reported that lower family income was significantly associated with higher caregiver burden, primarily due to economic stress and limited access to therapeutic and supportive resources. Similarly, Secinti et al. (2017), studying 120 Turkish caregivers of patients with SCI, reported that lower household income and unemployment status significantly increased ZCBS scores. The relationship observed between patient income and caregiver burden in our study may be explained by the reduction in economic stress when patients have sufficient financial resources to independently cover their medical, rehabilitation, and daily living expenses. Financial stability can reduce both the direct costs of care and the emotional stress associated with resource scarcity. Therefore, interventions aimed at improving financial support mechanisms and social insurance coverage for SCI patients may play a critical role in reducing caregiver burden and improving family well-being.

The average ZCBS score of the family caregivers included in our study was found to be at a moderate level of 22.76±11.6 (Table 4). The higher the score obtained from the caregiving burden scale, the greater the burden of the caregiver individuals (İnci, 2006). Waweru (2023) reported the average score of the care burden scale as 58.56. It was calculated as 50.2 in Zhang et al.'s study, 29.84 in Lahoz et al.'s study, and 32.11 in Karimollahi et al.'s study (Waweru 2023, Zhang et al., 2024, Lahoz et al., 2021, Karimollahi et al., 2021). The reason for the average ZCBS score of the family members participating in our study being at a moderate level can be said to be that Turkish society accepts caregiving as a cultural tradition rather than perceiving it as a burden. It is thought that individuals receive the

the support they need more from their families because family ties are stronger in our society. Having other caregivers other than the family members who participated in our study may also cause the burden to be perceived at a moderate level. Having other caregivers may have provided the caregivers who participated in our study with advantages such as more rest and spending time on their home and work lives.

When the mean knowledge scores of caregivers in our study were examined, the cardiovascular system knowledge score (10.83 ± 4.78) was found to be higher than those for other domains, while the sexuality and infertility knowledge score (1.68 ± 0.60) was the lowest. This finding suggests that caregivers prioritize information about immediately life-threatening or clinically visible complications over topics perceived as sensitive or socially taboo. Similar results were reported by Jeyathevan et al. (2020) who investigated the knowledge levels of 158 family caregivers of individuals with SCI and found that caregivers had high awareness of cardiovascular and urinary tract complications but inadequate understanding of sexual health and fertility issues. In Turkey, Secinti et al. (2017) also reported that family caregivers of 120 individuals with SCI tended to focus primarily on physical and functional care, while emotional and sexual health needs were often neglected. The low mean score in the sexuality and infertility domain in our study may therefore be attributed to the combined influence of cultural value judgments surrounding sexuality and the prioritization of acute physiological concerns such as cardiovascular, nutritional, and excretory issues during the early recovery period after injury. This pattern indicates a persistent educational gap in comprehensive caregiver training for SCI, particularly regarding sensitive yet quality-of-life–related topics. Strengthening rehabilitation programs with culturally sensitive sexual education and open communication strategies could help caregivers provide more holistic and informed care.

Conclusion

This study revealed that family caregivers of individuals with SCI experience a moderate but significant level of burden in the post-surgical period. Also, it was found that burden was higher among caregivers of younger and lower-income patients. Clinicians working in neurosurgery and SCI rehabilitation should routinely assess caregiver burden and information needs, identify caregivers at greater socio-economic and clinical risk, and provide structured education including daily care procedures and prevention of complications. Future studies should employ longitudinal and interventional designs to examine how structured, multi-session caregiver education and psychosocial support programmes influence caregiver burden, care-related knowledge and patient outcomes over time.

Limitations

One limitation of this study is that it included a specific sample of individuals with SCI and their family caregivers who met the inclusion criteria and agreed to participate within the designated data collection period. Therefore, the findings may not be fully generalizable to all individuals with SCI or to caregivers in different clinical or community settings. Another limitation is the use of a cross-sectional design, which prevents establishing causal relationships between variables such as caregiver burden, knowledge level, and patient characteristics. Additionally, data were collected through self-report measures, which may be subject to recall and social desirability biases. Despite these limitations, the single-center setting ensured consistency in patient care protocols, data collection procedures, and researcher oversight, thereby enhancing the study’s internal validity. Future research should employ longitudinal and multi-center designs with larger, more diverse samples to confirm these findings and better understand the long-term dynamics of caregiver burden and knowledge in SCI populations.

Ethics committee approval:

Ethical permission and institutional permission were obtained from the Malatya Clinical Research Ethics Committee (Date: 11.04.2013, Decision No: 2012/237) for the conduct of the study. Informed consent was also obtained from the family members.

Conflict of interest: The authors declared that they have no conflict of interest.

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