

The Burden on Caregivers and Affecting Factors in Patients with Spinal Cord Injuries

Spinal Kord Yaralanmalı Hastalarda Bakım Verenlerin Yükü ve Etkileyen Faktörler

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ABSTRACT Objective: In the rehabilitation period of patients with spinal cord injuries (SCI), factors that can affect the success of rehabilitation programs include the caregiver's adaptation to the new situation, his/her motivation and attitude towards possible challenges. This study was conducted for the determine the related factors with burden of caregivers of patients with SCI. **Material and Methods:** Forty patients with SCI aged 18 to 65 and 40 caregivers were enrolled to the study, that they admitted to Gaziantep University Medical Faculty, Physiotherapy and Rehabilitation Clinic. American Spinal Injury Association (ASIA) and Functional Independence Measurement (FIM) were used for clinical assessment of patients; the Beck anxiety and depression inventory was used for psychiatric assessment; and the Zarit caregiver burden scale was used for assessment of caregivers' status. **Results:** 14 caregivers (10 female and 4 male) were the patients' spouses. Other caregivers consisted of the patients' parents (11), siblings (7), children (5) and other relatives (3). A significant positive correlation was identified between the SCI clinical stage, anxiety and depression scores with caregiver burden. However a significant negative correlation was identified between the patient's functional status with caregiver burden scores. While reviewing the relation between the patients' ASIA grades and caregiver burden levels, it was determined that the average care burden level decreased when moving from ASIA grade A to D. **Conclusion:** We think that timely determination of the potential risk factors such as anxiety and depression, poor clinic and functional status factor for caregiver burden in SCI, as well as providing an appropriate therapy support, may contribute to higher quality in treatment and care of patients with SCI.

Key Words: Spinal cord injuries; caregivers; paraplegia, depression, anxiety

ÖZET Amaç: Spinal Kord Yaralanması (SKY) olan hastaların rehabilitasyon sürecinde hastanın bakımını üstlenen kişinin mevcut yeni duruma adaptasyonu, motivasyonu ve karşılaşılabileceği zorluklar karşısında sergileyeceği tutum rehabilitasyon programlarının başarısını etkileyebilecek faktörler arasındadır. Bu çalışma SKY'li hastalarda, bakım veren yükü ile ilişkili olabilecek faktörleri belirlemek amacıyla yapıldı. **Gereç ve Yöntemler:** Gaziantep Üniversitesi Tıp Fakültesi Fizik Tedavi ve Rehabilitasyon Kliniğine başvuran, SKY'lı, 18-65 yaş arası 40 hasta ve bunların 40 bakım vereni çalışma kapsamına alındı. Hastaların klinik değerlendirmesinde American Spinal Injury Association (ASIA) ve Fonksiyonel Bağımsızlık Ölçeği (FBÖ) ve psikiyatrik değerlendirmede Beck anksiyete ve depresyon envanteri ile bakım verenlerin durumunun değerlendirilmesinde ise Zarit Bakım Veren Yükü Ölçeği kullanıldı. **Bulgular:** Bakım verenlerin 14'ü hastaların eşleri (10 kadın ve 4 erkek) idi. Diğer bakım verenlerin 11'i anne veya baba, 7'si kardeş, 5'i çocukları ve 3'ü diğer akrabalarından oluşuyordu. SKY klinik evresi, anksiyete ve depresyon skorları ile bakım veren yükü arasında anlamlı düzeyde pozitif korelasyon olduğu ancak hastanın fonksiyonel durumu ile bakım veren yükü arasında anlamlı düzeyde negatif korelasyon olduğu tespit edildi. Hastaların ASIA evresi ile bakım veren yükü seviyeleri arasındaki ilişkiye baktığımızda; ASIA evresi A'dan D'ye doğru gittikçe bakım yükü düzeyi ortalamalarında azalma olduğu saptandı. Bakım yükü düzeyleri arasındaki farklılık ASIA-A ve D arasında anlamlı iken, diğer ASIA evreleri arasındaki fark anlamlı değildi. **Sonuç:** SKY'de bakım veren yükü ile ilişkili olabilecek, hasta anksiyete ve depresyonu, kötü klinik ve fonksiyonel durum gibi potansiyel risk faktörlerinin zamanında belirlenmesi ve uygun tedavi desteğinin sağlanmasının, SKY'li hasta tedavisi ve bakımında kalitenin artmasına katkı sağlayabileceğini düşünmekteyiz.

Anahtar Kelimeler: Omurilik yaralanmaları; bakıcılar; parapleji, depresyon, anksiyete

The spinal cord is the most significant component of the locomotor system. Injury of the spinal cord due to various reasons is an important problem with both personal and social aspects, due to the accompanying physical, psychosocial and economic problems. Today, traumas like especially traffic accidents as well as gunshot wound, falling from height, occupational accidents and sports injuries lead to increasingly more spinal cord injuries (SCI). In addition, survival and life expectancy of patients are increased because of the first aid facilities, improved patient care and widespread rehabilitation programs. In the past, the treatment objective for patients with SCI was to save patients' lives. Today, we see that clinicians focus on patients' functional, psychological and social health, i.e., quality of life and rehabilitation practice.¹

After SCI, usually motor losses are developed, resulting in loss of ambulation, pain, incontinence, sexual dysfunction, metabolic problems, respiratory problems and many other complications. As a result, future expectations of individuals as well as their social and business life compliance are decreased. On the other hand, the difficulty of dealing with the permanent results of physical trauma and injury may lead to psychiatric disorders, primarily depression and anxiety.²

In the 21st century, when globalization, industrialization and transition from rural life to urban life become widespread, family units are reduced, the number of family members in working life is increased and the number of family members who can care for a family member with a chronic disease is decreased. The *caregiver burden* concept is a term reflecting the physical, psychosocial or financial reactions which may be experienced while providing care. Caregiving may have many positive characteristics like personal development, development of close relations, satisfaction, social support from other individuals and self-respect; however, it may also result in many difficulties. The burden of caregiving is closely related with the qualifications of care requirements.^{3,4}

In the rehabilitation period of patients with SCI, factors that can affect the success of rehabilitation programs include the caregiver's adaptation to the new situation, his/her motivation and attitude towards possible challenges.^{4,5}

At this point, it can be considered that determining the factors affecting the level of *caregiver burden* that each patients with SCI places on his/her caregiver, and developing suitable supportive treatment strategies can contribute to the well-being of caregivers and maintenance of a qualified patient care. The objective of this study was to explore the factors (patients & caregiver age, patients & caregiver gender, patients & caregiver education, disease duration, functional status, injury severity, patients & caregiver anxiety, depression, etc.) that could be related with the problems experienced by caregivers in SCI, which may cause long-term disability.

MATERIAL AND METHODS

40 patients aged 18 to 65 years who were diagnosed with *spinal cord injury* and presented to Gaziantep University Faculty of Medicine, Physical Medicine and Rehabilitation polyclinic as of July 2012-November 2012, and 40 healthy individuals who were primarily responsible for caring for these patients were enrolled into the study. Approval was obtained from the local ethics committee prior to the study. Histories and socio-demographic features of patients were inquired, examinations of their systems were performed and any required information was recorded. Neurological level and completeness of the injury was determined according to the classification of American Spinal Injury Association (ASIA).

Patients in the spinal shock period and patients with a neurological disorder affecting the central or peripheral nervous system (other than SCI) or with any additional disease that limits the functional status were excluded.

The caregivers aged less than 18 or older than 65 years with any psychological or physical condition were not included in the study.

The functional levels were evaluated with the “Functional Independence Measurement (FIM)”, the anxiety and depression levels were evaluated with the “Beck anxiety and depression inventory” and caregiving features were evaluated with the “Zarit caregiver burden scale”.

ASIA;

A Complete: There is no sensory and motor function maintained in the S4-S5 sacral segments.

B Incomplete: There is no motor function below the neurological level; only sensory function is maintained and S4-S5 sacral segments are also included.

C Incomplete: Motor function is preserved below the neurological level and more than the half of the key muscles below the neurological level is below 3.

D Incomplete: Motor function is maintained below the neurological level and minimum half of the key muscles below the neurological level are at the level of 3 or above 3.

E Normal: Sensory and motor functions are normal.⁶

FIM comprises 2 sections, motor and cognitive skills. Each section includes 18 sub-items that can be grouped in 6 main items (self-care, sphincter control, mobility and transfer, ability to move and walk, communication and social perception). Each item is scored between 1 and 7 to evaluate the dependency status of the patients for the activities including these items; 1-2 points mean dependent, 3-5 points mean semi-dependent and 6-7 points mean independent. The lowest score on the scale is 18 and the highest score is 126.⁷

Beck Depression Inventory: It is a self-assessment scale to measure the severity of symptoms observed in emotional, cognitive and motivational dimensions related with depression (Beck et al. 1961). The validity-reliability test of BDI in Turkish was performed by Hisli (1988). In Hisli’s work studying the reliability of BDI with the Minnesota Multiphasic Personality Inventory Depression

Scale, the validity coefficient is reported to be $r=0.63$. Clinical observations are combined systematically under 21 symptoms and attitudes are scored 0 to 3 according to their intensity.⁸

Beck Anxiety Inventory (BAI): It is used to determine the frequency of anxiety signs experienced by individuals. It is a self-assessment scale. This scale is a Likert type scale, consisting of 21 items with scores between 0 and 3. It was developed by Beck et al. (1988) and adapted for Turkish by Ulu-soy et al. (1998).⁸

Zarit caregiver burden scale: It is a scale used for evaluating the stress experienced by caregivers. It includes the subunits of mental tension and disruption of private life, limitedness and restriction, deterioration of social relations, financial burden and dependency. The range of scoring is 22-110, and a given score of 22-46 is evaluated as “mild burden”; 47-55 as “moderate burden”; and 56-110 as “severe burden”. The Zarit caregiver burden scale is used more commonly compared to other scales, due to various reasons like that it was inclusive and not specific to the condition requiring caregiving, and it has valid subunits.⁹

STATISTICAL ANALYSIS

The data were analyzed using the SPSS 16 program for Windows. In accordance with the distribution characteristics, a Pearson or Spearman correlation analysis was used for determination of the direction and level of the relation between the variables. The Mann-Whitney U test and Kruskal-Wallis test were used for comparison of quantitative data across groups. The p values below 0.05 were considered as statistical significance.

RESULTS

In general, demographic data of patients and caregivers were similar; however, the number of men was higher among patients and the number of women was higher among caregivers. 14 caregivers (10 female and 4 male) were the patients’ spouses. Other caregivers consisted of the patients’ parents (11), siblings (7), children (5) and other relatives

(3). Demographic characteristics of the patients and caregivers are shown in Table 1. Among the patients enrolled in our study, the most frequent etiological factors resulting in SCI were traffic accidents and falling from height. In addition, when our patients were evaluated in terms of SCI severity, it was observed that the majority had motor complete SCI. The SCI-related characteristics of the patients are shown in Table 2. Anxiety and depression scores were high in both patients and caregivers. According to Beck Depression Scale; 30 (%75) of patients and 28 (%70) of caregivers had a depression scale score (DSS) higher than cut-off point 10. According to Beck Anxiety Scale; 28 (%62) of patient and caregivers had an anxiety scale score (DSS) higher than cut-off point 10. A significant positive correlation was identified between the SCI clinical stage, anxiety and depression scores with caregiver burden scores (respectively; $p=0.043$, $p<0.001$, $p<0.001$). However a significant negative correlation was identified between the patient's functional status with caregiver burden scores ($p<0.001$).

While reviewing the relation between the patients' ASIA grades and caregiver burden levels, it was determined that the average care burden level decreased when moving from ASIA grade A to D. In the post hoc (Dunn's multiple comparison) test, the difference between the care burden levels was significant between ASIA A and D ($p=0.026$), while the difference was not significant between other ASIA grades. Distribution of the caregiver burden according to different SCI features is shown in Table 3.

DISCUSSION

In this study, the factors affecting the caregiver burden in spinal cord injury were evaluated. Our results showed a strong correlation between severity of injury, the patient's functional status and ASIA scores, anxiety and depression scores, and caregiver burden.

It was reported that people exposed to SCI were mostly in the 3rd and 4th decade of their lives, and men were affected more frequently when compared to women. Trauma was the first factor

TABLE 1: Demographic characteristics of the patients and caregivers.

	Patients (n=40)	Caregivers (n=40)
Mean age± SD (years)	34.00±11.5	36.47±47
Gender		
Male n.(%)	26 (%65)	17 (%42.5)
Female n.(%)	14 (%35)	23 (%57.5)
Employment status n (%)		
Employed	16 (%40)	7 (%17.5)
Official	3 (%7.5)	4 (%10)
Homemaker	8 (%20)	15 (%37.5)
Others	13 (%32.5)	14 (%35)
Marital status		
Married n. (%)	16 (%40)	19 (%47.5)
Single n. (%)	20 (%50)	21 (%52.5)
Divorced n. (%)	4 (%10)	2 (%5)
Education±SD (years)	7.75±3.5	7.52±3.6
Beck Anksiyete	22.5±13.2	20.2±4.5
Beck Depression	25.4±15.4	24.1±7.1

SD: Standard deviation.

TABLE 2: Characteristics of spinal cord injury.

Etiology	n (%)
Traffic accident	15 (37.5)
Falls	14 (35)
Gun shot	6 (15)
Other	5 (12.5)
Severity of injury (ASIA)	
Motor complete (A,B)	26 (65)
Motor incomplete (C,D)	14 (35)
Level of the lesion	
Tetraplegia	11 (27.5)
Paraplegia	29 (72.5)
	Mean±SD
SCI duration (month)	32.2±5.2
Motor FIM score	69.3±12.3

SCI: Spinal cord injury; FIM: Functional independence measurement; SD: Standard deviation.

among etiological factors.¹⁰ Our study can be considered as consistent with the literature, considering the fact that 65% of our patients were male, and that SCI occurred at the age of 31.2 on average (based on the duration of disease) and due to trauma by 72.5%.¹⁰

TABLE 3: Distribution of the caregiver burden according to different features in spinal cord injury.

Characteristics&care burden	Number (%) [Care burden median]	Correlation/r (p)
Patients		
The relationship between patient's age & care burden		r=- 0.26 (p>0.05)
The care burden's exchange according to gender		
Women	14 (35) [30]	MW-U=180.50 (p>0.05)
Men	26(65) [29.5]	
Marital status & care burden		KW=0.90 (p>0.05)
Married	19 (47.5) [30]	
Single	14 (35) [28]	
Divorced	7 (17.5) [32]	
Functional status&care burden		r=-0.79 (p<0.001)*
Injury severity (ASIA)&care burden		KW=9.84 (p=0.043)
A	14 (35) [33.5]	
B	8 (20) [33]	
C	9 (22.5) [26]	
D	9 (22.5)[16]	
The level of injury&care burden		MW-U=86.50 (p=0.027*)
Tetraplegia	11(27.5)[34]	
Paraplegia	29(72.5) [25]	
Anxiety score&care burden		r=0.666 (p<0.001) *
Depression score&care burden		r=0.602 (p<0.001) *
Caregiver		
Gender&care burden		MW-U=186.0 (p>0.05)
Women	23(57.5)[27]	
Men	17(42.5) [32]	
Age&care burden		r=0.267 (p>0.05)
Educate years&care burden		r=-0.135 (p>0.05)

MW-U= Mann-Whitney U test; KW= Kruskal-Wallis test; r=correlation coefficient; considered as statistically significant if p<0.05.

Stone et al. reported that 23% of all caregivers were female spouses and 13% were male spouses.¹¹ In a research by Altun et al. in Turkey, it was found that 78% of the caregivers were female, and 34% of them provided care for their spouses.¹² In our study, 35% of the caregivers were also spouses. In addition, 71.5% of the caregiving spouses were female.

In the case of diseases requiring long-term care like SCI, it was reported that the caregiver burden resulted in depression, anxiety, exhaustion, deterioration of general health, social isolation and economic problems.¹³ It was also determined in our study that anxiety and depression scores were high in both patients and caregivers. In this context, it

may be an appropriate approach to evaluate patients with SCI also in terms of psychological disorders secondary to the disease, in addition to their physical evaluation.

For many studies comparing the caregiver burden between female and male caregivers in SCI, it was reported that the care burden level was higher in women compared to men. It was stated that this high level might be related with the fact that female caregivers were less supported by a paid caregiver.¹⁴ In our study, which did not include any paid caregivers, the caregiver burden was also higher in women compared to men. This difference may be related with the fact that women have more difficulty in providing the physical support

that a SCI patient needs when fulfilling his/her daily needs. It can also be considered that this difference may also result from the fact that additional responsibilities like housework and childcare are more associated with women in our society.

In the literature, there are some studies reporting that a strong correlation exists between the injury severity and physical disability in SCI and the caregiver burden; however, there are also some studies reporting no relationship.¹⁵⁻¹⁷ In our study, a statistically significant positive correlation was detected between the patients' SCI level, severity and functional disability, and the caregiver burden. We think that the different results in some studies may be due to varying social support for patients with SCI in each country or varying perception in each society for the concept of caregiver burden.

It was reported in the literature that the caregiver burden was higher in people with a lower level of education.¹⁸ Our study also detected a similar (although not statistically significant) relationship between education level and caregiver burden.

The cross-sectional design of the study, the participants not homogeneous in terms of the role

within the family and gender and the relatively small size of the SCI patients and family caregiver were limitations for our study.

It is possible that there are other factors which may play a role in occurrence or perception of caregiver burden in SCI. The personal factors which may be related with the caregiver's perception of burden include: other health problems of patients and caregivers; different sociocultural, ethnicity, belief and economic settings; willingness of the caregiver, and his/her ability to cope with problems.¹⁹ In this context, multi-center studies with broad participation enrolling caregivers with different sociocultural characteristics are needed to evaluate the caregiver burden in SCI extensively.

CONCLUSION

We think that timely determination of the potential risk factors such as anxiety and depression, poor clinic and functional status factor for caregiver burden in SCI, as well as providing an appropriate therapy support, may contribute to higher quality in treatment and care of patients with SCI.

REFERENCES

- Kennedy P, Lude P, Elfström ML, Smithson E. Cognitive appraisals, coping and quality of life outcomes: a multi-centre study of spinal cord injury rehabilitation. *Spinal Cord* 2010;48(10):762-9.
- Kennedy P, Lude P, Elfström ML, Smithson EF. Psychological contributions to functional independence: a longitudinal investigation of spinal cord injury rehabilitation. *Arch Phys Med Rehabil* 2011;92(4):597-602.
- Zarit SH. Family care and burden at the end of life. *CMAJ* 2004;170(12):1811-2.
- Paker N, Bugdayci D, Dere D, Altuncu Y. Comparison of the coping strategies, anxiety, and depression in a group of Turkish spinal cord injured patients and their family caregivers in a rehabilitation center. *Eur J Phys Rehabil Med* 2011;47(4):595-600.
- Schulz R, Czaja SJ, Lustig A, Zdaniuk B, Martire LM, Perdomo D. Improving the quality of life of caregivers of persons with spinal cord injury: a randomized controlled trial. *Rehabil Psychol* 2009;54(1):1-15.
- Kirshblum SC, Groah SL, McKinley WO, Gittler MS, Stiens SA. Spinal cord injury medicine. 1. Etiology, classification, and acute medical management. *Arch Phys Med Rehabil* 2002;83(3 Suppl 1):S50-7, S90-8.
- Küçükdeveci AA, Yavuzer G, Elhan AH, Sonel B, Tennant A. Adaptation of the Functional Independence Measure for use in Turkey. *Clin Rehabil* 2001;15(3):311-9.
- Snaith RP. The Hospital Anxiety And Depression Scale. *Health Qual Life Outcomes* 2003;1:29. doi:10.1186/1477-7525-1-29
- Buchanan KM, Elias LJ. Psychological distress and family burden following spinal cord injury: concurrent traumatic brain injury cannot be overlooked. *Axone* 2001;22(3):16-7.
- DeVivo MJ, Rutt RD, Black KJ, Go BK, Stover SL. Trends in spinal cord injury demographics and treatment outcomes between 1973 and 1986. *Arch Phys Med Rehabil* 1992;73(5):424-30.
- Stone R, Cafferata GL, Sangl J. Caregivers of the frail elderly: a national profile. *Gerontologist* 1987;27(5):616-26.
- Altun I. [The strain situations of patient's relatives at the role of caregiving]. *Birinci Evde Bakım Kongresi Özet Kitabı*. İstanbul: Marmara Üniversitesi Yayını; 1998. p.71-8.
- Dunkin JJ, Anderson-Hanley C. Dementia caregiver burden: a review of the literature and guidelines for assessment and intervention. *Neurology* 1998;51(1 Suppl 1):S53-60; discussion S65-7.
- Shackelford M, Farley T, Vines CL. A comparison of women and men with spinal cord injury. *Spinal Cord* 1998;36(5):337-9.
- Post MW, Bloemen J, de Witte LP. Burden of support for partners of persons with spinal cord injuries. *Spinal Cord* 2005;43(5):311-9.

16. Manigandan C, Saravanan B, Macaden A, Gopalan L, Tharion G, Bhattacharji S. Psychological wellbeing among carers of people with spinal cord injury: a preliminary investigation from South India. *Spinal Cord* 2000;38(9):559-62.
17. Unalan H, Gençosmanoğlu B, Akgün K, Karamehmetoğlu S, Tuna H, Ones K, et al. Quality of life of primary caregivers of spinal cord injury survivors living in the community: controlled study with short form-36 questionnaire. *Spinal Cord* 2001;39(6):318-22.
18. Gitlin LN, Belle SH, Burgio LD, Czaja SJ, Mahoney D, Gallagher-Thompson D, et al.; REACH Investigators. Effect of multicomponent interventions on caregiver burden and depression: the REACH multisite initiative at 6-month follow-up. *Psychol Aging* 2003;18(3):361-74.
19. Martorell A, Pereda A, Salvador-Carulla L, Ochoa S, Ayuso-Mateos JL. Validation of the Subjective and Objective Family Burden Interview (SOFBI/ECFOS) in primary caregivers to adults with intellectual disabilities living in the community. *J Intellect Disabil Res* 2007;51(Pt 11):892-901.