ORİJİNAL ARAŞTIRMA ORIGINAL RESEARCH

Depression, Anxiety and Health Related Quality of Life in the Caregivers of the Persons with Chronic Neurological Illness

Kronik Nörolojik Hastalığı Olan Kişilere Bakım Verenlerde Depresyon, Anksiyete ve Yaşam Kalitesi

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Geliş Tarihi/*Received:* 02.09.2008
Kabul Tarihi/*Accepted:* 18.01.2009

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ABSTRACT Objective: This study was designed to determine the emotional status and health related quality of life (HRQOL) of caregivers of mild to moderately dependent patients with chronic neurological disorders and to compare them with the patients themselves, and to reveal the influence of factors related to physical stressors and emotional status on HRQOL of caregivers. **Material and Methods:** Fifty two patients with chronic neurological illness and their caregivers (n= 52) were recruited. The Functional Independence Measurement (FIM) was used to evaluate the dependence of patients in daily living activities. Patients and their caregivers were assessed with the Beck Depression Inventory (BDI), the State-Trait Anxiety Inventory (STAI) and the Nottingham Health Profile (NHP). **Results:** No significant difference was found between the patients and the caregivers with respect to BDI and STAI scores ($p > 0.05$). The significant correlates of NHP and FIM locomotion (which showed a trend toward significance) were added simultaneously in a multivariate model. BDI score of the caregivers was the only predictor of their NHP score (model R2= 0.45). When all of the variables were entered sequentially in a stepwise analysis, it was found that FIM locomotion, as well as BDI score of the caregivers contributed significantly to the explanatory power of the model. Our final model explained 43% of the variance in QOL of the caregivers of which BDI score of the caregivers accounted for 36%. **Conclusion:** Health care professionals should apply a holistic care approach in the rehabilitation of mildly dependent patients with chronic neurological illness including the psychiatric management of caregivers in the process.

Key Words: Depression; anxiety; quality of life; caregivers; nervous system diseases

ÖZET Amaç: Bu çalışmanın amacı, kronik nörolojik bozuklukları olan hafif-orta düzeyde bağımlı hastalara bakım verenlerde emosyonel durum ve yaşam kalitesini- hastalarınki ile karşılaştırarak-değerlendirmek ve fiziksel stresörler ve emosyonel durumla ilgili faktörlerin bakım verenlerin yaşam kaliteleri üzerindeki etkisini saptamaktır. **Gereç ve Yöntemler:** Çalışmaya 52 kronik nörolojik bozukluğu olan hasta ve onların 52 bakım vereni alınmıştır. Hastaların günlük yaşam aktivitelerinde bağımlılık düzeyini değerlendirmek için Fonksiyonel Bağımsızlık Ölçeği (FBÖ) kullanılmıştır. Hastalar ve bakım verenleri Beck Depresyon Envanteri (BDE), Durumluk-Sürekli Kaygı Envanteri (DSKE) ve Nottingham Sağlık Profili (NSP) kullanılarak değerlendirilmiştir. **Bulgular:** BDE ve DSKE puanları bakımından hastalar ve bakım verenleri arasında anlamlı fark bulunmamıştır ($p > 0.05$). Hastalar ve bakım verenlerin DSKE (sürekli) puanları ilişkili bulundu ($\rho = 0.35$, $p < 0.05$). Bakım verenlerin NSP puanları ile FBÖ toplam puanı ve alt grupları bağıntılı değildi, ancak FBÖ lokomosyon için anlamlılık düzeyine yaklaşmaktaydı ($\rho = -0.27$, $p = 0.053$). Bakım verenlerin NSP puanlarının bağıntılı bulunduğu değişkenler ve FBÖ lokomosyon (bağıntı için eğilim gösteren) regresyon analizine aynı anda sokulmuştur. Bakım verenlerin BDE puanları NSP puanlarının tek yordayıcısı olarak saptanmıştır (model R2= 0.45). Değişkenlerin hepsi aşamalı regresyon analizine sokulduğunda, BDE puanları ile birlikte FBÖ lokomosyonun da eşitliğe girdiği görülmüştür. Son model varyansın %43'ünü (BDE puanları varyansın %36'sını) açıklamaktadır. **Sonuç:** Sağlık profesyonellerinin kronik nörolojik bozukluğu olan hafif-orta düzeyde bağımlı hastalarda, süreç içerisinde bakım verenlerin psikiyatrik durumlarının ele alınmasını da içeren bütüncül bir yaklaşım uygulamaları gereklidir.

Anahtar Kelimeler: Depresyon; bunaltı; yaşam kalitesi; bakımverenler; nörolojik bozukluk

Turkiye Klinikleri J Med Sci 2009;29(6):1535-42

Patients, who have chronic and progressive neurological diseases, often require assistance in their daily living activities (ADL), to a large extent. As a consequence, caregivers might become active members of the health care team, with inadequate or no preparation. They deal with extensive coordination of care, including symptom management, and disability. As the necessary support, training and information regarding these issues are frequently not available, caring family members may feel exhausted, isolated and overwhelmed due to these challenges and responsibilities. They may experience profound physical, psychological, social, and financial strain.[1-5] On the other hand the coping skills, anxious or depressive personality traits and psychopathological distress in various dimensions may influence how they deal with and perceive this inevitable major life change. However, the contribution of physical stressors (i.e. disability, duration of illness and care) has been more emphasized than emotional stressors (i.e. depression and anxiety level) on caregivers' quality of life (QOL) yet the psychological wellbeing of caregiver may be crucial in coping with this chronic process.

HRQOL is a multidimensional construct that encompasses a person's perceptions about the burden of a disease on several dimensions. In recent years, there has been a growing awareness that a comprehensive assessment of health outcomes must involve patient-reported judgments of physical, mental, social and psychological functioning as well as traditional indicators of disease severity and functional status.[6] In the past, HRQOL studies focused almost exclusively on patients, but increasing attention is now being paid to the impact of chronic disease on the caregivers. QOL is suggested to be a more appropriate concept for determining how care giving affects family members.[7] It is important to determine the factors relevant to QOL of both patients and caregivers who are interrelated in the chronic neurological illnesses as mentioned above.

The QOL and psychological state of caregivers were examined in various chronic neurological disorders including stroke, traumatic brain injury, and MS.[8-11] ADL dependency has been accepted as a primary stressor for QOL in patients with a chronic neurological illness.[8,12] Generally it is suggested that there is a correlation with dependency level of the patient and QOL of the caring family member. Severe dependency on ADL upon others (for example; for bed confined patients), is reported to reduce caring family member's QOL and increase his/her anxiety and depression level.[13,14] Although there are several reports that studied the caregiver burden in severely disabling, untreatable and fatal neurological diseases such as amyotrophic lateral sclerosis, the mild to moderately disabled patients and their caregivers' have not been investigated thoroughly regarding their QOL.[15-17] Mildly dependent chronic patients may seek less care and may not constitute substantial physical burden for their caregivers. However they may give rise to important emotional distress for their caregivers throughout their slowly progressive unpredictable course. The specific determinants of QOL of caregivers of mild to moderately dependent patients are not documented so far, though it is crucial for the long term rehabilitation process of these patients.

This investigation was designed to 1) determine the level of depression, anxiety and HRQOL of caregivers of mild to moderately dependent patients with chronic neurological disorders and to compare them with the patients themselves, 2) reveal the influence of factors related to physical stressors and emotional status on HRQOL of caregivers. We hypothesized that both the physical stressors and emotional status due to taking care of patients who were relatively independent on ADL have been involved in HRQOL of caregivers, comparably.

MATERIAL AND METHODS

PARTICIPANTS

Fifty two patients with chronic neurological illness and their caregivers who all were their family members were recruited in the study. The caregivers were living with the patients. They were referred by Neurology Department and admitted to

Neurological Rehabilitation Outpatient Unit, Hacettepe University School of Physical Therapy and Rehabilitation, between May 2004 and November 2005. Both the patients and the caregivers provided their written informed consents. Questionnaires and functional evaluations were applied to the subjects by the same researcher throughout the study. The self-report instruments were all completed in the unit, and completing them took approximately 30 minutes.

At least 1 year duration of the neurological disease and independent walking ability in the community, with a need of moderate assistance while performing daily living activities FIM total score limit was above 37) were sought for inclusion into the study. Patients were all living at home but not in an institution, in accordance with the latter inclusion criterion.

Neither the patients nor the caregivers were ever diagnosed and treated or had a family history for a major psychiatric disorder. Individuals with other medically unstable major physical disease, cognitive impairment (with scores lower than 24 in Mini Mental Test) and without sphincter control were excluded. The existence of a caring family member eligible for completing the self-report instruments was sought as well.

MEASURES

Basic demographic information was collected including age, sex, education, duration of illness, duration of care, type of care (regarding the activities such as hygiene, transfer, feeding, exercise program, physical care, for which assistance were needed), the relation of caring family member with the patient, the recent and previous psychiatric history and the knowledge of the caring family member about the nature of the neurological illness.

This FIM was employed to evaluate the functional status. The instrument is an 18-item, 6-level scale that scores the care needs from 18 (complete dependence) to 126 (full independence) the severity of disability. Six subscales are formed, including self-care, sphincter control, mobility, locomotion, communication and social communication. The scoring scale includes two independent levels and five helper levels. The need for supervision or assistance of a patient is rated. The highest level (7) indicates total independence; the lowest level (1) indicates total need for the assistance of two helpers to perform the activity. Normal range of the FIM score is between 0 and 126. (0-36: completely dependent, 37-90: needed supervision and assistance while performing activities, 90-126 completely independent). It was adapted for Turkish language and found to be reliable and valid in a spinal cord injury sample.[18] In our study, since we excluded the patients with cognitive impairment, cognitive parameters (communication and social communication) scores were calculated totally.

For the assessment of psychological distress; i.e. depression, anxiety and HRQOL, both the patients and their caregivers were requested to fill out relevant self-report scales: BDI, STAI and the NHP.

BDI is a self rating instrument developed by Beck and his colleagues and psychometric properties were evaluated rigorously.[19,20] It is used to identify potential cases of depressive illness and to measure the severity of twenty one depressive symptoms on a 4-point scale ranging from 0-3. The total maximum score is 63. The optimum cut-off point was found to be 16/17 in the reliability and validity study of Turkish version, in accordance with the original study.[21]

State anxiety (S-Anxiety) refers to the subjective and transitory feeling of tension, nervousness, and worries at a given moment. Trait anxiety (T-Anxiety) refers to relatively stable individual differences in anxiety proneness as a personality trait in the tendency to perceive and respond to stressful situations with elevations in the intensity of state anxiety reactions. The S-Anxiety scale consists of twenty statements that evaluate how the respondent feels “right now, at this moment”. The T-Anxiety scale consists of twenty statements that evaluate how the respondent feels “generally”. Each STAI item is given a weighted score of 1 to 4. A rating of 4 indicates the presence of high levels of anxiety for ten S-Anxiety items (#3, 4, 6, 7, 9, 12, 13, 14, 17 and 18) and eleven T-Anxiety items (#22, 24, 25, 28, 29, 31, 32, 35, 37, 38, 40). A high rating indicates the absence of anxiety for the remaining ten S-Anxiety items and nine T-Anxiety items. Scores for both the S-Anxiety and the T-Anxiety scales can vary from a minimum of 20 to a maximum of 80. Usually a cut-off score <40 and >40 were used in prior studies.[22] The inventory has been shown to be valid in Turkish language.

The NHP is a self administered questionnaire which assesses the subjective perception of the physical, emotional, and social aspects of health. The NHP evaluates 6 health dimensions: energy, pain, physical mobility, emotional reactions, sleep, and social isolation. The profile has dichotomized questions; the subjects may answer as 'yes' or 'no'. Higher scores on the NHP represent worse quality of life. Turkish versions of these scales have been developed and thoroughly tested for reliability and validity in Turkey.[23]

STATISTICAL ANALYSIS

Statistical analysis was performed using SPSS (version 13.0) statistical software. Data are expressed as mean (SD) or frequency (percentage). Most of the variables including demographics, functional and psychological measures and QOL scores (including the six dimensions of NHP evaluated separately) of the patients and the caregivers (except age, STAI, T-anxiety, S-anxiety of caregivers and S-anxiety of patients) were not normally distributed. Therefore initially interrelationships among the functional and psychological measures and QOL were assessed by using Spearman rank-order correlations, and then QOL of the caregivers, variables that are significantly correlated with it (BDI of patients and caregivers, QOL of patients), and the FIM locomotion score which showed a statistical trend, were transformed. Positively skewed variables (QOL, BDI of both patients and caregivers) have been subjected to power (square root) transformations to normalize their distribution. For FIM locomotion score which was negatively skewed, the data was reflected and then reciprocal root transformations were applied. The distribution of all of the variables were normalized other than FIM locomotion score for which the skewness was reduced (from -0, 79 to 0, 15) and best approximation to normality was obtained for this variable. Exceptionally none of the six dimensions of NHP for both the patients and the caregivers could be transformed in a reliable manner. Consequently, only total score was used for the exploration of QOL of caregivers in regression analysis.

The derived variables were first tested by using a multivariate model in which all of the independent variables (FIM locomotion score, BDI and QOL of patients and age and BDI of caregivers) were added simultaneously after controlling for the age of the caregivers (by entering age in the first block). To ascertain the relative contribution of each independent variable to QOL of caregivers, stepwise multiple regression analyses were performed by adding each measure to the model sequentially (again after controlling for the age of the caregivers). P values <0.05 were considered statistically significant.

Anxiety and depression scores of patients and caregivers were compared using Wilcoxon signed test and paired-samples t test as needed. Caregivers' QOL scores were compared with respect to gender of the caregivers and gender of the patients by using independent t test.

RESULTS

We analyzed responses of 52 patients (25 female and 27 male) with a chronic neurological illness and their caregivers (38 female and 14 male) in this study. Thirty of the patients (58.5%) had neuromuscular diseases, 6 patients (11.3%) had ischemic stroke and 16 patients (30.2%) had other neurological diseases (spinal cord pathologies and etc). The caregivers were partners (n= 17, 32.7%), children (n= 20, 38.5%), mothers (n= 12, 23.1%), fathers (n= 2, 3.8%) or another family members of the patients (n= 1, 1.9%). Demographics and clinical characteristics of patients and caregivers are summarized in Table 1.

Patients needed little assistance or supervision for hygiene (n= 14, 26.5%), transfer (n= 18, 33.9%), feeding (n= 7, 13.2%), social (n= 12, 22.6%) and other daily living activities (n= 6, 11.3%), exercise program (n= 19, 35.8%), physical care (n= 9, 16.9%), or economic support (n= 11, 20.7%).

TABLE 1: Patients' and caregivers' characteristics.

Variables	Patients (n= 52)	Caregivers (n= 52)
Gender n (%)		
Male	27 (51.9)	14 (26.9)
Female	25 (48.1)	38 (73.07)
Age (years)		
Mean ± SD	35.4 ± 16.8	45.5 ± 12.4
Duration of illness (years)		
Mean ± SD	10.5 ± 9.1	
Duration of care (hours)		
Mean ± SD	13.3 ± 7.9	
Total FIM Score		
Mean ± SD	85.6 ± 17.2	
Subgroups of the FIM scores		
-Self-care	11.2 ± 4.2	
-Sphincter control	13.6 ± 2.6	
-Mobility	18.2 ± 5.1	
-Locomotion	10.5 ± 3.9	
-Communication and Social integration	32.2 ± 5.9	

FIM: Functional Independence Measurement.

BDI scores of the patients (8.9 ± 7.9) and the caregivers (10.4 ± 8.8) were both below the cut-off score of 16/17. 17.6 % of the patients and 23.1% of the caregivers scored above the cut-off point of 16/17. The caregivers scored slightly higher (more depressed) than the patients, though the difference between them was not significant (Wilcoxon signed rank rest z= -0.90, p= 0.368).

The mean trait and state anxiety score on the STAI of the patients were 47.8 ± 8.1 and 45.7 ± 7.3, respectively, and the caregivers of the patients' were 47.1 ± 6.8 and 44.6 ± 5.7, respectively. The mean trait and state anxiety score did not differ significantly between the patients and the caregivers (Wilcoxon signed rank test z= -0.312, p= 0.755; t=1.2 df= 35, p= 0.237).

HRQOL, as measured by NHP, was mildly high (worse) in the patients (159.3 ± 145.1) than the caregivers (132.5 ± 130.6), but the difference between two groups was not significant (Wilcoxon signed rank test: z=-1.76, p=0.08). Normative data for NHP score is not available either for the patients or for the caregivers.

NHP scores of the caregivers was significantly correlated with NHP and BDI scores of the patients (ρ= 0.41 and ρ= 0.40, p<0.001, respectively). Among the significant associations, the strongest was between BDI scores of caregivers and NHP scores of them (*ρ*=0.62, *p*< 0.001). No significant correlation was found between the anxiety scores (state or trait) of either the patients or the caregivers and NHP scores of caregivers (p<0.05).

All of the subgroups of the FIM and FIM total score did not correlate with NHP scores of the caregivers, however only FIM locomotion showed a trend toward significance (ρ= -0.27, p= 0.053, poorer FIM locomotion was associated with poorer HRQOL of caregivers). There was no significant correlation between HRQOL scores of caregivers and the age of patients or caregivers, the duration of disease and the duration of care.

The variables (BDI scores of the patients and the caregivers, NHP scores of the patients and FIM locomotion though only with a trend) that were found to be correlated with NHP score of the caregivers were transformed, and regression analyses were conducted. In all regression analysis, the age of the caregivers was included as a covariate. Although age did not correlate with the NHP score of the caregivers, as it is frequently reported to be an important variable which may have an impact on QOL, it was taken into consideration. The significant correlates of NHP stated above (after entering the age in the first block) were added simultaneously in a multivariate model (without considering the interaction between independent variables), BDI scores of the caregivers was the only predictor for their NHP score (model R2= 0.45) (Table 2). When four of the over mentioned variables were entered to the model sequentially in a stepwise analysis, it was found that FIM locomotion, as well as BDI score of caregivers contributed significantly to the explanatory power of the model, but BDI score of the patients and the NHP score of them did not. Our final model explained 43% of the variance in QOL of the caregivers of which BDI score of the caregivers accounted for 36% (Table 3).

TABLE 2: Effects on quality of life of caregivers as measured by Nottingham Health Profile

Variable	Multivariate model β (SE)	P value
BDI-Caregivers	0.5(0.52)	0.000
BDI –Patients	0.03(0.74)	0.49
NHP- Patients	-0.2(0.05)	0.086
FIM-Locomotion	-0.24(2.59)	0.062

Multivariate model indicates all of the four variables plus the age of the patients
BDI: Beck Depression Inventory,
NHP: Nottingham Health Profile,
FIM: Functional Independent Measurement.

TABLE 3: Stepwise regression showing the contributions of variables in quality of life of the caregivers*

Model	Model R^2	ΔR^2	P
Age of the caregiver	0.04	0.04	0.19
Age of the caregiver +BDI-Caregiver	0.36	0.33	0.000
Age of the caregiver +BDI-Caregiver +FIM-Locomotion	0.43	0.07	0.027

* The dependent variable was QOL of caregivers as measured by NPH
BDI: Beck Depression Inventory,
FIM: Functional Independence Measurement.

In a separate analysis, BDI score of the patients, NHP score of the patients and FIM locomotion (BDI scores of the caregivers were not included this time) were entered sequentially again. BDI score of the patients predicted NHP score of the caregivers significantly, but FIM locomotion did not entered in the equation in this second stepwise regression analysis (data not shown).

DISCUSSION

The results of this study revealed that although the patients had a higher functional level during ADL (particularly in terms of sphincter control and mobility), the caregivers were affected comparable to their care recipients with respect to anxiety, depression and HRQOL. As for the influence of the emotional status of the caregivers and the patients, our findings indicate that HRQOL is associated with the depression level of the caregivers and the patients. However depression level of the patients does not predict the HRQOL of the the caregivers. None of the parameters examined to determine physical stressors was found to be associated with the caregivers' HRQOL. Although FIM total scores were not significantly correlated with HRQOL, there was a trend towards significance for FIM locomotion.

In literature, the severity level of psychopathology was reported to be similar in caregivers and the patients, and even more severe emotional distress was found in the caregivers. Cliff and MacDonagh found that illness related distress was very common and significantly more severe as well as concerns about physical limitations and pain among the caregivers than in the patients.[24] The spouses of patients with spinal cord injuries were scored higher in depression scales than the patients.[25] The most consistent results reporting greater psychological distress in caregivers compared to their care receiver partners come from cancer literature.[26] In this study actually, emotional distress in caregivers was not higher than normal population values, but the caregivers who carry the responsibility of in fact mild to moderately dependent patients, had similar emotional distress scores with patients who themselves experience the illness. In fact, these patients do not have difficulties in sphincter/ bowel control or cognitive impairment and therefore they have high FIM scores and low dependency levels. On the other hand, they need continuous supervision during the self-care, mobility and locomotion as they may perform the activities in a clumsy pattern. Therefore the responsibility regarding the relevant risks may cause emotional distress in the caregivers. In this study, neither the patients nor the caregivers displayed significant psychopathology with respect to current depression and anxiety scores on the symptom scales. However, the anxiety levels of both the patients and the caregivers were above the frequently used threshold (STAI score > 40).[22,27] The caregivers expressed more anxiety than male or female "university students".[28] We can tentatively suggest that the caregivers in our study have relatively higher psychological distress and comparable HRQOL to their care recipients.

The depression level of patients was moderately associated with HRQOL of caregivers though it did not predict the HRQOL of the caregivers' in this study. It is suggested that the link between the patient and the caregiver psychological morbidity supports the notion that any improvement in the health and/or emotional status of the patient will have some positive consequence on the caregiver.[13] More specifically, an intervention targeting the patient may lessen the burden on the caregiver thereby reduce caregivers' depression, and vice versa. Recognizing high psychological distress level in the caregiver and the interventions to improve it may have a positive impact on the patient's wellbeing.

The extent of the physical disability was reported to be associated with diminished QOL for the caregivers of stroke patients though there are conflicting findings in relevant studies.[14] In a study exploring the spouses of chronic stroke patients, QOL of caregivers (assessed by a VAS) was found to be associated with FIM global scores and FIM locomotion scores.[14] In contrast, Grant et al. did not find any relationship between physical disability and life satisfaction of caregivers.[29] Similarly, Anderson could not find a consistent relation between physical disability and life satisfaction of caregivers.[2] In other studies, the physical consequences of stroke were found to be less strongly associated with the caregiver's HRQOL, when compared to the cognitive, behavioral, and emotional consequences of the illness.[9]

In this study, physical disability was not found to be associated (except FIM locomotion scores which showed a trend for statistical significance) with HRQOL of the caregivers. However the results of two consecutive stepwise regressions highlight the significant interaction between FIM locomotion and depression level of the caregivers. It may be suggested tentatively that depression level of the caregiver may have a mediating effect in this context to facilitate the contribution of FIM locomotion score on HRQOL. In other words, it may be the depression level of caregiver that determines his/her perception of the virtual problem regarding dependency. Hence, FIM locomotion would not reduce the HRQOL of caregivers, unless they interpret it through a distorted perception stemming from their depressive symptoms.

The main limitations of our study include a relatively small sample size and heterogeneity at diagnoses. Another limitation is the lack of information about the initial psychopathology levels of the patients and the caregivers. Moreover, physical burden was not evaluated by a structured tool. The other factors which may have an impact on the HRQOL of caregivers such as socioeconomic status were not taken into consideration as well. Besides, as available normative data does not exist for NHP scores, the level of QOL of both the patients and the caregivers could not be interpreted appropriately. Larger, cross-sectional and longitudinal studies including case control design need to be conducted to conclude unequivocally, about the correlates of HRQOL in the caregivers of mild to moderately disabled chronic neurological patients. In addition to that, treatment options and interventions such as individual therapy, family therapy, education and problem solving programs for caring family members need to be discussed. The study group will be followed with the aim of exploring the progress of same variables along with the increasing disability or to assess them as an outcome of rehabilitation in a subsequent study.

CONCLUSION

The caregivers of patients in chronic stage with only minimal disability have similar psychological distress, depression, anxiety and life satisfaction levels to their care recipients. This finding has implications regarding the risk of an increasing strain and burden along the trajectory of the illness. So the concerns of caregivers about the prognosis of the illness or psychological distress and particularly depression may impede the patience of the caregivers, and in return may influence the wellbeing of the patients. The necessary interventions should be taken into consideration to improve the psychological distress of caregivers who care for patients with progressive or Long lasting illnesses. These interventions would be advantageous at this stage while the patients are still not demanding severely, which may be the case in the future, even more increasing the anxiety levels of the caregivers.

In clinical practice, the emotional status of the caregivers of the patients with mild to moderate disability are overlooked, and usually the emotional distress is not anticipated in this group. The psychosocial rehabilitation of the caregivers should be conducted along with the neurological rehabilitation of the patients.

REFERENCES

1. Glozman JM. Quality of life of caregivers. Neuropsychol Rev. 2004;14(4):183-96.
2. Andersen CK, Wittrup-Jensen KU, Lolk A, Andersen K, Kragh-Sørensen P. Ability to perform activities of daily living is the main factor affecting quality of life in patients with dementia. Health Qual Life Outcomes 2004;2:52.
3. Wallander JL, Marullo DS. Handicap-related problems in mothers of children with physical impairments. Res Dev Disabil 1997;18(2):151-65.
4. Cameron JI, Franche RL, Cheung AM, Stewart DE. Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. Cancer 2002;94(2):521-7.
5. Yılmaz A, Turan E. [Burnout in caregivers of Alzheimer patients, factors leading toburnout and coping ways: scientific letter]. Turkiye Klinikleri J Med Sci 2007: 27(3):445-54.
6. Aydemir Ö. [Consultation liaison psychiatry and quality of life]. Turkiye Klinikleri J Int Med Sci 2006:2(47):85-8.
7. Canam C, Acorn S. Quality of life for family caregivers of people with chronic health problems. Rehabil Nurs 1999;24(5):192-6, 200.
8. Jenkinson C, Fitzpatrick R, Swash M, Peto V; ALS-HPS Steering Group. The ALS Health Profile Study: quality of life of amyotrophic lateral sclerosis patients and carers in Europe. J Neurol 2000;247(11):835-40.
9. White CL, Lauzon S, Yaffe MJ, Wood-Dauphinee S. Toward a model of quality of life for family caregivers of stroke survivors. Qual Life Res 2004;13(3):625-38.
10. Pozzilli C, Palmisano L, Mainero C, Tomassini V, Marinelli F, Ristori G, et al. Relationship between emotional distress in caregivers and health status in persons with multiple sclerosis. Mult Scler 2004;10(4):442-6.
11. Inzaghi MG, De Tanti A, Sozzi M. The effects of traumatic brain injury on patients and their families. A follow-up study. Eura Medicophys 2005;41(4):265-73.
12. McDonald CM. Physical activity, health impairments, and disability in neuromuscular disease. Am J Phys Med Rehabil 2002;81(11 Suppl):S108-20.
13. Lim JW, Zebrack B. Caring for family members with chronic physical illness: a critical review of caregiver literature. Health Qual Life Outcomes 2004;2:50.
14. Béthoux F, Calmels P, Gautheron V, Minaire P. Quality of life of the spouses of stroke patients: a preliminary study. Int J Rehabil Res 1996;19(4):291-9.
15. Adelman EE, Albert SM, Rabkin JG, Del Bene ML, Tider T, O'Sullivan I. Disparities in perceptions of distress and burden in ALS patients and family caregivers. Neurology 2004;62(10):1766-70.
16. Chiò A, Gauthier A, Calvo A, Ghiglione P, Mutani R. Caregiver burden and patients' perception of being a burden in ALS. Neurology 2005;64(10):1780-2.
17. Thommessen B, Aarsland D, Braekhus A, Oksengaard AR, Engedal K, Laake K. The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson's disease. Int J Geriatr Psychiatry 2002;17(1):78-84.
18. 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.
19. Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. Arch Gen Psychiatry 1961;4:561-71.
20. Beck AT, Steer RA, Garbin MG. Psychometric properties of the Beck depression Inventory: twenty-five years of evaluation. Clinical Psychology Review 1988;8(1):77-100.
21. Hisli N. [A reliability and validity study of Beck Depression Inventory in a university student sample]. J Psychol 1989;7(23):3-13.
22. Oner N. [The validity study of adapted Turkish version of an anxiety inventory. An abstract of a research]. J Psychol 1978;1(1):12-7.
23. Kücükdeveci AA, McKenna SP, Kutlay S, Gürsel Y, Whalley D, Arasil T. The development and psychometric assessment of the Turkish version of the Nottingham Health Profile. Int J Rehabil Res 2000;23(1):31-8.
24. Cliff AM, MacDonagh RP. Psychosocial morbidity in prostate cancer: II. A comparison of patients and partners. BJU Int 2000;86(7):834-9.
25. Weitzenkamp DA, Gerhart KA, Charlifue SW, Whiteneck GG, Savic G. Spouses of spinal cord injury survivors: the added impact of caregiving. Arch Phys Med Rehabil 1997;78(8):822-7.
26. Kornblith AB, Herr HW, Ofman US, Scher HI, Holland JC. Quality of life of patients with prostate cancer and their spouses. The value of a data base in clinical care. Cancer 1994;73(11):2791-802.
27. Spilberger CD, Gorsuch RL, Lushene R, Vagg P, Jacobs GA. Manual for the State-Trait Anxiety Inventory STAI (Form Y): Self-evaluation questionnaire. 1st ed. CA: Palo Alto: Consulting Psychologists Press; 1983.
28. Öner N, LeCompte A. [Manual for State-Trait Anxiety Inventory]. 2nd ed. The Istanbul: The Bosphorous University Press; 1985.
29. Grant J, Elliott T, Weaver M, Bartolucci A, Giger J. A telephone intervention with family caregivers of stroke survivors after hospital discharge. Stroke 2002:33;2060-5.