

Original Article

Quality of life of primary caregivers of spinal cord injury survivors living in the community: controlled study with short form-36 questionnaire

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Objective: To compare the quality of life scores of primary caregivers of spinal cord injury survivors living in the community with healthy age matched-population based controls and to determine the relationship between some severity parameters related with spinal cord injury and the quality of life scores of primary caregivers.

Setting: University hospital, rehabilitation centre.

Methods: Fifty primary caregivers of spinal cord injured patients living in the community and 40 healthy age-matched controls completed SF-36 (short form-36) questionnaire forms. Questionnaires were administered by interviewers who were psychiatrists and the authors of the present study. All the patients were rehabilitated by the authors and data about the duration of injury, lesion levels, ASIA scores, degree of spasticity, presence of bladder and bowel incontinence and pressure sores were gathered from the hospital recordings and/or by physical examinations during control visits when the primary caregivers were administered the questionnaires.

Results: Quality of life scores measured by SF-36 were significantly low in the primary caregivers group compared to age-matched healthy population based controls. No significant relation was demonstrated between the quality of life scores of primary caregivers and parameters such as the duration of injury, lesion levels, ASIA scores, degree of spasticity, bladder and/or bowel incontinence and pressure sores respectively.

Conclusion: According to the results of the present study, being a primary caregiver of a spinal cord injured victim significantly interferes with quality of life; some severity parameters related to the injury however do not seem to have an additional impact on the primary caregiver's life quality.

Spinal Cord (2001) **39**, 318–322

Keywords: quality of life; primary caregiver; spinal cord injury

Introduction

Spinal cord injury (SCI) affects all aspects of a patient's life, including the physical, behavioural, psychological and social functioning. This disability and distress make it unlikely that patient's family members, especially the primary caregivers and/or spouses remain untouched. Primary caregivers and/or spouses of SCI survivors may experience various problems due to this disorder.^{1–5}

Research in the literature regarding the quality of lives of primary caregivers of SCI survivors is

relatively limited.^{1–8} Although care giving family members have a crucial importance in the adjustment of the patient to SCI, many reports stress that research in this area had been slow to develop and future research with controlled longitudinal studies are essential for a better understanding of the impact of injury on the family system.^{1–8} The present study focused on the primary caregiver who is in almost all cases a close family member.

Primary caregivers, living together with the patients in the community, often have to take over many of the responsibilities of the patient. The potential impact of the SCI include the aggravation of old and new

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problems as well as the creation of a significant burden on spouses and family members.⁹ The patient's disability prevents the primary caregiver from engaging in usual enjoyable activities and his or her social life may well be curtailed. Also various complications commonly seen in SCI survivors distress the family members and especially the primary caregiver who is more engaged in the problems. Schulz *et al*¹⁰ reported that the level of assistance provided in daily living activities and hours per day spent assisting the persons with SCI were strongly correlated with depression in caregivers. Kester and co-workers¹¹ found that wives of persons with SCI reported a greater number of health problems than the normal controls.

SCI cases occurring after the marriage were reported to have more negative outcomes on the family system.¹² Carers experience significant burden, especially in the social role functioning and adjustment to the ongoing recovery process.^{13,14} De Vivo and Fine¹⁵ reported that people with SCI have fewer marriages and more divorces.

Another problem a primary caregiver has to deal with is the negative effects of this catastrophic event on the psychological health of the patient such as depression and attempted suicide.^{1,16,17} While spouses try to improve the quality of life of their patients with SCI through intensive care, their own quality of life may deteriorate. Therefore, allied professionals in spinal injuries care should be aware of psychological morbidity and quality of life states of the caregivers and spouses of SCI patients.

From this point of view this study was designed to investigate two main hypotheses. The first hypothesis was that primary caregivers of SCI survivors experience various problems due to this disorder which will result in a lower quality of life. The second was that some factors associated with the severity and medical consequence of the injury would cause an additional impact and would lead to a worse outcome regarding the quality of life of the primary caregiver.

Materials and methods

Fifty primary caregivers of spinal cord injury survivors living in the community and 40 healthy controls of the same age and sex range were included in the study. Mean ages were 38.26 ± 7.64 years in primary caregivers group and 37.30 ± 7.60 in healthy control group. Eighty-four per cent ($n=42$) of caregivers and 80% of controls ($n=32$) were female; no difference existed between the two groups for age and sex. Eighty per cent ($n=40$) of all caregivers were spouses.

All the patients were rehabilitated by the authors and they were followed-up regularly as out-patients. The primary caregivers accompanying the patients in follow-up visits were recruited. Healthy controls were recruited from the non-medical staff working in the rehabilitation centers where the study was conducted. All the subjects were informed about the study protocol and all of them signed the consent forms.

All the subjects completed SF-36 (Short Form-36) questionnaire forms. The major two aims were: (1) to determine the possible differences in quality of lives of primary caregivers of SCI survivors and the healthy controls living in the community and (2) to evaluate probable additional impact of some factors related to the severity of SCI on the primary caregiver's life quality.

Inclusion criteria for primary caregivers were: (1) living in the community with the spinal cord injured survivor as a primary caregiver; (2) being a primary caregiver who does not have any serious or chronic disorder occurred before and/or after the event; (3) being a primary caregiver who had not sought medical help for any reason at least in the last 3 months.

Inclusion criteria for healthy controls were: (1) having no serious or chronic disorder that could interfere with general quality of life; (2) not being a primary caregiver of any patient or disabled; (3) having never sought medical help for any reason at least in the last 3 months.

Demographic characteristics of all the subjects in both groups were recorded. Additional information about the education and level of income, drug and/or alcohol abuse or smoking habits of all the subjects were also collected.

Quality of life was measured using SF-36. Questionnaires were administered both to the primary caregiver and healthy control groups by interviewers who were psychiatrists and the authors of the present study. The SF-36 is designed for self-administration, telephone administration, or administration during a face to face interview with respondents aged 14 years of age and older.^{18,19}

All the patients were rehabilitated by the authors and data about the duration of injury, lesion levels, ASIA scores, degree of spasticity, presence of bladder and bowel incontinence and pressure sores were gathered from the hospital recordings and/or by physical examinations during control visits when the primary caregivers were administered the questionnaires. Spasticity was recorded as 0 (none) and 1, 2, 3, 4 according to Ashworth scale.²⁰ Pressure sores were recorded as 0 (none) and 1, 2, 3, 4 according to pressure ulcer grades.²¹ Bladder and/or bowel incontinence was noted as 0 (absent) and 1 (present). Caregivers were divided into three groups according to duration of spinal cord injury as 0–12 months, 13–48 months and more than 49 months by taking into consideration the dispersion. Lesion levels were recorded as cervical, thoracic and lumbar. ASIA grades according to 1996 revised standards were recorded as A, B, C, D and E.²²

SF-36 (short form-36)

The SF-36 health survey has 36 items and measures eight concepts: (1) limitations in physical activity due to health problems; (2) limitations in social activities due to physical or emotional problems; (3) limitations

in role activities due to physical health problems; (4) bodily pain; (5) general mental health; (6) limitations in usual role activity due to emotional problems; (7) vitality and (8) general health perceptions. Higher scores indicate better functioning and well-being.^{18,19}

The Turkish version of SF-36 was translated by Güler Fisek, PhD Prof. from Bosphorus University (Istanbul, Turkey) which was approved by MOS-Trust (originator of SF-36). This approved version has been tested in a study conducted in Turkey and found valid and reliable.²³

Statistical analysis

Descriptive statistics were used for the evaluation of the demographic data. The comparison of the SF-36 subscale scores were conducted using Analysis of Variance (One-way ANOVA). The first comparison was made between the primary caregivers and the healthy controls. The second comparison (One-way ANOVA) was between the primary caregivers' scores and the presence and degree of spasticity (which was categorized from 1 to 4); presence and degree of pressure sores (which was categorized from 1 to 4); bowel and bladder incontinence; lesion level (categorized into 3) and ASIA grades.

Results

Fifty primary caregivers of spinal cord injury survivors living in the community and 40 healthy controls of the same age and sex range were included in the study. SF-36 questionnaires were administered by interview method to all the subjects and the response rate was 100%; there was no drop-out in the study.

For the duration of SCI, caregivers were divided into three groups (according to the distribution) as those care giving since 0–12 months (44%), 13–48 months (40%) and >49 months (16%). Lesion level was cervical in 26%, thoracic in 44% and lumbar in 30% of the patients. ASIA grades of the patients were A in 36%, B in 30%, C in 16% and D in 18%.

Primary caregivers' and healthy controls' S-36 subscale scores were compared using analysis of variance. All SF-36 subscale scores except 'bodily pain' were significantly ($P < 0.05$) lower in primary

caregivers group compared to healthy controls (Table 1).

No significant relation by Analysis of Variance could be demonstrated between each eight SF-36 subscale scores of primary caregivers and bladder and/or bowel incontinence, lesion level, duration of injury, presence and/or degree of spasticity, presence and/or degree of pressure sores and ASIA grades respectively ($P > 0.05$). In other words, bladder and/or bowel incontinence, lesion level, duration of spinal cord injury, presence and degree of spasticity, presence and degree of pressure sores and ASIA grades had no significant effect on the eight SF-36 subscale scores of the primary caregivers.

No significant difference existed between the two groups in the aspects of education, income level, drug or alcohol abuse and smoking habits.

Discussion

According to the results, our first hypothesis was confirmed. But the data obtained in the present study seemed far from confirming the second hypothesis which suggests that some severity parameters related to the injury would result in a worse outcome in the primary caregiver's life quality.

Before discussion of these results, important characteristics of our study group should be remembered: 84% of all primary caregivers were female and 80% of them were spouses. Therefore the results will be discussed by giving more emphasis on female spouses although other family members and/or primary caregivers will also be taken into consideration.

Almost all the reports in this field share a common message regarding the negative effects of SCI on close family members, including the primary caregivers and/or the spouses.^{1,11,24–28} A majority of people with SCI are young adults and after this catastrophic event, they and their families have to live with disability and handicap for 3, 4 or even 5 decades.²⁴ During that time they will have to face immobility, physical dependence and vocational employment and financial problems. They will also encounter many barriers including the architectural and attitudinal. Eventually, most of these people will experience some

Table 1 Primary caregivers and controls means and standard deviations on SF-36 subscale scores

SF-36 health survey scales	Primary caregivers M (SD)	Controls M (SD)	P
Physical functioning	51.70 (36.57)*	74.38 (23.24)	0.001
Physical role	38.50 (38.86)*	77.50 (32.42)	0.000
Bodily pain	54.30 (25.75)	61.00 (22.62)	0.199
Vitality	55.40 (19.66)*	63.50 (14.29)	0.032
General health	45.86 (19.98)*	56.43 (19.96)	0.015
Mental health	44.72 (18.88)*	57.60 (16.12)	0.001
Emotional role	32.00 (40.94)*	83.33 (44.02)	0.000
Social functioning	48.00 (23.60)*	67.19 (19.13)	0.000

* $P < 0.05$

changes in self-esteem, in ability to cope with daily life and in many relationships with society. Eventually, quality of life will be affected for both the individual with SCI and his or her family members.^{1,11,24–28}

On the other hand, there are conflicting reports in the literature about the effects of the severity of spinal cord injury and/or the disability on the patient's life quality.^{29–32} But, to the best of our knowledge, the effects of the severity on primary caregivers' or other family members' quality of lives have never been investigated extensively. Manigandan *et al*³³ reported that while carers were psychologically distressed, they were not significantly depressed or anxious. In this study, the majority of the SCI patients were functionally independent and the authors explained the lack of correlation between FIM scores of patients and psychological distress of caregivers by this feature of their sample.³³ Kester *et al*¹¹ reported that general health and mental problems are more prominent in female spouses of patients with SCI compared to the healthy controls; a finding similar to the results of the present study.

The main finding of the present study is that the quality of lives of primary caregivers of SCI survivors are negatively affected as a whole, but factors associated with the severity of the injury seemed to have no more impact on well primary caregivers. Once a catastrophic event occurs, its severity seems to have minor importance. Cultural, ethnical and social factors among others might be effective in this finding. The effects of SCI (not the severity) on family have been extensively studied.^{1–5,25–28} It has been reported that the impact of SCI might lead to radical changes on the roles of the family members.¹ SCI creates a sense of vulnerability in the patient's spouse in terms of the security of the marital relationship. Spouses have also reported that they have a stronger fear of separation and a higher sense of dependency as a result of SCI.^{1,26,27} The spouses of SCI patients who in most cases are also the carers were reported to have much stress related to the injury in aspects of financial, psychological, marital and social relationships.^{9,11,13} Kreuter²⁸ reported that care giving often changes the balance of power in the marriage. According to the author, partner relationships seem to be impacted by SCI; although not as much as is widely believed. Manigandan *et al*³³ reported that carers' low education, and patients' suicidal and aggressive behaviour were found to be significantly associated with carers psychological distress. The variability in reports might be due to cultural differences, changes in family life in society in general and the different methodologies used.²⁸

Considering that the majority of the primary caregivers were female spouses in the present study, one should take into account the cultural background and especially the patriarchal family structure which is very common in this country. Generally in normal population and under normal conditions being a

caregiver is a usual task of a woman who is relatively less educated and more economically dependent than the man in most of the families in underdeveloped or developing countries. Factors such as fear of separation and economic dependency on the family may force female spouses of SCI survivors more concentrated in their care giving task in such societies. On the other hand care giving cannot easily change the balance of power in the marriage in a patriarchal family.

Whether these facts can or cannot explain, the insignificant relation between the quality of lives of the caregivers (or spouses) and the severity of the complications, needs further investigation.

This study has some limitations among which, more importantly, seems to be the lack of an additional psychological outcome measure testing. But the approved Turkish versions of such outcome measures are still lacking in Turkey. Another limitation is the lack of the national mean values of SF-36 scores; since the scores for healthy Turkish population have not been studied or reported, we considered a healthy control group of the same age and sex for comparison. Approved version of SF-36 Health Survey, on the other hand, has been tested in a study conducted in Turkey and found valid and reliable.²³

The SF-36 is designed for self-administration, telephone administration, or administration during a face to face interview with respondents aged 14 years and older.^{18,19} These different modes of administration have some strengths and weaknesses. Interviewer method maximizes response rate, decreases missing items and minimizes errors of understanding but on the other hand, requires many resources, training of interviewers and may reduce willingness to acknowledge problems. Self administration requires minimal resources but in this method there is a greater likelihood of low response rate, missing items and misunderstanding.³⁴

Interview was chosen as the mode of administration of SF-36 in the present study. During a direct interview, people may not report all the problems and there is always a risk of bias due to the relationship (being in a position of dependence) between the primary caregiver and the interviewers, but if it is remembered that quality of life is a subjective concept, we have to consider the information, provided directly from the caregiver, valid.

In spite of some limitations, one clear message could be drawn from this study and that is, being a primary caregiver of a SCI survivor in Turkey significantly interferes with quality of life. On the other hand, according to the results obtained in our sample, severity and/or some medical consequences of the injury such as bladder and bowel incontinence, pressure sores, spasticity and completeness of the injury according to ASIA scores do not seem to have an additional impact on the primary caregiver's life quality.

Acknowledgements

The authors wish to thank Professor G Fişek PhD, and C Demirsoy MD, for their collaboration in this study.

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