# ORIGINAL ARTICLE The effects of using the internet on the health-related quality of life in people with spinal cord injury: a controlled study

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Study design: Prospective cohort study.

**Objectives:** To compare the health-related quality of life (HRQoL) in people with spinal cord injury (SCI) who use the Internet versus those who don't and with a control group of able-bodied individuals. To investigate the frequency of Internet usage before and after injury. To evaluate the differences in terms of demographic features of both groups, analyze the variation in the Internet usage pattern of people with SCI before and after the injury.

Setting: Istanbul, Turkey.

**Methods:** A total of 60 people with SCI (38 Internet users, 22 nonusers) were included in the study. The control group consisted of 33 healthy persons of similar age and sex. The HRQoL was evaluated with the SF-36 Health Survey.

**Results:** The scores of all the subscales of the SF-36, except vitality, were significantly lower in people with SCI than those of the controls'. The bodily pain subscale and physical component scores were found to be significantly higher in people with SCI using the Internet than the nonuser group with SCI (P<0.05). The Internet usage frequency increased significantly in people with SCI after injury (P<0.05). A significant correlation was found between time since injury and Internet use (r=0.365, P=0.007).

**Conclusion:** Although HRQoL scores were lower in people with an SCI, the physical status component score was better in the Internet user SCI group. As there is a significant increase in the time spent online after injury, the Internet could be an effective modality to contact and educate people with an SCI.

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### INTRODUCTION

As life expectancy increases in people with spinal cord injury (SCI), the health-related quality of life (HRQoL) and participation outcomes become increasingly important for this group.<sup>1,2</sup> However, people with an SCI face serious problems including health, education, employment issues as well as physical barriers in the activities of daily living.<sup>3</sup> Therefore, they continue to experience the disadvantage of their disability.

The Internet is a global network of interconnected computers. It carries an extensive range of information and provides people who use it to access distant resources. Turkey has had public Internet access since 1993, and ADSL since 2003. 3G, high speed fiber optic Internet and VDSL are also available. According to the Turkish Statistics Office, half of the households have internet access as of 2013. The average minimum speed is 8 Mbit/s and up to 100 MBit/s speed is available. Many experts believe that the opportunities provided by the Internet and using the computer may be effective for promoting the health, well-being, activity and participation of individuals with an SCI.<sup>4</sup> The Internet may allow individuals with an SCI to overcome barriers in the physical world and to accomplish their daily and professional goals such as shopping for groceries, completing online educational courses and networking (socially or professionally).<sup>3</sup>

SCI has a sudden impact on the life of affected individuals, and the main challenge is to keep oneself informed, set personal goals, deal with social and physical barriers so as to self-actualize, keep autonomy and conduct life in a positive way. In a theoretical framework, the Internet, with its tremendous resources, could independently add new skills and value to life of people with an SCI. In light of ongoing new developments in this field, the adaptation of people with an SCI could be expected to be quicker and near normal in the developed and/or developing countries, which have access to the Internet and new technologies.<sup>5</sup>

In this study, we aimed to compare the HRQoL in people with an SCI using the Internet versus those who did not use the Internet and a control group of able-bodied individuals, to evaluate the differences in terms of demographic features of the groups and to analyze the variation in the Internet usage pattern of people with an SCI before and after the injury, if any.

#### MATERIALS AND METHODS

This study was conducted between 1 October, 2011 and 31 May, 2012 in a Physical Medicine and Rehabilitation Training Hospital. A total of 102 people with an SCI who had been hospitalized since 2008, and then discharged upon completion of the inpatient rehabilitation programme, were initially included

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in the study. Forty-two patients could not be reached due to the change in contact information. We contacted 60 people with an SCI who completed the inpatient rehabilitation programme in the Physical Medicine and Rehabilitation Training Hospital in Istanbul. Inclusion criteria for participants included being in the age group compatible with the administration of the SF-36 Health survey, ability to speak and understand Turkish and having been discharged for at least 1 month before the interview. Exclusion criteria included a documented head injury or cognitive deficits that might prevent participation in abstract thought and reasoning required for the understanding and completion of the questionnaires, and the presence of a coincident impairment, which might influence the physical and mental health scores of the questionnaires. A control group consisting of 33 healthy subjects with similar sex distribution and with a mean age 37.5  $\pm$  12.8 years was included in the study. The control group selection was based on a random population sample, which excluded institutionalized people.

The interviews were conducted by telephone, face-to-face interview and internet communication. The duration of the interview was approximately 30 min and no patient refused to complete it. During the interview, patients were questionned about their internet use habit and their internet access facility as well.

The Turkish version of the SF-36 Health Survey was used to measure HRQoL. The questionnaire was tested in a study conducted in Turkey and found to be valid and reliable. <sup>6</sup> Scores for subscales range from 0 to 100, with higher scores indicating a better health state. The SF-36 was constructed to represent eight of the most important health concepts including physical functioning, physical roles, bodily pain, general health, vitality, social functioning, role-emotional and mental health, and designed for self-administration, telephone administration or administration during a face-to-face interview with respondents aged 14 years and older. In this study, scoring rules for the developmental version of the SF-36 were used.<sup>7</sup> The ethics committee approved the protocol of the study. Informed consent was obtained from the patients.

#### Statistical analysis

The study group was divided into two subgroups with regard to Internet use. The SF-36 scores were obtained for both the study subgroups and the controls. The Kolmagorov-Smirnov and Shapiro-Wilk tests were used to evaluate the distribution of variables, as applicable. The ANOVA and post hoc Tukey analysis were performed to compare the age among people with an SCI using Internet, non-Internet users with an SCI and the control group. The Chi-Square test was used to compare the gender distribution among the three groups including the study subgroups and the healthy control group. The Student-t test was used to compare parametric values. The Mann-Whitney U-test was used to compare the SF-36 subscales and the education level in people with an SCI using the Internet vs non-users and the controls. As there were three hypotheses to be tested, Bonferroni correction was done and the P-value was set as P < 0.0167 (= 0.05/3). The educational status was divided into four categories being as literate, primary school, high school and more than high school, and then was compared by Chi-Square test with regard to Internet usage. The frequency of Internet use was divided into five subgroups as follows: (1) everyday, (2) more than 1 day per week, (3) a day per week, (4)monthly, (5) less than monthly. The Mc Nemar test was used to compare the frequency of Internet usage before and after the injury. The comparison was found to be significant, and then Internet usage was dichotomised into two groups: usage less than or equal to a month and usage of more than a month. The significance was re-evaluated by using the Mc Nemar test. Spearman's Rank Order correlation test was used for correlations between neurologic level and Internet usage frequency, Internet usage and age, time since injury. Partial correlation was used between time since injury and Internet usage after adjusting for age. The statistical significance was set at the 0.05 level. SPSS 16.0 version was used for the analyses.8

#### RESULTS

Thirty-eight people with an SCI using Internet with a mean age and s.d.  $32.9 \pm 10.3$  years, and twenty-two non-Internet users with an SCI with a mean age and s.d.  $51.0 \pm 13.1$  years were included in the study.

Demographic features of the study subgroups and the control group are presented in Table 1. The gender and age characteristics of the study's subgroups were normally distributed. No significant difference was found between the groups in terms of gender distribution (Chi- square = 0.574, df = 1, P = 0.449). The mean age was significantly higher in the non-Internet user SCI group than the group with an SCI using Internet and the control group (at the levels P = 0.000, df = 57 and P = 0.000, df = 69, respectively) as calculated by the one-way ANOVA *post hoc* Tukey analysis.

The educational level was significantly different between the two subgroups in people with an SCI (P = 0.003, df = 58). The educational status was then divided into two subgroups; those being less than or more than high school. The two subgroups were recompared

# Table 1 Demographic features of people with spinal cord injury and the control group

	People with an SCI using Internet (n = 38)	People with an SCI Internet non-users (n = 22)	Control group (n = 33)
Age, y, mean±s.d.	32.9±10.3	51.0±13.1	37.5±12.8
Time since injury month	(16-36)	(19-75)	(16–70)
moon + s d	(14 432)	(6, 360)	
Gender $n$ (%)	(14-432)	(0-300)	
Female	6 (15.8)	5 (22 7)	11 (33 3)
Male	32 (84.2)	17 (77.3)	22 (66.7)
Educational status n (%)			
Literate	2 (5.3)	0	
Primary school	14 (36.8)	19 (86.4)	
High school	21 (55.3)	3 (13.6)	
More than high school	1 (2.6)	0	
Marital status n (%)			
Married	12 (36.6)	18 (81.8)	
Single	26 (73.4)	4 (18.2)	
Employment status at time of			
interview n (%)			
Employed	4 (10.5)	1 (4.5)	
Student	2 (5.3)	0	
Unemployed	25 (65.8)	20 (91)	
Retired	5 (13.2)	0	
Other	2 (5.2)	1 (4.5)	
Neurologic category n (%)			
Paraplegia complete	15 (39.5)	3 (13.8)	
Paraplegia incomplete	15 (39.5)	15 (68.2)	
Tetraplegia complete	2 (5.3)	1 (4.6)	
Tetraplegia incomplete	6 (15.8)	3 (13.6)	
Etiology of SCI n (%)			
Traumatic (falls and motor	25 (65.8)	3 (59.1)	
vehicle crashes)			
Sports injuries	3 (7.9)	1 (4.5)	
Acts of violence	6 (15.8)	0	
Work-related injury	1 (2.6)	2 (9.1)	
Other	3 (7.9)	6 (27.3)	
Abbreviation: SCI, spinal cord injury	/.		

#### Table 2 Comparison of SF-36 scores of people with an SCI subgroups and controls

	People with an SCI using Internet ( $n = 38$ ) mean $\pm$ s.d.	People with an SCI Internet non-users ( $n = 22$ ) mean $\pm$ s.d.	Controls (n = 33) mean $\pm$ s.d.	P-value <sup>a</sup>	P- <i>value</i> <sup>b</sup>	P-value <sup>c</sup>
Physical functioning	$17.8 \pm 19.4$	12.0±22.3	91.5±13.8	>0.05	0.000	0.000
Role-physical	31.6±36.2	$16.1 \pm 26.0$	$90.2 \pm 26.5$	>0.05	0.000	0.000
Bodily pain	57.6±30.3	38.9±26.9	75.9±26.8	0.012	0.011	0.000
General health	57.4±22.8	48.7±21.4	73.9±20.2	>0.05	0.003	0.000
Vitality	58.4±21.7	52.0±22.9	$64.2 \pm 17.0$	>0.05	>0.05	> 0.05
Social functioning	50.0±23.2	47.7±31.3	82.6±21.2	>0.05	0.000	0.000
Role-emotional	44.7±46.7	34.9±45.41	$73.7 \pm 35.1$	>0.05	0.01	0.002
Mental health	$61.7 \pm 17.4$	58.4±20.8	$71.3 \pm 15.5$	>0.05	0.013	0.026
Physical component score	$44.5 \pm 18.6$	33.6±18.1	$79.1 \pm 17.1$	0.017	0.000	0.000
Mental component score	$54.4 \pm 19.3$	48.3±21.4	$73.1 \pm 16.0$	>0.05	0.000	0.000
Total SF-36 score	$47.4 \pm 18.2$	$38.6 \pm 18.7$	$77.9 \pm 16.5$	>0.05	0.000	0.000

Abbreviation: SCI, spinal cord injury.

<sup>a</sup>Significance between the values of people with an SCI using the Internet and non-users (Mann–Whitney U-test).

<sup>b</sup>Significance between the values of people with an SCI using the Internet and controls (Mann–Whitney U-test).

<sup>c</sup>Significance between the values of non-Internet users with an SCI and controls (Mann-Whitney U-test).

according to the cutoff value set for educational level. An educational level of high school or more than high school was found to be significantly higher in Internet-users with an SCI than non-users with an SCI (Chi-square = 8.82, df = 1, P = 0.001).

The scores of all the dimensions of the SF-36, except vitality, were significantly lower in people with an SCI who were using or not using the Internet than the controls' as shown in Table 2. Bodily pain subscale and physical component scores were found to be significantly higher in people with an SCI using the Internet as compared with the non-user group with an SCI (P=0.012, df=58 and P=0.017, df = 58, respectively) (Table 2). The *P*-value was found to be significant for the bodily pain subscale and remained in the limit of significance for physical component scores after Bonferroni correction. However, no significant difference was found in terms of the other SF-36 subscales for these SCI subgroups (P > 0.05, df = 58). Then, we compared the group of SCI as a whole with the control group for statistically nonsignificant subscales. The scores of the SF-36, except vitality, were again found to be significantly lower in people with an SCI than the controls' (P < 0.01, df = 91). No significant difference was found between the SCI subgroups in terms of neurologic category (P > 0.05, df = 58).

The neurological level was also ranked from the most rostral to the caudal segment gradually. No significant difference was found in terms of neurological level (df=52) and time since injury (df=51) between people with an SCI in the two subgroups (P>0.05).

The before and after injury Internet usage frequencies are shown in Table 3. A significant difference was found in the frequency of Internet usage following the injury in people with an SCI using Internet (P = 0.001, df = 7, contingency coefficient = 0.534). The cutoff value of Internet usage was set as equal to or more than a month. Twenty-one people with an SCI were not using the Internet or using it at a frequency of less than a month before injury. Twenty people with an SCI started to use the Internet more frequently after the injury. Only one individual remained in the same 'less than a month' frequency group after injury. The comparison of the before and after injury frequencies in the Internet user subgroup according to the cutoff value was found to be significant at P = 0.000 level (df = 1). People with an SCI using the Internet started to use it more frequently after injury.

No significant correlation was found between the frequency of Internet use and the injury level (P > 0.05, df = 34). Table 4 shows the

## Table 3 The frequencies of Internet usage in people with an SCI before and after the injury

	<i>Before injury</i> (n = <i>38</i> )	After injury (n = 38)
Daily	8	22
More than 1day per week	5	9
A day per week	2	4
Monthly	2	2
Less than a month	21	1

Abbreviation: SCI, spinal cord injury. Twenty-one people with an SCI did not use the Internet or used it in a frequency of less than a month before injury. Twenty people started to use the Internet more frequently after injury. Only one individual remained in the same category of 'less than a month frequency'.

## Table 4 The reasons to use Internet before and after injury in people with SCI

	Before injury <sup>a</sup> (n = $38$ )	After injury <sup>b</sup> (n = 38)
Education-school	6	4
Professional (work)	5	2
Personal needs (ex:shopping)	3	6
Social (ex: networking with friends)	11	29

Abbreviation: SCI, spinal cord injury. Numbers were calculated as the sum of the options marked by the patients on the survey. Twenty-one people with SCI were not using the Internet or were using it in a frequency of less than a month before injury.

<sup>a</sup>Five people with SCI marked more than 1 reason on the survey for use before injury. <sup>b</sup>Three people with SCI marked more than 1 reason on the survey for use after injury.

presentation of the survey regarding the aim of Internet use among people with an SCI before and after the injury. As can be seen on Table 4, the main purpose to use Internet among people with an SCI was social entertainment.

A significant correlation was found between time since injury and the Internet use (r = 0.37, P = 0.007, df = 52). As time since injury lengthens, Internet usage increases. The correlation remained significant even after adjusting for age (r = 0.38, P = 0.004, df = 49).

## DISCUSSION

The main findings in our study were as follows: (1) all the subscales of the SF-36, except vitality, were significantly lower in both SCI subgroups, (2) a perception of less pain was found in people with an SCI using the Internet than non-users, (3) better physical status as determined by a higher physical component score was found in people with an SCI who were using the Internet than that of non-users' (4) approximately half of Internet-users with an SCI started using the Internet more frequently after injury, (5) online social entertainment was the main purpose that people with an SCI used the Internet in this study.

We think the results of this study reflect the daily social life and HRQoL perception of relatively young people with an SCI in Turkey, having a middle educational level, who started to use a new networking system, the Internet, more frequently.

Physical component scores and bodily pain scores in this study were significantly higher in people with an SCI who were using the Internet, whereas both groups were similar in terms of neurologic level and time since injury. Drainoni *et al.*<sup>9</sup> found in their study that self-reported HRQoL improved for those given first-time Internet access. They concluded there was a marked improvement in outcomes from nonuse to rare use and then no further effect for frequent use. In contrast, they found there was even a slight detrimental effect from rare to frequent use in the case of health status and occupational score.<sup>9</sup> We think the results of our study are similar to those of Drainoni *et al.*<sup>9</sup> The Internet seems to work as an alternative tool for communication so as to contact friends and overcome physical barriers in the activities of daily living via online access.

A major concern regarding spending time using the Internet is whether people with an SCI stay in a certain position longer than before, and put themselves at risk of immobilisation such as pressure sores. We think this issue needs to be evaluated in detail in future research.

Although there was a finding of less pain perception from the SF-36 Health survey perspective for the SCI subgroup using the Internet, further study would need to determine the reason for this.

Goodman et al.<sup>10</sup> found in their study that 15% of respondents used chat rooms. Doble et al.<sup>11</sup> found that patients with locked-in syndrome, including people with an SCI experience an increase in communication with family and friends at 11 years related to technology use.<sup>10</sup> At least 52% of respondents increased the time they spent using the Internet after injury, and 76% of people with an SCI used the Internet for social entertainment in our study. The major trend to use Internet seems to be social integration and social support according to the results of this study. These findings could support the assumption that people with an SCI using Internet have increased autonomy over their social life. However, both subgroups of people with an SCI exhibited lower scores than the controls approximately in all domains of HRQoL measurement. Although Internet access could be a new way to fulfill personal needs, the basic expectations of people with an SCI seem to remain the same as before the injury regardless of the presence and availability of technology (for example, walking and so on).

The strength of this study is that it is the first one in Turkey that evaluates the effects of Internet on the HRQoL in SCI to our knowledge. The limitation of the study is that the low number of participants limits the generalisability of the results. The spread of Internet use among people with an SCI seems to be similar to the use of the Internet in Turkey in general. Relative high costs of getting Internet connection at home could be a limitation of Internet usage. In conclusion, the HRQoL scores were lower, except for vitality, in people with an SCI. Physical status was better in people with an SCI who were using the Internet. Moreover, the findings of this study point out that the Internet could be an effective modality to contact people with an SCI. Time spent online for entertainment might need to be reset in the SCI group in a way more useful such as online educational programmes, email reminders and so on. People with an SCI using the Internet could be potential candidates to access information more easily about the new developments in the field of SCI, to increase self- awareness about routine daily health practices and to gain new skills for future employment and paticipate in society.

### DATA ARCHIVING

There were no data to deposit.

## CONFLICT OF INTEREST

The authors declare no conflict of interest.

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