Quality of Life (QoL) of People with Spinal Cord Injury (SCI) in Western Greece

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Abstract: Community living individuals with SCI face major health-related QoL challenges, especially in countries such as Greece, due to the lack of infrastructure and support networks. The aim of this study is to evaluate QoL of people with SCI who have already completed the rehabilitation program and live in the geographic area of Western Greece and to identify the clinical and demographic factors that affect QoL in this population. Thirty-six individuals with SCI living in Western Greece participated in this study. We used World Health Organization Quality of Life BREF (WHOQOL-BREF) questionnaire to estimate their QoL levels. Additional data were collected by clinical measurements and a demographic questionnaire. The mean age of the sample was 45.1±9.8 years, the mean time since injury was 13.1±11.7 years and 89% of the participants were male. The mean values of QoL parameters ranged from 56.6±16.6 up to 100 (physical health) to 67.7±18.1 up to 100 (environment). Lower education level (p = 0.035) and married life (p = 0.006) are associated with higher QoL levels regarding environment and social relationships respectively. Additionally, as time since injury passes, the aspect of Qol that is related with social relationships improves (p = 0.04). The study documents relatively high rates of QoL in the population of individuals with SCI in Western Greece. Married life, low educational level and long time post injury are determinants of high QoL levels in this population.

Keywords: Spinal Cord Injury, Quality of Life, Physical Activity, Pressure Ulcers, Urinary Incontinence

1. Introduction

Spinal cord injury is a severe medical condition, which may result in paralysis, sensory deficits and sphincter dysfunction [1]. People with acquired SCI, after completing the inpatient rehabilitation program and enter community life, they face major health-related QoL challenges, regarding well-being, social participation and ability to perform activities of daily life [2]. The technology development during the last decades has promoted QoL of individuals with SCI· the wide use of computer assisted technology and the advances in motor devices have enhanced the ability of those people to have access in knowledge, education, and work, to travel and to participate in leisure activities [3].

Previous studies have identified the major factors that affect QoL of individuals with SCI in various countries and regions. Age, time passed since the injury, gender, marital status, level of injury, employment status, education level and presence of pain or pressure ulcers (PUs) are the main variables that have been thoroughly examined in literature [4-7]. There is a general consensus that short time since the injury, pain and PUs are the main predicting factors of low QoL levels in various populations of people with SCI [4-7].

However, every country has its own structural and cultural characteristics that differentiate the profile of challenges for persons with SCI. In Greece, there is a lack of policies for support and infrastructure for people with disabilities [8]. On the other hand, family and social networks play an important supportive role in an individual's life which compensates for these difficulties [9]. The aim of this cross-sectional study is to evaluate the levels of QoL of people with SCI that live in Western Greece and to highlight the major sociodemographic and clinical factors that tend to limit the QoL levels in this

population.

2. Methods

Participants, design and setting

Thirty-six individuals with SCI of several causes living in the Prefecture of Western Greece cooperated for the implementation of the current scientific project. The recruitment of the sample was enhanced by having access to the medical archives of outpatients and previous inpatients of the Spinal Cord Injury Rehabilitation Department of the University Hospital of Patras which is the only SCI institution in Western Greece. The local association of people with SCI also collaborated with the research team in order to detect the whole SCI population of this region. Thirty-six out of fifty persons with SCI found in Western Greece approved to participate in this study. The collection of the data took place during the term from August 2018 to October 2018.

Inclusion criteria

We included in this study both male and female individuals with SCI that had already completed a rehabilitation program and had been living in the community for at least one year. We also included both paraplegic and tetraplegic persons with all classes of severity of SCI according to the American Spinal Injury Association (ASIA) classification. However, we excluded persons with SCI that presented with concurrent traumatic brain injury or with cognitive deficits of any reason. We also excluded people with SCI that were aged<18 years and those that were not fluent Greek language speakers.

Hypothesis

We hypothesized that QoL levels of individuals with SCI in Western Greece would be similar to those that were found in previous literature regarding the whole country. We also hypothesized that the presence of PUs and unemployment would be determinants of low levels of QoL in this population of people with SCI.

Questionnaires

World Health Organization Quality of Life BREF (WHOQOL-BREF) questionnaire was administered to all participants along with a demographic questionnaire in interview form and clinical evaluation. The WHOQOL-BREF scale was utilized in order to assess QoL. The WHOQOL project was initiated in 1991 in purpose of developing an international cross-culturally comparable QoL measurement tool [7]. It evaluates the individual's perceptions regarding their culture and principle systems, along with personal ambitions, standards and worries [10]. The WHOQOL-BREF is the brief version of the original tool. It consists of 26 items that assess four broad domains: physical health, psychological well-being, social relationships, and environment. It is generally approved as useful in large research projects or clinical trials [11, 12]. However, the demographic questionnaire included information concerning age, gender, marital status, place of residence, injury date, educational level and occupation profile. The clinical assessment provided information regarding the level of injury (paraplegia or tetraplegia), the existence of pressure ulcers, the report of urinary incontinence symptoms and the involvement of the participants in physical activity during the last six months. We also used the American Spinal Injury Association Impairment Scale (AIS), which is consistent with the ASIA neurological classification system, in order to evaluate the severity of the SCI [13]. Furthermore, we used the 0-10 point pain scale to assess the intensity of pain of the respondents, asking them to self-grade their pain degree during the last week.

Ethical issues

This study had obtained approval from the University Hospital of Patras Ethics Committee. All participants that were consisted with the inclusion criteria were asked to participate after getting an explanation of the study's aims and information about being entitled to withdraw from the study whenever they want with no consequences. The participants were also asked to sign a consent form that fully complied with the rules of the Helsinki declaration and the Hellenic State Medical ethics legislation (Hellenic State Law No. 3418/2005). Thus, we confirm that all relevant institutional and administrative regulations regarding the ethical participation of human volunteers were adhered to during the setting of this scientific research.

Statistical analysis

The data is expressed as means ± standard deviation (SD) for continuous parameters and as percentages for categorical variables. The normality of the distribution of the variables was measured with the Kolmogorov-Smirnov test and the normal probability plot. The bivariate analysis was performed using the Student's t-test in order to investigate the correlation between the dependent parameter (instrument's scores) and the qualitative variables. Pearson's correlation coefficient was utilized to explore the correlation between each dependent parameter and the quantitative variables. A p-value of <0.05 indicated statistical significance. All analyses were made utilizing the statistical package SPSS version 17.00 (Statistical Package for the Social Sciences, SPSS Inc., Chicago, Ill., USA).

3. Results

The mean age was 45.1±9.8 years, the mean time since the initiation of the disability was 13.1±11.7 years and 89% of the participants were male. They were also primarily graduates of primary or secondary school (83.3%) and they resided mainly in urban territories (72.2%). However, the majority of the participants were unmarried (61.1%) and only the 16.7% of the sample was professionally active (students and working people). The sociodemographic characteristics of the sample are presented in Table 1.

The participants were mainly paraplegic (83.3%) and with a motor complete injury, namely classified as A or B in AIS (63.9%). They also mainly presented without PUs (83.3%) and without reported symptoms of urinary incontinence (58.3%). Furthermore, the majority of the sample (72.2%) was involved in physical activity during the last six months

(72.2%). Moreover, the participants' pain score during the week prior the evaluation was 4.2±2.4, measured according to the 0-10 point pain scale. The clinical features of the sample are presented in Table 2.

The mean values of QoL parameters in our sample according to WHOQOL-BREF scale were 56.6±16.6 up to 100 (physical health), 65±18.2 up to 100 (psychological), 65.5±24.8 up to 100 (social relationships) and 67.7±18.1 up to 100 (environment).

Gender, place of residence, occupation status, level of injury, AIS, presence of PUs or urinary incontinence, involvement in physical activity, age, and pain intensity had no statistically significant correlation with any of the four QoL domains of WHOQOL-BREF scale. On the other hand, married participants presented with higher WHOQOL-BREF scores regarding social relationships than the unmarried ones (p = 0.006) and those who have graduated from tertiary education presented with lower WHOQOL-BREF scores regarding environment than those with lower education level (p = 0.035). Furthermore, as the participants were more years far apart the injury, they exhibited higher WHOQOL-BREF scores regarding social relationships (r = 0.343, p = 0.04).

***Table 1.** Sociodemographic characteristics of the sample.*

		N	%
Gender	Male	32	88.9
	Female	4	11.1
Marital status	Married	14	38.9
	Unmarried	22	61.1
Place of residence	Urban	26	72.2
	Suburban/Rural	10	27.8
Educational level	Primary/Secondary	30	83.3
	Tertiary	6	16.7
Occupation	Unemployed/Pensioner	30	83.3
	Working/Student	6	16.7
	Mean	SD	Min	Max
Age	45.1	9.8	29	74
Years post Injury	13.1	11.7	1	39

***Table 2.** Clinical characteristics of the sample.*

		N	%
Type of SCI	Paraplegia	30	83.3
	Tetraplegia	6	16.7
AIS	A, B (motor complete)	23	63.9
	C, D, E (motor incomplete)	13	36.1
Pressure ulcers	No	30	83.3
	Yes	6	16.7
Urinary incontinence	No	21	58.3
	Yes	15	41.7
Physical activity	No	10	27.8
	Yes	26	72.2
	Mean	SD	Min	Max
Pain score	4.2	2.4	0	10

***Table 3.** Correlation of WHOQOL-BREF with qualitative measurements of the sample.*

	WHOQOL –BREF Physical Health		WHOQOL –BREF Psychological		WHOQOL –BREF Social Relationships		WHOQOL –BREF Environment	
	mean±sd	p	mean±sd	p	mean±sd	p	mean±sd	p
Male	57±16.7	0.562	67.1±16.4	0.178	68.6±24.1	0.433	69.1±16.8	0.098
Female	53.5±17.9		48.8±26.6		40.8±15.6		56.5±26.7	
Unmarried	57.3±15.3	0.602	61.7±19	0.528	59.4±27.7	0.006	67±19.4	0.188
Married	55.6±19.1		70.2±16.2		75.1±15.7		68.9±16.5	
Primary/Secondary education	57.1±17.4	0.689	64.9±19.6	0.15	69±23.5	0.655	69.6±19.1	0.035
Tertiary education	54.5±13.4		65.7±9.5		48±25.4		58.5±7.8	
Urban	58.3±16.9	0.994	67.6±17.7	0.816	66.2±25.2	0.631	65.9±18.1	0.6
Rural -suburban	52.2±15.9		58.3±18.8		63.9±24.9		72.5±18.1	
Non-working	55.6±17	0.547	63.1±18.3	0.893	64.7±24.7	0.694	68.1±18.3	0.838
Working/ students	61.8±15.1		77.8±15.4		69.8±27.1		65.8±18.4	
Paraplegia	57.1±15.1	0.881	65.6±16.9	0.242	64.4±24.4	0.555	66.6±18	0.845
Tetraplegia	54.2±20.5		62.3±25.6		71±28		73.2±19.2	
Pressure Ulcers YES	53.3±15.3	0.976	63.7±16.8	0.939	64.7±28.8	0.663	61.7±21	0.462
Pressure Ulcers NO	57.3±17		65.3±18.8		65.7±24.4		68.9±17.6	
Urinary Incontinence YES	59.8±15	0.549	66.4±20.6	0.477	67.9±22.6	0.432	67.7±19.6	0.881
Urinary Incontinence NO	54.4±17.7		64±16.8		63.8±26.6		67.7±17.4	
ASIA A, B	59.8±16.2	0.859	66.4±20.5	0.322	65.3±25.4	0.716	66.8±20	0.112

	WHOQOL –BREF Physical Health		WHOQOL –BREF Psychological		WHOQOL –BREF Social Relationships		WHOQOL –BREF Environment	
	mean±sd	p	mean±sd	p	mean±sd	p	mean±sd	p
ASIA C, D, E	51±16.5		62.5±13.6		66±24.4		69.3±14.7	
Physical Activity YES	57.7±15.8	0.568	68.1±14.5	0.124	67.8±24.7	0.668	69.4±16.7	0.229
Physical Activity NO	54±19.2		57.1±24.7		59.5±25.3		63.3±21.8	

Table 4. Correlation of WHOQOL-BREF with quantitative measurements of the sample.

	WHOQOL – BREF Physical Health		WHOQOL – BREF Psychological		WHOQOL – BREF Social Relationships		WHOQOL – BREF Environment	
	R	p	R	p	R	p	R	p
Age	-0.144	0.402	-0.127	0.460	-0.069	0.688	-0.038	0.824
Years post SCI	0.209	0.221	0.121	0.482	0.343	**0.04**	0.224	0.189
Pain intensity	0.284	0.093	0.268	0.114	0.186	0.277	-0.013	0.940

R: Pearson's correlation coefficient.

4. Discussion

The results of this study show that QoL levels in people with SCI in Western Greece are slightly higher than those reported in other European countries [4, 5]. However, we did not find any difference in comparison with results from the whole Greek territory according to previous data [9]. Although people with SCI in Western Greece face major limitations regarding mobility, accessibility (streets, buildings, transportation, etc) and work opportunities due to the lack of the essential policies [8], other factors such as the traditional family support network, the supporting role of church, the existence of a free access Public Health Care System, and the Greek culture, that is characterized by warm human relationships, are of greater significance [14]. Furthermore, the foundation and operation of the Rehabilitation Department for Patients with SCI during the last years provides high level medical, nursing and psychological surveillance and support. The Department has also empowered the formation of networks between people with SCI and it has enhanced their involvement in sports activities, promoting their social life and relationships [15].

Despite that previous studies have reported that women with SCI are characterized by decreased vitality and vigor [6], and with a higher rate of medical, social and psychological problems [16] compared with men, in our sample women and men showed equal levels of QoL. We also found that married people with SCI in this region exhibit greater QoL in the domain of social relations. This result is consistent with other studies that have reported that living with a spouse is associated with lower depression rates, better psychological well-being and increased social participation [17, 18].

Our findings regarding decreased QoL among people that have graduated from tertiary education could attributed to the fact that high education level is often associated with jobs with increased working stress. This is contrary to studies from other countries [19-22]. Specifically, it has been reported that education in patients with SCI enhances job finding, especially jobs with higher income, which provides access to goods and recreation [19], and improves confidence and self-efficacy [21]. Moreover, despite our findings, employment has been identified as having a positive effect on QoL, enhancing social

relationships, interaction with community and adoption of productive social roles [6, 7]. However, in our sample, only 16.7% of the participants declared having a job, which is a very low number considering that the mean age was 45 years. This finding could be partially explained by the high unemployment rate in Western Greece during data collection (>20%) and by the existing benefit policies, that lead individuals with SCI to prefer retirement instead of continuing working or searching for a job.

Contrary to our results, age has been reported as a factor that affects QoL of people with SCI [5, 23]. More specifically, as age increases, it seems to deteriorate QoL by worsening health level, due to multiple co-morbidities and increasing fatigue and disability in the elderly [5, 23]. However, long time since the initiation of the disability had a beneficial effect in QoL in our sample. This is consistent with part of the literature [6, 19] and attributed to the improvement of psychology and self-perception of health state of people with SCI as time passes, while other authors did not find any significant correlation [23, 24]. Furthermore, there was no difference in QoL between residents of urban and rural areas in our sample. This is consistent with previous results from the whole country [9], while a study from Brazil found that residing with SCI in urban areas is associated with a greater level of satisfaction with life compared to those living in rural areas [25].

The level of injury, the severity of the injury according to AIS, the presence of PUs, the lack of physical activity, the occurrence of urinary incontinence and the intensity of pain were not significantly correlated with QoL levels in our sample. However, other authors have reported that paraplegic individuals exhibit higher QoL than tetraplegic individuals, which is partly attributed to their higher independence level, their lower mobility limitations and therefore higher ability to work and to participate in leisure and social activities [5, 23]. Furthermore, the presence of PUs has been previously associated with low QoL levels, having a negative impact on self-care, mobility, self-esteem [26], physical and community functioning [7], independence in activities of daily life [24], and emotional status [25]. Moreover, pain has also been considered as a predictor of low QoL levels in persons with SCI, as it negatively affects mood, sleep, self-care and

mobility [27], it increases depression risk [28], it reduces satisfaction with life [28], and it restricts participation in recreation and leisure activities [27]. One the other hand, although Burke et al highlighted the significant and negative effect of pain, especially neuropathic pain and high intensity pain on QoL of people with acquired SCI, they identified simple pain existence as the most accurate predictor of low QoL levels regarding all the four domains of WHOQOL-BREF scale rather than pain intensity or pain type (neuropathic or nociceptive pain [29].

5. Study limitations

This study has various limitations. The size of our sample was relatively small and this resulted to a limited number of female and tetraplegic subjects. This could mean that it is disputable that the target population is represented accurately by our sample. In addition, the enrollment was voluntary and this could have an impact on the medical and demographic characteristics of the sample that limits the generalization of our findings. Another limitation of the study is the self-report method to evaluate pain which may be influenced by other variables such as depression.

6. Conclusions

This study documents similar to relatively high rates of QoL in the population of individuals with SCI in Western Greece in comparison with other countries and approximately similar rates with the rest of Greek territory. This could be interpreted by the easy and well-organized access to health services (good out-of-hospital follow up) and the steady medical surveillance by physiatrists in the SCI rehabilitation department of the University Hospital of Patras. Married life, low education level and long time since the initiation of the disability are determinants of high levels of QoL among people with SCI in this region.

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Conflicts of Interest

There are no conflicts of interest.

Abbreviations

SCI	Spinal cord injury
QoL	Quality of Life
WHOQOL	World Health Organization Quality of Life
PUs	Pressure ulcers
ASIA	American Spinal Injury Association
AIS	American Spinal Injury Association Impairment Scale

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