QUALITY OF LIFE IN PATIENTS WITH TETRAPLEGIA AND PARAPLEGIA AFTER TRAUMATIC SPINAL CORD INJURY

Justyna Frasuńska\textsuperscript{1,2}, Beata Tarnacka\textsuperscript{1,2}, Piotr Wojdasiewicz\textsuperscript{2,3}

\textsuperscript{1}Department of Rehabilitation, Medical University of Warsaw, Warsaw, Poland
\textsuperscript{2}Department of Rehabilitation, Eleonora Reicher National Institute of Geriatrics, Rheumatology and Rehabilitation, Warsaw, Poland
\textsuperscript{3}Department of General and Experimental Pathology, Centre for Preclinical Research and Technology (CePT), Medical University of Warsaw, Warsaw, Poland

Abstract

Purpose: The study compares the quality of life (QOL) in tetra- and paraplegic patients over the first 3 years after injury. An additional goal is to determine whether there is correlation between selected factors based on medical records, the WHOQOL-BREF (World Health Organization Quality of Life – short version of the questionnaire), and the SIP68 (Sickness Impact Profile – short version of the questionnaire) scales and these groups of patients.

Methods: A total of 72 patients with locomotor disability, following spinal cord injury (SCI), were involved in the study. Patients completed the WHOQOL-BREF and SIP68 scales. The comparative analysis between the paraplegic ($n=33$) and tetraplegic ($n=39$) group, and correlations between selected factors based on medical records and the above-mentioned scales was made.

Results: There were statistically significant differences in the assessment of SIP68 subscales: the somatic autonomy score was higher in paraplegic patients and the social behavior and mobility range scores were higher in patients with tetraplegia. Correlations between total WHOQOL-BREF score and ability to concentrate, refraining from any recreational activity, lack of gait and no professional activity were noticed in tetraplegia patients. Statistical significance was observed in correlations between total WHOQOL-BREF score and inability to bathe and get dressed without assistance, doing the washing, shopping and reduced socializing in paraplegia patients.

Conclusions: The presented differences in the assessment of QOL between both patient groups revealed the specific social, psychological and physical needs of patients. This is necessary for the development of effective treatment, depending on the level of injury, which may enable a faster return to optimal QOL for SCI patients.

Key words: quality of life, spinal cord injury, tetraplegia, paraplegia.

INTRODUCTION

Spinal cord injury (SCI) leads to incommensurable individual and social effects [1], although it is not a common injury. SCI disrupts the functioning of body systems and causes enormous changes and limitations in many areas of life (psychological, social and socio-professional), resulting in disability. Those changes significantly affect the quality of life (QOL) of patients who are discharged from a rehabilitation ward.

Early comprehensive rehabilitation and progress in the treatment of SCI patients contribute to an improvement in the QOL and to prolonging the lifespan in SCI patients.

QOL assessment in SCI patients has been frequently analyzed. Numerous scales are used to assess the QOL, such as the WHOQOL BREF (World Health Organization Quality of Life – short version of the questionnaire) and SIP68 scales (Sickness Impact Profile short form, 68 items drawn from the 136-item version) [2-8]. According to the literature, structure-and function-related factors influence QOL assessment following SCI [7]. QOL is positively correlated with younger age and employment, while a negative correlation occurs in the presence of secondary conditions (spasticity, pain, depression) [9-11].

The study proposed aimed to assess and compare QOL in patients with locomotor impairment in the course of SCI of the cervical (C) and thoracolumbar (Th-L) level over the first 3 years after injury, when the patient has the greatest medical and psychosocial needs. An additional goal of this study was to determine whether there is any correlation between selected factors based on the WHOQOL-BREF scale, SIP68 scale and medical records (regarding structure, function, person-
Table 1. General description of patients included in the study (N = 72)

| Parameter                                | Paraplegia (n = 33) | Tetraplegia (n = 39) | All          |
|------------------------------------------|---------------------|----------------------|-------------|
| Sex, p = 0.03* (Chi)                     |                     |                      |             |
| Women                                    | 10                  | 4                    | 14          | 19.5       |
| Men                                      | 23                  | 35                   | 58          | 80.5       |
| Age, p = 0.27 (S)                        |                     |                      |             |
| Mean age (minimum-maximum) ± SD          | 40.06 (18-78) ± 14.14 | 44.08 (17-78) ± 16.14 | 42.24 ± 16.28 |

Place of residence, p = 0.50 (F)

| Place of residence                       | Paraplegia          | Tetraplegia         | All          |
|------------------------------------------|---------------------|---------------------|-------------|
| Village                                  | 10                  | 17                  | 27          | 37.5       |
| Town (below 20,000 inhabitants)         | 7                   | 16                  | 23          | 33.3       |
| Town/city (over 20,000 inhabitants)     | 16                  | 16                  | 32          | 44.4       |

Education, p = 0.25 (F)

| Education      | Paraplegia | Tetraplegia | All  |
|----------------|------------|-------------|------|
| Primary        | 8          | 4           | 12   |
| Secondary      | 20         | 26          | 46   |
| Tertiary       | 5          | 1           | 14   |

Marital status, p = 0.065 (F)

| Marital status | Paraplegia | Tetraplegia | All  |
|----------------|------------|-------------|------|
| Unmarried      | 10         | 9           | 19   |
| Married        | 17         | 24          | 41   |
| Cohabitation   | 2          | 1           | 3    |
| Separation     | 0          | 0           | 0    |
| Divorced       | 3          | 4           | 7    |
| Widowed        | 1          | 1           | 2    |

Injury level, p = 0.37 (Chi)

| Injury level | Paraplegia | Tetraplegia | All  |
|--------------|------------|-------------|------|
| Complete     | 23         | 16          | 39   |
| Incomplete   | 16         | 17          | 33   |

Causes of traumatic SCI, p = 0.13 (F)

| Causes of traumatic SCI | Paraplegia | Tetraplegia | All  |
|-------------------------|------------|-------------|------|
| Road traffic accident   | 13         | 16          | 29   |
| Fall from a height over 1 m | 12       | 8           | 20   |
| Fall from a height below 1 m | 0        | 3           | 3    |
| Fall from body height   | 4          | 6           | 10   |
| Jump into water         | 0          | 4           | 4    |
| Crush injury            | 2          | 2           | 4    |
| Others                  | 2          | 0           | 2    |

Functional status according to the Barthel index, p = 0.13 (F)

| Functional status according to the Barthel index | Paraplegia | Tetraplegia | All  |
|-------------------------------------------------|------------|-------------|------|
| 18-20                                           | 8          | 12          | 20   |
| 5-17                                            | 23         | 19          | 42   |
| 0-4                                             | 2          | 8           | 10   |

Locomotor capacity according to WISCI-II, p = 0.002* (Chi)

| Locomotor capacity according to WISCI-II | Paraplegia | Tetraplegia | All  |
|-----------------------------------------|------------|-------------|------|
| Lack of gait, transfer via wheelchair, WISCI-II 0 = 0 | 10         | 26          | 36   |
| Functional gait, WISCI-II = 1-20         | 23         | 13          | 36   |

Discharge referral after completing rehabilitation, p = 0.05 (F)

| Discharge referral after completing rehabilitation | Paraplegia | Tetraplegia | All  |
|---------------------------------------------------|------------|-------------|------|
| Home                                              | 31         | 36          | 67   |
| Long-term care facility                           | 0          | 2           | 2    |
| Another hospital                                  | 2          | 1           | 3    |

Time between discharge from rehabilitation center and study entry, p = 0.30 (S)

| Time between discharge from rehabilitation center and study entry | Paraplegia | Tetraplegia | All  |
|------------------------------------------------------------------|------------|-------------|------|
| Average time (months) ± SD                                        | 25.81 ± 8.49 | 27.62 ± 10.15 | 26.79 ± 9.94 |

AIS – American Spinal Cord Injury Impairment Scale, Chi – \( \chi^2 \) test, F – Fisher’s exact test, LCF – long-term care facility, n – number of respondents, p – statistical significance level, S – t-Student test, SD – standard deviation, WISCI-II – Walking Index Spinal Cord Injury. *significant difference
al and environmental factors, activity and participation) and total WHOQOL-BREF score in paraplegia and tetraplegia patients.

To the best of our knowledge, no previous Polish study has analyzed QOL in patients with tetra- and paraplegia in this manner. Moreover, no Polish studies seem to tackle the issue of the use of the WHOQOL-BREF and SIP68 scales in QOL assessment in SCI patients.

Presenting the most sensitive factors influencing QOL assessment in tetra- and paraplegia patients over the first 3 years after discharge from a rehabilitation ward may be useful in working out the direction of changes that should be introduced in the care system of SCI patients.

METHODS

Medical records, the authors’ questionnaire, and the WHOQOL BREF [13] and SIP68 (a Polish version of SIP as translated by Wołowicka) [7, 8] scales were subjected to comparative analysis.

The authors’ questionnaire was an extensive survey covering questions, comprising issues of socio-professional re-adaptation, compliance with hospital recommendations, and social, health-related, professional and financial problems. For the purposes of the study, only selected questions from the questionnaire were used, including age, place of residence, education, marital status, and location of rehabilitation provision. The WHOQOL BREF scale is a 26-item version of the WHOQOL-100 scale, which was initiated in 1991. These scales measures QOL based on questions covering the four domains of a patient’s life: physical, psychological, social and environmental.

The SIP68 scale is a shorter version of the wider SIP scale, created by Bergner in 1981 and covering 136 questions [7, 8]. Sixty-eight of these questions are dedicated to SCI patients. It enables the assessment of the impact of the disease on physical and psychosocial functioning. It presents the issues of patient activity and participation in a more detailed manner than the WHOQOL-BREF scale.

From the aforementioned scales and records the authors chose selected issues (Regarding patients’ structure, function, personal and environmental factors, activity and participation) which – in their opinion – describe the QOL after SCI in the most accurate way. The study was approved by the Bioethics Committee. Signing an informed consent form was a necessary condition of participation in the study.

Initially, a total of 104 patients were invited to participate. The participants came from various parts of Poland and were discharged consecutively from the STOCER Mazovian Rehabilitation Centre (MRC) in Konstancin-Jeziorna in Poland 1 to 3 years before. Questionnaires were obtained from 72; 6 patients had died, and 9 changed their contact details, since being discharged from hospital, and the rest did not respond to the survey. A general description of all patients included in the study is presented in Table 1. They had all experienced a traumatic SCI at C, Th or L level with motor impairment. The neurological assessment was done according to the guidelines of the American Society of Spinal Cord Injury, as AIS-A, B, C, D (American Spinal Injury Association Impairment Scale – A, B, C, D) [12]. Functional status was assessed with the Barthel scale and walking ability with the Walking Index Spinal Cord Injury (WISCI II) scale. All the information for this study was collected with use of telemedicine techniques.

At first, all potential participants were sent letters by post. Patients who did not answer the letter were contacted by phone. A response sent by post was obtained from 60 persons, e-mail or personal contact were chosen by another 12. In some cases, the information was collected by telephone conversations, e-mails or during a personal meeting.

Patients with co-morbidities that could influence the quality of life (e.g. mental illness, severe head injuries) were excluded from the study. In the submitted questionnaires, the patients reported the following medical problems: spasticity (55 patients), pressure ulcers (10 patients), no control of the bladder (42 patients), and no control of intestinal function (39 patients).

The statistical, comparative analysis between the paraplegia and tetraplegia groups was based on the following methods: rate, percentage, arithmetic mean, minimum, maximum and standard deviation.

Correlations between selected factors based on medical records, the WHOQOL-BREF and SIP68 scales and total WHOQOL-BREF score were performed with the use of the Fisher exact test.

The analysis was performed with the use of the statistical software R 3.5.1 (R Core Team (2018). R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. URL https://www.R-project.org/).

RESULTS

General description of the study groups

Questionnaires were obtained from 72 of the 104 individuals invited to participate in the study. As regards 32 non-responders (30.8% of patients included in the study) 6 patients had died, and 9 changed their contact details since their discharge from hospital. All those participating in the study had a locomotor disability after traumatic SCI. Sociodemographic characteristics and statistical comparisons of the participants from both groups are presented in Table 1.
There was no significant relationship in QOL between both groups of patients and their clinical condition (neurological state based on the ASIA scale – American Spinal Injury Association Impairment Scale, the presence of pressure sores, spasticity) and sociodemographic factors (age, sex, place of residence, education, marital status).

### Quality of life assessment based on the WHOQOL-BREF

The general assessment of the QOL in the study population was at the level of 3.22 ± 1.46 on a subjective five-grade scale (WHOQOL-BREF). The percentage of patients with paraplegia (complete and incomplete) who were satisfied and very satisfied with their health status was 12.1% \(n = 4\), while the percentage of satisfied and very satisfied patients with tetraplegia (complete and incomplete) in this matter was 17.9% \(n = 7\). 51.9% of all paraplegia patients \(n = 17\) and 30.8% of all tetraplegia patients \(n = 12\) were dissatisfied or very dissatisfied.

A total of 42.4% of paraplegia patients \(n = 14\) assessed their QOL as good or very good; similar assessments were given by 35.9% of the tetraplegia patients \(n = 14\). QOL as poor or very poor was assessed as such by 21.2% paraplegia patients \(n = 7\) and 12.8% tetraplegia patients \(n = 5\).

No statistical difference between C and Th/L impaired groups was seen (Table 2).

### Health status assessment

- Poor and very poor: 21.2% (7/33) vs. 12.8% (5/39), \(p = 0.397\) (Fis).
- Neither satisfied nor dissatisfied: 36.4% (12/33) vs. 51.3% (20/39), \(p = 0.202\) (Fis).
- Satisfied: 42.4% (14/33) vs. 35.9% (14/39), \(p = 0.106\) (Fis).

### Correlations between selected factors based on medical records, the authors’ questionnaire, the WHOQOL-BREF and SIP68 scales and the total WHOQOL-BREF score

Correlations between total WHOQOL-BREF score and ability to concentrate were noticed in tetraplegia patients \(p = 0.04\).

Both groups investigated presented correlations between total WHOQOL-BREF score and need of medical treatment to function in everyday life, self-acceptance, sense of security, satisfaction with one’s sexual activity, interpersonal relations and ability to pursue one’s interests.

A summary of the QOL based on WHOQOL-BREF, including 4 domains of patient’s life: physical, psychological, social and environmental are presented in Figure I.

### Quality of Life assessment based on SIP68 scale

A comparative analysis of the QOL in patients with C versus Th impairment based on the SIP68 scale revealed statistically significant differences in the assessment of subscales: somatic autonomy, social behavior and mobility range (Figure II and Table 3). The mean score concerning somatic autonomy in patients with paraplegia was 10.8, in comparison to tetraplegia patients, where the mean score was 6.9. On the other hand, the mean score of social behavior and mobility range on the SIP68 scale were higher in tetraplegia patients compared to paraplegia patients (7.7 to 7.1 and 5.2 to 3.8 respectively). More detailed information with statistical analysis is given in Table 3.

**Table 2. The comparison of the assessment of the quality of life in individual areas of physical, mental, social and environmental subjective assessment of the quality of life and health status in patients with an injury to the spinal cord at the cervical and thoracolumbar spine (based on WHOQOL-BREF scale)**

| WHOQOL-BREF scale | Paraplegia \((n = 33)\) | Tetraplegia \((n = 39)\) | \(p\) |
|-------------------|------------------------|------------------------|-----|
| **Areas**         |                        |                        |     |
| Physical          | 11.6 (1.6)             | 11.1 (2.3)             | 0.085 (F) |
| Mental            | 13.3 (1.7)             | 13.0 (1.8)             | 0.399 (F) |
| Social            | 13.6 (2.8)             | 12.7 (2.9)             | 0.191 (F) |
| Environmental     | 13.2 (2.2)             | 12.3 (2.2)             | 0.106 (F) |
| **Quality of life assessment** |    |                        |     |
| Poor and very poor| 7 (21.2)               | 5 (12.8)               | 0.397 (F) |
| Neither good nor poor | 12 (36.4)             | 20 (51.3)             |     |
| Good and very good| 14 (42.4)              | 14 (35.9)              |     |
| **Health status assessment** | |                        |     |
| Dissatisfied      | 17 (51.5)              | 12 (30.8)              | 0.202 (F) |
| Neither satisfied nor dissatisfied | 12 (36.4)             | 20 (51.3)             |     |
| Satisfied         | 4 (12.1)               | 7 (17.9)               |     |

\(F\) – Fisher’s test, \(n\) – number of respondents, \(p\) – level of statistical significance
Statistical significance was observed in correlations between total WHOQOL-BREF score and inability to bathe and get dressed without assistance, doing the washing, shopping, and reduced socializing (based on SIP68) in paraplegia patients. Correlations between total WHOQOL-BREF score and refraining from any recreational activity were noticed in tetraplegia patients ($p = 0.007$).

Correlations between total WHOQOL-BREF score and lack of gait ($p = 0.007$) and no professional activity ($p = 0.013$) were noticed only in tetraplegia patients.

Correlations between the mentioned selected factors (based on medical records, the authors’ questionnaire, and the WHOQOL-BREF and SIP68 scales) and the total WHOQOL-BREF score in both study groups are presented in a more detailed manner in Table 4.
### Table 4. Correlation between selected factors associated with structures and functions - A, personal and environmental factors - B, activity and participation - C (based on medical records, authors’ questionnaire, and the WHOQOL-BREF, SIP68 scales) and the total WHOQOL-BREF score

#### A. Structures and functions

| Neuronal deficit-based on ASIA scale (medical record) | Total WHOQOL-BREF score | Paraplegia | Tetraplegia |
|-------------------------------------------------------|--------------------------|------------|------------|
| AIS-A                                                 | 85.2 ± 15.8              | 76.0 ± 13.9|            |
| AIS-B                                                 | 75.0 ± 14.1              | 59.0 ± 0.0 |            |
| AIS-C                                                 | 78.7 ± 8.7               | 82.4 ± 9.2 |            |
| AIS-D                                                 | 84.4 ± 8.7               | 84.4 ± 9.7 |            |

| Pressure ulcer(s) during the study (medical record) | p-value | Paraplegia | Tetraplegia |
|-----------------------------------------------------|---------|------------|------------|
| No                                                  | 0.238   |            |            |
| Yes                                                 | 0.313   |            |            |

| Spasticity at discharge (medical record)            | p-value | Paraplegia | Tetraplegia |
|-----------------------------------------------------|---------|------------|------------|
| No                                                  | 0.553   |            | 0.115      |
| Yes                                                 | 82.0 ± 14.1 | 77.9 ± 12.7|            |

| Control of bowel movement (question 13 subscale Somatic Autonomy, SIP 68) | p-value | Paraplegia | Tetraplegia |
|-------------------------------------------------------------------------|---------|------------|------------|
| No                                                                      | 0.606   | 0.731      |            |
| Yes                                                                     | 81.5 ± 14.2 | 78.1 ± 12.5|            |

| Control of urinary function (miction) (question 11 subscale Somatic Autonomy, SIP 68) | p-value | Paraplegia | Tetraplegia |
|--------------------------------------------------------------------------------|---------|------------|------------|
| No                                                                         | 0.308   | 0.942      |            |
| Yes                                                                        | 80.7 ± 13.2 | 78.5 ± 12.4|            |

| Ability to concentrate (question 7 WHOQOL-BREF) | p-value | Paraplegia | Tetraplegia |
|-------------------------------------------------|---------|------------|------------|
| Not at all and a little                         | 0.148   | 0.040*     |            |
| A moderate amount                               | 84.1 ± 11.3 | 82.1 ± 10.6|            |
| Very much and extremely                         | 89.8 ± 17.8 | 79.5 ± 17.8|            |

#### B. Personal and environmental factors

| Total WHOQOL-BREF score | Paraplegia | Tetraplegia |
|-------------------------|------------|------------|
| Age (medical record)    |            |            |
| p-value                 | 0.283      | 0.375      |
| > 40 yo                 | 85.6 ± 11.4 | 80.7 ± 13.2|            |
| < 40 yo                 | 80.7 ± 14.1 | 77.0 ± 12.5|            |

| Sex (medical record)    | p-value | Paraplegia | Tetraplegia |
|-------------------------|---------|------------|------------|
| p-value                 | 0.362   | 0.125      |            |
| Women                   | 87.3 ± 18.5 | 92.0 ± 12.2|            |
| Man                     | 81.4 ± 9.4  | 77.3 ± 12.4|            |

#### B. Personal and environmental factors

| Total WHOQOL-BREF score | Paraplegia | Tetraplegia |
|-------------------------|------------|------------|
| Place of residence (medical record) |            |            |
| p-value                 | 0.256      | 0.299      |
| Village                 | 86.9 ± 11.3 | 76.2 ± 11.8|            |
| Town/city               | 81.6 ± 13.3 | 80.5 ± 13.5|            |

| Education (medical record) | p-value | Paraplegia | Tetraplegia |
|----------------------------|---------|------------|------------|
| Primary                    | 0.233   | 0.902      |            |
| Secondary                  | 83.4 ± 12.9 | 79.2 ± 11.7|            |
| Tertiary                   | 75.2 ± 10.0 | 77.9 ± 16.6|            |

| Marital status (medical record) | p-value | Paraplegia | Tetraplegia |
|---------------------------------|---------|------------|------------|
| In a relationship               | 0.053   | 0.845      |            |
| Living on one’s own             | 88.3 ± 12.8 | 78.0 ± 15.1|            |

| Time since injury sustained (months) (own questionnaire) | p-value | Paraplegia | Tetraplegia |
|--------------------------------------------------------|---------|------------|------------|
| < 20                                                    | 0.185   | 0.899      |            |
| 20-30                                                   | 86.2 ± 11.6 | 78.1 ± 6.3 |            |
| > 30                                                    | 78.4 ± 7.5  | 79.5 ± 15.1|            |

| Location of rehabilitation provision (own questionnaire) | p-value | Paraplegia | Tetraplegia |
|---------------------------------------------------------|---------|------------|------------|
| Only at home                                            | 0.393   | 0.0957     |            |
| Home/rehabilitation facility                            | 81.1 ± 9.2  | 85.0 ± 8.2 |            |
| Only rehabilitation facility                            | 89.7 ± 19.6 | 78.2 ± 18.3|            |

| Satisfaction with one’s living conditions (question 23 WHOQOL-BREF) | p-value | Paraplegia | Tetraplegia |
|-------------------------------------------------------------------|---------|------------|------------|
| Very dissatisfied and dissatisfied                                 | 0.141   | 0.172      |            |
| Neither satisfied and dissatisfied                                | 75.4 ± 10.0 | 78.1 ± 9.5 |            |
| Very satisfied and satisfied                                      | 86.2 ± 14.1 | 82.8 ± 16.5|            |

| Need of medical treatment to function in everyday life (question 4 WHOQOL-BREF) | p-value | Paraplegia | Tetraplegia |
|-------------------------------------------------------------------------------|---------|------------|------------|
| Not at all and a little                                                      | 0.048*  | 0.006*     |            |
| A moderate amount                                                            | 88.9 ± 10.8 | 82.4 ± 10.6|            |
| Very much and an extreme amount                                              | 87.2 ± 23.0 | 91.7 ± 10.7|            |

| Self-acceptance (question 11 WHOQOL-BREF) | p-value | Paraplegia | Tetraplegia |
|------------------------------------------|---------|------------|------------|
| Not at all and a little                  | 0.001*  | 0.001*     |            |
| A moderate amount                        | 73.8 ± 9.4  | 72.0 ± 12.4|            |
| Mostly and completely                    | 79.5 ± 7.0  | 82.4 ± 10.6|            |

| Sense of security (question 8 WHOQOL-BREF) | p-value | Paraplegia | Tetraplegia |
|-------------------------------------------|---------|------------|------------|
| Not at all and a little                   | 0.001*  | 0.042*     |            |
| A moderate amount                         | 76.1 ± 8.9  | 79.8 ± 9.6 |            |
| Very much and extremely                   | 89.4 ± 11.8 | 84.2 ± 12.9|            |
### Table 4. Cont.

| C. Activity and participation | Total WHOQOL-BREF score | Paraplegia | Tetraplegia |
|-------------------------------|-------------------------|------------|-------------|
| **Severity according to the Barthel scale (medical record)** | | | |
| p-value | 0.587 | 0.349 |
| ≤ 17 pts | 92.6 ± 13.9 | 77.7 ± 12.3 |
| ≥ 18 pts | 85.0 ± 9.1 | 94.5 ± 14.8 |
| **Lack of gait-based on WISCI-II (medical record)** | | | |
| p-value | 0.329 | 0.007* |
| WISCI-II = 0 | 87.7 ± 19.0 | 75.3 ± 13.6 |
| WISCI-II = 1-20 | 81.3 ± 8.8 | 85.2 ± 8.0 |
| **Transfer via wheelchair (medical record)** | | | |
| p-value | 0.698 | 0.275 |
| Yes | 84.3 ± 8.2 | 82.8 ± 14.0 |
| No | 82.7 ± 14.5 | 77.1 ± 12.1 |
| **No professional activity (medical record)** | | | |
| p-value | 0.867 | 0.013* |
| Yes | 83.4 ± 12.8 | 77.0 ± 13.1 |
| No | 82.4 ± 13.7 | 87.2 ± 6.7 |
| **Inability to get dressed without assistance (question 2 subscale Somatic Autonomy, SIP 68)** | | | |
| p-value | 0.040* | 0.379 |
| Yes | 84.1 ± 12.7 | 80.0 ± 14.1 |
| No | 69.0 ± 4.2 | 76.5 ± 10.7 |
| **Satisfaction with one’s sexual activity (question 21 WHOQOL-BREF)** | | | |
| p-value | 0.001* | 0.060* |
| Very dissatisfied and dissatisfied | 78.1 ± 12.1 | 78.1 ± 25.0 |
| Neither satisfied and dissatisfied | 87.3 ± 4.9 | 73.8 ± 14.5 |
| Very satisfied and satisfied | 97.9 ± 16.0 | 88.8 ± 10.8 |
| **Inability to bathe without assistance (question 10 subscale Somatic Autonomy, SIP 68)** | | | |
| p-value | 0.003* | 0.137 |
| Yes | 84.4 ± 12.8 | 80.4 ± 12.8 |
| No | 71.3 ± 6.0 | 73.4 ± 12.0 |
| **Satisfaction with interpersonal relations (question 20 WHOQOL-BREF)** | | | |
| p-value | 0.035* | > 0.001** |
| Very dissatisfied and dissatisfied | 80.0 ± 10.8 | 77.0 ± 13.1 |
| Neither satisfied and dissatisfied | 74.3 ± 10.4 | 68.9 ± 10.1 |
| Very satisfied and satisfied | 85.6 ± 12.5 | 83.5 ± 11.1 |
| **Inability to do the washing (question 6 subscale Mobility Range, SIP 68)** | | | |
| p-value | 0.019* | 0.099 |
| Yes | 87.7 ± 14.4 | 84.2 ± 14.4 |
| No | 77.8 ± 8.2 | 76.1 ± 11.4 |
| **Inability to clean the house/flat (question 3 subscale Mobility Range, SIP 68)** | | | |
| p-value | 0.101 | 0.189 |
| Yes | 87.2 ± 11.8 | 82.2 ± 14.1 |
| No | 79.9 ± 13.0 | 76.3 ± 11.7 |
| **Inability to do the shopping (question 1 subscale Mobility Range, SIP 68)** | | | |
| p-value | 0.036* | 0.140 |
| Yes | 87.5 ± 11.0 | 82.9 ± 14.1 |
| No | 78.1 ± 13.3 | 76.2 ± 11.6 |

AIS – American Spinal Cord Injury Impairment Scale, p – level of statistical significance, WHOQOL-BREF – World Health Organization Quality of Life – Brief, WISCI-II Walking Index Spinal Cord Injury, *significant difference, **very significant difference.
DISCUSSION

To the best of our knowledge it is the first study conducted in Poland to compare QOL (based on the WHOQOL-BREF and SIP68 scales) between patients with traumatic SCI with tetraplegia and patients with paraplegia. At the same time, it is the first Polish publication to search for correlations between selected factors based on medical records, the WHOQOL-BREF and SIP68 scales and total WHOQOL-BREF score in these groups of patients.

To determine whether there are any health, psychological or social factors that influence the QOL of paraplegic and tetraplegic patients in a statistically significant manner, we searched for correlations between selected factors based on medical records, the authors’ questionnaire, the WHOQOL-BREF and SIP68 scales and the total WHOQOL-BREF score (Table 4).

The neurological status of patients in both groups does not affect their quality of life, which is congruent with other studies [14, 15]. This is probably related to individuals’ acceptance of their disability and changes in patients’ expectations due to different functioning. Iorio-Morin et al. [14] present self-acceptance as the cause of living a happy life, referring to the phenomenon of “response shift” documented in the theoretical model of Sprangers et al. [16].

Pressure ulcers, spasticity and chronic pain are common complications after SCI that result in poorer QOL [17, 18], depression [19] and sleep disturbances [20]. In our study these complications did not influence the QOL of patients in both groups. The authors believe that our patients, due to the lack of continuous multidisciplinary care after the SCI, simply got used to the fact that their illness is related to these complications.

Although the neurological status of patients does not determine QOL in both groups, lack of gait has a different effect on QOL in patients with tetraplegia (Table 4). This, in turn, can be explained by the fact that lack of gait is associated with the limitation of many activities, including the ability to pursue one’s own interests and recreation, and patients’ activity and participation in social, public or cultural life. In addition, awareness of these restrictions is the cause of sadness, which affects the quality of mental health. This may manifest itself, e.g., in attention deficit disorder (worsened ability to concentrate). Perhaps the assessment of other parameters of depression parameters not mentioned would also provide statistically significant relationships with QOL in patients with tetraplegia.

Similarly, to the factors detailing clinical status, most sociodemographic factors (with the exception of professional activity) have no statistically significant effect on the QOL of both groups. This could also be associated with the change of patients’ expectations from factors determining structure and function in favor of factors related to activity and participation.

The reduced professional activity of patients with SCI is responsible for changes in social status and may affect the financial situation of the family [1, 21, 22]. Returning to professional activity after SCI is very challenging for most of patients. According to the professional literature a higher unemployment rate is observed in people with SCI [23-26]. The present study shows that the professional inactivity of tetraplegic patients affects in a significant way their total WHOQOL-BREF score. This result corresponds with another Polish study, in which the absence of professional activity correlated with worse QOL and was observed in individuals with an injury at the C segment of the spine [8].

A comparative analysis revealed no significant differences in the assessment of individual QOL components of the WHOQOL-BREF scale. The results of our study do not differ from those of other authors [27].

Both groups presented correlations between total WHOQOL-BREF score and need of medical treatment to function in everyday life, self-acceptance, sense of security, satisfaction with sexual activity, interpersonal relations and ability to pursue one’s interests (Table 4).

Self-acceptance is extremely important in the context of maintaining mental health and it significantly correlated with the assessment of QOL in both studied groups. Although the study did not assess depression according to specific scales, its individual components such as loss of interest or limitation of interpersonal relations are serious mental health problem in patients after SCI. This is similar to a loss of the sense of security, which may be interpreted as ‘freedom from danger, fear or assault’ [28]. A decreased sense of security may have a negative impact on other mental health factors associated with the activity and participation section of WHOQOL-BREF, and in that way may lead to a vicious circle paradox and/or domino effect.

The quality of sexual life with interpersonal relations becomes particularly important, especially in persons with a marked reduction of independence [29, 30]. Sexual functions are a very important factor in the QOL; recovery of these activities is the highest priority in patients with paraplegia and is in second place of priority in the tetraplegic patients after recovery of hand function [31, 32]. Numerous studies have shown that sexual life is one of lower-graded components of the WHOQOL-BREF scale [33-35], with lower scores compared to the general population [36]. Anderson et al. [37] attempted to answer the question of whether improvement of sexual function might significantly improve the QOL. The vast majority of post-SCI respondents gave a positive response. In our study a significant correlation was observed between the satisfaction with one’s sexual activity and total WHOQOL-BREF score in both the paraplegic and tetraplegic groups ($p = 0.001$ and $p = 0.060$ respectively). The observed similarity of results in our study may result from the increasing sexual awareness of Polish society, improving sex
Quality of life in patients with tetraplegia and paraplegia after traumatic spinal cord injury

education and decreasing disproportion of general QOL between Poland and other European countries [21, 22].

Statistical significance was observed in correlations between total WHOQOL-BREF score and inability to bathe and get dressed without assistance, doing the washing, shopping and reduced socializing in paraplegia patients (Table 4).

Dependence on others may be a cause of demotivation, which can lead to a decrease in patients’ daily living activity. The present study showed that the QOL of patients with paraplegia is influenced greatly by the ability to engage in activities connected with housework. Patients with paraplegia keep the complete function of the upper limbs, which gives them much greater functional capabilities compared to the patients with tetraplegia. Awareness of keeping hand function is connected with high expectations of the ability to perform most household activities. In the end, it turns out that paraplegia seriously affects household function in the confrontation with everyday reality. This can cause irritability, which correlates with the level of QOL of paraplegia patients. This correlation corresponds with other results from our study, where we observed a statistically significant difference in the assessment of mobility range and social behavior in the SIP68 scale, which was lower in paraplegia patients compared to tetraplegia patients.

The authors believe that the above results may be useful for many specialists working with SCI patients: neurologists, psychologists, neurosurgeons, orthopedists, physiotherapists and the health sector management staff in Poland.

Understanding the specific needs of patients with paraplegia and tetraplegia and the impact of these on QOL can help in planning an optimal and specific treatment and care system for patients of this kind. For example, to improve QOL paraplegia patients should learn, in particular, how to deal with housework, and receive some help with socializing programs, while tetraplegia patients could obtain more benefit from being helped to find satisfying work or a sports group with which to practice recreational activity.

LIMITATIONS

The present study was conducted at one center and the majority of the population of patients with SCI presented in this study resided in central Poland. The study presents an outline of the QOL-related problems of Polish SCI patients, but a more thorough analysis would require the conduct of multicenter or international research.

Polish rehabilitation wards do not offer programs of socio-professional care for patients with SCI, which may cause certain problems with comparing the present results to those obtained in other countries.

The present authors did not analyze all of the factors associated with structure and functions, environmental and personal aspects of patients with SCI. Elaborating on those aspects (which were beyond the range possible with the research tools that were used) might put the study in a slightly different light.

The inability to perform an objective assessment of the health status of patients with SCI undoubtedly limited the possibility of conducting a detailed assessment of other parameters regarding the structures and functions according to the ICF (The International Classification of Functioning, Disability and Health) concept. Further research on QOL assessment in SCI patients should deal with the above-mentioned limitations for the objectivization of QOL assessment in patients with SCI.

The authors are aware that having participated in a telephone conversation may have affected some patients’ responses as it is considered easier to answer some questions by filling in a questionnaire yourself than during a telephone or face-to-face conversation (e.g. questions about sexual life, earnings, etc.).

CONCLUSIONS

This study shows and helps to understand differences in the assessment of QOL between patients with paraplegia and tetraplegia. Based on the observed results, specific social, psychological and physical needs of both groups of SCI patients in Poland were revealed. Health sector management staff and specialists should take into consideration the differences between the two groups and plan optimal treatment and care plans for them. Changes to the Polish health care system should focus on increasing QOL by helping paraplegia patients to learn how to deal with everyday problems, and encourage their participation in socializing programs, while tetraplegia patients could obtain more benefit from being helped to find satisfying work or a sports group with which to practice recreational activity. In the authors’ opinion, this knowledge could be used to develop an effective treatment and care system, depending on the level of injury.

Conflict of interest

Absent.
Financial support

Absent.

References

1. LeuLfsrud AS, Solheim EF, Reinhardt JD, Post MWM, Horsewell J, Biering-Sorensen F, et al. Gender, class, employment status and social mobility following spinal cord injury in Denmark, the Netherlands, Norway and Switzerland. Spinal Cord 2020; 58: 224-231.
2. Valenti L, Nachtegaal J, Faber W, Smit C, Kaandorp E, Pratt-Sutherland S, et al. Experienced sitting-related problems and association with personal, lesion and wheelchair characteristics in persons with long-standing paraplegia and tetraplegia. Spinal Cord 2019; 57: 603-613.
3. Hill MR, Noonan VK, Sakakibara BM, Miller WC. Quality of life instruments and definitions in individuals with spinal cord injury: a systematic review. Spinal Cord 2010; 48: 438-450.
4. Opara J, Tasiemski T, Gustowski D, Mehlik Ch. Quality of life following spinal cord injury. Ortop Traumatol Rehabil 2002; 30: 632-638.
5. Pokazaczoł J, Tasiemski T. Analysis of selected determinants of health-related quality of life in persons with spinal cord injury. Fizjoterapia 2015; 23: 3-13.
6. Pokazaczoł J, Tasiemski T, Urbański P. Relationship between spinal cord injury-related knowledge and health-related quality of life in persons with spinal cord injury. Adv Rehabil 2016; 39: 5-10.
7. Post M, De Witte L, Van Asbeck F, Schrijvers A. Predictors of health status and life satisfaction of people with spinal cord injuries. Arch Phys Med Rehabil 1998; 79: 395-402.
8. Kázmierczak K. Ocena sytuacji socjomedycznej osób po urazie rdzenia kręgowego. Rozprawa doktorska. Poznań 2015.
9. Fekete Ch, Währendorf M, Reinhardt JD, Post MWM. Work stress and quality of life in person with disabilities from four European countries: the case of spinal cord injury. Qual Life Res 2014; 23: 1661-1671.
10. Kumar N, Gupta B. Effect of spinal cord injury on quality of life of affected soldiers in India: a cross-sectional study. Asian Spine J 2016; 10: 267-275.
11. Müller R, Landmann G, Bechir M, Hinrichs T, Arnet U, Jordan X, et al. Chronic pain, depression and quality of life in individuals with spinal cord injury: mediating role of participation. J Rehabil Med 2017; 49: 489-496.
12. Schuld C, Franz S, Brüggemann K, Heutehaus L, Weidner N, Kirshblum SC, et al.; EMSCI study group. International standards for neurological classification of spinal cord injury: impact of the revised worksheet (revision 02/13) on classification performance. J Spinal Cord Med 2016; 39: 504-512.
13. Jang Y, Hsieh CL, Wang YH, Wu YH. A validity study of the WHOQOL-BREF assessment in persons with traumatic spinal cord injury. Arch Phys Med Rehabil 2004; 85: 1890-1895.
14. Iorio-Morin C, Noonan VK, White B, Noreau L, Leblond J, Dumont FS, et al. Quality of life and health utility scores among Canadians living with traumatic spinal cord injury – a national cross-sectional study. Spine 2018; 43: 999-1006.
15. Tzanos IA, Kyriakides A, Gkintoni E, Panagiotopoulos E. Quality of life (QoL) of people with spinal cord injury (SCI) in Western Greece. Rehab Sci 2019: 4: 7-12.
16. Sprangers MA, Schwartz CE. Integrating response shift into health-related quality of life research: a theoretical model. Soc Sci Med 1999; 48: 1507-1515.
17. Vural M, Yalcinkaya EY, Celik EC, Gunduz B, Bozan A, Erhan B. Assessment of quality of life in relation to spasticity severity and socio-demographic and clinical factors among patients with spinal cord injury. J Spinal Cord Med 2020; 43: 193-200.
18. Rivers CS, Fallah N, Noonan VK, Whitehurst DG, Schwartz CE, Finkelstein JA, et al. Health conditions: effect on function, health-related quality of life, and life satisfaction after traumatic spinal cord injury. A prospective observational registry cohort study. Arch Phys Med Rehabil 2018; 99: 443-451.
19. Müller R, Landmann G, Béchir M, Hinrichs T, Arnet U, Jordan X, et al. Chronic pain, depression and quality of life in individuals with spinal cord injury: mediating role of participation. J Rehabil Med 2017; 49: 489-496.
20. Spong J, Graco M, Brown D, Schembri R, Berlowitz DJ. Subjective sleep disturbances and quality of life in chronic tetraplegia. Spinal Cord 2015; 53: 636-640.
21. Czapinski J, Panek T. Diagnoza społeczna 2009. Raporty. Available at: http://www.diagnoza.com.
22. Parker R, Wellings K, Lazarus JV. Sexuality education in Europe: an overview of current policies. Sex Educ 2009; 9: 227-242.
23. Kawczyńska-Butrym Z. Niepełnosprawność – specyfika pomocy społecznej. Katowice: Wydawnictwo Śląskie; 1999.
24. Krause JS, Dismuke-Greer CE, Reed K, Backus D, Rumrill P. Gainful employment and earnings among those with spinal cord injury and multiple sclerosis. J Vocat Rehabil 2020; 52: 19-28.
25. Krause JS, Dismuke-Greer CE, Järnecke M, Reed KS. Differential odds of employment and estimation of earnings among those with spinal cord injury. Rehabilitation Counseling Bulletin 2020; 63: 67-78.
26. Celik HD, Turk AC, Sahin F, Yilmaz F, Kuran B. Comparison of disability and quality of life between patients with paediatric and adult onset paraplegia. J Spinal Cord Med 2018; 41: 645-652.
Quality of life in patients with tetraplegia and paraplegia after traumatic spinal cord injury

28. Stańczyk J. Współczesne pojmowanie bezpieczeństwa. Warszawa: Instytut Studiów Politycznych PAN; 1996.
29. Merghati-Khoei E, Emami-Razavi S, Bakhtiyari M, Iamyian M, Hajmirzaei S, Tontab Haghighi S, et al. Spinal cord injury and women's sexual life: case-control study. Spinal Cord 2017; 55: 269-273.
30. Jörgensen S, Hedgren L, Sundelin A, Lexell J. Global and domain-specific life satisfaction among older adults with long-term spinal cord injury. J Spinal Cord Med 2019. DOI: 10.1080/10790268.2019.1610618.
31. Simpson LA, End JJ, Hsieh JTC, Wolff DL and the Spinal Cord Injury Rehabilitation Evidence (SCIRE) Research Team. The health and life priorities of individuals with spinal cord injury: a systematic review. J Neurotrauma 2012; 29: 1548-1555.
32. Aikman K, Oliffe JL, Kelly MT, McCuaig F. Sexual health in men with traumatic spinal cord injuries: a review and recommendations for primary health-care providers. Am J Mens Health 2018; 12: 2044-2054.
33. Ali Shah SZ, Rafiullah, Ilyas SM. Assessment of the quality of life of spinal cord injury patients in Peshawar. J Pak Med Assoc 2017; 67: 434-437.
34. Gautam P, Marasini RP, Shrestha R, Gautam P, Marasini L. Quality of life in patients with spinal cord injury attending selected rehabilitation centers of Nepal. J Nepal Health Res Coun 2019; 17: 297-300.
35. Aquarone RL, e Faro ACM, Nogueira PC. Central neuropathic pain: implications on quality of life of spinal cord injury patients. Rev Dor 2015; 16: 280-284.
36. Post MW, Van Dijk AJ, Van Asbeck FW, Schrijvers AJ. Life satisfaction of persons with spinal cord injury compared to a population group. Scand J Rehabil Med 1998; 30: 23-30.
37. Anderson K, Borisoff J, Johnson R, Stiens S, Elliott S. The impact of spinal cord injury on sexual function: concerns of the general population. Spinal Cord 2007; 45: 328-337.