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The effect of Foundation for Active Rehabilitation camps on the quality of life of individuals with spinal cord injury

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Summary

Introduction. The consequences of spinal cord damages rank among the most serious dysfunctions of the human musculoskeletal system. In spite of the development of medicine, the effects of treatment and rehabilitation are still insufficient for patients and their families.
Purpose. The aim of this study was to determine the effect of the participation of individuals with spinal cord injury in the introductory camps organized by the Foundation for Active Rehabilitation in the subjective sense of quality of life and the meaning of life and the motivation to search for the meaning of life.
Material and methods. It involved a group of 100 participants of the introductory camp organized by the Foundation for Active Rehabilitation. These same 100 subjects were then followed up three months after the end of camp. Quality of Life Index Ferrans and Powers; PIL-Test ; SONG-Test.
Results. As a result of camp participation of persons with spinal cord injury in the camp, significant increase was observed in the global Quality of Life Index score, health and functioning subscale and psychological/spiritual subscale. As a result of camp attendance, global PIL test score significantly increased, while global SONG test score significantly decreased.
Conclusions. Participation by individuals with spinal cord injury in the introductory camps organized by the Foundation for Active Rehabilitation has a positive impact on the subjective quality of life, strengthens sense of the meaning of life and decreases the motivation to find its purpose.

Keywords: Active Rehabilitation, PIL Test, Quality of Life Index, SONG Test, spinal cord injury.

Introduction

The consequences of spinal cord damages rank among the most serious dysfunctions of the human musculoskeletal system. In spite of the development of medicine, the effects of treatment and rehabilitation are still insufficient for patients and their families. The aim of the rehabilitation is not only to rescue life and to reduce effects of the spinal damage, but also to help people who are confined to wheelchair gain the ability to overcome natural obstacles of different kinds and learn the basic self-service activities. The patients can become more independent in everyday life and improve their psychophysical condition through the system of the Active Rehabilitation. In Poland it is being fulfilled by The Foundation of the Active Rehabilitation which uses sport and physical recreation as a method of reconstructing the efficiency and self-dependance in day-to day activities.

Foundation for Active Rehabilitation conducts camps, designed for individuals with spinal cord injury. Attendance requirements include a medical certificate confirming lack of medical contraindications and no evidence of pressure ulcers. In order to provide the best possible environment for the betterment and improvement of motor skills in individuals with spinal cord injury, their participation in the camp should take place at least 8-9 months from the time of injury. This is the optimal time, because as experience had shown, those who participate too early may not able to master some physical activities conducted at the camp [1].

The camp is conducted in accordance with the Swedish model. Following qualification procedure, attendees are accommodated along with the instructors. Instructors have the same or similar motor dysfunction as participants and they teach courses on motor skills with the assistance of non-disabled staff.

Shared accommodations at the camp provide an opportunity for participants to observe and learn from their instructors the techniques used to perform activities of daily living, observe the progress of rehabilitation and allow for creation of social relationships.

The camp is scheduled for 8 days of training. Each day, participants with spinal cord injury attend three 90-minute training sessions from the following areas: riding a wheelchair, swimming, fitness and strength, table tennis and archery. They also attend lectures concerning: legislation related to persons with disabilities, education opportunities, employment, necessary orthopedic equipment, choosing a proper wheelchair, pressure sore prophylaxis, body hygiene, urological protection, problems related to sex and procreation [2].

Study purpose

To assess the impact of participation in the introductory camps organized by the Foundation for Active Rehabilitation on the subjective sense of quality of life, the meaning of life and the motivation to search for the meaning of life, in individuals with spinal cord injury.

Materials and methods

Study took place between March 2009 and March 2010. It was conducted at introductory camps organized by the Foundation for Active Rehabilitation in Poland at the Olympic Training Center in Spala, Sports and Recreation Center in Zamość and the School of Ecology in Zielona Góra.

Upon arrival at the introductory camp organized by the Foundation for Active Rehabilitation, persons eligible for the study received written information about the study, informed consent form for participation in the survey and a questionnaire. On the same day, documents were collected from all those who have expressed their willingness to participate in the study. Only one person did not consent to the study. At the beginning of the camp, 120 individuals with spinal cord injuries took part in the study, three individuals submitted incomplete questionnaires that were rejected. Three months after the end of the camp 100 questionnaires were completed. All participants were over the age of 18. Three months after the end of camp, an e-mail questionnaire was sent to those participants who provided their e-mail address. Others were contacted via a telephone at which time the questionnaires were filled out.

Eventually, the study involved a group of 100 individuals who participated in the introductory camp organized by the Foundation for Active Rehabilitation and the same group of 100 individuals three months following camp completion. 86 men and 14 women were among study participants.46 participants lived in rural areas, while 54 resided in metropolitan areas.

As far as the level of injury is concerned, 33 respondents suffered from injury at cervical level, 57 at thoracic level and 10 at lumbar region of the spinal cord.

Analysis of participants‘ ages indicated that the study involved mainly young people with spinal cord injury. More than half of respondents - 67 people were in the age group 21-40 years. Study participants were all adults. There were 9 subjects ages 18-20, 41 in the 21-30 age group, 26 in the 31-40 age group, 12 in 41-50 age group and 12 in the 51-60 age group.

Study utilized a diagnostic survey based on a questionnaire. Research involved Quality of Life Index (QLI) Ferrans and Powers, polish adaptation by K. Jaracz et al. Quality of Life

Index Ferrans and Powers Version III General (Poland), allows for assessment of the quality of life in terms of satisfaction and dissatisfaction with all aspects of life and an analysis of their significance by the person being studied. Quality of Life Index Ferrans and Powers Version III General (Poland), consists of two parts: the first measures satisfaction with various aspects of life, while the second measures the validity of those same elements. Each part of QLI contains 33 questions. Test-taker responds using a six-point scale, ranging from „Very satisfied to "Very dissatisfied" and „Very important" to „Very unimportant." Each answer concerning satisfaction is weighed according on priority. The quality of life is better when high satisfaction score is accompanied by high importance score. Quality of life is worse, when high score on the scale of importance accompanied by low satisfaction score [3].

Score is calculated for the total scale, which reflects the quality of life on a global scale (total score Quality of Life Index) and four subscales: health and functioning, socioeconomic, psychological / spiritual. Calculation is performed based on the procedure developed by scale authors. Final result represents weighted score for the total scale and the four subscales. Score range for the total scale and for each subscale is from 0 to 30. The higher the score, the better the quality of life [4].

Assessment of the sense of life was made using the Purpose in Life Test (PIL), developed by Crumbaugha and Maholicka. In Poland, it is known as the "Test of the meaning of life" translation by Z. Płużek [5].

According to its authors, test measures the intensity level of the meaning of life and allows for detection of pathological and "Normal" functioning of individuals [6].

Test consists of three parts, labeled A, B and C. Part A is made up of 20 claims. Part B consists of 13 unfinished sentences that the respondent is asked to complete using the first thought that appears in his or her mind. In Part C, respondents are asked to write a few sentences about their aspirations, ambitions and goals in life. In our study, only Part A of the test was used. Claims are awarded a response from a seven-point rating scale. Test taker selects one of the values from the scale. Number 1 represents the most disapproval, number 4 represents a neutral state (intermediate), number 7 equals the highest intensity of approval. In order to reduce scoring position preference, scale of individual claims is non-uniform. This means that in some cases the numbers are placed in an ascending order from 1 to 7, while at other times in a descending order. Test taker circles the number that most closely reflects the intensity of claim approval or disapproval. Test authors suggest against selecting a „neutral" response, that is, the number 4 [5].

During the study, an interpretation of quantitative and qualitative components of PIL test was performed. Quantitative Interpretation is the sum of raw points earned and represents the intensity of one's sense of meaning of life. According to its authors, PIL differentiates healthy individuals from those at risk of noogenic (spiritual) neurosis [5].

Qualitative interpretation was made possible by categorizing claims as proposed by the author of the Polish version of the test. The following categories were analyzed: purpose of life, meaning of life, affirmation of life, self-assessment, assessment of one's own life, freedom and responsibility, attitude toward death and suicide. Data arrangement according to the proposed categories allows the development of percentage values and trends of specific behaviors included in the scale of 1-7, or their distribution as specified in the categories of results: low (1-3), medium (4), high (5-7).

The authors provided test norms: healthy women 121 points, healthy men 118 points. Borderline result equals 111.5 points [5].

Experiences with the PIL test described in the literature, indicate that it is a helpful diagnostic tool in determining the extent to which the meaning and purpose of life were found and achieved. However, it does not provide very important data concerning the strength of motivation to find the meaning of life in the event of its loss. This information is provided by a tool complementary to the PIL test – the SONG test. According to the authors, both tests must be analyzed in order to get an objective view of the meaning of life and the motivation for its implementation.

Assessment of the strength of motivation to search for the meaning of life was made using the Polish version of The Seeking of Noetic Goals Test (SONG) referred to as the „Test for Seeking Noetic Goals (spiritual)", translation by K. Popielski.

The SONG test consists of 20 claims. Test taker marks the intensity of a phenomenon on a seven-point scale, ranging from „Never" (1 point) to „Constantly" (7 points). Similarly to PIL, the order of numbers on the scale alternates between ascending from 1 to 7, and descending from 7 to 1. Sum of results may range from 20 to 140 points. Calculation of results is done by adding the chosen answer numbers. Borderline score equals 79 points [5].

Custom questionnaire was also used for the purposes of the study. The aim of the survey was to obtain information concerning the age, sex, place of residence, date of spinal cord injury, level of injury and the length of time between the injury and participation in the introductory camp organized by the foundation.

For the purposes of statistical method, the study employed two non-parametric tests: sign test and Wilcoxon rank-sum test [7]. The concept of dual testing contributes to an increased confidence in the reached conclusions.

Statistical analysis used qualitative variables resulting from the Quality of Life Index Version III General (Polish) with subscales, along with PIL and SONG tests with test categories. Analysis was to compare the results before and after the camp, the first stage of the Foundation for Active Rehabilitation for each subject.

The analysis compared each participant's results recorded before and after the introductory camp of the Foundation for Active Rehabilitation.

The level of statistical significance was set at $p < 0.05$ for all analyses, $p < 0.01$ - high statistical significance, $p < 0.001$ - very high statistical significance.

Results

Table 1. Basic statistical parameters of Quality of Life Index, PIL and SONG tests in individuals with spinal cord injury - status before the camp

Variable (before the camp)	**N**	**Mean**	**Minimum**	**Maximum**	**SD**	**Std error**
QLI – global	100	16.14	6.68	25.39	4.00	0.40
QLI – health and function	100	14.08	3.27	25.35	5.16	0.52
QLI – socjo-economic	100	16.42	3.75	24.75	3.68	0.37
QLI – psychologic/spiritual	100	16.16	1.43	30.00	5.78	0.58
QLI – family	100	20.99	3.60	30.00	5.56	0.56
PIL – global	100	98.16	44.00	134.00	17.58	1.76
PIL – life goals	100	25.64	7.00	35.00	5.40	0.54
PIL – meaning of life	100	14.22	3.00	21.00	3.54	0.35
PIL – affirmation of life	100	19.17	9.00	28.00	4.69	0.47
PIL – self assessment	100	10.14	5.00	14.00	1.93	0.19
PIL – own life assessment	100	9.45	2.00	14.00	2.64	0.26
PIL – freedom and independence	100	10.03	3.00	14.00	2.33	0.23
PIL – attitude toward death and suicide	100	9.51	4.00	14.00	2.50	0.25
SONG – global	100	75.71	35.00	106.00	13.01	1.30
SONG – meaning of life	100	11.63	2.00	18.00	2.37	0.24
SONG – life goals	100	7.03	2.00	12.00	2.41	0.24
SONG – temporal bias	100	8.65	3.00	14.00	2.63	0.26
SONG – assessment of own goals	100	10.48	3.00	20.00	3.20	0.32
SONG – creative fear	100	10.77	3.00	18.00	3.08	0.31
SONG – feeling of lacking	100	11.17	3.00	19.00	3.27	0.33
SONG – need of action	100	15.98	5.00	28.00	4.71	0.47

Legend
Std error- standard error
QLI- Quality of Life Index
N- number of subjects
PIL- Purpose in Life Test
SD- standard deviation
SONG- The Seeking of Noetic Goals Test

Table 2. Basic statistical parameters of Quality of Life Index, PIL and SONG tests in individuals with spinal cord injury - status after the camp

Variable (after the camp)	**N**	**Mean**	**Minimum**	**Maximum**	**SD**	**Std error**
QLI – global	100	17.49	9.27	25.29	3.30	0.33
QLI – fitness and function	100	16.12	4.31	26.92	4.48	0.45
QLI – socjo-conomic	100	16.68	5.94	25.06	3.40	0.34
QLI – psychologic/spiritual	100	18.10	6.36	30.00	4.45	0.45
QLI – family	100	21.52	8.40	30.00	4.96	0.50
PIL – global	100	104.03	50.00	138.00	18.46	1.85
PIL – goal in life	100	27.27	11.00	35.00	5.29	0.53
PIL – meaning of life	100	15.50	5.00	21.00	3.64	0.36
PIL – affirmation of life	100	20.23	4.00	28.00	4.91	0.49
PIL – own assessment	100	10.65	5.00	14.00	2.10	0.21
PIL – own life assessment	100	10.21	2.00	14.00	2.53	0.25
PIL – freedom and independence	100	10.38	4.00	14.00	2.29	0.23
PIL – attitude toward death and suicide	100	9.79	2.00	14.00	2.63	0.26
SONG – global	100	73.09	33.00	100.00	13.69	1.37
SONG – meaning of life	100	15.71	8.00	21.00	2.94	0.29
SONG – life goals	100	6.98	2.00	13.00	2.28	0.23
SONG – temporal bias	100	8.93	2.00	14.00	2.64	0.26
SONG – assessment of own goals	100	9.23	3.00	18.00	3.53	0.35
SONG – creative fear	100	9.91	3.00	20.00	3.18	0.32
SONG – feeling of lacking	100	10.64	3.00	19.00	3.45	0.35
SONG – need of action	100	16.37	7.00	28.00	4.39	0.44

Legend
Std error- standard error
QLI- Quality of Life Index
N- number of subjects
PIL- Purpose in Life Test
SD- standard deviation
SONG- The Seeking of Noetic Goals Test

Table 3. Comparison of Quality of Life Index, PIL and SONG tests before and after the camp in persons with spinal cord injury. Results of sign test and Wilcoxon rank-sum test

Variable (camp attendance)	**Sign test**		**Wilcoxon rank-sum test**	
	LN	**p**	**N**	**p**
QLI – global	100	$p < 0.01$	100	$p < 0.001$
QLI –health and function	100	$p < 0.001$	100	$p < 0.001$
QLI – socjo-economic	99	ns	100	ns
QLI – psychologic/spiritual	99	$p < 0.001$	100	$p < 0.001$
QLI – family	91	ns	100	ns
PIL – global	100	$p < 0.01$	100	$p < 0.001$
PIL – entire life	92	$p < 0.05$	100	$p < 0.05$
PIL – meaning of life	81	$p < 0.01$	100	$p < 0.001$
PIL – affirmation of life	91	ns	100	$p < 0.05$
PIL – self assessment	70	$p < 0.01$	100	$p < 0.01$
PIL – own life assessment	80	ns	100	$p < 0.01$
PIL – freedom & independence	72	ns	100	ns
PIL – attitude toward death and suicide	72	ns	100	ns
SONG – global	94	ns	100	$p < 0.05$
SONG – meaning of life	98	$p < 0.001$	100	$p < 0.001$
SONG – life goals	80	ns	100	ns
SONG – temporal bias	76	ns	100	ns
SONG – assessment of own goals	89	$p < 0.05$	100	$p < 0.01$
SONG – creative fear	90	$p < 0.05$	100	$p < 0.05$
SONG – feeling of lacking	88	ns	100	ns
SONG – need of action	80	ns	100	ns

Legend
Std error- standard error
QLI- Quality of Life Index
LN- number of non-pairs
N- number of subjects
ns- statistically non-significant
PIL- Purpose in Life Test
SD- standard deviation
SONG- The Seeking of Noetic Goals Test

Discussion

Participation in the introductory camps organized by the Foundation for Active Rehabilitation has a positive impact on the subjective sense of quality of life on a global scale and the health and functioning, and psychological / spiritual subscales. This may be interpreted as an increase in physical function associated with the development of ability to self-serve without the help of others. This is associated with an increased sense of control over one's own life, organization of leisure time and entertainment. Physical activity promoted at the camp is very important to health and well being of individuals with spinal cord injury. It facilitates independence in the activities of daily living, provides relaxation and thereby reduces level of stress in a daily life. Stress negatively affects human somatic and psychological function, as confirmed by the findings of Jacobs, Roswal, Horaut and Gorman who stated that the overall quality of life improves when playing sports [8].

Sports and recreational activities of individuals with spinal cord injury aim to accept disability, eliminate depression, restore self-confidence and improved self-image [9, 10].

Research by Katula and McAuley has shown that physical activity increases the effectiveness of one's actions and the independence in life [11].

Research by Valliant, Bezzubyk, Daley and Asu indicates that disabled persons who practice athletics have much higher sense of self-confidence and self-assurance. Furthermore, compared to non-physically active individuals, they exhibited more satisfaction with life, presented positive thinking despite their disability and put more stress on an intellectual and academic advancement [12].

In a British-Polish study, Tasiemski found a positive relationship between sport activity and the level of satisfaction with life following SCI. Passive individuals had lower level of life satisfaction than people with SCI, who practiced sports and recreation [13].

According to Chojnicki, Klimek, Tyka and Tchórzewski sports play a significant role in motor-skill improvement, competition and integration, all of which affect the recovery of a lost meaning of life [14].

Besides the physical benefits and a positive impact on the psyche of individuals involved with sports, physical activity may also be a factor facilitating development of interpersonal relationships and social inclusion [10, 15,16].

Participant well-being during the camp was not only influenced by sports, but also by the possibility of establishing interpersonal relationships with other camp participants of similar experience, as well as integration with non-disabled people. The newly established contacts

provide a sense of belonging and usefulness to others, enrich the intellectually and allow for exchange of life experiences. Camp participants support others at difficult times while receiving support from others. Participation in the camp increases satisfaction with life, as reflected by achieving personal goals in life, a sense of accomplishment and satisfaction with life and increased self-acceptance.

According to a study by Kennedy, Taylor, Hindson, measures must be taken to ensure access to sports and recreation for persons with spinal cord injury [17].

At the end of the camp, Foundation for Active Rehabilitation provides spinal cord injury participants with the opportunity to participate in the activities organized by local branches of the foundation. During these activities, skills improve and relationships with other camp participants grow.

In summary, the results of the Quality of Life Index study indicate an improvement in the quality of life, as reflected globally and associated with an increased sense of satisfaction with life in all of its dimensions. Improvement in physical, mental and spiritual function contributes to the above findings.

When comparing study results using PIL test in SCI patients before and after the camp, it may be concluded that the global PIL test result is significantly ($p < 0.001$) higher following attendance at the Active Rehabilitation Foundation camp. Significant increase in the global PIL test result may suggest that the acquired skills, established relationships with others, a sense of belonging with individuals facing similar experiences of trauma and therefore living with similar problems of everyday life, has a positive impact on the functioning of camp participants.

In the life goals category, significant ($p < 0.05$) change has been observed. An increase in perception and definition of life's objectives, such as control of one's life in an attempt to receive satisfaction and fulfillment. This applies not only to the fulfillment of physical needs, but also psychological ones.

It has been observed that camp participants tend to be forward-thinking, planning their future life, self-achieving and not dwelling on a difficult life experience from the past.

Camp design places great emphasis on the pursuit of self-reliance and independence through improvement of motor function. Development of these skills enables an individual to address the needs of higher order, such as mental and spiritual. Improvement of physical function according to one's capability is observed in all patients, therefore enabling them to grow their interests and pursue rewarding activities. Participation in the camp has allowed them to strengthen their meaning of life. Providing meaning to life is based on a belief that

traumatic experience and suffering may enable individuals to expand their own abilities and overcome weaknesses and challenges encountered in the daily life.

Another PIL test category relates to affirmation of life that is reflected in an individual's attitude toward life. This category also saw an increase in the intensity of approval of life among camp participants. Based on this finding, it may be concluded that these individuals have the ability to notice positive aspects of life, focus on experiences that bring joy and satisfaction, and treat each day of life as something new and unique, despite difficult life experiences from the past. Perhaps this attitude was the result of functioning in a group of individuals with similar experiences, similar movement disorders, giving them a sense of belonging, social ties and mutual support. Support provided by Foundation for Active Rehabilitation instructors with similar dysfunctions who have acquired skills allowing them to become self-reliant and independent, certainly played a role. Instructor may be regarded by the participants as an authority figure, motivating them to overcome their own weaknesses, providing hope for improvement in everyday functioning and help explore new opportunities that are yet to be discovered.

Comparison of PIL test – self evaluation results obtained before and after FAR camp indicates that self-perception may have been positively influenced by the camp. It may be assumed that the change is related to adequate self-assessment made by camp participants, allowing them to react according to their true abilities and problem requirements. By acquiring new skills, participants began to see themselves as more competent, believing in their abilities, possessing an optimistic attitude toward the future, feeling responsible for their own lives and setting realistic goals. Close relationships with other camp participants, self-opinion and comparison with others, may have a positive effect on one's self-esteem.

Analysis of own life assessment shows significant ($p < 0.01$) increase in the category. This may be interpreted as a reflection on the course of one's life, which is associated with a sense of control over it. Despite the limitations it is progressing well and is valuable.

Analysis of the meaning of life SONG test indicated low meaning of life before the camp. Since the camp motivated individuals with spinal cord injury to explore their existence and use their experiences in creative ways, significant ($p < 0.001$) increase in the sense of life is seen after the camp.

A decrease was observed in the assessment of one's aspirations and creative anxiety SONG test categories. This finding may be related to an adjustment of aspirations and opportunities resulting from the limitations that individuals with spinal cord injury face.

Participation in the camp significantly improves the subjective quality and meaning of life. However, the motivation to find the meaning of life is significantly lower after attending the camp. This may be interpreted in accordance with the assumption that camp participants have less need of finding the meaning and purpose in life, because of decreased levels of existential frustration.

Conducted study confirms the validity of the research problem posed. Results show validity of training camps and rehabilitation by FAR for individuals with spinal cord injury. Participation in the camps shows individuals with spinal cord injuries that they too have a chance to improve their motor function, further contributing to greater self-reliance and independence, thus improving their quality of life. Camp participants have increased levels of self-acceptance, self-esteem and self-confidence. Collective action, as part of program activity, has developed a pro-social behavior that facilitates integration with society, eliminates the phenomenon of social exclusion and the feeling of being a burden to others. Motor skills progress within a relatively short period of time as observed in majority of respondents, allows them to realize that with the right amount of consistency, regularity and tenacity, they can reach a level of self-reliance and independence that will significantly improve not only their quality of life, but also their mental state.

Conclusions

1.Participation by individuals with spinal cord injury in the introductory camps organized by the Foundation for Active Rehabilitation has a positive impact on the subjective quality of life on a global scale, health and functioning subscale and the psychological and spiritual subscale.

2.Participation in the camps facilitates the development of meaning of life and decreases the motivation to find it. This may be interpreted in accordance with the assumption that camp participants have less need of finding the meaning and purpose in life, because of decreased levels of existential frustration.

3.Participation in the introductory camps organized by the Foundation for Active Rehabilitation by persons with spinal cord injury could improve motor function and contribute to greater self-reliance and independence, thus improving their quality of life.

4.Study results indicated the validity of organizing Foundation for Active Rehabilitation camp training and rehabilitation for individuals with spinal cord injury.

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