

Analiza wybranych czynników determinujących wiedzę o stanie zdrowia osób po urazie rdzenia

Analysis of selected determinants of knowledge about the health in persons with spinal cord injury

Jarosław Pokaczajło^(A,B,C,D,E,F), Tomasz Tasiemski^(A,C,D,E,F)

Zakład Sportu Osób Niepełnosprawnych, Wydział Wychowania Fizycznego, Sportu i Rehabilitacji, Akademia Wychowania Fizycznego im. Eugeniusza Piaseckiego w Poznaniu, Polska/
Department of Sport for People with Disabilities, Poznan University of Physical Education, Poznan, Poland

Streszczenie

Cel pracy. Głównym celem pracy była analiza wybranych czynników determinujących poziom wiedzy na temat stanu zdrowia osób po urazach rdzenia kręgowego (URK). Wybrane zmienne podzielono na dwie grupy: 1) socjodemograficzne: wiek w dniu badania, płeć, stan cywilny, poziom wykształcenia, miejsce zamieszkania oraz 2) związane z URK: wiek w dniu urazu, czas od urazu, udział w obozach Aktywnej Rehabilitacji (AR), obraz kliniczny, tj. paraplegia/tetraplegia.

Materiał i metodyka. Badaniami objęto 100 osób po URK (22 kobiety oraz 78 mężczyzn) uzależnionych w codziennym funkcjonowaniu od wózka inwalidzkiego. Narzędziem wykorzystanym do przeprowadzenia badań był test wiedzy na temat stanu zdrowia osób po URK.

Wyniki. Średni wynik uzyskany przez respondentów w teście wiedzy wyniósł 27,11 pkt. (zakres: 10-45 pkt.), co wskazuje na dostateczną znajomość stanu zdrowia osób po URK. Najlepszą wiedzę badani wykazali w zakresie odżywiania/diety. Obszarami, na temat których posiadali najmniejszą wiedzę było uzyskiwanie pomocy oraz zaopatrzenie ortopedyczne. Do czynników istotnie różnicujących poziom wiedzy na temat stanu zdrowia osób po URK należały: udział w obozach AR, wiek w dniu urazu oraz czas od urazu.

Wnioski. Dostateczna ogólna ocena wiedzy oraz niedostateczne wyniki w obrębie poszczególnych obszarów funkcjonowania osób po URK wskazały zagadnienia, którym w trakcie procesu rehabilitacji i edukacji pacjentów należy poświęcić szczególną uwagę.

Słowa kluczowe:

wiedza, uraz rdzenia kręgowego, edukacja, rehabilitacja

Abstract

Aim of the Study. The main aim of this study has been to analyze the selected factors determining level of knowledge of the health condition of persons after the spinal cord injury (SCI). Selected variables have been divided into two groups: 1) Socio-demographic: age on the day of the test, gender, marital status, level of education, place of residence, and 2) associated with the SCI: age on the day of the injury, time elapsed from the injury, participation in the Active Rehabilitation (AR) camps, clinical picture, i.e. paraplegia/quadruplegia.

Materials and Methods. In the study participated 100 persons after the SCI (22 women and 78 men), dependent on a wheelchair in the everyday functions. To carry out the study, we have used the test of knowledge of the health condition of persons after the SCI.

Results. The mean score obtained by the respondents in the test of knowledge has been 27.11 points (Derived from the range: 10-45 points), which indicates a sufficient knowledge of the health condition of persons after the SCI. The best knowledge the respondents have shown on the issues related to nutrition and diet. The least knowledgeable they were in the areas of requesting support and orthopedic supplies. The factors significantly differentiating the level of knowledge about the health of persons after the SCI included: participation in the AR camps, age on the day of the injury and the time elapsed from the day of the injury.

Conclusions. The overall evaluation of knowledge as sufficient, and the unsatisfactory results within the particular areas of the functioning of persons after the SCI, have indicated the issues, which during the process of rehabilitation and education of the patients should be given particular attention.

Key words:

knowledge, spinal cord injury, education, rehabilitation

Introduction

The fundamental problem for persons after the spinal cord injury (SCI) is coping with the changes, that have occurred in their lives as a result of the injury. In order to adapt to the newly developed situation, they need to acquire the necessary knowledge about the SCI pathophysiology, and the medical and social consequences of the injury, including in particular prevention of the early and late post traumatic complications. The patient education is considered by many foreign rehabilitation centers as the a key element for rehabilitation after the SCI, and regarded as absolutely essential during the first stage of rehabilitation, since it does make it easier for the patient to return from hospital to the place of residence, and to get on with everyday life in the community, with his or her disability [1, 2]. The acquired knowledge on the health condition is also one of the basic components, affecting the efficiency of rehabilitation of persons after the SCI [3]. Patients must be prepared to the new way of life and well equipped with the information and skills, necessary to maintain their best health and well-being. So the need to acquire knowledge about the SCI by people who have experienced such injury seems to be quite obvious, considering the benefits, which they may gain by it.

In the Polish health care system, there is a clear gap in the area of the post-hospital rehabilitation (community based), addressed to the persons after the SCI and there is not, as yet, any government program, which would be addressed to the persons after the spinal cord injury, who leave a hospital and come back home to try and function in their community. Rehabilitation, being a process of both medical and social nature, requires collaboration between the various institutions on the national and the local government level. In the absence of the specific, multifaceted rehabilitation program provided by the state to help the persons after the SCI, it is vital that both, medical community (doctors, nurses, physiotherapists) and social institutions, work closely together. The gap in this area, in the Polish health care system, is being filled up by the Active Rehabilitation (AR) [4] program. The AR System, a movement which draws knowledge from many years of experience of the persons dependent on a wheelchair in their everyday lives, constitutes the most valuable and very important complement to the comprehensive rehabilitation after the SCI [5].

In psychology, knowledge is being defined as the “general content fixed in the human mind, as a result of the cumulative experience and learning. (...) In a narrower sense, knowledge is the personal status of a man’s cognition, which comes from the influence of the surrounding, objective reality” [6]. Knowledge is a very important aspect of the predisposition defined as “formed in the process of fulfilling needs, in the specific social conditions, or compatible and consistent organization of knowledge, beliefs, feelings, motives and certain forms of actions and expressive reactions of the subject, related to a specific object or a class of objects” [7].

The issue of knowledge concerning the health condition of persons after the SCI has already been noted in the 1980s, at the State University of New York in Buffalo, where they have developed a test verifying the level of knowledge of the health condition of persons after the SCI [8]. The subject however,

has not been pursued by other research centers, as there are no English-language publications regarding this area. The first translation of the original version of the test, and its adaptation to the conditions in Poland, has been done by Opara and Opieczzonek in 1995 [9]. The original version of the test consisted of 39 questions, regarding nine issues related to the SCI. From that moment on, work on the further improvement of the test has been done simultaneously in two Polish centers: Upper Silesian Rehabilitation Center "Repty" in Tarnowskie Góry, and the Institute of Rehabilitation at the Academy of Physical Education in Poznań. In 1998 Tasiemski and Kost [10] did their research evaluating the level of knowledge of persons after the SCI, on the group of 40 participants of the AR camps. The knowledge level of the participants has been assessed as good. The respondents had the best knowledge about nutrition and diet (91.2% of correct answers), while the least they knew about the autonomic dysreflexia (40.6% of correct answers). In the same year, another research has also been conducted by Opara et al. [11]. It included a group of 15 persons after the SCI, hospitalized in the Upper Silesian Rehabilitation Center. The respondents completed the knowledge test twice - first time on the day of their admission to the center, the second time - after two months of stay. The results have shown, that the majority of patients (14 out of 15 persons) have extended their knowledge about their health condition.

The final outcome of the research in both centers, has been the development and publication by Tasiemski and Opara in 2002 the new test of knowledge about the health condition of persons after the SCI, modified and adapted to the Polish conditions. The new version has been extended to 50 questions related to thirteen areas of functioning of the persons after the SCI [2]. The extended version of the test has not yet been used to assess the knowledge of persons after the SCI.

In the foreign literature, it has been possible to find only five publications on the evaluation of knowledge related to the SCI. The first of these, by May et al., has been oriented on the education of patients after the SCI [13]. In addition to knowledge, it has also evaluated the ability to solve problems and has determined the perception of importance of the particular topics included in the education program, in which the respondents participated. The survey has been conducted three times: 2 weeks after admission to the hospital, when leaving the hospital and 6 months after the hospitalization. To evaluate the knowledge, a multiple choice questionnaire has been used, consisting of 29 questions/items, referring to twelve topics related to the SCI, which were being discussed during the educational program for the patients. The research has shown statistically significant improvement in the knowledge of the examined persons, in the subsequent tests. The matters related to defecation, taking care of the urinary bladder and the skin care have been consistently regarded as the most important educational topics. Majority of the incorrect answers have been related to: temperature control and autonomic dysreflexia, sexuality, skin care, spinal cord functions, taking care of a urinary bladder and servicing a wheelchair.

In 2009, McGillivray et al. have published their research about the assessment of knowledge of the SCI patients, and their family members, on the autonomic dysreflexia [14]. This stu-

dy has shown that both, patients and members of their families, have lacked some knowledge on the topic. The respondents with the traumatic spinal injury have had a higher level of knowledge, but 41% of them declared, that they have never heard of such complication. The authors have been very much concerned with the result, showing that 22% of the persons after the SCI reported symptoms consistent with the unrecognized autonomic dysreflexia.

In 2009 Schottler et al. have presented their work regarding relationship between the knowledge about autonomic dysreflexia and the spinal cord injury classification, degree of injury, its cause, gender and race of the patient [15]. The respondents in the survey have been both, persons after the SCI and their caregivers, and the knowledge concerned only the issue of the autonomic dysreflexia. On the basis of the obtained results the authors concluded, that the autonomic dysreflexia concerned only the persons with the injury on the level Th6 or above, with the higher degree of injury (A and B according to the American Spinal Injury Association) and with the post traumatic spinal cord injury. Greater knowledge about the autonomic dysreflexia have had the persons with the traumatic causes of their spinal cord injury, with the SCI on the level Th6 or above, and the persons older on the day of the survey.

The same authors presented in 2010 their study, showing the knowledge test results of the patients after the SCI and their caregivers, in relation to the type (total/partial) and the level of the SCI [16]. This research has shown, that 16% of persons with the SCI and 20% of their caregivers knew the difference between the total and partial SCI. The respondents who provided the incorrect information concerning the level of their injury, more frequently evaluated their injury as total and declared it to be at a higher level than it was actually the case.

Another study has been done by Thiethe et al. in 2011. Their aim has been to examine the knowledge of patients after the SCI, regarding two post traumatic complications: pressure ulcers and disorders of the functioning of the urinary bladder [17]. The results here have been collected after examining the knowledge of 213 patients at several points in time, i.e. at the time of the admission to the hospital, 1 and 3 months after the admission, and 6, 8 and 30 months after the discharge from the hospital. These studies have shown, inter alia, the greater respondents' knowledge at the time of the hospital discharge (11.2 points out of maximum 20 points), than during the first test, i.e. during admission to the hospital (5.4 points). However the same test repeated in 30 months after the hospital discharge has shown the decrease in knowledge (10.8 points). As stated above, a small number of publications concerning the topic of knowledge of their own health condition, among persons after the SCI, confirms the need for further research in this area.

Aim of the Study

The main aim of this study has been to analyze the factors differentiating level of knowledge of health condition of persons after the SCI. Among the analyzed variables the following factors have been identified as socio-demographic (age on the day of the test, gender, marital status, level of education, place of residence), and the variables associated with the SCI (age on the day of the injury, time elapsed from the injury, participation in the AR camps, clinical picture, i.e. paraplegia/quadruplegia).

Material and Methods

In the study participated 100 persons after the SCI (22 women and 78 men), dependent on a wheelchair in their everyday functioning. The mean age on the day of the survey was 32 years (SD=9.3), and the mean age on the day of the injury 27 years (SD=8.6). The tests have been carried out in the early days of the AR camps, in order to avoid the participation of respondents in the thematic lectures, which presented information on various topics related to the SCI.

The tool applied for the research has been the test regarding knowledge of their health condition of persons after the SCI, which consisted of 50 questions referring to the thirteen issues particularly important for the daily functioning of persons after the SCI, i.e.:

1. skin care,
2. nutrition/diet,
3. medications taken,
4. orthopedic supplies and aids,
5. wheelchair,
6. passive exercises,
7. autonomic dysreflexia,
8. respiratory infections,
9. urinary tract infections,
10. urological supplies,
11. thrombosis,
12. sex and procreation,
13. requesting help.

To different issues there has been assigned a different number of questions, depending on the scope and the substance of the issue. Regardless of the number of possible answers (list), always only one answer has been correct. For every correct answer the respondent has received 1 point, and for the incorrect one 0 points. In total there has been the maximum of 50 points to be gained. The score of 0-25 indicated the insufficient knowledge on the health condition, 26-35 points meant sufficient knowledge, 36-45 points – good, and 46-50 points – very good [12].

To collect the demographic information a form has been used, containing questions regarding the basic personal data (age, gender, marital status, place of residence, education) and the information related to the SCI (time elapsed from injury, level of injury, participation in the AR camps).

Analysis of the relationship between the age on the day of the test, the age on the day of the injury and the knowledge about the health condition, has been carried out by estimating the Spearman's rank correlation coefficient. The test results in relation to gender, marital status, education and clinical form of the SCI (paraplegia/quadruplegia) have been analyzed using the Mann-Whitney U test (Z). The results of the knowledge test considering the place of residence have been analyzed test with the Kruskal-Wallis (H) test.

Research Results

The persons participating in the research (n = 100) have obtained in the knowledge test the mean result of 27.11 points, which indicates a sufficient knowledge of their health condition in patients after the SCI. 41% of the participants have obtained the result below 26 points (\bar{x} =18.44), showing the insufficient knowledge, while 22% have achieved the good

result ($\bar{x}=38,95$). In the examined group, none of the respondents has received the very good note. Details of the results showing the level of knowledge on the health condition of persons after the SCI are presented in Table 1.

Table 1. The level of knowledge on the health condition of persons after the SCI

Knowledge level assessment	Persons after SCI	Knowledge test	
	n*	\bar{x}	SD
Good (36-45 points)	22	38.95	2.57
Sufficient (26-35 points)	37	29.68	3.04
Insufficient (0-25 points)	41	18.44	4.37
General tested population	100	27.11	8.79

* The numbers given are also the percentage values

Among the researched areas, which are important for the functioning of the SCI patients, the respondents have presented best knowledge in the area of nutrition/diet (85.0% of correct answers). They have also demonstrated good knowledge in the areas of skin care (67.8% of correct answers) and infections (65.3% of correct answers). Areas on which the respondents have had the least knowledge, have been requesting help (36.3% of correct answers) and orthopedic supplies (44.5% of correct answers). Detailed data for all the thirteen tested areas of knowledge are given in the Figure 1.

Among the variables that have been examined for the potential relevancy with the knowledge on health condition of persons after the SCI, significant dependencies have been confirmed with the three variables related to the SCI: participation in the AR camp, age on the day of the injury and time elapsed from the injury. The carried out analysis has shown, that persons who have participated, in the past, in the AR camps ($n = 50$) have obtained better results in the knowledge test ($\bar{x}=32.24$, $SD=7.29$), if compared with the persons who never before took part in the AR camps ($n=50$) ($\bar{x}=21.98$, $SD=7.02$). The difference has been highly statistically significant ($Z=-5.961$, $p\leq 0.001$). Age on the day of the injury has been significantly negatively correlated ($r_s=-0.238$, $p=0.017$), and time elapsed from the injury has been significantly positively correlated with the level of knowledge about the health condition of persons after the SCI ($r_s=0.215$, $p=0.032$). In the case of all the other variables analyzed for the potential relevancy with the knowledge on the health condition, i.e. gender ($Z=-0.816$, $p=0.414$), marital status ($Z=-1.817$, $p=0.069$), education ($Z=-1.934$, $p=0.072$), place of residence ($H=3.707$, $p=0.066$), clinical for of the SCI ($Z=-0.314$, $p=0.730$), significant correlation has not been found.

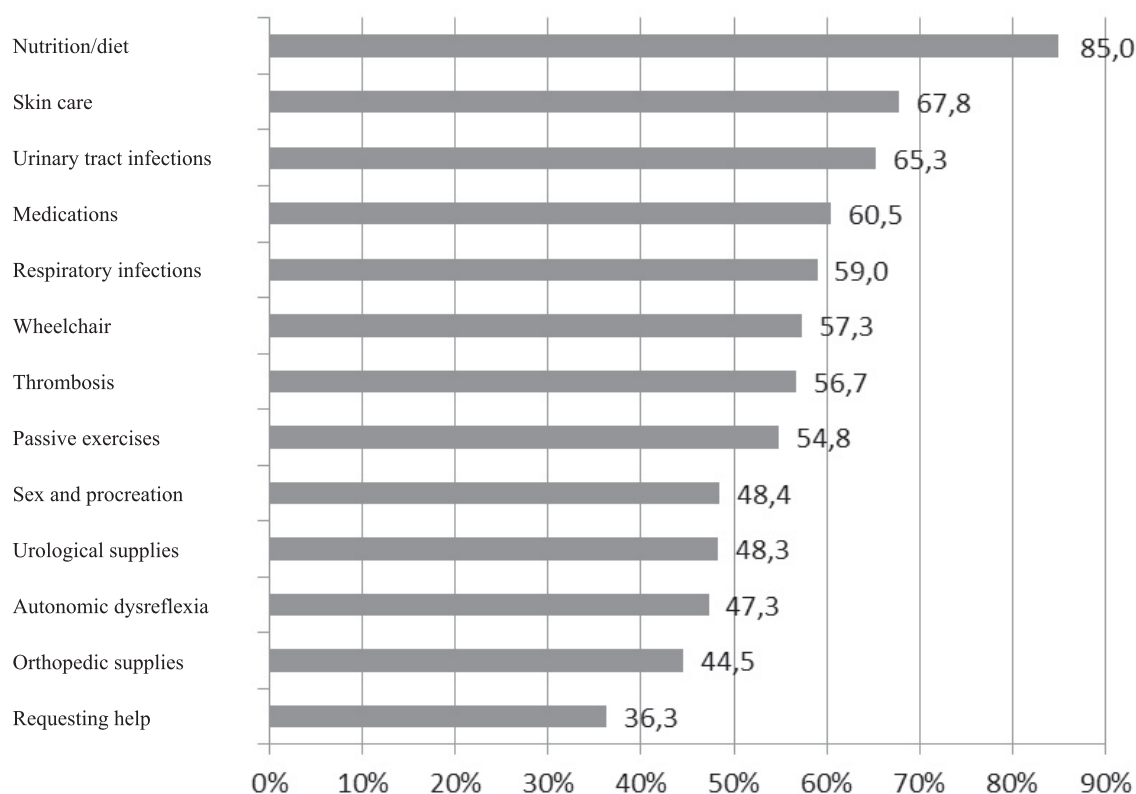


Figure 1. Percentage of correct answers regarding the particular areas of the functioning of the SCI patients

Discussion

The main topic of this study has been to provide information regarding the factors differentiating the level of knowledge of their health condition, in the persons after the SCI. So far only a few research projects have touched on the subject of knowledge among the SCI patients, and those have been projects focusing on a particular topic, which makes our study unique in a way. The analysis of the results obtained by the respondents, allowed to assess their knowledge of their health condition as sufficient (mean result = 27.11 points, which constituted 54.22% of correct answers). However, while performing a more detailed analysis, it has been noted, that 41% of the respondents did not answer correctly to more than half of the questions, which has led to evaluation of their knowledge as insufficient. Also, no one's knowledge has been assessed as very good in the test. The results obtained are similar to those presented by Opara et al., on the basis of their tests carried out on the group of 15 persons after the SCI, who stayed at the Upper Silesian Rehabilitation Center [9]. Their respondents completed the initial version of the knowledge test twice - once on the day of their admission to the Center, the second time - after two months of stay. In the first test, the participants have obtained the mean result of 18 correct answers on 39 possible, which has indicated a sufficient knowledge of their health condition (46.15% of correct answers). The second test, also performed with the initial test version, has shown an improvement of the results obtained - mean score of 23 correct answers (58.95% of correct answers - the knowledge of the health condition assessed as good). Good knowledge of their health condition, also has been presented by the respondents of the tests carried out by Tasiemski and Kost, i.e. the per-

sons after the SCI, who participated in the AR camps [10]. Higher evaluation of the knowledge in both above studies, in comparison with our own research, may be due to the fact, that the studies were carried out during the stay of the respondents either in hospital [9], or at the AR camp (10). Thus, it was time during which the respondents were undergoing treatment or rehabilitation, and therefore had the opportunity to be acquiring new knowledge and new skills in the field of SCI, which could have translated directly into the higher scores on the test. It should also be noted, that in our study the research material has been collected in the first days after the camp started, to minimize the probability that the AR camp activities would influence the participants' level of knowledge of their health condition after the SCI.

Different results in the assessment of knowledge on the issues related to the SCI, have obtained the respondents in tests carried out by May et al. [13]. Although in those tests a different tool has been applied than in our study, still since very similar issues have been assessed in both cases, some comparison of the results obtained may be done. The mean score obtained by the respondents in May's knowledge evaluation tests performed on the last day of the study, i.e. 6 months after the discharge from the hospital, amounted to 24.22 points. Bearing in mind that the research questionnaire consisted of 29 questions, this is 83.5% of correct answers. This result is decisively better than the result obtained in our own study (54.22% of correct answers). Due to the lack of knowledge of the tool which has been used by May, we cannot reject the assumption, that the result differences may have been due to the specific nature of the research tool itself, e.g. the degree of difficulty of the questions it contained. There is however yet another issue, which could explain the differences in the results. The main objective of the May's research has been to assess the process of education, which is being conducted in a hospital in Alberta, Canada. The mere existence of such a program in a clinical hospital allows the conclusion, that the hospital personnel is well prepared to convey to the patients information regarding the SCI, both in terms of methodology and content. While comparing the results of our own research with the results obtained by May et al., we can also find some similarities in the areas, within which the respondents gave the lowest number of correct answers [13]. Most incorrect answers in both carried out tests have been related to such issues as: temperature control and autonomic dysreflexia, sexuality, skin care, spinal cord functions, servicing the wheelchair and caring for the urinary bladder. Even though in our own research the autonomic dysreflexia has not been the area, where the respondents acquired the lowest score, still the result below 50% of correct answers may be defined as low. The autonomic dysreflexia has also been the lowest-ranking area in the Polish surveys, which have used the initial version of the test of knowledge of the health condition [10]. Low score, like in the May's research, the respondents in our own study have obtained in the area of sex and procreation [18]. The other low-ranking areas have been: requesting help, orthopedic supplies and urological supplies. By far, the most correct answers the respondents gave to questions in the field of nutrition/diet, the area best assessed also in the study by Tasiemski and Kost [10].

The results of the analysis of the factors determining the knowledge of the health condition have shown, that the participation

in the AR camps, where there are theoretical lectures, is a valuable source of information about the SCI. It is worth mentioning, that the whole AR movement, with its the wide range of activities, is a valuable source of knowledge on the SCI for persons dependent on a wheelchair in their everyday functioning. The persons after the SCI, who join an AR camp, are invited to participate in a wide range of activities, which are offered today by the Foundation for Active Rehabilitation. Therefore it can be assumed, that the persons who attend the camps more than once are active members of the AR movement and participate in the various types of activities or events, organized by the Foundation. Even if these are not of educational nature, still the participation alone in the various initiatives, together with other persons after the SCI, provides the opportunity to exchange experiences between the individuals with the similar disabilities and problems. This example shows just how important the AR movement is in the Polish system for comprehensive rehabilitation of the SCI patients, and within the area of the post-hospitalization (community based) rehabilitation addressed to this population, the movement practically constitutes an exception.

Characteristics of the respondents indicated, that their mean age at the date of injury was 27 years. This has confirmed the fact, that the spinal injuries occur mostly in young persons.¹⁰ Studies have shown, that they have obtained higher scores than persons, who had been injured at a later age. This result suggests that young persons after the SCI better adapt to the new conditions than older people. It is quite possible, that the prospect of a long life to come after the injury causes the desire to preserve the best possible health condition in the years ahead. Indirectly this is related to the knowledge of the various aspects of functioning after the SCI, which should have a positive impact on the ability to cope with any disadvantages that may be occurring in the everyday life.

The last variable that has been verified for the potential relevance with the knowledge of the health condition of persons after the SCI, has been the time which elapsed from the date of the injury. Statistical analysis of the research material has confirmed this relevance. The length of time which has passed since the injury, directly translates into the longer lifespan with the disability, and therefore greater experience, skills and the greater knowledge of how to cope with the effects of the SCI.

In the course of the research process we have encountered certain restrictions, and it seems to be worthwhile to mention them for the researchers, who would want study the issue of knowledge in persons after the SCI in the future. One of the first restrictions has been the difficulty in collecting sufficient amount of the research material. Because of the research tool used for assessing the knowledge (test), it was required that the respondents will fill out the questionnaire by themselves, under the supervision of a researcher. Other possibilities of executing the test (e.g. by email via the Internet) have been ruled out, as in this case the objectivity of the data could be easily questioned, as it would be quite likely, that the respondents will be tempted to get the maximum score and will try help themselves by looking for the correct answers in various external sources (Internet, books etc.). In the research participated 100 persons, however this number does not allow to consider the tested group as representative for the population of persons after the SCI who live in

Poland. An additional doubt factor in this respect is the fact, that the study has been carried out only on the AR camps, which has already meant a selection and choice of the specific group from the general population of persons after the SCI. However, bearing in mind the lack of earlier research in this area on the national level, in view of the results obtained one can speak of a certain trend among the persons after the SCI. Still, it is recommended to conduct tests on a larger group of persons after the SCI. Another restriction was the cross-section nature of the carried out tests. Despite the fact, that we have attempted to evaluate all the respondents at the same time (in the early days of the camp), the fact that the test has been performed only once in the test group, may have affected the reliability of the results obtained.

Taking into account the results obtained in our own study, the practical consequence should be the development of a framework program for training persons after the SCI, which could be used in the future to work with patients in the national rehabilitation centers. In the Polish health care system, so far there is no universal, uniform educational program, within which persons after the SCI could acquire knowledge about their disability (especially in the course of the clinical rehabilitation). Development of such educational program (e.g. on the basis of the already existing manuals and knowledge about the SCI) and its practical implementation in the health care facilities in Poland, where the persons after the SCI are being treated, appears to be the key element in the process of preparing the patients to meet the challenges awaiting for them throughout their future life [19, 20, 21, 22, 23, 24]. Such action may have one more positive aspect - financial one. Education of persons in the chronic condition, one of which the SCI is, may also contribute to the reduction of the costs of health care provided for persons after the SCI [25]. Education of the SCI patients could be provided by physiotherapists, although the up to date studies show, that the knowledge of health condition of persons after the SCI, among the physiotherapists employed in the public health care facilities, has been assessed only as sufficient [26]. In order to effectively educate the SCI patients, a higher level of expertise among the personnel who works daily with this group of disabled persons should be ensured.

Conclusions

Our study has allowed to draw up the following conclusions:

1. The persons after the SCI have only sufficient knowledge of their health condition, which suggests the need for more education provided for such persons.
2. Factors differentiating the knowledge of health condition of persons after the SCI have been the age at the date of the injury, time elapsed from the injury and participation in the AR camps.
3. In the process of education of persons after the SCI, special attention should be paid to the areas of knowledge, where the respondents got the lowest scores, i.e.: requesting help, orthopedic supply, autonomic dysreflexia, urological supply and sex and procreation.
4. AR camps are the valuable source of knowledge of health of persons after the SCI.



prof. nadzw. dr hab. Tomasz Tasiemski

Akademia Wychowania Fizycznego
ul. Królowej Jadwigi 27/39
61-871 Poznań
Tel. 502377014
e-mail: tasiemski@awf.poznan.pl

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