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Lundstrom, Ulrica; Lilja, Margareta; Petersson, Ingela; Lexell, Jan; Isaksson, Gunilla

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PO Box 117  
221 00 Lund  
+46 46-222 00 00

## **Leisure repertoire among persons with a spinal cord injury:**

### **Interest, performance and well-being.**

Ulrica Lundström<sup>1</sup> OT, MSc, PhD Student; Margareta Lilja<sup>1</sup> OT, PhD, Professor; Ingela Petersson<sup>2†</sup> OT, PhD; Jan Lexell<sup>3,4</sup> MD, Med Dr, Professor; and Gunilla Isaksson<sup>1</sup> OT, PhD, Associate Professor.

<sup>1</sup> Department of Health Sciences – Health and Rehabilitation, Luleå University of Technology, Luleå, Sweden.

<sup>2</sup> Division of Occupational Therapy, Department of Neurobiology, Care sciences and Society, Karolinska institutet, Stockholm, Sweden.

<sup>3</sup> Department of Health Sciences, Lund University, Lund, Sweden.

<sup>4</sup> Department of Rehabilitation Medicine, Skåne University Hospital, Lund, Sweden.

†Ingela Petersson died January 2013.

#### **Corresponding author:**

Ulrica Lundström

Department of Health Sciences

Health and Rehabilitation

Luleå University of Technology,

S – 971 87 Luleå, Sweden.

Telephone: +46 70 653 19 73.

E-mail address: [ulrica.lundstrom@ltu.se](mailto:ulrica.lundstrom@ltu.se)

## **Abstract**

**Objective:** To explore and describe the leisure repertoire of persons with traumatic spinal cord injury (SCI) and how the repertoire is related to interest, performance, and well-being.

**Design:** Cross-sectional study.

**Setting:** A total of 97 persons with traumatic SCI were recruited from the non-profit national organization, RG Active Rehabilitation in Sweden.

**Outcome measure:** Data was collected through a two-part postal survey. The first comprised of questions investigating socio-demographic variables and injury characteristics; the second part included an interest checklist with 20 areas of leisure activities.

**Results:** The participants were mostly interested in, performed and experienced well-being from social and culture activities, and TV/DVD/movies. The areas of leisure activities in which they had most likely experienced changes after the SCI were outdoor activities, exercise, and gardening. Sex, age, and to some extent, time since injury were related to interest, performance, well-being, and changed performance.

**Conclusions:** The results provided an explanation and limited description of a changed leisure repertoire among persons after a traumatic SCI. The study showed that sex, age, and time since injury, were more closely related to the choice of leisure activities to include in the leisure repertoire than the level of injury. This knowledge can be of importance when professionals in the field of rehabilitation are planning and implementing interventions concerning leisure activities for persons with SCI.

**Key words:** Leisure activities, Rehabilitation, Spinal cord injuries, Well-being, Disability, Quality of life

## **Introduction**

Leisure activities can be described as activities in which people participate, in order to socialize, relax or to pursue interest and hobbies. Therefore, these activities can be considered enjoyable and freely chosen rather than chosen by necessity. Each person has a unique leisure repertoire of leisure activities that he or she finds meaningful and practices regularly.<sup>1</sup> After a traumatic spinal cord injury (SCI), persons might experience disrupted living patterns including a changed leisure repertoire, regardless of the localization of the injury and the time since the injury<sup>2</sup>. This can mean changes in hours spent on various leisure activities and changes in leisure activities that are accessible to the individual, which can affect their well-being.

Earlier research about persons with SCI has focused mainly on the reasons why they experienced difficulties performing leisure activities. To a great extent, this research has described personal and/or environmental factors associated with the difficulties performing leisure activities and implied that the absence or lack of skills required for performing leisure activities can result in negative attitudes toward life after the injury and to a lowered sense of self-esteem.<sup>3,4</sup> In addition, the consequences of the SCI can result in personal feelings of a reduced freedom to choose appealing leisure activities and an altered perception of the meaning of performing leisure activities.<sup>5,6</sup> The changes that occur in leisure activities after a SCI may also be affected by the reduced time and energy available to perform desired leisure activities, since self-care activities can take considerably longer to perform for persons with SCI.<sup>7</sup> Earlier research has also described how persons with SCI reduced or even completely ceased, engaging in desired leisure activities because of barriers in the physical environment, including in-accessible buildings, long distances,<sup>3</sup> and lack of suitable transportation<sup>8</sup> or weather conditions.<sup>9</sup> Feelings of being dependent on others, the absence of social support, a

lack of appropriate assistance, and negative attitudes in society toward people with disabilities have also been reported as hindrances to performing leisure activities.<sup>4,10,11</sup> However, persons with SCI spend significantly more time every day on leisure activities than persons without disabilities,<sup>12-14</sup> and these leisure activities contain an over-representation of sedentary activities, such as listening to music, watching TV, reading,<sup>6,7,13,14</sup> and engaging in computer-based activities.<sup>7</sup> Reports have also indicated that persons with SCI can experience dissatisfaction and boredom in everyday life when they are unable to achieve an optimal level of well-being because they are not satisfied with their leisure activities.<sup>15</sup>

On the other hand, research has shown that persons with SCI who frequently participate in sports have greater life satisfaction and self-esteem than persons with SCI who do not participate in sports.<sup>4,6,16</sup> Researchers have explored how persons with SCI could overcome barriers to participation in an active leisure life by pursuing pre-injury leisure activities with appropriate adaptations and/or by exploring new interests.<sup>17-19</sup> Martin Ginis, et al<sup>20</sup> has investigated the physical activities in which persons with SCI choose to engage in their free time based on a definition for leisure time physical activity (LTPA);<sup>21</sup> they found that some persons with SCI chose, for example walking/wheeling, playing sports, or exercising at a gym.

To summarize, several studies have described different reasons why persons with SCI can experience difficulties performing leisure activities and why they often spend much time engaging in mainly sedentary leisure activities. However, research has also revealed that persons with SCI can be interested in and perform physical activities, and that engaging in such activities can positively affect their feelings of life satisfaction and self-esteem. Yet, these studies did not explore the types of leisure activities chosen by persons after a SCI.

Therefore, in an effort to respond to this gap in knowledge, the purpose of this study was to explore and describe the leisure repertoire of persons with traumatic SCI and how the repertoire is related to interest, performance and well-being.

## **Material and methods**

### *Study population*

Participants in this cross-sectional study were recruited through the non-profit national organization, RG Active Rehabilitation in Sweden, which has approximately 800 members. The constitution of the membership list included members with a SCI and supporting members and it was not possible to discern them from each other. A simple random sampling method<sup>22</sup> was used to select 200 participants from the membership list; this method was used with the intention of ensuring that all members had an equal probability of being selected to participate. A postal survey was sent to the 200 selected members. Ten surveys were returned due to incorrect address information, and 90 of the selected members did not respond. Therefore, 100 members in total returned the survey. The inclusion criteria were as follows: i) males and females with a traumatic SCI, ii) at least two years post-injury, and iii) 18 years of age or older. Three respondents were excluded; two declared that they were supportive members and one had spina bifida. Thus, a total of 97 participants who corresponded with the inclusion criteria's were included. No reminders were sent.

### *Survey*

The survey consisted of two parts. The first part was developed by the authors for this study and consisted of questions related to socio-demographic variables and injury characteristics (e.g., gender, age, level of injury, the time since the injury, type of mobility device used, marital status, residential location, level of education, and employment status).

The second part of the survey consisted of the NPS-interest checklist,<sup>23</sup> which is an extension of the original interest checklist devised by Norling and Jägnert.<sup>24</sup> NPS stands for the initials of Norling, the constructor of the original interest checklist and Pettersson and Selander, the ones extending the original version by adding two areas of leisure activities (cooking and house work) and additional information. The NPS-interest checklist (Table 1) was developed in Sweden for persons with disabilities caused by disease or injury. It consists of 20 areas of leisure activities for which participants provide self-reported answers to the following questions: (a) are you interested in the activity, (b) do you perform the activity, (c) is the activity of importance for your well-being, and (d) has your performance of the activity changed since injury? Sub-questions (a) and (d) enabled the respondents to give one of the following three possible answers: yes, very much; somewhat; or not at all. Sub-questions (b) and (c) allowed for two possible answers: yes or no. Participants were also able to add comments, but only the quantitative data was used for this study.

*Insert Table 1 about here*

The validity of the original interest checklist has been supported.<sup>24</sup> However, since the NPS-interest checklist has not been used to survey persons with SCI, information regarding the validity of the instrument among this group of persons was lacking. Therefore, the four sub-questions in the NPS-interest checklist were investigated via a series of Rasch analyses,<sup>25</sup> using the software FACETS.<sup>26</sup> This method has been increasingly used in rehabilitation medicine for testing both new and existing assessments and questionnaires.<sup>27</sup> The person response validity indicated that 95% of the participants demonstrated acceptable goodness-of-fit, which can be judged as sufficient based on the criteria proposed by Linacre,<sup>28</sup> and thus not a threat to validity.<sup>25</sup> Bond and Fox<sup>25</sup> further stated that goodness-of-fit statistics evaluate the degree of fit between the observed responses and the responses expected by the Rasch

measurement model. Thus, the analyses provided evidence of the validity of the NPS-interest checklist for measuring interest, performance, experience of well-being, and changed performance of leisure activities for persons with SCI.

### *Statistical analysis*

The Predictive Analytics Software (PASW, 18<sup>th</sup> version), previously referred to as SPSS, was used for the descriptive statistical analyses, cross-tabulation, and Chi-square tests. In the first step, descriptive statistical analyses, such as mean, standard deviation (SD), and frequencies, were performed to examine the study population. Secondly, the results from the testing and analysis of the validity of the NPS-interest check list through Rasch analyses<sup>25</sup> were used to describe the leisure repertoires among the participants with SCI. That is, the participants answers from each of the four sub-questions and every one of the 20 areas of leisure activities were converted through logistic transformation into abstract interval measures in units called log-odds probability units (so-called, logits) by using FACETS.<sup>26</sup> Through the analyses, all participants receive a measure presented in logits on an interval scale representing the extent to which the participants were more or less likely to report that area of leisure activity in relation to interest, performance, well-being and changed performance. Finally, cross-tabulations and Chi-square tests were used to examine the socio-demographic variables, the injury characteristics, and the sub-questions for the 20 areas of leisure activities in the NPS-interest checklist. A dichotomization of the answer alternatives for the NPS-interest checklist was applied to the sub-questions (a) and (d), in order to ensure that the outcome could take on only one of the following of two values: yes (i.e., yes, very much and somewhat) or no (i.e., not at all). Due to the wide range in age (19-69 years) and time since injury (2-31 years), sub-groups were formed to facilitate the analysis. Age was divided into two groups; age group 1 included persons between 19 to 44 years of age, and age group 2 included those between 45 to



69 years of age. Time since injury was divided into three groups based on the quartiles; group 1: 2-4 years; group 2: 5-8 years; and group 3: 9-31 years. A  $p$ -value of  $<0.05$  represented statistical significance.<sup>22</sup>

### *Statement of ethics*

The principles of the Declaration of Helsinki were followed and the study was approved by the Regional Ethical Review Board in Umeå, Sweden (08-005M).

### **Results**

A summary of the socio-demographic data and injury characteristics of the participants is presented in Table 2. The mean age of the participants was 43.5 years with a SD of 12.0, and at the time of this study, the participants had been injured on average for 7.3 years  $\pm 5.6$  SD. The sample distribution for males and females and also for tetra- and paraplegia was marginally different but not statistically significant.

*Insert Table 2 about here*

In Table 3, the leisure repertoires of the participants showed that they were most interested in, performed and experienced well-being from both social and cultural activities, and TV/DVD/movies. The areas of leisure activities in which participants have reported the most changes were outdoor activities, exercise, and gardening. Religious activities and gambling were the leisure activities least reported for interest, performance, well-being and changed performance.

*Insert Table 3 about here*

Overall, sex and to some extent, age were the variables that related most to the participants' interest, performance, well-being and changed performance in some areas of leisure activities. For example, females were most interested in and performed cooking, and experienced changes in leisure activities such as taking care of animals and house work. In contrast, ball and equipment sports, and fishing/hunting/shooting were areas of leisure activities that males reported as most interesting, performed, and frequently endorsed as a source of well-being. Outdoor activities were of interest and a source to well-being for participants who had lived with their SCI for 2 to 4 years, but it was also the area of leisure activities where they experienced changed performance. Furthermore, the levels of injury among the participants were only related to gambling and cooking, i.e., participants with tetraplegia were more likely to be interested in gambling and participants with paraplegia were more likely to perform cooking.

In addition to the results shown in Table 3, other variables that were related to interest, performance, well-being, and changed performance to a certain extent were residential location, level of education, employment status, and marital status. For example, TV/DVD/movies were reported as interesting (98%,  $p < .001$ ), performed (95%,  $p < .01$ ), and a source of well-being (84%,  $p < .001$ ) from participants living in urban/suburban areas. Participants living in rural areas reported interest in outdoor activities (92%,  $p < .01$ ) and fishing/hunting/shooting (57%,  $p < .01$ ). Participants with college/university degrees were most interested in areas of leisure activities such as pleasure (87%,  $p < .001$ ) and performed bathing/boating (49%,  $p < .05$ ) and ball sports (30%,  $p < .01$ ). Participants with degrees from high school or less were interested in (58%,  $p < .01$ ) and experienced wellbeing (35%,  $p < .05$ ) from fishing/hunting/shooting. Participants working full time reported that they

performed bathing/boating (60%,  $p < .05$ ) and participants who lived alone experienced well-being from ball sports (38%,  $p < .05$ ). Finally, no relationship was observed between the variable mobility device and the leisure repertoire among the participants.

## **Discussion**

The results of this study provide an explanation for and to some extent a description of a changed leisure repertoire among persons following a traumatic SCI. However, the determination of whether this change was positive or negative was not possible, i.e., whether an increase or decrease in performance had occurred. For example, the results suggested that the participants reported that they did not perform outdoor activities and exercise as frequently after their SCI. This is in contrast to a study by Martin Ginis et al,<sup>20</sup> in which persons with SCI reported walking/wheeling, aerobic exercise and resistance training as the most frequent types of LTPA. Within our study population, the participants were most interested in, performed and experienced well-being from social and cultural activities as well as TV/DVD/ movies. Their social and cultural activities consisted of sedentary and more active leisure activities, this mean that there were a great variety of leisure activities e.g. reading, listening to the radio, going to concerts, meeting with friends and family, which could took place either in their homes or in public places. An interesting finding was that even though they engaged mostly in social activities, this area of leisure activity was also one that the participants reported a relatively high degree of changed performance in after the SCI. Earlier research likewise describes a rather complex picture of how the social activities among persons with SCI can be limited in comparison to that of nondisabled persons.<sup>29,30</sup> Furthermore, the importance of social relationships for persons with a SCI increases when they are trying to perform their earlier leisure activities or to find new ones to explore.<sup>9,10,31</sup> Another area of leisure activities among the participants' leisure repertoire that was reported

as a source of well-being was watching TV/DVD/movies. This is interesting because earlier research has shown that watching TV can contribute to social isolation and can be a predictor of free-time boredom.<sup>14,32</sup> Our results imply that watching TV/DVD/movies do not necessarily indicate that a person is “killing time”: instead, this could depend on how the participants choose to use the time that they spend in front of the TV. Watching TV/DVD/movies can also provide a complement to social and cultural activities that the participants included in their leisure repertoires, thereby creating a balance between both sedentary and more active leisure activities, which can contribute to experiences of well-being. This result indicates that a changed attitude toward sedentary activities after a SCI, such as screen activities, may be needed.

Some areas of leisure activities in this study were significantly related to the socio-demographic variables and injury characteristics of the participants. More specifically, sex, age, and time since injury were significantly associated with different areas of leisure activities in their leisure repertoire. In contrast, level of injury was only significantly associated with two areas of leisure activities. This is somewhat consistent with earlier research that indicated that well-being among persons with SCI is more closely related to community functioning, social interactions, and satisfaction with leisure activities as compared to level of injury and functional independence.<sup>33-37</sup> One fact that may help to explain our results is that the study population was made up entirely of members of a non-profit organization. This organization offers opportunities for persons with SCI to meet role models, persons who have experiences of living with a comparable type of injury and also chances to try different leisure activities at organized camps. Other studies also showed that participating in camps or leisure intervention groups with the intention to find new leisure activities and meet other persons with SCI increased self-confidence, self-esteem, and the perception of possibilities and capabilities after a SCI.<sup>17,18</sup> Thus, attending such a program

may enhance the process of adjusting to life with a SCI, help to redefine identity, and facilitate community re-integration .<sup>37,38</sup>

Participants who were 2 to 4 years post-injury were interested in and reported well-being from outdoor activities. They also reported the highest changes in performance of outdoor activities. In contrast, participants who were 9 to 31 years post-injury were interested in observing sports, performing ball sports, and bathing/boating. These results are consistent with earlier research<sup>32,39</sup> that describe how persons who are newly injured and had just finished their rehabilitation after a SCI might be overwhelmed by the many challenges facing them in everyday life and feelings of grief/loss concerning previously performed leisure activities. Meanwhile, persons with long experiences of living with SCI might have more knowledge about the resources available for engaging in leisure activities, since they have had more time to explore and find new leisure activities. The results also showed that the areas of leisure activities reported by males versus that of females were different; moreover, the age-groups (i.e., 19 to 44 and 45 to 69) were interested in and performed different areas of leisure activities as well. The results probably reflect a more general pattern that is exhibited in samples in the general population within the Western culture. Furthermore, our results showed that socio-demographical variables such as residential living, level of education, employment status, and marital status, were only related to some extent to the participants' interest, performance, and well-being in a few areas of leisure activities.

#### *Methodological limitations*

The study results may have changed if a better response rate had been achieved. Nevertheless, the actual response rate for this study can still be considered as acceptable based on the recommendations for a 50 % response rate in the literature.<sup>22</sup> The participants were recruited

from a non-profit organization with a special interest in active rehabilitation. Therefore, the participants representing persons with SCI in this study were likely more active and felt more positive about their leisure repertoires, thereby limiting the ability to generalize the results<sup>22</sup> from this study to the whole population with SCI. A specific limitation of the NPS-interest checklist and thus also in our study is that the last sub-question, only provides information about a changed performance. Therefore determining whether a change is perceived to be positive or negative by the participants is not possible. Nevertheless, the NPS-interest checklist provided a convenient way to capture the participants' experiences of well-being in relation to areas of leisure activities and gave a comprehensive picture of the leisure activities in which they were interested in, performed, and reported changes because of the SCI.

## **Conclusion**

The study provided an explanation and limited description of a changed leisure repertoire among persons after a traumatic SCI. Yet, determining whether the change was positive or negative was impossible, thereby implicating the need for further studies to investigate how persons with SCI experience changes in their leisure repertoires. The participants were most interested in, performed, and reported well-being from social and cultural activities as well as TV/DVD/movies. In addition, the areas of leisure activities in which they had most likely experienced changes after the SCI were outdoor activities, exercise, and gardening. Furthermore, the study showed that gender, age, and time since injury, were more closely related to the choice of leisure activities to include in the leisure repertoire by persons with SCI than the level of injury. This knowledge can be of importance to rehabilitation professionals for planning and implementing interventions concerning leisure activities for persons with SCI.

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### **Declaration of interest**

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**Table 1. Leisure activities on NPS-interest checklist**

**1. Outdoor activities**, e.g. walking/wheeling, camping, being in the nature

**2. Gardening**, e.g. cultivate

**3. Animals**, e.g. taking care of animals

**4. Culture activities**, e.g. reading, listening to radio, theater, concerts

**5. TV, DVD, movies**

**6. Music**, e.g. listening, playing, singing

**7. Physical exercise**, e.g. workout, swimming, jogging/wheeling

**8. Equipment sports**, e.g. ice hockey, athletics

**9. Ball sports**, e.g. football, handball, table tennis

**10. Bath, boating**

**11. Sport observation**

**12. Fishing, hunting, shooting**

**13. Hobby**, e.g. mechanical work, knitting, needlework, stamps

**14. Associations**, e.g. club activities, politics, union work, voluntary work

**15. Religious activities**

**16. Pleasure**, e.g. restaurants, dancing

**17. Social activities**, e.g. being with friends, family, relatives

**18. Gambling**, e.g. bingo, poker, lottery

**19. Cooking**, e.g. prepare food, baking

**20. House work**, e.g. cleaning, doing laundry

**21: Additional information**

\*Sub-questions for each area of leisure activities 1-20: (a) are you interested in the activity, (b) do you perform the activity, (c) is the activity of importance for your well-being, and (d) has your performance of the activity changed since injury?

NOTE: The translation of the NPS-interest checklist from Swedish to English was made by the first author.

**Table 2. Socio-demographic data and injury characteristics for the participants (n = 97)**

	<b>Mean±SD</b>
Age (years)	43.5±12.0
Time since injury (years)	7.3±5.6
	<b>n (%)</b>
Participants	
Male	55 (56.7)
Female	42 (43.3)
Injury level	
Tetraplegia	46 (47.4)
Paraplegia	44 (45.4)
Not reported	7 (7.2)
Mobility device	
Wheelchair	77 (79.4)
Walking aid	18 (18.6)
Not reported	2 (2.0)
Marital status	
Single/divorced or widowed	42 (43.3)
Married or common law	55 (56.7)
Residential location	
Rural	36 (37.1)
Urban/Suburban	61 (62.9)
Education	
High school or less	60 (61.9)
College/university	37 (38.1)
Employment status	
Full time	10 (10.3)
Part time	52 (53.6)
Not working	34 (35.1)
Not reported	1 (1.0)

**Table 3. The 6 most or least likely activities in the participants' leisure repertoire and significant differences related to sex, age, level of injury, and time since injury**

	<b>Interest</b>	<b>Performance</b>	<b>Well-being</b>	<b>Changed performance</b>
<b>Most likely</b>	2.57 Social <sup>1</sup>	4.06 Social (A2:44%**) <sup>2</sup>	4.27 Social	1.44 Outdoor (TI 1:100%**)
	1.08 TV/DVD/movies	2.48 TV/ DVD/movies	1.37 Culture (F:91%***)	1.20 Physical exercise
	0.69 Culture	1.90 Culture	1.18 TV/DVD//movies	0.80 Gardening
	0.42 Cooking (F:91%*)	1.20 Music	0.89 Physical exercise	0.73 Housework (F:91%***)
	0.38 Outdoor (TI 1:91%*)	1.08 Cooking (F:86%***;P:82%**)	0.78 Outdoor (TI 1:88%***)	0.60 Pleasure
	0.38 Physical exercise	0.60 Pleasure	0.78 Music	0.56 Bath/boating (M:75%*)
<b>Least likely</b>	-0.49 Ball sports (A1:70%***;M:62%**)	-0.65 Bath/boating (A1:45%**;TI3:58%**)	-1.12 Associations	-0.40 Sport observation
	-0.57 Fish/hunt/shooting (M:67%***)	-0.85 Associations	-1.14 Ball sports (A1:43%***;M:40%***)	-0.44 Animals (W:57%***; A2:55%**)
	-0.73 Equipment sports (A1:55%***;M:53%***)	-1.57 Fish/hunt/shooting (M:29%**)	-1.14 Fish/hunt/shooting (M:42%***)	-0.57 Associations
	-0.89 Associations	-1.65 Ball sports (A1:30%***;M:27%**;TI 3:31%*)	-1.40 Equipment sports(A1:34%**; M:36%***)	-0.66 Music
	-0.98 Gambling (T:57%***)	-2.30 Religious	-2.23 Gambling	-1.56 Gambling
	-2.14 Religious	-2.42 Equipment sports (M:18%***)	-2.58 Religious	-2.20 Religious

<sup>1</sup>All data were Rasch adjusted. Values are given in linear logits (log-odds probability unit, in range between -5 to +5) and indicate the extent to which the participants were most (higher value, ) or least (lower value) likely to report the area of leisure activity in their leisure repertoire in relation to interest, performance, well-being and changed performance.

<sup>2</sup>The percentages of the variable being significant, for example “A2:44%<sup>\*\*\*</sup>” communicates that 44% of the participants being between 45-69 years of age performed social activities, and this was significantly greater than the proportion of participants being between 19-44 years of age.

Sex: F (Female), M (Male). Age: A1(19-44 years), A2 (45-69 years) of age. Level of injury: P (Paraplegia), T (Tetraplegia). Time since Injury: TI 1(2-4 years), TI 2(5-8 years), TI 3(9-31 years). Levels of statistical significance: <sup>\*\*\*</sup> $p < 0,001$ ; <sup>\*\*</sup> $p < 0,01$ ; <sup>\*</sup> $p < 0,05$ .