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ORIGINAL REPORT

BARRIERS TO AND FACILITATORS OF EVERYDAY PHYSICAL ACTIVITY IN PERSONS WITH A SPINAL CORD INJURY AFTER DISCHARGE FROM THE REHABILITATION CENTRE

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Objective: **To determine the most important barriers to and facilitators of the level of everyday physical activity in persons with a spinal cord injury after discharge from the rehabilitation centre.**
Design: **Qualitative study with both cross-sectional and retrospective questions.**
Subjects: **Thirty-two persons with a spinal cord injury.**
Methods: **Semi-structured interview with questions concerning the current situation (>9 months after discharge) and retrospective questions concerning the period shortly after discharge (<3 months). The interview consisted of 10 topic categories assumed to have an impact on the level of everyday physical activity and covering the main parts of the International Classification of Functioning, Disability and Health (ICF) model.**
Results: **In the current situation, the most important barriers were problems with accessibility of stores and buildings, physical health problems and mental health problems. Shortly after discharge, the most important barriers were emotional distress, problems with self-care, and mental health problems. The most frequently mentioned facilitators were preparation in the rehabilitation centre with respect to daily activities and social activities and stimulation to be physically active.**
Conclusion: **Persons with a spinal cord injury experience important barriers to physical activity, particularly on the ICF component Body Functions and Structure.**

Key words: spinal cord injury, barriers, facilitators, everyday physical activity.

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INTRODUCTION

Due to loss of motor, sensory and/or autonomic innervation below the level of injury, persons with a spinal cord injury (SCI) are at risk for developing a hypoactive lifestyle (1). Hypoactivity may have negative effects on physical fitness, social participation and quality of life (2, 3). Furthermore, a hypoactive lifestyle may increase the risk of developing secondary health problems, such as cardiovascular diseases, obesity and non-insulin-dependent diabetes mellitus (4, 5). Cardiovascular diseases are nowadays one of the major causes of morbidity and mortality in the SCI population (6, 7). Therefore, the level of everyday physical activity is an important aspect and outcome measure of the rehabilitation process of persons with SCI. A previous study by our group indicated that the level of everyday physical activity in persons with SCI improves during the inpatient rehabilitation period (1). However, shortly after discharge, a strong decline in the level of everyday physical activity occurs, which partly restores in the year after discharge, but is still low compared with normative values (1). This finding of a hypoactive lifestyle in persons with SCI after discharge from the rehabilitation centre is consistent with the literature (8–11) and implies that stimulation of a physically active lifestyle after discharge is warranted in persons with SCI.

However, to optimize the rehabilitation programme in persons with SCI after discharge with respect to a more physically active lifestyle, it is important to determine the barriers to and facilitators of physical activity after their discharge. In contrast to the numerous studies regarding the barriers and facilitators of physical activity in the general public (12–18), little is known about the factors that influence the level of everyday physical activity in persons with disabilities, (8, 19, 20) and even less is known about these factors in persons with SCI (9, 21).

The present study aimed to determine the most important barriers to and facilitators of the level of everyday physical activity in persons with SCI after discharge from the rehabilitation centre.

MATERIAL AND METHODS

Subjects

Persons with SCI who had been discharged from the rehabilitation centre more than 9 months earlier were recruited from a database of discharged patients who received their inpatient or outpatient rehabilitation at Rijndam Rehabilitation Centre, Rotterdam, the Netherlands. Rijndam Rehabilitation Centre is one of the 8 rehabilitation centres in the Netherlands with a specialized department for SCI care. As soon as

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their physical condition is stable, patients with SCI in the Netherlands are mostly transferred from university hospitals or general hospitals to one of these specialized rehabilitation centres. After an inpatient rehabilitation period, patients go home or go to a special adapted house and receive outpatient treatment from the rehabilitation centre.

Exclusion criteria were: insufficient knowledge of the Dutch language to understand the purpose of the study and to conduct the semi-structured interview; known psychiatric problems; and known progressive diseases; in addition, completely ambulatory persons and persons completely dependent on an electric wheelchair were excluded.

A total of 81 patients was found to be eligible for the study, of whom 32 patients (40%) agreed to participate. The reasons for not participating in the study were not known. Characteristics of the study sample are shown in Table I.

The study was approved by the medical ethics committee of Erasmus MC. Each subject gave their written informed consent prior to participation.

Instruments

A semi-structured interview, which was developed for this study after an extensive review of the literature on this topic (8, 9, 19–23) and consultation with physiotherapists and rehabilitation physicians working with people with SCI, was used to determine the barriers to and facilitators of everyday physical activity after discharge from the rehabilitation centre. The design of the interview was both cross-sectional (questions with respect to the current situation, i.e. >9 months after discharge) and retrospective (questions with respect to the period shortly after discharge, i.e. <3 months). The interview consisted of 10 topic categories assumed to have an impact on the level of everyday physical activity and covering the main parts of the International Classification of Functioning, Disability and Health (ICF) model (24). The 10 topic categories were: subject characteristics, lesion characteristics, attitude against a physically active lifestyle, daily physical activities, social activities, quality of life, health, care needs, coping, and other factors. The subjects were first asked to mention barriers and facilitators in open questions within these 10 categories. Besides the open questions, the interview also consisted of questions that were rated by the subjects on a visual analogue scale (VAS) (25). When subjects reported barriers in the open questions, the subjects were asked to rate the experienced impact of these barriers on the level of everyday physical activity in the VAS questions, in which 0 denoted a very small impact and 10 denoted a very large impact of a barrier on the level of physical activity. We did not gather information about the impact of facilitators on the level of physical activity. The interviewer made notes during the interviews. The reported barriers to physical activity on the open questions were clustered together in categories (Table II.)

Each interview lasted about 60 min and was performed by the same researcher (MV) in each participant's home environment.

Data analysis

Descriptive analyses were performed to describe the prevalence of the barriers to and facilitators of everyday physical activity on the different items and to describe the impact of the barriers on the level of everyday physical activity. The difference in prevalence of barriers and facilitators between the current situation and shortly after discharge was analysed with a McNemar test. The difference in impact of the barriers on the level of everyday physical activity between the current situation and shortly after discharge was analysed with a paired *t*-test. Furthermore, at a group level, the importance of the barriers was calculated as the product of the prevalence of barriers and the experienced impact on the level of everyday physical activity. The importance was calculated because the most frequently mentioned barriers were not necessarily the ones with the largest impact.

All statistics were done with SPSS version 12.0. A probability value of $p \leq 0.05$ was considered to indicate a significant difference.

Table I. *Characteristics of the subjects (n = 32)*

Characteristics	
Gender (male/female), *n*	24/8
Age, years (mean (SD))	45 (12)
Level of SCI (tetraplegic/paraplegic), *n*	12/20
Completeness of lesion (complete/incomplete/unknown), *n*	19/10/3
Causes of SCI (traumatic/non-traumatic), *n*	22/10
Time since injury, months (mean (SD))	103.5 (103.1)
Time since discharge, months (mean (SD))	82.6 (95.4)

SCI: spinal cord injury; SD: standard deviation.

RESULTS

Participants

The characteristics of the participants ($n = 32$, Table I) were not different from the characteristics of the subjects who decided not to participate in the study ($n = 49$) with respect to gender, level of SCI, completeness of the SCI, and cause of SCI. However, the participants were significantly older than the subjects who decided not to participate (mean age of non-participants was 38.8 (standard deviation (SD) 12.4) years; $p = 0.04$).

Barriers

The participants reported a large number of barriers to physical activity in the current situation and shortly after discharge on the open questions regarding the different items (Tables II and III). In the current situation, the 3 most important barriers (largest product of prevalence and impact) were problems with the accessibility of stores and buildings (ICF: Environmental factor), physical health problems and mental health problems (ICF: Body Functions and Structures) (Table II and IV). Problems with the accessibility of stores and buildings also had the largest prevalence.

Shortly after discharge, the 3 most important barriers were emotional distress (ICF: Body Functions and Structures), problems with self-care (ICF: Activities), and mental health problems (ICF: Body Functions and Structures). Problems with self-care had the largest prevalence. Emotional distress and mental health problems also had a relatively high impact on the level of everyday physical activity shortly after discharge (Tables II and IV).

In general, the importance of the barriers was greater shortly after discharge; only for problems with work activities and for a bad acceptance, the importance was greater in the current situation (Table II).

Facilitators

In the current situation, the 3 most frequently mentioned facilitators were preparation in the rehabilitation centre with respect to daily physical activities, stimulation in the rehabilitation centre to be physically active, and preparation in the rehabilitation centre with respect to social activities (ICF: Environmental factor). Shortly after discharge relatively few questions were asked with respect to facilitators of everyday physical activity. Support from family, friends and people in

Table II. *Prevalence of barriers, their impact on the level of everyday physical activity, and the importance of barriers*

	Current			Shortly after discharge[1]		
Item	Prevalence[2] % (*n*)	Impact[3] (VAS score)	Importance (prevalence (%) ×impact)	Prevalence[2] % (*n*)	Impact[3] (VAS score)	Importance (prevalence (%) ×impact)
Daily physical activities						
Problems with self-care	47 (15)	3.5	165	94* (30)	5.0	470
Problems with movement possibilities in house	25 (8)	1.9	48	72* (23)	5.8	418
Problems with movement possibilities around house	16 (5)	2.1	34	72* (23)	5.6†	403
Problems with sport activities	25 (8)	3.7	93	69* (22)	4.9	338
Problems with work activities	63 (20)	3.8	239	69 (22)	2.8	193
Social activities						
Problems with transport	22 (7)	4.8	106	78* (25)	4.8	374
Problems with accessibility stores and buildings	72 (23)	4.6	331	n.a.	n.a.	n.a.
Problems with accessibility and presence of supply of sports	47 (15)	5.1	240	n.a.	n.a.	n.a.
Problems with attitudes of family and friends	13 (4)	3.0	39	38* (12)	5.8	220
Problems with societal attitudes	9 (3)	6.6	59	56* (18)	3.8	213
Health problems						
Physical health problems	53 (17)	5.8	307	81* (26)	5.1	413
Mental health problems	47 (15)	5.3	249	69 (22)	6.6†	455
Quality of life						
Dissatisfaction with life situation	38 (12)	5.4	205	66* (21)	4.3	284
Dissatisfaction with level of physical activity	41 (13)	3.5	144	66 (21)	4.1	271
Dissatisfaction with social support	19 (6)	2.4	46	59* (19)	5.6	330
Dissatisfaction with financial situation	34 (11)	3.4	116	47 (15)	3.8	179
Needs						
Need for information about supply of sports	0 (0)	0	0	28* (9)	5.1†	143
Need for stimulation to participate in sport activities	0 (0)	0	0	19* (6)	5.3†	101
Need for other help or information	38 (12)	2.8	106	56 (18)	5.2	291
Coping						
Emotional distress	69 (22)	3.3	228	81 (26)	6.1†	494
Poor acceptance	50 (16)	2.7	135	53 (17)	2.3	122
Dissatisfaction with the body	66 (21)	3.7	244	72 (23)	3.9	281
Dissatisfaction with relationships	16 (5)	3.9	62	34* (11)	4.8	163
Rehabilitation programme						
Dissatisfaction about stimulation in the rehabilitation centre with respect to physical activity	19 (6)	0.7	13			
Dissatisfaction about preparation in the rehabilitation centre with respect to daily physical activities	34 (11)	3.2	109			
Dissatisfaction about preparation in the rehabilitation centre with respect to social activities	44 (14)	4.0	176			

[1]Shortly after discharge = less than 3 months after discharge.
[2]Number of subjects that mentioned the barrier.
[3]Experienced influence of the reported barrier rated on the visual analogue scale (VAS).
*Significant difference in the prevalence of subjects that mentioned the barrier between the current situation and shortly after discharge.
†Significant difference in the impact of the mentioned barrier between the current situation and shortly after discharge.
n.a.: not available.

society was the most frequently mentioned facilitator shortly after discharge (ICF: Environmental factor, Table V).

Almost all participants (> 90%) considered physical activity to be important, pleasant, and healthy (Table VI).

DISCUSSION

The results of this study indicate that there are many barriers to everyday physical activity in persons with SCI, both in the current situation and shortly after discharge from the rehabilitation centre (Tables II and III). The barriers were primarily on the ICF component Body Functions and Structures.

The results of the study by Levins et al. (9) in persons with SCI (both shortly and longer after discharge), are partly consistent with our results. Shortly after discharge, Levins et al. (9) found that the main individual barriers to participate in physical activity were related to the process of restart and rediscovering the new life and the new situation. We found that shortly after discharge problems with self-care were relatively important. Furthermore, Levins et al. (9) found that inaccessibility of many facilities, lack of equipment suited to needs, and negative societal attitudes were the most important social barriers to participate in physical activity. In our study, problems with the accessibility of stores and buildings were

Table III. *Specification of the most frequently mentioned barriers related to the different items*

Item	Current situation Prevalence[2] % (*n*)	Shortly after discharge[1] Prevalence[2] % (*n*)
Daily physical activities		
Problems with self-care and movement possibilities		
- Lack of adaptations in and around the house	9 (3)	69 (22)
- Not skilful in self-care, dependent on other people	16 (5)	56 (18)
Problems with sport and work activities		
- Lack of sports equipment	0 (0)	25 (8)
- Problems with transport	3 (1)	13 (4)
- Lack of motivation	0 (0)	13 (4)
- Problems relating to functional ability and health	25 (8)	25 (8)
- Bad attitude of employer	6 (2)	6 (2)
Social activities		
Problems with transport		
- No transport of their own, dependent on other people	6 (2)	47 (15)
- Dissatisfaction about taxi transport	9 (3)	50 (16)
Problems with accessibility		
- Problems with accessibility of small, old stores and buildings	44 (14)	n.a.
- Problems with accessibility of other people's houses	16 (5)	n.a.
- No adapted toilets in buildings and other people's houses	16 (5)	n.a.
- No accessible supply of sport in own society	41 (13)	n.a.
- No accessible supply of sport in surrounding societies	9 (3)	n.a.
Problems with the attitude of other people		
- Little support from friends	13 (4)	22 (7)
- Difficulty with societal attitude	9 (3)	16 (5)
Health problems		
Physical health problems		
- Bladder problems	19 (6)	47 (15)
- Bowel problems	9 (3)	25 (8)
- Decubitus	16 (5)	28 (9)
- Pain	34 (11)	34 (11)
- Incontinence	3 (1)	22 (7)
- Spasms	13 (4)	3 (1)
Mental health problems		
- Sad feelings	31 (10)	47 (15)
- No motivation	16 (5)	25 (8)
- Sleeping problems	13 (4)	22 (7)
- Depressive feelings	13 (4)	13 (4)
Quality of life		
Dissatisfaction with social support		
- Dissatisfaction with support of community	9 (3)	50 (16)
- Dissatisfaction with support of friends	9 (3)	19 (6)
Dissatisfaction with financial situation		
- Dissatisfaction with unemployment benefit	16 (5)	22 (7)
- Dissatisfaction with financial situation due to the high costs	19 (6)	19 (6)
Dissatisfaction with life situation and level of physical activity		
- Wants to do more, but is impossible, frustrated	13 (4)	34 (11)
Needs		
- Need for help with arranging everything in and around the house	6 (2)	59 (19)
- Need for information about SCI research	13 (4)	0
Coping		
Angry, frustrated	69 (22)	81 (26)
Dissatisfaction with the body		
- Dissatisfaction about the body because everything is different	31 (10)	34 (11)
- Ashamed about incontinence	9 (3)	13 (4)
- Difficulty with increase of body weight	16 (5)	9 (3)
Dissatisfaction with relationships		
- No sexual activity	0	13 (4)
- Difficulty with changed relationship	0	16 (5)

[1]Shortly after discharge = less than three months after discharge
[2]number of subjects that mentioned the barrier.
SCI: spinal cord injury; n.a.: not available.

Table IV. *Barriers with the highest score for the different outcome measures*

Current situation			Shortly after discharge[1]		
Prevalence[2] (%)	Impact[3] (VAS score)	Importance (prevalence × impact)	Prevalence[2] (%)	Impact[3] (VAS score)	Importance (prevalence × impact)
1. Problems with accessibility stores and buildings	1. Problems with societal attitudes	1. Problems with accessibility of stores and buildings	1. Problems with self-care	1. Mental health problems	1. Emotional distress
2. Emotional distress	2. Physical health problems	2. Physical health problems	2. Physical health problems	2. Emotional distress	2. Problems with self-care
3. Dissatisfaction with the body	3. Dissatisfaction with life situation	3. Mental health problems	3. Emotional distress	3. Problems with movement possibilities in house/problems with attitudes of family and friends	3. Mental health problems

[1]Shortly after discharge = less than 3 months after discharge.
[2]Number of subjects that mentioned the barrier.
[3]Experienced influence of the reported barrier rated on the visual analogue scale (VAS).

the most important barrier in the current situation and problems with societal attitudes had the highest impact on the level of everyday physical activity in the current situation. The most important facilitator for participation in physical activity found by Levins et al. (9) was stimulation from the societal environment. Kerstin et al. (21) found that social support and stimulation to be physically active were important facilitators for participating in physical activity longer after discharge, which is in agreement with our study. However, contrary to the study of Levins et al. (9), we found that both mental and physical health problems were relatively important barriers to everyday physical activity in the period longer after discharge and that mental health problems were also relatively important barriers shortly after discharge.

The importance of all barriers was less in the current situation than in the period after discharge, except for problems with work activities and with acceptance. Problems with work activities in the current situation were related to functional ability and health, problems with transport, and problems related to a bad attitude of employers (Table III). In the current situation, only 34% of the subjects performed work activities compared with 81% before injury.

Shortly after discharge, problems with self-care and problems with movement in and around the house were relatively important. In the current situation, these problems were relatively unimportant, because all adaptations in and around the house were present and the subjects became more skilful in self-care (Tables II and III). By contrast, physical and mental health problems were, both shortly after discharge and in the current situation, relatively important. The most frequently mentioned mental health problem, both shortly after discharge and in the current situation, were feelings of sadness. Shortly after discharge the most frequently mentioned physical health problems were bladder problems. In the current situation the most frequently mentioned problem was pain (Tables II and III).

Table V. *Prevalence of facilitators for participation in physical activity*

Item	Current situation Prevalence[2] % (*n*)	Shortly after discharge[1] Prevalence[2] % (*n*)
Rehabilitation centre		
- Stimulation in the rehabilitation centre to be physically active	81 (26)	n.a.
- Good preparation in the rehabilitation centre with respect to daily physical activities	84 (27)	n.a.
- Good preparation in the rehabilitation centre with respect to social activities	72 (23)	n.a.
Daily and social activities		
- Positive and stimulating attitude of their employer and colleagues	6 (2)	31 (10)
- Support from family, friends and society	28 (9)	66 (21)
- Easily accessible stores and buildings in the neighbourhood	25 (8)	n.a.
- Easily accessible supply of sports in own society	22 (7)	n.a.
- Very good bicycle paths in neighbourhood for hand-biking	9 (3)	n.a.
Help and information		
- Information about supply of sports from rehabilitation centre	0 (0)	22 (7)
- Stimulation after discharge from the rehabilitation centre to be physically active	0 (0)	9 (3)
- Stimulation by family or friends to be physically active	0 (0)	9 (3)

[1]Shortly after discharge = less than 3 months after discharge.
[2]Number of subjects, expressed as percentage of the sample and as the number that mentioned the facilitator.
n.a.: not available.

Table VI. *Attitude of the subjects against a physically active lifestyle*

Item	Current situation Prevalence[1] % (number)
Attitude against physical activity	
- Participation in sport activities before SCI	72 (23)
- Physical activity is important	91 (29)
- Physical activity does improve health	97 (31)
- Physical activity is pleasant	91 (29)
- Good self-esteem with respect to sport activities	75 (24)
- Not afraid of injuries during sport activities	56 (18)

[1]Number of subjects who answered yes to the question.
SCI: spinal cord injury.

Implications for the treatment of persons with SCI shortly after discharge

The results of this study suggest that an intervention shortly after discharge must not involve much time because patients have to restart and reorganize their lives, which is a time-consuming process. Secondly, the intervention should preferably take place in the home environment, because many patients reported problems with transport or lack of their own transport shortly after discharge. Furthermore, an intervention in the home environment is less time-consuming. In the third place, special attention should be paid to the equipment used in the home environment, which should be inexpensive, suited for wheelchair users, and practical. Stimulation from family and friends to participate in the training intervention is important shortly after discharge. Finally, attention must be paid to physical and mental health problems and emotional problems shortly after discharge. Therefore, we propose a structured, low-intensity, behavioural intervention (counselling) shortly after discharge. The focus of this intervention is to attain structured everyday physical activity in the lives of persons with SCI. Van der Ploeg et al. (26) suggested that a counselling intervention is successful in increasing participation in physical activity in people with disabilities.

Implications for the treatment of persons with SCI longer after discharge

The results of this study suggest that the intervention longer after discharge should be relatively inexpensive and there must be some stimulation from the social environment of the patient to participate in the intervention. Furthermore, special attention must be paid to mental and physical health problems. Longer after discharge, when the persons with SCI have established a routine in their lives, we propose a counselling intervention combined with an exercise intervention. The objective of these interventions is to improve the level of everyday physical activity and increase physical fitness.

Study limitations

This study may have some limitations. First, we excluded persons with psychiatric problems and progressive diseases, and persons who were completely ambulatory or who were completely dependent on an electric wheelchair, which may have hampered the representativeness of our study sample. However, in this study, we aimed to determine the most important barriers to and facilitators of everyday physical activity in SCI, in view of developing intervention programmes to improve physical activity. Because the excluded subgroups probably experience specific barriers and facilitators other than those found in our study, and they will therefore probably need specific interventions, we did not focus on them in this stage of our research.

We do not believe that the relatively low response rate (40%) has hampered the representativeness of our study sample because there were no significant differences in gender, level of SCI, completeness of SCI, and cause of SCI between the subjects who participated and the subjects who decided not to participate. We did find a significant difference in age between participants (mean 45 (SD 12) years) and subjects who decided not to participate (mean 39 (SD 12) years), but both participants and non-participants were on average in the same phase of their life and we do not consider this age difference to be clinically relevant. Furthermore, we found no significant difference in the impact of the barriers on the level of everyday physical activity between the "younger" participants (aged 18–40 years) and the "older" participants (aged 41–65 years).

Furthermore, the validity and reliability of the semi-structured interview used in this study was not tested. However, a comparable interview was performed with the partners of 7 patients, which produced comparable results. The results concerning the situation shortly after discharge may be less accurate than those concerning the current situation, because of the retrospective questioning method. Therefore, the focus in our study was on the current situation, and the results for the period shortly after discharge from the rehabilitation centre should be interpreted with caution.

Finally, in the current situation, problems with the accessibility and/or the presence of stores, buildings, and supply of sprts in the environment were relatively important. The interview contained no retrospective questions about these factors because we did not expect them or their impact to change over time. However, the subjects who were discharged more than 10 years ago reported that the accessibility of buildings had improved over time. Furthermore, some subjects reported that they had become more skilful in entering stores and buildings.

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