J Rehabil Med 2006; 38: 159–165

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OCCUPATIONAL GAPS IN EVERYDAY LIFE 1–4 YEARS AFTER ACQUIRED BRAIN INJURY

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Objective: **To explore adaptation, by examining the occupational gaps occurring between what individuals want to do and what they actually do in terms of their everyday activities before and after brain injury. In addition, the relationships between occupational gaps and impairment/activity limitations and the time lapse since the brain injury were explored.**
Design: **A cross-sectional study.**
Subjects: **A total of 187 persons, affected by traumatic brain injury or subarachnoid haemorrhage 1–4 years previously.**
Methods: **A postal questionnaire encompassing questions concerning gaps in the performance of activities in everyday life before and after the brain injury and perceived impairment/activity limitations.**
Results: **The numbers of occupational gaps increased after the injury, with the number of gaps having increased from 46% to 71%. The number of occupational gaps was significantly related to executive impairment/activity limitations, and motor impairment/activity limitations and other somatic impairments, such as headache, also had an impact. The time lapse since the brain injury had no significant effect on the number of occupational gaps.**
Conclusion: **The results suggests that there is a need for adaptation in everyday activities, even several years after a brain injury, which indicates that follow-up and access to individualized rehabilitation interventions in the long-term are required.**

Key words: activities of daily living, rehabilitation, occupational therapy, brain injuries, cerebrovascular accident.

J Rehabil Med 2006; 38: 159–165

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Submitted April 25, 2005; accepted September 30, 2005

INTRODUCTION

Participation, viewed as involvement in a life situation according to the definition of the World Health Organization (WHO) (1), has been explored in several studies on persons with acquired brain injury, demonstrating a decreased ability to participate in the everyday activities they had participated in before being affected by their injury (2–4). However, there is limited knowledge regarding adaptation in everyday activities, which might be considered to be an important determinant of the perceived participation in persons with acquired brain injury.

Adaptation is an essential concept in rehabilitation, and there are various definitions of it. In the occupational therapy literature focusing on adaptation of everyday activities, the term commonly defined is occupational adaptation. Most authors view occupational adaptation as a process involving the person, their environment and the interaction between them (5–7). This continuous process of adapting to meet one's own demands and environmental demands in the performance of everyday activities takes place throughout one's life. In the occupational therapy literature, occupation has been defined as the ordinary and familiar things people do everyday (8), with an emphasis being placed on the individuals' engagement in doing meaningful things – in what he or she wants and needs to perform (9).

The ongoing process of continuous adaptation is threatened by disruptions to life, such as illness (10). For those affected by a brain injury, the results will often be a decrease in the ability to perform everyday activities (6). A gap might occur between what the individuals can do, and what they want and need to do. Thus, one approach by which to further explore adaptation in everyday activities after acquiring a brain injury might be to examine the gap that occurs between what the individual wants and needs to do and what he or she actually does, which is what we consider to be an occupational gap.

One of the aims of rehabilitation interventions is to reduce these gaps (5) by using a client-centred rehabilitation context (11, 12). There is a need for studies focusing on the brain-injured clients' perspective of their adaptation in everyday activities to be able to support the process of adaptation. In addition, knowledge of the influence that time has after illness on the adaptation in everyday activities is limited. It could be expected that the time lapse since the brain injury should influence the adaptation, for example through the extent of restored function, the use of adaptive strategies (9), and decreased expectations relating to the performance of everyday activities (5). In a qualitative study of 100 persons who had experienced stroke, Becker (10) hypothesized that it takes a long time to adapt to the consequences of physical impairments and reorganize life in terms of attaining former everyday activities.

© 2006 Taylor & Francis. *ISSN 1650-1977*
DOI: 10.1080/16501970500415322

The aim of this study was to explore one aspect of adaptation, namely, the occupational gaps occurring between what individuals want to do and what they actually do in terms of everyday activities, by examining the number of occupational gaps before and after brain injury. In addition, the relationship between occupational gaps and impairments/activity limitations has been explored, and the relationship between occupational gaps and the time lapse since the brain injury for people 1–4 years after they were affected by traumatic brain injury (TBI) or subarachnoid haemorrhage (SAH).

METHODS

Participants

This survey is based on postal questionnaires sent to participants 1–4 years after they were treated for acquired brain injuries in a neurosurgical department of a regional hospital in central Sweden. The inclusion criteria were: admission to intensive care for TBI or SAH; being aged 20–65 years at the time of the survey; and having been assessed in the acute stages by a rehabilitation physician. Exclusion criteria were death before the survey was conducted ($n = 14$), emigration abroad ($n = 1$) and not being identified in the national register ($n = 6$). The questionnaire was sent to 217 persons who fulfilled the criteria. In the introductory letter the brain-injured persons were informed that participation in the study was voluntary. A reminder was sent 1 month later to non-respondents.

Three questionnaires were returned stating "address unknown". For 3 other persons, a relative reported that it would not be possible for their brain-injured relatives to answer. And there were 24 non-respondents of whom 19 were men, 14 were diagnosed TBI and their mean age was 43 years. Information relating to the injury and socio-demographic characteristics of the 187 persons (89%) who responded to the questionnaire are shown in Table I. The mean age was 47 years for the whole group. For those affected by TBI the mean age was 39 years and for those affected by SAH it was 51 years. Fifty-one percent of the participants were men. The mean and median time lapse since the brain injury was 26 months (range 11–47 months). The flow of participants was equally distributed over the 4-year period. The grading of the severity of the injury was based on post-resuscitation scores of the Swedish Reaction Level Scale (RLS) (13), which is used in the routine assessments of these patients. The RLS is an 8-graded scale designed for bedside assessment of overall conscious level in patients with acute brain disorders. The inter-observer agreement for the RLS is good when used on individuals with traumatic brain injuries or vascular disorders and the scale is sensitive for change. This study was approved by the Research Ethics Committee of Uppsala University, Sweden.

Questionnaire

The questionnaire included questions concerning socio-economic characteristics, perceived impairments and activity limitations, and gaps in performing activities in everyday life before and after receiving the brain injury. Twenty-three questions (corresponding to the items shown in Table III) were asked relating to cognitive and emotional impairments, executive, communicative and motor impairments/activity limitations and other somatic impairments. Our interest was primarily in examining perceived impairments. With the ambition of posing clear questions, the wording was quite concrete in the intention of measuring impairments. However, the questions could be interpreted as measuring both impairments and activity limitations. The operationalization of occupational gaps has been developed for this study and has not previously been used. Occupational gaps were examined for 28 activities, including 8 instrumental activities of daily living, 6 social activities, 10 leisure activities and 4 work-related activities (see Table II). The selection of the activities was based upon the Interest Checklist and the Role Checklist (14) and a Swedish version of an activity profile (B. Wallgren, Department of Occupational Therapy, Uppsala University Hospital, personal communication) based on work by Baum (15). Four questions were posed in connection with each activity. They were "Did you perform the activity before the brain injury?"; "Did you want to perform the activity before the brain injury?"; "Do you perform the activity now?" and "Do you want to perform the activity now?"

Data analysis

When analysing the prevalence of occupational gaps before and after brain injury, the 4 questions were paired up, with the two questions "Did you perform the activity before the brain injury?" and "Did you want to perform the activity before the brain injury?" forming one pair and the other two questions "Do you perform the activity now?" and "Do you want to perform the activity now?" comprising the other pair. If a person answered either "yes" or "no" to both of the associated questions, then there was no occupational gap, but if the answer was "yes" to one question and "no" to the other, then this was considered to constitute an occupational gap. The analysis required that all 28 questions be answered on perceived occupational gaps before or after brain injury.

Statistics

Uni-variate analyses. Cross-tabulations (χ^2) were used to describe the sample. A Wilcoxon signed-rank test was used to analyse changes in what the participants reported that they did before their brain injury and what they did afterwards. Wilcoxon matched pairs test was used to analyse the differences in numbers of occupational gaps before and after the brain injury. Spearman's rho was used to analyse the association between numbers of occupational gaps and injury severity and time to have elapsed since the injury. The same analysis was used; together with scatter plots, to guide the choice of multivariate analyses of the relationship between numbers of occupational gaps, impairments and

Table I. *Injury and socio-demographic characteristics of the responding group*

	Number with SAH (%)	Number with TBI (%)	Total number (%)	Responses (n)
Diagnoses	120 (64)	67 (36)	187 (100)	187
RLS-level 1*	76 (41)	17 (9)	93 (50)	
RLS-level 2–3*	34 (18)	30 (16)	64 (34)	
RLS-level 4–8*	10 (5)	20 (11)	30 (16)	
Male/female	42 (22)/78 (42)	54 (29)/13 (7)	96 (51)/91 (49)	187
Cohabiting/married	86 (46)	27 (15)	131 (61)	185
Born in Sweden	104 (56)	59 (32)	163 (88)	186
Education to at least upper secondary school	63 (34)	45 (24)	108 (58)	184
Worked/studied before	107 (58)	55 (30)	162 (88)	186
Working/studying after	65 (35)	35 (19)	100 (54)	186

*Reaction Level Scale (RLS) 1 = alert; RLS 2–3 = drowsy, or very drowsy or confused; RLS 4–8 = unconscious; localizes or does not localize pain.
SAH = subarachnoid haemorrhage; TBI = traumatic brain injuries.

Table II. *Frequency with which everyday activities were performed before and after receiving a brain injury (n = 113)*

Activity	Number engaged % Before	After	*p*-value
Instrumental ADL			
Shopping	96	81	<0.001
Cooking	89	81	0.051
Washing clothes	81	73	0.055
Cleaning	88	74	0.003
Light maintenance (home, garden, car)	86	69	<0.001
Heavy-duty maintenance	60	39	<0.001
Administering economy	83	69	0.003
Transportation	99	76	<0.001
Leisure activities			
Sports	71	50	<0.001
Outdoor life	91	67	<0.001
Hobbies	77	60	<0.001
Cultural activities	75	63	0.009
TV/video/radio	99	96	0.14
Reading newspaper	95	86	0.011
Reading periodicals/literature	83	68	0.001
Writing	52	40	0.006
Games, pools, crossword	80	69	0.019
Computer games & surfing the Internet	44	46	>0.30
Social activities			
Seeing partner and children	91	87	0.18
Seeing relatives, friends & neighbours	99	92	0.025
Activities in societies, clubs or unions	48	35	0.009
Religious activities	6	3	0.06
Visiting restaurants and bars	81	67	0.003
Travelling for pleasure	80	65	0.002
Work or work-related activities			
Working full or part-time	87	53	<0.001
Studying full or part-time	19	14	0.15
Taking care of and raising children	48	35	0.002
Voluntary work	13	9	0.09

ADL = activities of daily living.

activity limitations and the time to have elapsed since the brain injury. A Mann-Whitney *U* test was used to analyse the differences between those participants included in the analyses of number of occupational gaps and those who were not. A distance-weighted scatter plot was used to illustrate the relative number of occupational gaps in the group for whom data were missing ($n = 67$).

Multi-variate analyses. Factor analyses (orthogonal design, varimax type, normalized principal components and 5-factor option) were performed to determine whether there were any interpretable patterns in the items concerning perceived impairments/activity limitations. The dichotomized questions were then weighted and combined to form factors. All factors had an eigen-value higher than 1.

A linear multiple regression analysis was performed to explore the influences of impairments and activity limitations and time to have elapsed since the brain injury on the number of occupational gaps. The 5 impairment/activity limitation factors resulting from the factor analyses, and the number of months to have passed since the brain injury and the classification of the severity of the injury (RLS) were all included in the regression model as prognostic factors. As far as the RLS classification was concerned, it should be noted that inhomogenic variances were controlled in the model. In the analyses, the influence of all 2-factor interactions was evaluated. The model was controlled with normal probability plots. Variables that did not contribute significantly to the model were eliminated. The Statistica statistical program (version 6.0) was used and, for the multiple regression analyses, it was used in conjunction with the SAS system.

RESULTS

Prevalence of occupational gaps before and after brain injury

The questions concerning occupational gaps before and after brain injury were answered in their entirety by 118 and 120 persons, respectively. The numbers of occupational gaps after the brain injury was higher than before the brain injury, as illustrated in Fig. 1. Before the brain injury, the majority (54%) of the 118 persons included had had no occupational gaps. After the injury, in contrast, only 29% of the 120 persons included did not experience any occupational gaps. This difference in occupational gaps before and after brain injury was significant ($p < 0.001$).

All of the occupational gaps that were identified from before the brain injury occurred because the participants had wanted to do more than they actually did. After the brain injury, 17 of those 85 participants with occupational gaps actually did more than they wanted to do. Twelve of them participated in just 1 or 2 activities that they did not want to do and the other 5 participants did up to 6 activities that they did not want to do.

In the groups included in ($n = 120$) or excluded from ($n = 67$) the analysis on occupational gaps after brain injury, half of the participants were men, the median age was 50 years, and 64% had experienced an SAH. The injury severity was a little higher in the excluded group together with the median number of months since the brain injury, 28 months compared with 21 months. Of the participants included 58% had taken up work again, which was more than for those excluded (44%). There was, however, no significant difference between the included group and those excluded from the analysis on occupational gaps in terms of gender, age, diagnosis, RLS level, the time to

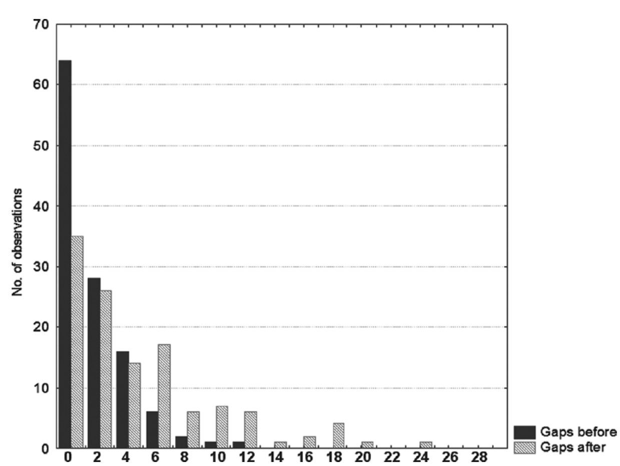

Fig. 1. Number of occupational gaps before and after acquired brain injury.

have elapsed since receiving the brain injury or whether or not the person had taken up work again. The relative number of occupational gaps in the group of people excluded is illustrated in Fig. 2.

Amongst the 118 and 120 persons who answered all questions concerning perceived occupational gaps before or after receiving the brain injury, respectively, 113 persons were included in both groups. A comparison between what this group of 113 persons did before and after brain injury is provided in Table II. The largest differences in the performance of activities was reported for work, where there was a 34% decrease, outdoor life (24% decrease), transportation (23% decrease), heavy maintenance, i.e. undertaking car repairs, renovating accommodation, gardening (22% decrease) and in sports (21% decrease).

Prevalence of perceived impairments/activity limitations

The prevalence of impairments/activity limitations subsequent to being inflicted with a brain injury amongst the 120 persons comprising this group is shown in Table III together with results from the factor analysis. The highest prevalence of impairment was reported for the items incorporated in factor 1, which were fatigue (62%), difficulty in concentrating (51%) and memory impairment (50%).

There were significant correlations between the impairments/activity limitations and number of occupational gaps for all the 5 factors when univariate analysis was performed. A high number of occupational gaps correlated to high ratings in terms of perceived impairments/activity limitations.

Relationship between occupational gaps, perceived impairments/activity limitations and the time lapse since the brain injury

When performing univariate analyses there was a significant association ($p < 0.001$) between number of occupational gaps and severity of injury, where the more severe injured had significantly more occupational gaps. There was no significant association between number of gaps and time elapsed since brain injury. The regression model that best described the relationship between the number of occupational gaps and the prevalence of impairments/activity limitations is presented in Table IV. When controlling the model, the residuals were approximately normally distributed. In the regression analysis, the variables that did not significantly contribute to the model were excluded. That was for example the case with the variable "months to have elapsed since the brain injury" and factor 1, relating to cognitive and emotional impairment.

The model suggests that factor 4 (executive impairments/activity limitations) has the greatest influence and that factor 2 (motor impairments/activity limitations) and factor 5, relating to other somatic impairments, also have an impact on the number of occupational gaps on a group-level ($R^2 = 0.65$). The model indicates that factor 4 has more than twice as much influence on the number of occupational gaps as factor 5 (reflected by the "Parameter estimate" in Table IV). The 2-factor interaction between factor 2 (motor impairments/activity limitations) and the RLS-ratings had an influence on the number of occupational gaps. Individuals rated as alert (RLS 1) in the acute stage, having motor impairments at time of survey, had a steeper increase in occupational gaps.

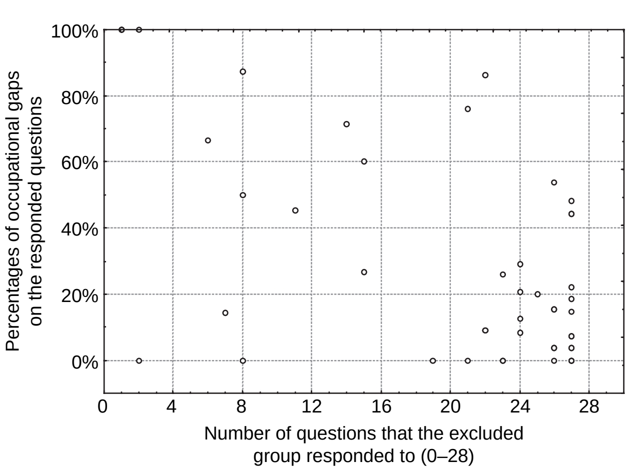

Fig. 2. Percentages of occupational gaps after brain injury on the questions that were responded to by the excluded group ($n = 67$) that did not respond to all questions on gaps in performing activities.

Table III. *Occurrence of perceived impairments/activity limitations after brain injury (n = 120). The items are grouped according to the results from a factor analysis*

Variable	%	Eigen-value
Lacking initiative	40	7.308416 (factor 1: cognitive and emotional impairments)
Concentration difficulties	51	
Depressed	37	
Getting angry more easily	34	
Suffering from fatigue	62	
Memory impairment	50	
Reduced simultaneous capacity	43	
Sensitivity to light and sound	30	
Spasticity	11	3.038075 (factor 2: motor impairments/activity limitations)
Reduced mobility in arm/hand	23	
Reduced mobility in leg	21	
Difficulty walking	20	
Need to use a wheelchair daily	6	
Difficulty writing	19	
Difficulty writing	19	1.300198 (factor 3: communicative impairments/activity limitations)
Difficulty speaking	18	
Difficulty reading	18	
Difficulty carrying out own plans	33	1.222770 (factor 4: executive impairments/activity limitations)
Difficulty finding the way	12	
Difficulty being in time	13	
Lacking initiative	40	
Sensitivity to light and sound	30	1.113259 (factor 5: other somatic impairments)
Headache	28	
Dizziness	28	
Sleeplessness	26	
Reduced speed of mental processing	38	

Table IV. *Relationship between number of occupational gaps after brain injury, factor-analysed perceived impairments/activity limitations and the Reaction Level Scale (RLS) ratings (n = 120)*

Variable	Parameter estimate	Standard error	95% CI for parameter	*p*-value
Factor 2 (motor impairments/activity limitations)	1.3221	0.4585	0.4137–2.2305	0.005
Factor 4 (executive impairments/activity limitations)	2.0749	0.5107	1.0630–3.0868	<0.001
Factor 5 (other somatic impairment)	0.7947	0.3410	0.1191–1.4702	0.022
*RLS 1/ RLS 2–8	−1.5599	0.8115	−3.1677–0.04790	0.057
Factor 2 × RLS†	1.7926	0.5656	0.6718–2.9133	0.002

*RLS-ratings are dichotomized in RLS 1 vs RLS 2–8 according to previous analyses
†The 2-factor interaction between factor 2 and RLS implies that the RLS 1-group with motor impairment (factor 2) have a steeper increase in occupational gaps compared with RLS-group 2–8 with motor impairment.

DISCUSSION

The focus of this study was adaptation in the context of everyday activities. The study shows that persons with acquired brain injury have an increased number of occupational gaps, compared with before their injury. The number of occupational gaps was related to perceived impairment/activity limitations, significantly to executive and less so for motor impairments/ activity limitations, and other somatic impairments. The time elapsed since brain injury had no significant effect on the numbers of occupational gaps. These findings indicate that there is a need for adaptation in everyday activities, even 2–4 years after the injury. While several outcome studies have reported activity limitations after brain injury (3, 4), to the best of our knowledge no studies have reported on the discrepancies between what an individual wants to do and what he or she actually does.

Occupational gaps

The definition and the assessment of occupational gaps was developed for this study. We suggest that occupational gaps reflect adaptation in the context of everyday activities, which is of importance to client-centred practice during both assessment and intervention (6, 11). The increased number of occupational gaps reported in this study was expected because the ability to do what one wants to do is commonly decreased after acquired brain injury. However, assessing occupational gaps might provide important information about what clients want, need, and can do, which can serve as a guide to rehabilitation interventions. In order to enable the clients to do what they want and need to do (9), rehabilitation interventions should aim at reducing the occupational gaps. It is expected that enabling clients to achieve their vital goals will positively influence adaptation and life satisfaction (6, 16). In a nationally representative Swedish sample, individuals who perceived a decreased ability to perform activities rated their overall life satisfaction low, while individuals who were active, in for example sports, reported high overall life satisfaction (17). However, the relationship between occupational gaps and life satisfaction is not clear. It would be of importance for rehabilitation to explore the association between life satisfaction and number of occupational gaps in a brain-injured sample.

Relationship between occupational gaps, impairments/activity limitations and the time lapse since the injury

Executive impairment/activity limitations, such as lacking initiative and having difficulty carrying out plans, had an influence on the prevalence of occupational gaps. These gaps can be viewed as self-evident causes of inability to carry out activities, whether desired or not. The consequences of executive impairments are also obvious in the brain injury rehabilitation unit. Yet, interventions aiming to reduce the consequences of executive impairments in everyday life have not been sufficiently explored in rehabilitation research (18), and have often been neglected during rehabilitation assessments and interventions (19). Goal-directed and meaningful activities in real life situations within familiar environments have been recommended both for intervention and assessment of executive functions (19).

An unexpected finding was that the length of time since injury had no effect on the number of occupational gaps. Thus, there was no difference between whether a person was injured 1 year ago or 4 years ago. This is in contrast to the clinical experience that persons with brain injury manage everyday life better in the long term. A small number of studies about adaptation after stroke (10) or polio (20), indicate that the adaptation process might continue for many years. Adaptation in everyday activities is a process that takes place over time, where competence in doing an activity and the identity as a doer co-develop (6). When continuous adaptation is disrupted by a brain injury, it might consequently be necessary to rebuild competence as well as reconstruct and reinforce identity through the performance of everyday activities (21). In this study we did not explore the identity of the doer nor the perceived competence, which are two elements of importance for occupational adaptation according to Kielhofner (6). Occupational gaps are probably just one aspect of adaptation. In order to understand the complex phenomenon of adaptation over time there is a need to use qualitative research methods (22). The results indicate that there is a need for adaptation in everyday activities over time, which implies a need for rehabilitation interventions and support over a longer period of time.

Study limitations

It might be difficult to capture experiences from everyday life in a reliable way by using postal questionnaires. Other methods of collecting data, for example face to face interviews, have been considered to be more applicable and useful in generating a deeper understanding of a perceived life situation. In this large sample, geographically spread throughout Sweden, we chose to collect data by post. It has been shown that collecting outcome data after acquired brain injury via postal questionnaires is as reliable and valid as conducting interviews (23, 24).

The survey questionnaire included retrospective data. Thus there is a risk that there was some recall bias owing to memory difficulties related to the brain injury. Other causes might be the amount of time that had elapsed or a tendency to remember everyday life as being better than it really had been before receiving the brain injury. Another risk is that participants who lacked self-awareness might have been influenced in how they perceived the consequences of their injury on their ability in everyday activities (25).

Implications

Although the majority of the sample studied (71%) experienced a gap in the performance of wanted or unwanted activities, only approximately one-quarter of the participants had received post-acute rehabilitation interventions. Our result indicates that more patients need a follow-up and access to rehabilitation interventions. A goal for rehabilitation would be to support in this adaptation process and reduce the number of occupational gaps. There are several aspects of importance for adaptation that needs to be considered. Support in the adaptation process during rehabilitation can focus on enabling individuals to do what they want and need to do. This can be done through improving impaired functions or the performance of these activities, finding new ways to perform activities, or modifying the physical or social environment (9). A brain injury poses a significant challenge to the family system (26). Therefore, it is essential that rehabilitation should take place in familiar and meaningful environments (27, 28).

The measure of occupational gaps seems to be an appropriate tool in the follow-up of persons with acquired brain injury. The questionnaire was sensitive enough to capture gaps in this sample. However, further studies are needed to develop this tool. There is also a need for empirical studies to explore the association between experience of life satisfaction and self-reported occupational gaps. Moreover, empirical studies are needed to deepen the understanding of the phenomenon of not being able to perform wanted activities, and what this means for the individual.

ACKNOWLEDGEMENTS

We thank Professor Axel Fugl-Meyer, Uppsala University, for inspiring co-operation in developing the study questionnaire, and the statisticians at the Department of Learning, Informatics, Management and Ethics at Karolinska Institutet for their assistance. The study was supported by the Swedish Research Council, the R&D group, Uppsala County Council and with a scholarship from the Swedish Association of Occupational Therapists.

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