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A retrospective follow-up of persons with acquired brain injury. Factors associated with life satisfaction

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Abstract: 105 patients with acquired brain injury (61% stroke, 36% TBI) were interviewed 6-7 years after rehabilitation. Over 25% of the group was dissatisfied with their current quality of life (QoL), another 10% neither satisfied nor dissatisfied. Approximately 80% of the patients were employed prior to the injury, while only about 30% were employed at 6-7 years post-rehabilitation. Half of the group had currently no productive activity. The majority of the social contacts consisted of contacts with the immediate family. The patients, most dissatisfied with QoL tended to be older. They reported a larger economical loss, a significant decrease in the enjoyment of leisure time and hobbies, less appreciation from their families and friends. They reported themselves as more depressed and irritated, and having more communication problems. **Key words:** brain injury, life satisfaction, follow-up, rehabilitation, quality of life, depression

Estudio retrospectivo de personas con daño cerebral adquirido. Factores asociados a la satisfacción con su estilo de vida

Resumen: 105 pacientes con daño cerebral adquirido (61% infarto, 36% TCE) fueron entrevistados 6-7 años después de rehabilitación. Más del 25% del grupo no estaba satisfecho con su actual calidad de vida (QoL), otro 10% se encontraba en estado indiferente. Aproximadamente el 80% de los pacientes fueron contratados antes del daño, mientras que sólo 30% fueron contratados 6-7 años después de rehabilitación. La mitad del grupo no tenía ninguna actividad productiva. La mayoría del contacto social consistía en contacto con la familia más cercana. Los pacientes menos satisfechos con la calidad de vida solían ser mayores. Informaron de una mayor perdida económica, un significante incremento en el disfrute del tiempo de ocio, menos apreciación de su familia y amistades. Informaron estar más deprimidos e irritados y tenían más problemas de comunicación. **Palabras clave:** daño cerebral, satisfacción de vida, seguimiento, rehabilitación, calidad de vida, depresión.

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Long-term sequelae of brain injury have been extensively investigated in a number of follow-up studies (Oddy, Coughlin, Tyerman, et.al., 1985; Brooks, Campsie, Symington, et.al., 1986; Ponsford, Olver, & Curran, 1995; Sbordone, Liter, & Pettler-Jennings, 1995; Olver, Ponsford, & Curran, 1996). Fewer studies have focused on the patients' own experiences expressed in self-reported measures, concerning also psychosocial factors and life satisfaction (Dikmen, Machamer, & Temkin, 1993; Finset, Dyrnes, Krogstad, & Berstad, 1995). The reason for this was a concern about the ability of brain-injured patients to provide reliable estimates of their subjective cognitive and emotional states, needs and abilities, but several studies indicated the possibility and power of such an approach (Dikmen, Machamer, & Temkin, 1993; Finset, Dyrnes, Krogstad, & Berstad, 1995; McKinlay, 1984). There is also the question of *what* to assess concerning outcome after head injury, and rehabilitation. "Objective measurements", such as employment status, economical changes, changes in living conditions have been traditionally considered to be good indicators. As Warren (Warren, Wrigley, Yoels, & Fine, 1996) puts it, "employment was once considered the ultimate expression of a successful rehabilitation program". However, changes in society, in the legal status of disabled on the work market and finally the transition from the industrial to the postindustrial society with increasing stress-load and increasing demands on information-processing changed the reintegration of the brain injured person into society in a major way. It was also shown that the subjective experience of reentry into the workforce, i.e. satisfaction at work and the meaningfulness of the task are important factors (Melamed, Grosswasser, & Stern, 1992; Oddy, Coughlin, Tyerman, et.al., 1985). Life satisfaction, on the other hand is found to be a highly individual and subjective issue, requiring some capacity for self-reflection and individual judgment [Fugl-Meyer, 2002] (Warren, Wrigley, Yoels, & Fine, 1996). Despite the obvious difficulties in using the concept of Life Satisfaction and the possible bias in individual ratings, the measure is considered an important indicator of outcome after brain injury. The relationship between life-satisfaction and "objective measurements", such as return to work, economical status, living conditions, family status and social network is often mediated by underlying psychological variables, such as coping capacity (Nieves, Charter, Aspinall, 1991) or satisfaction at work (Melamed, Grosswasser, & Stern, 1992). Although the effects of mood disorders on the adjustment process after brain injury have been studied (Najenson, Grosswasser, & Mendelson, et al., 1980; Lundholm, Jeppson, & Thornval, 1975; Morton, & Wehman, 1995) in patients with traumatic brain injury and stroke (Ramasubbu, 2000; Chemerinski, Robinson, 2000) estimates about the extent of the problem in

TBI vary in different studies between 26% and 77 % (Bowen, Neumann, Conner, Tennant, & Chamberlain, 1998). Bowen (1998) found that 38% of the patients admitted in one study reported significant mood disorder.

The present study is a long-term follow-up of a consecutive group of patients with TBI or stroke referred for in- and outpatient rehabilitation within the framework of a comprehensive health-care system and with a multidisciplinary treatment approach in inpatient and outpatient units. In the outpatient setting the patients are at the unit five days a week for at least four hours of rehabilitation. Patients and families are offered psychosocial support, vocational training and assistance in home adaptation.

Method

Procedure

Consecutive patients with non-progressive brain injury, hospitalized at the clinic were contacted by mail. The letter contained some introductory information about the study and was followed up by a telephone call by one of the registered nurses in the study. Date for the interview at the clinic was agreed. If the patient did not show up for the interview, he/she was contacted again until a new date was scheduled. If the former patient could not be reached by phone another mail contact was attempted. Patients with three unsuccessful contacts were considered dropouts. The interview was carried out by one of the investigators in the outpatient clinic’s offices. The duration of an interview was 1.5-2 hours.

Participants

Patients reported in this study were consecutive subjects. During the two years selected for the study 177 adults with acquired brain injury were hospitalized at the clinic. From this group 104 were interviewed (67 men and 38 women). Reasons for dropouts are characterized in Table 1. Mean age at the time of the first contact with the clinic was 39 years (age range 16-70 years). The median time elapsed between the first contact with the clinic and the follow up was 6.3 years.

Reason for dropout	Nr of pats
Refused to participate	23
No show on interview	15
Dead	9
Moved from the area	8
Address unknown	6
Journal missing	5
No contact with patient	4
No communication capacity left	2

Table 1. *Reasons for dropout*

There was a relatively high dropout rate despite several various attempts to contact the patients. Possible differences between the interview and dropout group were examined on the basis of journal records (Table 2). Analyses of variance were carried out. Significant differences were found in the number of days in the acute hospitalization stage, indicating that patients who were willing to be interviewed had markedly longer time of hospitalization.

	Interview group	Dropout group	F
Male/Female	66/38	48/24	n.s.
Mean age* (yrs.)	47,4	51,6	n.s.
Age range (yrs)	24-78	23-82	n.s.
Diagnoses			
TBI	36	23	n.s.
CVI	66	34	n.s.
Other	3	1	n.s.
Acute hospital care (mean nr of days)	52	5	19,7 ***
Inpatient rehab care (mean nr of days)	102	69	2,7^{+}
Outpatient rehab care (mean nr of days)	129	88	n.s.

Total length of hospitalization (mean nr of days)	283	162	15,3***

*At the time of the interview
***p<.01
+p<.10

Table 2. *Comparison of some characteristics between the interviewed patients and dropouts*

Patients in the interview-group had the following diagnoses: cerebrovascular illness (CVI) 63%, traumatic brain injury (TBI) 31%, open skull fractures 3% and benign tumors and other CNS diseases 3%. The distribution of patients according to lesion localization is described in Figure 1.

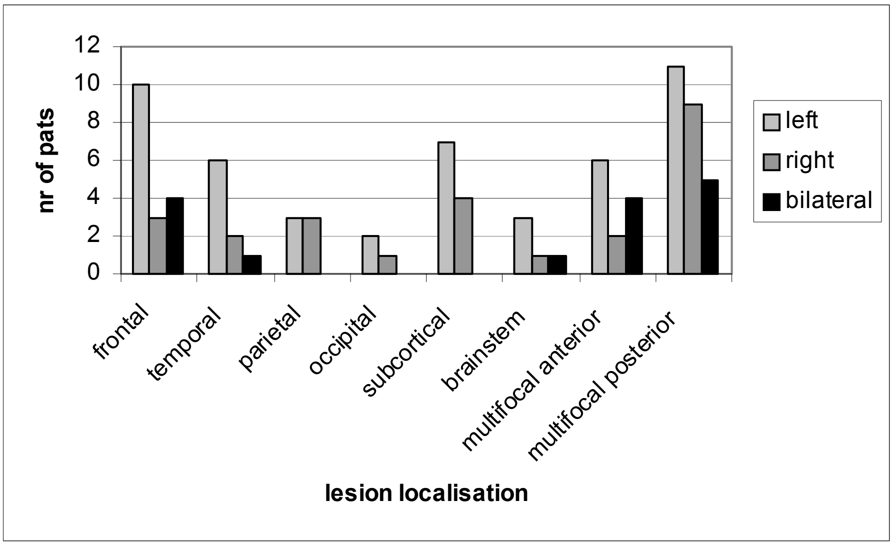

Figure 1. Distribution of patients according to lesion localization (n=88).

Eight of these patients had been in contact with the clinic earlier due to an earlier brain damage. Data on earlier brain damage were missing for seven patients. Marital status at the time of the hospitalization and at follow-up is reported in Table 3.

At hospitalization	Single	Living with partner	Married	**Total**
	37	26	39	102
At follow-up				
Single	27	13	6	46
Living with partner	8	9	0	17
Married	2	4	33	39

Table 3. *Marital status at the time of hospitalization and at follow-up*

The follow-up interview

The follow-up interview was based on a questionnaire covering data: during hospitalization, residual somatic symptoms, current medical and therapeutic contacts, need for assistance, social data at the time of the injury and at follow-up, social network, interests, hobbies, neuropsychological symptoms, such as sensory, cognitive and emotional symptoms, rating of life satisfaction. The interviewer rated the neuropsychological symptoms on a 5-point scale for severity. The measurement of life satisfaction was based on a self-report checklist (LiSat 11) [Fugl-Meyer, 2002] but were administered by the interviewer. Questions concerning life satisfaction were covering the following areas: the general life situation, living and working conditions, quality of leisure time, private economy, partnership, sex-life, perceived appreciation by family, friends, colleagues and superiors at work. The interviewer rated the reported life-satisfaction on a 5- point scale: not satisfied at all – very satisfied.

Results

Approximately one-third of the interviewed patients had a TBI. Figure 1 indicates the distribution of patients according to lesion localization. Interestingly, patients with left-sided lesions dominate for all localizations except for parietal lesions. Thus patients with possible verbal dysfunction and/or right sided motor problems are dominating, most possibly reflecting admission policies from acute care and patients' motivation depending on the degree of insight in the problems

Marital status and living conditions

Data on marital status are presented in table 3 and on living conditions in table 4. Partnerships based on marriage appeared to be more stabile, since only 15% of the married patients were divorced at the time of the follow-up, while 35% of the patients living with a partner, but not married, were separated. The number of patients living independently has in fact increased and 83% reported that they are still satisfied with their living conditions. 7% reported some minor or major deterioration and the same number of patients reported an improvement in living conditions.

At hospitalization	Independent	With parents	Other	**Total**
	87	16	3	105
At follow-up				
Independent	77	12	2	91
With parents	0	2	0	2
In specialized home	4	1	0	5
Service home	3	0	0	3
Nursing home	1	0	0	1
Other	0	1	1	2
Group-home	1	0	0	1

Table 4. *Living arrangements at the time of hospitalization and at follow-up*

Occupational status

At the time of the follow-up 47 patients were working or studied. In this group 70 % were rather satisfied with their occupational situation, 13% reported a marked deterioration in occupational status, while 11% experienced a marked improvement! 31 patients (38%) of those earlier employed were still in non-supported employment. About 10% received different types of support, either for work or for retraining and 38% received early disability benefits. The rest of the group reached retirement age or were homemakers. All 31 patients in non-supported employment worked full time before their hospitalization. At the time of the follow-up only 14 worked full time, 11 worked half time and the rest of the group less than 50%. Almost half of this group (15 patients) continued to work with time same tasks, 10 patients needed to change their responsibilities and 6 did not answered the question. On the other hand several patients who had not been working or studying before their hospitalization have changed their occupational status positively (Table 5).

At hospitalization	Employed	Studies	Other	**Total**
	81	14	9	104
At follow-up				
Employed	29	2	0	31
Studies	3	5	0	8
Supported employment	5	0	1	6
Reeducation program	2	0	0	2
Homemaker	2	0	1	3
Unemployed	5	2	1	8
Disability pension	29	5	3	37
Retired	6	0	3	9

Table 5. *Employment status at hospitalization and at follow-up*

Social contacts at the time of follow-up

Patients were asked about the frequency of their social contacts with members of the immediate family, such as parents, siblings and children, with friends and neighbors and with relatives. The results are described in Figure 2. In the group there were 46 singles living alone. Among these 11 (24%) has at most one social contact in a week. Three of these patients had only occasional social contacts, not even once a week.

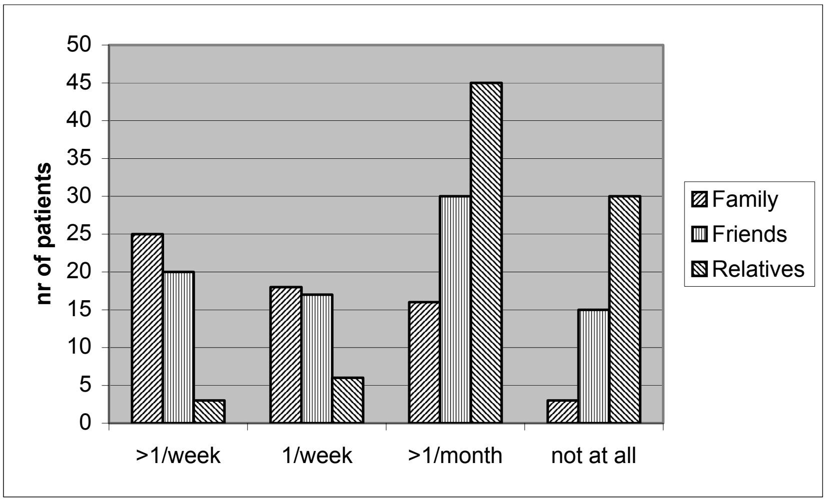

Figure 2. Distribution of the frequency of social contacts with the immediate family, with friends and neighbors and with relatives.

Quality of Life ratings, comparisons between patients who reported a good vs. poor quality of life

Patients were asked about if they were satisfied with the quality life in general and how they felt about this question before their injury/illness. The answers were classified in the following categories by the interviewer: very satisfied, rather satisfied, neither satisfied nor dissatisfied rather dissatisfied. One third of the patients were dissatisfied generally with their present quality of life (Table 6). The proportion of former patients dissatisfied with their current QoL is high (26%) compared to recently published data on a nationally representative Swedish sample [Fugl-Meyer, 2002] where the corresponding figure was only 3%. The proportion of subjects being very satisfied or satisfied was similar in the two studies (65% and 70% respectively), but there were fewer patients then healthy subjects who have taken a more neutral position.

At hospitalization	Dissatisfied	Neither satisfied nor dissatisfied	Very satisfied, rather satisfied
	6	3	92
At follow-up			
Dissatisfied	1	1	24 (26%)
Neither satisfied nor dissatisfied	0	0	8
Very satisfied, rather satisfied	5	2	60 (65%)

Table 6. *Quality of life before injury/illness and at follow-up (n=101)*

In the following patients are compared who were satisfied and those who were dissatisfied and with those who have taken a more neutral position. Dissatisfied patients were slightly older (F=2,43 p<.10) (mean age 52,3 years), then satisfied (mean age 45,1 years), and neutral patients (mean age 46,2 years). The major concern for the dissatisfied patients was the loss of friend's esteem (F=7.91, p<.001), decreased quality of leisure time (F=13.38, p<.001) and economical changes (F=6.48, p<.01). The effects of working and living conditions did not seem to differ. Dissatisfied patients reported themselves as significantly more depressed (Chi2= 21.4, p<.001), more irritable (Chi2= 6.66, p<.01), and restless(Chi2= 6.72, p<.01) and tended to have more communication difficulties (Chi2= 4.75, p<.10),. There were no significant differences in the distribution of males and females within the groups, or in the marital status of the patients. Nor were there any differences according to etiology of the brain damage (TBI, CVI or other), in the number of days of unconsciousness after the brain damage, or in the total length of hospitalization.

Discussion

The aim of this follow-up study was to look at the situation of patients with acquired cognitive dysfunction from the patients' point of view. The authors are aware of the inherent risks and problems of relying on direct reports, despite the efforts invested in obtaining fairly reliable information from the patients. Significant others were always invited to the interviews, but the non-show rate was too high for summarizing systematic results.

Patients were consecutive admissions with TBI or brain damage due to vascular disorder. Only 60% of the consecutive patients, who were contacted, were also interviewed. This is a rather high percentage of dropouts, but not unusual. Some studies reported higher response rates 78-

85% (Teasdale, Christensen, Pinner 1993; Schalén, Hansson, Nordström,G, Nordström, CH. 1994), but others reported comparable or even lower response rates 70-48%: (Ponsford, Olver, & Curran, 1995; Finset, Dyrnes, Krogstad, & Berstad, 1995). Dropout rates increase also with increased time since first contact, as could be observed in the second follow-up of the Ponsford-group (Olver, Ponsford, & Curran, 1996) where only 40 % of the patients attending the earlier follow up responded.

Analysis of the available data has indicated no differences between in age, sex distribution and etiology of disease. However, significant differences were found in the number of days in acute and in inpatient rehabilitation hospitalization. Considerable effort was invested in tracking down the former patients and reasons for dropout are presented in Table 1, indicating a complex picture. Some of these patients, in line with the short time of hospitalization might have refused participation because they were doing quite well and wanted to put the whole experience behind them. Others might be out of reach because of their disabilities. There was also a surprising majority of patients with left hemisphere damage. This finding should be followed up more closely, if this is due to referral problems from acute treatment units or if it is patient who is refusing rehabilitation due to impaired insight in cognitive problems related to right-hemispheric functions.

In the study group the mean age of the patients was near 40 years, reflecting the intake policy of both traumatic and vascular disorders in the clinic. Thus, the mean age was considerably higher than in most of the follow-up studies (Oddy, Coughlin, Tyerman, et.al., 1985; Ponsford, Olver, & Curran, 1995; Dikmen, Machamer, & Temkin, 1993; Finset, Dyrnes, Krogstad, & Berstad, 1995), but nearly the same age as the Sbordone (Sbordone, Liter, & Pettler-Jennings, 1995) study. Consequently family status was also different. A higher than usual number of patients was living in stable relationships and the divorce rate was rather low. The number of patients living independently is the highest reported in the literature. The number rather increased since discharge from hospitalization, probably due to social services' policy to provide personal assistance to achieve a higher level of independence.

As stated earlier, occupational status can be regarded as the most traditional outcome measure after brain injury (Warren, Wrigley, Yoels, & Fine, 1996). There were major changes in the occupational status of these patients. The results are in the same range as reported by some studies (Ponsford, Olver, & Curran, 1995; Teasdale, Christensen, Pinner, 1993; Malec, Smigielski, DePompolo, Thompson, 1993b) and higher than other reports (19%) (Dikmen, Machamer, & Temkin, 1993). An earlier Swedish study (Schalén, Hansson, Nordström, G, Nordström, C.H., 1994) reported a higher combined incidence (70%) of working in non-supported and supported jobs and studies. The corresponding figure in the present study is 48%. One reason for this difference is the difference might be due to the substantial changes during the last decade in the type of jobs offered, requiring more skills and learning capacity. It is noteworthy that there were some positive changes too. 11% found that their working situation has improved since the injury and several patients who were unemployed earlier had changed their occupational status.

In contrast with the relatively good outcome concerning economical, occupational and living conditions the interviews concerning social contacts of the patients give another picture. The daily social network of many patients consists of the immediate family and 25 % of those living alone have at most one social contact per week or fewer. These results are in line with earlier studies. Finset reported 60% fewer social contacts (Finset, Dyrnes, Krogstad, & Berstad, 1995) for patients after brain injury.

The measure of the QoL concept was highly subjective in this study. The interpretation of the concept was individual for each of the interviewed patients. However, 2/3 of the patients stated that they were satisfied with their QoL and only 1/3 reported dissatisfaction. At comparison it was found that dissatisfied patients were somewhat older. The main concern for the dissatisfied patients was the worry how their friends might perceive them and how they social status might have changed. Unfortunately this concern is corroborated by the reported decrease of social contacts with others than family. Another concern was how to spend leisure time. Leisure time is an issue rarely addressed systematically within the framework of rehabilitation, despite the fact that patients usually have more time at their disposal after discharge and frequently there is a need to find new activities than before the injury. But the same cognitive disturbances, such as loss of initiative, executive problems, spatial problems, which prevent patients from returning to a successful professional life, also block attempts to find new leisure activities or carry through old familiar activities. From a neuropsychological point of view leisure time activities should be addressed the same systematic manner as ADL tasks or occupational rehabilitation.

These issues could be addressed more strongly within the framework of current rehabilitation by increased attention to the social network through network interventions and by systematic use of a neuropsychological approach in recreational therapy. Concern for private economy was somewhat less. Dissatisfied patients reported also significantly more emotional problems.

It is not possible from the present follow up to draw conclusions about the underlying factors for decreased QoL. It seems to be a viscous circle of decreased abilities, social isolation and emotional problems. The results show the importance of psychosocial factors for the life quality of this group. Depression is a major problem, also reported in a number of other studies. Rates vary between 39-57% (Ponsford, Olver, & Curran, 1995; Schalén, Hansson, Nordström G, Nordström CH., 1994) in TBI groups and a series of studies in stroke have indicated the detrimental impact of depression on recovery after stroke (Chemerinski, Robinson 2000). The importance of social network and of being able to spend leisure time meaningfully is also stressed by the results. Patients work less, their work tasks have often changed. The importance of the professional life has decreased or disappeared. Despite of this, rehabilitation programs still focus almost exclusively on occupational skills and do not offer proper training in social skills or recreational activities. Although the resistance for and difficulties in resuming old recreational activities must be as high as work related problems, there seems to be an expectation that the fun-part should somehow function by itself. It does not. The need for balance has been stressed e.g. by Prigatano (Prigatano 1989). But you need training in how to resume old activities and how to find new ones, corresponding to your personal wishes and new abilities more closely. You have to have practical guidelines about how to get new information, how to learn new skills your way and how to have the courage to meet new people in those activities. The aim of rehabilitation is to give a possibility to realize the patients' inherent capacity, no just in ADL and at work, but around the clock in all kinds of activities and contexts.

When summarizing the picture, the positive components in the life of persons after a brain injury seem to outweigh the negative aspects, particularly with regard to living and economic conditions. The family situation in our patient group was more stabile, than reported earlier, possibly due to the higher mean age and more stabile relationships before the injury. Those who had jobs were also rather satisfied, although the number of patients maintaining a professional life was limited. This latter finding indicates the problems of the post-industrial society, where changes job requirements render the professional readjustment more difficult. The main finding of this follow up study was, however, the importance of the social context and leisure time for the quality of life experience. These issues should be more systematically addressed in future rehabilitation programs.

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