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Psychosocial sequelae after acquired brain injury: A 5-year follow-up

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Abstract

Objective: Several studies have investigated biopsychosocial consequences after acquired brain injury (ABI) in the early rehabilitation phases. However, longitudinal studies are rare and few go beyond three years post-injury. The aim of the present study was to assess biopsychosocial challenges in a long term perspective and investigate which challenges remain after five years. With reference to the biopsychosocial model our study holds a special emphasis on the psychosocial aspects of it. **Methods:** Adults (N = 45) with moderate or severe ABI were evaluated at three time points: at discharge from hospitalization, 1-year post-injury, and 5-year follow-up. Data were derived from self-reported questionnaires: Major Depression Inventory, Quality of life, Impact on Participation and Autonomy Questionnaire and self-reports on work and marital status. Repeated measures ANOVAs were used for analysis. **Results:** Physical QOL and aspects of autonomy increased over time whereas social QOL decreased. Family roles were challenged at discharge and remained so at 1-year and 5-year follow-up, and the frequency of being married or in a relationship dropped. Level of depression did not change significantly over time, and one in four were still above clinical cut-off at the 5-year follow-up. Employment increased over time but remained less than half of the pre-injury level. **Conclusion:** Improvements in perceived physical function and autonomy are possible long after the injury, whereas social relations remain a challenge and signs of depression persist.

Keywords: quality of life, psychological rehabilitation, bio-psycho-social outcome, longitudinal study, transitions, ABI

Impact

- Our study provides novel research on the long-term biopsychosocial outcomes, with a special emphasis on the psychosocial sequelae, for persons with ABI in a 5-year follow-up study.
- Results indicate that improvements in perceived physical function and autonomy are possible long after the injury, whereas social relations remain a challenge and signs of depression persist.
- ABI-survivors' psychosocial needs are insufficiently addressed in rehabilitation. Thus, rehabilitation programs could benefit from promoting psychological rehabilitation.
- The role of hope in rehabilitation has gained limited attention within ABI research. If functional improvement continues beyond the time period commonly expected, as

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revealed in this study, this is important information for professionals in order not to hamper hope for functional improvement.

Introduction

The early rehabilitation phase following acquired brain injuries (ABI) has received increasing attention in the literature over the past 20 years (Langhorne et al., 2011). Encompassing rehabilitation interventions are now widely considered to be beneficial and are recommended in clinical guidelines. These include interdisciplinary rehabilitation, early supported discharge, and coordinated rehabilitation programmes to ensure seamless service transitions and comprehensive rehabilitation practices within the home and outpatient settings (Danish Board of Health (Sundhedsstyrelsen), 2011a, 2011b).

Interdisciplinary rehabilitation and early supported discharge interventions have contributed to an upward trend in the number of people who return to independent living. However, many are living with residual deficits following their ABI, and optimal management of these individuals is less well understood in a long-term perspective (Langhorne et al., 2011; McKeivitt et al., 2011; Turner et al., 2008).

At present it is still widely agreed that the major part of functional improvement happens in the first year post-injury (Dikmen et al., 1990; Jang, 2009). Therefore, intensive functional training has high priority in the early rehabilitation phases. However, some previous studies have found long-term improvement of independence or a relative stability (Olver et al., 1996; Ponsford et al., 2014).

International research has highlighted substantial emotional difficulties, relationship disruption, unemployment and financial problems during the later stages of ABI recovery (National Stroke Foundation, 2007; Turner et al., 2008). For instance, persons who had an ABI experience difficulties returning to work (Wang et al., 2014; Wolfenden & Grace, 2009) as well as a loss of autonomy and social participation in daily life activities (Walsh et al., 2015; Wolfenden & Grace, 2009). Walsh et al. (2015) showed that, 5 years after a stroke, only 23% of the persons under 66 years of age had worked since their stroke, and 42% of those who were in a relationship felt that their relationship was significantly affected by their stroke. Severity of the ABI is a consistent predictor of return to work (Alaszewski et al., 2007; Hannerz et al., 2016; Saeki & Toyonaga, 2010; Trygged et al., 2011; Walsh et al., 2015). By contrast, the location of the ABI was not found to be a predictor of return to work (Saeki & Hachisuka, 2004). In a qualitative meta-synthesis, Frostad Liaset and Lorås (2016) identified four key concepts for return to work after ABI: empowerment, self-awareness, motivation and facilitation. Regarding traumatic brain injury (TBI), a systematic review of TBI survivors working prior to injury found that only 41% of TBI survivors (range 0–85%) were at work one and two years post-injury (van Velzen et al., 2009). People with TBI who do not return to work within 2 years are unlikely to work again (Kendall et al., 2006). However, we know that those not returning to work are more likely to be depressed, to be anxious, and to report a poorer quality of life (QOL; Franulic et al., 2004). Watkin et al. (2020) found that TBI survivors with higher functional ability, lower anxiety, and higher health-related quality of life (HRQOL) were most likely to achieve a complete return to work.

Moreover, quality of life decreases after an ABI (King, 1996; Walsh et al., 2015). King (1996) found that depression, social support and functional status were predictors of quality of life.

Nestvold & Stavem assessed determinants of HRQOL in a TBI cohort 22 years after injury, and found no association between HRQOL and injury data (Nestvold & Stavem, 2009). The quality of life of persons with ABI is significantly modified even 10 years after the trauma (Teasdale & Engberg, 2004, 2005). Development may also differ across quality of life categories, with physical progress accompanied by mental and psychological stagnation. In fact, quality of life evaluations often focus on the 36 months after the brain injury has occurred, with few assessing its evolution beyond that point. Even though it is well known that clients with an ABI are at risk of mental health problems, there is limited research worldwide on the very long-term outcomes after ABI (e.g. Andelic et al., 2018; Ruet et al., 2019; Teasdale & Engberg, 2004, 2005). Andelic et al. (2018) investigated the functional outcomes and health-related quality of life in patients with TBI 20 years post-injury. They found that functional limitations persist even decades after moderate and severe TBI, with poorer prognosis for females and persons who were depressed at the 10-year follow-up. Development and evaluation of targeted long-term follow-up programs and access to rehabilitation services for these groups should be a focus of research. Improved community integration despite stable functional limitations draws attention to long-term adaptation to adversity and illness. Ruet et al. (2019) 8 year follow up study revealed similar findings.

To investigate which challenges remain for patients after stroke and TBI, this study reports a 5-year follow-up on the long-term biopsychosocial health of people with brain injuries who were included in coordinated cross-disciplinary rehabilitation programmes in the Northern Region of Denmark in 2013/2014.

Assuming that the physiological recovery had been achieved to the fullest extent possible after 1 year, we did not expect to see changes in physical QOL from 1 year post-injury to 5 years post-injury. Based on previous research on psychosocial consequences, we hypothesized that 1) social consequences increase over time and 2) psychological consequences decrease over time.

Theoretical framework

Our understanding of rehabilitation is based on the biopsychosocial model of health represented by the International Classification of Functioning (ICF) (WHO 1996/2006). The biopsychosocial model focuses on the dynamic interaction between the client, relatives, professionals and the community/home environment (Engel, 1977). It emphasizes the importance of paying equal attention to biological/physical, psychological and social aspects following acquired disabilities and of adjusting rehabilitation efforts to changes in the individual's biopsychosocial needs. Since our focus is mainly on the long-term course of psychological symptoms, we especially address the psychosocial aspects of the model here.

Materials and methods

The coordinated rehabilitation programme

The coordinated rehabilitation programmes involved interdisciplinary coordination of services across hospital and municipal sectors. A person designated as the brain injury coordinator was present at the first status meeting about each client at the hospital's Neuro-Rehabilitation Centre, and again at the discharge meeting in order to ensure that the

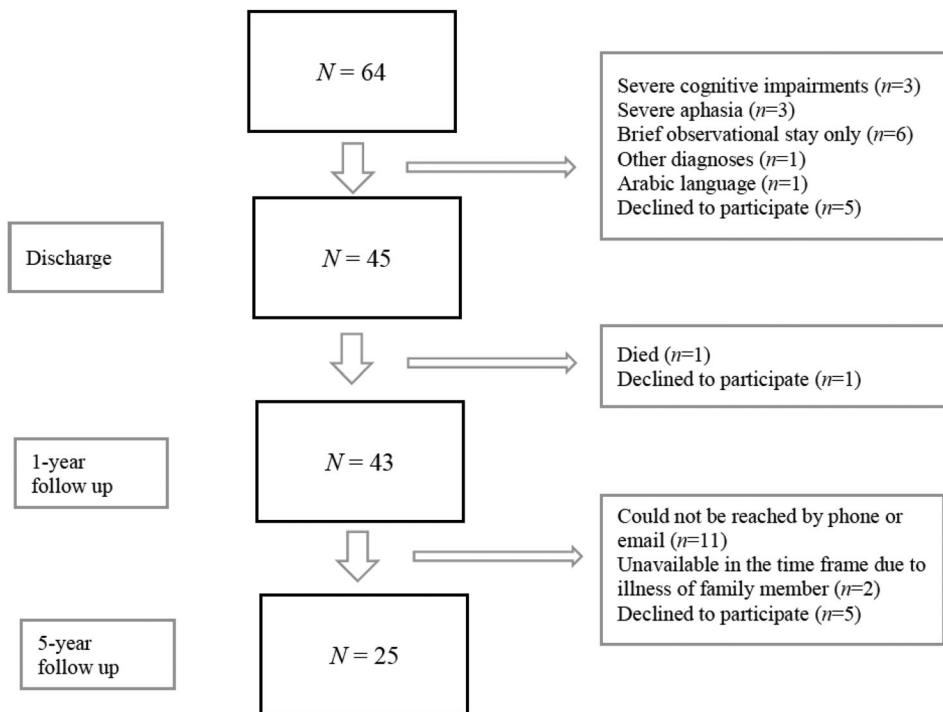


Figure 1. Flow chart of recruitment, exclusion and reasons for attrition.

necessary rehabilitation services would be ready in the municipality at discharge. After the client's discharge, this coordinator was a key person during the entire rehabilitation process in tailoring services to the client's physical, psychological and social needs. All clients in the programme were assessed by a neuropsychologist at the Neuro-Rehabilitation Centre. In addition, the programme included a joint rehabilitation plan across sectors (hospital/Neuro-Rehabilitation Centre and municipality). The Neuro-Rehabilitation Centre developed the initial rehabilitation plan. Subsequently, this plan was continuously adjusted to the client's needs, including after discharge. In this way, the municipality sought to ensure management continuity and could make relevant efforts ready at discharge.

Study population

All clients included in the study were adults (18–66 years) with a moderate or severe traumatic brain injury or stroke. ABI severity is defined according to the Glasgow Coma Scale (GCS). Scores range from 15 to 3 (best to worst) with moderate ABI 9–13 and severe ABI 3–8. GCS scores were retrieved from the clients' medical journals. Clients lived in four municipalities in the Northern Region of Denmark. All clients were admitted to the Regional Neuro-Rehabilitation Centre in Northern Denmark between April 2013 and June 2014.

From a total of 64 ABI clients in the relevant time frame, 45 were included in the study. The flowchart (Figure 1) illustrates recruitment, exclusions and reasons for attrition over the course of the study.

Table 1. Client overview

Time	N	Age (admission)	Gender	Diagnosis	Hospitalized (days)	Total FIM at admission	Total FIM at discharge
		<i>M (SD)</i>			<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>
Discharge	45	52.9 (11.3)	Female: 15 Male: 30	Stroke: 37 TBI: 8	55.84 (37.3)	85.1 (29.7)	109.7 (16.2)
5-year	25	53.4 (11.3)	Female: 9 Male: 16	Stroke: 19 TBI: 6	57.2 (41.1)	86.8 (28.8)	110.7 (14.1)

Note. FIM = Functional Independence Measure.

From the original sample of 45 participants, 25 could be reached and participate again after five years. The 25 participants remaining in the study had numerically higher FIM scores than drop-outs at both admission. Comparing the 25 participants in the study with the 20 who dropped out, there were no significant differences in FIM scores at admission ($t = 0.97$, $p > 0.05$) or discharge ($t = 0.9$, $p > 0.05$), nor in ABI severity as measured by number of days hospitalized ($t = 0.11$, $p > 0.05$), nor in age ($t = 0.37$, $p > 0.05$). Participants' gender and diagnoses reveal no differences either (Table 1).

Since the study involved human participants and person-sensitive data, the study was approved by the Danish Data Protection Agency (Datatilsynet) on January 28, 2013 and an extension was approved on December 1, 2016. The project was also reported to the Regional Research Ethics Committees for the Region of Northern Jutland (Nordjylland) who found it exempt from full review. Informed written consent from participants was obtained before each assessment.

Standardized measures

Four standardized measures were used:

The *Functional Independence Measure (FIM)* was used to measure motor-functional and cognitive daily life skills at discharge from the Neuro-Rehabilitation Centre. FIM is systematically used when clients are hospitalized and discharged from the Centre. Thus, experienced hospital staff members (physiotherapists or occupational therapists) conducted the FIM tests. These FIM data (from the sub-acute phase) have been made available and are included in this study. FIM is a generic instrument consisting of 18 items, and the total possible FIM score ranges from 18–126 (worst to best). The scale is comprised of two subscales: a motor scale (13 items) and a cognitive scale (5 items). Each item is ranked on a 7-point scale (7 = Complete independence/fully independent, to 1 = Total assistance/subject contributes < 25% of the effort or is unable to do the task; Keith et al., 1987). In our study, the FIM had high internal consistency (Cronbach's $\alpha = .84$).

Note that the FIMTM instrument was originally developed to measure outcomes in the acute and subacute phase of rehabilitation. When used in longitudinal studies, it may lack sensitivity, and a known disadvantage is the risk of ceiling effects. Therefore, we did not use this measure at follow-up. The following three measures were obtained at three time-points: at discharge, 1 year follow-up and 5 year follow-up.

Depression was measured by the Major Depression Inventory (*MDI*). MDI is a self-report instrument designed to screen for depression. MDI scores range from 0 to 50: the cut-off for depression is a score above 20 (Beck, Rasmussen, Olsen, Noerholm & Abildgaard, 2001). The MDI differs from other self-report inventories, such as the Beck Depression Inventory (BDI), because it is able to generate an ICD-10 (WHO, 1996/2006) or DSM-IV (APA, 2000) diagnosis of clinical depression in addition to an estimate of symptom severity. The MDI has shown good psychometric properties with a Cronbach's $\alpha = .82$.

Quality of life (QOL) was measured by the WHO-Quality of Life-BREF (*WHOQOL-BREF*). WHOQOL-BREF is a self-report instrument with four subscales: physical QOL, psychological QOL, social QOL and environmental QOL (WHO, 1996). Raw scores are transformed into a scale score from 0–100 (worst to best). Scores indicate: very satisfied (81–100), satisfied (61–80), neither/nor (41–60), dissatisfied (21–40) and very dissatisfied (0–20). In our study, all subscales had high internal consistency with all Cronbach's $\alpha > .81$.

The Impact on Autonomy and Independence Questionnaire (IPAQ-DK) measures client-perceived participation restrictions via 32 items organized into five subscales: autonomy indoors, family roles, autonomy outdoors, social life and relationships, and work and education. IPAQ is a generic, self-completed questionnaire for adults with disabilities and chronic impairments. IPAQ scores range from 0 to 4 (best to worst). IPAQ is available in different languages and has well-documented psychometric properties (Ghaziani et al., 2013). Cronbach's α for the subscales ranged between .81 and .91, indicating good homogeneity.

According to Noonan et al. (2009), the IPAQ covers the following ICF activity and participation domains: Mobility; Self-care; Domestic life; Interpersonal interactions and relationships; Major life areas; and Community, social, and civil life. It includes the influence of environmental factors (e.g. Products and technology; Support and relationships) on participation. Additionally, it considers decisional autonomy as a prerequisite for participation (e.g. item 5a: spend leisure time the way you want).

Marital status & return to work. As part of a background data questionnaire, every participant was asked standard questions about their employment status and marital status (i.e., whether they were in a relationship or single) at all three assessment points.

Procedure

The first author collected MDI, WHOQOL-BREF and IPAQ-DK data at three time-points: when the clients were discharged from the Neuro-Rehabilitation Centre, and in their personal homes one year and five years after hospitalization. This author has clinical experience in the field of rehabilitation and is thus familiar with communicating with adults with various cognitive disabilities. Clients managed the questionnaires themselves; however, support was provided if further explanation of questions was needed or if the client requested questions or words to be read for them.

Statistics

Data were processed and analysed with the statistical software program IBM SPSS 25. Assessment of normality was done using a Shapiro Wilk test. Differences across time were tested by one-way repeated measures ANOVAs followed by pairwise comparisons. Effect sizes were measured with partial eta squared (partial $\eta^2 = \frac{SS_{Effect}}{SS_{Effect} + SS_{Residual}}$).

Table 2. Clients' marital status and return to work

	Discharge N = 45	1-year N = 43	5-year N = 25
	n (%)	n (%)	n (%)
<i>Marital status</i>		<i>a</i>	<i>b</i>
Married (or cohabiting partner)	26 (57.8 %)	24 (57.1 %)	12 (57.1 %)
Romantic partner (non-cohabiting)	3 (6.7 %)	4 (9.5 %)	1 (4.8 %)
Single or divorced	16 (35.6 %)	14 (33.3 %)	8 (38.1 %)
<i>Return to work</i>		<i>b</i>	
Ordinary job or education enrolment	29 (64.4 %)	8 (20.5 %)	7 (28.0 %)
Flexible job	0	1 (2.6 %)	1 (4.0 %)
Job seeker	2 (4.4 %)	2 (5.1 %)	0
Sick leave	1 (2.2 %)	0	0
Vocational rehabilitation	1 (2.2 %)	10 (25.6 %)	0
Social pension	7 (15.6 %)	11 (28.2 %)	6 (24.0 %)
Early retirement	5 (11.1 %)	7 (17.9 %)	11 (44.0 %)

Note. a = 1 missing value, b = 4 missing values; percentages are of answers obtained.

For non-normally distributed data, Friedman's test was used. Sample size was determined by availability (all possible clients) instead of power analysis.

Missing data

Loss of participants at follow-up may bias the results. We controlled for attrition by re-running analyses using the Last Observation Carried Forward (LOCF) imputation method, which is relevant for longitudinal data (i.e. repeated measures have been taken per subject by time point). This method assumes that missing values from participants lost to follow-up have remained constant since they were last observed.

Results

Return to work or education

Before the injury, 64% of the 45 participants were enrolled in education or had an ordinary job, one was in vocational rehabilitation, and 27% were on a social pension or early retirement (for details, see Table 2).

In Denmark, there is a distinction between social pension and early retirement. A social pension is granted when a person's ability to work is reduced due to a chronic disability. In 2013, the Danish Government implemented employment reforms which included new initiatives to ensure that more people would return to work after an illness, and reduced access to social pensions. There has been a drop in adults (18–66 years old) on a social pension from 8% (2012) to 5.7% (2019) at a national level due to this reform. However, because our

Table 3. Depression index (MDI) mean scores.

	Discharge <i>N</i> = 45	1-year <i>N</i> = 43	5-year <i>N</i> = 25
	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)
MDI	15.11 (10.67)	17.95 (10.79) ^a	15.28 (11.47)

Note. Lower is better. a = 5 missing values.

data were collected prior to this reform, these clients did not access the new initiatives and we consequently expected a large proportion of clients to have social pensions. Early retirement is unrelated to working ability. It is a voluntary option from 3 to 5 years prior to ordinary retirement in Denmark. Given the high mean age for stroke survivors, it was expected that some participants would have taken early retirement.

At 1 year follow-up, 20% of participants had returned to ordinary work or education and 25% were in vocational rehabilitation. At 5 year follow-up, 28% had returned to work or education.

Marital status

At 5 year follow-up, one participant reported having divorced in the first year post-discharge and at least three participants had changed their status to single between the 1 year and 5 year follow-up studies. However, across the sample little change was seen in marital status, as indicated in Table 2.

Depression

In terms of clinical cut-offs for depression measured on MDI (< 20 = no depression, 20–24 = mild depression, 25–29 = moderate depression and >29 = severe depression; Bech et al., 2001), we found that 27% of the clients showed signs of clinical depression at discharge. One year later, 37% of the clients showed signs of clinical depression, and 24% of the clients showed signs of clinical depression at 5 years post-discharge. For comparison, in a Danish general population study, only 2.3% of participants (*N* = 14,787) showed signs of clinical depression (Ellervik et al., 2014).

Although means suggested an increase in depression from discharge to 1-year follow-up and a decline from 1-year follow-up to 5-year follow-up, one-way repeated measures ANOVA revealed no significant change over time. The mean scores on MDI did not surpass the cut-off for clinical depression. Also, the variation in scores in terms of SDs are quite sizable (Table 3).

Quality of life

Physical QOL. Mauchly's Test of Sphericity indicated that the assumption of sphericity had been violated ($\chi^2(2) = 6.73, p = .035$) (Table 4), therefore the Greenhouse-Geisser corrected results are reported ($\epsilon = .79$). A one-way within-subjects ANOVA showed a significant effect of time on physical QOL ($F(1.58, 36.40) = 10.62, p < .001, \eta^2 = .38$).

Table 4. Quality of life (QOL) mean scores

	Discharge N = 45	1-year N = 43	5-year N = 25
	M (SD)	M (SD)	M (SD)
Physical	42.82(19.70)	49.37 (22.66) ^a	56.64 (16.80)*
Psychological	50.82 (20.12)	53.10 (21.45) ^a	57.32 (22.19)
Social	69.00 (17.68)	67.07 (19.96) ^a	53.00 (22.10)*
Environment	56.36 (12.40)	59.12 (15.52) ^a	63.64 (17.30)

Note. Higher is better. a = 4 missing values.
*Indicates significant difference across time

Psychological QOL. A one-way within-subjects ANOVA showed no significant effect of time on Psychological Quality of life ($F(2,46) = 1.886, p < .08$).

Social QOL. A one-way within-subjects ANOVA showed a significant effect of time on social Quality of life ($F(2,44) = 5.494, p < .05, \eta^2 = .20$). A significant linear trend emerged ($F(1,22) = 267.406, p < .001, \eta^2 = .92$) with social QOL decreasing over time.

Environmental QOL. A one-way within-subjects ANOVA showed no significant effect of time on Environmental Quality of life ($F(2, 46) = 2.767, p < .07$).

Autonomy and independence

Indoor autonomy. Indoor autonomy varied significantly across the three assessment points ($\chi^2(2, N = 23) = 14.08, p < .001$) (Table 5). This kind of autonomy increased to ceiling from discharge to 1 year follow-up.

Family roles. Family roles did not vary significantly across the three assessment points ($\chi^2(2, N = 22) = 3.714, p < .16$).

Outdoor autonomy. Outdoor autonomy varied significantly across the three assessment points ($\chi^2(2, N = 23) = 11.30, p < .005$). This kind of autonomy increased from discharge to 1 year follow-up with no further increase to 5-year follow-up.

Social relations. Social relations did not vary significantly across the three assessment points ($\chi^2(2, N = 20) = .295, p < .86$).

Control for attrition

To control for possible attrition bias, ANOVAs were re-run with $N = 45$ using LOCF for missing observations. Except for Social QOL, the same results were obtained. For Social QOL, the difference reached statistical significance for $N = 25$ ($p = .007$); for $N = 45$ with LOCF, it did not ($p = .078$).

Interactions between ABI severity and scores on depression, QOL and IPAQ

As seen in Table 6, we found no significant correlation between FIM (admission as well as discharge) and physical, psychological and environmental QOL scores nor depression scores at 5 year follow-up. This indicates no relationship between ABI severity and depression or physical, psychological or environmental QOL at 5 years post-injury. However, we found

Table 5. Impact on autonomy and participation (IPAQ) median scores

	Discharge N = 45	1-year N = 43	5-year N = 25
	Median	Median	Median
Indoor autonomy	1.00	.00 ^a	.00 ^{a*}
Family roles	2.00 ^a	2.00 ^a	2.00 ^a
Outdoor autonomy	3.00	2.00 ^a	2.00 ^{a*}
Social relations	.00 ^b	1.00 ^a	1.00 ^a

Note. Lower is better. a = 1 missing value, b = 3 missing values.

Table 6. Correlations between original client status and 5-year outcome

Outcome at 5 year follow-up	Status during hospitalization			
	Age	Hospitalized (days)	Total FIM at admission	Total FIM at discharge
MDI	-.35 ^a	-.02 ^a	.16 ^b	-.12 ^a
QOL physical	-.07 ^a	-.08 ^a	-.12 ^b	.07 ^b
QOL psychological	.09 ^a	.15 ^a	-.21 ^b	.12 ^a
QOL social	.04 ^a	-.29 ^a	.35 ^b	.45 ^{a*}
QOL environmental	-.01 ^a	-.12 ^a	.04 ^b	.25 ^a
IPAQ indoor autonomy	.25	.18	-.25 ^a	-.48 [*]
IPAQ family roles	.09	.40 [*]	-.42 ^{a*}	-.63 ^{**}
IPAQ outdoor autonomy	-.17	.30	-.17	-.33
IPAQ social relations	-.23	.16	-.11	-.38

Note. Pearson's correlations.

^{*}Indicates $p < .05$,

^{**}Indicates $p < .001$.

N = 25, except aN = 24 and bN = 23. FIM = Functional Independence Measure.

significant correlations between FIM discharge and indoor autonomy, social QOL, and family roles, and between days of hospitalization and family roles. Thus, the results indicate that severe ABI has a greater impact on family roles, Social QOL and indoor autonomy.

Pattern of results: Which challenges remain?

In sum, our results reveal that some psychosocial problems still represent a challenge at 5 year follow-up. Participants already revealed signs of depression at discharge from the Rehabilitation Centre and some of these clients developed moderate or severe depression over time (1 year follow-up). At 5 year follow-up, the rate of depression may have dropped again (although mean MDI scores did not decrease significantly); however, 24% still revealed signs of depression.

Participants' indoor and outdoor autonomy increased significantly over time. Family roles were already affected at discharge and remained a challenge over time; clients expressed that they felt different and unable to fulfil their role as a partner or parent. Participants' social QOL decreased significantly over time, suggesting a more withdrawn life and greater social isolation. Clients did not report problems in social relations at discharge or at 1 year follow-up, but they did so at 5 year follow-up.

Participants' physical QOL increased significantly from discharge to 5 year follow-up, which is in accordance with the increased indoor and outdoor mobility reported by IPAQ. Psychological QOL may improve over time but there were no statistically significant changes in mean IPAQ over the timeframe of this study.

Only 20% of participants in this study had returned to work or education at 1 year follow-up, but 28% had returned to work at 5 year follow-up. Enhanced efforts to support clients' return to work or education may be a consequence of employment reforms introduced by the Danish government in 2013.

Discussion

Much is known about the prevalence of biopsychosocial consequences following ABI, but less is known about the long-term course of these. The aim of the present study was to assess biopsychosocial challenges in a long term perspective and investigate which challenges remain after five years. With reference to the biopsychosocial model, our study places a special emphasis on psychosocial aspects. We report a 5 year follow-up on adults with ABI who were included in coordinated cross-disciplinary rehabilitation programmes in the Northern Region of Denmark in 2013/2014.

The first round of results (at 1 year follow-up) found ABI to have psychological consequences, e.g., depression and reduced quality of life (Glintborg & Hansen, 2016). These outcomes did not improve from hospital discharge to 1 year follow-up. We previously suggested that, physiological recovery had probably been achieved to the fullest extent possible 1 year post-injury, but depression and reduced psychological well-being remained prevalent.

The 5 year follow-up in fact disclosed a further significant increase in physical quality of life over time, contrary to our previous expectations. During assessment, participants orally reported that they still experienced physical progress even 5 years post-injury, despite what they had been told to expect by professionals.

However, notwithstanding these increases in physical quality of life, our study revealed that social quality of life decreased significantly over time. Moreover, we found that family roles, which already present a challenge at discharge, continue to do so both at 1 year follow-up and at 5 year follow up. Considering participants' marital status, four had separated and one had divorced. This is in line with previous studies (Arango-Lasprilla et al., 2008; Kreutzer et al., 2007).

In addition, approximately one third of all clients exhibited clinical level signs of depression at all three timepoints. Numerically these signs increased from discharge to 1 year follow-up and decreased at 5 year follow-up, but these changes were not statistically significant. The hospitals in the Northern Region of Denmark follow the national neurological treatment guidelines. In these guidelines, antidepressants are identified as a potential component of treatment for stroke survivors. Thus, rapid assessment of poststroke

depression takes place and treatment can be initiated. However, guidelines for TBI patients are not mentioned.

Our results resonates with previous longitudinal studies of clients with ABI which found that the psychosocial problems after ABI represent a particular long-term challenge in rehabilitation (e.g. Teasdale & Engberg, 2004, 2005). Participation limitations have been described in numerous studies focusing on ABI. Recent studies (Andelic et al., 2018; Ruet et al., 2019) revealed that, long after the injury, persisting impairments still interfere with social integration and participation. Moreover, a British study on traumatic brain injury found that clients experienced a decrease in social communication skills one year post-hospitalization which was associated with decreases in community integration and quality of life (Dahlberg et al., 2007).

The finding in our study of continued progression in perceived physical quality of life was unexpected. It is standard knowledge that the major part of functional improvement occurs in the first year post-injury (Dikmen et al., 1990; Jang, 2009). However, some previous studies have found long-term improvements in independence, or at least a relative stability (Olver et al., 1996; Ponsford et al., 2014).

Limitations

Some limitations of the present study should be noted. The level of dropouts between 1 and 5 year follow-up is fairly high. We tried to control for attrition bias by using the LOCF. However, there are also certain limitations to LOCF. For instance, assuming no progression after dropout could bias results. In such a case, a LOCF analysis could give overly optimistic findings.

Moreover, self-report measures are inherently subject to bias, even when established instruments such as MDI, QOL and IPAQ are used. Participants may prefer the more socially accepted answer, and for adults with ABI some concerns might arise regarding their level of insight (i.e. whether they have the capacity to perform such self-assessments). Nevertheless, ABI survivors' view of their situation is important, since it influences their perceived well-being and their level of adaptation to new life circumstances.

Hope in rehabilitation

If functional improvement continues beyond the time period commonly expected, this is important information for professionals in order not to hamper hope for functional improvement. Hope is an important part of the rehabilitation process and connected to motivation. Some authors have emphasized the dilemma of balancing long-term hope and current realism (Alaszewski & Wilkinson, 2015; Glintborg, 2019). Hope is created by envisioning a desired future and taking steps toward it. As progress is made in rehabilitation, ABI survivors may be hoping for possible futures that are unrealistic, which makes them vulnerable to experiences of hopelessness. However, for adults with ABI, despair may pose a greater threat to recovery.

When clients are encouraged to keep their hopes realistic – that is, limited to what their official prognosis predicts – they have to live through the distress of abandoning previous life ideals and aspirations in the sense of Frank and Frank (1991). Barnard (1995) has focused on the 'dynamics of hoping' in the context of chronic illness, emphasizing that

patients are set to live in the tension of a particularly troubling boundary situation: 'the boundary between old formulations of the self and new formulations not yet born' (p. 50). Illness narratives are suggested to perform a vital role in constructing possibilities that enable people to engage with different modalities of hope. Due to the sheer scale of the existential challenge of recovery, the experience of biographical disruption and the process of narrative identity reconstruction (Glintborg, 2019) is liable to be extensive. When the effects of ABI are experienced as permanent, their significance for a person's life orientation and purpose is magnified (Williams, 1984) and this may itself lead to demoralization.

Vocational rehabilitation

Vocational rehabilitation (VR) is another area of rehabilitation that needs more attention. We know that those not returning to work are more likely to be depressed, anxious, and report a poor quality of life (Franulic et al., 2004). Thus, employment is associated with reduced stress, improved quality of life, and enhanced physical and mental well-being. Encouraging those who can work to seek employment is a Danish government priority. However, employment services rarely aid adults with ABI sufficiently to find work. In line with other studies, our study highlights the struggles associated with working after ABI (Watkin et al., 2020). However, one strategy to support return to work is VR. VR is described as "whatever helps someone with a health problem to stay at, return to, or remain in work" (Waddell et al., 2008, p. 10). A recommendation for future rehabilitation practice could be to direct resources towards VR including working with employers to facilitate job retention.

A medical blind spot

A substantial amount of research has highlighted the emotional sequelae following ABI. Despite rehabilitation practice since the 1980s aspiring to a dynamic, coherent and holistic approach, addressing the effects of ABI on life transitions still seems to be a challenge and research has revealed persisting psychosocial impairments after ABI (Glintborg, 2016). Rehabilitation originates from a biomedical field (the medical model) where identification of pathology was seen as a first step to problem solving. Rehabilitation practices and research are still mainly influenced by rehabilitation's origin in physical medicine.

However, modern medicine has a blind spot. With its principal focus on pathology, it ignores the existential dimension of life-changing illness and its impact on emotional well-being. When applied to closed-head injuries, the model of modern medicine suggests that deficits in behavior or cognition could be explained by deficits in the brain. This is unfortunate since rehabilitation is more than the rehabilitation of the body and the brain: it also concerns the rehabilitation of lives. The challenges of human existence can only be addressed if a new sub-discipline is added to rehabilitation – that of rehabilitation psychology. Rehabilitation psychology targets a non-objectifying understanding of suffering (and existence) so that it may be accepted, and growth may continue. Fortunately, with the work of figures such as Rita Charon (2018), Arthur Kleinman (1988), and Janice Morse (2016), there is a growing body of healthcare research that may be found stepping beyond the confines of the modern medical model.

The concept of resilience also challenges the medical model. The study of resilience in individuals with ABI is in its infancy, but initial results already suggest that resilience contributes

to positive rehabilitation outcomes (Bertisch et al., 2014). The focus should not only be on the fact that the individual has deficits, which are internalized into a new self-perception, and ABI identities, which could lead to emotional distress, but also on the issue of how to strengthen personal skills for handling difficult life transitions, and how this happens in social settings and in interaction with others. The important questions to be raised are: what are the natural mechanisms that allow most people to cope successfully with adversity? What are they doing and how are they coping? To this end, the concept of resilience is useful. In the study of resilient outcomes in adults, there have been approaches that have suffered from serious conceptual misunderstandings, e.g. treating resilience as a personality characteristic, as the absence of symptoms and full recovery, or as a general term to connote average levels of psychological adjustment. In fact, resilience can be summarized as a mix of several factors: (1) personal competencies such as optimism and the ability to adapt; (2) psychosocial factors in an individual's family; and (3) context-based factors such as a supportive school, workplace, etc. Research has indicated that most people who experience a traumatic event are resilient and "bounce back," even though initially they may catastrophize when predicting their emotional reactions (Gilbert et al., 2004). In general, people are poor at predicting how long their emotional reactions will last: overprediction of distress is generally matched by a faster-than-anticipated return to baseline functioning. Although this response pattern has been documented in individuals without cognitive impairment (Gilbert et al., 2004), it has not been adequately examined among people with cognitive and emotional changes secondary to a neurologic injury, such as ABI.

To sum up, there is a need for changes in rehabilitation practice. Like previous research (Glintborg & Hansen, 2016; Turner et al., 2008), our study indicates that psychological aspects of life transitions are important, and we suggest that these need more attention in rehabilitation practice. Long-term hope may be an important factor in this, and while family life and return to work pose obvious challenges, the sustained possibility of increased autonomy and physical functioning might assist hope and counteract demoralization.

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