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Citation

Allonsius, F., Kloet, A. J. de, Markus-Doornbosch, F. van, Meesters, J. J. L., Kromme, C. H., Vlieland, T. P. M. V., & Holst, M. van der. (2021). Parent-reported family impact in children and young adults with acquired brain injury in the outpatient rehabilitation setting. *Brain Injury*, *35*(5), 563-573. doi:10.1080/02699052.2021.1891287

Version: Publisher's Version

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Downloaded from: https://hdl.handle.net/1887/3196102

Note: To cite this publication please use the final published version (if applicable).

BRAIN INJURY
2021, VOL. 35, NO. 5, 563–573
https://doi.org/10.1080/02699052.2021.1891287

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Parent-reported family impact in children and young adults with acquired brain injury in the outpatient rehabilitation setting

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ABSTRACT

Purpose: To increase knowledge/awareness on family impact (FI) after acquired brain injury (ABI) in rehabilitation settings, it is essential to investigate the associations between patient-functioning and impact on families. This has been explored in hospital-based cohorts, but not in rehabilitation settings.
Methods: A cross-sectional, multi-center study among parents of children/young adults (aged 5–24 years) with ABI referred to rehabilitation was performed. Patient/injury/family-characteristics were noted, and parents completed the PedsQL™Family-Impact-Module and PedsQL™generic-core-4.0 to assess FI and health-related quality of life (HRQoL). Univariate- and multivariable-regression analyses were performed to investigate associations between HRQoL/patient/injury/family-related factors and FI.
Results: 246 families participated; patients' median age was 14 year (IQR 11–16), 65 had non-traumatic-brain-injury (nTBI) (26%), 127 were female. FI was found to be considerable (median FIM-score 71.9, IQR:60–85). Especially referral to rehabilitation >6 months after onset, diminished patients' mental/emotional health and HRQoL (child/family factors), and premorbid problems were associated with higher FI.
Conclusions: In this rehabilitation cohort, pediatric ABI caused considerably higher FI than in hospital-based studies with referral to rehabilitation >6 months, diminished child/family factors and presence of premorbid problems increasing FI. Assessing and monitoring FI and its associated factors enables professionals to individualize treatment, psychoeducation, support and follow-up.

ARTICLE HISTORY
Received 4 May 2020
Revised 3 December 2020
Accepted 12 February 2021

KEYWORDS
Family impact; acquired brain injury; rehabilitation; pediatric

Introduction

Acquired brain injury (ABI) refers to any damage to the brain that occurs after birth and can be categorized in traumatic brain injuries (TBI) and non-traumatic brain injuries (nTBI) (1). TBI is caused by external trauma (e.g., traffic accidents, sports accidents, abuse), while nTBI results from internal causes (e.g., stroke, tumors, infections, hypoxia) (1). The estimated yearly incidence rates in the Netherlands are: 288.9 (0–14 years) and 296.6 (15–24 years) per 100.000 for TBI and 108.8 (0–14 years) and 81.5 (15–24 years) for nTBI (2). ABI may cause a variety of long-term deficits for patients including motor, communication, cognitive, and behavioral impairments (2–6).

It is well known that due to natural brain adaptation a majority of the patients with ABI will recover within the first year after brain injury (7–9). However, a group of patients (approximately 30% (2,8,10)) with ABI will remain with persisting daily life problems. These problems can have a considerable negative impact on functioning, participation and health-related quality of life (HRQoL) for the patient, as well as the family (8,9,11–14).

Previous studies regarding family impact in patients (either TBI and/or nTBI) mostly concern hospital-based cohorts (12,15–29). Hospitalization of a child after ABI may influence the impact on families negatively, mainly due to a shift in routines, roles and responsibilities, worrying, flawed communication and increased stress (15,16,28). In 40–45% of the families this negative impact lasts longer than 12 months (16–18,28,30).

A Dutch hospital-based study among children and young adults with ABI (75%TBI) found considerable impact in families after pediatric ABI (19). In other (hospital based) studies, several factors were found to increase family impact, like higher age at ABI onset, premorbid problems of the child (e.g., behavioral problems), a non-traumatic brain injury (e.g., stroke or brain tumor) and severity of limitations (2,8,19,22,31). However, in these studies the variation in age groups, setting, the time point of assessments and questionnaires used to assess family impact, makes it difficult to compare results (15–21,30,32,33).

Knowledge gained on family impact in the group of patients with ABI during the later phase of recovery (at the start of rehabilitation treatment) is scarce. In the previous literature, only one rehabilitation-based study was found. This study found that parents experienced significant emotional distress and a high burden of care. However, this study only focussed on patients with TBI, it used a small sample size ($n = 10$) and was interview-based (no valid outcome measures were used) (25).

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The present study aims to further increase knowledge/awareness on family impact after acquired brain injury (ABI) in outpatient rehabilitation settings and investigate the associations between patient functioning and impact on families. Since referral to rehabilitation means there are persisting problems in functioning, activities, and participation we expect greater family impact in a rehabilitation cohort compared to a hospital cohort.

Results of this study may help to better tailor and utilize (family centered (34,35)) rehabilitation treatment to improve and personalize help and meet the wishes and needs for both the patient and his/her family.

Methods

Study design

This study was part of a larger multicenter, prospective cohort study on family impact, fatigue, participation and HRQoL in children and young adults with ABI, referred to a rehabilitation center for outpatient treatment. Inclusion started in 2015 in 10 rehabilitation centers in The Netherlands, i.e., Basalt, The Hague; De Hoogstraat, Utrecht; Heliomare, Wijk aan Zee; Vogellanden, Zwolle; Klimmendaal, Arnhem/Apeldoorn; Revalidatie Friesland, Beetsterzwaag; Libra, Tilburg; Revant, Breda; Reade, Amsterdam and Merem, Hilversum. This study was approved by the medical ethics committee of the Leiden University Medical Center (P15.165) which provided an exempt from full medical ethical review since data was collected as part of regular care (assessing possible problems and restrictions for discussion during rehabilitation intake). All local research committees of the participating centers approved the study. This study concerns parent-reported data gathered at admission, collected between September 2015 and December 2018. For presenting the results, the Strengthening the Reporting of Observational studies in Epidemiology (STROBE) guidelines were used (36).

Participants

For this study, all parents of patients who were diagnosed with ABI and referred by a general practitioner or medical specialist to 1 of the 10 participating rehabilitation centers, between 2015 and 2018 were eligible to participate. Participants were excluded if: parents and/or patients were unable/limited to write and/or understand the Dutch language and were therefore unable to complete the questionnaires.

Procedure and assessments

Prior to the first appointment, parents received a link to the digital questionnaires (www.Questback.nl), requesting parents to complete the questionnaires before the first appointment, after gaining permission of the patient (when over 16 years old).

Information from medical records

Information regarding the patient's demographics and injury-related characteristics was obtained from the medical records by the treating physician, and included: gender (male/female), date of injury, date of birth. Furthermore, the causes of ABI were noted as follows: TBI with, if known, severity levels (i.e., mild, moderate/severe based on the Glasgow coma scale (37)). Finally, nTBI, including cause (i.e., stroke/, (brain) tumors, meningitis/encephalitis, hypoxia/intoxication, and other). Since there is no valid instrument to assess the severity levels of nTBI due to the wide variety of causes and expected outcomes, severity levels for nTBI were not reported in this study. Time between onset (date of injury) and referral to rehabilitation was calculated and categorized in less than 6 months or more than 6 months after onset.

Outcome measures

Family impact

The Pediatric Quality of Life Inventory™ Family Impact Module (PedsQL™ FIM) was used to measure family impact (33). This 36-item questionnaire is considered to be a valid tool to assess impact on families with a child with a (chronic) disability and has been used in an ABI study previously (19). Items in the PedsQL™ FIM are answered on a 0–4 Likert-scale (0 = never to 4 = almost always) and thereafter linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0). The PedsQL™ FIM yields a total score (the sum of the 36 items, divided by the number of items answered) and 4 scale scores: a parental Quality of Life (QoL) summary score (20 items, divided over physical, emotional, social, and cognitive functioning subscales), a family functioning summary score (8 items, divided over "daily activities" and "family relationships" subscales), a worrying score (5 items), and a communication score (3 items). The scale scores range from 0 to 100 where lower scores indicate higher parent-reported family impact (22,25).

Health-related quality of life (HRQoL)

The Dutch version of the Pediatric Quality of Life Inventory™ Generic Core Scale 4.0 (PedsQL™) was used to measure HRQoL (31,32). This questionnaire is considered to be a valid tool to assess HRQoL and it has been validated for the ABI (both TBI and nTBI) population (38–40). The questionnaire consists of 23 items and yields a total score (the sum of the 23 items, divided by the number of items answered) and 4 scales; physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), school functioning (5 items) (39). Items in the PedsQL™ are answered on a 0–4 Likert-scale (0 = never to 4 = almost always) and thereafter linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0). Lower scores indicate diminished HRQoL (39).

Child and family functioning

To gather a broad perspective on family functioning we wanted to investigate if it is necessary to use added questions (from another validated outcome measure regarding child and family functioning) on the same construct as the used validated outcome measures (FIM and PedsQL™) to and strengthen findings. Poor to moderate correlation between added validated questions and an outcome measure could mean that added questions are needed to gather a broader perspective.

Therefore, we added seven additional questions regarding both the patients' and their family's potential disabilities in daily life from the validated Child and Family Functioning Scale – Dutch language version (CFFS-DLV) questionnaire (41,42). Parents were asked about (Question [Q] 1 and 2) the presence of premorbid problems (i.e., learning and/or behavioral and/or health-related, yes/no) and the presence of current problems (i.e., learning and/or behavioral and/or health-related, yes/no). They were also asked (Q3 and 4) to rate their child's current physical and mental/emotional health using a Likert-scale (1 = a lot of problems to 5 = no problems), their child's current quality of life (Q5: QoL, 1 = bad to 5 = excellent), and the QoL of the whole family (Q6:1 = bad to 5 = excellent).

For questions 3–6, answers were further divided into two categories: good health or QoL (Likert scores 3–5) or diminished health or QoL (Likert scores 1–2).

Finally, (Q7) parents were asked if they currently experienced a lack of support or guidance related to their child's ABI (yes/no).

Parent and family questions

Parents also completed questions regarding family-related characteristics; does the patient live in a single parent household (yes/no), are there siblings present (yes/no), does the patient live without his/her parents (yes/no), and the parents' educational levels (low [prevocational practical education or less]/intermediate [prevocational theoretical education and upper secondary vocational education]/high [secondary education, higher education and/or university level education]) (2,42).

For this study, only data from parents who completed all questionnaires and outcome measures (PedsQL™ FIM and the PedsQL™ GCS 4.0) was used.

Hypotheses related to family impact

Previous literature, merely pertaining to patients with ABI in hospital-based cohorts, studied patients' demographics, injury and family-related characteristics influencing family impact cause, severity, social economic status (based on educational level parents), and single-parent households (12,15–29). In our study, we examined whether these findings also hold for patients with an ABI in an outpatient rehabilitation cohort. Furthermore, we added four hypotheses to investigate other factors possibly influencing outcomes in our cohort:

- Parents of patients with a higher age will report higher family impact after ABI compared to parents of patients with a younger age (i.e., the higher the patient's age, the higher the parent-reported family impact), due to the transitional age phase and expected roles and responsibilities in society of older patients.
- Patient and family functioning factors (i.e., premorbid and current learning/behavioral/health problems; diminished quality of life of the patient; diminished quality of life of the whole family; diminished physical health of the patient; diminished mental/emotional health of the patient) are related to higher family impact
- Shorter time between onset of ABI and referral to rehabilitation is associated with higher family impact, since early referral is mostly due to more problems in daily life directly after ABI onset.
- Diminished pediatric health-related quality of life (HRQoL) is related to higher family impact

Statistical analysis

Descriptive statistics were used for all variables and outcomes. All continuous variables were expressed as medians with interquartile range (IQR) or means with standard deviation (SD), based on their distributions (Kolmogorov–Smirnoff test). To assess the correlation between the outcome measure (PedsQL™ GCS 4.0 for HRQoL) and the added (CFFS-DLV) questions, Pearson correlations were used (poor to fair agreement below 0.40: poor; between 0.41 and 0.60: moderate; between 0.61 and 0.80 good; above 0.81: excellent (43)).

To investigate which factors (independent variables) were related to family impact (PedsQL™ FIM total score and scale scores: dependent variables), univariate linear regression analyses were used. Thereafter (after checking for multicollinearity), multivariable linear regression analyses were used to further assess risk-factors regarding family impact.

Univariate linear regression analyses

The following factors were entered independently, one at the time: Demographic/injury/family related: cause of ABI (TBI/nTBI), severity levels of TBI (mild or moderate/severe), timing of referral to rehabilitation after onset of ABI (<6 months/>6 months), educational levels parent (low/medium-high), single-parent household (yes/no), living with parents (yes/no), the absence of siblings (yes/no), age (continuous),

patient/family functioning: pre-morbid problems (learning and/or behavioral and/or health-related problems, yes/no), more than 2 pre-morbid problems (yes/no), having more than 2 current learning and/or behavioral and/or health-related problems (yes/no), quality of life of the whole family (diminished/good), quality of life of the patient (diminished/good), physical health (diminished/good), mental/emotional health (diminished/good), and parents experiencing a lack of support regarding their child's ABI (yes/no).

Finally, the PedsQL™ GCS 4.0 for HRQoL (independent variable) was entered as continuous variable.

Multivariable linear regression analysis

Multivariable linear regression analysis was performed with only those variables with *p*-values <0.20 in the univariate analysis.

Outcomes (for both univariate and multivariable regression) were expressed as β-estimates with 95% confidence intervals (95%CI) and *p*-values (level of significance $p < .05$).

All data were analyzed using SPSS software, version 22.0 (IBM SPSS statistics for Windows, Armonk, NY: IBM Corp).

Results

Patients' demographic/injury/family-related characteristics

Families of 246 patients with ABI participated in this study (Figure 1). The patients' median age was 14 years (IQR 11–16), with 127 (52%) being female. There were 181 patients (74%) with TBI, of whom 143 had a mild injury (78%). Of the 65 patients with nTBI, 25 (40%) had a brain tumor. One-hundred-and-forty-seven (60%) patients were referred to a rehabilitation center less than 6 months after onset of ABI. The largest percentage of patients lived with their parent(s) (97%), with 17% (42) living in a single-parent household. Twenty-eight of the parents (11%) had a low educational level.

Patient/family functioning (CFFS-DLV)

Seventy-one (29%) patients had premorbid learning/behavioral/health-related problems, 200 patients (81%) currently have more than 2 learning/behavioral/health-related problems. One-hundred-seventy-seven parents (72%) reported both diminished mental/emotional and physical health of their child, and 64 (26%) reported diminished quality of life of the whole family. Finally, 122 parents (50%) currently experience a lack of help and guidance related to their child's injury.

Family impact scores and parent reported HRQoL

In Table 3 the results regarding the parent-reported family impact and patient HRQoL are presented. The total median PedsQL™ FIM score was 71.9 (IQR 60–85). The lowest scores (i.e., more problems) were found on the worrying scale (median 65.0, IQR 50– 80). The highest scores (i.e., fewer problems) were found on the communication scale (median 83.3, IQR 58–100). For the parent-reported patients' HRQoL, the total median score was 60.9 (48–75). The lowest scores were found on the school/work functioning scale (median 50.0, IQR 30–60) and the highest on the social functioning scale (median 75.0, IQR 60–95).Table 1 Table 2

Correlations between different measures of parent reported HRQoL

A poor–moderate correlation (0.38–0.51) was found between the The PedsQL™ GCS 4.0 (total score and both mental/emotional and physical scale scores) and the additional questions from the CFFS-DLV (parent-reported questions about their child's quality of life and mental/emotional and physical problems).

Demographic/illness/family factors related to family impact

In the univariate regression analyses (Tables 4a and 4b) the cause of ABI (nTBI), a single-parent household and lower parental educational levels were significantly associated with higher family impact (lower PedsQL™ FIM scores, $p < .05$). Furthermore, the time between referral to rehabilitation and the onset of ABI more than 6 months (>6 months) was significantly associated with higher family impact (lower FIM scores).

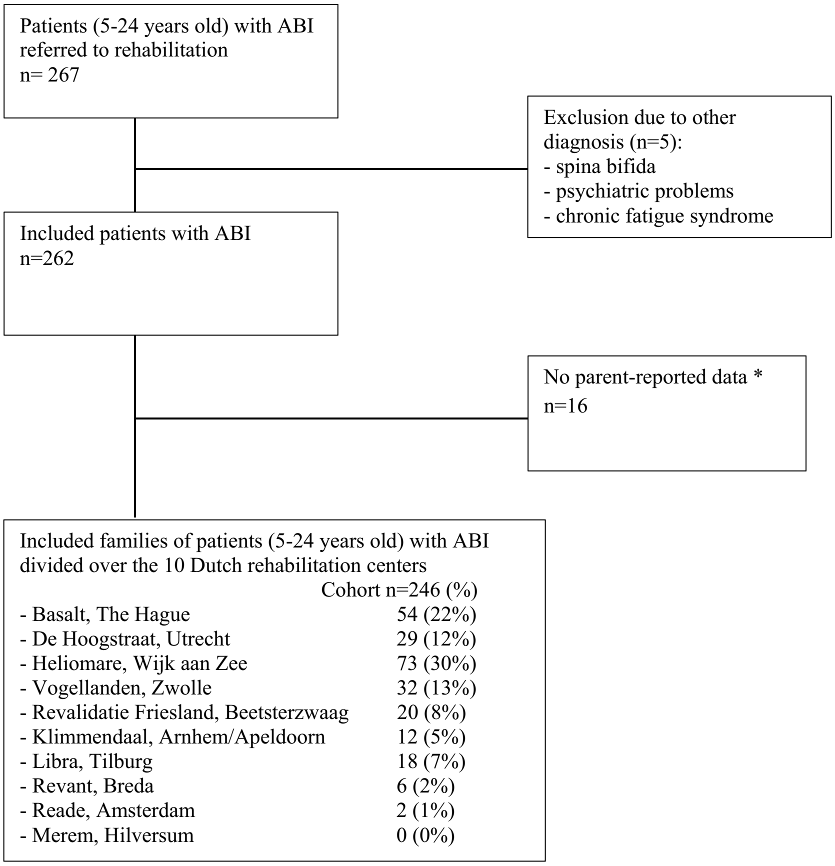

Figure 1. Flow diagram of the 246 patients and their families eligible to participate in this study. *In the Netherlands, children ≥16 years old have the legal right to exclude their parents from healthcare decision making.

Table 1. Patients' demographic/injury/family characteristics of 246 children and young adults with acquired brain injury (ABI) referred for outpatient rehabilitation treatment.

Demographic characteristics	Cohort (n=246)
Sex: female; number (%)	127 (52%)
Age (years) at admission; median (IQR)	14 (11-16)
- 5-11 years old; number (%)	68 (28%)
- 12-17 years old; number (%)	161 (65%)
- 18-24 years old; number (%)	17 (7%)
Time (months) between ABI onset and referral to rehabilitation; median (range)	147 (60%)
- Less than (<) 6 months; number (%)	147 (60%)
Injury characteristics	
Traumatic brain injury (TBI); number (%)	181 (74%)
Severity levels TBI (based on GCS*); number (%)	
- Mild	143 (78%)
- Moderate-severe	18 (10%)
- Unknown:	20 (12%)
Non-traumatic brain injury (nTBI); number (%)	65 (26%)
Causes nTBI; number (%)	
- Brain tumor	25 (40%)
- Stroke	15 (24%)
- Hypoxia/intoxication	2 (3%)
- Encephalitis/meningitis	11 (18%)
- Other	9 (15%)
Family characteristics	
Living with their parents; number (%)	238 (97%)
Living in a single-parent household; number (%)	42 (17%)
Having (a) sibling(s); number (%)	214 (87%)
Educational level parent**; number (%)	
- Low	28 (11%)
- Intermediate	108 (44%)
- High	110 (45%)

* Glasgow Coma Scale (1)

** Educational level parent: low; prevocational practical education or less, intermediate; prevocational theoretical education and upper secondary vocational education, high; secondary education, higher education and/or university level education.

Patient/family functioning factors related to family impact

In the univariate regression analyses (Tables 4a and 4b), currently having either mental/emotional or physical, or both mental/emotional and physical health problems, the presence of pre-morbid problems, and parent-reported diminished QoL of the whole family were significantly associated with higher family impact (lower PedsQL™ FIM scores, $p < .05$).

Demographic/illness/family and patient/family functioning related factors in the multivariable regression model

After checking for multicollinearity (there were none) all the variables with $p < .20$ (demographic/illness/family and Patient/family functioning related factors) from the univariate analyses were used in the multivariable regression analyses (marked as Bold values in Tables 4a and 4b). NTBI, parent-reported patients' diminished mental/emotional health, and diminished quality of life for the whole family remained significantly associated with higher family impact (lower PedsQL™ FIM scores).

Family impact related to HRQoL

In the univariate analyses diminished parent-reported HRQoL was significantly associated with higher family impact on the total score and almost all scale-scores ($p < .05$, except for physical functioning [$p < .20$]). All outcomes can be found in Table 4c.

Table 2. Child and family functioning in 246 families of children and young adults, aged 5–24 years old, with acquired brain injury (ABI) referred for outpatient rehabilitation treatment.

*Child and family functioning **	Cohort (n=246)
Patients with Pre-morbid problems; number (%)	71 (29%)
- Learning-related	37 (15%)
- Behaviour-related	28 (11%)
- Health-related	33 (13%)
More than 2 premorbid problems reported	20 (8%)
Patients with current problems; number (%)	230 (94%)
- Learning-related	207 (84%)
- Behaviour-related	160 (65%)
- Health-related	179 (73%)
More than 2 current problems reported	200 (81%)
Child functioning; number (%)	
- Diminished physical health	111 (45%)
- Diminished mental/emotional health	158 (64%)
- Both diminished mental/emotional and physical health	177 (72%)
- Diminished quality of life	119 (48%)
Family functioning; number (%)	
- Diminished quality of life of the whole family	64 (26%)
- Experiencing a lack of help and/or guidance related to the child's ABI	122 (50%)

*Parent-reported questions, from the Dutch version of the Child and Family Functioning Scale (CFFS-DLV) (2, 3)

Discussion

In this cross-sectional study including 246 families of children and young adults (aged 5–24 years old) with ABI, referred to rehabilitation for outpatient treatment, we found a substantial parent reported family impact (median; 71.9 IRQ;60–85). Associated factors related to higher family impact were having nTBI, referral to rehabilitation > 6 months after onset, diminished mental/emotional health, diminished HRQoL of the whole family, and the presence of premorbid learning/behavioral/health-related problems. Family impact was specifically greater when a patient had nTBI, when parents reported that mental/emotional health and HRQoL of the whole family was diminished. Finally, a diminished parent-reported health-related quality of life (HRQoL) was significantly associated with higher family impact on all domains of the PedsQL™FIM.

Family impact

Until now, knowledge regarding family impact of families with patients (children/young adults) with ABI who were referred for rehabilitation treatment remained scarce. Only one study (with a small sample size of only 10 patients with TBI, and no outcome measures) reported that pediatric TBI affects the whole family and that parents experienced emotional distress and worrying as was in line with our study (25). It is generally acknowledged that five stages are recognizable in every emotional response to personal trauma and change: denial – anger – bargaining – sadness/depression – acceptance (Kübler-Ross model). However, this is not as a linear process that everyone goes through step by step, nor will everyone go through all steps. Several factors determine the impact of pediatric ABI on a family of which time is one. We found in our cross-sectional study that a longer time since onset was related to higher family

Table 3. Family Impact and health related quality of life of 246 children and young adults, aged 5–24 years old with acquired brain injury (ABI) referred for outpatient rehabilitation treatment.

			Median	Interquartile range (IQR)
PedsQL™ Family impact module (FIM)	Total score*		71.9	(60-85)
	Scale scores*	Worrying	65.0	(50-80)
		Communication	83.3	(58-100)
		Family functioning summary scale	75.0	(59-94)
		• Daily activities	75.0	(50-100)
		• Family relations	75.0	(60-95)
		Parental health-related quality of life	72.5	(60-86)
		• Physical Functioning	66.7	(50-83)
		• Emotional Functioning	70.0	(55-90)
		• Social functioning	81.3	(63-100)
		• Cognitive functioning	85.0	(60-100)
PedsQL™ Generic	Total score*		60.9	(48-75)
Core Set 4.0*	Scale scores*	Physical and social health summary score	68.6	(47-82)
		• Physical Functioning	60.0	(47-17)
		• Emotional Functioning	60.0	(40-75)
		• Social functioning	75.0	(60-95)
		• School/work functioning	50.0	(30-60)

*For all outcomes 0 to 100, lower scores indicate higher parent-reported family impact (PedsQL™ FIM) and poorer health-related quality of life (PedsQL™ Generic Core set)

impact. How families move through the different phases of emotional response, how family impact truly changes over time and what the possible influence of cognitive and personality changes of the patient have on this needs to be investigated in future longitudinal studies. When compared to a Dutch hospital-based ABI cohort (in children and young adults), the family impact scores in our study are consistently lower, meaning more impact (19): median total PedsQL™ FIM score; 71.9 (our study) versus mean; 82.9 (hospital-based cohort). For the scale scores regarding our cohort versus hospital-based cohort: parental HRQoL; 72.5 versus 85.4, family functioning; 75.0 versus 81.7, communication; 83.3 versus 100, worrying; 65.0 versus 90.0 (19). These results were in line with our expectations that parents in our rehabilitation-based cohort report higher family impact than those in other (hospital-based) cohorts. This could be due to the persisting problems in patients' functioning, activities, and participation, at time of referral in our cohort for which they were referred to a rehabilitation center.

Compared to an American cohort with parents of children with healthy children and children with a chronic condition we found similar family impact (mean total PedsQL™ FIM score: 80.4 [SD 16.1] for healthy children, and 70.8 [SD 14.5] for children with a chronic condition (21), respectively, while 2 hospital-based studies in patients with nTBI (in a brain tumor and stroke population) found higher family impact than we found (mean total PedsQL™ FIM scores 58.8 [SD 16.9] and 53.4 [SD 17.4], respectively) (18,22).

Nonetheless, due to small sample sizes, differences in health care systems (in the Netherlands and in the USA), and differences between subjects and causes (TBI, nTBI and/or both), these similarities have to be interpreted with caution.

Factors related to family impact, outcomes in hospital-based cohorts compared to a rehabilitation-based cohort

Previously found factors influencing family impact in hospital-based cohorts (i.e., cause, severity, educational levels of parents, and single parent households) were tested in our rehabilitation

Table 4a. Demographic/injury/family factors associated with family impact in a cohort of 246 children and young adults, aged 5–24 years old with acquired brain injury (ABI) referred for outpatient rehabilitation treatment.

PedsQL™ Family Impact Module	*Total score* β (95% CI)	*Worrying* β (95% CI)	*Communication* β (95% CI)	*Family functioning summary scale)* β (95% CI)	*Parental Health related Quality of Life (HRQoL)* β (95% CI)
Demographic related factors					
Age at onset of ABI	-0.2 (-0.8, 0.3)	0.1 (-0.6, 0.7)	0.3 (-0.5, 1.0)	-0.2 (-0.9, 0.5)	-0.4 (-1.0, 0.2)
Referral to rehabilitation < 6 months	5.5 (1.3, 9.6) **	6.4 (1.5, 11.3) **	12.4 (6.7, 18.0) *** **7.4 (12.9, 1.9)**	4.2 (-0.8, 9.2) *	4.7 (-0.1, 9.3) *
Injury related factors					
nTBI	-7.9 (-3.4, -12.5) **	-10.4 (-5.0, -15.8) ***	-10.9 (-4.6, -17.4) **	-8.2 (-2.6, -13.7) **	-6.8 (-1.8, -11.8) **
Moderate/severe TBI	**-4.8 (-8.9, -0.7)** 3.6 (-11.5, -4.3)	**-8.1 (-13.4, -2.8)** -0.01 (9.4, -9.4)	-5.4 (5.5, -16.3)	-8.0 (-17.3, 1.3) *	-4.1 (-12.9, 4.8)
Family related factors					
Single parent household	-7.6 (-2.2, -12.9) **	-5.9 (0.5, -12.4) *	- 7.5 (0.1, -15.1) *	-8.9 (-2.4, -15.4) **	-7.4 (-1.5, -13.3) **
Lowest educational level parent	-20.7 (-39.4, -2.0) **	-23.2 (-45.3, -0.9) **	-28.4 (-54.4, -2.5) **	-16.2 (-38.7, 6.4) *	-20.7 (-41.2, -0.3) **
Absence of siblings	-5.7 (11.8, -0.4) *	-2.4 (-9.6, 4.9)	-13.3 (-21.7, 4.8) ** **-8.4 (-0.7, -15.9)**	-4.9 (-12.2, 2.4) *	-5.6 (-12.3, 1.0) *

Linear regression analyses, data presented as β-estimates, 95% confidence interval (95%CI). PedsQL™ Family Impact Module (FIM, 0-100, with lower scores indicating more parent-reported family impact.): dependent variables and possible factors influencing family impact: independent variables.

* p<0.20; ** p<0.05, *** p<0.001 Significant factors, and included in the multivariable regression analyses (done with only factors entered which were significantly associated (p<0.2) with FIM scales according to the univariate analysis). Multivariable regression: **Bold scores**: p< 0.05 significant variable in the multivariable regression analyses. # health/learning/behavioural problems

Table 4b. Child and family functioning factors associated with family impact in a cohort of 246 children and young adults, aged 5–24 years old with acquired brain injury (ABI) referred for outpatient rehabilitation treatment.

PedsQL™ Family Impact Module	*Total score* β (95%CI)	*Worrying* β (95%CI)	*Communication* β (95%CI)	*Family functioning summary scale (FFSS)* β (95%CI)	*Parental Health related Quality of Life (HRQoL)* β (95%CI)
Related child functioning factors					
Premorbid problems #	-6.2 (-1.7, -10.7) **	-6.9 (-1.7, -12.3) **	-6.7 (-0.4, -13.0) **	-7.0 (-1.7, -12.4) **	-5.6 (-0.7, -10.5) **
More than 2 premorbid problems	-11.6 (-4.2, -19.0) ***	-14.8 (-6.1, -23.6) **	-12.9 (-2.5, -23.3) **	**-7.9 (-14.8, -1.1)**	-11.1 (-2.9, -19.2) **
				-6.2 (-16.3, 3.8) *	
More than 2 current problems #	-6.3 (-12.6, 0.01)	-8.2 (-19, -14.3) **	-5.8 (1.5, -13.2) *	-1.5 (4.9, -7.8)	-4.7 (1.0, -10.5) *
Diminished mental/emotional health	-13.9 (-10.0, -17.9) ***	-13.4 (-8.6, -18.2) ***	-16.0 (-10.4, -21.7) ***	-13.8 (-8.9, -18.6) ***	-13.9 (-9.6, -18.3) ***
	-10.6 (-17.5, -3.6)		**-11.2 (-21.4, -1.1)**		**-13.5 (-21.5, -5.6)**
Diminished physical health	-8.0 (-4.0, -12.0) ***	-9.9 (-5.2, -14.7) ***	-7.8 (-2.0, -13.5) **	-7.9 (-3.1, -12.8) **	-7.6 (-3.2, -12.0) **
Diminished mental/emotional and physical health	-13.3 (-9.0, -17.5) ***	-14.8 (9.7, 19.9) ***	-14.8 (-8.6, -21.0) ***	-14.4 (-9.2, -19.6) ***	-12.2 (-7.4, -16.9) ***
Related family functioning factor	-17.9 (-13.8, -22.1) ***	-13.4 (-8.1, -18.7) ***	-20.5 (-14.5, -26.6) ***	-20.9 (-15.9, -25.9) ***	-17.6 (-12.9, -22.2) ***
Diminished QoL of the whole family	**-12.9 (-17.2, -8.5)**	**-6.4 (-11.9, -0.7)**	**-12.6 (-19.1, -6.2)**	**-17.9 (-24.6, -10.9)**	**-12.8 (-17.8, -7.7)**

Linear regression analyses, data presented as β-estimates, 95% confidence interval (95%CI). PedsQL™ Family Impact Module (FIM, 0-100, with lower scores indicating more parent-reported family impact.): dependent variables and possible factors influencing family impact: independent variables.

* p<0.20; ** p<0.05, *** p<0.001 Significant factors, and included in the multivariable regression analyses (done with only factors entered which were significantly associated (p<0.2) with FIM scales according to the univariate analysis). Multivariable regression: **Bold scores**: p< 0.05 significant variable in the multivariable regression analyses. # health/learning/behavioural problems

Table 4c. Patients' health related quality of life associated with family impact (FIM) in a cohort of 246 children and young adults, aged 5–24 years old with acquired brain injury (ABI) referred for outpatient rehabilitation treatment.

PedsQL™ Family Impact Module	*Total score* β (95%CI)	*Worrying* β (95%CI)	*Communication* β (95%CI)	*Family functioning summary scale (FFSS)* β (95%CI)	*Parental Health related Quality of Life (HRQoL)* β (95%CI)
PedsQL™ generic core-4.0 (HRQoL)					
Total score	0.6 (0.5, 0.7) ***	0.6 (0.4, 0.7) ***	0.4 (0.3, 0.6) ***	0.6 (0.4, 0.7) ***	0.6 (0.5, 0.7) ***
Physical functioning	0.2 (0.2, 0.3) ***	0.3 (0.1, 0.4) ***	0.1 (-0.04, 0.2) *	0.3 (0.2, 0.4) ***	0.3 (0.2, 0.3) ***
Emotional functioning	0.5 (0.4, 0.5) ***	0.5 (0.4, 0.6) ***	0.4 (0.3, 0.5) ***	0.4 (0.3, 0.5) ***	0.5 (0.4, 0.5) ***
Social functioning	0.4 (0.3, 0.5) ***	0.4 (0.3, 0.5) ***	0.5 (0.3, 0.6) ***	0.4 (0.3, 0.5) ***	0.4 (0.2, 0.4) ***
School/work functioning	0.3 (0.2, 0.3) ***	0.2 (0.1, 0.3) ***	0.2 (0.04, 0.3) **	0.2 (0.1, 0.3) ***	0.3 (0.2, 0.4) ***

Univariate regression analyses, data presented as β-estimates, 95% confidence interval (95%CI). PedsQL™ Family Impact Module (FIM, 0-100, with lower scores indicating more parent-reported family impact.): dependent variables and possible factors influencing family impact: independent variables.

* p<0.20; ** p<0.05, *** p<0.001 Significant factors

cohort with pediatric patients with ABI as well and we found generally the same influence (12,15–29).

This study confirmed that having nTBI results in higher family impact than having TBI. This can possibly be explained by the wide variety of causes, and outcomes of nTBI. These patients with nTBI probably faced a more complex and longer hospital treatment and uncertain prognosis than the patients with TBI in our cohort (with similar severity) (18,22).

Lower educational levels of parents and patients living in single-parent households also resulted in significantly higher family impact, which confirmed both our expectations and findings in previous studies (23,24,26).

A systematic review containing hospital-based cohorts only and patients with moderate-severe (based on Glasgow coma scale) TBI showed that higher injury severity levels in patients with moderate-severe TBI resulted in higher family impact (15). The differences in outcome between our study and previous studies can be partially explained by difference in type of patient included, and our relatively small sample size of the moderate/severe group (*n* = 18) compared to the mild group (*n* = 143).

In future studies, the family impact should be monitored over time as the impact may persist over time, also for the group of patients with mild TBI.

Furthermore, almost half of the parents in our study were experiencing a lack of help/information concerning their child's ABI. This could result in worrying about the child's future or frustration toward health care professionals. It is thus important that patients and parents receive the appropriate information in a timely manner as this could decrease the family impact.

Age related to family impact

Regarding age, this study found that age is not a significant factor related to family impact. These results differ from previous studies, where age was presented as an associated factor (15,19). In the whole age range in this cohort there is a substantial impact on the family after a child suffered from ABI, no matter the age.

Patient and family functioning factors related to family impact (CFFS-DLV)

This study also supports the use of specific questions regarding child/family functioning (CFFS-DLV questions) (41,42). All additional questions on functioning had a poor-moderate correlation with the PedsQL™ GCS 4.0 (on the total score and the emotional functioning scale) (39). A poor correlation suggests that questions, additional to standardized outcome measures are probably needed to create a broader perspective on QoL and child/family functioning. Next to the standardized outcome measures, we used the above described additional questions and as we assumed (more than 2) premorbid health and/or learning and/or behavioral related problems was significantly related to higher family impact in our study. This was also reported in previous studies (19,31). It could be explained by the fact that premorbid existing problems already caused family impact before the onset of the brain injury. Patients who were having (more than 2) current health- and/or learning and/or behavioral related problems (*n* = 230, 94%) also related to higher family impact, confirming that almost all patients referred for rehabilitation treatment perceive daily life problems at that point. Diminished mental/emotional or physical problems (or both) in daily life also related to significantly higher family impact, which also confirmed our expectations. Finally, parents reporting diminished quality of life of the whole family was significantly related to higher family impact.

These findings underline the importance of involving the families in the rehabilitation treatment programs. This could for example be done by providing tailor-made psychoeducation, follow-up and support for parents, brothers and sisters and/or by including families in home-based therapy activities. To what extent this could contribute to reducing family impact must be further examined (34,35).

Time between onset and referral related to family impact

Referral to (one of the 10 participating) rehabilitation centers less than 6 months after the onset of ABI was significantly associated with less family impact (i.e., higher scores) on the PedsQL™ FIM total score, worrying scale and communication scale. An explanation could be that the earlier the referral, the sooner parents felt that they were being helped and heard by healthcare professionals, which could positively influence family impact contrary to late referral (>6 months). Furthermore, a large portion of recovery after ABI occurs in the first months after onset, when parents tend to worry less (2,10). Despite the late referral to rehabilitation (>6 months), 54 families (44.3%) of patients that were referred to the rehabilitation after 6 months still experienced a lack of help/

information regarding their child's ABI diagnosis, worry more about their child's future (mean FIM worrying scale: for <6 months; 67.0 SD; 18.3, for >6 months; 60.0 SD; 21.0), or see less reduction of symptoms (due to natural adaptation/recovery of the brain) than they expected. In hospital-based cohorts of pediatric patients with ABI, it is known that the long-term outcome is related to family and environmental factors (including family cohesion, resources, social support, socioeconomic status) and persisting parental stress (5,16,28). Families in rehabilitation-based cohorts are presumably in another stage of grief at the time of referral to rehabilitation, and parental stress may still be present. Helping parents cope with this stress may influence outcomes in terms of family impact. However, we did not study this, and future research should focus on longitudinal outcomes of family impact and how this relates to parental stress in rehabilitation-based cohorts. We hypothesized that a longer time between the onset of the ABI and referral to rehabilitation would result in lower family impact. However, the opposite was true.

Findings in our study underline the importance of assessing and monitoring family impact on the long-term and timely referral to rehabilitation programs for children and young adults so that treatment can begin before family impact increases.

HRQoL related to family impact

This study confirmed the assumption that diminished HRQoL was significantly associated with higher family impact. We found one study (in patients with ADHD) with similar results (31). Aiming to positively influence health-related quality of life during (family centered) rehabilitation treatment could possibly decrease family impact (34,35).

PedsQL™ FIM

This study used the PedsQL™ FIM to measure parent-reported family impact. Neither cutoff scores nor minimal clinically important differences (MCID) are available for the FIM. The PedsQL™ FIM has been proven to be a valid and reliable tool to measure family impact in families of patients with a (chronic) disease or impairment (19,21,33). Furthermore, it has been used previously in patients diagnosed with ABI and it has been translated and validated into the Dutch language (19). Therefore, we recommend using the PedsQL™FIM in future ABI studies to further investigate the psychometric properties (including cutoff scores and MCIDs) in this patient population.

Study limitations

This study had a number of limitations. We collected only parent-reported data. It needs to be considered whether only the parents' perspective on family impact is enough to measure family impact (27), i.e., the siblings or professional perspective regarding family impact were not taken into account. Future research should consider including other perspectives to investigate family impact in children and young adults with ABI. Furthermore, the results of questionnaires could be biased by limitations of language comprehension, motivation, or parental stress and mood at the moment of completing the questionnaire.

For 20 patients with TBI (12%), although registered by healthcare professionals as TBI, no Glasgow Coma Scale (GCS) score to classify the severity was available.

Finally, our population was rather diverse in terms of cause and severity of ABI which may have influenced outcomes as well.

Conclusions

Acquired brain injury in children and young adults results in a substantial impact on families. The most significant risk factors related to higher family impact were: time of referral to rehabilitation more than 6 months after the onset of ABI, presence of premorbid (health/learning/behavioral) problems, diminished mental/emotional health of the patient. Diminished health-related quality of life of the patient was also significantly associated with higher family impact. The patient's age was found to be a non-significant factor related to family impact. This study underlines the importance of measuring and monitoring family impact in the outpatient rehabilitation setting. Future longitudinal follow-up studies are needed to further decrease the knowledge gap on family impact in rehabilitation after pediatric ABI.

Acknowledgments

We would like to thank all the patients and their families participating in this study. Furthermore, we would like to thank dr. Stefanie Rosema, dr. Ilse DeKoeyer-Laros, dr. Merel Jansen, Gerard Volker and Åsa Mennema for contributing to this study. Finally, we would like to thank all clinical healthcare professionals and medical secretaries from the participating rehabilitation centers: Basalt the Hague, De Hoogstraat Utrecht, Heliomare Wijk aan Zee, Vogellanden Zwolle, Klimmendaal Arnhem/Apeldoorn, Revalidatie Friesland Beesterswaag, Libra Tilburg, Revant Breda, Reade Amsterdam, and Merem Hilversum.

Funding

This work was supported by the Hersenstichting [PZ2015.01.10]; Revalidatiefonds [R2014.124].

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Declaration of Interest

The authors of this study have no conflicts of interest to declare. Financial support was obtained from the "Hersenstichting" (Grant PZ2015.01.10) and "Revalidatiefonds" (Grant R2014.124).

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Appendix

Correlations between the PedsQL™ GCS 4.0 and the parent-reported questions as part of the CFFS-DLV in 246 families of children and young adults, aged 5–24 years old with acquired brain injury (ABI) referred for outpatient rehabilitation treatment.

Assessed correlations		
PedsQL™ GCS 4.0	CFFS-DLV	Correlation#
PedsQL™ GCS 4.0 Total Score[1]	Parent-reported Quality of life	0.44 (moderate)
PedsQL™ GCS 4.0 Physical functioning scale score[2]	Parent-reported physical health problems	0.38 (poor)
PedsQL™ GCS 4.0 Emotional functioning scale score[3]	Parent-reported mental/emotional health problems	0.51 (moderate)

Pearson Correlation: poor to fair agreement below 0.40: poor; between 0.41 and 0.60: moderate; between 0.61 and 0.80 good; above 0.81: excellent (4). 1: Correlations between parent reported quality of life and PedsQL™ GCS 4.0 for HRQoL. 2: Correlations between parent-reported physical health and PedsQL™ GCS 4.0 Physical functioning scale score. 3: Correlations between parent-reported mental/emotional health and PedsQL™ GCS 4.0 Emotional functioning scale score