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To cite this article: Frederike van Markus-Doornbosch, Menno van der Holst, Arend J. de Kloet, Thea P. M. Vliet Vlieland & Jorit J. L. Meesters (2019): Fatigue, Participation and Quality of Life in Adolescents and Young Adults with Acquired Brain Injury in an Outpatient Rehabilitation Cohort, Developmental Neurorehabilitation, DOI: [10.1080/17518423.2019.1692948](https://doi.org/10.1080/17518423.2019.1692948)

To link to this article: <https://doi.org/10.1080/17518423.2019.1692948>



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Published online: 20 Nov 2019.



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Fatigue, Participation and Quality of Life in Adolescents and Young Adults with Acquired Brain Injury in an Outpatient Rehabilitation Cohort

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ABSTRACT

Purpose: To study the association between fatigue and participation and QoL after acquired brain injury (ABI) in adolescents and young adults (AYAs).

Materials & Methods: Cross-sectional study with AYAs aged 14–25 years, diagnosed with ABI. The PedsQL™ Multidimensional Fatigue Scale, Child & Adolescent Scale of Participation, and PedsQL™4.0 Generic Core Scales were administered.

Results: Sixty-four AYAs participated in the study, 47 with traumatic brain injury (TBI). Median age at admission was 17.6 yrs, 0.8 yrs since injury. High levels of fatigue (median 44.4 (IQR 34.7, 59.7)), limited participation (median 82.5 (IQR 68.8, 92.3)), and diminished QoL (median 63.0 (IQR 47.8, 78.3)) were reported. More fatigue was significantly associated with more participation restrictions (β 0.64, 95%CI 0.44, 0.85) and diminished QoL (β 0.87, 95%CI 0.72, 1.02).

Conclusions: AYAs with ABI reported high levels of fatigue, limited participation and diminished quality of life with a significant association between fatigue and both participation and QoL. Targeting fatigue in rehabilitation treatment could potentially improve participation and QoL.

ARTICLE HISTORY

Received September 29, 2019

Revised November 04, 2019

Accepted November 10, 2019

KEYWORDS

Fatigue; participation; quality of life; acquired brain injury; adolescents and young adults

Introduction

Acquired brain injury (ABI) refers to any damage to the brain that occurs after birth, due to a traumatic (TBI) or non-traumatic (NTBI) cause.¹ Like in children and older patients, the sequelae of ABI in adolescents and young adults (AYAs) may have a considerable negative impact on functioning, participation and health-related quality of life (HRQoL) of AYAs during their development to adulthood.^{1–7}

Fatigue is one of the most common physical symptoms occurring after pediatric ABI, irrespective of the severity of TBI^{8,9} or NTBI (brain tumors¹⁰; stroke¹¹), and may persist long after injury.¹² Although fatigue is difficult to define due to complex interactions between biological, behavioral and psychosocial processes, it can be seen as a multidimensional symptom with physical, mental and emotional components.¹³

Fatigue was found to be associated with poorer psychosocial, physical, and (school) participation in childhood stroke¹⁴ and brain tumors,¹⁰ as well as other childhood conditions (multiple sclerosis¹⁵; cerebral palsy¹⁶; leukemia^{17,18}; chronic pain¹⁹) as well as the adult stroke population.^{20,21} Furthermore, it was found to be related to diminished HRQoL, but this was studied only in adults with TBI.²²

Participation is defined as involvement in life situations²³ and is vital for the development of physical, psychological and social-emotional skills. These skills, specifically in the age group of AYAs, subsequently determine future healthy living and participation.²⁴ However, in studies on determinants of participation of youth (up to 18 years old) after ABI, fatigue was not taken into account. These studies did find that the

severity of ABI, motor, cognitive, behavior and sensory functioning was determinants of participation restrictions.^{25–27} The possible mutual relationship between fatigue and participation remains unknown in AYAs with ABI.

Health-related quality of life (HRQoL) could also possibly be affected by fatigue. HRQoL is a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning.²⁸ Pediatric and adult patients with TBI may experience decreased HRQoL during and after the first year of TBI,^{3,29,30} with mental HRQoL more affected than physical HRQoL.³¹ Reduced HRQoL has also been found in children with a stroke⁶ and brain tumors.³² The relationship between fatigue and HRQoL, however, has not been studied yet in AYAs in the ABI population.

Knowledge on fatigue in AYAs with ABI is scarce and it is not known whether targeting fatigue in rehabilitation treatment may improve outcomes on participation and HRQoL. To be able to determine this, the first step is to investigate the relation between fatigue, participation and HRQoL. The aim of the present study was therefore to explore multidimensional fatigue symptoms, participation and HRQoL in AYAs with ABI, and to study the association of fatigue and both participation and HRQoL.

Method

Study Design

This study is part of a larger multi-center longitudinal prospective cohort study on ABI in children and young adolescents (4 to 25

years old) referred for rehabilitation treatment to one of the eight participating rehabilitation centers in The Netherlands. This longitudinal study was started, integrated in regular care, in June 2014 and is still ongoing. Data were collected at the time of admission (T0), as part of the routine assessment, and patients and their parents were asked to complete the same questionnaires 1 year (T1) and 2 years (T2) thereafter. For the present study only admission data collected at one center, Basalt Rehabilitation in The Hague, were used.

This study was approved by the Medical Ethics Committee of the Leiden University Medical Center (P15.165). The Committee approved the study and provided an exempt from full medical ethical review since data were 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.

Patients

Patients were included in the current study if they were referred to the AYA (14–25 years) outpatient clinic (Basalt Rehabilitation in The Hague) with a diagnosis of ABI.

All eligible patients and their parents were asked to fill in a set of questionnaires prior to their first appointment at the outpatient clinic. Patients were included in this study if either the patient or the parent or both completed the questionnaires.

General and Sociodemographic Characteristics

Patient and injury characteristics were obtained from the patients' medical record by the primary investigator (FvM-D) and included the date of birth, sex, date of injury and description of ABI (categorized in NTBI (stroke, asphyxia, brain tumor, meningitis or encephalitis, hypoxia-ischemia) or TBI). The severity of TBI was determined by means of the Glasgow Coma Scale (GCS) at hospital admission (mild when GCS 13–15, moderate when 9–12 and severe when ≤ 8).³³ Age at admission was calculated using the date of the first appointment at the outpatient clinic.

Assessments

Assessments included a survey comprising three validated Patient-Reported Outcome Measures (PROMs), which had to be completed by patients and parents (electronically www.QuestBack.nl, or on paper). The questionnaires were administered as part of the regular care. Patients were sent an e-mail link to the patient version of the questionnaires and were also requested to forward a link to their parents/caregivers to fill out the parent version of the questionnaires. Those not responding to the electronic questionnaire were given the opportunity to complete the questionnaire on paper prior to the first appointment at the outpatient clinic. If a patient came without parents to the clinic, parents were asked to complete the questionnaires on paper or electronically within 1 week after the first appointment. For patients 16 years and older, this was only done after permission of the patient.

Fatigue

The PedsQL™ Multidimensional Fatigue Scale (MFS),³⁴ Dutch language version,^{35,36} was used to measure fatigue. This 18-item questionnaire yields a Total Scale Score, and three subscale scores: general fatigue (six items), sleep/rest fatigue (six items), and cognitive fatigue (six items). The items are reversely scored using a five-point Likert scale. Subsequently, scores are linearly transformed to a 0–100 scale (0 (never) = 100, 1 = 75, 2 = 50, 3 = 25, 4 (always) = 0), with lower scores indicating more fatigue. Scale scores are computed as the sum of the items divided by the number of items answered (this accounts for missing data). If more than 50% of the items in a subscale were missing, the subscale score is not computed. Normative data have been collected in several cohorts of adolescents³⁵ and young adults^{34,36} making a comparison between healthy and chronically ill individuals. The average score of healthy AYAs in the Netherlands is 71.8–77.4 (SD 10.1–14.6).^{35,36} Panepinto³⁷ defined severe fatigue as a score more than 2SD from the norm on the MFS Total Score.

Participation

The Child and Adolescent Scale of Participation (CASP), part of the Child & Family Follow-up Survey (CFFS), was administered to measure participation restrictions. The CFFS is a parent-reported questionnaire developed and validated for children and youth with ABI³⁸ and has been validated in the Dutch language.³⁹ A child and youth self-reported version of the CASP is available⁴⁰ and was used next to the parent-reported version in the present study.

The CASP consists of 20 items in 4 subdomains measuring the child's home participation (6 items), community participation (4 items), school participation (5 items) and home & community living activities (5 items). Activities are rated on a four-point ordinal scale: age expected (full participation), somewhat limited, very limited and unable. Items marked as not applicable do not receive a score. Scores for each item are summed and divided by the maximum possible score based on the number of items rated, multiplied by 100 to give a final score between 0 and 100. Higher scores are considered to be participating closer to age-expected levels. A score below 97.5 is defined as restricted participation (unpublished correspondence with author GM Bedell).

Health-related Quality of Life (HRQoL)

For HRQoL, the Pediatric Quality of Life Inventory™ Generic Core Scales (PedsQL) Dutch language version,⁴¹ assessing five dimensions of QoL (physical functioning (eight items), emotional functioning (five items), social functioning (five items), school functioning (five items), and total HRQoL) was used.⁴² In this study, the parent- and child-reported versions for children 13–18 years old were applied. The scoring system is similar to that of the MFS. Varni⁴³ defined the impaired quality of life as more than 1 SD below the population mean. Normative score for 13–18 year olds in The Netherlands is a mean of 83.1 (SD 9.0)⁴⁴ and for 18–25 year olds 85.9 (SD 11.5)⁴¹ for the PedsQL Total Score. The PedsQL has been validated for the pediatric TBI population⁴⁵ as well as the young adult population.⁴¹

Data Analysis

Sociodemographic and injury characteristics as well as all clinical outcome variables were described and reported as medians with interquartile ranges based on the distribution of the data (Kolmogorov–Smirnov test). Comparisons between patients' and parents' scores of the MFS, CASP, and PedsQL were done using the paired-samples Wilcoxon signed-rank tests and by calculating the Intraclass Correlation coefficient (ICC_{2,1}, absolute agreement, single measures). Linear regression was performed with participation (CASP total and subscales) and quality of life (PedsQL total and subscales) as dependent variables and fatigue (MFS) as the independent variable, adjusted for sex, age at admission (<18 or >18), and type of injury (TBI/NTBI). The level of statistical significance was defined as $p < .05$ and ICC scores rated according to Bartko⁴⁶: below 0.40: poor; between 0.41 and 0.60: moderate; between 0.61 and 0.80 good; above 0.81: excellent. All analyses were performed using SPSS 22 for Windows.⁴⁷

Results

Sixty-four patients and/or their parents participated in this study. The age of the AYA at admission was 17.6 years (IQR 16.2, 20.0), with 38 (59%) under 18 years. Thirty-two (50%) were male and 47 (73%) patients had a TBI. All other clinical characteristics are presented in Table 1.

In Table 2, outcomes regarding fatigue, participation and HRQoL as perceived by patients and parents are presented. Patients and parents reported considerable fatigue (MFS median total score 44.4, respectively, 56.9) and diminished HRQoL scores (PedsQL median total score 59.8, respectively, 69.6). Participation restrictions were reported as well (CASP median total score 79.7, respectively, 91.1). When comparing patient- to parent-reported outcomes, only a few significant differences were found; with parents reporting significantly more general fatigue than patients and patients reporting significantly more restrictions than their parents in participation at home, in the community and at school. Correlations between patient- and parent-reported outcomes were moderate to good (ICC 0.52–0.66, 49–50 pairs) for fatigue (MFS), moderate to poor (ICC 0.30–0.55, 38–49 pairs) for participation (CASP), and moderate to good (ICC 0.60–0.78, 49–50 pairs) for HRQoL (PedsQL).

In Table 3 the association between patient-reported fatigue and participation and HRQoL is shown. The linear regression analyses, adjusted for sex, age and type of injury, clearly showed that more fatigue is associated with more participation restrictions in all subdomains of the CASP and diminished HRQoL in all subscales of functioning in the PedsQL (all $p < .001$).

In the parent-reported data (Table 4), similar relationships were found between fatigue and participation restrictions and HRQoL (almost all $p < .05$). However, no significant associations between sleep/rest fatigue and home participation and home and community activities were found. Furthermore, parent-reported fatigue was not significantly associated with social functioning according to the PedsQL.

Discussion

This study in a cohort of AYAs with ABI referred for outpatient rehabilitation treatment found that AYAs and their parents reported high levels of fatigue, limited participation in school and society, and diminished quality of life. Higher levels of fatigue were found to be associated with both participation restrictions and diminished HRQoL. Fatigue may be a modifiable symptom to be targeted in rehabilitation treatment to possibly decrease participation restrictions and improve HRQoL.

Patient Characteristics

The distribution of severity of TBI in our cohort is similar to published incidence data.⁴⁸ Based on the literature, it is expected that 90% of mild injuries resolve within 4–6 weeks^{49,50} with no need for rehabilitation treatment. The high percentage of mild injuries in our cohort reflects the subgroup of patients in the generally 'mild injury' group with persisting symptoms. The question remains whether an initial mild classification can always be properly made early after injury and if the classification is suitable for outcomes.

Fatigue

AYAs and their parents in this study report high levels of fatigue, comparable to previous studies.^{9,13} The median fatigue score of the AYAs in our cohort (44.4) is considerably lower than the average scores of healthy AYAs in the

Table 1. Patient characteristics of AYAs with ABI referred for outpatient rehabilitation treatment.

	Patients n = 64	TBI n = 47	NTBI n = 17
Sex, male, n (%)	32 (50)	21 (45)	11 (65)
Age at injury, years; median (IQR)	16.3 (14.6, 18.3)	17.2 (15.6, 18.7)	15.0 (9.3, 17.0)
Time since injury, years; median (IQR)	0.8 (0.2, 2.3)	0.6 (0.2, 1.4)	2.4 (0.3, 7.0)
Age at admission, years; median (IQR)	17.6 (16.2, 20.0)	17.7 (16.0, 20.8)	17.4 (16.1, 18.4)
under 18 years, n (%)	38 (59)	26 (55)	12 (70)
18 years and older, n (%)	26 (41)	21 (45)	5 (30)
Severity of injury, n (%)			
mild		37 (79)	
moderate/severe		8 (17)	
unknown		2 (4)	

TBI = traumatic brain injury, NTBI = non-traumatic brain injury

IQR = interquartile range

Severity of injury based on Glasgow Coma Scale, 13–15 is mild, 9–12 is moderate, 8 and under is severe injury.

Table 2. Patient- and parent-reported fatigue, participation and quality of life outcomes in a cohort of AYAs with ABI referred to an outpatient rehabilitation clinic.

		median (IQR)		number of pairs	ICC _{2,1}
		Patients, n = 59	Parents, n = 54		
PedsQL™ MFS	Total Score	44.4 (34.7, 59.7)	47.9 (36.1, 63.9)	50	0.64
	General fatigue	45.8 (29.2, 66.7)	44.4 (25.0, 62.5)*	50	0.66
	Score sleep/rest fatigue	50.0 (41.7, 62.5)	54.2 (39.6, 68.8)	49	0.52
	Cognitive fatigue	41.7 (25.0, 58.3)	43.8 (25.0, 70.8)	50	0.64
CASP	Total Score	82.5 (68.8, 92.3)	91.1 (80.0, 96.9)*	49	0.54
	Home participation	87.5 (75.0, 100.0)	93.8 (86.9, 100.0)*	49	0.44
	Community participation	75.0 (50.0, 100.0)	89.6 (75.0, 100.0)**	49	0.55
	School participation	85.0 (65.0, 95.0)	90.0 (80.0, 100.0)*	38	0.40
	Home & community living activities	85.0 (69.7, 94.1)	88.8 (78.8, 100.0)*	48	0.30
PedsQL™ Generic Core Scales	Total Score	63.0 (47.8, 78.3)	63.6 (46.7, 75.3)	50	0.78
	Physical functioning	62.5 (50.0, 90.6)	64.1 (43.8, 82.0)	50	0.75
	Emotional functioning	60.0 (45.0, 85.0)	60.0 (40.0, 81.3)	50	0.68
	Social functioning	80.0 (60.0, 95.0)	75.0 (60.0, 100.0)	50	0.60
	School functioning	45.0 (30.0, 65.0)	45.0 (27.5, 67.5)	49	0.72

* $p < .05$, ** $p < .001$; Wilcoxon signed-rank test for nonparametric data outcomes, for differences between patient- and parent-reported outcomes.

Fifty patient-parent pairs (37 traumatic brain injury and 13 non-traumatic brain injury) were used for this analysis.

PedsQL™ Multidimensional Fatigue Scale (MFS), 0–100, with lower scores indicating more fatigue.

Child and Adolescent Scale of Participation (CASP), 0–100 with lower scores indicating more participation restrictions.

PedsQL™ Generic Core Scales (0–100), with lower scores indicating the diminished health-related quality of life.

ICC_{2,1}; Intraclass Correlation Coefficients, absolute agreement, single measures.

Table 3. Patient-reported outcomes: the association between fatigue and participation and quality of life in AYAs with ABI, adjusted for sex, age at admission and type of injury.

		CASP				
		Total Score	Home participation	Community participation	School participation	Home & community activities
		β (95%CI)				
PedsQL™ MFS	Total Score	0.64 (0.44, 0.85)**	0.52 (0.33, 0.72)**	0.73 (0.43, 1.04)**	0.65 (0.34, 0.96)**	0.68 (0.43, 0.92)**
	General fatigue	0.51 (0.35, 0.68)**	0.45 (0.30, 0.60)**	0.63 (0.39, 0.87)**	0.58 (0.33, 0.83)**	0.49 (0.29, 0.70)**
	Sleep/rest fatigue	0.46 (0.21, 0.71)**	0.37 (0.14, 0.60)**	0.44 (0.08, 0.80)*	0.53 (0.20, 0.86)*	0.51 (0.23, 0.80)**
	Cognitive fatigue	0.36 (0.19, 0.53)**	0.27 (0.11, 0.43)**	0.42 (0.18, 0.66)**	0.31 (0.05, 0.56)*	0.41 (0.22, 0.61)**
		PedsQL™ Generic Core Scales				
		Total Score	Physical functioning	Emotional functioning	Social functioning	School functioning
		β (95%CI)				
PedsQL™ MFS	Total Score	0.87 (0.72, 1.02)**	0.90 (0.65, 1.14)**	0.90 (0.61, 1.18)**	0.63 (0.39, 0.87)**	1.05 (0.82, 1.29)**
	General fatigue	0.69 (0.56, 0.81)**	0.76 (0.58, 0.94)**	0.72 (0.50, 0.95)**	0.48 (0.29, 0.67)**	0.75 (0.53, 0.96)**
	Sleep/rest fatigue	0.65 (0.42, 0.88)**	0.76 (0.47, 1.05)**	0.52 (0.16, 0.88)*	0.46 (0.19, 0.74)**	0.80 (0.48, 1.11)**
	Cognitive fatigue	0.49 (0.33, 0.64)**	0.41 (0.19, 0.64)**	0.56 (0.33, 0.79)**	0.37 (0.18, 0.55)**	0.65 (0.45, 0.86)**

Linear regression analyses with data represented as β-estimates (95% confidence interval, 95%CI) with CASP and PedsQL™ Generic Core Scales (dependent variables) and MFS (independent variables) adjusted for sex, age at admission (18 or >18) and type of injury (TBI/NTBI).

* $p < .05$; ** $p < .001$

PedsQL™ Multidimensional Fatigue Scale (MFS), 0–100, with lower scores indicating more fatigue.

Child and Adolescent Scale of Participation (CASP), 0–100 with lower scores indicating more participation restrictions.

PedsQL™ Generic Core Scales, 0–100, with lower scores indicating the diminished health-related quality of life.

Netherlands (71.8–77.4).^{35,36} With a definition of severe fatigue as a score more than 2SD from the norm on the MFS Total Score³⁷, using the normative data collected by Haverman,³⁶ our patients, on average, can be considered severely fatigued.

In the subscales, sleep/rest and cognitive fatigue patients reported more fatigue than their parents, similar to other studies using the PedsQL™ MFS^{35,51}; however, these differences in our study were not statistically significant. Parents did report significantly more general fatigue than their children but the actual median difference was rather small (1.4 points on a 0–100 scale) and it is to be determined whether this difference is clinically meaningful. Moreover, there was moderate to good agreement between patient- and parent-reported data, also in the general fatigue scale (ICC 0.66, 50 pairs). Therefore, the question remains whether it is necessary to measure both patient- and parent-reported fatigue as was suggested in other studies.^{15,51,52}

Participation

Patients and their parents in this study reported participation restrictions in all domains of participation (median total score 82.5 (IQR 68.8, 92.3), 91.1 (80.0, 96.9), respectively), supporting earlier studies in this patient population (pediatric ABI^{27,53}; adult mTBI⁵⁴; stroke.⁵⁵) In the current study, AYAs reported significantly more participation restrictions than their parents, in home, community and school activities. Previous research on patient- and parent-reported participation with the CASP has found patients reporting less participation restrictions than their parents.⁴⁰ The question remains whether the differences found (patient median 82.5 versus parent median 91.1) are actually clinically meaningful, since the minimal clinically important differences are unavailable for this instrument. Agreement between patient- and parent-reported data is poor to moderate, supporting studies that use both patient- and parent-reported data. By using both perspectives, a broad view on overall functioning is

Table 4. Parent-reported outcomes: the association between fatigue and participation and quality of life in AYAs with ABI, adjusted for sex, age at admission and type of injury.

		CASP				
		Total Score	Home participation	Community participation	School participation	Home & community activities
		β (95%CI)				
PedsQL™ MFS	Total Score	0.32 (0.14, 0.50)**	0.22 (0.06, 0.38)*	0.39 (0.15, 0.64)*	0.51 (0.24, 0.79)*	0.28 (0.06, 0.50)*
	General fatigue	0.25 (0.10, 0.41)*	0.15 (0.02, 0.29)*	0.37 (0.17, 0.57)**	0.37 (0.13, 0.60)*	0.20 (0.01, 0.39)*
	Sleep/rest fatigue	0.19 (0.03, 0.34)*	0.09 (−0.04, 0.23)	0.30 (0.11, 0.49)*	0.32 (0.07, 0.57)*	0.14 (−0.04, 0.33)
	Cognitive fatigue	0.17 (0.03, 0.31)*	0.16 (0.04, 0.28)*	0.12 (−0.04, 0.31)	0.29 (0.07, 0.50)*	0.17 (0.01, 0.34)*
		PedsQL™ Generic Core Scales				
		Total Score	Physical functioning	Emotional functioning	Social functioning	School functioning
		β (95%CI)				
PedsQL™ MFS	Total Score	0.62 (0.43, 0.82)**	0.66 (0.39, 0.94)**	0.77 (0.49, 1.05)**	0.25 (−0.07, 0.57)	0.79 (0.46, 1.12)**
	General fatigue	0.46 (0.28, 0.63)**	0.50 (0.26, 0.74)**	0.50 (0.24, 0.76)**	0.18 (−0.09, 0.44)	0.62 (0.34, 0.90)**
	Sleep/rest fatigue	0.38 (0.20, 0.56)**	0.53 (0.31, 0.75)**	0.45 (0.19, 0.71)**	−0.01 (−0.28, 0.25)	0.48 (0.19, 0.77)*
	Cognitive fatigue	0.32 (0.15, 0.49)**	0.23 (−0.001, 0.46)	0.46 (0.24, 0.68)**	0.27 (0.05, 0.50)*	0.38 (0.11, 0.64)*

Linear regression analyses with data represented as β -estimates (95% confidence interval, 95%CI); CASP Total Score and subdomains (dependent variables) and MFS (independent variables) adjusted for sex, age at admission (<18 or >18) and type of injury (TBI/NTBI). * $p < .05$; ** $p < .001$

PedsQL™ Multidimensional Fatigue Scale (MFS), 0–100, with lower scores indicating more fatigue.

Child and Adolescent Scale of Participation (CASP), 0–100 with lower scores indicating more participation restrictions.

PedsQL™ Generic Core Scales, 0–100, with lower scores indicating the diminished health-related quality of life.

attained⁴⁰ and gives professionals the opportunity to address both patient and parent rehabilitation goals. Therefore, both patients' and parents' perspectives on participation should be measured in ABI studies.

Health-related Quality of Life (HRQoL)

HRQoL is impaired in children, adolescents and adults with ABI^{30,31,56} which concurs with the findings in our study. In our study, a median patient Total Score of 63.0 was found; using Varni's definition of impaired QoL as a value greater than 1 SD from the population norm⁴³, compared to the Dutch population norm of 83.1–85.9,^{41,44} our patients have an impaired quality of life. In the current study, there was no difference between patient- and parent-reported HRQoL with a good agreement between patient and parent data. In the previous literature, a difference was found where parents tended to underestimate their child's HRQoL.⁵⁷

Although the patient perspective is considered more important in evaluating the quality of life, the parent perspective reflects the utilization of health-care services, including rehabilitation treatment⁴² and possibly a reflection of their own HRQoL⁵⁸ and should therefore also be taken into account.

Relationship between Fatigue, Participation and HRQoL

Regarding the relationship between fatigue and participation and HRQoL, this is the first study which shows the relationship between these important aspects of life in AYAs with ABI. In other pediatric (chronic fatigue syndrome⁵⁹; stroke¹⁴; juvenile idiopathic arthritis⁶⁰) and adult (stroke²¹; TBI⁶¹) cohorts, a relationship between fatigue and participation was found as well. The relationship between fatigue and quality of life has also been shown in other patient populations (pediatric brain tumors¹⁰; chronic disorders⁶²; adult stroke²⁰) and these findings support the results found in this study. We found that more patient-reported fatigue was associated with diminished HRQoL on all subscales, while the association

between parent-reported fatigue was significant for specific subscales. These results underline the need to explore fatigue as a multidimensional symptom influencing the quality of life in specific domains and should be addressed in rehabilitation treatment.

Limitations and Directions for Future Research

The current study had a number of limitations. The small size of the cohort as well as collecting data was from only one rehabilitation center limits the generalizability of the results. The cohort included only patients with symptoms, and/or restrictions in activities and participation and therefore outcomes may not be generalizable for all patients with ABI. However, we were specifically interested in outcomes in patients treated in rehabilitation which automatically leads to confounding by indication. The study also limited itself to the symptoms of fatigue and does not take into account the effect of other symptoms (e.g. pain, sleep) on participation or HRQoL. The latter has however been the subject of research in previous studies⁶³ concluding that sleep-wake disturbances were associated with poor quality of life following pediatric TBI. Finally, this study only used questionnaires filled out by patients and parents. Answers within these questionnaires could be influenced by several factors, e.g. bad mood, stress within the family, amongst others.

Future rehabilitation research should include a prospective cohort study of ABI patients with an emphasis on intervention programs focussing on fatigue and other common symptoms after ABI while promoting participation. The associations between fatigue, participation and QoL deem to be further explored in a larger cohort where all potential mutual associations and their directions are explored, preferably based on a conceptual theoretical model.

Conclusions

Fatigue is an often reported symptom after ABI which significantly affects activities, participation and health-related quality

of life in adolescence and young adulthood. Fatigue is possibly a modifiable multidimensional symptom which, when targeted during rehabilitation treatment, could potentially improve participation and HRQoL. When reporting fatigue, the patient perspective is sufficient, while for participation and HRQoL, the patient and parent viewpoint give a complete perspective of functioning.

Acknowledgments

We would like to thank all the participants that participated in this study. Further, we would like to thank Cedric Kromme, Rosa Yahood, Mirjam van Ooijen and Bart Mertens.

Declaration of interest

The authors report no conflicts of interest. Financial support was obtained from the Hersenstichting (PZ2015.01.10) and the Revalidatiefonds (R2014124).

Funding

This work was supported by the Hersenstichting [PZ2015.01.10]; Revalidatiefonds [R2014124].

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