

Predictors of participation by children in life situations following traumatic injury

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Introduction

The goal of every medical and rehabilitation service for children experiencing traumatic injury is to return the child and family to full participation in typical and meaningful daily activities. While previous studies have described the cognitive, physical, behavioral and health outcomes of traumatic and acquired brain injury, massive burn injury and orthopedic injury (Anderson et al, 2001; Keenan et al, 2007; Rice et al, 2005; Sheridan et al, 2000; Stancin et al, 2002; Taylor et al, 2002; Yeates et al, 2004), factors that are predictive of children's recovery in activity participation following traumatic injury are largely unknown. Specifically, no evidence is provided about how impairments resulting from traumatic injury influence the *extent* of the child's participation in life activities, i.e. the child's use of time, or *satisfaction* with his/her level of involvement.

In rehabilitation settings, functional skill assessments are considered the standard for measuring a patient's progress in recovery after traumatic injury and define the frequency, duration and goals for intervention, and the timing of discharge. Further, injury severity measures are used routinely to determine likely outcomes following trauma. The capacity of functional skill and injury severity assessments to predict outcomes related to activity participation has not been demonstrated, however (Johnston et al, 1998; Robertson & Colborn, 1997). Knowledge of the factors predictive of participation recovery and the predictive validity of current rehabilitation tools will assist rehabilitation service providers in planning the most effective and efficient methods of restoring children experiencing traumatic injury to meaningful daily activity participation.

The purpose of this study was to examine the capacity of current functional skill and injury severity assessments used in pediatric rehabilitation practice to predict participation in meaningful daily activities by children recovering from traumatic injury. Specifically, the study examined the value of the Functional Independence Measure for Children (Wee FIM) and the Injury Severity Scale (ISS) in predicting the: 1) intensity, frequency, location and diversity of daily activities participated in by children following traumatic injury; and 2) level of perceived satisfaction of children and their families with participation in daily activities.

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Executive Summary

This study explored the outcomes of traumatic injuries in children with an emphasis on participation (or involvement in life situations) outcomes. Participants were recruited if they were 3-21 years of age and sustained an injury meriting admission to an inpatient pediatric rehabilitation unit. They were evaluated 4-12 months after hospital discharge. As a group, the 15 children in the study demonstrated severe injuries that resulted in persistent deficits. Following discharge home, the study participants had a reduced number of activities outside the home, a small sphere of social activity, and a participation profile very much like that of children with cerebral palsy. They were less physically active and slept more than healthy peers. The more severe their deficits and the longer their hospital stay, the more circumscribed their participation. These findings demonstrate a profound effect of severe traumatic injury on the day to day activities within the home and community for children and youth.

Literature review

Participation in daily activities and routines is considered by the World Health Organization (WHO) as the ultimate indicator of health and functioning (WHO, 2001). Participation is defined in the International Classification of Functioning, Disability and Health (ICF) as ‘involvement in life situations’. As such, it refers to the engagement by individuals in activities that are required for mobility, self-care, community activities, social function, learning, domestic life and other major life areas (WHO, 2001). In addition, participation consists of both the extent to which an individual is involved in activities (i.e. use of time) and expressed satisfaction with level of involvement (Australian Institute of Health & Welfare, 2003). Full participation in life activities is considered important to child development assisting in the achievement of intellectual, physical, social, emotional and communicative potential (King et al, 2003; Law, 2002). The subjective and complex nature of the construct of participation has hindered the development of participation outcome measures for use in medical and rehabilitation settings. Recently, however, new measures have emerged and so it is now possible to document the participation patterns of children following traumatic injury.

One study, Bedell and Dumas (2004), reports on the social participation of children and youth following acquired brain injury. This follow-up study used a cross-sectional survey design to identify the caregiver’s perception of the child’s participation in home, school and community life in comparison to peers. Results from this study indicate that children and youth with acquired brain injury are perceived by their caregivers to be more restricted in peer social-play, structured community activities and managing daily routines than their age-peers.

A related study examined quality-of-life in children following traumatic brain injury (Limond et al, 2009). This study reported that 40% of children in their sample had reduced quality-of-life 1-5 years post-injury. Specifically, this group experienced greater difficulties in physical, emotional, social, and school functioning than non-injured peers compared using a normative dataset. Further, the group reported higher levels of fatigue. Quality-of-life was associated with access to follow-up services following hospital discharge. Those reporting little access to services also reported the lowest levels of quality-of-life.

In studies of children with physical impairments other than traumatic injury, for example, cerebral palsy, participation restrictions have been consistently reported (Raghavendra et al, 2011; Imms et al, 2008; Law et al, 2006). In particular, children with cerebral palsy are observed to participate in recreational activities less intensely than their same-aged peers and tended to be involved in informal (less structured) rather than formal activities. Increased severity of physical, cognitive and communication impairment was associated with greater participation restriction (Raghavendra et al, 2011; Orlin et al, 2009; Fauconnier et al, 2009).

Considered together, the current literature confirms that children who experience traumatic injury are at high risk of participation restrictions. There is less known, however, about factors predictive of participation in pediatric disability groups. Bedell and Dumas (2004) reported that self-care function at discharge contributed most strongly to participation patterns after acquired brain injury explaining 50% of the variance in this factor. Further variance (82%) in participation patterns was explained when child-specific factors such as attention, problem solving and behavior, and environmental factors such as physical barriers in the home and community acceptance, were considered in addition to self-care function at discharge. A weakness of this study is its exclusive reliance on caregivers' perspectives of functional capacity and children's use their time. Clinical observation of functional capacity along with direct measures of use-of-time such as time diaries would yield more precise information about factors predictive of participation after traumatic injury.

Schenker et al (2005) examined factors predictive of school participation of students with cerebral palsy in Israel. This study reported that physical function was the strongest predictor of participation in school contexts such as the classroom, playground, transportation, mealtime areas and bathroom. In a more recent study, Wells et al (2009), concluded that age at injury, clinical impression of injury severity and environmental factors were significantly predictive of participation after injury. These authors utilized a retrospective study design to examine the relationship of injury severity and standardized clinical test scores with social participation and cognitive outcomes following pediatric TBI. Participants in this study were aged between 0-10 years at the time of injury with participation data being collected on average 10 years post-injury. As in Bedell and Dumas (2004), participation data was collected exclusively using caregiver report tools rather than via direct measures such as use-of-time tools.

In summary, only a handful of studies have reported on factors predictive of participation in children with disabilities including those following traumatic injury. Comparisons of these studies are limited by their focus on differing patient populations (i.e. some developmental disability versus traumatic injury). Further, many of the measurement tools used to capture participation outcomes are based exclusively in caregiver report. While caregiver perspectives are important to consider, these tools will not provide a precise representation of variables such as functional capacity and use-of-time. It is not yet possible, therefore, to detail the pathway to participation recovery. Additional research is required to consolidate our understanding in this area.

Summary of findings

Method

Overview of Design and Procedures

This study employed retrospective recruitment methods to describe the participation patterns of children within one year of discharge following traumatic injury. Participants were children and youth who had experienced traumatic injury and were admitted to the inpatient rehabilitation unit at Cincinnati Children's Hospital Medical Center (CCHMC). Inpatient records for the period from August 2008-April 2010 were reviewed and a list of 41 potential participants between 3 and 21 years of age were approached to participate. All participants were recruited via mailed invitation. These invitations were followed up with reminder cards two weeks after the initial mailing. If the project coordinator received no response within two weeks of the reminder cards being sent, one or more phone calls were made to the participant or parent. A list of potential participants came from pediatric rehabilitation physicians who had already established a relationship with the child. In each case, an MD from the pediatric rehabilitation unit signed the invitation letter.

The project coordinator explained the study in detail, reviewed the consent/assent forms, and answered any questions posed by the family or participant. Permission was obtained from one parent (having legal custody) and assent or consent was obtained from the participant. Each participant attended a single study visit 4-12 months following discharge. At the study visit, the project coordinator administered the outcome measures (described below) to the participant when possible, and most often to the participant and caregiver. The majority of the study visits were completed in the participants' homes. The remaining participants completed the measures at CCHMC. The implementation of all measures required approximately 2.5 hours. Permission was obtained from all participants to access scores from the predictor measures (described below) and other demographic and medical information directly from the medical record.

Outcome Measures

The Children's Assessment of Participation and Enjoyment (CAPE) (King et al, 2004) is a recently developed self-report measure of extent and satisfaction with participation for children with and without disabilities. On completion of the CAPE survey of 55 activities, a description of the number (diversity), frequency, social and geographical context and

enjoyment of non-school activities engaged in during the last 4 months was gained for each participant. Where self-report was not possible due to the child's age or impairments, caregivers completed the survey on behalf of the child.

The Multimedia Activity Recall for Children and Adolescents – Participation Edition (MARCA-PE) (Ridley, Olds & Hill, 2006; Taylor, 2011) is a 24-hour use of time diary that was administered via phone or face-to-face interview. The MARCA-PE captured each participant's typical daily time use over a 24-hour period. A sample of 2 days covering a weekend day and a weekday was collected and time use averaged across those days. Analysis of the data revealed the diversity of activities engaged in daily, difficulty experienced with and enjoyment of activities and average daily energy expenditure. MARCA-PE scores include: Physical Activity Level (PAL), Moderate-Vigorous Physical Activity (MVPA), average time spent watching television (avTV), average time spent using a computer (avPC), average time spent either watching television or using a computer (avScreen), and average time spent in sleep.

The Canadian Occupational Performance Measure (COPM), 4th edition (Law et al, 2005), was used in this study as the measure of satisfaction with participation in daily activity. The COPM is a semi-structured interview with the patient and/or caregiver about problem areas in the performance in tasks relating to: personal care, functional mobility, community management, paid/unpaid work, household management, play/school, quiet recreation, active recreation and socialization. At the completion of the interview, the participants were asked to rate priority problem areas on a scale of 1 – 10 based on their perception of current levels of performance and their current level of satisfaction with performance. Total scores on the COPM are the ratio of total performance or satisfaction scores and the number of problems identified.

Predictor Measures

The Functional Independence Measure for Children (WeeFIM) (Braun et al, 1994) was used to describe functional status at the time of discharge from the inpatient rehabilitation unit. The WeeFIM is a widely used assessment of disability that addresses a child's status in realms of mobility, locomotion, self-care, sphincter control, communication, and social functioning and is modeled after the adult instrument, the Functional Independence Measure (FIM). Scores reflect the degree of assistance a child requires within each domain of function. Because WeeFIM scores were calculated for each

rehabilitation inpatient on a weekly basis, a WeeFIM change score (discharge score – admission score) was calculated and used as an additional predictor variable.

The Injury Severity Score (ISS) was used to describe initial injury status. This composite measure of bodily anatomic injury is commonly applied to cases of trauma and can be calculated within hours of the traumatic event. These scores were collected from the emergency department records or trauma registries either at CCHMC or at a referring hospital.

Results

Participants

Fifteen participants consented to and met the criteria for involvement in the study. An additional participant expressed interest in involvement in the study but was not included as they were unable to participate in the self-report measures due to the extent of their physical and communication disability. Participants were aged between 3.58 years and 18.58 years (mean = 14.52, SD = 4.01; females = 4). Participants' average length of stay in rehabilitation was 32.80 days (range: 5-84 days). Most participants (n=12) experienced traumatic brain injury. Several participants (n=7) experienced multiple trauma including brain and organ injury and bone fractures. Three participants had spinal cord injury. Two participants experienced multiple bone fractures. The most common injury cause was motor vehicle collision (including car, pedestrian, motorcycle and all-terrain vehicle crashes). Two participants sustained injuries secondary to direct head blows (baseball, tree limb). Average time since discharge at the time of participation in the study was 7.79 months (SD = 2.68 months) with a range of 4 -12 months. As one of the participants' was significantly younger than the rest of the sample (age 3 years at time of interview, next youngest aged 9 years), this participant was excluded from all remaining analyses. With this participant excluded, the mean age of the participants at the time of the study was: 14.64 years (SD = 2.82; females = 4); average length of stay in rehabilitation was 29.21 days (range: 5-57 days); and average time since discharge at the time of participation in the study was 7.70 months (SD = 2.76 months; range: 4-12 months).

Predictor and Outcome Measures

Summary WeeFIM and ISS scores are reported in Table 1. An ISS score for one participant was not able to be obtained as the patient transferred to the rehabilitation facility from an out-of-state hospital without an identified trauma registry. A

summary of participants' scores on the outcome variables is reported in Table 2. All scores reported for the CAPE reflect the aggregated scores for Overall CAPE domains rather than activity subsets.

Table 1 Summary of WeeFIM and ISS scores

	Admission WeeFIM Score (n=14)	Discharge WeeFIM Score (n=14)	WeeFIM change Score (n=14)	ISS (n=13)
Mean	37.57	81.93	44.36	26.54
SD	19.19	20.74	23.44	8.26
Range	18-71	21-102	3-74	9-38

Table 2 Summary of CAPE, COPM and MARCA-PE scores (n=14)

Outcome Measure		Mean	SD	Range
CAPE	Diversity	26.21	5.25	15-39
	Intensity	2.28	.46	1.35-3.35
	With Whom	2.56	.37	2.03-3.04
	Where	2.99	.47	2.04-3.75
	Enjoyment	3.61	.55	2.43-4.40
COPM	Performance*	4.01	2.34	1-8
	Satisfaction *	3.72	1.37	2.4-7.6
	# Problems	4.29	1.64	0-5
MARCA-PE	PAL	1.51	.24	1.09-1.94
	MVPA (mins/day)	101.61	116.42	0-335
	TV (mins/day)	123.93	88.73	0-307.5
	PC (mins/day)	85.89	75.13	0-197.5
	Screen (mins/day)	209.82	115.37	55-425
	Sleep (mins/day)	602.14	71.37	480-792.5

*n=13; One participant reported '0' occupational performance problems, therefore, performance and satisfaction scores could not be calculated.

Summaries of participants' scores on both predictor and outcome measures indicate that: 1) functional capacity improved between admission and discharge in the majority of participants (n=13) as shown by increasing WeeFIM scores; and 2) injury severity fell in the severe range. One study has found that ISS's greater than or equal to 25 were associated with significant mortality and morbidity (Mayer et al, 1980). Participants reported involvement in a range of recreational activities. A mean diversity score of 26.21 is comparable with other reports in the literature of the number of activities participated in by similarly aged children with cerebral palsy (Raghavendra et al, 2011; Imms et al, 2008) and is lower than that reported in studies of children without disabilities (mean diversity score = 31.90; King et al, 2009). Similarly, participants in this study reported lower frequency of activity (mean intensity = 2.28) when compared to children without disabilities (mean intensity = 2.71; King et al, 2009). Further, the social context (with whom) and geographic location (where) of the activities tended to be restricted to family and close friends at home or immediate neighborhood.

Figure 1 shows how participants in our study compared to their same-aged non-disabled peers in terms of daily physical and sedentary activity and daily sleep. A mean z-score of '0' equates to the average daily activity and sleep completed by age-matched, non-disabled peers. Overall, participants in our sample tended to engage in less physical activity (MVPA, PAL) and screen time (PC, Screen & TV) but more sleep than their same-aged peers.

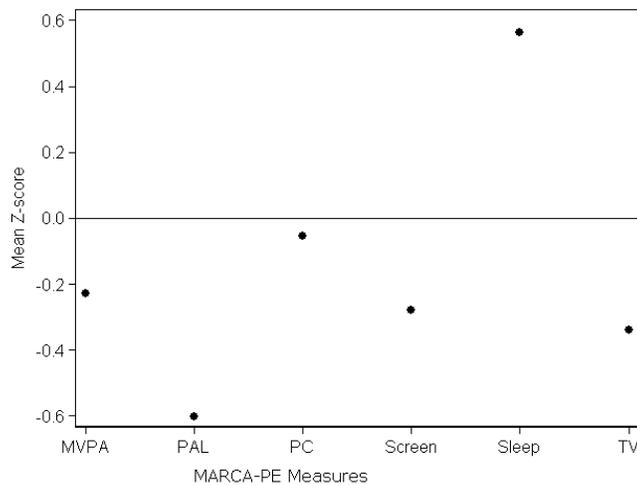


Figure 1 Comparison of participants to normative dataset on MARCA-PE measures

Association of predictor to outcome measures

Pearson correlation analysis was performed to examine the association of change in WeeFIM score from admission to discharge and ISS score with performance on the COPM, CAPE and MARCA-PE. Tables 3 and 4 report the results of this analysis.

Table 3 Association of WeeFIM change score with COPM, CAPE and MARCA-PE

Instrument	Outcome	Pearson correlation	p-value
COPM	Performance score	-0.18	0.56
	Satisfaction score	0.01	0.97
CAPE	Overall Diversity	0.62	0.02*
	Overall Intensity	0.59	0.03*
	Overall With Whom	-0.32	0.27
	Overall Where	-0.10	0.74
	Overall Enjoyment	-0.10	0.74
MARCA-PE	PAL	-0.21	0.48
	MVPA	-0.11	0.7
	TV	0.18	0.54
	PC	-0.06	0.84
	Screen	0.11	0.70
	Sleep	0.34	0.23

*indicates significant result at $p < .05$

As can be seen, strong, significant associations were observed between change in WeeFIM scores and the number and intensity of activity participation post-discharge (CAPE: Overall Diversity and Intensity). These associations were positive indicating that participants who made the biggest improvements in functional capacity during their rehabilitation stay, participated in the highest numbers of activities at the greatest intensity. Further, ISS was strongly and significantly associated with the geographic location of activities and the level of physical activity engaged in (MARCA-PE: PAL and MVPA). These associations were negative indicating that participants with the least severe injuries participated in activities further away from the home and immediate neighborhood and in higher and more vigorous levels of physical activity. No associations of significance were observed between WeeFIM and ISS, and the participants' perception of their own performance or satisfaction with performance (COPM).

Table 4 Association of ISS score with COPM, CAPE and MARCA-PE

Instrument	Outcome	Pearson correlation	p-value
COPM	Performance score	-0.01	0.97
	Satisfaction score	-0.11	0.73
CAPE	Overall Diversity	-0.27	0.38
	Overall Intensity	-0.11	0.72
	Overall With Whom	-0.38	0.20
	Overall Where	-0.59	0.04*
	Overall Enjoyment	-0.06	0.86
MARCA-PE	PAL	-0.64	0.02*
	MVPA	-0.71	0.01**
	TV	0.38	0.21
	PC	-0.27	0.38
	Screen	0.14	0.64
	Sleep	-0.04	0.90

*indicates significant result at $p < .05$; **indicates significant result at $p < .01$

Prediction of participation in daily activities by functional capacity, length of stay and injury severity

Multivariate linear regression analysis was used to examine the ability of functional capacity (WeeFIM), length of rehabilitation stay (LOS) and injury severity (ISS) to predict activity participation (CAPE) in young people following traumatic injury. Change in WeeFIM score and LOS combined were found to be the strongest predictors of Overall Diversity and Intensity ($R^2 = .57$; $F_{(2, 11)} = 9.63$, $p = .004$ and $R^2 = .64$, $F_{(2, 11)} = 12.46$, $p = .002$ respectively). This result indicates that 57% of the variance in Overall Diversity score can be explained by WeeFIM change score and LOS. Participants who made the biggest gains in functional capacity in the shortest amount of time participated in the highest number of activities post-discharge. Similarly, regression analysis indicates that 63% of the variance in Overall Intensity score can be explained by the combination of WeeFIM change score and LOS. Participants who made the biggest gains in the shortest amount of time tended to participate in activities more intensely post-discharge.

When examining the social and geographic context of activity participation, a different prediction model was revealed. LOS and Admission WeeFIM score were the best predictors of the social context of activity post-discharge (Overall With Whom) ($R^2 = .41$, $F_{(1, 12)} = 10.10$, $p = .008$ and $R^2 = .40$, $F_{(1, 12)} = 9.83$, $p = .009$ respectively). These results indicate that up to 41%

of the variance in Overall With Whom score can be explained by LOS and Admission WeeFIM score separately.

Participants who had longer stays and lower functional capacity at admission tended to participate in activities with family and close friends rather than with less well-known community members. In terms of the geographic context of activity participation (Overall Where), LOS and Discharge WeeFIM combined were shown to be the best predictors ($R^2=.47$, $F_{(2,11)}=6.74$, $p=.012$). This result indicates that participants with shorter stays and higher functional capacity at discharge tended to participate in activities further away from home and in the community.

Conclusions

1) Patterns of participation restriction in children following traumatic injury are similar to those reported in children with physical disabilities such as cerebral palsy. Young people in our study tended to be engaged in a reduced variety of activities and at lower intensity. Additionally, the social and geographic context of activities reported in this study tended to be restricted to close families and friends at home and the immediate neighborhood.

2) Patterns of engagement in physical and sedentary activity in children following traumatic injury differ from those of same-aged peers without disabilities. Less time is spent by children recovering from traumatic injury in physical activity and television watching. In general, children in the study spent more time sleeping than their peers.

3) Functional capacity and length of stay were the strongest predictors of quality of activity participation in this study. Rate of recovery in functional capacity combined with length of stay was a very strong predictor of the number and intensity of activities participated in. Further, functional capacity at admission and discharge were predictive of the social and geographic context of activity participation respectively along with length of stay.

Study Limitations

Target participant enrolment was not achieved in this study. A number of factors contributed to low study enrolment including:

a) short, over-the-weekend hospital stays – children admitted for 48 hours over a weekend for their injury were not as well represented in our sample. These children were more difficult to enroll as opportunities for a face-to-face approach regarding the study were limited. Consequently, children in our study tended to have more severe injury and longer hospital lengths of stay. Our results cannot be generalized to children admitted for shorter hospital stays.

b) several parents declined the opportunity for their children to participate in the study on the basis that they felt their child was now fully recovered and had no problems. Children participating in daily activities more normally following their injury may not have been included in this study. Participation patterns reported here, therefore, may not be representative of the full range of participation outcomes following traumatic injury.

c) low census – during the time of recruitment and data collection, CCHMC experienced lower census in the rehabilitation unit than for the same period in previous years. While this may be indicative of encouraging trend toward fewer serious injuries sustained by children, it affected our ability to achieve target enrollment.

Although sample size was small, the measures used in our study included opportunities for direct reporting by participants on perceptions of performance and satisfaction, and diarized use of time. Trends for participation reported in this study and their associations with functional capacity and injury severity, therefore, are among the most precise reported in the literature to date. Further, this study focused on the first year post-discharge following traumatic injury. Previous studies have reported participation patterns in children up to 10 years post-injury. Children in our study will likely make further gains in functional capacity as part of normal injury recovery. These additional gains may further impact participation patterns.

Recommendations

Our study has provided a preliminary profile of the participation recovery of children experiencing severe traumatic injury in the first year following hospital discharge. Further research is required to determine if this profile is representative of the broader range of children following trauma. Our results indicate that functional capacity and length of stay rather than injury severity are the most critical factors predictive of participation outcomes. Clinical factors associated with rate of recovery in functional capacity should be examined further to determine trauma and rehabilitation service delivery models that support the most efficient and effective pathway to optimal participation post-discharge.

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