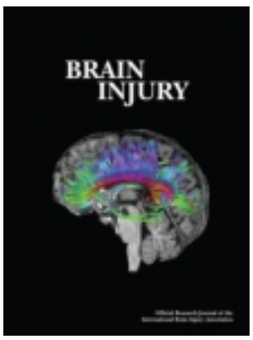

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# Participation patterns of children with acquired brain injury

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**Abstract**

*Objective*: To describe the participation patterns of children and youth with Acquired Brain Injury (ABI) and to compare these patterns with typically-developing peers.

*Methods*: One hundred and thirty-five children with ABI completed the Children Assessment of Participation and Enjoyment (CAPE) to measure their participation diversity and intensity in outside-of-school activities (i.e. recreational, physical, social, self-improvement and skill-based activities). Results were compared to 354 typically-developing peers. ANOVA analyses were performed while controlling for age and gender.

*Results*: Similar to typically-developing children, individuals with ABI proportionally participated mostly in social and recreational activities and were less likely to engage in skill-based activities. However, level of intensity and diversity within each activity type was different between the two groups. Children with ABI participated in fewer activities and were less frequently involved in all the CAPE's activity types except for intensity in social activities. These differences, characterized by small-to-medium effect sizes, were not dependent on the child's age and gender.

*Conclusions*: Participation of children with ABI is restricted in comparison to their typically-developing peers even in a sample where minor injury is predominant. Future studies might address additional factors that potentially affect participation, e.g. child's preferences and family function.

**Keywords:** *Activity, paediatric, leisure*

## Introduction

Participation, defined by the World Health Organization International Classification of Functioning, Disability and Health as involvement in a life situation [1], is thought to influence health and well-being. Participation occurs across many locations, including environments of work, school, play, sport, entertainment, learning, civic life and religious practise. Particularly, participation in non-school activities such as play, interaction with family members and friends provides an important context for learning and positive development [2, 3]. In fact, participating in activities that are discretionary in nature and meet the child's preference and needs provides a context for developing skills and competencies, shaping self-identity, achieving mental and physical health [4], expressing creativity and determining meaning and purpose in life [2].

Several studies have demonstrated that participation patterns of children with disabilities are restricted. These studies examined participation of children with various physical disabilities [5–7] and specific populations such as children with cerebral palsy [8, 9] and Down syndrome [10]. However, little is known about the specific participation patterns of children and youth with Acquired Brain Injury (ABI); a population that continues to grow every year. For example, according to Centres of Disease Control [11] almost half a million

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emergency visits are made annually for ABI by children age 0–14 in the US. Moreover, ABI is a complex condition that potentially affects physical, cognitive, behaviour, medical and social skills and, hence, there could be a substantive impact on participation.

One study examined the participation patterns of 60 children with ABI (aged 3–21 years; mean = 13, SD = 4.9) using the Child and Adolescent Scale of Participation (CASP) and found that children's participation was most restricted in structured community activities, in school-based activities (e.g. peer-social play) and in home and community living activities (e.g. managing daily routine/schedule) [12]. The CASP item ratings compare the child to same-age peers based on the parents' judgement. Another study examined the experience of Australian adolescents (mean age 15.9 years; range 14–17.3) following severe ABI [13], yet was focusing on only one domain of participation, i.e. returning back to school. Studies that explored functional outcomes of children and youth with ABI tend to focus on moderate-to-severe conditions [14]. Yet, children with minor head injuries comprise the largest group [15] and there is growing evidence that they demonstrate difficulties throughout their recovery process [14, 16].

Additional representative studies that explore participation of children with ABI are needed using measurements that tap broader domains of participation while considering children with mild injury as well. When examining the participation patterns of children with and without disabilities (aged 6–14 years and 5–18 years, respectively), demographic factors such as age and gender need to be considered [6, 17]. For example, girls tend to engage more in social and skill-bases activities while boys prefer physical activities; overall there is evidence that child's participation changes mainly as they transition to adolescence, that is at the age of 12 years old.

This study had two objectives: (1) to describe the participation patterns of children and youth with ABI in five different activity types (i.e. recreational, physical, social, skill-based and self-improvement) and (2) to compare these patterns with typically-developing peers while controlling for differences due to the child's age and gender. Three types of comparisons were examined: (1) the five most common/popular activities, (2) the relative proportion or trend of participation diversity *across* activity types and (3) diversity and intensity rates *within* each activity type. Since this initial study was exploratory in nature, specific hypotheses regarding participation patterns were not proposed.

## Methods

### *Participants and procedure*

This study analysed data from two research projects. Sample one included 135 children with ABI and sample two included 354 children without disabilities. Both studies were approved by the McMaster University Health Sciences Ethics Review Board. Children were included in sample one if (1) they were between 5–18 years of age upon admission; (2) they were admitted to the McMaster Children's Hospital, Hamilton, Ontario, Canada with a diagnosis of ABI and (3) their initial CT results were available to confirm the diagnosis. ABI in this study was defined as damage to the brain that is not related to a congenital neurodevelopment disorder. The damage may be caused by traumatic or non-traumatic injuries to the brain such as stroke, aneurysm, anoxia, near drowning, falls and brain tumours.

Children were identified through checking ward lists and emergency room lists every morning. To introduce the study to the families, an informative handout was left in the child's hospital room and the nature of the study was explained by a research assistant. If families agreed to participate, a consent form was obtained and signed by the parents. Medical information was collected prospectively from the children's hospital charts. Four weeks post-discharge, a package of self-administrated questionnaires was mailed to the participants' home and was returned upon completion. Out of the 434 children that were identified with ABI, 250 met the inclusion criteria. Of the 250, 65 did not consent. Of the 185 packages that were mailed, 135 were returned (73% response rate). A comparative analysis indicated that participants who did not return the questionnaires ($n = 50$) did not differ systematically from the studied sample ($n = 135$) in terms of gender ($\chi^2 = 0.26$, $p = 0.61$), severity of injury ($\chi^2 = 0.64$, $p = 0.42$) and age ($t = 1.1$, $p = 0.29$).

Demographic information of the two samples, i.e. children with ABI and typically-developing, is presented in Table I. Sample one included 135 children and youth with ABI (87 boys and 48 girls) aged 4–17 (mean = 11.1, SD = 3.3). Forty-six per cent of the children/youth were adolescents (above 12 years old). The cause of brain injury was MVA (37%), fall (18%), sports, bicycle and assault (28%) and the remainder (17%) from other causes (e.g. brain tumour, near drowning). The majority of the participants had a mild injury (74%), based on the Glasgow Coma Scores (GCS) of 13–15 [18, 19], while 26% had a moderate-to-severe injury (GSC $\leq$ 12). Length of stay in the hospital ranged from 1–89 days (inter-quartile ranged from 4.5–9) and the majority of the children (80%) returned to

Table I. Characteristics of samples of children with and without ABI.

| | | ABI ($n = 135$) | | Typical ($n = 354$) | |
|---|---|---|---|---|---|
| Variable | Category | *n* | % | *n* | % |
| Age and gender | Boys $\geq 12$ | 47 | 34.8 | 111 | 31.4 |
| | Boys $< 12$ | 40 | 29.6 | 36 | 10.2 |
| | Girls $\geq 12$ | 26 | 19.3 | 139 | 39.3 |
| | Girls $< 12$ | 22 | 16.3 | 68 | 19.2 |
| Family income | <$30 000 | 17 | 12.6 | 33 | 9.3 |
| | $30 000–$59 999 | 36 | 26.7 | 92 | 26 |
| | $60 000–$89 999 | 40 | 29.6 | 112 | 31.6 |
| | ≥$90 000 | 31 | 23 | 103 | 29.1 |
| | Missing | 11 | 8.1 | 14 | 4 |
| Ethnicity background | Caucasian | 101 | 75 | 309 | 87 |
| | Asian | 12 | 9 | 12 | 3.3 |
| | African-American | 1 | 0.7 | 0 | 0 |
| | Arab/West-Asian | 3 | 2.2 | 6 | 1.7 |
| | Latin | 1 | 0.7 | 3 | 0.8 |
| | N. American Indian | 5 | 3.7 | 0 | 0 |
| | Missing | 12 | 8.8 | 24 | 6.7 |
| Community | Major urban | 63 | 46.7 | 257 | 72.6 |
| | Small urban | 41 | 30.4 | 31 | 8.8 |
| | Rural | 24 | 17.8 | 60 | 16.9 |
| | Missing | 7 | 5.2 | 6 | 1.7 |

school right after discharge. Thirty-nine per cent of the children lost consciousness due to injury and 61% had an abnormal initial CT. At discharge, 77% were able to walk independently; 15% used an aid for walking and 8% used a wheelchair. English was the language most often spoken at home (97%).

Children in sample two were recruited through the Thames Valley District School Board in London, Ontario, Canada. Schools with grades kindergarten through grade Eight were stratified by income distribution within the district and 16 schools were randomly selected from within these income bands. Packages containing questionnaires and study information were sent to the schools to be randomly distributed to every second, third or fourth child on the alphabetical class list (depending on the size of the class) and taken home. Children were excluded if (1) they had physical disability; (2) they were studying in a segregate class or (3) they/their parents could not read English well. In the typically-developing sample, the participants included 354 children (147 boys and 207 girls) aged 6.5–15 (mean = 10.4, SD = 2.2).

The majority of children in both samples had a Caucasian background (75% and 87%, respectively) and similar annual family income falling between $60 000–89 999 (29.6% and 31.6%, respectively). In both samples, the majority of the families had two children living at home (38% and 52%, respectively). However, the samples were different in terms of age and gender. The sample of typically-developing children had a smaller percentage of boys (41% and 64%, respectively) and a larger percentage of adolescents, i.e. above 12 years old (70% and 54%, respectively). It is typical for clinical samples of children with ABI to have a higher proportion of boys [11].

### *Measurements*

Participation patterns were measured using the Children Assessment of Participation and Enjoyment (CAPE), a measure of involvement in everyday activities outside of mandated school activities [20]. The CAPE, designed for use with children/youth aged 5–21 years, includes 49 different activities in five activity categories/types: recreational (12 items), active physical (9), social (9), skill-based (9) and self-improvement activities (10). The children indicated (with parent/caregiver assistance, as needed) (a) what activities they participate in and (b) how often they have done the activities (using a 7-point scale). Each activity is presented to the child/youth on a card with a drawing of the activity and a phrase (in words) describing the activity. For further details see Imms' [21] review.

Two types of scores were generated from the CAPE: (1) diversity (a count of the number of activities in which the child participated) and (2) intensity (a mean score was calculated by summing/adding up the values assigned to each item frequency in each activity category and then dividing this sum by the number of possible activities in each activity category/scale of interest). The frequency scale is a

Table II. Three types of comparisons between ABI and typically-developing children.

| Type of comparison | Description/explanation |
|---|---|
| (1) Top 5 activities | The 5 most common activities in which children take part (out of the 49 possible activities). |
| (2) Participation *across* activity types | The relative proportion or trend of participation across all five activity types. For example, participation in recreational activities vs physical vs social vs skill-based vs self-improvement. |
| (3) Participation *within* each activity type | Level of participation diversity and intensity of each activity type separately. |

7-point scale and, thus, the intensity score ranged from 1–7. The diversity score was computed in percentages as well to allow comparison across activity categories. Higher scores indicated greater frequency. Diversity and intensity were calculated for each of the five activity categories, thus overall 10 scores were computed. The CAPE's construct validity was demonstrated [22] as well as its reliability [21] and was utilized within children with various disabilities [23, 24].

### *Data analysis*

As the two samples were not individually matched by age and gender, a *block* or a strata variable with four levels was created: boys/girls × under 12/above 12 years old. The *block* variable was formed based on previous findings showing that participation changes significantly as children move to adolescence (around age 12) and between the genders among children with [6] and without disabilities [17]. The blocking factor effect enabled the analysis to control for the characteristics of the groups (in terms of age and gender) while examining the differences in participation patterns between the groups [25].

Since the sample of children with ABI included participants with different levels of severity (i.e. 74% mild and 26% moderate-to-severe), *T*-tests were performed to verify that children's participation patterns, i.e. diversity and intensity, were not associated with severity of injury. Indeed, no significant differences in participation patterns were found between children with mild injury and those with moderate-to-severe injury ($0.05 < p < 0.95$ for intensity scores; $0.26 < p < 0.91$ for diversity scores).

Following the study's objectives, participation patterns in both groups were compared. Table II presents the three types of comparisons that were performed. In the first comparison, the five most frequent/common activities in each group were identified using descriptive statistics. Then, to examine if engaging in these activities is different between children with ABI and their typically-developing peers, Chi-square tests were performed for the identified activities.

In the second comparison, Repeated Measures ANOVA was performed using a Polynomial approach to determine whether the relative proportion of participation or trend, i.e. diversity scores *across activity types*, depends on the group type. Hence, an interaction effect of participation *across* activity categories and group type was examined.

Finally, in the third comparison, the effect of group type on diversity and intensity of *each* activity type (10 scores generated from the CAPE) was analysed while controlling for the groups characteristics (in terms of age and gender). Two-way ANOVAs tests were performed using the following design: 2 (group type) × 4 (blocks). Since the purpose of the blocking effect is to account for variability due to these factors (i.e. age and gender), the significance of the block effect itself was not of interest. However, the interaction effect was tested to determine whether the differences in participation depended on the child's age and gender. In addition, in order to examine the magnitude of the differences, Effect Size (ES) was calculated using the partial eta square ($\eta_p^2$) values based on the following formula: $\eta_p^2 = SS_b/(SS_b + SS_w)$ [26]. These values were interpreted according to Kirk's [27] classification where $\eta_p^2 = 0.01$ is considered as a small effect, $\eta_p^2 = 0.06$ as medium and $\eta_p^2 = 0.14$ as a large effect size.

Due to the multiple comparisons, the level of significant was set to 0.01 in order to reduce the chance for type I error.

## Results

### *Most common activities among the groups*

For the five most frequent activities, descriptive statistics indicated that children in both groups predominantly engaged in watching TV, playing board or cards games and playing computer or video games. These activities fall within the recreational category/activity type and are informal activities in nature (see Table III). Children with ABI also engaged in activities such as listening to music and talking on the phone which are considered as social activities, whereas typically-developing children

Table III. Most frequent five activities for children and youth with and without ABI.

| Group | Activity | Type | Frequency | $\chi^2$ |
|---|---|---|---|---|
| Children with ABI ($n = 135$) | Watching TV | Recreational | 97% | 8.13** |
| | Listening to music | Social | 96.2% | N/A |
| | Talking on the phone | Social | 93.9% | N/A |
| | Playing board or cards games | Recreational | 93.9% | 5.4* |
| | Playing computer or video games | Recreational | 91.7% | 1.12 |
| Typically-developing children ($n = 354$) | Watching TV | Recreational | 99.7% | |
| | Doing homework | Self-improvement | 98% | |
| | Reading | Self-improvement | 98% | |
| | Playing board or cards games | Recreational | 98% | |
| | Playing computer or video games | Recreational | 95% | |

**$p < 0.001$; *$p < 0.05$.
N/A = Not applicable.

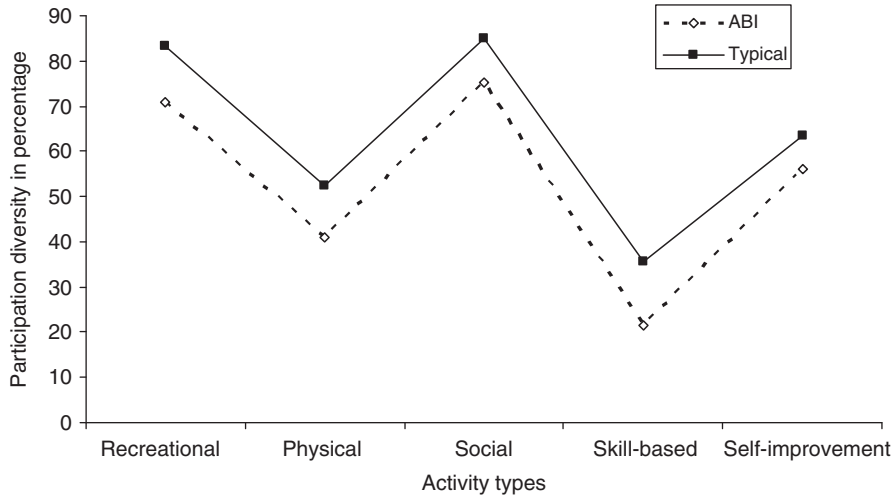


Figure 1. Relative proportion or trend of participation diversity (in percentage) across the CAPE's activity types and between the groups.

participated in reading and doing home work which are part of self-improvement activities.

Considering the most common activities found in *both* groups (i.e. watching TV, playing board/card games and computer/video games), Chi-square tests indicated that engaging in these activities was significantly associated with group type except for playing computer/video games. In other words, engaging in watching TV and playing board/card games was reported more often by children of the typical group, whereas taking part in computer/video games was similar among children with and without ABI.

### *Relative proportion of participation across activity types*

When examining participation diversity scores across the five CAPE activity types and between the groups, a similar trend or proportion across activity types was observed (Figure 1). Proportionally, both groups participated most in social activities followed by recreational activities, self-improvement and physical activities, while the least common activities were skilled-based (see Figure 1). Anova's test of Repeated Measures indicated this proportion across activity types was not dependant on group type ($F = 2.9$, $p = 0.02$). Both children with and without ABI have the same participation proportion or trend across activity types.

### *Participation within each activity type*

Examining participation diversity in each activity type revealed that children with ABI had a significantly lower level of participation in all of the five activity types. Effect size values for these differences range from small-to-medium (see Table IV).

Significant differences between the groups were also found for participation intensity across all the

Table IV. Participation scores across the CAPE activity types: Descriptive statistics and differences between the groups.

| | ABI | | | Typical | | | Anova | |
|---|---|---|---|---|---|---|---|---|
| | Min–max | Mean | (SD) | Min–max | Mean | (SD) | $F_{(df)}$ | $\eta_p^2$ |
| *Recreational activities* | | | | | | | | |
| Diversity | 2–12 | 8.7 | (2.3) | 5–12 | 10 | (1.7) | 38.80**(1,481) | 0.08 |
| Intensity | 0.8–6.3 | 3.7 | (1.3) | 1.6–6.4 | 4.4 | (1) | 23.07**(1,478) | 0.05 |
| *Active physical activities* | | | | | | | | |
| Diversity | 0–8 | 3.8 | (2.3) | 0–9 | 4.7 | (1.5) | 33.80**(1,481) | 0.07 |
| Intensity | 0–5.1 | 1.9 | (1.3) | 0–5.3 | 2.7 | (0.9) | 62.80**(1,478) | 0.12 |
| *Social activities* | | | | | | | | |
| Diversity | 0–9 | 6.9 | (1.7) | 2–9 | 7.6 | (1.4) | 26.62**(1,481) | 0.05 |
| Intensity | 0–5.7 | 3.5 | (1) | 0.2–5.9 | 3.6 | (0.9) | 2.09(1,478) | <0.01 |
| *Self-improvement activities* | | | | | | | | |
| Diversity | 0–9 | 5.8 | (1.8) | 3–10 | 6.3 | (1.4) | 12.15**(1,481) | 0.03 |
| Intensity | 0–4.9 | 2.7 | (0.9) | 1.3–5.3 | 3.2 | (0.7) | 17.73**(1,478) | 0.04 |
| *Skill-based activities* | | | | | | | | |
| Diversity | 0–7 | 1.98 | (1.6) | 0–9 | 3.2 | (1.7) | 33.28**(3,481) | 0.07 |
| Intensity | 0–3.9 | 0.98 | (0.86) | 0–5.3 | 1.7 | (0.9) | 30.72**(1,478) | 0.06 |

**$p < 0.001$, $\eta_p^2$ = Effect size.

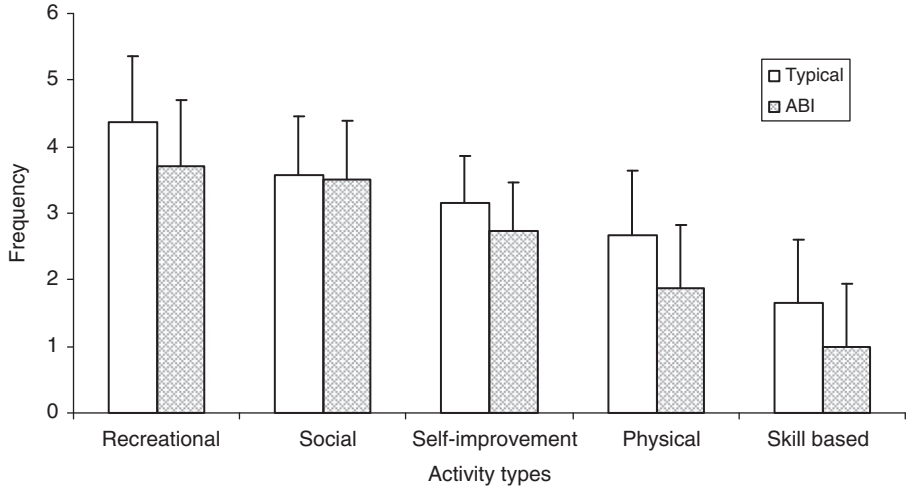


Figure 2. Level of intensity within each CAPE activity type and between the groups.

CAPE activity types except for intensity in social activities (see Table III). Children with ABI were less frequently involved in activities than typically-developing children (see Figure 2). Effect size values were small-to-moderate.

No significant interaction was found between group type and the age and gender groups. This finding indicated that the differences in participation patterns between the groups were not influenced by the child's age and gender.

## Discussion

This study is the first to examine similarities and differences in participation patterns between children and youth with ABI and their typically-developing peers. These findings indicate that participation diversity and intensity of children with ABI was lower across all the CAPE activity types, with the exception of intensity of social activities. These differences were not dependent on the child's age and gender. These results are very similar to previous studies that compared the participation of children with a range of physical disabilities [28] and youth with cerebral palsy [23] to their typically-developing peers. The findings also concur with the work of Bedell and Dumas [12], who found that participation of children and youth with ABI was restricted in comparison to what was expected at their age. Although the differences between the two

groups had low-to-moderate effect size, it is important to note that even small differences over time could impact on a child's development, socialization and competencies [2, 16]. Remarkably, differences in participation patterns exist even in a sample where the the majority of participants had only a mild ABI (74%).

Interestingly, the only activity category in which children with and without ABI had a similar level of intensity was involvement in social activities. Social activities are informal in nature and typically include activities such as *Talking over the phone*, *Going to a party*, *Going to the movies*, *Hanging out*. Informal activities are more spontaneous, involving fewer rules and structures, so could be relatively easier to engage in for children with ABI where concentration and behaviour problems might be present. However, it is not known how many of these activities were chosen by the children or whether parents initiated and scheduled these activities. Creating opportunities and planning was found to be one of the strategies parents used to enhance their child's social participation [29]. At the same time, preference for specific activities has been shown to significantly impact participation [30]. Future studies can explore this by including a measure of a child's preference for specific activities in the research as well as parents involvement/control.

Similar findings were revealed when identifying the five most frequent activities between the groups. Both groups engaged in recreational activities, yet children with ABI tend to be involved in social activities whereas the typically-developing peers participated in skill-based activities. It could be that skill-based activities (e.g. reading, writing a story) are more challenging considering the implication of a brain injury (e.g. attention span problems) and, hence, children with ABI may avoid such activities. Further studies are warranted to tease out the reason for choosing certain activities over others.

Although the participation diversity of children with ABI was restricted compared to typically-developing children, when examining each activity type separately, a similar proportion of participation across activities was observed for both groups. Both groups were more likely to engage in social and recreational activities and less in skilled-based activities. The explanation for this finding might be embedded in the characteristics of the sample. The majority of the participants had mild severity (74%) so may have been able to maintain a similar proportion of participation even after a brain injury. The children and youth with a brain injury were still in a recovery phase when these data were collected. Further changes to participation could take place [12] and a longitudinal analysis of participation after ABI is warranted. If participation remains restricted even after recovery has occurred, it is worth examining the factors that predict changes in participation and, consequently, potential strategies for enhancement.

These findings support the growing evidence for the potential implications of a mild brain injury, a level of severity that has been under-studied [14, 16]. Hence, the findings draw both researchers and therapists' attention to carefully consider the inclusion of a mild condition in intervention and future studies. It will be interesting to examine how participation patterns change over time across different levels of severities.

It was surprising that there were no significant difference between the mild and the non-mild groups in levels of participation. This finding may have been influenced by the characteristics of the sample in that only 17% of the participants had a severe level of injury (GCS $\leq 8$). If the sample was more diverse in terms of level of severity, significant differences may be observed. Further studies can clarify this relationship.

The fact that the ABI group included both children with traumatic (83%) and non-traumatic (17%) brain injury is noted. However, differences in overall participation diversity and intensity between the two sub-groups: traumatic/non-traumatic were minor/negligible and insignificant ($t = 0.86$, $p = 0.39$; $t = 1.32$, $p = 0.19$, respectively). Further exploration of the impact of cause of injury on participation patterns in larger samples/sub-groups is warranted.

Caution may be employed when generalizing this study results. Although the non-responders in the ABI group did not differ from the responders in terms of age, gender and severity of injury, 26% of the participants who met the inclusion criteria refused to consent. Since information regards the characteristics of this sub-group and the reason for refusal was not available, it could potentially influence the representative of the sample. At the same time, the sample aligns well with the general characteristics of children with ABI suggested by the Centres of Disease Control [11] in terms of age and gender.

Notably, this study used the CAPE to measure participation. Although the CAPE is a valid and reliable measure that addresses a broad range of activities, it focuses on leisure or after-school activities and, therefore, does not cover all domains of participation such as school and self-care. Future studies can complement these findings by capturing participation in different settings or life situations.

Another limitation of this study is that it did not examine the impact of other factors on participation. Further studies are warranted to explain why differences in participation patterns occur. Factors from

other studies which demonstrate significant impact on participation and are worth of investigation include child's abilities, environmental barriers, family cohesion and child and family preferences [30, 31].

In conclusion, participation diversity and intensity of children with ABI is restricted in comparison to their typically-developing peers, even in a sample in which a minor injury is predominant. Since participation has important influences on children's health and well-being and is considered as an intervention outcome, this finding indicates the importance of a focus on this outcome area for all children with ABI, including those with a mild injury. Findings from this study underscore the importance of participation for all children with minor brain injury.

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