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Laura K. Brunton

Western University, lbrunto3@uwo.ca

Doreen J. Bartlett

Western University, djbartle@uwo.ca

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Profiles of fatigue severity and variability among adolescents and young adults with cerebral palsy

Shortened Title: Fatigue Severity and Variability in Cerebral Palsy

Laura K. Brunton¹, PT, PhD, Postdoctoral Fellow, Faculty of Kinesiology,
University of Calgary, Calgary AB, Canada

Doreen J. Bartlett, PT, PhD, Professor, The School of Physical Therapy,
Western University, London ON, Canada

¹ Corresponding Author. Email: lbrunto3@uwo.ca

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Abstract

Background: Individuals with cerebral palsy (CP) experience progressive changes in functional status with the development of secondary impairments such as fatigue.

Detailed accounts of the fatigue experience in CP are lacking.

Purpose: This study describes the severity and variability of fatigue in CP using the Fatigue Impact and Severity Self-Assessment.

Methods: This was a descriptive cross-sectional study surveying 130 (61 males) individuals (mean age 18 years, 11 months; SD four years, six months) with CP.

Analyses comprised comparisons between two groups (Gross Motor Function Classification System (GMFCS) I and II-V), frequency counts and proportions.

Results: Significant differences exist between GMFCS groups for all fatigue severity questions. In addition, 38% of individuals classified as GMFCS level I reported their average fatigue as moderate to severe and 53% experienced fatigue on three or more days in the previous week. Sixty-eight percent of individuals classified as GMFCS II-V reported their average fatigue to be moderate to severe and 78% were fatigued on three or more days in the previous week.

Conclusions: Fatigue is a highly individualized phenomenon with significant burden for individuals with CP regardless of functional ability. Individuals in GMFCS Levels II-V reported increased fatigue severity and would benefit from specific management interventions.

Keywords: Fatigue, severity, variability, cerebral palsy, adolescents, young adults

Introduction

Cerebral palsy (CP) is a permanent disorder of movement and posture that leads to activity limitations as a result of non-progressive disturbances that occurred in the developing fetal or infant brain.[1] Although the pathophysiology is non-progressive in nature, it is well established that individuals with CP experience progressive changes in functional status over time.[2-6] With growth and maturation children and youth with CP may develop secondary impairments. Fatigue is a common secondary impairment associated with CP [7-8] and may be connected to observed declines in physical function, including the cessation of walking.[9] Youth and adults with CP are known to be more fatigued than the general population.[10-13] Taken together, between 18-39% of adults with CP (aged 16-80 years) are estimated to experience fatigue, and of those who are fatigued, anywhere from 12-41% are considered to be severely fatigued, as determined by a Fatigue Severity Score (FSS) ≥ 5.1 . [11-13]

Fatigue may be related to the level of the motor impairment experienced; however, fatigue has not consistently been shown to differ by level of functional ability as measured by Gross Motor Function Classification System (GMFCS) [14] level, [12-13,15] or the Gillette Functional Assessment Questionnaire.[8] However, individuals with bilateral distribution of CP (a potential proxy measure of increased functional limitation) have been found to be more fatigued than those with unilateral involvement.[13] What is clear is that fatigue represents a significant issue for individuals with CP regardless of age and functional ability level, but

detailed descriptions regarding self-reported severity and information about the variability of fatigue are not yet available.

Current Measurement Challenges

The lack of detailed information regarding self-reported severity of fatigue may stem from inadequate tools used to measure fatigue in this population. Many of the studies conducted to date have used measures of fatigue that are not validated for use within the CP population and/or provide only limited information about fatigue severity. For example, the FSS, although widely used to assess fatigue in samples with CP, has never been validated in this population. The FSS has been validated for use in other neurological conditions and generally demonstrates satisfactory convergent validity with varying strength of significant correlations with other measures of fatigue and health status. However, the original nine-item FSS did not withstand tests of unidimensionality, illustrating that calculating a summary score of the nine items may be inappropriate in neurological conditions.[16-17] In addition, the validity of the seven-point scoring system of the original FSS has been questioned.[16] The rating scale of the FSS ranges from one (completely disagree) to seven (completely agree) for all nine items. A score ≥ 5.1 has been shown to be equal to two standard deviations above the mean of reference sample and has been used to classify individuals as “severely fatigued” [18] despite the fact that neither the scoring system nor any of the individual items include descriptors specifically related to severity. As a result, using the FSS provides limited information about the perceived severity and no information about the variability of fatigue experienced by individuals.

The Fatigue Impact and Severity Self-Assessment

The unpredictable and highly variable nature of fatigue were highlighted as important by youth and young adults with CP in a qualitative study regarding the bodily experience of CP [19]; these issues need to be quantified and investigated further. To address some of the inadequacies of available tools to measure fatigue, the Fatigue Impact and Severity Self-Assessment (FISSA) was created and validated for youth and young adults with CP.[15] Specifically, the FISSA was created to assist with identifying individuals who are experiencing fatigue related to CP and to promote discussions between clinicians and their clients about fatigue and possible management strategies.[15]

The FISSA is a 37-item self-report questionnaire. The first 31 questions are generally scored using a five-point Likert scale from one (completely disagree) to five (completely agree). Questions related to the severity and variability of fatigue have a variety of scaling options and include questions related to fatigue experienced on weekdays vs. weekend days, average and cumulative fatigue over the week, and days where the most and least fatigue was experienced. Questions related to severity ask for a rating from one (no fatigue) to five (severe fatigue).[15] An impact score can be calculated by summing items one to 17 contained in the Impact Subscale (includes the severity profile) and a management score can be calculated by summing items 18-31 in the Management and Activity Modification Subscale.[15] Together the scores on both subscales produce a total score from responses to the first 31 questions and describes the fatigue experienced in terms of impact, severity and individual management. The remaining six questions are

comprised of asking individuals about diurnal fatigue as well as open-ended questions about managing fatigue for intervention planning.[15] Although these questions are not scored as part of either subscale or the total score, they provide a starting point for the clinical conversation about fatigue management. The FISSA was validated for use with adolescents and young adults with CP. An exploratory factor analysis and a known groups validation approach provided evidence of content and construct validity of the FISSA.[15] The FISSA also demonstrated adequate test-retest reliability for adolescents and young adults with CP.[15] Use of the FISSA will provide a more detailed understanding of fatigue for individuals with CP as they experience it.

The purpose of this quantitative study was to describe, in detail, the severity and variability of fatigue as reported by youth and young adults with CP. The primary objective was to describe and compare responses to the severity and variability questions of the FISSA between two functionally defined groups (individuals classified as GMFCS level I and individuals classified as GMFCS levels II-V). A secondary objective of this study was to describe and compare the severity and variability responses of the FISSA between two groups defined by distribution of CP (unilateral and bilateral).

Method

This was a descriptive cross-sectional study of fatigue experienced by adolescents and young adults with CP. A total of 367 youth and young adults with CP were contacted by regular post or electronic mail as part a larger study. Potential

participants were recruited from participating children's rehabilitation centres in Ontario, Canada, past research studies conducted by the research team, existing facebook groups for individuals with CP and through the Ontario Federation for Cerebral Palsy website and newsletter. Eligibility criteria included individuals aged 14 to 31 years of age, those who were English speaking and had the ability to complete self-report questionnaires with some degree of independence. Returned surveys completed entirely by parental proxy were excluded from the study. Diagnosis of CP was self-reported by all individuals. The survey mailing contained the FISSA, a self-report version of the GMFCS-Extended and Revised Version [20] to describe the functional abilities of respondents (self-report version available from <https://www.canchild.ca>) and a simple demographic questionnaire used to obtain self-reported distribution of involvement, age, sex and information regarding the amount of assistance required to complete the survey. The study followed a modified Dillman method.[21] This study received approval from the ethics review boards at Western University, McMaster University and specific clinical sites as appropriate. For the purposes of this study returning a completed questionnaire was considered implied consent.

Of the 367 individuals contacted, 163 questionnaires were returned over the course of the study, for a response rate of 44%. Ten questionnaires were returned blank, eight individuals reported that they did not meet eligibility criteria and therefore did not complete the questionnaire, and a further 15 questionnaires were completed entirely by parental proxy and were excluded from the analyses. A final convenience sample of 130 youth and young adults with CP participated in the study

by returning a questionnaire completed at least semi-independently (ranging from independent completion to having some assistance completing the questionnaire). Participant demographics are presented in Table 1 [table 1 near here].

As a result of the small number of participants in each GMFCS level, GMFCS levels were grouped together to increase the subgroup sample size and consisted of individuals who self-classified as level I (individuals who walk without limitations) separately, levels II (individuals who walk with limitations) and III (individuals who walk using a hand-held mobility device) were grouped together and levels IV (individuals who may use powered mobility due to limitations in self-mobilization) and V (individuals without the ability to self-mobilize) formed the third group.[20] These groups were based on an a priori hypothesis that individuals who had greater functional ability would experience less fatigue. A Kruskal-Wallis statistic was used to determine if the FISSA scores (total score, impact subscale score and management subscale score) differed by GMFCS grouping. To determine if the FISSA scores were different for individuals with unilateral versus bilateral involvement a Mann-Whitney U test was performed for the total score, impact score and management score. To determine if the responses to the severity and variability questions differed by GMFCS grouping, a Pearson's Chi-Square analysis was performed. Descriptive analysis of the survey responses comprised frequency counts and proportions by GMFCS grouping. Individuals with missing GMFCS data (6 participants) or distribution of involvement data (4 participants) were excluded from grouped analyses. Similar analyses were conducted for an additional two groups, individuals with unilateral involvement regardless of functional ability level

and individuals with bilateral involvement regardless of functional ability level because fatigue is thought to be related to distribution of involvement.¹³ These results are available in a supplementary file.

Results

Individuals classified as GMFCS level I experienced significantly less fatigue than individuals classified in any other GMFCS level (II-V) ($p < 0.001$). There were no significant differences in any of the FISSA scores (total score, impact subscale or management subscale score) for individuals classified as GMFCS levels II- V. Therefore, the remaining results will be presented for two functional groups, individuals classified as GMFCS level I separately and individuals classified as GMFCS II-V as a whole. A summary of the FISSA total and subscale scores by group can be found in Table 2 [table 2 near here]. Total fatigue ($\chi^2 = 28.504$, $p < .0001$), impact score ($\chi^2 = 34.677$, $p < .0001$) and management score ($\chi^2 = 13.805$, $p < .0001$) were significantly different between GMFCS groups. Total fatigue score and the impact score significantly differed between distribution of involvement groups. Specifically, individuals with bilateral distribution of CP experienced higher total fatigue ($U = 1217$, $p = 0.021$) and higher impact of fatigue ($U = 987.5$, $p = 0.005$) than those with unilateral distribution of CP. The management score was not significantly different between the two distribution groups ($U = 1110.5$, $p = 0.067$). Further details of the distribution of involvement data can be found in a supplementary file (Appendix A) as the focus of this manuscript is the comparison of fatigue based on functional ability level.

Comparisons between functional groups

Significant differences were found to exist between GMFCS grouping and all questions related to severity of fatigue, including level of fatigue on the most ($\chi^2 = 21.428, p < .001$), least ($\chi^2 = 14.149, p = .007$), and average ($\chi^2 = 24.025, p < .0001$) day. Similar results were found for the questions regarding how much of the day they were fatigued ($\chi^2 = 13.291, p = .01$) and how many days in the previous week they were fatigued ($\chi^2 = 20.019, p = .006$). However, questions regarding the variability of fatigue were not significantly different by GMFCS grouping, including changes in fatigue depending on time of day ($\chi^2 = 3.877, p = .05$) and changes in fatigue depending on day of the week ($\chi^2 = 0.580, p = .45$).

GMFCS Level I

When asked to report on the severity of their fatigue on the day in the previous week that they were most fatigued, 58% reported having experienced moderate to severe fatigue. When asked about the day in the previous week that they were least fatigued 33% reported some fatigue and fewer than 10% reported this to be moderate to severe fatigue. When asked to report their average level of fatigue for the previous week, 38% reported experiencing moderate fatigue with no participant in GMFCS level I reporting their average fatigue level to be severe. Twenty-seven percent reported that on the average day they experienced no fatigue at all (Figure 1) [figure 1 near here].

Participants were asked to report, on average, how much of the day that they felt fatigued. Seventy percent responded that they were fatigued at least a quarter of the average day or more. Participants were then asked how many days in the

previous week that they felt fatigued, the most frequently reported option was one day; however, when combined, 53% reported experiencing fatigue on at least three or more days of the previous week. In regards to variability of fatigue, 70% reported that their fatigue changed depending on the time of day; but only 33% reported their fatigue varied by day of the week. Of those who reported fatigue varied by time of day, 30% reported that late afternoon was when they were most fatigued, and an additional 30% reported the evening was when their fatigue was at its worst. Notably, another 26% chose the early morning as the time when they were most fatigued. For individuals who reported that the fatigue varied by the day of the week, Monday was reported as the day where they experienced the most fatigue by 31% of the sample, followed by Tuesday and Friday, equally, with 23% of individuals reporting the most fatigue on those days (Table 3) [table 3 near here].

GMFCS Levels II-V

Regarding severity of fatigue on the day in the previous week that they were most fatigued, all reported some level of fatigue, with 86% reported having moderate to severe fatigue. When asked about their fatigue level on the day in the previous week that they were least fatigued only 38% reported no fatigue, while 33% still reported moderate to severe fatigue. When asked to report their average level of fatigue for the previous week, only one percent reported no fatigue and 68% reported experiencing moderate to severe fatigue (Figure 1).

On the average day, 92% indicated that they were fatigued at least a quarter of the day or more. Participants also reported on how many days in the previous

week that they felt fatigued, the most frequently reported option was all seven days; however, when combined, 78% reported experiencing fatigue on at least three or more days of the previous week. Questions about the variability of fatigue revealed that 85% felt their fatigue changed depending on the time of day, while only 41% reported their fatigue differed depending on the day of the week. Specifically, individuals felt that fatigue was at its worst in the late afternoon (48%), followed by the evening (21.5%), and then by the early morning (16.5%). For those individuals who reported different levels of fatigue over the course of the week, fatigue was most commonly reported to be at its highest on Mondays (37%) followed closely by the end of the work/school week (Friday, 34%). Only a few individuals reported increased fatigue mid-week or on the weekend days (Table 3).

Discussion

Individuals with CP consistently reported substantial fatigue that may affect activities of daily living. Despite the significant role fatigue may have in functional deterioration and loss of mobility there are currently no specific interventions targeted at reducing or managing fatigue. The FISSA was created to measure fatigue in greater detail to facilitate a better understanding of the fatigue experienced by people with CP at both the individual and group level.[15] This is the first study to describe, in depth, the severity and variability of fatigue experienced by youth and young adults with CP. The results of this study demonstrate that fatigue is a highly individualized phenomenon and that fatigue is more severe and more frequently reported by individuals with increased functional disability. More than 70% of

participants in this study reported being fatigued for at least a quarter of their average day. Similarly, more than half the participants in this study reported experiencing fatigue on three or more days in the previous week. In those with lower functional abilities (GMFCS II-V) this increased 78% experiencing fatigue on three or more days in the previous week. Thirty-eight percent of individuals classified as GMFCS level I reported their average fatigue to be moderate to severe, highlighting that fatigue is still a significant problem for individuals with relatively mild motor impairments. Sixty-eight percent of individuals classified as GMFCS level II-V reported their average level of fatigue as moderate to severe; clearly these individuals need management strategies aimed at reducing fatigue.

Future Directions

This study provides a rich description of the fatigue experienced by individuals with CP and can serve as step towards intervention planning related to energy conservation strategies. A self-report measure such as the FISSA can provide a comprehensive description of fatigue to ensure all potential aspects of the condition are considered for intervention. Eken et al. [23] demonstrated that adolescents with CP have lower levels of muscular endurance than their peers. Furthermore, they demonstrated a significant relationship between muscular endurance and level of subjective fatigue,[23] this may indicate that interventions aimed at increasing muscular endurance could be beneficial for individuals reporting high levels of fatigue on the FISSA. The FISSA contains a few items that speak to the mental component of fatigue for individuals with CP; however, further information is needed about the effect of mental state on fatigue in individuals with

CP and should be explored in future studies. Although fatigue has been identified as a factor contributing to loss of mobility in the early years of adulthood [2-5,7,9] there is limited descriptive data regarding the severity and variability of fatigue necessary to plan interventions aimed at mitigating the consequences of fatigue.[2-3,5,9] A better understanding of the fatigue experienced during the years where functional decline is prevalent will help elucidate the role that fatigue may play in loss of functional ability for people with CP and how it can be best managed.

Limitations

This study used a convenience sampling approach that could have resulted in a selection bias. It is possible that individuals experiencing fatigue were more likely to respond to the survey and this could result in an over-estimation of the fatigue experienced by the population with CP. This is a limitation of the current study. The treatment centres used to identify potential participants required an internal staff member to facilitate the survey mailing and the authors did not have access to any descriptors for individuals who did not respond to the survey mailing. As a result, we were unable to determine if the characteristics of responders and non-responders were different, potentially limiting the generalizability of the findings from this study. Finally, in the validation of the FISSA, the items contained in the management scale explained only 6.2% of variance in addition to the impact scale items. Although this is a low contribution to explained variance, and thus a potential limitation, the management scale provides more in-depth clinically relevant information and was retained as part of the scale to enhance the clinical utility of the

FISSA. Despite these limitations, the results of this study are in agreement with the available literature for both children and adults with CP.

Conclusions

A more descriptive understanding of the fatigue experienced by individuals with CP across the spectrum of functional abilities and the lifespan is needed to develop interventions aimed at maintaining optimal functioning for as long as possible. Decreased physical activity and increased sedentary behaviour associated with loss of mobility are risk factors for the development of chronic diseases such as obesity, cardiovascular disease and type II diabetes. Adequate fatigue management may allow individuals with CP to remain active longer, potentially delaying or preventing the onset of chronic disease and enhancing overall quality of life. This is the first study to provide detailed descriptive information about fatigue severity and the related variability for youth and young adults with CP. This information can be used to understand the fatigue experienced by an individual person when considering clinical interventions or describing groups that may benefit from the design and implementation of new interventions to reduce fatigue.

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Table 1 - Participant Characteristics and Demographic Information of the Sample

Characteristic		Total (n=130)
		n (%)
Sex ^a	Male	61 (47%)
	Female	68 (53%)
Age	Mean, years (SD)	18.9 (4.5)
	Median	17
	Range	14-31
GMFCS Level ^b	I	34 (27%)
	II	39 (32%)
	III	21 (17%)
	IV	18 (14%)
	V	12 (10%)
Distribution of Involvement ^c	Monoplegia	6 (5%)
	Hemiplegia	31 (25%)
	Diplegia	44 (35%)
	Triplegia	11 (9%)
	Quadriplegia	34 (26%)

GMFCS= Gross Motor Function Classification System; Note: ^aone participant did not report their sex; ^bsix participants did not report GMFCS level; ^cfour participants did not report distribution of involvement.

Table 2 - Summary of Fatigue Scores by Classification Group

	GMFCS I ^a (n=34)	GMFCS II-V ^a (n=90)	Unilateral CP ^b (n=37)	Bilateral CP ^b (n=89)
Total Fatigue Score				
Mean (SD)	71 (23.3)	102 (25.3)	85 (32.1)	99 (25.8)
Median (Range)	72 (31-127)	105 (40-149)	91 (31-147)	98 (37-162)
Impact Scale Score				
Mean (SD)	32 (11.4)	52 (15.4)	41 (17.8)	50 (16.2)
Median (Range)	31 (16-62)	54 (20-83)	37 (16-78)	50 (17-87)
Management Score				
Mean (SD)	37 (13.2)	47 (11.5)	40 (15.5)	46 (11.2)
Median (Range)	38 (14-60)	50 (14-66)	42 (14-66)	50 (17-70)

GMFCS= Gross Motor Function Classification System; Note:^asix participants did not report GMFCS level; ^bfour participants did not report distribution of involvement.

Table 3 – Frequency of Responses to Questions Regarding Variability of Fatigue

Fatigue Related Question	Possible Responses	GMFCS I^a (n=34)	GMFCS II-V^a (n=90)
On average, how much of the day do you feel fatigued?	None	29%	8%
	A Quarter of the Day	47%	42%
	Half the Day	18%	31%
	Three Quarters of the Day	6%	13%
	All Day	0%	6%
For how many days last week did you feel fatigued at least part of the day?	1 Day	29%	12%
	2 Days	18%	10%
	3 Days	9%	21%
	4 Days	9%	13%
	5 Days	23%	15%
	6 Days	6%	1%
	7 Days	6%	28%
Does your level of fatigue change depending on the time of day?	Yes	70%	85%
	No	30%	15%
If your fatigue changes depending on time of day, what	Early Morning	26%	16%
	Mid-Morning	5%	6%

time of day is your fatigue the worst?	Noon	9%	8%
	Late Afternoon	30%	48%
	Evening	30 %	22%
Does your level of fatigue change depending on day of the week?	Yes	33%	41%
	No	67%	59%
If your fatigue changes depending on day of the week, on which day are you most fatigued?	Monday	31%	37%
	Tuesday	23%	5%
	Wednesday	0%	7%
	Thursday	15 %	15%
	Friday	23%	34%
	Saturday	8%	2%
	Sunday	0%	0%

GMFCS= Gross Motor Function Classification System; Note:^asix participants did not report GMFCS level.

Figure 1 – Fatigue Severity Profiles by Gross Motor Function Classification System (GMFCS) Level

