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Construction and validation of the fatigue impact and severity self-assessment for youth and young adults with cerebral palsy.

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Construction and Validation of the Fatigue Impact and Severity Self-Assessment for Youth and Young Adults with Cerebral Palsy

Abstract

Purpose: The Fatigue Impact and Severity Self-Assessment (FISSA) was created to assess the impact, severity and self-management of fatigue for individuals with cerebral palsy (CP) aged 14-31.

Methods Used: Items were generated from a review of measures and interviews with individuals with CP. Focus groups with healthcare professionals were used for item reduction. A mailed survey was conducted (n=163/367) to assess the factor structure, known-groups validity and test-retest reliability.

Results Obtained: The final measure contained 31-items in two factors and discriminated between individuals expected to have different levels of fatigue. Individuals with more functional abilities reported less fatigue ($p< 0.002$) and those with higher pain reported higher fatigue ($p< 0.001$). The FISSA was shown to have adequate test-retest reliability, ICC(3,1)=0.74 (95% CI 0.53-0.87).

Conclusions Reached: The FISSA valid and reliable for individuals with CP. It allows for identification of the activities that may be compromised by fatigue to enhance collaborative goal setting and intervention planning.

Key words: Fatigue, Measurement, Cerebral Palsy, Adolescents, Young Adults

1. Introduction

Fatigue has been identified as one of the top three cerebral palsy (CP)-related impairments in adulthood that can affect activities of daily life [1]. Approximately 20% of physicians reported a noticeable functional deterioration in the adults with CP they treat [1]; some self-reported causes of such deterioration include spasticity, fatigue, pain and lack of physical training [2, 3]. Fatigue has been shown to be more prevalent in adults with CP compared to the general population [4]. A 20% prevalence of fatigue in a sample of adults with CP has been reported and notably, 41% of those individuals were classified as severely fatigued [5]. Individuals who reported severe fatigue were 2.3 times more likely to report concurrent chronic pain and 3.4 times more likely to report concurrent depressive symptoms [5]. In addition, there are reports that fatigue may play a role in physiological burnout experienced by adults with CP. Deficits in muscle function, combined with the natural history of CP and the development of secondary conditions (such as fatigue) during growth and maturation, have been hypothesized to lead to functional deterioration and early loss of mobility [6, 7], the specific role fatigue may play in this cycle remains unknown. In a personal reflection, Jones [3] discussed her experience of aging with CP and discussed the need to better understand the prevention and management of secondary conditions such as fatigue.

There are numerous published scales available to measure fatigue; however, none have been validated for use in a population of individuals with CP. The purpose of this study was to create and validate a new measure of fatigue, the Fatigue Impact and Severity Self-Assessment (FISSA), to gain a better understanding of fatigue experienced and to enhance self-management of fatigue for individuals with CP.

2. Methods

Phase 1 – Initial item generation

As part of a larger study, a search was conducted in the CINAHL and EMBASE databases for articles that assessed the psychometric properties of published fatigue scales [8]. Fatigue scales identified in the search were then reviewed and items were identified based on relationships to themes in the existing literature. Secondly, items were generated based on the themes discussed by individuals with CP in a phenomenological inquiry (n=10) described elsewhere [9]. The collated items were rephrased to enhance relevance and to simplify or standardized the language and formatted into a new questionnaire.

Phase 2 – Item reduction and refinement

Two focus groups were then held with healthcare providers at children's treatment centres in Ontario, Canada. Healthcare professionals who normally treat individuals with CP helped reduce the number of items to a small, relevant subset of questions [8]. Involving expert clinicians in the refinement of this measure enhances the content validity, which strengthens the clinical inferences that may be drawn from the questionnaire [10].

A modified nominal group technique [11] was used to reduce the items from the scale, and to add items that that were overlooked in the previous stages of item generation. The use of both activities (reduction and addition of new items) ensured balance between preserving a high level of content validity, creating a feasible questionnaire, limiting respondent burden and incorporating the perspectives of service providers who work with individuals with CP.

Phase 3 - Feasibility testing

Ten questionnaires were distributed to individuals with CP between the ages of 14 and18 years from children's treatment centres in Ontario, Canada; who were classified as level I or II on the Communication Function Classification System (CFCS) [12] and as levels I to IV on the Expanded and Revised Version of the Gross Motor Function Classification System (GMFCS-ER) [13]. Participants were asked to read the FISSA and complete a feasibility questionnaire to ensure that the items were comprehensible, unambiguous and easy to respond to. This step was considered a separate assessment of the content validity of the scale.

Phase 4 – Psychometric assessment

A large survey mailing was used to assess the psychometric properties, specifically the factor structure, known-groups validity, internal consistency and test-retest reliability, of the FISSA. A total of 367 youth and young adults with CP were contacted as potential participants for the study from participating children's rehabilitation centres in Ontario, Canada, previous research studies, existing facebook groups for individuals with CP and through the Ontario Federation for Cerebral Palsy website and newsletter. Due to the diverse recruitment methods, individuals of all functional ability levels elected to participate. Study eligibility criteria included individuals aged 14 to 31 years of age, English speaking and the ability to complete the questionnaire with some degree of independence. Returned surveys that were completed entirely by parental proxy were excluded from the study. In addition to the FISSA, a self-report version of the GMFCS-ER [13] was used to collect information on the participants' level of functional ability. Other measures included a simple demographic questionnaire used to obtain self-reported distribution of involvement, age and sex and a pain questionnaire to collect information on prevalence, severity, impact and location of pain [14]. The final page of the survey booklet asked for information regarding the amount of assistance required to complete the survey.

The study followed a modified Dillman method [15]. All potential participants initially received a full survey package (either a hard copy or a link to an online version of the survey materials). A reminder letter was mailed (or emailed) to each potential participant approximately two weeks following the initial mailing. All individuals who had not returned or completed the survey two weeks after the reminder letters were sent received a second full questionnaire package or an email containing the original link. To assess the test-retest reliability of the FISSA and pain questionnaires, a small subset of the sample were asked to complete these portions of the survey a second time approximately two weeks after their initial response. All phases of this study received ethical approval from the ethics review boards at Western University, McMaster University and specific clinical sites as appropriate. Each individual participant provided written informed consent, or in case of the survey, completion implied consent, to participate in this study.

An exploratory factor analysis was conducted using principal components analysis on the final data set obtained from the FISSA. Prior to conducting the factor analysis, the data were screened for suitability using inspection of the magnitude of correlations among items [16], the Kaiser-Meyer-Olkin measure of sampling adequacy and Bartlett's test of sphericity. Cattell's Scree test and parallel analysis were used to determine the number of factors extracted and retained for the remainder of the analysis. The remaining factors were then rotated to better understand the meaning of each factor using the direct oblimin approach as it was hypothesized that the factors would be related. A final model was then created to explain the underlying structure of the questionnaire and to understand how the factors were acting in the scale.

The known groups validity of the FISSA was examined by investigating the difference in fatigue score by GMFCS level and between high and low pain (represented by both severity and impact of pain). GMFCS levels were grouped together to increase the subgroup sample size and consisted of individuals who self-classified as level I separately, levels II and III were grouped together and levels IV and V formed the third group. The Kruskal-Wallis statistic was used to compare the difference in fatigue between groups of GMFCS levels. A median split was applied to the pain severity and impact data and a Mann-Whitney U was used to assess the difference in fatigue by pain level. Internal consistency of the FISSA was assessed using Cronbach's alpha. Test-retest reliability of the FISSA and pain questionnaire were analysed using an intraclass correlation, specifically the ICC(3,1) model was used [17].

3. Results

Phase 1 – Initial item generation

The initial draft of the scale comprised 50 items. Forty-four items were selected from 9 different fatigue scales identified in the review [8]. Furthermore, the author created 6 additional items to represent concepts discussed in the interviews conducted with youth and young adults with CP in the study by Brunton and Bartlett [9].

Phase 2 – Item reduction and refinement

A total of 11 healthcare professionals (5 Physical Therapists, 3 Occupational Therapists, 1 Recreation Therapist/Kinesiologist, 1 Nurse and 1 Physiatrist) participated in one of two focus groups. The initial focus group resulted in removal of 11 items, rephrasing the remaining items for consistency and clarity, and the addition of 4 items to the questionnaire. The second focus group resulted in removal of 3 items and the addition of 4 items. The participants in the second focus group informed the draft definition of fatigue as follows 'Please answer the following questions about your experience with fatigue. For the purposes of this questionnaire we would like you to think about fatigue in terms of: physical tiredness, muscle soreness, exhaustion of your muscles and body, or any related feeling. When answering the questions, please try to focus on fatigue as it is defined above and not pain you may experience that is different from muscle soreness'.

Response options were then set to a 1 to 5 Likert scale, allowing for a neutral option and anchors provided on each number from 'Completely Disagree' to 'Completely Agree'. This scale was chosen to align with the scaling requirements for a reliable discriminative measure [18, 19]. Several questions related to the severity of fatigue were given a variety of scaling options as related to individual questions as appropriate. Specifically, 5 questions regarding severity and variability of fatigue were given separate scaling options. Questions asking about level of fatigue on the most and least fatiguing days and on the average day were scaled to have the labels reflect “No Fatigue” to “Severe Fatigue” with the middle label representing “Moderate Fatigue”. Similarly question 16 “On average, how much of the day do you feel fatigued?” was scaled to divide the day into quarters and provide a no fatigue option. Question 17 “For how many days last week did you feel fatigued at least part of the day?” was scaled according to the possible 7 days in a week. It was felt that these changes were required to accurately capture meaningful information regarding fatigue severity and variability that could not be captured in with the scoring system used in the rest of the measure. Finally, a timeframe of 7 days was added to the questionnaire to orient users to consider the same timeframe when completing the questionnaire.

Phase 3 - Feasibility testing

Five feasibility questionnaires were returned completed; two individuals withdrew from the project - one due to the time required to complete the questionnaire and one due to feeling overwhelmed by the impact of fatigue on their daily life as a result of reading the questionnaire. The remaining three questionnaires were not returned for unknown reasons. Three participants felt that the FISSA was easy or not too difficult to understand, with one participant needing help understanding the meaning of some words. The final participant found the impact section of the questionnaire confusing and felt it was only relevant to individuals who were ambulatory. Four of the five participants indicated that the response options were appropriate given the questions that were being asked and on consideration of this feedback, no changes were made to the FISSA [8].

Phase 4 – Psychometric assessment

Of the 367 individuals contacted, 163 questionnaires were returned over the course of the study, for a response rate of 44.4%. 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). Figure 1 provides a detailed breakdown of the returned questionnaires. Table 1 contains the participant characteristics and demographic information of the 130 participants.

During the data screening for adequacy for factor analysis the internal consistency of the 32 items together was 0.95. The non-parametric Spearman's Rho correlations did not reveal any correlations above 0.9 and 62% of the correlations were above 0.3, the Kaiser-Meyer-Olkin measure of sampling adequacy was demonstrated to be 0.90, which is considered to be excellent [20], and Bartlett's test of sphericity was found to be significant (p< .001) all indicating that the data set was appropriate for factor analysis. Based on Cattell's Scree plot and parallel analysis, two factors (Impact of Fatigue on Daily Living and Management and Activity Modification) were retained in the factor structure of the FISSA and together they explained 48.7% of the variance. The Impact factor explained 42.5% of the variance and the Management and Modification Factor explained an additional 6.2% of the variance in fatigue scores. Item loadings found to be 0.4 or greater were considered significant [21]. In total 17 items loaded on the first factor (Impact of Fatigue on Daily Living) and 15 items loaded on the second factor (Management and Activity

Modification). One item (*Fatigue interferes with my participation in social activities*) loaded moderately on both factors; however, it is considered to be part of the first factor given its slightly larger loading. Finally one item (*Fatigue interferes with my ability to control my mood*) did not load sufficiently on either factor and was removed from the scale, resulting in a final 31-item version of the FISSA (Appendix A). Refer to Table 2 for the individual factor loadings.

Table 3 contains the descriptive information of the FISSA score by grouped GMFCS level, and low or high pain level. Individuals classified as GMFCS level I experienced significantly less fatigue than individuals classified in any other GMFCS level (II-V) ($p< 0.001$). Individuals classified as GMFCS level IV or V did not experience significantly more fatigue when compared to individuals classified as GMFCS level II or III regardless of whether the total score ($p= 0.063$) or the individual factor scores were assessed (Impact $p=0.069$; Management $p=1.0$). Individuals with higher pain (both impact and severity) reported higher total FISSA scores and higher individual factor scores ($p< 0.001$).

The Cronbach's alpha for the 31-item FISSA was 0.95. The average test-retest interval in this study was 36 days (range 13 to 87 days). A total of 31 individuals returned their test-retest package completed. The FISSA as a whole demonstrated moderate reliability with an ICC(3,1) = 0.75 (95% CI 0.54-0.87). The pain questionnaire demonstrated an ICC(3,1) = 0.73 (95% CI 0.50-0.86) for the impact component and an ICC(3,1) = 0.78 (95% CI 0.59-0.89) for the severity component.

4. Discussion

A new fatigue scale, the FISSA, was created using a variety of methods to ensure relevance to the users of the scale: youth and young adults with CP and their healthcare providers. A review of fatigue measures in the context of knowledge of the clinical course of CP allowed for inclusion of items known to be related to fatigue in CP. The interviews described in the study by Brunton and Bartlett [9] provided a client-centered approach to item generation and selection to enhance the applicability of the questionnaire to individuals with CP. The healthcare providers who participated in focus groups offered an expertise-based method of reducing and adding items to the scale to balance respondent burden while retaining a complete and relevant set of items. The FISSA was then pilot tested in a sample of youth and young adults with CP to ensure the questions were easily understood and completed by potential users of the scale. One participant posed the question 'Why do my muscles ache when I am fatigued?' to her doctor as a result of reading and completing the questionnaire, providing evidence that the FISSA is prompting individuals to think about fatigue and the consequences of activity, which may contribute to the development of self-awareness [8].

An exploratory factor analysis and a known groups validation approach were used to provide evidence of content and construct validity of the FISSA as there is currently no accepted measure available to provide information about fatigue in individuals with CP. The FISSA demonstrated a related 2-factor solution that explained 49% of the variance and was able to discriminate between groups expected to experience more fatigue (individuals classified as having more functional impairment according to the GMFCS and individuals experiencing a high degree of pain, both in terms of severity and impact). Finally, the FISSA was shown to be reliable with a high degree of internal consistency and a moderate correlation coefficient over a period of time where no change was expected.

Many individuals (regardless of GMFCS level) live with fatigue as a consequence of daily activities [22] and there are limited strategies available to these individuals to effectively manage their fatigue. There is a great need to understand how fatigue is impacting a client's life and the ability to accomplish activities of daily living [23]. The FISSA was created with this goal in mind: to assist with identifying individuals who are experiencing fatigue related to CP and as a method of fostering a clinical discussion between clinicians and their clients about fatigue and possible management strategies. The FISSA provides a preliminary description of activities that fatigue interferes with, an overview of the severity of fatigue experienced by the individual and a report on the management strategies that an individual may or may not have tried to effectively limit or manage their fatigue. Early identification of fatigue and the activities that are most affected may assist with intervention selection to interrupt the cycle of deconditioning described in individuals with CP [7]. The progression of the activity limitations in CP as a result of fatigue are thought to be linked to functional decline that can affect independence in adult life [7]. Once fatigue is identified, strategies and adaptions to increase fatigue management in specific areas may be more easily conceivable and available to these individuals. This self-assessment can be used on an individual basis to streamline a clinical conversation to the salient fatigue-related issues. For example, fatigue experienced in community settings that require long distance ambulation or activities that are of a long duration might be managed and mitigated by initiating discussions on the use of powered mobility. The goal would be to highlight the individual's ability to increase their engagement in the activity while recognizing that fatigue may be a limiting factor. Another example would be discussing the opportunities for rest or napping during a typical day or week to manage fatigue that accumulates or changes based on daily or weekly tasks. The FISSA may help clinicians effectively discuss possible solutions and strategies to limit or manage the impact of fatigue that is specific to the individual (i.e. daily or weekly patterns of fatigue, specific challenges or activities) while being mindful of limited time and resources in the clinical setting.

Limitations

Several authors have suggested a ratio of between five to ten participants per item when determining sample size adequacy for factor analysis. This is a limitation in this study as the ratio of participants to items was 4:1. However, these guidelines have been challenged [24] and it was found that changes to the participant to item ratio made little difference in the stability of the factor solution when parallel analysis was used as the primary extraction method. In addition, it has been argued that factors that contain four or more loadings of 0.60 or higher are reliably extracted regardless of the sample size [25]. In the case of the FISSA, both factors readily met this criterion. The FISSA was unable to discriminate individuals classified as GMFCS Level II and III from those classified as GMFCS Level IV and V, this could have been due to the relatively small subgroup sample sizes and should be investigated with a larger study in the future. Presently the FISSA has only been validated for use as a discriminative measure. Future validation efforts are needed prior to using the FISSA as a predictive or evaluative measure. The authors of this study plan to continue to evaluate the validity of the FISSA in terms of it's utility as a predictive and/or evaluative measure. Similarly, ongoing use of the FISSA in both clinical practice and research will allow for evolution of the measure through increased refinement of items and through additional testing of the factor structure and subscale profiles. Finally, more research is needed regarding the effectiveness of fatigue management strategies used by individuals with CP.

Conclusion

The FISSA represents a valid and reliable tool that can be used to identify individuals who have a significant impact of fatigue on their lives. We hope that clinicians will use the FISSA to initiate conversations about the functional restrictions individuals are experiencing as a result of fatigue and use the measure as a starting point for discussion about possible management strategies. Jones [3] recognized the need to identify and collaborate on interventions to address functional problems; the FISSA can facilitate this collaboration. Clinicians can examine the responses to individual items of the FISSA as a method of identifying the specific areas of the individual's life that fatigue is impacting most, especially given the highly individualized presentation of CP. Ideally, the FISSA will then be used to facilitate collaborative goal setting and future intervention planning between clinicians and their clients and families.

Declaration of Interest

This work was supported through a Canadian Doctoral Student Scholarship awarded to L. Brunton from the Canadian Institutes of Health Research.

Appendix A

Fatigue Impact and Severity Self-Assessment (FISSA)

Please answer the following questions about your experience with fatigue. For the purposes of this questionnaire we would like you to think about fatigue in terms of:

- physical tiredness
- muscle soreness
- exhaustion of your muscles and body
- or any related feeling

When answering the questions, please try to focus on fatigue as it is defined above and not pain you may experience that is different from muscle soreness.

Impact Scale

Completely Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Completely Agree
1	2	3	4	5

Using the scale above and thinking about **a <u>typical</u> week** (7 days), to what extent do you agree with the following statements?

Fatigue interferes with …

1. my general everyday activities	1	2	3	4	5
2. my ability to move around indoors	1	2	3	4	5
3. my ability to do things on my own	1	2	3	4	5
4. my ability to move around in my community	1	2	3	4	5
5. my ability to get outside of my house	1	2	3	4	5
6. my ability to finish things	1	2	3	4	5
7. my participation in social activities	1	2	3	4	5
8. my ability to start things	1	2	3	4	5
9. my ability to take care of myself (examples: dressing, eating, bathing, brushing my teeth/hair, toileting etc.)	1	2	3	4	5

In addition,

10. I use adaptive equipment to manage my fatigue (examples: a walker, manual wheelchair, power wheelchair etc.)	1	2	3	4	5
11. I have had to reduce my work responsibilities outside of my home because of fatigue (examples: school work, job-related work, volunteering etc.)	1	2	3	4	5
12. I have had to reduce my responsibilities at home because of fatigue	1	2	3	4	5

Appendix A

Using the scale given with each question, please think about the **<u>last</u> seven (7) days** and answer the following statements or questions.

13. Rate your level of fatigue on the day within the last week that you felt the **<u>most</u>** fatigued:

No Fatigue		Moderate Fatigue		Severe Fatigue
1	2	3	4	5

14. Rate your level of fatigue on the day within the last week that you felt the **<u>least</u>** fatigued:

No Fatigue		Moderate Fatigue		Severe Fatigue
1	2	3	4	5

15. Rate your **average** level of fatigue for the past week:

No Fatigue		Moderate Fatigue		Severe Fatigue
1	2	3	4	5

16. On average, how much of the day do you feel fatigued?

None	A Quarter of the Day	Half the Day	Three Quarters of the Day	All Day
1	2	3	4	5

17. For how many days <u>last week</u> did you feel fatigued at least part of the day?

1 2 3 4 5 6 7

Management and Activity Modification Scale

Using the scale below and thinking about a **typical week** (7 days), to what extent do you agree with the following statements?

Completely Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Completely Agree
1	2	3	4	5

Fatigue interferes with …

18. my enjoyment of life	1	2	3	4	5
19. my leisure and recreational activities	1	2	3	4	5
20. the length of time I can be physically active	1	2	3	4	5
21. my balance and coordination	1	2	3	4	5
22. my motivation to do physical activities	1	2	3	4	5
23. my motivation to participate in social activities	1	2	3	4	5

In addition,

24. my muscles ache when I am fatigued	1	2	3	4	5
25. long periods of inactivity increase my fatigue	1	2	3	4	5
26. stress increases my fatigue	1	2	3	4	5
27. fatigue increases my stress	1	2	3	4	5
28. I pace my physical activities to manage my fatigue	1	2	3	4	5
29. I think about fatigue when I plan my day	1	2	3	4	5
30. I limit my physical activity to manage my fatigue	1	2	3	4	5
31. I stop and rest during activity to manage my fatigue	1	2	3	4	5

Appendix A

Additional Questions:

32. Does your level of fatigue change depending on the time of day?

Yes (If yes, please answer question 32b) No

32b. What time of day is your fatigue the worst?

Early Morning	Mid-morning	Noon	Late afternoon	Evening
1	2	3	4	5

33. Does your level of fatigue change depending on the day of the week?

Yes (If yes, please answer question 33b) No

33b. On which day of the week are you most fatigued?

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
1	2	3	4	5	6	7

34. What factors are responsible for or contribute to your fatigue?

35. What do you do to reduce or manage your fatigue?

36. What else could you do to reduce or manage your fatigue?

37. What could other people do to help reduce your fatigue?

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Table 1 - Participant Characteristics and Demographic Information of the Sample

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

GMFCS= Gross Motor Function Classification System; Note: [*]one participant did not report their sex; [□]six participants did not report GMFCS level; [□□] four participants did not report distribution of involvement.

Table 2 – Fatigue Impact and Severity Self-Assessment Item Factor Loadings

	Rotated Factor Loadings	
Item	**Factor 1 – Impact of Fatigue on Daily Living**	**Factor 2 – Management and Activity Modification**
Fatigue interferes with my ability to do things on my own	**.77**	.03
I use adaptive equipment to manage my fatigue	**.77**	-.27
Fatigue interferes with my ability to take care of myself	**.73**	-.07
Fatigue interferes with my ability to move around indoors	**.73**	.12
Fatigue interferes with my ability to get outside of my house	**.70**	.10
I have had to reduce my work responsibilities outside my home because of fatigue	**.70**	.06
Fatigue interferes with my ability to move around in my community	**.70**	.17
Rate your average level of fatigue for the past week	**.70**	.18
I have had to reduce my responsibilities at home because of fatigue	**.69**	.08
Rate your level of fatigue on the day within the last week that you felt the least fatigued	**.68**	-.09
On average, how much of the day do you feel fatigued	**.68**	.07
Rate your level of fatigue on the day within the last week that you felt most fatigued	**.64**	.17
Fatigue interferes with my general everyday activities	**.57**	.31
Fatigue interferes with my ability to start things	**.50**	.18
For how many days last week did you feel fatigued at least part of the day	**.50**	.24
Fatigue interferes with my ability to finish things	**.46**	.36
Fatigue interferes with my participation in social activities	**.43**	**.41**
Fatigue interferes with the length of time I can be physically active	.12	**.72**
I limit my physical activity to manage my fatigue	-.05	**.71**
My motivation to do physical activities	.05	**.70**
I stop and rest during activity to manage my fatigue	-.01	**.68**
Fatigue interferes with my balance and coordination	.03	**.68**

Table 3 - Summary of Fatigue Scores for Known Groups Validity Testing

Construct	**Subgroups**	**FISSA Score Median, (Range)**	**FISSA Impact Score Median (Range)**	**FISSA Management Score Median (Range)**
Functional Level	GMFCS Level I (n=35)	69 (30, 122)	31 (16, 62)	39 (14, 60)
	GMFCS Level II and III (n=63)	96 (37, 147)	49 (20, 78)	49 (14, 66)
	GMFCS Level IV and V (n=39)	106 (38, 146)	57 (21, 83)	51 (17, 61)
Pain Severity	Low Pain Severity ≤ 50th percentile (n=84)	75 (30, 146)	38 (16, 83)	42 (14, 64)
	High Pain Severity ≥ 51st percentile (n=60)	109 (39, 157)	58 (20, 87)	53 (19, 70)
Pain Impact	Low Pain Impact ≤ 50th percentile (n=79)	75 (30, 146)	35.5 (16, 83)	41.5 (14, 64)
	High Pain Impact Severity ≥ 51st percentile (n=63)	108 (39, 157)	56 (19, 70)	53 (19, 70)

GMFCS= Gross Motor Function Classification System

Figure 1 – Breakdown of Inclusion and Exclusion of Returned Surveys