



## Research article

## Illness perception in children with cerebral palsy, a longitudinal cohort study

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## HIGHLIGHTS

- Parents reported significantly more negative impact of CP than their children.
- Parents reported stable perception of their child's CP across a four-year period.
- Parents and children reported significant impact of CP on leisure activities.
- Impact of CP was significant in children with co-occurring psychiatric disorders.

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## ABSTRACT

**Background:** The perception of a disorder could be of importance both in problem solving behaviors, and in the emotional approach towards a disorder.

**Aims:** In this paper, we wanted to assess changes in illness perception in children with Cerebral Palsy (CP) over a four-year interval, to compare parental and self-ratings, and to assess illness perceptions according to co-occurring medical and psychiatric disorders.

**Methods:** Parents in a cohort of children with CP (N = 36), filled in the Illness Perception Questionnaire at age seven and again at age eleven, and self-reports were gathered at age eleven. Stability across time, informant differences and scores according to motor function, intellectual disability and the prevalence of psychiatric disorders were assessed.

**Results:** We found stable parental perceptions across a four –year interval. Parents reported significantly higher impact of CP on the child, than that reported by the child itself. In children with a more severe motor disability and/or co-occurring psychiatric disorders, parents reported significantly higher median scores for perceived impact of the CP condition on symptoms, duration of the condition, and impact on leisure activities, compared to those who had less severe motor disability and/or intellectual abilities within the normal range.

**Conclusions:** We propose that illness perception should be included in the follow-up of children with CP, as it may provide a mutual understanding between the child/family and professionals involved in follow-up services, with possible impact on treatment adherence and outcome of the condition.

## 1. Introduction

Cerebral Palsy (CP) is a life-long motor disorder affecting 0.2–0.4 % of the population, commonly presenting with co-occurring medical and sensory conditions as well as mental health problems (Andersen et al., 2008; Novak et al., 2012). Perceptions of the CP condition, and coping behaviors often affect the impact of the condition on the child and

his/her family (Chong et al., 2012). The Illness perception concept evolved from the self-regulation model (Meyer et al., 1985), and describes the impact of the patient's beliefs regarding his/her disorder on behavioral and emotional responses that may be of importance in understanding coping behavior and treatment adherence.

Illness Perception has been used to assess a range of mental- and physical health outcomes across disorders and age groups (Broadbent

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et al., 2015), and embraces the consequences of a condition, the expected timeline, sense of control, and the experience of pain and coherence. Three phases were distinguished in the Illness Perception model; forming the perception of the specific illness, coping reactions, and lastly the appraisal process where the coping reaction is evaluated (Broadbent et al., 2006). Perception of the disorder plays an important part both in problem solving behaviors, and in the emotional approach towards the disorder.

Increasing focus on the importance of an holistic approach towards childhood disabilities has led to the World Health Organization (WHO)'s classification model for disability "the ICF-International Classification of Functioning, Disability and Health for Children and Youth", which is an attempt to operationalize a multidimensional and holistic understanding of disability for children and young people (WHO, 2001). A Canadian research cluster, the Canchild, has taken the ICF-CY concept a step further, and translated the concept of ICF-CY into the F-words of childhood disability; Family, Function, Fitness, Fun, Friends and Future, covering the areas of importance for children and young people with disability (Rosenbaum and Gorter, 2012). The idea of ICF-CY and the F-words of childhood disability is to capture the dynamic process of the different functional and environmental factors interacting with each other. This is similar to the illness perception concept, which also acknowledges the importance of factors related to the child and his/her functional status, as well as to the environment.

Differences in illness perception across medical conditions have been described, such as in a study concluding that children who had undergone cancer treatment perceived greater control than those who had a chronic condition (Petrie et al., 2007). Few studies have addressed changes in illness perceptions over time in children and adolescents with chronic disorders. One exception is a study of adolescents with diabetes that did find changes in illness perceptions over time and that these changes were related to outcome, for instance more favorable illness perception and coherence were associated with better control of the disorder (Fortenberry et al., 2014). For children with CP however, we do not know if illness perception changes in the course of time, nor if there are differences in illness perceptions between the child and the parents.

Discrepancy between parental perceptions of the condition, and the child's perceptions was found in a study in children with Spinal Muscular Atrophy (SMA) (Fischer et al., 2020), reporting overall more negative parental perceptions on the impact of the disorder than the corresponding reports from their children. Whether or not children with a chronic disorder such as CP also report a more optimistic illness perception than their parents, is unknown. We are aware of only one previous study that has investigated illness perceptions in children with CP, finding self-reported illness perceptions related to their life satisfaction, especially lower levels of concerns and fewer perceived consequences of their CP (Chong et al., 2012). In the same study, no associations were found between Gross Motor Function Classification System (GMFCS) levels and illness perceptions (Palisano et al., 2000), however children with the best functional ability, (GMFCS levels I-II), tended to perceive CP as a short-term condition. In a previous study, we have found that children with CP have an elevated risk of psychiatric disorders, increasing from school starting age to pre-adolescence (Bjorgaas et al., 2021). It is however still unknown what role co-occurring medical- and psychiatric disorders play in the perception of the CP condition.

### 1.1. Aim of the study

In this study, we aim to assess illness perception in children with CP, and in their parents. We will assess changes in parental illness perceptions across a four-year interval, and compare parental and children's reports at age eleven. Further, we will assess the association between illness perceptions and level of motor function, intellectual disability (ID), and co-existing psychiatric disorders in children with CP.

## 2. Methods

### 2.1. Population

All 97 children with a known CP diagnosis born 2001–2003 and living in the Western Health Region of Norway were invited to take part in the study at age seven. Of these children, 67 participated, of whom 56 had GMFCS levels I-IV (Bjorgaas et al., 2012). The 11 children with GMFCS level V were not included in the follow-up study, as these children could not be diagnosed using the Kiddie-SADS, a semi-structured child psychiatric diagnostic instrument, due to the severity of their motor and/or cognitive level (Bjorgaas et al., 2012). The 56 children with GMFCS levels I-IV were invited again at age eleven to participate in a second assessment of psychiatric disorders and illness perception. Of the invited children, 47 participated, of whom 64% were boys, and one in five had Intellectual Disability (ID) and/or GMFCS levels III-IV (Bjorgaas et al., 2019). Parents of children in the present longitudinal study took part in a semi-structured child psychiatric diagnostic interview lasting 3–4 h, in their homes or close to their homes, at both assessment points. At age eleven, parents of 36 children filled in the illness perception questionnaire, and 29 children self-reported illness perception. In the present study, we included the longitudinal sample of 36 children with valid parental illness perception data at both time points, and with self-report data at age eleven (a response rate of 77% and 62% respectively).

### 2.2. Perceptions of the CP condition-rated by parents at age seven and eleven, and self-rated at age eleven

Illness perception was assessed using the Brief Illness Perception Questionnaire (BIPQ) both at age seven and again at age eleven (Broadbent et al., 2006). The parental version included 15 questions on a scale from 1-10 embracing pain, impact on the child, perceived understanding of the CP condition and sense of control, as well as the perceived effect of treatment. It also included parental worries related to the condition, as well as emotional impact of having CP. Self-ratings included four items, covering pain, absence due to the condition, impact on leisure activities and impact on the child on a scale from 0-10. Positively worded items in the BIPQ were reversed, and higher scores reflected higher risk for all items. The illness perception Questionnaire has shown good psychometric properties in studies across several disorders, including both somatic- and mental health (Broadbent et al., 2015).

### 2.3. Classification, functional levels, medical information

Functional classification of CP given in the medical record was obtained, or classification was done during the medical examination at the onset of the study, if information was not available prior to the study. We classified the CP condition according to ICD-10 criteria G80.0-G80.9, with the following subgroups: Spastic bilateral and unilateral, dyskinetic, atactic or not further classified. Functional level was classified by the Gross Motor Function Classification System (GMFCS) (Palisano et al., 2000), distinguishing five groups. Classification for gross motor function was based on self-initiated movement, functional limitations, and the use of mobility devices in everyday life. Classification was grouped as follows: light disability (GMFCS I and II) moderate (GMFCS III and IV), and severe disability (GMFCS V). Children with GMFCS levels I-IV were included in this study. We recorded Intellectual Disability (ID) through information in the medical record, and verified by parents during the interview. Likewise, gestational age and birthweight was recorded. We gathered information regarding impaired communication from the medical record and during the clinical examination at the onset of the study. At age 11, we also gathered information regarding possible changes in functioning or medical conditions during the four -year interval.

## 2.4. Mental health assessment instrument

The *Kiddie-SADS*, a semi structured child and adolescent psychiatric diagnostic instrument, was used to ascertain psychiatric disorders according to DSM IV criteria. Parents of children with CP were interviewed using the *Kiddie-SADS* (PL) 2009 version for ages 6–18 at age seven and at age eleven (Bjorgaas et al., 2012; Bjorgaas et al., 2019; Kaufman et al., 1997). The *Kiddie-SADS* is designed to assess psychiatric symptoms within the following groups of disorders: affective-, anxiety-, psychotic-, eating-, attention/hyperactivity-, oppositional defiant-, conduct-, tics-, substance abuse- and posttraumatic stress disorders, as well as encopresis and enuresis and autism spectrum disorders. The *Kiddie-SADS* has been validated with good psychometric properties (Kaufman et al., 1997), and has been used in previous studies to assess the prevalence of psychiatric disorders in children with CP (Bjorgaas et al., 2021; Bjorgaas et al., 2012; Bjorgaas et al., 2019). Being a semi-structured interview, the *Kiddie-SADS* permits questions and answers to be elaborated during the interview, and it is designed to be administered by mental health professionals trained in diagnosing child psychiatric disorders, and in evaluating symptoms according to the individual child's level of development.

In the present study, we dichotomized psychiatric disorders according to whether or not the child met criteria for one or more psychiatric disorders.

## 2.5. Statistical analysis

Descriptive analyses were used for cohort description. Median parental illness perception scores compared at ages seven and eleven, and parental illness perception scores and self-scores compared at age eleven, were assessed using Wilcoxon signed rank tests. Median parental illness perception scores were assessed at ages seven and eleven, and median self-report scores were assessed at age eleven, according to GMFCS levels, ID and psychiatric disorders using Mann-Whitney-U tests.

## 2.6. Ethical approval

Parents of the study participants provided written consent prior to the study, and the study was approved by the Regional Committee for Medical Research Ethics in Western Norway.

## 3. Results

### 3.1. Population

In the study population consisting of 36 participants, 21 (58%) were boys, 7 (19%) had GMFCS levels III-IV, and 11 (31%) had ID. Further, 22 (61%) of the study population met criteria for one or more psychiatric disorders at age seven, with the equivalent number of 24 (67%) at age eleven. For children who did not take part at age eleven, we found similar percentages for gender and GMFCS levels compared to those who took part in the present study. For the prevalence of ID and prevalence of psychiatric disorders at age seven, percentages were lower in the drop-out group compared to participants in the present study, however differences were not significant.

### 3.2. Illness perception across time and informant

No significant changes in parental perceptions across a four-year interval were found, and self-reported impact of the CP condition was significantly lower compared to parental-reports at age eleven (Table 1).

### 3.3. Illness perception and functional characteristics

Parents having children with a more severe motor disability (GMFCS level III-IV) as well as those with ID, reported a significantly higher

**Table 1.** Median parental scores of illness perception at ages seven and 11, and self-scores at age 11 in children with cerebral palsy.

N = 36	Parent-7 <sup>i</sup>	Parents-11 <sup>ii</sup>	Self-report-11	z-scores p-values parents 7–11 <sup>iii</sup>		z-scores p-values parents-self 11	
Pain	2.0	3.0	3.0	-1.2	0.24	-0.56	0.60
Absence	2.0	2.0	2.0	-1.3	0.19	-1.1	0.30
Impact leisure	3.0	6.0	3.0	-1.5	0.14	-1.7	0.08
Imp. CP child	7.0	7.0	4.0	-0.5	0.65	-3.5	0.00*
Imp. CP parent	7.0	7.0		-0.8	0.44		
Duration	6.0	7.0		1.0	0.34		
Control	6.0	7.0		-0.8	0.43		
Treatment effect	8.0	7.0		-1.1	0.26		
Symptoms	7.0	7.0		-0.1	0.93		
Worries	7.0	8.0		-1.9	0.06		
Emo. Imp child	4.0	6.5		-1.6	0.11		
Emo. Imp. Parent	7.5	8.0		-1.1	0.27		

<sup>i</sup> Parental illness perception median cores at age 7.

<sup>ii</sup> Parental illness perception median scores at age 11.

<sup>iii</sup> P-values according to Wilcoxon non-parametric t-test.

\* significance level at or below 0.05.

impact on leisure activities, more symptoms associated with CP, and they perceived a longer duration of the disorder compared to children with GMFCS levels I-II and/those without ID (Table 2). Both for children with GMFCS level III-IV and/or ID, parents reported significantly higher median scores for lack of expected treatment effect at age seven compared to children with GMFCS levels I-II and/or children without ID, whereas this was not found at age eleven. For GMFCS level III-IV and/or ID, parents reported significantly higher median scores for emotional impact on parent and child compared to children with GMFCS levels I-II and/or children without ID at age seven. For GMFCS levels III-IV, self-reports were significantly higher regarding impact on leisure activities compared to children with GMFCS levels I-II (Table 2.).

### 3.4. Illness perception and psychiatric disorders

Parents reported significantly higher median illness perception scores in children meeting criteria for co-occurring psychiatric disorders in general, and for behavioral- and emotional disorders more specifically compared to children who did not meet criteria for co-occurring psychiatric disorders (Table 3). Similarly, both for children with co-occurring psychiatric disorders in general, and emotional- or behavioral disorders specifically, median scores for perceived impact of CP on the parents, anticipated duration of the disorder, symptoms of the disorder as well as impact on leisure activities were significantly higher compared to those not meeting criteria for co-occurring psychiatric disorders. For emotional disorders, children self-reported significantly higher median scores for negative impact on leisure activities compared to those who did not meet criteria for co-occurring emotional disorders (Table 3).

## 4. Discussion

In the present cohort of children with CP, parental illness perceptions were stable across the assessment interval. However, parents reported significantly higher impact of the CP condition than did the children themselves. We found that median scores for illness perception parameters were significantly higher in children with GMFCS levels III-IV and/or ID and in children meeting criteria for one or more psychiatric

**Table 2.** Median illness perception values and differences in median values measured by Mann-Whitney-U tests according to dichotomized motor functional level and cognitive level in children with cerebral palsy assessed by parents at ages 7 and 11, and self-rated at age 11.

	Gross Motor Function Classification System <sup>i</sup>									Intellectual Disability <sup>ii</sup>								
	IP <sup>iii</sup> Parent report age 7			IP Parent report age 11			IP Self report age 11			IP Parent report age 7			IP Parent report age 11			IP Self report age 11		
	Median	MWU <sup>iv</sup>	p-val. <sup>v</sup>	Median	MWU	p-val.	Median	MWU	p-val.	Median	MWU	p-val.	Median	MWU	p-val.	Median	MWU	p-val.
Pain	3.0	41.0	0.41	5.0	45.5	0.12	3.5	37.5	0.66	3.0	47.0	0.06	4.0	71.0	0.12	4.5	40.5	0.24
Absence	2.0	60.5	0.66	4.0	57.0	0.14	3.0	39.0	0.41	2.0	81.0	0.54	3.0	88.0	0.22	2.0	65.0	0.96
Impact Leisure	8.0	30.5	0.04*	10.0	19.5	0.00*	10.0	15.0	0.01*	7.5	26.0	0.00*	8.0	57.5	0.01*	4.0	43.0	0.15
CP impact child	10.0	7.0	0.00*	10.0	25.5	0.00*	4.5	26.5	0.26	8.0	46.0	0.02*	8.0	65.0	0.03*	4.5	35.5	0.18
CP impact parent	10.0	9.0	0.00*	10.0	16.0	0.00*				8.0	39.5	0.01*	9.0	42.5	0.00*			
Duration impact	10.0	13.0	0.01*	10.0	9.0	0.00*				7.5	27.0	0.02*	9.0	31.0	0.00*			
Parent control	5.0	38.0	0.31	7.0	91.0	1.00				8.0	77.0	0.86	7.0	112.0	0.75			
Treatment effect	5.5	13.0	0.00*	4.0	52.0	0.27				5.5	44.5	0.04*	7.0	101.0	0.88			
Child symptoms	9.0	9.0	0.00*	10.0	18.0	0.00*				9.0	28.5	0.01*	8.0	34.0	0.00*			
Parent worried	8.0	47.0	0.31	10.0	41.0	0.03*				8.5	54.5	0.09	10.0	59.0	0.02*			
Emo. Imp <sup>vi</sup> . Child	0.5	13.5	0.00*	8.5	56.0	0.36				3.0	45.5	0.02*	7.0	89.5	0.52			
Emo. Imp <sup>vii</sup> . Parent	10.0	15.0	0.00*	9.0	40.0	0.09				8.0	40.0	0.02*	9.0	32.5	0.01*			

<sup>i</sup> Gross motor functional levels dichotomized according to GMFCS levels I-II and levels III-IV

<sup>ii</sup> Intellectual Disability dichotomized according to cognitive level at or below IQ70, and above IQ70.

<sup>iii</sup> Illness Perception.

<sup>iv</sup> Mann-Whitney-U test Mean rank value.

<sup>v</sup> P-value for significance level at or below 0.05.

<sup>vi</sup> Emotional impact on child.

<sup>vii</sup> Emotional impact on parent.

**Table 3.** Parental- and self-rated Median Illness perception values assessed at age 11 according to psychiatric disorders.

	Illness perceptions parental report age 11									Illness perception self- report age 11								
	Psychiatric Disorders <sup>i</sup>			Behavioral Disorders			Emotional Disorders			Psychiatric Disorders			Behavioral Disorders			Emotional Disorders		
	Median	MWU <sup>ii</sup>	p-val. <sup>iii</sup>	Median	MWU	p-val.	Median	MWU	p-val.	Median	MWU	p-val.	Median	MWU	p-val.	Median	MWU	p-val.
Pain	3.0	75.5	0.25	3.0	96.0	0.37	3.0	87.0	0.37	3.5	64.5	0.68	3.5	69.5	0.59	4.0	57.0	0.61
Absence	3.0	46.5	0.01*	3.0	89.0	0.18	3.0	89.5	0.23	2.0	40.0	0.14	2.0	56.0	0.29	3.0	43.5	0.12
Impact Leisure	7.5	31.5	0.00*	8.0	56.5	0.01*	8.0	58.0	0.02*	4.0	43.5	0.08	4.0	62.0	0.26	9.0	20.0	0.00*
CP impact Child	7.0	58.5	0.04*	7.0	88.5	0.16	8.0	57.0	0.01*	4.0	40.5	0.18	4.0	65.5	0.72	4.0	37.0	0.13
CP impact Parent	8.0	28.0	0.00*	8.0	58.5	0.01*	9.0	66.0	0.04*									
Imp. Duration	8.0	34.0	0.00*	8.0	44.5	0.00*	8.0	61.5	0.05*									
Parent control	6.0	51.0	0.02*	6.0	81.0	0.10	6.0	103.0	0.51									
Treatment effect	7.5	74.5	0.29	7.0	105.0	0.86	6.0	95.5	0.88									
Child Symptoms	7.0	40.0	0.01*	7.0	60.0	0.03*	8.0	50.5	0.01*									
Parent worried	9.0	60.5	0.05*	9.0	94.0	0.24	9.0	68.0	0.04*									
Emo <sup>iv</sup> . Imp child	7.0	40.5	0.01*	7.0	83.5	0.22	8.0	45.5	0.01*									
Emo <sup>v</sup> . Imp. Parent	8.0	60.5	0.09	8.0	72.0	0.12	8.0	69.0	0.14									

<sup>i</sup> Psychiatric disorders, all types.

<sup>ii</sup> Mann Whitney U test, mean rank value.

<sup>iii</sup> Significance value at or below 0.05.

<sup>iv</sup> Emotional impact on child.

<sup>v</sup> Emotional impact on parent.

disorders compared to children with GMFCS levels I-II and/or intellectual abilities within the normal range. For children meeting criteria for emotional disorders, median illness perception scores for parents and children were significantly higher for impact on leisure activities compared to those not meeting criteria for emotional disorders.

In the present study, we found stable median scores for parental illness perceptions across the study period, perhaps reflecting the chronicity of the condition, and that parents perceive considerable challenges related to the CP condition throughout childhood. Interestingly, children self-reported significantly less impact of the CP condition than did the parents, similar to a study assessing differences in illness perception between children with chronic illnesses and their parents (Szentcs et al., 2018). This is in accordance with a previous study finding that family members of adult patients reported less optimistic perceptions of illness than that reported by the patients themselves (Giannousi et al., 2016). Being aware of diverting perceptions of the impact of CP between parents and children, could be of relevance to service providers in their attempt to understand what issues the family itself considers important, knowing that this information may also have impact on treatment compliance (Sawyer et al., 2019). It has been suggested that a shared illness perception between parents and children may be beneficial (Sonney et al., 2019). On the other hand, another study found that greater agreement regarding the perception of the condition between parent and child was not unambiguously associated with a better Quality of Life (QoL) (Fischer et al., 2020). Assessing both parental and self-rated illness perceptions could facilitate an open dialogue between the child, parents and the service providers to explore important issues related to having a disability. By encouraging the individual child and his/her family to present their own perceptions of CP, joint decisions and priorities related to the follow-up of the child could be made together with the child/family to enhance their own coping strategies and empower them to make decisions according to their own values and priorities.

Interestingly, self-ratings revealed that impact of CP on leisure activities stood out as an important issue both for the child and parents, a priority that could easily have been overshadowed in a regular follow-up session by the child's motor-and intellectual disability or co-occurring medical conditions. Impact on leisure activities could be related to physical limitations and lack of opportunities to be included in regular activities. A recent study however, also pointed to lack of social support, such as attitudes and behaviors, as barriers for participation (McKenzie et al., 2021). They suggested that a sense of social connection could be crucial for persons with disability to participate in leisure activities, perhaps indicating that a broader perspective regarding participation should be taken, such as in a recent study co-authored by young people with neuro-disabilities and their parents to include their own perspectives (Brooks et al., 2021). In this study, the authors suggested key elements such as peer involvement, feedback, direct instruction and role modelling as well as adaptation to the environment to enhance participation for persons with neuro-disabilities.

In the present study, parents of children more severely affected by motor impairment, reported significant impact of the condition on both parents and child, and that they were pessimistic regarding the perceived symptoms and duration of the condition across the study period. Similarly, perceived lack of treatment effect at age seven was significant, whereas this finding was not consistent across the study period. This could be related to improved treatment effect, or simply to the fact that parents may have come to accept the permanence of the condition with limitations in treatment options, in line with a previous study finding more pessimistic illness perceptions in children with a chronic disorder compared to children who had undergone cancer treatment (Szentcs et al., 2018). In the present study, emotional impact on the parents continued to be significant across the study period for children with ID. This is consistent with a sense of weariness due to a perceived long-haul emotional burden of caring for a child with ID, in line with other studies pointing to an elevated prevalence of mental health problems in caregivers of children with CP (Lach et al., 2009). Despite the majority of

children in the present study having a light motor disability, median illness perception scores across the study period were significantly higher in children with co-occurring psychiatric disorders, in line with previous studies finding a consistently elevated prevalence of psychiatric disorders across childhood (Bjorgaas et al., 2021). Further, children meeting criteria for behavioral and/or emotional disorders, scored significantly higher on the impact of CP on the parents, as well as perceived symptoms and duration of the condition. For emotional disorders, median scores for parental worries and emotional impact on the child were significantly higher than in children without emotional disorders, indicating that co-occurring psychiatric disorders, could add an extra burden to the parents.

Even if our knowledge regarding the perception of CP in children and their families is still fragmented, results from the present study seem to indicate that pursuing a broader understanding of illness perception could be useful. Perhaps therefore, a more comprehensive understanding of the issues that are of importance to the families, and their responses to interventions provided by follow-up services, could have impact on the outcome of the treatment offered.

#### 4.1. Strengths and limitations

To our knowledge, this is the first study to assess the long-term trajectory of parental perception of CP, and to compare parental assessment and self-reported perceptions according to motor functional level, ID and co-occurring psychiatric disorders. Numbers are however limited, and with an attrition rate of 36%, conclusions should be drawn cautiously. Parents of children in the present longitudinal study took part in a comprehensive, time-consuming semi-structured child psychiatric diagnostic interview by a child psychiatrist in their homes or close to their homes. There is reason to believe that the attrition rate could be associated with the fact that many of these families were under stress due to their child's CP condition, and that attending the comprehensive assessment could add to that burden. Despite finding a lower prevalence of ID and/or psychiatric disorders among children dropping out of the study between the assessment points, we could not find any significant differences between participants and drop-outs at age eleven.

#### 4.2. Conclusions and clinical implications

We found that parents perceived more negative impact of CP on the child than that reported by children themselves. Children however, self-reported significant impact of CP on leisure activities. In children with more severe motor impairment and/or ID, as well as in children meeting criteria for one or more psychiatric disorders, median scores for illness perception parameters were significantly higher than in those with a less severe motor impairment and without ID. Understanding the child and parents' perceptions of CP seems of importance in providing information and services aligned to their needs and priorities. Perhaps by exploring the child and parent's own perception of the CP condition at regular intervals, we could shape a sense of coherence in illness perception between service providers and the child/family, which in the long run hopefully could pay off in terms of treatment adherence and improved outcome of the disorder.

#### Declarations

##### Author contribution statement

Hanne Marit Bjorgaas: Conceived and designed the experiments; Performed the experiments; Analyzed and interpreted the data; Wrote the paper.

Elgen Bircow Irene and Mari Hysing: Conceived and designed the experiments; Analyzed and interpreted the data; Wrote the paper.

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The authors do not have permission to share data.

**Declaration of interests statement**

The authors declare no conflict of interest.

**Additional information**

No additional information is available for this paper.

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## What this paper adds

Parents perceived a more negative impact of Cerebral Palsy (CP) than children themselves, however a significant impact of CP on leisure activities was reported by both children and parents. Parents of children affected by more severe motor disability with or without intellectual disability, as well as children meeting criteria for one or more co-occurring psychiatric disorders, perceived significantly more negative impact of the condition than children who had less severe motor disability or intellectual ability within the normal range. Including assessment of the perceived impact of the CP condition on the child and parents could add valuable information regarding follow-up issues that are of importance to the families.