

Clinical Prognostic Messages From a Systematic Review on Cerebral Palsy

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KEY WORDS

cerebral palsy, meta-analytic methods, parent friendly, population register, prognosis, systematic review

ABBREVIATIONS

CI—confidence interval

GMFCS—Gross Motor Function Classification System

ID—intellectual disability

SCPE—Surveillance of Cerebral Palsy in Europe

UKCP—United Kingdom Cerebral Palsy register

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abstract



OBJECTIVE: To summarize evidence on the rates of co-occurring impairments, diseases, and functional limitations with cerebral palsy into succinct clinical messages.

METHODS: A search was conducted of the databases PubMed, Medline, CINAHL, and PsycINFO, and the results were supplemented with hand searches. Two independent reviewers determined whether retrieved abstracts met the following inclusion criteria: human subjects; >90% were children or adults with cerebral palsy; published after 1999; and population-based data. Articles were appraised, analyzing design, participants, level of evidence, rates of impairments, and functional implications. Methodologic quality was rated by using a standardized checklist.

RESULTS: A total of 1366 papers were identified in the search; 82 were appraised and 30 were included in the meta-analyses. High-level evidence existed, as rated on the Oxford 2011 Levels of Evidence: 97% of prevalence studies were level 1. The data were of a moderate to high quality grade (with the exception of sleep disorders), allowing plain English clinical messages to be developed.

CONCLUSIONS: Among children with cerebral palsy, 3 in 4 were in pain; 1 in 2 had an intellectual disability; 1 in 3 could not walk; 1 in 3 had a hip displacement; 1 in 4 could not talk; 1 in 4 had epilepsy; 1 in 4 had a behavior disorder; 1 in 4 had bladder control problems; 1 in 5 had a sleep disorder; 1 in 5 dribbled; 1 in 10 were blind; 1 in 15 were tube-fed; and 1 in 25 were deaf. *Pediatrics* 2012;130:1–28

Parents of children with cerebral palsy often ask pediatricians and allied health professionals, “will my child walk?”, “will my child talk?” and “will my child work and live independently?”¹ In essence, parents want to know “how bad is it?” and what will their child’s future look like.^{1,2} The answer to the question depends on the severity of physical disability, the type of motor impairment, and the presence of comorbid conditions. Research exists to help clinicians identify impairments and predict future function, such as walking, in children with cerebral palsy. Yet parents report that they are rarely given prognostic information.³ Parents believe professionals withhold prognostic information in an attempt to protect them from bad news. Research, however, suggests that the absence of prognostic information makes it more difficult, not easier, for parents to cope.⁴ Dissatisfaction with delayed receipt of diagnostic information has been linked to higher rates of parental depression. In qualitative studies, parents advise professionals that they want and need prognostic information to assist them with planning services.³ In addition, parents recommend that medical information be presented in “parent-friendly” language to facilitate their understanding and acceptance of information.⁵

Cerebral palsy is the most common physical disability in childhood, occurring in 2 to 2.5/1000 births.⁶ Pediatricians and allied health professionals therefore need to have up-to-date prognostic information readily available to communicate with families at diagnosis and throughout the child’s life span to develop interventions. The definition of cerebral palsy has recently been expanded to include the impairments commonly associated with the condition because of their substantial impact on the child. “Cerebral palsy

describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems.”⁷ The inclusion of secondary impairments and functional limitations within the definition heightens the importance of understanding and communicating the impact of these co-occurring impairments, diseases, and functional limitations to parents to help predict outcomes. Furthermore, although the brain injury in cerebral palsy is nonprogressive, the co-occurring impairments, diseases, and functional limitations change over time, reducing function and quality of life.⁸ Definitive information about the real extent of co-occurring impairments, diseases, and functional limitations with cerebral palsy is essential for parents in choosing services and for providers in terms of pediatric resource allocation.⁴ Moreover, the psychological and physical health of parents of children with cerebral palsy is strongly influenced by the child’s behavior and the complexity of caregiving demands.⁹ Thus, the opportunity to introduce preventative mental and physical health measures for parents and children exists when professionals proactively identify and forecast the extent of a child’s disability.

The diagnosis of cerebral palsy is typically made in the toddler years, after metabolic and degenerative conditions have been ruled out.¹⁰ In the period of “wait and see” leading up to diagnosis, parents experience great distress.⁴ The description and ultimately the diagnosis of cerebral palsy can in some cases

be made earlier; for example, if a pre-term child has abnormal brain imaging coupled with abnormal motor signs on tools with good predictive psychometrics (such as General Movements or the Test of Infant Motor Performance).¹¹ MRI is useful for identifying the presence and location of an injury in ~89% of children with cerebral palsy.¹⁰ The location and type of brain injury generally correlate with subtype of cerebral palsy, which can provide physicians with some guidance in prognosticating future function.¹² Despite this, significant limitations exist in the accuracy of MRI predicting the severity of cerebral palsy and long-term functional outcomes.¹³ In addition, cerebral palsy is an umbrella term for many different brain lesions (with the type and size of the lesion responsible for the different motor impairments and accompanying impairments), which explains why professionals encounter so many difficulties in giving an accurate prognosis to parents. Despite the lack of an evidence-based tool to prognosticate the severity of cerebral palsy early, many parents anecdotally report being told that their child will be profoundly disabled and will not walk, talk, or work. For this reason, prognostic evidence drawn from more sources than an abnormal MRI is needed to help accurately answer parents’ questions. Because no guideline or systematic review about prognosis of cerebral palsy existed, we conjectured that this might explain why clinicians have not yet developed clear clinical messages for communicating to parents. The lack of synthesized information may compound professionals’ preference to avoid giving bad news. Recommendations for intervention might be based on specialists’ opinions about their own area of expertise based on experience, rather than on an overview of evidence from cerebral palsy population data. Given that

interdisciplinary care is believed to be best practice, we considered the lack of synthesized clinical messages to be a major gap in cerebral palsy knowledge. Our answerable clinical questions therefore were: What are the rates of co-occurring impairments, diseases, and functional limitations in cerebral palsy? In addition, what is the prognosis of individuals with cerebral palsy? The objective of the current study was to systematically review the highest levels of evidence available relating to rates of co-occurring impairments, diseases, and functional limitations in cerebral palsy, presented in parent-friendly clinical prognostic messages. We hypothesized that it was possible to develop from the literature a series of succinct clinical messages in plain English for clinicians to communicate to parents of children with cerebral palsy, to promote understanding and to inform intervention planning.

METHODS

Search Strategy

We conducted this systematic review using a protocol based on recommendations for conducting systematic reviews from the Cochrane Collaboration and PRISMA statements and in accordance with the quality of reporting of meta-analysis of observational studies statements.^{14,15,16} We identified relevant articles by searching PubMed (1999–2011), Medline (1999–2011), CINAHL (1999–2011), and PsycINFO (1999–2011). Searches were supplemented by hand searching bibliographies of included articles and review articles. Relevant studies known to the investigators through previous research work were also included. The search of published studies was originally performed in January 2009, and an updated search was conducted in January 2011.

We searched electronic databases by using EBSCO host software including the

following search terms: (i) cerebral palsy OR hemipleg* OR dipleg* OR quadripleg*; AND (ii) incidence OR prevalence OR prognosis OR rate OR proportion; AND (iii) behavior*/behavior*/emotion*/psycholog*/psychiatr*/autis* OR continen*/incontinen* OR drool*/saliva/sialorrea OR eat*/dysphagia/mealtime*/feed*/aspirat*/nutrition*/videofluoroscopy/video fluoroscopy/swallow*/deglutition OR epilepsy OR hearing OR hip/disloc*/displac*/scoliosis/lordosis/kyphosis/windsw* OR intellectual/intelligen*/mental* retard*/learning disab*/cognit* OR pain OR sleep OR communication/nonverbal communication/speech/intelligibility/articulation/dysarthria/anarthria/apraxia/dyspraxia/language/augmentative communication/alternative communication/AAC/speech generating device/SGD/communication methods/communication aid* OR walk*/motor/ambulat* OR vision/visual/nystagmus/strabismus/hemianopia/blind*; AND (iii) population OR registry OR register. The list of associated impairments searched were generated from the definition of cerebral palsy and seminal texts,⁶ and assigned plain English terms for parents.

Inclusion Criteria

Studies published in English regarding the prevalence of co-occurring impairments, diseases, and functional limitations fulfilling the following criteria were included:

1. Type of study: Observational studies were specifically sought, because it is neither logical nor ethical to prospectively randomize individuals to risk association studies. To improve the quality of the review and minimize bias, studies using a population sample (ie, a cerebral palsy register) were preferentially sought. There was a scarcity of research about some functional limitations

(eg, behavior, bladder control, dribbling, pain, sleep), and more generous inclusion criteria were required to achieve the study aim for these topics (eg, nonpopulation studies). The search strategy only included studies with greater levels of bias when no higher-quality observational studies were available.

2. Type of outcome: studies that involved ascertaining the rates of co-occurring impairments, diseases, and functional limitations for children or adults with cerebral palsy.
3. Types of subjects: studies that explicitly involved human subjects in which >90% of the participants were children or adults with cerebral palsy.

Studies were excluded from the systematic review if: (1) they were nonpopulation \-based surveys (unless population evidence was unavailable); (2) a second publication of the same study was published, which found the same results; (3) they were not available in English; and (4) they were published before 1999, given the marked advances in obstetric and neonatal care in the last 10 years.

Data Abstraction

A data abstraction sheet was developed based on the Cochrane recommendations. Two independent assessors determined eligibility of the abstracts identified from searches for further review. Abstracts were retained for full review if they met the inclusion criteria or if more information was required from the full text to ascertain eligibility. The same 2 reviewers then reviewed full-text versions of all retained articles and all additional articles identified by hand searching. Full-text articles were retained if they met inclusion criteria; 100% agreement was reached on inclusion and exclusion assignment for the full-text articles.

Data extracted from included studies included: authors and date of study; number of participants; participants' diagnosis; study design; and description of findings. The data extracted from each included study are summarized in Table 1. All the data required to answer the study questions were published within the papers, so no contact with authors was necessary.

Quality Assessment

Evidence experts acknowledge that conforming to gold standard systematic review conventions is difficult when critiquing etiologic, risk factor, and prognostic studies.^{17,18} This difference is because evidence hierarchies heavily favor treatment studies.¹⁸ Our review of the cerebral palsy literature confirmed this problem: a lack of agreement existed in literature regarding a preferred quality rating scale for observational studies, and studies had for the most part examined only single groups, which therefore precluded standard meta-analyses.¹⁷ In the absence of an endorsed systematic review guideline for epidemiologic studies, the following course of action was chosen: First, we rated the level of evidence on the Oxford 2011 Levels of Evidence as per convention.¹⁹ Second, we assessed quality by using the standardized checklist developed by Boyle.²⁰ Third, the overarching body of prevalence evidence was rated by using the GRADE system.²¹

Ethics

The Human Research Ethics Committee waived the need for ethical approval because the study did not involve any contact with humans.

Analyses

Our intention was to conduct a meta-analysis if the retrieved studies were of sufficient clinical and statistical ho-

mogeneity. We encountered 2 problems. First, the prevalence studies predominantly only studied 1 group (ie, the cerebral palsy population). Thus, conducting 2-group prevalence meta-analyses by using standard Mantel-Haenszel techniques was not possible.¹⁴ For the prevalence meta-analysis, we therefore needed to use simple descriptive statistics, calculating population prevalence mean impairment rates with 95% confidence intervals (CIs). To increase the rigor of these descriptive analyses, studies had to meet these additional stringent criteria for inclusion within the meta-analyses: (1) study sample was >80% of population (as per public health conventions) or the total sample size needed to be >500 cases of cerebral palsy; (2) study sample included all subtypes of cerebral palsy so as not to skew the estimates; and (3) case data were not duplicated in other publications. Studies meeting these extra criteria are denoted in Table 1. When studies included near-duplicate data, older and smaller duplicates were preferentially excluded to improve rigor, unless the newest study had collapsed data, in which case the next best available study was included. Review articles were not included in the meta-analysis, as per convention. The second problem was that although we originally intended to conduct the meta-analysis by using Gross Motor Function Classification System (GMFCS) levels, there were insufficient numbers of studies reporting GMFCS data for this to be possible.

RESULTS

A total of 1366 citations were identified in our search; 82 articles met the inclusion criteria for full appraisal, but only 30 studies met the additional stringent inclusion criteria for meta-analyses (Fig 1).

Levels of Evidence

Evidence from these studies was generally very high when rated by using the Oxford 2011 Levels of Evidence; 97% of the prevalence articles included in the meta-analysis were rated as level 1 evidence ("most relevant local and current random sample survey or census") because they were cerebral palsy register studies capturing data from >80% of the population. Only 1 lower-level evidence (level 5) prevalence article, on the topic of sleep difficulties, was included in the meta-analyses because no higher-level evidence could be found in the literature.

Rating of Study Quality

Table 2 presents quality analysis for the prevalence studies by using the standardized checklist developed by Boyle.²⁰

Prevalence of Co-occurring Impairments, Diseases, and Functional Limitations

Average rates of impairments, diseases, and functional limitations associated with cerebral palsy were calculated by aggregating the findings of the included prevalence studies to identify a mean rate and a 95% CI. The findings were: (1) behavior (818 cases for analysis): 26% (95% CI: 24–28) had abnormal behavior (the rate and CI were from Parkes et al²² because new CIs were unable to be calculated because only 1 study met inclusion criteria); (2) bladder and bowel control (601 cases for analysis): 24% had bladder control problems (95% CI unable to be calculated because only 1 study met inclusion criteria); (3) dribbling (1119 cases for analysis): 22% had excessive drooling (95% CI unable to be calculated because only 1 study met inclusion criteria); (4) eating (1299 cases for analysis): 6% (95% CI: 3–9) were tube-fed; (5) epilepsy (12 140 cases for analysis): 35% (95% CI:

TABLE 1 Included Studies According to Alterations of Body Function, Activity Limitations, and Co-occurring Diseases

Study	Participants	Analyzed <i>n</i>	Research Design	Level of Evidence	Results	Included/ Excluded Meta-analysis
Alterations of a body function						
Behavior						
Par-kes et al (2008) ²²	CP: All subtypes	818	Prospective cross-sectional survey from 8 population CP registers (70% participation rate)	1	26% had abnormal behavior (95% CI: 24–28) (as measured on the Strengths and Difficulties Questionnaire) 32% had peer problems (95% CI: 30–35) 31% had hyperactivity (95% CI: 29–33) 29% had emotional difficulties (95% CI: 26–31) 17% had conduct problems (95% CI: 15–19) Behavioral problems rates were higher with a moderate to severe intellectual impairment compared with those with mild intellectual impairment or normal intelligence (OR: 3.2 [95% CI: 2.1–4.8]) Rates of behavioral problems were higher in children with severe pain compared with children without pain (OR: 2.7 [95% CI: 1.5–4.6]) Rates of behavioral problems were higher in children with better gross motor ability (OR: 1.0 GMFCS I) compared with children without more severe physical disability (OR: 0.2 [95% CI: 0.1–0.3] GMFCS V)	Included: <i>n</i> > 500
	8–12 y					
Russo et al (2008) ³⁰	CP: hemiplegia only	107	Population CP register: Prospective assessment (75% participation rate, 100% completion rate)	1	48% had pain Rates of behavioral competence were higher for children without pain (mean: 3.3) than for children with pain (mean: 2.9) (<i>P</i> < .01)	Excluded: Not all subtypes but included in Table 3
	3–16 y					
Sigurdardottir et al (2010) ³¹	CP: GMFCS I–IV	CP: 36 Controls: 110	Population CP register; Iceland (69% of 1999–2004 birth cohort)	3 [Prognostic]	40% to 50% had abnormal behavior as rated by parents and 60% to 65% had abnormal behavior as rated by teachers Rates of behavioral problems were 4 times higher in children with CP compared with controls	Excluded: Not all subtypes but included in Table 3
	4–6 y					
Bladder and bowel control						
Roijen et al (2001) ³²	CP: All subtypes	601	Prospective cohort study, 6 sites, the Netherlands (76% response rate)	1	24% had enuresis Bladder control was delayed in CP. The likelihood of developing bladder control decreased over time 97% who had daytime enuresis went on to achieve nocturnal continence Nocturnal enuresis was significantly delayed if initial daytime bladder control was achieved after 8 y (<i>P</i> < .001) Children with spastic quadriplegia and ID were less likely to have bladder control (OR: 2.6 [95% CI: 1.7–3.5])	Included: <i>n</i> > 500
	4–18 y					

TABLE 1 Continued

Study	Participants	Analyzed <i>n</i>	Research Design	Level of Evidence	Results	Included/ Excluded Meta-analysis
Singh et al (2006) ³³	CP: Bilateral only 4-18 y	55	Cohort study (55% participation rate of Special Needs Database)	5 ^a	Daytime and nocturnal enuresis rates were higher in nonambulant children compared with those who could walk (85% vs 15%, and 77% vs 23%, respectively) Daytime and nocturnal enuresis rates were higher with severe ID compared with those without ID or mild to moderate ID (80% vs 20% and 62% vs 38%, respectively) 33% had stool incontinence. Rates of stool incontinence were higher in nonambulant children (83% GMFCS IV-V) compared with those who could walk (17% GMFCS I-III). Rates of stool incontinence were higher in children with severe ID (83%) compared with those without ID or mild to moderate ID (17%) 26% had constipation	Excluded: <80% of population and not all subtypes but included in Table 3
Sullivan et al (2000) ³⁴	CP: All subtypes CP = 95% sample with neurologic impairments	271	CP register, Oxford, UK (72% response rate)	1		Excluded: <80% of population but included in Table 3
Dribbling Parkes et al (2010) ³⁵	CP: All subtypes ≥5 y	1119	Population CP register, Northern Ireland (86% of 1980-2001 birth cohort)	1	22% had excessive drooling Rates of drooling were highest among children with more severe physical disability (GMFCS IV OR: 4.8; GMFCS V OR: 12.9)	Included
Hearing Arnaud et al (2008) ²⁸	CP: All subtypes 8-12 y	818	Prospective cross-sectional survey from 8 population CP registers (63% participation rate)	1	2% had a severe hearing impairment	Excluded: part duplicate cases with Surman et al (2006) ³⁶
Australian CP Register Group (2009) ³⁷	CP: All subtypes	1897	Population CP register, Victoria and WA, Australia (1993-2003 birth cohort)	1	3% had bilateral deafness 9% had some hearing impairment	Included
Himmelmann et al (2006) ³⁸	CP: All subtypes 4-8 y	367	Population CP register, Western Sweden (89% of 1911-1998 birth cohorts)	1	2% had a hearing impairment	Included
Mongan et al (2006) ³⁹	CP: All subtypes ≥5 y	75	Population CP register, West Ireland (88% of 1990-1999 birth cohort)	1	10% had a hearing impairment 3% had a severe hearing impairment	Included
Parkes et al (2001) ⁴⁰	CP: All subtypes 5 y	745	Population CP register, Northern Ireland (95% of 1981-1993 birth cohorts)	1	2% had a severe hearing impairment	Excluded: part duplicate cases with Surman et al (2006) ³⁶
Shevell et al (2009) ⁴¹	CP: All subtypes 2-5 y	243	CP register, Quebec, Canada (80% of 1999-2002 birth cohort, 80% response rate)	1	11% had a severe hearing impairment Rates of hearing impairment were higher in those with more severe physical disability (18% GMFCS IV and V) compared with those with less physical disability (8% GMFCS I-III) (<i>P</i> < .003)	Included
Sigurdardottir et al (2008) ⁴²	CP: All subtypes 4-6 y	148	Population CP register, Iceland (85% had data available from 1985-2000 birth cohort)	1	2% had some hearing impairment	Excluded: part duplicate cases with Sigurdardottir and Vik (2011) ⁴³

TABLE 1 Continued

Study	Participants	Analyzed <i>n</i>	Research Design	Level of Evidence	Results	Included/ Excluded Meta-analysis
Sigurdardottir et al (2009) ⁴⁴	CP: All subtypes	139	Population CP register, Iceland (100% of 1990–1996 and 2997–2003 birth cohort)	1	1% to 2% had some hearing impairment	Excluded: part duplicate cases with Sigurdardottir and Vik (2011) ⁴⁵
Sigurdardottir and Vik (2011) ⁴⁵	CP: All subtypes 4–6 y	152	Population CP register, Iceland (100% of 1989–2004 birth cohort)	1	3% had some hearing impairment or deafness	Excluded: Data could not be separated
Surman et al (2006) ³⁶	CP: All subtypes	6910	CP register, UK. UKCP = 5 CP registers, 2 are population based (Northern Ireland and Scotland) (1960–1997 CP birth cohort) (87% had data available)	1	7% to 8% had a hearing impairment 2% had a severe hearing impairment	Included: <i>n</i> > 500
Surman et al (2009) ⁴⁵	CP: All subtypes	5019	CP register, UK. UKCP = 5 CP registers, 2 are population based (Northern Ireland and Scotland) (1976–1999 birth cohort) (73% data available)	1	8% had a hearing impairment	Excluded: part duplicate cases with Surman et al (2006) ³⁶
Intellectual function						
Arnaud et al (2008) ²⁸	CP: All subtypes 8–12 y	818	Prospective cross-sectional survey from 8 population CP registers (63% consented)	1	53% had an ID	Excluded: part duplicate cases with SCPE (2000) ⁴⁶
Australian CP Register Group (2009) ³⁷	CP: All subtypes	1195	Population CP register, Victoria, Australia (1993–2003 birth cohort)	1	47% had an ID (IQ <70)	Included
Baird et al (2000) ⁴	CP: All subtypes	107	Population CP cohort, South East Thames, UK (100% of 1989–1992 birth cohort)	1	31% had a severe ID (IQ <50) 53% had an ID 31% had a severe ID	Excluded: part duplicate cases with Surman et al (2009) ⁴⁵
Dolk et al (2006) ⁴⁷	CP: All subtypes	909	Population CP register, Northern Ireland (93% 1981–1987 birth cohorts)	1	46% had an ID	Excluded: part duplicate cases with SCPE (2000) ⁴⁶
Dolk et al (2010) ⁴⁸	CP: All subtypes	3758	CP register: UKCP5 CP registers (1984–1997 birth cohorts)	1	20% had a severe ID	Excluded: Rates not provided for IQ 50–70
El-Tallawy et al (2011) ⁴⁹	CP: All subtypes	52	Population survey, with door knocking, Egypt (100% of 1990–2007 birth cohort)	1	70% had an ID	Included
Himmelmann et al (2006) ³⁸	CP: All subtypes 4–8 y	367	Population CP register, Western Sweden (89% of 1991–1998 birth cohort)	1	40% had an ID 21% had a severe ID	Included
Himmelmann et al (2009) ⁵⁰	CP: Dyskinesia only ≥5 y	572	CP register: SCPE (1976–1996 birth cohorts)	1	52% had a severe ID (IQ <50), compared with 35% of children with the bilateral spastic subtype	Excluded: Not all subtypes but included in Table 3
Jarvis et al (2005) ⁵¹	CP: All subtypes	3454	CP register: SCPE (77% of 1976–1990 birth cohorts)	1	28% had a severe ID (IQ <50)	Excluded: part duplicate cases with SCPE (2000) ⁴⁶
McManus et al (2006) ⁵²	CP: All subtypes	9128	SCPE register (1980–1996 birth cohorts)	1	30% had a severe ID (IQ <50)	Excluded: part duplicate cases with SCPE (2000) ⁴⁶
Mongan et al (2006) ³⁹	CP: All subtypes ≥5 y	75	Population CP Register, West Ireland (88% of 1990–1999 birth cohort)	1	56% had an ID (IQ <70) 35% had a severe ID (IQ <50)	Included
Nordmark et al (2001) ⁵³	CP: All subtypes 6–9 y	167	Population CP Register, South Sweden (100% of 1990–1993 birth cohort)	1	52% had an ID (IQ <70) 26% had a severe ID (IQ <50)	Included
Parkes et al (2001) ⁴⁰	CP: All subtypes 5 y	745	Population CP register, Northern Ireland (95% of 1981–1993 birth cohorts)	1	45% had an ID (IQ <70)	Excluded: part duplicate cases with SCPE (2000) ⁴⁶

TABLE 1 Continued

Study	Participants	Analyzed <i>n</i>	Research Design	Level of Evidence	Results	Included/ Excluded Meta-analysis
Par-kes et al (2010) ⁵⁵	CP: All subtypes ≥5 y	1357	Population CP register, Northern Ireland (89% of 1980–2001 birth cohort)	1	48% had an ID (IQ <70)	Excluded: part duplicate cases with SCPE (2000) ⁴⁶
Rankin et al (2010) ⁵⁴	CP: All subtypes acquired excluded	1104	CP Register: Surveillance of Cerebral Palsy in Europe (SCPE), record linkage for France, Denmark, and Northern England (87% available data)	1	31% had a severe ID (IQ <50) 26% had a severe ID (IQ <50)	Excluded: part duplicate cases with SCPE (2000) ⁴⁶
Ravn et al (2010) ⁵⁵	CP: All subtypes 5–6 y	1185	Population CP register, Denmark (>85% ascertainment, 1983–1998 birth cohort of Eastern Denmark)	1	62% had an ID	Included
SCPE (2000) ⁴⁶	CP: All subtypes	3714	CP register: SCPE (1980–1990 birth cohorts)	1	23% to 44% had an ID (IQ <70) 30% to 41% had a severe ID (IQ <50)	Included: <i>n</i> > 500
SCPE (2002) ⁵⁶	CP: All subtypes	6502	CP register: SCPE (73% of 1980–1990 birth cohorts)	1	31% had a severe ID (IQ <50)	Excluded: part duplicate cases with SCPE (2000) ⁴⁶
Sigurdardottir et al (2008) ⁴²	CP: All subtypes 4–6 y	148	Population CP register, Iceland (85% had data available from 1985–2000 birth cohort)	1	40% had an ID (IQ <70) 21% had a severe ID (IQ <50)	Excluded: part duplicate cases with Sigurdardottir and Vik (2011) ⁴³
Sigurdardottir et al (2009) ⁴⁴	CP: All subtypes	139	Population CP register, Iceland (100% of 1990–1996 and 1997–2003 birth cohort)	1	40% to 51% had an ID (IQ <70)	Excluded: part duplicate cases with Sigurdardottir and Vik (2011) ⁴³
Sigurdardottir and Vik (2011) ⁴³	CP: All subtypes 4–6 y	152	Population CP register, Iceland (100% of 1989–2004 birth cohort)	1	39% had an ID (IQ <70) 21% had a severe ID (IQ <50)	Included
Surman et al (2003) ⁵⁷	CP: All subtypes	898	Oxford Register of Early Childhood Impairments, England (1984–1995 CP birth cohort)	1	50% had an ID	Excluded: part duplicate cases with Surman et al (2009) ⁴⁵
Surman et al (2006) ³⁶	CP: All subtypes	6910	CP register, UK. UKCP = 5 CP registers, 2 are population based (Northern Ireland and Scotland) (1960–1997 CP birth cohort)	1	39% to 51% had an ID 24% to 31% had a severe ID	Excluded: part duplicate cases with Surman et al (2009) ⁴⁵
Surman et al (2009) ⁴⁵	CP: All subtypes	5019	CP register, UK. UKCP = 5 CP registers, 2 are population based (Northern Ireland and Scotland) (1976–1999 birth cohort) (73% data available)	1	48% had an ID	Included: <i>n</i> > 500
Wichers et al (2005) ⁵⁸	CP: All subtypes 6–19 y	127	Population CP study, Netherlands (100% of 1977–1988 birth cohort population)	1	34% to 43% had an ID (IQ <70)	Included
Pain						
Arnaud et al (2008) ²⁸	CP: All subtypes 8–12 y	818	Prospective cross-sectional survey from 8 population CP registers (63% participation rate)	1	72% had pain 54% had moderate pain and 18% had severe pain Pain was associated with poor quality of life in the physical well-being (OR: 5.2 [95% CI: 2.7–9.7]) (<i>P</i> < .001) and psychological well-being (OR: 2.9 [95% CI: 1.7–4.9]) (<i>P</i> < .001) and self-perception (OR: 2.7 [95% CI: 1.6–4.4]) (<i>P</i> < .001) domains	Included: <i>n</i> > 500

TABLE 1 Continued

Study	Participants	Analyzed <i>n</i>	Research Design	Level of Evidence	Results	Included/ Excluded Meta-analysis
Jahnsen et al (2004) ⁵⁹	CP: All subtypes without ID 18–72 y	CP: 406 Controls: 2287	Prospective population cohort study, Norway (53% response rate)	3 [Prognostic]	78% had pain; 45% had moderate to severe pain 28% had chronic pain compared with 15% in the population 82% had pain in at least 1 body part. Pain in number of body parts: 1 only, 18%; 2 to 3 parts, 45%; 3 to 5 parts, 42%; and ≥5 parts, 13% Number of painful body parts was significantly associated with number of joints with contracture ($P < 0.001$) Pain increased with overactivity (73%), inactivity (26%), and cold weather (14%) Pain decreased with rest (51%), physiotherapy (49%), and medication (35%), and warm weather (28%)	Included: <80% of population but best population data available because of case controls
Kennes et al (2002) ²⁹	CP: All subtypes 5–13 y	408	Prospective cohort study, Canada (18% of population cohort randomly sampled, 96% return rate)	1	14% had pain Pain was not related to level of physical disability (GMFCS) ($P = .37$)	Excluded: <80% of population but included in Table 3
Opheim et al (2011) ⁶⁰	CP: Hemiplegia and diplegia subtypes without ID 18–72 y	288	Prospective population cohort study, Norway (51% longitudinal follow up to study by Jahnsen et al (2004) ⁵⁹)	5 ^a	83% had pain More people experienced pain as they aged, 22% were pain-free initially, but only 17% were pain-free 7 years later	Excluded: Not all subtypes but included in Table 3
Parke et al (2008) ²²	CP: All subtypes 8–12 y	818	Cross-sectional survey from 8 CP registers: SCPE (70% participation rate)	1	Back/neck, foot, and ankle pain were most common Rates of behavioral problems were higher in children with severe pain compared with children without pain (OR: 2.7 [95% CI: 1.5–4.6])	Excluded: Duplicate cases with Arnaud et al (2008) ²⁸ but included in Table 3
Russo et al (2008) ³⁰	CP: Hemiplegia only 3–16 y	107	Population CP register; prospective assessment (75% participation rate, 100% follow-up)	1	48% had pain Rates of behavioral competence were higher for children without pain (mean: 3.3) than for children with pain (mean: 2.9) ($P < .01$)	Excluded: Not all subtypes but included in Table 3

Sleeping

TABLE 1 Continued

Study	Participants	Analyzed <i>n</i>	Research Design	Level of Evidence	Results	Included/ Excluded Meta-analysis
Newman et al (2006) ⁶¹	CP: All subtypes 6–11 y	173	Prospective cohort study, Ireland (70% response rate)	5 ^a	23% had pathologic sleep disorder 24% had difficulty initiating and maintaining sleep 18% had sleep–wake transition disorders 15% had sleep-related breathing disorders 11% had excessive somnolence 8% had arousal disorders 8% had sleep hyperhidrosis Pathologic sleep was highly associated with uncontrolled epilepsy, single-parent families, and costleeping	Included: Only study available
Vision						
Arnaud et al (2008) ²⁸	CP: All subtypes 8–12 y	818	Prospective cross-sectional survey from 8 population CP registers (63% consented, 93% follow-up)	1	7% had functional blindness	Excluded: part duplicate cases with McManus et al (2006) ⁵²
Australian CP Register Group (2009) ³⁷	CP: All subtypes	1897	Population CP register, Victoria and WA, Australia (1993–2003 birth cohort)	1	5% had functional blindness 29% had some vision impairment 13% had strabismus only	Included
Himmelfmann et al (2006) ³⁶	CP: All subtypes 4–8 y	367	Population CP register, Western Sweden (89% of 1991–1998 birth cohort)	1	19% had severe visual impairments Rates of visual impairment were higher in those with severe physical disability	Included
McManus et al (2006) ⁵²	CP: All subtypes	9128	SOPE register (1980–1996 birth cohorts)	1	12% had a severe visual impairment	Included: <i>n</i> > 500
Mongan et al (2006) ³⁹	CP: All subtypes ≥5 y	85	Population CP register, West Ireland (88% of 1990–1999 birth cohort)	1	12% had a visual impairment	Included
Nordmark et al (2001) ⁵³	CP: All subtypes 6–9 y	167	Population CP Register, South Sweden (100% of 1990–1993 birth cohort)	1	6% had a severe visual impairment 22% had a visual impairment	Included
Parke et al (2001) ⁴⁰	CP: All subtypes 5 y	745	Population CP register, Northern Ireland (95% of 1981–1993 birth cohorts)	1	11% had a severe vision impairment	Excluded: part duplicate cases with Surman et al (2006) ³⁶

TABLE 1 Continued

Study	Participants	Analyzed <i>n</i>	Research Design	Level of Evidence	Results	Included/ Excluded Meta-analysis
Saunders et al (2010) ⁶²	CP: All subtypes 4–23 y	CP: 118 Controls: 128	Population CP register, Northern Ireland (100% of data available)	1	High refractive errors were more common in CP than matched controls Rates of high myopia were more common in CP (9%) compared with controls (0%) (<i>P</i> < .05) Rates of low–moderate hypermetropia were more common in CP (42%) compared with controls (9%) (<i>P</i> < .05) Rates of high hypermetropia were more common in CP (12%) compared with controls (2%) (<i>P</i> < .05) Rates of astigmatism were more common in CP (36%) compared with controls (3%) (<i>P</i> < .05) Rates of anisometropia were more common in CP (18%) compared with controls (7%) (<i>P</i> < .05) 11% had a severe vision impairment	Excluded: part duplicate cases with Surman et al (2006) ³⁶
SCPE (2002) ⁵⁶	CP: All subtypes	6502	CP register: SCPE (73% of 1980–1990 birth cohorts)	1	9% had a severe vision impairment Rates of vision impairment were higher in those with more severe physical disability (22% GMFCS IV and V) compared with those with less physical disability (3% GMFCS I–III) (<i>P</i> < .001) 12% had some visual impairment	Excluded: part duplicate cases with McManus et al (2006) ⁵² Included
Shevell et al (2009) ⁴¹	CP: All subtypes 2–5 y	243	CP Register, Quebec, Canada (80% of 1999–2002 birth cohort, 80% response rate)	1	11% to 19% had a visual impairment	Excluded: part duplicate cases with Sigurdardottir et al (2011) ⁴³ Included
Sigurdardottir et al (2008) ⁴²	CP: All subtypes 4–6 y	148	Population CP register, Iceland (85% had data available from 1985–2000 birth cohort)	1	11% to 19% had a visual impairment	Excluded: part duplicate cases with Sigurdardottir et al (2011) ⁴³ Included
Sigurdardottir et al (2009) ⁴⁴	CP: All subtypes	139	Population CP register, Iceland (100% of 1990–1996 and 1997–2003 birth cohort)	1	13% had some visual impairment or functional blindness 23% had a vision impairment	Excluded: part duplicate cases with Sigurdardottir et al (2011) ⁴³ Included
Sigurdardottir and Vik (2011) ⁴³	CP: All subtypes 4–6 y	152	Population CP register, Iceland (100% of 1989–2004 birth cohort)	1	34% to 40% had a vision impairment 9% to 11% has a severe vision impairment	Excluded: part duplicate cases with Surman et al (2006) ³⁶
Surman et al (2003) ⁵⁷	CP: All subtypes	898	Oxford Register of Early Childhood Impairments, UK (1984–1995 CP birth cohort)	1	43% had a vision impairment	Excluded: part duplicate cases with Surman et al (2006) ³⁶
Surman et al (2006) ³⁶	CP: All subtypes	6910	CP register, UK. UKCP = 5 CP registers, 2 are population based (Northern Ireland and Scotland) (1960–1997 birth cohort) (83% had data available)	1	25% to 42% has a vision impairment 5% to 19% had a severe vision impairment	Excluded: part duplicate cases with Surman et al (2006) ³⁶
Surman et al (2009) ⁴⁵	CP: All subtypes	5019	CP register, UK. UKCP = 5 CP registers, 2 are population based (Northern Ireland and Scotland) (1976–1999 birth cohort) (73% data available)	1		
Wichers et al (2005) ⁵⁸	CP: All subtypes 6–19 y	127	Population CP study, Netherlands (100% of 1977–1988 birth cohort)	1		

Activity limitations
Eating

TABLE 1 Continued

Study	Participants	Analyzed <i>n</i>	Research Design	Level of Evidence	Results	Included/ Excluded Meta-analysis
Andersen et al (2010) ⁶⁵	CP: All subtypes ≥4 y	557	Population CP register; Norway (97% of 1996–2003 birth cohorts)	1	24% were totally dependent for feeding or were tube-fed	Excluded: Prevalence data about dependent eating and tube feeding combined
Himmelmann et al (2007) ⁶⁴	CP: Bilateral spastic only	167	Population CP register; Western Sweden (97% of 1991–1998 birth cohort)	1	12% were underweight (>2 SDs below mean for BMI)	Excluded: Not all subtypes but included in Table 3
Motion et al (2002) ⁶⁵	CP: All subtypes as an outcome of early feeding problems	CP: 37	Longitudinal cohort population study (prevalence of 2.6/1000)	2 [Prognostic]	Rates of weak sucking at 4 weeks of age were higher in CP (48%) compared with normal population (18%) (<i>P</i> < .001)	Excluded: Insufficient prevalence detail but included in Table 3
	7–8 y	Controls: 12 332			Rates of feeding difficulties at 6 months were higher with CP (10%) compared with normal population (3%) (<i>P</i> = .017)	
Par-kes et al (2010) ³⁵	CP: All subtypes ≥5 y	1119	Population CP register; Northern Ireland (86% of 1980–2001 birth cohort)	1	Weak sucking and exhaustion with feeding at 4 weeks of age was associated with spastic quadriplegic CP	Excluded: Insufficient prevalence detail
Shevell et al (2009) ⁴¹	CP: All subtypes 2–5 y	243	CP Register; Quebec, Canada (80% of 1999–2002 birth cohort, 80% response rate)	1	21% had a swallowing or chewing impairment	Included
Sigurdardottir and Vik (2011) ⁴³	CP: All subtypes 4–6 y	152	Population CP register; Iceland (100% of 1989–2004 birth cohort)	1	8% were tube-fed	
Strauss et al (2004) ⁸⁶	CP: All subtypes 20, 40, and 60 y	904	Longitudinal cohort study, California (100% of available data)	1	Rates of tube feeding were higher in those with more severe physical disability (79% GMFCS IV and V) compared with those with less physical disability (21% GMFCS I–III) (<i>P</i> < .001)	Included
Wichers et al (2009) ⁶⁷	CP: Spastic only 6–19 y	119	Prospective cross-sectional population based survey, Netherlands (>90% of 1977–1988 birth cohort, 100% follow-up)	1	7% were tube-fed	
Talking Andersen et al (2010) ⁶⁵	CP: All subtypes ≥4 y	557	Population CP register; Norway (97% of 1996–2003 birth cohorts)	1	Rates of tube feeding were comparable in CP at 20 years (4%) and 60 years (2%) Rates of dependent feeding were comparable at 20 years (16%) and 60 years (14%) Rates of finger feeding were comparable in CP at 20 years (9%) and 60 years (6%) Rates of eating with cutlery were comparable in CP at 20 years (71%) and 60 years (78%) 2% to 6% unable to feed self 15 years later 23% had feeding and drinking problems or dependent for care	Excluded: Not all subtypes
					19% were nonverbal 31% had some impairment 48% had normal speech Of those with speech impairments, 54% used Alternative and Augmentative Communication	Included

TABLE 1 Continued

Study	Participants	Analyzed <i>n</i>	Research Design	Level of Evidence	Results	Included/ Excluded Meta-analysis
Arnaud et al (2008) ²⁸	CP: All subtypes 8–12 y	818	Prospective cross-sectional survey from 8 population CP Registers (63% participation rate)	1	27% were nonverbal 43% had some impairment, of these 16% used speech but with difficulty	Excluded: part duplicate cases with Parkes et al (2010) ³⁵
Australian CP Register Group (2009) ³⁷	CP: All subtypes	1897	Population CP register, Victoria and WA, Australia (1993–2003 birth cohort)	1	27% were nonverbal 33% had some impairment	Included
Parkes et al (2010) ³⁵	CP: All subtypes ≥5 y	1119	Population CP register, Northern Ireland (88% of 1980–2001 birth cohort)	1	19% were nonverbal 36% had some speech impairment	Included
Shevell et al (2009) ⁴¹	CP: All subtypes 2–5 y	243	CP register, Quebec, Canada (80% of 1999–2002 birth cohort, 80% response rate)	1	22% were nonverbal Rates of being nonverbal were higher in those with more severe physical disability (57% GMFCS IV and V) compared with those with less physical disability (4% GMFCS I–III) ($P < .001$)	Included
Sigurdardottir and Vik (2011) ⁴³	CP: All subtypes 4–6 y	152	Population CP register, Iceland (100% of 1989–2004 birth cohort)	1	24% were nonverbal Rates of being nonverbal were higher in those with more severe physical disability	Included
Strauss et al (2004) ⁶⁶	CP: All subtypes 20, 40, and 60 y	904	Longitudinal cohort study, California (100% of available data)	1	19% to 36% were nonverbal	Included: $n > 500$
Walking Andersen et al (2010) ⁶³	CP: All subtypes ≥4 y	557	Population CP register, Norway (97% of 1996–2003 birth cohorts)	1	26% did not walk 19% walked using a walking frame or device 55% walked independently GMFCS unavailable (collapsed)	Included
Arnaud et al (2008) ²⁸	CP: All subtypes 8–12 y	818	Prospective cross-sectional survey from 8 population CP Registers (63% parent participation rate)	1	32% did not walk 17% walked using a walking frame or device 51% walked independently GMFCS available	Excluded: part duplicate cases with Beckung et al (2008) ⁶⁸
Australian CP Register Group (2009) ³⁷	CP: All subtypes	1195	Population CP register Victoria, Australia (1993–2003 birth cohort)	1	30% did not walk 12% walked using a walking frame or device 58% walked independently GMFCS available	Included
Beckung et al (2008) ⁶⁸	CP: All subtypes <21 y	9012	CP Register: Surveillance of Cerebral Palsy in Europe (SCOPE) (1976–1996 birth cohorts)	1	30% did not walk 16% walked using a walking frame or device 54% walked independently Inability to walk more common with ID (IQ <50) (71% compared with no ID (IQ >85) (8%) Inability to walk more common with active epilepsy (60% compared with no epilepsy (25%) GMFCS unavailable	Included: $n > 500$

TABLE 1 Continued

Study	Participants	Analyzed <i>n</i>	Research Design	Level of Evidence	Results	Included/ Excluded Meta-analysis
Day et al (2007) ⁶⁹	CP: All subtypes, ambulant only	CP 10 y: 7550 CP 25 y: 5721	Retrospective cohort California	1	16% of 10-year-olds and 9% of 25-year-olds did not walk 26% of 10-year-olds and 19% of 25-year-olds walked using a walking frame or device 58% of 10-year-olds and 72% of 25-year-olds walked independently Children that could walk and climb stairs at age 10 years only had a 23% chance of decline 15 years later Children that could walk with difficulty but did not need a chair had a 33% chance of improvement 15 years later and an 11% chance of being wheelchair dependent Children that used a wheelchair were 34% more likely to lose their walking ability GMFCS unavailable 29% did not walk GMFCS unavailable (partial reporting) 40% did not walk 19% walked using a walking frame or device 41% walked independently GMFCS available 31% did not walk 8% walked using a walking frame or device 61% walked independently GMFCS available 34% did not walk 14% walked using a walking frame or device 52% walked independently GMFCS available 45% did not walk or walked using a walking frame or device 55% walked independently GMFCS unavailable 30% did not walk GMFCS unavailable 16% did not walk 22% walked using a walking frame or device 62% walked independently GMFCS unavailable 18% did not walk 18% walked using a walking frame or device 64% walked independently GMFCS unavailable	Excluded: not all severity levels. Included in Table 3
Dolk et al (2006) ⁴⁷	CP: All subtypes	909	Population CP Register, Northern Ireland (1981–1987 birth cohorts)	1		Excluded: part duplicate cases with Beckung et al (2008) ⁶⁸ Included: <i>n</i> > 500
Hanna et al (2008) ⁷⁰	CP: All subtypes ≥ 6 y	657	Longitudinal study, Ontario Canada (75% consented)	1		
Himmelmann et al (2006) ³⁸	CP: All subtypes 4–8 y	367	Population CP register, Western Sweden (89% of 1911–1998 birth cohorts)	1		Included
Howard et al (2005) ⁷¹	CP: All subtypes	323	Population CP Register, Victoria, Australia (86% of 1990–1993 birth cohort)	1		Excluded: part duplicate cases with AGPR (2009) ³⁷
Jarvis et al (2005) ⁵¹	CP: All subtypes	3454	CP Register: Surveillance of Cerebral Palsy in Europe (SCOPE) (1976–1990 birth cohorts)	1		Excluded: part duplicate cases with Beckung et al (2008) ⁶⁸
McManus et al (2006) ⁵²	CP: All subtypes	9128	CP register: SCOPE (1980–1996 birth cohorts)	1		Excluded: part duplicate cases with Beckung et al (2008) ⁶⁸ Included
Michelsen et al (2005) ²	CP: All subtypes 21–35 y	CP: 819 Controls: 4406	Population CP register, Denmark (<i>n</i> = 819 CP, (100%) of 1965–1978 CP birth cohort)	2 (Prognostic)		
Mongan et al (2006) ³⁹	CP: All subtypes ≥ 5 y	85	Population CP register, West Ireland (88% of 1950–1999 birth cohort)	1		Included

TABLE 1 Continued

Study	Participants	Analyzed <i>n</i>	Research Design	Level of Evidence	Results	Included/ Excluded Meta-analysis
Nordmark et al (2001) ⁵³	CP: All subtypes 6–9 y	167	Population CP register, South Sweden (100% of 1990–1993 birth cohort)	1	27% did not walk 14% walked using a walking frame or device 59% walked independently GMFCS available	Excluded: part duplicate cases with Westborn et al (2007) ⁷²
Par-kes et al (2001) ⁴⁰	CP: All subtypes 5 y	745	Population CP register, Northern Ireland (95% of 1981–1993 birth cohorts)	1	29% did not walk GMFCS unavailable	Excluded: part duplicate cases with Beckung et al (2008) ⁶⁸
Par-kes et al (2010) ³⁵	CP: All subtypes ≥5 y	1215	Population CP register, Northern Ireland (90% of 1980–2001 birth cohort)	1	29% did not walk 10% walked using a walking frame or device 61% walked independently GMFCS available	Excluded: part duplicate cases with Beckung et al (2008) ⁶⁸
Ravn et al (2010) ⁵⁵	CP: All subtypes 5–6 y	1185	Population CP register, Denmark (>85% of 1983–1998 birth cohort Eastern Denmark)	1	40% did not walk or walked using a walking frame or device 60% walked independently GMFCS unavailable	Excluded: duplicate cases with Michelsen et al (2005) ²
Reid et al (2010) ⁷³	CP: All subtypes singletons only	CP: 1241 Controls: 2482	Population CP register, Victoria, Australia (1991–2004 birth cohort) (92% available data)	3 [Prognostic]	30% did not walk 12% walked using a walking frame or device 58% walked independently GMFCS available	Excluded: part duplicates with ACPR (2009) ³⁷
Rosenbaum et al (2002) ¹	CP: All subtypes 1–13 y	657	Cross-sectional study, Ontario Canada (31% of 1986–1996 birth cohort)	1	41% did not walk 19% walked using a walking frame or device 40% walked independently GMFCS available	Excluded: part duplicate with Hanna et al (2008) ⁷⁰
Saunders et al (2010) ⁶²	CP: All subtypes 4–23 y	CP: 118 Controls: 128	Population CP register, Northern Ireland (97% data available)	1	35% did not walk 24% walked using a walking frame or device 41% walked independently GMFCS available	Excluded: part duplicate cases with Beckung et al (2008) ⁶⁸
SCOPE (2002) ⁴⁶	CP: All subtypes	6502	CP register: SCPE (73% of 1980–1990 birth cohorts)	1	GMFCS available 31% did not walk GMFCS unavailable	Excluded: part duplicate cases with Beckung et al (2008) ⁶⁸
Shevell et al (2009) ⁴¹	CP: All subtypes	243	CP register, Quebec, Canada (80% of 1999–2002 birth cohort, 80% response rate)	1	34% did not walk 12% walked using a walking frame or device 54% walked independently GMFCS available	Included
Sigurdardottir et al (2008) ⁴²	CP: All subtypes 4–6 y	148	Population CP register, Iceland (85% had data available from 1985–2000 birth cohort)	1	23% did not walk 77% walked independently or walked using a walking frame or device GMFCS unavailable (collapsed)	Excluded: part duplicate cases with Sigurdardottir et al (2009) ⁴⁴
Sigurdardottir et al (2009) ⁴⁴	CP: All subtypes	139	Population CP register, Iceland (100% of 1985–2000 birth cohort)	1	25% did not walk 9% walked using a walking frame or device 66% walked independently GMFCS unavailable (collapsed)	Included
Sigurdardottir and Vik (2011) ⁴³	CP: All subtypes 4–6 y	152	Population CP register, Iceland (100% of 1989–2004 birth cohort)	1	24% did not walk 76% walked using a walking frame or device or walked independently GMFCS unavailable (collapsed)	Excluded: part duplicate cases with Sigurdardottir et al (2009) ⁴⁴

TABLE 1 Continued

Study	Participants	Analyzed <i>n</i>	Research Design	Level of Evidence	Results	Included/ Excluded Meta-analysis
Strauss et al (2004) ⁶⁶	CP: All subtypes 20, 40, and 60 y	904	Longitudinal cohort study, California (100% of available data)	1	35% to 40% did not walk 25% to 35% walked using a walking frame or device 25% to 39% walked independently GMFCS unavailable	Included: <i>n</i> >500
Surman et al (2006) ³⁶	CP: All subtypes	6910	UKCP database of 5 CP registers, 2 were population-based (Northern Ireland and Scotland) (1960–1997 birth cohort)	1	29% to 31% did not walk GMFCS unavailable	Included: <i>n</i> >500
Westboorn et al (2007) ⁷²	CP: All subtypes 4–11 y	343	Population CP register, Southern Sweden (100% of 1990–1997 birth cohort)	1	22% did not walk 12% walked using a walking frame or device 66% walked independently	Included
Wichers et al (2005) ⁶⁸	CP: All subtypes 6–19 y	127	Population study, the Netherlands 100% of 1977–1988 birth cohort)	1	GMFCS available 39% did not walk 61% walked independently or using a walking frame/ device	Excluded: part duplicate cases with Wichers et al (2009) ⁶⁷
Wichers et al (2009) ⁶⁷	CP: Spastic only 6–19 y	119	Prospective cross-sectional population survey, the Netherlands (>90% of 1977–1988 birth cohort, 100% follow-up)	1	GMFCS unavailable 27% did not walk 8% walked using a walking frame or device 65% walked independently	Included
Wu et al (2004) ⁷⁴	CP: All subtypes	2295	Retrospective cohort, California (43% follow-up, 1987–1999 birth cohort)	1	GMFCS available In 2-year-olds, prognosis of future ambulation by age 6 years is predicted by: (1) motor milestones at age 2 years (including: rolling [OR: 4.6 (95% CI: 2.2–9.6)]; sitting [OR: 12.5 (95% CI: 5.8–27.2)]; and pulling to stand [OR: 28.5 (95% CI: 13.4–60.4)]; (2) type of CP (spastic quadriplegia has highest risk for not walking); and (3) blindness GMFCS unavailable (collapsed)	Excluded: part duplicate cases with Strauss et al (2004) ⁶⁶ Included in Table 3
Co-occurring diseases Epilepsy	Nonambulant at 2–3.5 y					
Arnaud et al (2008) ²⁸	CP: All subtypes 8–12 y	818	Prospective cross-sectional survey from 8 population CP registers (65% consented)	1	30% had active epilepsy	Excluded: part duplicate cases with Surman et al (2006) ³⁶
Australian CP Register Group (2009) ³⁷	CP: All subtypes	1897	Population CP register, Victoria and WA, Australia (1993–2003 birth cohort)	1	28% had active epilepsy 2% had resolved epilepsy 36% had epilepsy	Included
Carlsson et al (2003) ⁷⁵	CP: All subtypes 6–14 y	146	Population CP register, Goteborg Sweden (100% 1987–1994 birth cohort)	1	Rates of epilepsy increased with severity of motor disability (<i>P</i> <.001). Rates of epilepsy were significantly higher for the spastic type born at term (48%) compared with preterm infants (28%), <i>P</i> = .04 Rates of epilepsy were significantly higher for children with CP plus ID (61%) compared with CP with normal intelligence (19%), <i>P</i> <.001	Included

TABLE 1 Continued

Study	Participants	Analyzed <i>n</i>	Research Design	Level of Evidence	Results	Included/ Excluded Meta-analysis
El-Tallawy et al (2011) ⁴⁹	CP: All subtypes	52	Population survey, with door knocking, Egypt (100% of 1990–2007 birth cohort)	1	52% had epilepsy	Included
Himmelmann et al (2006) ³⁸	CP: All subtypes 4–8 y	367	Population CP register, Western Sweden (89% of 1991–1998 birth cohort)	1	33% had epilepsy Rates of epilepsy were higher in those with more severe or bilateral motor involvement (87% tetraplegia; 52% dyskinesia; 34% diplegia) compared with those with hemiplegic/unilateral motor involvement (23%)	Included
Michelsen et al (2005) ²	CP: All subtypes 21–35 y	CP: 819 Controls: 4406	Population CP register, Denmark (100% of 1965–1978 birth cohort)	3 [Prognostic]	17% had epilepsy Epilepsy with CP was a significant predictor of not being competitively employed in adulthood (OR: 3.69 [95% CI: 1.46–9.36], <i>P</i> = .0439)	Included
Mongan et al (2006) ³⁹	CP: All subtypes ≥5 y	75	Population CP register, West Ireland (88% of 1990–1999 birth cohort)	1	46% had epilepsy at some time 35% had active epilepsy Of those with epilepsy, 58% had an ID and 44% had spastic quadriplegia	Included
Nordmark et al (2001) ⁵³	CP: All subtypes 6–9 y	167	Population CP register, South Sweden (100% of 1990–1993 birth cohort)	1	36% had epilepsy	Included
Parke et al (2001) ⁴⁰	CP: All subtypes 5 y	745	Population CP register, Northern Ireland (95% of 1981–1993 birth cohorts)	1	22% had active epilepsy	Excluded: part duplicate cases with Parkes et al (2010) ³⁵
Parke et al (2010) ³⁵	CP: All subtypes ≥5 y	1119	Population CP register, Northern Ireland (91% of 1980–2001 birth cohort)	1	43% had epilepsy at some time	Excluded: part duplicate cases with Surman et al (2006) ³⁶
Ravn et al (2010) ⁵⁵	CP: All subtypes 5–6 y	1185	Population CP register, Denmark (>85% of 1983–1998 birth cohort Eastern Denmark)	1	27% had active epilepsy 29% had epilepsy	Included
SCPE (2002) ⁵⁶	CP: All subtypes	6502	CP register: SCPE (73% of 1980–1990 birth cohorts)	1	21% had active epilepsy	Excluded: part duplicate cases with Surman et al (2006) ³⁶
Shevell et al (2009) ⁴¹	CP: All subtypes 2–5 y	243	CP register, Quebec, Canada (80% of 1999–2002 birth cohort, 80% response rate)	1	17% had active epilepsy Rates of active epilepsy were significantly higher in those with less gross motor function (32% in GMFCS IV and V) compared with those with better gross motor ability (9% in GMFCS I–III) (<i>P</i> < .001)	Included
Sigurdardottir et al (2008) ⁴²	CP: All subtypes 4–6 y	148	Population CP register, Iceland (85% had data available from 1985–2000 birth cohort)	1	27% had epilepsy	Excluded: part duplicate cases with Sigurdardottir et al (2010) ³¹
Sigurdardottir et al (2009) ⁴⁴	CP: All subtypes	139	Population CP register, Iceland (100% of 1997–2003 birth cohort)	1	15% to 38% had epilepsy (15% in 1997–2003 birth cohorts, 38% in 1990–1996 birth cohorts) Rates of epilepsy were significantly decreasing over time (<i>P</i> = .002)	Excluded: part duplicate cases with Sigurdardottir et al (2010) ³¹
Sigurdardottir and Vik (2011) ⁴⁵	CP: All subtypes 4–6 y	152	Population CP register, Iceland (100% of 1989–2004 birth cohort)	1	26% had active epilepsy	Included

TABLE 1 Continued

Study	Participants	Analyzed <i>n</i>	Research Design	Level of Evidence	Results	Included/ Excluded Meta-analysis
Surman et al (2006) ³⁶	CP: All subtypes	6910	CP register, UK, UKCP = 5 CP registers, 2 are population based (Northern Ireland and Scotland) (1960–1997 CP birth cohort) (52% had data available)	1	18% to 33% had epilepsy	Included: <i>n</i> > 500
Wichers et al (2005) ³⁸	CP: All subtypes 6–19 y	127	Population study, the Netherlands (100% of 1977–1988 birth cohort)	1	40% had active or previously treated epilepsy Rates of active or previously treated epilepsy were higher in those with bilateral spastic (42%) or ataxic/dyskinetic (63%) motor types compared with those with unilateral motor involvement (33%).	Included
Zafeiriou et al (1999) ⁷⁶	CP: All subtypes 5 y and ≥5 y follow-up	CP + Epilepsy: 178 Epilepsy Controls: 150	Longitudinal prospective cohort study, Greece (36% of CP population)	3 [Prognostic]	70% had their first seizure within their first year of life Rates of becoming seizure-free after 3 years of antiepileptic medication were lower in CP (75%), compared with those with epilepsy only (81%) (<i>P</i> < .05)	Excluded: <80% of population but included in Table 3
Hip displacement and spine deformities Haggglund et al (2005) ⁷⁷	CP: All subtypes	CP: 258 Control: 103	Southern Sweden cerebral palsy population register (89% of 1991–1997 birth cohort)	1	8% of controls had dislocated hips 0% of hip surveillance group had dislocated hips (<i>P</i> < .001) 21% of the hip surveillance group had displaced hips and received treatment, including orthopedic surgery After 10 years of follow-up, 2 children in southern Sweden had dislocated hips, neither of whom were in the hip surveillance program	Included
Haggglund et al (2005) ⁷⁸	CP: All subtypes	CP: 221 Control: 74	Population CP register, South Sweden (95% of 1991–1995 birth cohort)	1	Rates of orthopedic surgery to correct deformity, contracture, and salvage of dislocated hips were lower in the cohorts regularly treated with SDR, ITB, and botulinum and provided active surveillance were lower (15%) compared with the early control cohort in whom these treatments and active surveillance were not provided (40%) 27% had displaced hips Hip displacement was related to severity of physical disability (0% GMFCS I; 64% GMFCS V)	Excluded: part duplicate cases with Haggglund et al (2005) ⁷⁷
Haggglund et al (2007) ⁷⁹	CP: All subtypes	212	Population CP register, South Sweden (97% of 1992–1997 birth cohort)	1	Low-level evidence precluded firm recommendations on risk factors for scoliosis	Excluded: part duplicate cases with Haggglund et al (2005) ⁷⁷
Loeters et al (2010) ⁸⁰	CP: GMFCS IV–V	NA	Systematic review	4	12% of controls had windswept deformity 7% of hip surveillance group had windswept deformity	Excluded: As per convention for reviews
Persson-Bunke et al (2006) ⁸¹	CP: All subtypes	CP: 207 Control: 68	Population CP register, South Sweden (100% of 1991–1995 birth cohort)	1		Excluded: part duplicate cases with Haggglund et al (2005) ⁷⁷

TABLE 1 Continued

Study	Participants	Analyzed <i>n</i>	Research Design	Level of Evidence	Results	Included/ Excluded Meta-analysis
Soo et al (2006) ⁸²	CP: All subtypes	374	Retrospective study from Victorian CP population register, Australia (86% of CP population)	1	35% had hip displacement with a migration percentage >30° 7% had hip dislocation Rates of hip displacement were related to GMFCS severity level ($P < .001$) and motor type with spastic quadriplegia being the biggest risk factor (RR: 4.3 [95% CI: 2.7–6.8])	Included
Wichers et al (2009) ⁸⁸	CP: Spastic only 6–19 y	119	Prospective cross-sectional population survey, the Netherlands (>90% of 1977–1988 birth cohort, 100% follow-up)	1	3% had dislocated hips 8% had fixed scoliosis; 6% had fixed kyphosis Hip and spine deformities were all (100%) seen in children with bilateral spasticity	Excluded: Not all subtypes but included in Table 3

Excluded: Sample <80% of population OR not all subtypes OR duplicate data AND data did not further contribute to clinical messages. Behavior: Carlsson et al (2007)⁸⁴, Karaman et al (2005)⁸⁵, Ozturk et al (2006)⁸⁶, Parkes et al (2010)⁸⁷, Veugelers et al (2010)⁸⁸; Eating: Andersen et al (2008)⁸⁹, Himmelmann et al (2008)⁹⁰, Parkes et al (2007)⁹¹, Parkes et al (2008)⁹²; Hearing: Andersen et al (2008)⁹³, Himmelmann et al (2008)⁹⁴, Humphreys et al (2007)⁹⁵, Parkes et al (2008)⁹⁶; Hip and spine: Robinson et al (2010)⁹⁷, Sigurdardottir et al (2010)⁹⁸; Intelligence: Andersen et al (2008)⁹⁹, Himmelmann et al (2008)¹⁰⁰, Parkes et al (2008)¹⁰¹; Pain: Parkinsson et al (2010)¹⁰²; Sleeping: Andersen et al (2008)¹⁰³, Himmelmann et al (2008)¹⁰⁴; Vision: Andersen et al (2008)¹⁰⁵, Himmelmann et al (2008)¹⁰⁶; Walking: Andersen et al (2008)¹⁰⁷, Beaino et al (2010)¹⁰⁸, Benedict et al (2011)¹⁰⁹, Gorter et al (2004)¹¹⁰, Rosenbaum et al (2002)¹¹¹; Hanna et al (2009)¹¹²; Kennes et al (2009)¹¹³; Parkes et al (2007)¹¹⁴, Sigurdardottir et al (2010)¹¹⁵, Surman et al (2003)¹¹⁶; Vision: Andersen et al (2008)¹¹⁷, Himmelmann et al (2008)¹¹⁸; Kennes et al (2009)¹¹⁹, Rice et al (2009)¹²⁰, Shewell et al (2009)¹²¹; Parkes et al (2008)¹²²; (duplicate data with Arnaud et al (2010)¹²³); Pennefather and Tin (2000)¹²⁴; Sigurdardottir et al (2010)¹²⁵; CP, cerebral palsy; OR, odds ratio; RR, relative risk; SCPE, Surveillance of Cerebral Palsy in Europe; UKCP, United Kingdom Cerebral Palsy Register; ACPR, Australian Cerebral Palsy Register; ID, intellectual disability; IIB, Intrathecal Baclofen; NA, not applicable; SDR, Selective Dorsal Rhizotomy; WA, Western Australia.

^a Did not meet criteria for classification as a levels 1 through 4 study; therefore coded as level 5 evidence.

26–42) had epilepsy at some point, and 24% (95% CI: 17–29) had active epilepsy; (6) hearing (9492 cases for analysis): 4% (95% CI: 2–6) had a severe hearing impairment or were deaf; (7) hips and spine (632 cases for analysis): 28% (95% CI: 21–34) had displaced hips (ie, migration >30%) and 7.5% (95% CI: 7–8) had dislocated hips if they had not received hip surveillance, but this was reduced to 0% dislocation with surveillance; (8) intellectual function (12 053 cases for analysis): 49% had an intellectual disability (ID) (IQ <70) (95% CI: 34–64) and 28% had a severe ID (IQ <50) (95% CI: 21–35); (9) pain (1224 cases for analysis): 75% were in pain (95% CI: 72–78); (10) sleep (173 cases for analysis): 23% had a pathologic sleep disorder (95% CI unable to be calculated because only 1 study was included); (11) talking (4872 cases for analysis): 23% (95% CI: 19–27) were nonverbal; (12) walking (21 350 cases for analysis): 28% (95% CI: 16–40) could not walk, 16% walked with assistance (95% CI: 8–24), and 56% walked independently (95% CI: 32–80), with GMFCS (2924 cases for analysis) level I at 36% (95% CI: 26–46), level II at 22% (95% CI: 9–35), level III at 11% (95% CI: 8–14), level IV at 14% (95% CI: 8–20), and level V at 17% (95% CI: 13–21); and (13) vision (19 076 cases for analysis): 11% (95% CI: 5–17) were functionally blind.

The data regarding average rates of impairments were combined with prognostic data from the included studies regarding the likelihood of unwanted events occurring in the future. From these data, we developed a series of simple, plain English clinical messages that could be communicated to people with cerebral palsy and their families about the prognosis of the condition (Table 3).

DISCUSSION

In this systematic literature review regarding the rates of co-occurring

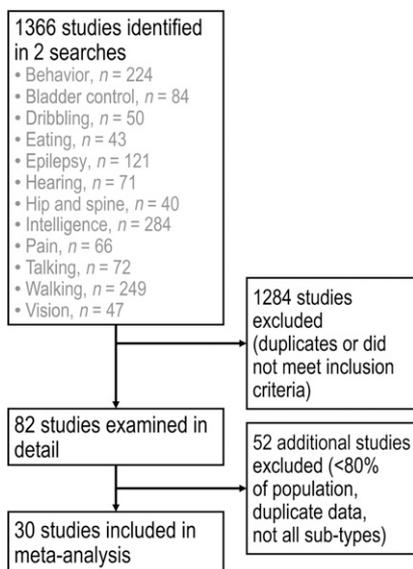


FIGURE 1
Flow diagram of eligible studies.

impairments, diseases, and functional limitations with cerebral palsy, we found that large volumes of either high-quality or moderate-quality evidence existed to provide guidance to parents about “how bad is it?” Included prevalence studies were nearly all rated as level 1 evidence on the Oxford Scale because they were cerebral palsy population registry studies. Furthermore, the methodologic quality of almost all studies was very high with low levels of bias, providing high degree of certainty about the plain English messages that were developed from the meta-analysis. The exception were data regarding behavior, bladder control, dribbling, pain, and sleep, in which more research, including that of a higher quality, was needed.

From the evidence appraised, we found that among children who have cerebral palsy: 3 in 4 were in pain; 1 in 2 had an ID; 1 in 3 could not walk; 1 in 3 had a hip displacement; 1 in 4 could not talk; 1 in 4 had epilepsy; 1 in 4 had a behavior disorder; 1 in 4 had bladder control problems; 1 in 5 had a sleep disorder; 1 in 5 dribbled; 1 in 10 were blind; 1 in 15 were tube-fed; and 1 in 25 were deaf. Rates of co-occurring impairments,

diseases, and functional limitations were strongly linked to the severity of the motor impairment, with the exception of pain and behavior disorders. Pain was very likely to be present at all levels of physical disability. Interestingly, behavior disorders were more common in children with milder levels of physical disability. In general, findings could potentially be explained to parents by saying, “All children with cerebral palsy will have physical challenges. The bigger the child’s brain injury, the more likely the child is to have other co-occurring impairments, diseases, and functional limitations accompanying the physical disability, except for pain and behavior, which are common regardless of the level of physical disability.” If these objective and simple messages are given to parents, this information may help alleviate the stress parents experience while trying to envisage the future at the time of diagnosis⁴ and in planning realistic and achievable services.³

The clinical messages we developed are consistent with cerebral palsy messages published elsewhere in the literature based on smaller, single-country, nonaggregated samples; for example, the Swedish register,²³ the Danish register,² and the Canadian register.¹² However, to the best of our knowledge, this is the first review to aggregate data from all the published international registries on a multitude of clinical problems associated with cerebral palsy to produce a suite of parent-friendly clinical messages.

Parents generally maintain a remarkably optimistic view of the future despite receiving bad news about their child’s prognosis.²⁴ Research suggests that parental recall about diagnostic information shared does not match what professionals claim to have communicated. Parents are thought to actively block the recall of bad news as a coping strategy. It is therefore paramount that

professionals understand that when communicating bad news with families, “truth disclosure is a process, not an event.”²⁵ The literature provides guidance about how professionals might communicate these cerebral palsy prognostic clinical messages. Parents recommend and prefer the following communication strategies when receiving bad news: (1) use of an honest, upfront, specific, and transparent communication style to enable parents to seek their right supports after receiving the news; (2) discussion about the child’s strengths to convey hope and reframe the future; (3) person-centered and respectful treatment of the child, so that the news feels personalized; (4) provision of a list of frequently asked questions to help parents prepare their own questions; (5) delivery of news to both parents simultaneously, or to one parent accompanied by a support person, to assist with information recall; (6) provision of a follow-up interview to assist with information recall, understanding, and acceptance; (7) provision of key information in writing; and (8) involvement of an advocate/keyworker/case manager to help with planning after the receipt of news.^{5,24,26,27} In light of this parental counsel about preference for a strengths-based approach, professionals could positively reinforce that the level of physical disability associated with cerebral palsy does not predetermine a child’s “happiness” and quality of life (high-quality GRADE).^{28,29}

Study Limitations

Our review was limited to evaluation of rates of co-occurring impairments, diseases, and functional limitations in studies published in English. Nevertheless, in most topic areas, publications were sourced from a wide range of developed countries across Europe, the United Kingdom, North

TABLE 2 Methodologic Quality of Prevalence Studies Retrieved

Study	Was the Target Population Defined by Clear Inclusion and Exclusion Criteria?	Was Probability Sampling Used to Identify Potential Respondents (or the Whole Population Approached)?	Did Characteristics of Respondents Match the Target Population, (ie, Was the Response Rate \geq 80% or Appropriate Analysis Included Comparing Responders and Non-Responders?)	Were Data Collection Methods Standardized?	Were Measures Used Valid?	Were Measures Used Reliable?	Were Features of Sampling Design Accounted for in the Analysis, Through Appropriate Weighting of the Data, or the Whole Population Approached?	Total Score Out of 7
Andersen et al (2010) ⁶⁵	Y	Y	Y	Y	P	P	Y	6
Andersen et al (2008) ⁶⁶	Y	Y	Y	Y	P	P	Y	6
Arnaud et al (2008) ²⁸	Y	P	N	P	P	P	P	3.5
Australian CP Register Group (2009) ³⁷	Y	Y	Y	P	P	P	Y	5.5
Baird et al (2000) ⁴	Y	N	N	Y	N	N	N	2
Beckung et al (2008) ⁶⁸	Y	Y	Y	P	P	P	Y	5.5
Carlsson et al (2003) ⁷⁵	Y	Y	Y	P	P	P	Y	5.5
Day et al (2007) ⁶⁹	Y	N	Y	P	Y	Y	N	4.5
Dolk et al (2006) ⁴⁷	Y	Y	Y	P	Y	Y	Y	6.5
Dolk et al (2010) ⁴⁸	Y	Y	P	P	P	P	Y	5
El-Tallawy et al (2011) ⁴⁹	Y	Y	P	Y	Y	Y	Y	6.5
Hagglund et al (2005) ⁷⁷	Y	Y	Y	Y	Y	Y	Y	7
Hagglund et al (2005) ⁷⁸	Y	Y	Y	Y	Y	Y	Y	7
Hagglund et al (2007) ⁷⁹	Y	Y	Y	Y	Y	Y	Y	7
Hanna et al (2008) ⁷⁰	Y	N	N	P	Y	Y	N	3.5
Himmelmann et al (2006) ³⁸	Y	Y	Y	P	P	P	Y	5.5
Howard et al (2005) ⁷¹	Y	Y	Y	P	P	P	Y	5.5
Jarvis et al (2005) ⁵¹	Y	Y	Y	P	P	P	Y	5
McManus et al (2006) ⁵²	Y	Y	P	P	P	P	Y	5.5
Mongan et al (2006) ⁵⁹	Y	Y	Y	P	P	P	Y	5.5
Newman et al (2006) ⁶¹	Y	N	N	P	Y	Y	N	3.5
Nordmark et al (2001) ⁵³	Y	Y	Y	P	P	P	Y	5.5
Parkes et al (2001) ⁴⁰	Y	Y	Y	P	N	N	Y	4.5
Parkes et al (2010) ³⁵	Y	Y	Y	P	P	P	Y	5.5
Parkes et al (2008) ²²	Y	Y	Y	P	Y	Y	Y	6.5
Persson-Bunke et al (2006) ⁸¹	Y	Y	Y	Y	Y	Y	Y	7
Rankin et al (2009) ⁵⁴	Y	Y	Y	P	N	N	Y	4.5
Ravn et al (2010) ⁵⁵	Y	Y	Y	P	P	P	Y	5.5
Røijen et al (2001) ³²	Y	N	Y	P	N	N	Y	2.5
Rosenbaum et al (2002) ¹	Y	N	N	P	Y	Y	N	3.5
Saunders et al (2010) ⁶²	Y	N	N	P	P	P	N	2.5
Shevell et al (2009a) ⁴¹	Y	Y	Y	P	P	P	Y	5.5
Sigurdardottir et al (2008) ⁴²	Y	Y	Y	Y	Y	Y	Y	7
Sigurdardottir et al (2009) ⁴⁴	Y	Y	Y	Y	P	P	Y	6
Sigurdardottir & Vik (2011) ⁴³	Y	Y	Y	Y	P	P	Y	6
Soo et al (2006) ⁸²	Y	Y	Y	Y	Y	Y	Y	7
Strauss et al (2004) ⁶⁶	Y	N	Y	P	Y	Y	N	4.5
Surman et al (2006) ³⁶	Y	Y	P	P	N	N	Y	4

TABLE 2 Continued

Study	Was the Target Population Defined by Clear Inclusion and Exclusion Criteria?	Was Probability Sampling Used to Identify Potential Respondents (or the Whole Population Approached)?	Did Characteristics of Respondents Match the Target Population, (ie, Was the Response Rate \geq 80% or Appropriate Analysis Included Comparing Responders and Non-Responders?)	Were Data Collection Methods Standardized?	Were Measures Used Valid?	Were Measures Used Reliable?	Were Features of Sampling Design Accounted for in the Analysis, Through Appropriate Weighting of the Data, or the Whole Population Approached?	Total Score Out of 7
Surman et al (2009) ⁴⁵	Y	Y	P	P	N	N	Y	4
Surman et al (2003) ⁵⁷	Y	Y	Y	P	N	N	Y	4.5
SCOPE (2000) ⁴⁶	Y	Y	Y	P	N	N	Y	4.5
SCOPE (2002) ⁵⁶	Y	Y	P	P	P	P	Y	5
Westbom et al (2007) ⁷²	Y	Y	Y	P	Y	Y	Y	6.5
Wichers et al (2009) ⁶⁷	Y	Y	Y	Y	P	P	Y	6
Wichers et al (2005) ⁵⁸	Y	Y	Y	P	N	N	Y	4.5
Wu et al (2004) ⁷⁴	Y	N	Y	P	Y	Y	N	4.5

N, No; P, Partially; Y, Yes. A score of 1 was given for "partially"; a score of 0.5 was given for "no." Prognostic studies were not rated for methodologic quality on this scale.

America, and Australia using cerebral palsy register population data. However, accurate cerebral palsy population data from developing countries are difficult to ascertain, and the issues may not be comparable. In the context of developing countries, public health strategies such as rubella vaccines and rhesus management are often unavailable, thus changing the profile of cerebral palsy. Publication bias is another potential study limitation. Studies may have evaluated the interaction of impairments and prognostic outcomes but published only those that were statistically significant. For vision and hearing impairments, there was a lack of consistency in coding of impairments between authors and registries, as some authors used the term "some impairment." To improve the rigor of the estimates calculated in the meta-analysis, only severe hearing and severe vision impairments were included because these impairments are formally tested. Rates were calculated with a CI, and the body of supporting evidence was graded as moderate to high, indicating that more research is likely to change our understanding and the precision of these estimates.

Implications for Research

There is a vital need for population studies that more precisely investigate the rates of behavioral problems, bladder control problems, dribbling, feeding problems, pain, and sleep disorders in cerebral palsy. These 6 problem areas have not received sufficient attention in the literature, and more data of a higher quality are likely to change and enhance our understanding of these problems. Moreover, more data would inform the design of future intervention studies, which may create the possibility for improved outcomes. The findings of this study suggest an underresearched link between chronic pain, sleep disorders, and behavioral problems. The

TABLE 3 Clinical Messages

Problem	How Common Is This Problem?	Who Is at Risk?	Long-term Implications?	Clinical Recommendations
Behavior	<p>1 in 4 children with cerebral palsy have a behavior disorder (moderate-quality GRADE)</p> <p>The rate of abnormal behavior in children with cerebral palsy is 2 to 4 times higher than the population (moderate-quality GRADE)</p>	<p>Children with cerebral palsy and an ID are more likely to have behavioral problems (high-quality GRADE)</p> <p>Children with cerebral palsy and epilepsy are more likely to have behavioral problems; these children are also more likely to have an intellectual impairment (moderate-quality GRADE)</p> <p>Children with cerebral palsy and severe pain are more likely to have behavioral problems (high-quality GRADE)</p> <p>Children with cerebral palsy and milder physical disability are more likely to have behavioral problems than children with severe physical disability (high-quality GRADE)</p>	Unknown	<p>Thorough assessment of behavior is recommended. Also a pain assessment is essential in the presence of behavioral problems, even for children with mild physical impairments.</p> <p>Pain control may remediate or minimize the behavioral problem.</p> <p>Standard psychometric IQ assessment is also recommended in the presence of behavioral problems to enable the family to understand the prognosis of the behavioral problem.</p>
Bladder and bowel control	<p>1 in 4 children with cerebral palsy do not have bladder control (moderate-quality GRADE)</p> <p>The rate of bladder control problems in children with cerebral palsy <4 years old is 2 to 3 times higher than the population (low-quality GRADE)</p> <p>1 in 3 to 4 children with cerebral palsy have constipation (low-quality GRADE)</p>	<p>The risk of bladder and bowel control problems increases with severity of physical disability (moderate-quality GRADE)</p> <p>Children with cerebral palsy who are unable to walk or have an ID are most at risk for bladder and bowel control problems (moderate-quality GRADE)</p>	Unknown	<p>Medical investigations are warranted as abnormal anatomic findings are common</p> <p>Children with cerebral palsy should be offered standard toilet training but over a longer period of time</p>
Dribbling	<p>1 in 5 children with cerebral palsy dribble (moderate-quality GRADE)</p>	<p>Children with severe physical disability are more likely to dribble (moderate-quality GRADE)</p>	Unknown	<p>Prescription of incontinence aides will be required for 1 in 3-4 and this will be for longer periods of time that children without physical disabilities</p> <p>Social stigma is a major problem arising from dribbling and effective treatments such as Botulinum toxin A or surgical interventions should be explored.</p>
Eating	<p>1 in 15 children with cerebral palsy are tube-fed (moderate-quality GRADE)</p> <p>Children with cerebral palsy are 3 times more likely to have feeding problems at 6 months of age (moderate-quality GRADE)</p>	<p>Children with a history of poor sucking during infancy are more likely to have feeding problems (moderate-quality GRADE)</p> <p>Children with severe physical disability are more likely to need someone to feed them (moderate-quality GRADE) and are more likely to need tube feeding (moderate-quality GRADE).</p> <p>Children who are nonverbal are more likely to have difficulty feeding (high-quality GRADE)</p>	<p>Eating skills remain stable in adulthood (high-quality GRADE)</p>	<p>Infants with cerebral palsy and poor sucking should have their eating comprehensively monitored.</p> <p>Swallowing safety should be comprehensively assessed if concerns are reported.</p> <p>Weight should also be measured regularly as those with more severe physical disability have higher risk for malnutrition.</p>

TABLE 3 Continued

Problem	How Common Is This Problem?	Who Is at Risk?	Long-term Implications?	Clinical Recommendations
Epilepsy	<p>1 in 4 children with cerebral palsy have active epilepsy (high-quality GRADE)</p> <p>1 in 3 children with cerebral palsy have had epilepsy at some time (high-quality GRADE)</p>	<p>The risk of epilepsy with cerebral palsy increases with severity of physical disability (high-quality GRADE)</p> <p>Children with both sides of the body affected are more likely to have epilepsy (high-quality GRADE)</p> <p>Children with cerebral palsy and an ID are more likely to have epilepsy (high-quality GRADE)</p> <p>Children with more severe physical disability are more likely to have a hearing impairment (moderate-quality GRADE)</p> <p>Children with both sides of the body affected and who cannot walk are at the greatest risk of hip problems (high-quality GRADE) and scoliosis (low-quality GRADE)</p> <p>The risk of hip abnormalities with cerebral palsy increases with severity of physical disability (high-quality GRADE)</p> <p>The risk of associated spinal deformity increases with severity of physical disability (low-quality GRADE)</p> <p>Children with more severe physical disability are more likely to have an intellectual impairment (moderate-quality GRADE)</p>	<p>Adults with cerebral palsy and epilepsy are less likely to work (high-quality GRADE)</p> <p>Children with cerebral palsy are less likely to become seizure-free (low-quality GRADE)</p> <p>Unknown</p> <p>Long-term active hip surveillance reduces the likelihood of progression from hip displacement to hip dislocation (moderate-quality GRADE)</p> <p>Unknown</p>	<p>Anti-epileptic medications are usually effective for managing seizures and are considered standard practice for managing epilepsy in children with cerebral palsy</p> <p>Early screening, assessment, and accommodation for hearing impairment is recommended</p> <p>6- to 12-month hip surveillance is recommended and is effective for ensuring access to early treatment.</p> <p>Radiograph and clinical assessment should commence very early. For those who receive hip surveillance the rate of salvage orthopedic surgery is lower</p> <p>Formal assessment and diagnosis of an ID is an important prognostic indicator for walking, bladder control, school performance, and likelihood of independent living</p> <p>If multiple impairments exist, psychometric screening of intelligence is highly recommended for intervention and school planning</p> <p>Parents and children report levels of pain differently and therefore the child's perceptions should always be sought</p> <p>Investigate a wide range of pain origins (eg, dental, gastrointestinal, muscular, neuropathic, rheumatology, skeletal, tonal)</p> <p>Comprehensive pain management should be instigated to minimize the likelihood of secondary behavioral problems from developing</p>
Hearing	<p>1 in 25 children with cerebral palsy have severe hearing impairment or are deaf (high-quality GRADE)</p>			
Hips and spine	<p>1 in 3 children with cerebral palsy have hip displacement (high-quality GRADE)</p> <p>1 in 10 children with cerebral palsy have hip dislocation without hip surveillance (high-quality GRADE)</p>			
Intellect	<p>1 in 2 children with cerebral palsy have an ID (moderate-quality GRADE)</p>			
Pain	<p>1 in 4 children with cerebral palsy have a severe ID (moderate-quality GRADE)</p> <p>3 in 4 children with cerebral palsy are in pain (moderate-quality GRADE)</p>	<p>Children with dyskinetic cerebral palsy who have an ID are more likely to have a severe ID than those with spastic cerebral palsy (moderate-quality GRADE)</p> <p>Children and adults with cerebral palsy regardless of level of disability are at risk for pain (high-quality GRADE)</p> <p>For those who can walk, neck, back, and feet are high-risk pain sites (low-quality GRADE)</p> <p>Children and adults with contracture are at higher risk of developing pain (moderate-quality GRADE)</p>	<p>Pain is linked to higher rates of behavioral problems and lower participation (high-quality GRADE)</p> <p>Pain increases with age (moderate-quality GRADE)</p>	

TABLE 3 Continued

Problem	How Common Is This Problem?	Who Is at Risk?	Long-term Implications?	Clinical Recommendations
Sleeping	1 in 5 children with cerebral palsy have a sleep disorder. (low-quality GRADE)	Children with cerebral palsy and active epilepsy are most at risk for sleep disorders (low-quality GRADE)	Unknown	Through and specialist assessment of sleep problems are recommended
	The rate of sleep disorders in children with cerebral palsy is 5 times higher than the population (low-quality GRADE)	Children with spastic quadriplegia or dyskinesia or a severe visual impairment are more likely to have difficulty initiating and maintaining sleep. (low-quality GRADE)		Early treatment of sleep problems (both medical and behavioral) is advisable before secondary academic and behavioral problems emerge or are established
Talking	1 in 4 children with cerebral palsy cannot talk (high-quality GRADE)	Children with more severe physical disability/nonambulatory are more likely to have a speech impairment (high-quality GRADE)	Unknown	Early assessment and recommendations of augmentative and alternative communication options for speech impairment is recommended
	1 in 3 children with cerebral palsy have some speech impairment (high-quality GRADE)	Children with dyskinesia are more likely to have speech problems (high-quality GRADE)		
Walking	1 in 3 children with cerebral palsy cannot walk (high-quality GRADE)	Children with cerebral palsy who have 4 limbs affected and/or ID and/or epilepsy and/or a vision impairment have a higher risk of being unable to walk (high-quality GRADE)	Children who walk using aids or cannot walk lose walking function during adolescence (moderate-quality GRADE)	Children who walk using aids and their families should be emotionally prepared for potential loss of motor function in adolescence
	1 in 6 children with cerebral palsy walk using aides (high-quality GRADE)	At age 2 years, children with cerebral palsy who are unable to roll, sit, or pull to stand have a very high risk of being unable to walk (high-quality GRADE)	Ability to walk further declines during later adulthood. (high-quality GRADE)	Children who walk using aides require mobility assessments at the commencement of adolescence to enable prescription of appropriate mobility devices to accommodate declining motor function
	1 in 2 children with cerebral palsy walk independently (high-quality GRADE)	A child's walking ability at age 12 years is predictive of their walking ability as an adult. (high-quality GRADE)		
Vision	1 in 10 children with cerebral palsy have a severe visual impairment or are blind (moderate-quality GRADE)	Children with severe physical disability are more likely to have a visual impairment (high-quality GRADE). Among those with severe physical disability, severe visual impairment occurs more frequently with spasticity than dyskinesia (high-quality GRADE)	Unknown	Early screening, assessment, and treatment of vision impairment is recommended
	1 in 4 children with cerebral palsy have a vision impairment (moderate-quality GRADE)	Children born prematurely with cerebral palsy are more likely than children without cerebral palsy to have visual impairments (high-quality GRADE)		

GRADE system (Guyatt et al [2008])²¹ was as follows: high-quality: further research is very unlikely to change our confidence in the estimate of effect; moderate-quality: further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate; low-quality: further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate; and very-low-quality: any estimate of effect is very uncertain.

relationship between pain, sleep, and behavior warrants urgent attention, as effective evidence-based intervention strategies exist in other diagnostic groups that may offer great promise to individuals with cerebral palsy.

Future research and cerebral palsy register data sets collecting information on vision and hearing impairments associated with cerebral palsy should use agreed data dictionary terminology to code impairments and therefore

improve data quality and ease of interpretation.

CONCLUSIONS

There is high-quality grade evidence that among children with cerebral palsy: 1 in 3 cannot walk; 1 in 4 cannot talk; 1 in 4 had epilepsy; and 1 in 25 were deaf. There is moderate-quality evidence that 3 in 4 were in pain; 1 in 2 had an ID; 1 in 3 had a hip displacement; 1 in 4 had a behavior disorder; 1 in 4 had

bladder control problems; 1 in 5 dribbled; 1 in 10 were blind; 1 in 15 were tube-fed. There is low-quality evidence that 1 in 5 had a sleep disorder. Children and adults unable to walk are more likely to experience these accompanying impairments. The risk for pain and behavioral problems occurs equally at all levels of physical disability. There is insufficient evidence to be certain about the rates of sleep disorders, and more research is warranted.

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