frontiers | Frontiers in Neurology

TYPE Review
PUBLISHED 18 July 2023
DOI 10.3389/fneur.2023.1122061

OPEN ACCESS

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RECEIVED 12 December 2022
ACCEPTED 30 June 2023
PUBLISHED 18 July 2023

CITATION
Sattoe JNT and Hilberink SR (2023) Impairments and comorbidities in adults with cerebral palsy and spina bifida: a meta-analysis. *Front. Neurol.* 14:1122061. doi: 10.3389/fneur.2023.1122061

Impairments and comorbidities in adults with cerebral palsy and spina bifida: a meta-analysis

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Introduction: Aging with a childhood-onset disability, such as cerebral palsy (CP), spina bifida (SB), and muscular diseases (MD), comes along with significant impairments and comorbidities. Despite the increasing evidence an overall picture is lacking. This study aimed to review the literature about adults with CP/SB/MD and impairments and comorbidities to perform a meta-analysis.

Materials and methods: Embase, PubMed, Cinahl, and Google Scholar were searched (2000–2020). Search terms included adults with one of the aforementioned disabilities combined with impairments and comorbidities. If specific impairments or comorbidities were reported by at least four studies, these were included in the study. Pooled prevalence (95% Confidence Interval) of impairments/comorbidities were calculated.

Results: The search yielded 7,054 studies of which 95 were included in the meta-analysis (64 CP, 31 SB, 0 MD). In total estimates were calculated for 26 (CP) and 11 (SB) outcomes. In adults with CP, pain [56.4% (95%CI 48.8–63.8)], deformities [44.2% (95%CI 12.9–78.4)], intellectual disability [37.2% (95%CI 26.7–48.3)], and fatigue [36.9% (95%CI 24.6–50.1)] were most prevalent; renal disease [3.0% (95%CI 2.1–4.2)] and stroke/rheumatic diseases {4.8% (95%CI 3.4–6.5; 4.8% (95%CI 1.5–9.9)] respectively} were least prevalent. For adults with SB, bladder incontinence [60.0% (95%CI 50.5–69.2)], bowel incontinence [49.2% (95%CI 34.5–64.0)], pain [44.1% (95%CI 27.4–61.5)], and sleeping problems [30.3% (95%CI 4.7–65.8)] were most prevalent; diabetes [4.8% (95%CI 2.8–7.3)] and renal disease [8.7% (95%CI 2.0–19.9)] were least prevalent. The included studies showed large heterogeneity.

Conclusions: More research is needed to study health issues in adults with MD. Adults with CP or SB deal with a variety of health issues. More attention for the mental health of these adults is needed. There also is a need for accessible and adequate screening, preventive measures and clinical follow-up.

KEYWORDS

cerebral palsy, spina bifida, muscular disease, comorbidity, impairment, prevalence, meta-analysis, epidemiology

1. Introduction

Healthcare for adults with life-long disabilities has gained attention in the literature in the last two decades. Ample research showed increased impairments and comorbidities (also referred to as health issues) in these adults as they age (1–3). Many studies target specific adult populations, such as cerebral palsy (CP), spina bifida (SB) or muscular diseases (MD) [i.e., spinal muscular disease (SMA) or Duchenne muscular disease (DMD)/Becker muscular disease (BMD)]. Of these, adults with CP have been studied most (4–10).

Pain, fatigue, epilepsy and asthma are prevalent in adults with CP (11). In addition, these adults are at risk of several health complaints, including hypertension, depressive symptoms, osteoarthritis, cardiovascular diseases, type 2 diabetes (6, 12, 13). Adults with SB often experience bladder and bowel problems and fatigue (14, 15); fecal incontinence is more often observed with increasing age. Moreover these adults are at risk of renal failure (16). Adult men with DMD/BMD report urine incontinence (17), as well as psychiatric problems such as depressive and stress symptoms (18) and cardiac and renal dysfunction (19). Pain and fatigue are also common (20).

Recently three systematic reviews were published on adults with CP (11, 21, 22). These studies focused on specific health issues (pain and hypertension) or aimed at the most studied outcomes (including participation). As shown, adults with SB or MD develop significant health issues. However, they experience many barriers to healthcare services and screening (23, 24), hampering timely detection and secondary preventive measures. To inform both healthcare professionals as well as adults with CP, SB, or MD, we aim to estimate the prevalence of a broader scope of impairments and comorbidities in these adults. The present study goes beyond focusing on one diagnosis group and had more strict criteria to include outcomes to have more robust estimates. As such, it provides a broader overview of comorbidities that people with CP, SB, or MD often have to deal with than current literature does.

2. Methods

2.1. Study design and participants

We conducted a systematic review of the literature including meta-analysis to estimate the prevalence of impairments and comorbidities in adults with CP, SB, or MD. No review protocol was prepared, and the review was not registered in any register.

2.2. Search strategy

A search strategy was formulated and used in four databases: Embase, Pubmed, Cinahl, and Google Scholar. Search terms included the conditions "cerebral palsy", "spina bifida", "spinal muscular atrophy", and "Duchenne muscular dystrophy" in combination with possible impairments and comorbidities such as "fatigue", "pain", and "diabetes. Some impairments and comorbidities were not included as search terms, but were still picked up, because they were often included as one among other outcomes in studies. This was the case for osteoporosis, obesity (as reflected by BMI) and gastroenterological problems. The full search strategy for Pubmed is presented in Supplementary material 1. After removing duplicates, publications were screened on title and abstract to check for eligibility (by both reviewers). Subsequently, full texts were screened, and disagreements were discussed and resolved.

2.3. Selection criteria

Studies were included if they met the following criteria:

1. Published in the period January 1st 2000–December 31th 2020;
2. Including a study sample of $n \geq 25$;
3. All participants ≥18 years of age;
4. Not a follow-up intervention study;
5. No selected samples (i.e., only dyskinetic CP).

Of longitudinal designs, the most recent follow-up study with the specific comorbidity or impairment as outcome was included.

2.4. Data extraction

Data extraction was done by both reviewers with a standardized data extraction form in Microsoft Excel. Study sample characteristics and number of cases reported to have an impairment or a comorbidity were recorded for every study. Sample characteristics included first author and publication year, country, sex, age (mean/median), sample size and for CP the GMFCS levels (25). All impairments or comorbidities reported in the studies were recorded, but if less than four studies reported on a specific impairment or comorbidity, we did not include this outcome in the analysis.

2.5. Data analysis

Overall mean proportions and 95% Confidence Interval (95%CI) were estimated for each comorbidity. Random-effects meta-analysis models were used (with DerSimonian and Laird estimator). Meta-analysis modeling was done using the proportion meta-analysis function in StatsDirect. The random-effects model takes the heterogeneity of samples into account. The I^2 measure indicated heterogeneity and represents the variation attributed to heterogeneity rather than sampling error across samples.

3. Results

3.1. Study characteristics

The full selection process is presented in Figure 1. In total 110 (of 7,054) studies met the inclusion criteria. Of these, 15 were excluded because these studies reported on impairments or comorbidities that were studied in less than three other studies. Of the 95 included studies, 64 reported on CP and 31 reported on SB. Regarding adults with MD, no outcome was reported more than three times, and therefore no results on health issues of these adults could be described. Risk of bias was assessed with a quality assessment checklist for prevalence studies that Nguyen and colleagues (26) adapted from Hoy and colleagues (27) and is presented in Table 1.

Almost half of all studies were conducted in the United States of America (USA) (n = 47), followed by eleven studies from Sweden (12%), eight studies conducted in the United Kingdom (UK) (8%), and seven studies from The Netherlands (7%). Other studies were

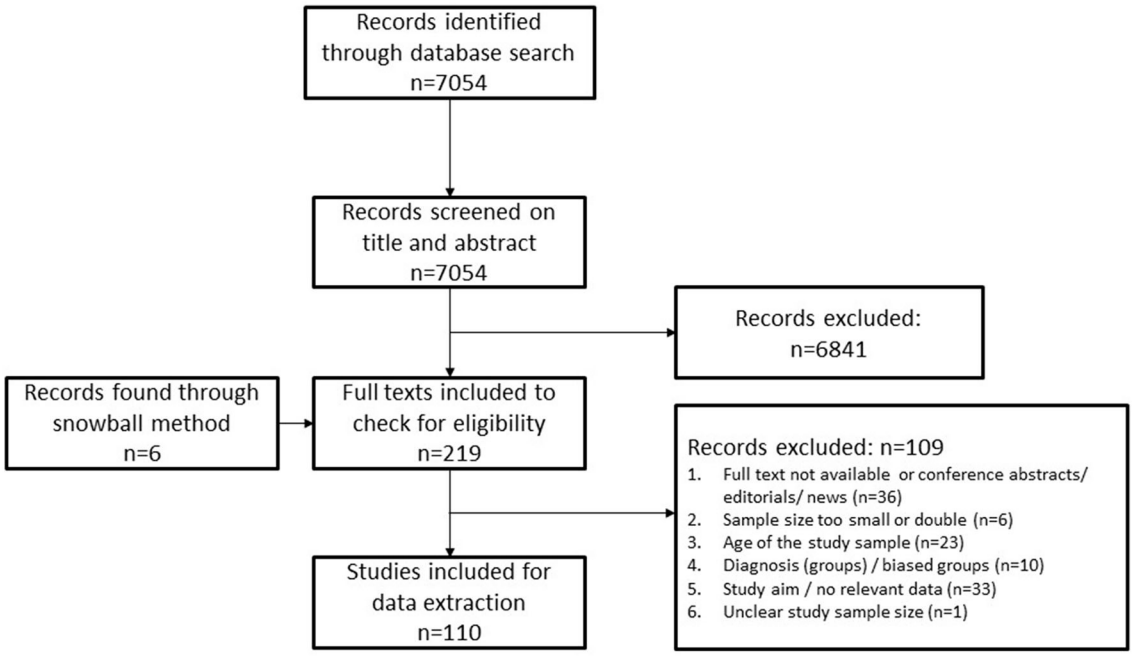

FIGURE 1
Search and selection of studies.

from different countries all over the world, but the number of studies for specific countries was small (range: 1–4). Sample size of the included studies varied from 26 to 17,212 people with CP or SB. One study only included females in the study population (Liu et al., 2016) and one study included only males (Mezaal et al., 2009). Other studies had mixed study populations in terms of sex, the proportion of males varied from 25 to 69%. Of these, 53 studies (57%) had a more or less equal distribution of males and females in the study population (between 45 and 55%). All study characteristics are presented in Table 1.

3.2. Health issues in adults with CP

Figure 2 shows the number of studies per impairment or comorbidity and the estimated prevalence (95%CI) of these in adults with CP. A total overview of the health issues, the studies that reported on them, and the number of cases included in the analyses is given in Supplementary material 2. For all analyses the level of heterogeneity (I^2) was high (>70%), indicating substantial variation in results across the studies.

The health issue that was most often included in study designs was hypertension ($n = 22$), followed by pain ($n = 21$) and epilepsy ($n = 19$). Least studied were stroke ($n = 4$), cancer ($n = 4$), bowel problems ($n = 4$), and anxiety ($n = 4$). The most prevalent comorbidity in adults with CP was pain, the overall prevalence was 56%. Deformities were the second most prevalent (44%). Intellectual disability, fatigue, obesity and hypertension, asthma, epilepsy, depression and anxiety were prevalent in more than 20% of adults with CP. Least common were renal diseases (3%), stroke (5%), and rheumatic disorders (5%).

3.3. Health issues in adults with SB

Figure 3 shows the number of studies per impairment or comorbidity and the overall proportion of these in adults with SB. A total overview of the health issues, the studies that reported on them and the number of cases included in the analyses is given in Supplementary material 3. For almost all of the analyses the level of heterogeneity was also high (>70%) except for diabetes ($I^2 = 41\%$).

The health issue that was most often included in study designs was bladder incontinence ($n = 13$), followed by epilepsy ($n = 9$) and renal disease ($n = 8$) and bowel incontinence ($n = 8$). Least studied were diabetes ($n = 4$), obesity ($n = 4$), and sleeping problems ($n = 4$). Bladder incontinence was most prevalent (60%), followed by bowel incontinence (49%) and pain (44%). Urinary tract infection, obesity and depression were present in more than 20% of adults with SB. Least common was diabetes (5%).

4. Discussion

4.1. Main findings

This meta-analysis is the first to review a wide scope of impairments and comorbidities in adults with CP or SB. Impairments and comorbidities in adults with MD could not be assessed due to limited studies. The overall picture may inform health professionals and adults with CP or SB about the common prevalent health issues.

For adults with CP, the results show a lower estimated prevalence of pain (56%) compared to a previous meta-analysis [70%; (21)]. This perhaps has to do with the difference in included studies and thus in other samples concerning sex, age, GMFCS

TABLE 1 Study characteristics and risk of bias assessment ($n = 95$).

First author	Publication Year	Reference number	Country	Diagnosis	Sample N	Male, N	Mean/Median Age/Range (in years)	GMFCS I-III, N	Risk of bias assessment score*
Andersson	2001	(28)	Sweden	CP	221	125	36	Not reported	2
Bellin	2013	(29)	USA	SB	48	22	22	-	2
Bendt	2020	(30)	Sweden	SB	196	92	33	-	2
Benner	2017	(31)	Netherlands	CP	49	27	40	39	3
Bottos	2001	(32)	Italy	CP	72	43	33	Not reported	2
Bowen	2021	(33)	USA	SB	75	34	22	-	2
Bowman	2001	(34)	USA	SB	71	33	22	-	1
Brochard	2017	(35)	France	SB	228	92	35	-	1
Chu	2019	(36)	USA	SB	75	34	20	-	1
Coco	2018	(37)	USA	SB	54	23	30	-	2
Cremer	2017	(38)	USA	CP	435	201	49	236	1
de la Torre-Olivares	2018	(39)	Spain	CP	30	14	31	30	4
Dicianno	2015	(40)	USA	SB	190	87	34	-	1
Dosa	2009	(41)	USA	SB	94	48	Range: 20–58	-	1
Edwards	2003	(42)	UK	SB	42	14	30	-	2
Ehrén	2020a	(43)	Sweden	SB	154	74	35	-	2
Ehrén	2020b	(44)	Sweden	SB	196	92	35	-	2
Engel	2003	(45)	USA	CP	100	55	41	18	1
Etter	2020	(46)	USA	CP	11,094	5,759	Not reported for whole study group	Not reported	0
Fortuna	2018	(47)	USA	CP	229	135	Not reported for whole study group	Not reported	1
Fowler	2015	(48)	USA	CP	48	21	34	26	1
French	2019	(49)	USA	CP	7,348	3,733	49	Not reported	0
Heyn	2019	(50)	USA	CP	70	34	25	70	3
Hilberink	2007	(51)	Netherlands	CP	54	26	30	37	3
Hirsh	2010	(52)	USA	CP	83	37	40	Not clear	2
Hung	2020	(53)	USA	CP	424	199	33	254	2
Içagasioglu	2020	(54)	Turkey	CP	70	37	29	40	3

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TABLE 1 (Continued)

First author	Publication Year	Reference number	Country	Diagnosis	Sample N	Male, N	Mean/Median Age/Range (in years)	GMFCS I-III, N	Risk of bias assessment score*
Jacobson	2020	(55)	Sweden	CP	61	34	21	40	3
Jahnsen	2004	(56)	Norway	CP	406	209	34	Not reported	2
Jarl	2019	(57)	Sweden	CP	408	219	27	326	0
Jeon	2019	(58)	Korea	CP	80	46	43	37	3
Jonsson	2019	(59)	Sweden	CP	581	337	Range: 39–58	481	0
Liu	2016a	(60)	USA	SB	33	0	33	-	2
Liu	2015	(61)	USA	SB	66	22	32	-	2
Liu	2016b	(62)	USA	SB	225	95	30	-	1
Lundberg Larsen	2020	(63)	Norway	SB	26	10	Range: 51–76	-	3
Lundh	2018	(64)	Sweden	CP	50	26	32	50	3
Marciniak	2014	(65)	USA	CP	91	46	36	34	3
Marciniak	2015	(66)	USA	CP	91	46	36	34	3
McDermott	2005	(67)	USA	CP	177	83	32	Not reported	0
McDonnell	2000	(68)	UK	SB	193	95	28	-	1
McMorris	2021	(69)	Canada	CP	14,155	7,052	Range: 18–64	Not reported	0
McPhee	2015	(70)	Canada	CP	42	21	34	24	2
McPhee	2017	(71)	Canada	CP	41	20	34	24	2
Mezaal	2009	(72)	Iraq	CP	50	50	21	Not reported	2
Morley	2020	(73)	USA	SB	852	221	37	-	2
Nieuwenhuijsen	2011	(74)	The Netherlands	CP	42	29	36	42	0
Oakeshott	2003	(75)	UK	SB	57	25	30	-	1
Oakeshott	2007	(76)	UK	SB	50	Not reported	38	-	1
O'Connell	2019	(77)	UK	CP	1,705	907	Median: 29	Not reported	0
Opheim	2011	(78)	Norway	CP	149	76	40	127	0
Opheim	2009	(79)	Norway	CP	149	76	40	127	2
Park	2018	(80)	Korea	CP	154	93	40	79	2
Park	2017	(81)	Korea	CP	52	33	31	33 (without GMFCS III)	1

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TABLE 1 (Continued)

First author	Publication Year	Reference number	Country	Diagnosis	Sample N	Male, N	Mean/Median Age/Range (in years)	GMFCS I-III, N	Risk of bias assessment score*
Peterson	2014	(82)	USA	CP	112	52	34	58	1
Peterson	2019	(10)	USA	CP	2,659	1,374	36	Not reported	1
Peterson	2012	(83)	USA	CP	43	23	37	29	3
Peterson	2015	(84)	USA	CP	1,015	669	58	Not reported	0
Pons	2017	(85)	France	CP	282	161	38	112	2
Roach	2011	(86)	USA	SB	84	Not reported	31	-	4
Rodby-Bousquet	2013	(87)	Sweden	CP	102	63	Median: 21 Range: 19–23	72	1
Ryan	2014	(88)	Ireland	CP	55	31	38	41	1
Ryan	2019	(89)	UK	CP	1,705	907	Median: 29	Not reported	0
Sandström	2004	(90)	Sweden	CP	48	23	33	34	1
Showen	2021	(91)	USA	SB	195	49	40	-	4
Sienko	2018	(92)	USA	CP	97	47	24	63	3
Slaman	2013	(93)	Netherlands	CP	36	23	36	36	1
Smith	2019	(94)	UK	CP	1,705	907	33	Not reported	0
Smith	2021	(95)	UK	CP	1,703	906	33	Not reported	0
Stepanczuk	2014	(96)	USA	SB	225	106	Not reported	-	1
Summers	2014	(97)	USA	SB	65	32	31	-	1
Trinh	2017	(98)	Australia	SB	49	20	Median: 33	-	1
Urrutia	2017	(99)	Chile	SB	235	95	38	-	1
Van der Slot	2012	(4)	Netherlands	CP	56	35	36	52	1
Van der Slot	2013	(100)	Netherlands	CP	43	27	36	41	1
Veenboer	2014	(14)	Netherlands	SB	61	22	Median: 45	-	2
Vukojevic	2017	(101)	Bosnia and Herzegovina	CP	100	62	Not reported	Not reported	2
Wagner	2015	(102)	USA	SB	72	25	Not reported	-	2
Werhagen	2013	(103)	Sweden	SB	127	61	34	-	1
Whitney	2018a	(104)	USA	CP	1,395	676	Not reported for whole study group	Not reported for whole study group	1
Whitney	2019a	(105)	USA	CP	5,052	50.4%	53	Not reported	1

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TABLE 1 (Continued)

First author	Publication Year	Reference number	Country	Diagnosis	Sample N	Male, N	Mean/Median Age/Range (in years)	GMFCS I-III, N	Risk of bias assessment score*
Whitney	2020a	(106)	USA	CP	646	264	58	Not reported	1
Whitney	2020–2 = 2020b	(107)	USA	CP	9,357	4,820	Not reported for whole study group	Not reported	1
Whitney	2020–3 = 2020c	(108)	USA	CP	5,888	3,133	Not reported for whole study group	Not reported	1
Whitney	2020d	(109)	USA	CP	5,603	2,813	54	Not reported	1
Whitney	2021a	(110)	USA	CP	294	144	Not reported	158	3
Whitney	2021 = 2021b	(111)	USA	CP	9,238	4,635	49.5	Not reported	1
Whitney	2018b	(112)	USA	CP	452	43.4%	23.6	231	1
Whitney	2019–3 = 2019b	(6)	USA	CP	5,555	52.2%	42.3	Not reported	1
Whitney	2020e	(113)	USA	CP	8,011	4,012	49.4	Not reported	1
Whitney	2020f	(7)	USA	CP	17,212	9,213	Not reported	Not reported	1
Wiener	2017	(114)	USA	SB	1,370	582	Range: 20–83	-	0
Wiener	2018	(115)	USA	SB	1,372	583	Range: 20–83	-	0
Wu	2017	(116)	Taiwan	CP	1,975	911	Not reported	Not reported	0
Yildiz	2017	(117)	Turkey	CP	117	64	25	86	1

*Low risk: 0–3, moderate risk: 4–6, high risk: 7–9.

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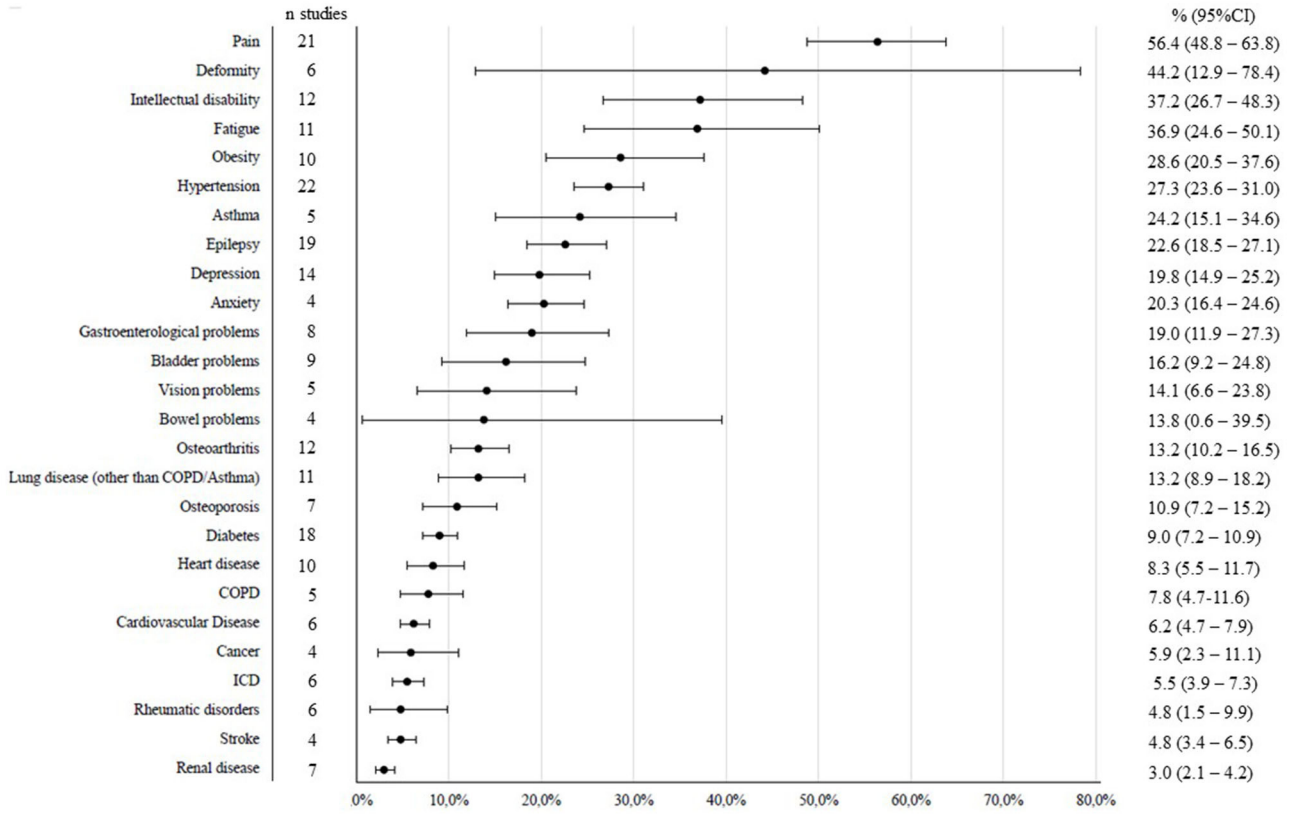

FIGURE 2
Impairments and comorbidities in adults with CP.

levels, and subtypes. Nevertheless, pain is the most prevalent impairment reported, not only in our study but also in another recent study (11); it was also the second most studied health issue. Attention for pain as a health problem in adults with CP is important in clinical practice (118). This is also the case for adults with SB: They also have a high prevalence of pain (44%), but less often studied. Pain is found to be an important health issue for almost all people with childhood-onset disabilities, starting from a young age. Research also shows that pain can have a profound impact on quality of life and mental health (119).

There seems to be a lack of attention for mental health. While for both depressive symptoms and anxiety, the prevalence rates in adults with CP are around 20%, these outcomes belong to the less studied ones, and this is especially true for anxiety. On the contrary, epilepsy and hypertension are not much more prevalent, but far more often studied, with hypertension being the most studied outcome among adults with CP in this review. For adults with SB, the same pattern was found. While depressive symptoms were prevalent in almost 25% of the people with SB, these were studied in <50% of the studies included. Other original studies also highlighted the risk of depression and anxiety in people with CP and SB and the need for more attention for mental health in these groups (94, 120, 121). Moreover, literature suggests that comprised mental health is associated with health issues such as pain and fatigue (4, 20). The results call for attention for mental health.

The overall results of this meta-analysis show profound health issues that people with CP and SB have to deal with. They have increased medical needs compared to the general population. Yet, screening of people with CP or SB on health issues is not common practice yet (122–124) and access to needed healthcare is not always self-evident (125). More attention is needed for this matter of how current healthcare practice can be tailored to these increased needs of people with CP or SB. The need for prevention and clinical follow-up of health issues (including mental health) has been emphasized before (120, 126). Moreover, comorbidities not only reflect medical challenges, preventive measures may positively impact social participation of adults with lifelong disabilities as well (125, 127).

4.2. Limitations

It is important to acknowledge the high levels of heterogeneity (I^2) in our analyses, indicating substantial variation in results across studies. These levels show that there is no clear pattern of comorbidities or impairments across studies. Yet, we felt it appropriate to summarize the outcomes, because the level of heterogeneity can also be influenced by the fact that outcome measures were not measured in a uniform way across studies. Also, there are differences in sex, age, disability and subtypes of conditions in the study samples. A limitation of this study is also

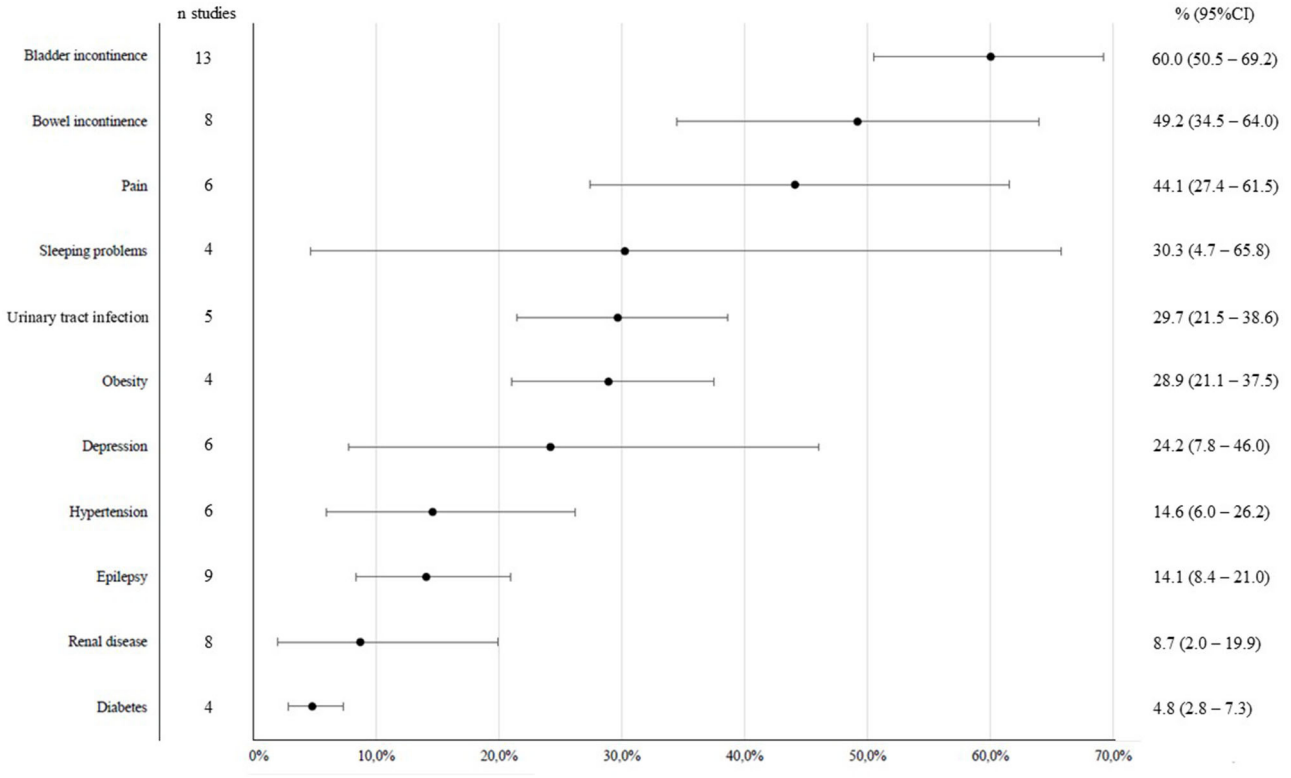

FIGURE 3
Impairments and comorbidities in adults with SB.

that, due to a small number of studies, other conditions than CP and SB (e.g., MD) could not be included in the analysis. Finally, it must be emphasized that most studies included in this meta-analysis were performed in high-income countries. Therefore, it is not representative for the whole world. More research in low- and middle-income countries is warranted.

4.3. Conclusions

Health issues in adults with MD are studied too less to perform a meta-analysis. Hence research on the impairments and comorbidities in this population is strongly recommended to inform health professionals and the adults themselves. Adults with CP or SB have to deal with a variety of health issues next to their main disability. Pain is found to be the most prevalent issue and can have profound impact on quality of life and mental health. Mental health of adults with CP or SB seems to be understudied and it is important to gain insight into useful interventions for mental wellbeing in these adults. There also is a need for accessible and adequate screening, preventive measures and clinical follow-up of health issues.

Author contributions

JS and SH contributed to the study conception and design, data collection, and interpretation of results. JS performed data analysis and drafted the manuscript. Both authors reviewed the results and approved the final version of the manuscript.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fneur.2023.1122061/full#supplementary-material

References

1. Kemp BJ. What the rehabilitation professional and the consumer need to know. *Phys Med Rehabil Clin.* (2005) 16:1–18. doi: 10.1016/j.pmr.2004.06.009

2. Klingbeil H, Baer HR, Wilson PE. Aging with a disability. *Arch Phys Med Rehabil.* (2004) 85:68–73. doi: 10.1016/j.apmr.2004.03.014

3. Hilberink SR, van der Slot WM, Klem M. Health and participation problems in older adults with long-term disability. *Disabil Health J.* (2017) 10:361–6. doi: 10.1016/j.dhjo.2016.12.004

4. Van Der Slot WM, Nieuwenhuijsen C, VAN DEN BERG-EMONS RJ, Bergen MP, Hilberink SR, Stam HJ, et al. Chronic pain, fatigue, and depressive symptoms in adults with spastic bilateral cerebral palsy. *Dev Med Child Neurol.* (2012) 54:836–42. doi: 10.1111/j.1469-8749.2012.04371.x

5. Benner JL, Hilberink SR, Veenis T, Stam HJ, van der Slot WM, Roebroeck ME. Long-term deterioration of perceived health and functioning in adults with cerebral palsy. *Arch Phys Med Rehabil.* (2017) 98:2196–205.e1. doi: 10.1016/j.apmr.2017.03.013

6. Whitney DG. Prevalence of high-burden medical conditions among young and middle-aged adults with pediatric-onset medical conditions: findings from US private and public administrative claims data. *Int J Health Policy Manage.* (2019) 8:629. doi: 10.15171/ijhpm.2019.62

7. Whitney DG, Warschausky SA, Whibley D, Kratz A, Murphy SL, Hurvitz EA, et al. Clinical factors associated with mood affective disorders among adults with cerebral palsy. *Neurology.* (2020) 10:206–13. doi: 10.1212/CPJ.0000000000000721

8. Whitney DG, Whitney RT, Kamdar NS, Hurvitz EA, Peterson MD. Early-onset noncommunicable disease and multimorbidity among adults with pediatric-onset disabilities. *Mayo Clin Proc.* (2020) 95:274–282. doi: 10.1016/j.mayocp.2019.07.010

9. Peterson MD, Haapala HJ, Kratz A. Pain Phenotypes in Adults Living With Cerebral Palsy. *Neurology.* (2021) 11:e848–e55. doi: 10.1097/j.pain.0000000000002240

10. Peterson MD, Kamdar N, Hurvitz EA. Age-related trends in cardiometabolic disease among adults with cerebral palsy. *Dev Med Child Neurol.* (2019) 61:484–9. doi: 10.1111/dmcn.13777

11. van Gorp M, Hilberink SR, Noten S, Benner JL, Stam HJ, van der Slot WM, et al. Epidemiology of cerebral palsy in adulthood: a systematic review and meta-analysis of the most frequently studied outcomes. *Arch Phys Med Rehabil.* (2020) 101:1041–52. doi: 10.1016/j.apmr.2020.01.009

12. French ZP, Caird MS, Whitney DG. Osteoporosis epidemiology among adults with cerebral palsy: findings from private and public administrative claims data. *JBMR plus.* (2019) 3:e10231. doi: 10.1002/jbm4.10231

13. Whitney DG, Kamdar NS, Ng S, Hurvitz EA, Peterson MD. Prevalence of high-burden medical conditions and health care resource utilization and costs among adults with cerebral palsy. *Clin Epidemiol.* (2019) 11:469. doi: 10.2147/CLEP.S205839

14. Veenboer PW, Procee AI, Verheijden JM, Bosch JR, van Asbeck FW, de Kort LM. Medical and psychosocial problems in middle-aged spina bifida patients: survey among members of the Dutch patients' association. *Disabil Rehabil.* (2014) 36:539–45. doi: 10.3109/09638288.2013.801522

15. de Wild N, Herrmann F, Bos G, Brouwer O, Trzpis M, Broens P. Anorectal dysfunction in adults with spina bifida and associated socio-emotional factors—a retrospective, cross-sectional cohort study. *Spinal Cord.* (2022) 60:679–686. doi: 10.1038/s41393-022-00754-5

16. Whitney DG, Pruente J, Schmidt M. Risk of advanced chronic kidney disease among adults with spina bifida. *Ann Epidemiol.* (2020) 43:71–4.e1. doi: 10.1016/j.annepidem.2020.01.003

17. Morse CI, Higham K, Bostock EL, Jacques MF. Urinary incontinence in men with Duchenne and Becker muscular dystrophy. *PLoS ONE.* (2020) 15:e0233527. doi: 10.1371/journal.pone.0233527

18. Mori-Yoshimura M, Mizuno Y, Yoshida S, Ishihara N, Minami N, Morimoto E, et al. Psychiatric and neurodevelopmental aspects of Becker muscular dystrophy. *Neuromusc Disor.* (2019) 29:930–9. doi: 10.1016/j.nmd.2019.09.006

19. Motoki T, Shimizu-Motohashi Y, Saito I, Komaki H, Ishiyama A, Aibara K, et al. Renal dysfunction can occur in advanced-stage Duchenne muscular dystrophy. *Muscle Nerve.* (2020) 61:192–7. doi: 10.1002/mus.26757

20. Pangalila RF, Van Den Bos GA, Bartels B, Bergen M, Stam HJ, Roebroeck ME. Prevalence of fatigue, pain, and affective disorders in adults with Duchenne muscular dystrophy and their associations with quality of life. *Arch Phys Med Rehabil.* (2015) 96:1242–7. doi: 10.1016/j.apmr.2015.02.012

21. van der Slot WM, Benner JL, Brunton L, Engel JM, Gallien P, Hilberink SR, et al. Pain in adults with cerebral palsy: a systematic review and meta-analysis of individual participant data. *Ann Phys Rehabil Med.* (2021) 64:101359. doi: 10.1016/j.rehab.2019.12.011

22. Noten S, van den Berg-emons RJ, Thorpe DE, Heyn PC, Marciniak CM, McPhee PG, et al. Blood pressure in adults with cerebral palsy: a systematic review and meta-analysis of individual participant data. *J Hyper.* (2021) 39:1942. doi: 10.1097/HJH.0000000000002912

23. Merten JW, Pomeranz JL, King JL, Moorhouse M, Wynn RD. Barriers to cancer screening for people with disabilities: a literature review. *Disabil Health J.* (2015) 8:9–16. doi: 10.1016/j.dhjo.2014.06.004

24. Peterson-Besse JJ, O'Brien MS, Walsh ES, Monroe-Gulick A, White G, Drum CE. Clinical preventive service use disparities among subgroups of people with disabilities: A scoping review. *Disabil Health J.* (2014) 7:373–93. doi: 10.1016/j.dhjo.2014.04.005

25. Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Dev Med Child Neurol.* (1997) 39:214–23. doi: 10.1111/j.1469-8749.1997.tb07414.x

26. Nguyen KA, Peer N, Mills EJ, Kengne AP, A. meta-analysis of the metabolic syndrome prevalence in the global HIV-infected population. *PLoS ONE.* (2016) 11:e0150970. doi: 10.1371/journal.pone.0150970

27. Hoy D, Brooks P, Woolf A, Blyth F, March L, Bain C, et al. Assessing risk of bias in prevalence studies: modification of an existing tool and evidence of interrater agreement. *J Clin Epidemiol.* (2012) 65:934–9. doi: 10.1016/j.jclinepi.2011.11.014

28. Andersson C, Mattsson E. Adults with cerebral palsy: a survey describing problems, needs, and resources, with special emphasis on locomotion. *Dev Med Child Neurol.* (2001) 43:76–82. doi: 10.1017/S0012162201

29. Bellin MH, Dicianno BE, Osteen P, Dosa N, Aparicio E, Braun P, et al. Family satisfaction, pain, and quality-of-life in emerging adults with spina bifida: a longitudinal analysis. *Am J Phys Med Rehabil.* (2013) 92:641–55. doi: 10.1097/PHM.0b013e31829b4bc1

30. Bendt M, Gabrielsson H, Riedel D, Hagman G, Hultling C, Franzén E, et al. Adults with spina bifida: A cross-sectional study of health issues and living conditions. *Brain Behav.* (2020) 10:e01736. doi: 10.1002/brb3.1736

31. Benner JL, Hilberink SR. Long-term deterioration of perceived health and functioning in adults with cerebral palsy. *Dev Med Child Neurol.* (2017) 59:14. doi: 10.1111/dmcn.13423

32. Bottos M, Feliciangeli A, Sciuto L, Gericke C, Vianello A. Functional status of adults with cerebral palsy and implications for treatment of children. *Dev Med Child Neurol.* (2001) 43:516–28. doi: 10.1017/S0012162201000950

33. Bowen DK, Balmert LC, Meyer T, Rosoklija I, Hodgkins KS, Ghossein C, et al. Variability in kidney function estimates in emerging adults with spina bifida: implications for transitioning from pediatric to adult care. *Urology.* (2021) 148:306–13. doi: 10.1016/j.urology.2020.10.050

34. Bowman RM, McLone DG, Grant JA, Tomita T, Ito JA. Spina bifida outcome: a 25-year prospective. *Pediatr Neurosurg.* (2001) 34:114–20. doi: 10.1159/000056005

35. Brochard C, Peyronnet B, Dariel A, Ménard H, Manunta A, Ropert A, et al. Bowel dysfunction related to spina bifida: keep it simple. *Dis Colon Rectum.* (2017) 60:1209–14. doi: 10.1097/DCR.0000000000000892

36. Chu DI, Balmert LC, Arkin CM, Meyer T, Rosoklija I, Li B, et al. Estimated kidney function in children and young adults with spina bifida: A retrospective cohort study. *Neurourol Urodyn.* (2019) 38:1907–14. doi: 10.1002/nau.24092

37. Coco CT, Meenakshi-Sundaram B, Eldefrawy A, Henry ML, Watts T, Aston CE, et al. A cross sectional single institution study of quality of life in adult patients with spina bifida. *Neurourol Urodyn.* (2018) 37:1757–63. doi: 10.1002/nau.23511

38. Cremer N, Hurvitz EA, Peterson MD. Multimorbidity in middle-aged adults with cerebral palsy. *Am J Med.* (2017) 130:744.e9–e15. doi: 10.1016/j.amjmed.2016.11.044

39. de la Torre-Olivares R, Moreno-Lorenzo C, Pérez-Mármol JM, Cabrera-Martos I, Villaverde-Gutierrez C, Sánchez AMC, et al. Evaluation of functional status associated with overweight in adults with cerebral palsy. *Rehabil Nurs.* (2018) 43:88–94. doi: 10.1002/rnj.293

40. Dicianno BE, Kinback N, Bellin MH, Chaikind L, Buhari AM, Holmbeck GN, et al. Depressive symptoms in adults with spina bifida. *Rehabil Psychol.* (2015) 60:246–53. doi: 10.1037/rep0000044

41. Dosa NP, Foley JT, Eckrich M, Woodall-Ruff D, Liptak GS. Obesity across the lifespan among persons with spina bifida. *Disabil Rehabil.* (2009) 31:914–20. doi: 10.1080/09638280802356476

42. Edwards RJ, Witchell C, Pople IK. Chronic headaches in adults with spina bifida and associated hydrocephalus. *Eur J Pediatr Surg.* (2003) 13:S13–7. doi: 10.1055/s-2003-44751

43. Ehrén I, Hagman G, Lindbo L, Gabrielsson H, Bendt M, Seiger Å. Cognitive challenges in persons with spina bifida: Bearing on urological dysfunctions? *Neurourol Urodyn.* (2020) 39:2139–45. doi: 10.1002/nau.24515

44. Ehrén I, Lindbo L, Gabrielsson H, Bendt M, Seiger Å. Voiding conditions, renal and bowel function in a cohort of adults with spina bifida. *Neurourol Urodyn.* (2020) 39:1796–802. doi: 10.1002/nau.24422

45. Engel JM, Jensen MP, Hoffman AJ, Kartin D. Pain in persons with cerebral palsy: extension and cross validation. *Arch Phys Med Rehabil.* (2003) 84:1125–8. doi: 10.1016/S0003-9993(03)00263-6

46. Etter JP, Kannikeswaran S, Hurvitz EA, Caird MS, Jepsen K, Whitney D. The respiratory disease burden of non-traumatic fractures for adults with cerebral palsy. *Bone Rep.* (2020) 13:100730. doi: 10.1016/j.bonr.2020.100730

47. Fortuna RJ, Holub A, Turk MA, Meccarello J, Davidson PW. Health conditions, functional status and health care utilization in adults with cerebral palsy. *Fam Pract.* (2018) 35:661–70. doi: 10.1093/fampra/cmy027

48. Fowler EG, Rao S, Nattiv A, Heberer K, Oppenheim WL. Bone density in premenopausal women and men under 50 years of age with cerebral palsy. *Arch Phys Med Rehabil.* (2015) 96:1304–9. doi: 10.1016/j.apmr.2015.03.012

49. French ZP, Torres RV, Whitney DG. Elevated prevalence of osteoarthritis among adults with cerebral palsy. *J Rehabil Med.* (2019) 51:575–81. doi: 10.2340/16501977-2582

50. Heyn PC, Tagawa A, Pan Z, Thomas S, Carollo JJ. Prevalence of metabolic syndrome and cardiovascular disease risk factors in adults with cerebral palsy. *Dev Med Child Neurol.* (2019) 61:477–83. doi: 10.1111/dmcn.14148

51. Hilberink SR, Roebroeck ME, Nieuwstraten W, Jalink L, Verheijden JMA, Stam HJ. Health issues in young adults with cerebral palsy: Towards a life-span perspective. *J Rehabil Med.* (2007) 39:605–11. doi: 10.2340/16501977-0103

52. Hirsh AT, Gallegos JC, Gertz KJ, Engel JM, Jensen MP. Symptom burden in individuals with cerebral palsy. *J Rehabil Res Dev.* (2010) 47:863–76. doi: 10.1682/JRRD.2010.03.0024

53. Hung CW, Matsumoto H, Ball JR, Plachta S, Dutkowsky JP, Kim H, et al. Symptomatic cervical spinal stenosis in spastic cerebral palsy. *Dev Med Child Neurol.* (2020) 62:1147–53. doi: 10.1111/dmcn.14607

54. Içagasioglu A, Dogruoz Karatekin B, Mesci E, Yumusakhuylu Y, Murat S, Yasin S. Assessment of adult patients with cerebral palsy. *Turk J Phys Med Rehabil.* (2020) 66:429–35. doi: 10.5606/tftrd.2020.5614

55. Jacobson DNO, Löwing K, Tedroff K. Health-related quality of life, pain, and fatigue in young adults with cerebral palsy. *Dev Med Child Neurol.* (2020) 62:372–8. doi: 10.1111/dmcn.14413

56. Jahnsen R, Villien L, Aamodt G, Stanghelle JK, Holm I. Musculoskeletal pain in adults with cerebral palsy compared with the general population. *J Rehabil Med.* (2004) 36:78–84. doi: 10.1080/16501970310018305

57. Jarl J, Alriksson-Schmidt A, Rodby-Bousquet E. Health-related quality of life in adults with cerebral palsy living in Sweden and relation to demographic and disability-specific factors. *Disabil Health J.* (2019) 12:460–6. doi: 10.1016/j.dhjo.2019.02.002

58. Jeon I, Bang MS, Lim JY, Shin HI, Leigh JH, Kim K, et al. Sarcopenia among Adults with Cerebral Palsy in South Korea. *PM R.* (2019) 11:1296–301. doi: 10.1002/pmrj.12134

59. Jonsson U, Eek MN, Sunnerhagen KS, Himmelmann K. Cerebral palsy prevalence, subtypes, and associated impairments: a population-based comparison study of adults and children. *Dev Med Child Neurol.* (2019) 61:1162–7. doi: 10.1111/dmcn.14229

60. Liu JS, Vo AX, Doolittle J, Hamoui N, Lewicky-Gaupp C, Kielb SJ. Characterizing pelvic organ prolapse in adult spina bifida patients. *Urology.* (2016) 97:273–6. doi: 10.1016/j.urology.2016.06.026

61. Liu JS, Dong C, Casey JT, Greiman A, Mukherjee S, Kielb SJ. Quality of life related to urinary continence in adult spina bifida patients. *Cent Eur J Urol.* (2015) 68:61–7. doi: 10.5173/ceju.2015.01.494

62. Liu JS, Greiman A, Casey JT, Mukherjee S, Kielb SJ, A. snapshot of the adult spina bifida patient - high incidence of urologic procedures. *Cent Eur J Urol.* (2016) 69:72–7. doi: 10.5173/ceju.2016.596

63. Lundberg Larsen K, Maalen-Johansen IK, Rennie L, Lidal IB. Gait Function in Adults Aged 50 Years and Older With Spina Bifida. *Arch Phys Med Rehabil.* (2020). doi: 10.1016/j.apmr.2020.10.118

64. Lundh S, Nasic S, Riad J. Fatigue, quality of life and walking ability in adults with cerebral palsy. *Gait Posture.* (2018) 61:1–6. doi: 10.1016/j.gaitpost.2017.12.017

65. Marciniak C, O'Shea SA, Lee J, Jesselson M, Dudas-Sheehan D, Beltran E, et al. Urinary incontinence in adults with cerebral palsy: prevalence, type, and effects on participation. *PM R.* (2014) 6:110–20. doi: 10.1016/j.pmrj.2013.07.012

66. Marciniak CM, Lee J, Jesselson M, Gaebler-Spira D. Cross-sectional study of bowel symptoms in adults with cerebral palsy: prevalence and impact on quality of life. *Arch Phys Med Rehabil.* (2015) 96:2176–83. doi: 10.1016/j.apmr.2015.08.411

67. McDermott S, Moran R, Platt T, Issac T, Wood H, Dasari S. Depression in adults with disabilities, in primary care. *Disabil Rehabil.* (2005) 27:117–23. doi: 10.1080/09638280400007380

68. McDonnell GV, McCann JP. Issues of medical management in adults with spina bifida. *Childs Nerv Syst.* (2000) 16:222–7. doi: 10.1007/s003810050502

69. McMorris CA, Lake J, Dobranowski K, McGarry C, Lin E, Wilton D, et al. Psychiatric disorders in adults with cerebral palsy. *Res Dev Disabil.* (2021) 111:103859. doi: 10.1016/j.ridd.2021.103859

70. McPhee PG, Gorter JW, Cotie LM, Timmons BW, Bentley T, MacDonald MJ. Descriptive data on cardiovascular and metabolic risk factors in ambulatory and non-ambulatory adults with cerebral palsy. *Data Brief.* (2015) 5:967–70. doi: 10.1016/j.dib.2015.10.045

71. McPhee PG, Brunton LK, Timmons BW, Bentley T, Gorter JW. Fatigue and its relationship with physical activity, age, and body composition in adults with cerebral palsy. *Dev Med Child Neurol.* (2017) 59:367–73. doi: 10.1111/dmcn.13306

72. Mezaal MA, Nouri KA, Abdool S, Safar KA, Nadeem AS. Cerebral palsy in adults consequences of non progressive pathology. *Open Neurol J.* (2009) 3:24–6. doi: 10.2174/1874205X00903010024

73. Morley CP, Struwe S, Pratte MA, Clayton GH, Wilson PE, Dicianno BE, et al. Survey of U.S. adults with spina bifida. *Disabil Health J.* (2020) 13:100833. doi: 10.1016/j.dhjo.2019.100833

74. Nieuwenhuijsen C, van der Slot WMA, Dallmeijer AJ, Janssens PJ, Stam HJ, Roebroeck ME, et al. Physical fitness, everyday physical activity, and fatigue in ambulatory adults with bilateral spastic cerebral palsy. *Scand J Med Sci Sports.* (2011) 21:535–42. doi: 10.1111/j.1600-0838.2009.01086.x

75. Oakeshott P, Hunt GM. Long-term outcome in open spina bifida. *Br J Gen Pract.* (2003) 53:632–6.

76. Oakeshott P, Hunt GM, Whitaker RH, Kerry S. Perineal sensation: an important predictor of long-term outcome in open spina bifida. *Arch Dis Child.* (2007) 92:67–70. doi: 10.1136/adc.2006.102079

77. O'Connell NE, Smith KJ, Peterson MD, Ryan N, Liverani S, Anokye N, et al. Incidence of osteoarthritis, osteoporosis and inflammatory musculoskeletal diseases in adults with cerebral palsy: A population-based cohort study. *Bone.* (2019) 125:30–5. doi: 10.1016/j.bone.2019.05.007

78. Opheim A, Jahnsen R, Olsson E, Stanghelle JK. Physical and mental components of health-related quality of life and musculoskeletal pain sites over seven years in adults with spastic cerebral palsy. *J Rehabil Med.* (2011) 43:382–7. doi: 10.2340/16501977-0787

79. Opheim A, Jahnsen R, Olsson E, Stanghelle JK. Walking function, pain, and fatigue in adults with cerebral palsy: a 7-year follow-up study. *Dev Med Child Neurol.* (2009) 51:381–8. doi: 10.1111/j.1469-8749.2008.03250.x

80. Park MW, Kim WS, Bang MS, Lim JY, Shin HI, Leigh JH, et al. Needs for medical and rehabilitation services in adults with cerebral palsy in Korea. *Ann Rehabil Med.* (2018) 42:465–72. doi: 10.5535/arm.2018.42.3.465

81. Park EY, Kim WH. Prevalence of secondary impairments of adults with cerebral palsy according to gross motor function classification system. *J Phys Ther Sci.* (2017) 29:266–9. doi: 10.1589/jpts.29.266

82. Peterson MD, Haapala HJ, Chaddha A, Hurvitz EA. Abdominal obesity is an independent predictor of serum 25-hydroxyvitamin D deficiency in adults with cerebral palsy. *Nutr Metab (Lond).* (2014) 11:22. doi: 10.1186/1743-7075-11-22

83. Peterson MD, Haapala HJ, Hurvitz EA. Predictors of cardiometabolic risk among adults with cerebral palsy. *Arch Phys Med Rehabil.* (2012) 93:816–21. doi: 10.1016/j.apmr.2011.12.024

84. Peterson MD, Ryan JM, Hurvitz EA, Mahmoudi E. Chronic conditions in adults with cerebral palsy. *JAMA.* (2015) 314:2303–5. doi: 10.1001/jama.2015.11025

85. Pons C, Brochard S, Gallien P, Nicolas B, Duruflé A, Roquet M, et al. Medication, rehabilitation and health care consumption in adults with cerebral palsy: a population based study. *Clin Rehabil.* (2017) 31:957–65. doi: 10.1177/0269215516663286

86. Roach JW, Short BF, Saltzman HM. Adult consequences of spina bifida: a cohort study. *Clin Orthop Relat Res.* (2011) 469:1246–52. doi: 10.1007/s11999-010-1594-z

87. Rodby-Bousquet E, Czuba T, Hägglund G, Westbom L. Postural asymmetries in young adults with cerebral palsy. *Dev Med Child Neurol.* (2013) 55:1009–15. doi: 10.1111/dmcn.12199

88. Ryan JM, Crowley VE, Hensey O, McGahey A, Gormley J. Waist circumference provides an indication of numerous cardiometabolic risk factors in adults with cerebral palsy. *Arch Phys Med Rehabil.* (2014) 95:1540–6. doi: 10.1016/j.apmr.2014.03.029

89. Ryan JM, Peterson MD, Matthews A, Ryan N, Smith KJ, O'Connell NE, et al. Noncommunicable disease among adults with cerebral palsy: A matched cohort study. *Neurology.* (2019) 93:e1385–e96. doi: 10.1212/WNL.0000000000008199

90. Sandström K, Alinder J, Oberg B. Descriptions of functioning and health and relations to a gross motor classification in adults with cerebral palsy. *Disabil Rehabil.* (2004) 26:1023–31. doi: 10.1080/09638280410001703503

91. Showen A, Copp HL, Allen IE, Baradaran N, Liaw A, Hampson LA. Characteristics associated with depression, anxiety, and social isolation in adults with Spina Bifida. *Urology.* (2021) 149:255–62. doi: 10.1016/j.urology.2020.11.016

92. Sienko SE. An exploratory study investigating the multidimensional factors impacting the health and well-being of young adults with cerebral palsy. *Disabil Rehabil.* (2018) 40:660–6. doi: 10.1080/09638288.2016.1274340

93. Slaman J, Bussmann J, van der Slot WM, Stam HJ, Roebroeck ME, van den Berg-Emons RJ. Physical strain of walking relates to activity level in adults with cerebral palsy. *Arch Phys Med Rehabil.* (2013) 94:896–901. doi: 10.1016/j.apmr.2012.11.005

94. Smith KJ, Peterson MD, O'Connell NE, Victor C, Liverani S, Anokye N, et al. Risk of depression and anxiety in adults with cerebral palsy. *JAMA Neurol.* (2019) 76:294–300. doi: 10.1001/jamaneurol.2018.4147

95. Smith KJ, Peterson MD, Victor C, Ryan JM. Risk of dementia in adults with cerebral palsy: a matched cohort study using general practice data. *BMJ Open.* (2021) 11:e042652. doi: 10.1136/bmjopen-2020-042652

96. Stepanczuk BC, Dicianno BE, Webb TS. Young adults with spina bifida may have higher occurrence of prehypertension and hypertension. *Am J Phys Med Rehabil.* (2014) 93:200–6. doi: 10.1097/PHM.0b013e3182a92b03

97. Summers SJ, Elliott S, McAdams S, Oottamasathien S, Brant WO, Presson AP, et al. Urologic problems in spina bifida patients transitioning to adult care. *Urology.* (2014) 84:440–4. doi: 10.1016/j.urology.2014.03.041

98. Trinh A, Wong P, Sakthivel A, Fahey MC, Hennel S, Brown J, et al. Fat-bone interactions in adults with spina bifida. *J Endocr Soc.* (2017) 1:1301–11. doi: 10.1210/js.2017-00258

99. Urrutia J, Zamora T, Cuellar J. Does the prevalence of spondylolysis and spina bifida occulta observed in pediatric patients remain stable in adults? *Clin Spine Surg.* (2017) 30:E1117–e21. doi: 10.1097/BSD.0000000000000209

100. van der Slot WM, Roebroeck ME, Nieuwenhuijsen C, Bergen MP, Stam HJ, Burdorf A, et al. Cardiovascular disease risk in adults with spastic bilateral cerebral palsy. *J Rehabil Med.* (2013) 45:866–72. doi: 10.2340/16501977-1185

101. Vukojević M, Cvitković T, Splavski B, Ostojić Z, Šumanović-Glamuzina D, Šimić J. Prevalence of Intellectual Disabilities and Epilepsy in Different Forms of Spastic Cerebral Palsy in Adults. *Psychiatr Danub.* (2017) 29:111–7.

102. Wagner R, Linroth R, Gangl C, Mitchell N, Hall M, Cady R, et al. Perception of secondary conditions in adults with spina bifida and impact on daily life. *Disabil Health J.* (2015) 8:492–8. doi: 10.1016/j.dhjo.2015.03.012

103. Werhagen L, Gabrielsson H, Westgren N, Borg K. Medical complication in adults with spina bifida. *Clin Neurol Neurosurg.* (2013) 115:1226–9. doi: 10.1016/j.clineuro.2012.11.014

104. Whitney D, Hurvitz E, Devlin M, Caird M, French Z, Ellenberg E, et al. Ageing trajectories of musculoskeletal morbidities in adults with cerebral palsy. *Dev Med Child Neurol.* (2018) 60:72. doi: 10.1111/dmcn.112_14017

105. Whitney DG, Warschausky SA, Ng S, Hurvitz EA, Kamdar NS, Peterson MD. Prevalence of mental health disorders among adults with cerebral palsy: a cross-sectional analysis. *Ann Intern Med.* (2019) 171:328–33. doi: 10.7326/M18-3420

106. Whitney DG. Nontrauma fracture increases risk for respiratory disease among adults with cerebral palsy. *J Orthop Res.* (2020) 38:2551–8. doi: 10.1002/jor.24675

107. Whitney DG, Bell S, Etter JP, Prisby RD. The cardiovascular disease burden of non-traumatic fractures for adults with and without cerebral palsy. *Bone.* (2020) 136:115376. doi: 10.1016/j.bone.2020.115376

108. Whitney DG, Bell S, Whibley D, Van der Slot WMA, Hurvitz EA, Haapala HJ, et al. Effect of pain on mood affective disorders in adults with cerebral palsy. *Dev Med Child Neurol.* (2020) 62:926–32. doi: 10.1111/dmcn.14559

109. Whitney DG, Schmidt M, Peterson MD, Haapala H. Polypharmacy Among Privately Insured Adults with Cerebral Palsy: A Retrospective Cohort Study. *J Manag Care Spec Pharm.* (2020) 26:1153–61. doi: 10.18553/jmcp.2020.26.9.1153

110. Whitney DG, Wolgat EM, Ellenberg EC, Hurvitz EA, Schmidt M. The paradoxical relationship between severity of cerebral palsy and renal function in middle-aged adults: better renal function or inappropriate clinical assessment? *Disabil Rehabil.* (2021) 44:3853–3859. doi: 10.1080/09638288.2021.1890841

111. Whitney DG, Schmidt M, Haapala H. Polypharmacy is a risk factor for mortality, severe chronic kidney disease, and liver disease among privately insured adults with cerebral palsy. *J Manag Care Spec Pharm.* (2021) 27:51–63. doi: 10.18553/jmcp.2021.27.1.051

112. Whitney DG, Hurvitz EA, Ryan JM, Devlin MJ, Caird MS, French ZP, et al. Noncommunicable disease and multimorbidity in young adults with cerebral palsy. *Clin Epidemiol.* (2018) 10:511–9. doi: 10.2147/CLEP.S159405

113. Whitney DG, Oliverio AL, Kamdar NS, Viglianti BL, Naik A, Schmidt M. Advanced CKD among adults with cerebral palsy: incidence and risk factors. *Kidney Med.* (2020) 2:569–77.e1. doi: 10.1016/j.xkme.2020.05.012

114. Wiener JS, Suson KD, Castillo J, Routh JC, Tanaka S, Liu T, et al. Bowel management and continence in adults with spina bifida: Results from the National Spina Bifida Patient Registry 2009–15. *J Pediatr Rehabil Med.* (2017) 10:335–43. doi: 10.3233/PRM-170466

115. Wiener JS, Suson KD, Castillo J, Routh JC, Tanaka ST, Liu T, et al. Bladder management and continence outcomes in adults with spina bifida: results from the national spina bifida patient registry, 2009 to 2015. *J Urol.* (2018) 200:187–94. doi: 10.1016/j.juro.2018.02.3101

116. Wu CW, Huang SW, Lin JW, Liou TH, Chou LC, Lin HW. Risk of stroke among patients with cerebral palsy: a population-based cohort study. *Dev Med Child Neurol.* (2017) 59:52–6. doi: 10.1111/dmcn.13180

117. Yildiz N, Akkoç Y, Ersöz M, Gündüz B, Erhan B, Yesil H, et al. Cross-sectional study of urinary problems in adults with cerebral palsy: awareness and impact on the quality of life. *Neurol Sci.* (2017) 38:1193–203. doi: 10.1007/s10072-017-2948-z

118. Shearer HM, Verville L, Côté P, Hogg-Johnson S, Fehlings DL. Clinical course of pain intensity in individuals with cerebral palsy: A prognostic systematic review. *Dev Med Child Neurol.* (2022). doi: 10.1111/dmcn.15358

119. Schmidt S, Markwart H, Rapp M, Guyard A, Arnaud C, Fauconnier J, et al. Quality of life and mental health in emerging adults with cerebral palsy compared to the general population. *Health Qual Life Outc.* (2022) 20:1–13. doi: 10.1186/s12955-022-01961-7

120. McMorris C, Lake J, Lunsky Y, Dobranowski K, Fehlings D, Bayley M, et al. Adults with cerebral palsy: physical and mental health issues and health service use patterns. *Int Rev Res Dev Disabil.* (2015) 48:115–49. doi: 10.1016/bs.irrdd.2015.03.003

121. Peterson MD, Lin P, Kamdar N, Mahmoudi E, Marsack-Topolewski CN, Haapala H, et al. Psychological morbidity among adults with cerebral palsy and spina bifida. *Psychol Med.* (2021) 51:694–701. doi: 10.1017/S0033291720001981

122. Turk MA. Health, mortality, and wellness issues in adults with cerebral palsy. *Dev Med Child Neurol.* (2009) 51:24–9. doi: 10.1111/j.1469-8749.2009.03429.x

123. Hilberink SR. The Whitney Comorbidity Index for adults with cerebral palsy: a challenge for practice. *Dev Med Child Neurol.* (2021) 63:767. doi: 10.1111/dmcn.14890

124. Mirkin K, Casey JT, Mukherjee S, Kielb SJ. Risk of bladder cancer in patients with spina bifida: case reports and review of the literature. *J Pediatr Rehabil Med.* (2013) 6:155–62. doi: 10.3233/PRM-130254

125. van Heijningen VG, Cardol M, van Heijningen-Tousain HJ, Oosterveer DM, van Markus-Doornbosch F, Sattoe JN, et al. Aging with cerebral palsy: a photovoice study into citizenship. *Front Neurol.* (2021) 12:729509. doi: 10.3389/fneur.2021.729509

126. Lidal IB, Lundberg Larsen K, Hoff M. 50 Years and older–born with spina bifida: participation, health issues and physical function. *Disabil Rehabil.* (2021) 43:241–50. doi: 10.1080/09638288.2019.1621953

127. Asuman D, Gerdtham UG, Alriksson-Schmidt AI, Rodby-Bousquet E, Andersen GL, Jarl J. Pain and labor outcomes: A longitudinal study of adults with cerebral palsy in Sweden. *Disabil Health J.* (2023) 16:101479. doi: 10.1016/j.dhjo.2023.101479