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Exploring the Characteristics and Utilization of General Practice Healthcare by Adults With Cerebral Palsy: A Systematic Review

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Abstract

Background: Individuals with cerebral palsy (CP) experience acute and chronic health issues requiring lifespan primary care. This review aimed to investigate characteristics and utilization of general practitioner (GP) access by adults with CP. Secondary aims included exploring reasons prompting access, identifying interventions provided, and personal features affecting access. **Methods:** Using systematic review methodology, 5 databases were searched using keywords relating to adults, CP, and primary care, relating to quantitative studies (January 2000-July 2024). Data was extracted, collated, and analyzed descriptively, with additional meta-analyses to estimate proportion of GP visits. **Results:** Fifteen studies were included describing GP access by 6231 adults with CP. The proportion annually accessing a GP was 78% (95% CI = 69%-85%). The frequency of GP access ranged from 1.76 to 11.7 visits per year, increased with advancing age and disability severity. Comorbid intellectual disability and pain also increased GP attendance. Limited data was available reporting healthcare needs prompting GP access, and no interventions were described. **Conclusions:** Advancing age, greater disability severity, comorbid intellectual disability, and pain may prompt increased GP access by adults with CP. Identification of reasons for seeking primary care, and interventions provided are required through data linkage studies to enhance lifespan care.

Keywords

cerebral palsy, adults, primary care, general practitioner, physician

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Introduction

Cerebral palsy (CP) is a lifelong neurological condition characterized by the abnormal development of posture, tone, and movement, arising before, during, or soon after birth.[1] It is the most common physical disability of childhood,[2] with international prevalence estimates ranging from 1.5 to more than 4 per 1000 live births.[3] More than 35 000 individuals in Australia live with CP and of these, approximately 3 quarters are adults.[4] Although a non-progressive condition, individuals with CP frequently experience a range of additional health issues such as gastroesophageal reflux, acute and chronic lung disease, type 2 diabetes, depression, hypertension, ischemic heart disease, stroke, asthma, osteoporosis, and have chronic kidney disease than adults without CP.[5] Primary healthcare providers should be the first point of contact for these chronic health issues with ongoing referral to specialist care where necessary.[6]

In many countries, primary healthcare relates to the first point of contact for an individual with the healthcare system unrelated to care provided by hospital visits.[7] General practices, responsible for care delivered by family doctors, or family physicians, are necessary primary health services accessed by everyone, including people with disabilities such as CP.[8] Doctors working within general practices (general practitioners; GPs) support an individual's non-critical

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healthcare requirements, provide preventative care including immunization and screening, and chronic health condition management, initiating specialist referrals as required. Healthcare and disability services are intertwined to enable quality care for people living with lifelong disabilities.

A recent systematic review[9] from a pooled analysis of 4 studies reported that GPs were the most commonly visited healthcare professional by adults with CP, with 84% using GP services annually or 404 GP visits per 100 person-years. However, 3 of 4 included studies were published before the year 2000, and several relevant publications have arisen since completion. Further, this review did not explore reasons prompting primary care access, nor interventions provided to the adult with CP by the GP. It is estimated that 1 in 3 people now use the internet to diagnose or learn about a health condition—potentially impacting contemporary primary care usage patterns.[10] In Australia, a survey of parents revealed 83% of children with CP attended their GP at least once in the previous year,[11] but the specific reason for GP attendance was not itemized, with possible reasons (such as epilepsy or gastrostomy care) combined with care provided by pediatric specialists. It is unknown whether the reasons for GP access in children with CP reflects that of adults, and/or if frequency of GP attendance by adults with CP has changed more recently.

Given the nature of the research question, a review was proposed to systematically review the current literature, synthesize outcomes, and identify knowledge gaps relating to GP access and service provision. The primary aim was to investigate the profile of GP access by adults with CP, for example, the frequency or proportion of adults with CP annually visiting a GP. Secondary aims were to explore reasons for access and interventions provided to adults with CP by GPs, and to identify characteristics of adults with CP which may influence primary care access.

Methods

The design and reporting of this systematic review was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Checklist.[12] Inclusion criteria and methods of synthesis analysis were identified in advance and documented in a protocol registered on PROSPERO (CRD42024579898).

Study Eligibility

Studies with participants who were adults (age ≥18 years) with a diagnosis of CP, containing information pertaining to primary care (GP or family doctor) access and service provision, English language (or English language translation available), peer reviewed, and published from January 1, 2000 until July 31, 2024 were considered. This timeframe was selected because older studies may not be relevant due to more recent changes in health service design, access, and provision. Studies with broader age groups (including pediatric data) were only included if adult data set was able to be extracted. Similarly, studies including participants with mixed diagnoses were only included if the CP specific data set were available. This review specifically sought to identify studies reporting GP access and service provision which may include medication prescription, chronic disease management, and more. Quantitative study designs were included such as randomized control trials, cohort studies, cross-sectional, and longitudinal studies. To avoid data duplication, systematic and scoping reviews were not considered although reference lists were interrogated.

Search Strategy

Potential articles were identified through 5 databases: Embase, Medline (Ovid), PubMed, CINAHL, and Scopus. Search terms based upon the inclusion and exclusion criteria were formulated with assistance from an expert subject matter librarian. The search strategy included a comprehensive list of keywords, MeSH headings, and derivatives which related to the subjects of CP and primary care (eg, cerebral palsy AND general practitioner OR family doctor OR family physician; refer to Supplemental Appendix A for sample search). Electronic searches were supplemented by reference lists checking of included articles guided by a clinical expert (PM).

The search yield from the 5 databases was imported into the Covidence systematic online review software.[13] Duplicate studies were deleted and the initial screening process performed. Studies were independently screened by 2 reviewers based on the title and abstract, guided by the inclusion and exclusion criteria. Full text review of any potential studies was undertaken to confirm inclusion criteria. Any conflicts which arose during the screening were resolved through discussion, with involvement of a third reviewer for consensus if required. Reasons for exclusion of articles at full text stage were recorded and reported. Authors of 2 included studies were contacted if clarification of inclusion criteria or data was required, of whom 1 author responded.

Data Extraction

Within Covidence, a standardized spreadsheet was developed and piloted to collect data regarding study design and relevant participant demographics (eg, country of origin, study design, data source, participant inclusion criteria, sample size, age, sex, and Gross Motor Functional Classification System[14] [GMFCS] level). If the GMFCS level was not specified, GMFCS equivalence was approximated based upon clinical descriptors (eg, wheelchair dependent=GMFCS IV/V). An additional spreadsheet was developed and piloted

with a sample of 3 studies to extract data regarding the proportion or frequency of primary care access, participant comorbidities and/or medications used, reason for attendance if specified (eg, medication review, infection management), and any interventions provided (eg, specialist referral, immunization). Minor adjustments were performed before charting commenced. Data charting was done by the authors firstly independently and then subsequently verified by the authors within the Covidence software.

Analysis and Synthesis of Evidence

Relevant findings were tabled, and organized into themes and categories particularly in reference to the GP interaction, and characteristics of the adults with CP. Frequency of annual GP use was illustrated using a bar chart. A DerSimonian-Laird random-effects meta-analysis was used to pool the proportion of GP service use over 12 months to account for the heterogeneity between studies.[15] In order to ensure confidence intervals of proportions did not exceed the range of 0 to 1, a Freeman-Tukey arcsine square root transformation was used to transform the variances of the raw proportions.[16] Variability in GP service use was quantified using the I^2 statistic, where values greater than 50% indicated statistical heterogeneity. All analyses were undertaken with Stata SE v18.0 (StataCorp; LLC).

Methodological Quality Assessment

Eligible studies were critically appraised by 2 independent reviewers using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Cross Sectional studies.[17] Any disagreements were resolved with discussion. No minimum quality score was specified in advance.

Results

The database search, supplemented by hand search of reference lists, yielded 727 studies (Figure 1). After duplicates were removed and screening of abstracts completed, 49 full text studies were assessed. The most common reasons for exclusion at full text stage was no CP specific data available (n = 10) or no GP data provided (n = 9).

Fifteen articles were included reporting on 12 studies. Three studies, conducted by Ryan et al,[18] Smith et al,[19,20] reported findings from essentially the same sample but analyzed different aspects of primary care access, thus all 3 studies have been retained but sample characteristics described once. In addition, 2 studies by Pons et al[21] and Roquet et al[22] also used the same adult sample. However only the data from Roquet et al[22] is included in data extraction because data relating to specific adult age groups was more complete, with the exception of cognitive dysfunction prevalence extracted from Pons et al.[21] Thus 6231 unique participants with CP from the resultant studies were included (Table 1). Ten studies provided data regarding GMFCS level/s or a GMFCS equivalent and of these, where identified, 713 participants (11.4%) were classified GMFCS Level IV or V. Some studies presented participants' age according to age groups ranging from young to late adulthood (eg, 18-29 up to ≥60 years).[23] Two studies included adult and pediatric participants however only the adult data sets were extracted.[22,24] One study included participants with a diagnosis of either CP or spina bifida, however only CP specific data was extracted.[25]

Sample sizes ranged from 32[26.] to 2906 participants.[24] Five included studies recruited participants using CP networks or disability service providers to distribute questionnaires,[21,22,27-29] 3 studies interrogated prior children's treatment center records,[30-32] 4 used primary care network databases,[18-20] 1 each used previous special school records,[26] clinic patients,[25] and registries.[24] All studies included in the review were conducted in developed countries or regions.

Quality assessment of included studies is presented in online Supplemental Appendix B. Of the 15 studies included, only 2 studies did not describe clearly their inclusion criteria.[22,26] It was unclear if the outcomes were measured in a valid and reliable way in 3 studies[21,22,27] and 4 studies[25,26,28,29] did not report relevant outcome measures at all.

The proportion of those accessing a GP at least annually ranged from a low of 20% (5/25 participants in Törnbom's study[25]) to more than 80% (eg, 87% of GMFCS Level IV/V participants ≥40 years old[22] or 100% of GMFCS Level I-III participants 25 to 45 years old proxy-report subgroup; Table 2).[30] The proportion of adults with CP accessing a GP at least annually was scrutinized, and cohort subgroups identified (age, GMFCS level) where data permitted. The overall pooled proportion of annual GP service use was 0.78 (95% CI 0.69, 0.85) with substantial statistical heterogeneity noted ($I^2 = 90\%$; $P \leq .001$; Figure 2). Fortuna's study reported the highest proportion of participants in their oldest cohort accessing a GP (92.5% of participants ≥60 years old), but this related to GP visits over a 2-year period[23] (Table 2). For studies that reported comparative data to individuals without CP, the frequency or proportion of annual visits was higher for adults with CP, for example, proportion with 12 or more annual visits: 7% (adults without CP) compared to 19% (adults with CP).[18]

Two studies[22,23] demonstrated that the proportion of participants accessing their GP typically progressively increased with age. In Fortuna's study[23] 39% of those aged 30 to 39 years visited their GP 3 or more times in 24 months, compared to 62.5% of those aged 60 years or older. In Roquet's cohort,[22] a higher percentage of those in the oldest age group (40 years plus) accessed their GP compared to younger participants for both ambulatory and non-ambulatory groups (eg, ambulatory group, 18-24 years: 62% annual visits; ≥40 years: 86% annual visits).

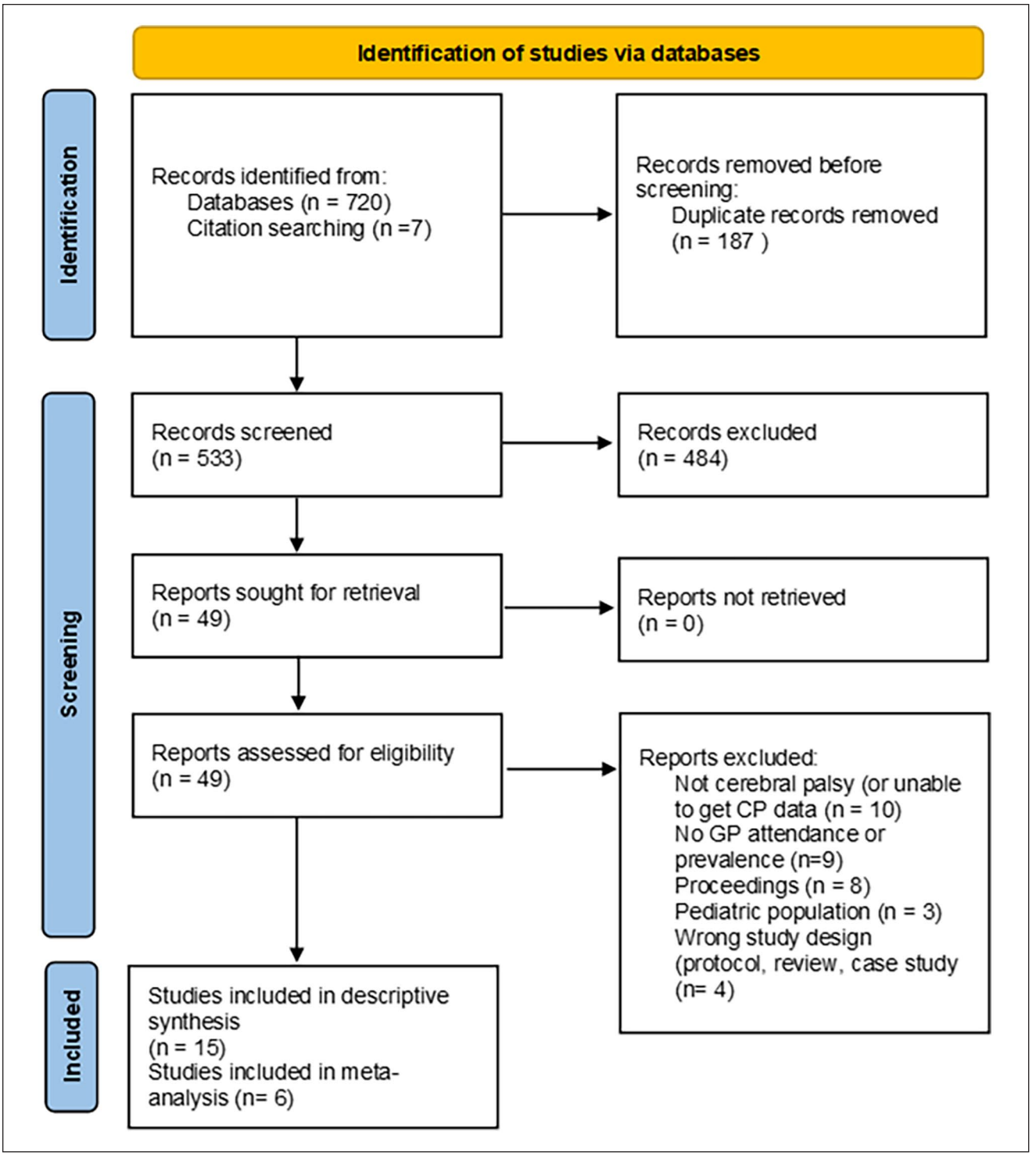

Figure 1. PRISMA flow chart of study selection process.

In Roquet et al[22] study, there was also a tendency for a greater percentage of participants with a higher GMFCS score (non-ambulatory, GMFCS IV or V) to access a GP compared to those with less severe disability (ambulatory GMFCS categories), although this was primarily evident in people less than 40 years old.

Table 1. Included Study Details and Participant Demographics.

Lead author; Publication year	Country	Study design	Inclusion criteria	Data source	Participant number	Mean age, (SD), range, n (%)	Male n (%)	GMFCS, n (%)
Beatty, P. 2003	USA	Cohort	-≥18 year -CP diagnosis -must have fee-for-service or managed care insurance	Postal questionnaires to members of CP organization	110	NR	NR	NR
Fortuna, R. 2018	USA	Cross-sectional	- ≥18 year - CP diagnosis	Electronic health records of primary care network (35 practices)	229	- 18-29 year: 56 (24.5) - 30-39 year: 41 (17.9) - 40-49 year: 51 (22.7) - 50-59 year: 41 (17.9) - ≥60 year: 40 (17.5)	M: 135 (59)	GMFCS I-III[a]: 18-29 year: (48.2) 30-39 year: (58.5) 40-49 year: (62.8) 50-59 year: (63.4) ≥60 year: (40.0) GMFCS IV/V[a]: 18-29 year: (51.8) 30-39 year: (41.5) 40-49 year: (37.3) 50-59 year: (36.6) ≥60 year: (60.0)
Hirsh, A. 2011	USA	Cohort	- ≥18 year - CP diagnosis - Score of ≥17 on MMSE (or ≥14 if communication device utilized)	In-person interviews or postal questionnaires	83	Mean (SD), range: 40.3 (13.6), 18-74	M: 37 (45)	GMFCS IV/V[a]: 63 (76)
Michelsen, S. 2020	Denmark	Population-based	- all age groups - CP diagnosis - Danish CP registry	Danish CP Registry and Danish National Health Service Registry	2906[b]	- 19-24 year: 451 - 25-24 year: 623 - 35-44 year: 675 - 45-54 year: 781 - ≥55 year: 376	NR	GMFCS I[b]: - 19-24 year: 180 (38) - 25-24 year: 272 (44) - 35-44 year: 284 (44) - 45-54 year: 280 (49) - ≥55 year: 162 (56)
Ng, S.Y. 2003	Singapore	Cohort study	- CP diagnosis - school leaver - previous student at special school	Standardized questionnaire and clinical examination (prior school records)	32[b]	Mean, range: 19.8, 17-22	M: 51/81[c]	GMFCS IV/V*: 14 (44)
Ramstad, K. 2015	Norway	Cohort	-age >18 year for Time point II of study (Time I <18 year) - CP diagnosis - lives in South East Norway	Postal questionnaire via service providers and CP association	42[d]	>18 year[d]	M: (55)[d]	Time I[d] GMFCS I: (39) GMFCS II: (23) GMFCS III: (8) GMFCS IV/V: (30)
Roquet, M. 2018 (Pons, C. 2017)	France	Cross-sectional	- CP diagnosis - all age groups - part of regional CP clinical network	Self-administered questionnaires via regional CP network	282[b]	- 18-24 year: 61 (21.6) - 25-39 year: 109 (38.7) - ≥40 year: 112 (39.7)	M:(61)[c]	GMFCS I-III[a]: 18-24 year: 29 (11) 25-39 year: 40 (15) ≥40 year: 43 (16) GMFCS IV-V[a]: 18-24 year: 32 (14) 25-39 year: 69 (29) ≥40 year: 69 (29)

(continued)

Table 1. (continued)

Lead author; Publication year	Country	Study design	Inclusion criteria	Data source	Participant number	Mean age, (SD), range, n (%)	Male n (%)	GMFCS, n (%)
Ryan, J.[e] 2019 Smith, K.[e] 2019 Smith, K.[e] 2021	UK UK UK	Cohort study	- ≥18 year - CP diagnosis - Attended GP at least once during study period (where CP diagnosis was recorded)	CPRD primary care database	1705 1703	Md (IQR): 29 (20-42) Mean (SD): 33.3 (15.5) - 18-30 year: 877 (51.4) - 30-39 year: 336 (19.7) - 40-49 year: 223 (13.1) - 50-59 year: 135 (7.9) - ≥60 year: 134 (7.9) - <40 year: 1213 (71.2) - 40-49 year: 223 (13.7) - 50-59 year: 134 (7.9) - 60-69 year: 77 (4.5) - ≥70 year: 56 (3.3)	M: 907 (53.2)	NR
Shrader, M. (2021)	USA	Cohort study	- 25-45 year - CP diagnosis - GMFCS I-III	Previous pediatric hospital medical records	126 (85 self report; 41 proxy report)	self-report; 29.7 (4.3) proxy-report; 29.7 (4.1)	Self-report; M: 44 Proxy-report; M: 26	Self-report; GMFCS I: 24 (28) GMFCS II: 40 (47) GMFCS III: 21 (25) Proxy-report; GMFCS I: 4 (10) GMFCS II: 28(68) GMFCS III: 9 (22)
Törnbom, M. 2013	Sweden	Longitudinal cohort follow up	- 19-33 year - CP or SB[h] diagnosis - Live in Goteborg - Ongoing contact with adult habilitation unit - IQ>70 (clinic requirement)	Adult habilitation clinic patients	Group A: 25 Group B: 15	Mean age (Time Point 2) Group A: 50 year[f] Group B: 38 year[g]	Group A—M: 15/28[f] Group B—M: 16/25[g]	GMFCS I-III[a] Group A: 14 (56) Group B: 7 (47) GMFCS IV-V[a] Group A: 11 (44) Group B: 8 (53)
Young, N. 2005	Canada	Cohort study	- born 1969-1976 (≥18 year) - prior patient of pediatric hospital - >1 health service interaction 1996-1999	Previous pediatric hospital records; Ontario Health Insurance Plan billing data	199	Mean: 22.0	NR	GMFCS I-III[a] (42.1) GMFCS IV-V[a] (57.9)
Young, N. 2007	Canada	Cross-sectional	- born 1970-1979 (≥18 year) - CP diagnosis - living in Ontario 1999-2002	Previous Childrens' Treatment Center records; Ontario Health Insurance Plan billing data and Registered Person Database (RPDB)	477	Female: Mean 26.4 Male: Mean 26.3	M: 275	GMFCS I-II[a] (36) GMFCS III[a] (19) GMFCS IV-V[a] (45)

Abbreviations: CP, cerebral palsy; CPRD, Clinical Practice Research Datalink; GMFCS, Gross Motor Function Classification System; GP, general practice; IQ, Intelligence Quotient; MMSE, Mini Mental State Examination; NR, not reported; SB, spina bifida.

[a]Author interpretation.

[b]Adult subset.

[c]Male percentage from combined pediatric and adult cohort.

[d]74 participants at Time I <18 years, participants were >18 years at Time II; no significant difference in subset who participated in Time II.

[e]used the same cohort.

[f]only CP data extracted.

[g]25/28 CP.

[h]15/25 CP.

Table 2. Study Participant Co-morbidities and GP Attendance.

Lead author (year)	Co-morbidities n (%)	GP attendance: frequency or proportion	GP attendance of population without CP
Beatty, P. (2003)	NR	Proportion accessing GP: 76.6% (those who needed GP and received GP service in prior 6 months)	NR
Fortuna, R. (2018)	Intellectual disability 124 (54.1) Proportion with comorbidity (range %) across age groups: Neurologic—seizure disorder (30-56) Gastrointestinal—GERD (34-57) Psychiatric—Depression (16-37) Heart and circulatory—Hypertension (16-80) Pulmonary—Asthma (36-61) Endocrine—Diabetes (4-13) Genito-urinary and kidney—Urinary incontinence (40-55) Musculoskeletal—Osteoporosis (10-24) Substance use—Tobacco (4-12) Infectious—STI (2-4) General—Obesity (38-47)	Frequency (categories) of GP visits per last 24 months: % Age 18-29 n = 56 - None: 26.8 - 1 or 2: 23.3 - ≥3: 50.0 Age 30-39 n = 41 - None: 22 - 1 or 2: 39 - ≥3: 39 Age 40-49 n = 51 - None 7.8 - 1 or 2: 43.1 - ≥3: 49.0 Age 50-59 n = 41 - None: 12.2 - 1 or 2: 34.2 - ≥3: 53.7 Age ≥60 n = 40 - None: 7.5 - 1 or 2: 30.0 - ≥3: 62.5	NR
Hirsh A. (2011)	Current pain or pain in prior 3 months: 52/83 (62.6) Most common pain locations: lower back (n = 37), legs and hips (both n = 30) Current pain medications (various): <(44)	Frequency of GP visits per previous 6 months: Mean (SD), range - Current or recent pain (n = 52): 2.4 (5.4), 0-30 - Moderate-severe pain rated ≥ 5/10 (n = 33): 3.6 (6.5), 0-30	NR
Michelsen, S. (2020)	Intellectual disability: n (%) 19-24 year: 264 (56) 25-34 year: 275 (44) 35-44 year: 274 (42) 45-54 year: 261 (36) ≥55 year: 111 (38)	Frequency of GP visits per year for those with ≥1 annual visit, Mean (range): 13.5 (12.8-14.1) Proportion accessing GP per year %: 82	Frequency of GP visits/year for those with ≥1 annual visit, Mean: 9.8 Proportion accessing GP/year %: 76
Ng, S.Y. (2003)	Poor growth/nutrition: 10 (31) Recurrent chest infection: 4 (13) Constipation: 13 (41) Seizures: 11(34) Incontinence: 11 (34) Kyphoscoliosis: 16 (50) Upper limb contractures: 7 (22) Lower limb contractures: 12 (38) Dental caries: 11 (34)	Frequency of GP visits per year: 1.76	NR

(continued)

Table 2. (continued)

Lead author (year)	Co-morbidities n (%)	GP attendance: frequency or proportion	GP attendance of population without CP
Ramstad, K. (2015)	Epilepsy medication: (32)[a] Regular pain—muscle or bone: (78)[a]	Proportion accessing GP per year %: 74	NR
Roquet, M. (2018; Pons, 2017)	Cognitive dysfunction (moderate or severe):164 (59.8; reported in Pons, 2017) ≥ 1 medication (Amb/Non Amb%): - Age 18-24: 45/65 - Age 25-39: 60/83 - Age ≥40: 70/80 Analgesics (Amb/Non Amb%) - Age 18-24: 7/9 - Age 25-39: 13/12 - Age ≥40: 30/22 Psychotropic (Amb/Non Amb%) - Age 18-24: 17/19 - Age 25-39: 18/35 - Age ≥40: 28/39 Oral antispastic (Amb/Non Amb%) - Age 18-24: 7/31 - Age 25-39: 8/38 - Age ≥40: 14/28 Antiepileptic (Amb/Non Amb%) - Age 18-24: 21/19 - Age 25-39: 28/38 - Age ≥40: 16/36 Digestive system (Amb/Non Amb%) - Age 18-24: 3/19 - Age 25-39: 3/39 - Age ≥40: 14/43	Proportion accessing GP per year %[a]: Ambulatory (GMFCS level I-III) - Age 18-24: 62 - Age 25-39: 75 - Age ≥40: 86 Non-ambulatory (GMFCS level IV/V) - Age 18-24: 72 - Age 25-39: 83 - Age ≥40: 87	NR
Ryan, J. (2019)[e]	Cancer: 15 (0.88) Diabetes: 47 (2.76) Cardiovascular disease: 248 (14.6) Heart failure: 30 (1.76) Hypertensive disease 187 (11.0) Ischemic heart disease: 35 (2.1) Cerebrovascular disease: 36 (2.1) Respiratory disease: 215 (12.6) COPD: 38 (2.2) Asthma: 197 (11.6) ID: 363 (21.3)	Frequency of GP visits per year, Md (IQR) - All participants, n = 1705: 6.03 (2.44-12.01) - CP no ID, n = 1342: 5.40 (2.20-10.70) - CP + ID, n = 363: 8.87 (4.5-16.24)	Frequency of GP visits per year, Md (IQR): - Patients without CP matched to all with CP 2.32 (0.82-5.05) - Patients without CP matched to patients with CP + ID 2.45 (0.98-5.10) - Patients without CP matched to patients with CP + no ID 2.28 (0.78-5.03)

(continued)

Table 2. (continued)

Lead author (year)	Co-morbidities n (%)	GP attendance: frequency or proportion	GP attendance of population without CP
Smith, K. (2019)[e]	Depression: 312 (18.3) Anxiety: 261 (15.3) Diabetes: 55 (3.2) Heart disease: 160 (9.4) Osteoarthritis: 87 (15.1) Epilepsy: 354 (20.8) Lung disease: 147 (8.6) Pain conditions: 166 (9.7) ID: 362 (21.3)	Frequency (categories) of GP visits per year, n: mean (%) CP no ID - 0-1.9: 123 (7.8) - 2-11.9: 956 (71.5) - ≥12: 258 (19.3) CP + ID - 0-1.9: 10 (2.8) - 2-11.9: 222 (61.3) - ≥12: 130 (35.9)	Frequency (categories) of GP visits per year for matched controls, n: mean (%) - 0-2 per year: (14) - 2.1-11.9 per year: (79) - ≥12 per year: (7)
Smith, K. (2021)[e]	Depression: 310 (18.2) Diabetes: 60 (3.5) Heart disease: 182 (10.7) Stroke: 69 (4.1) Sensory impairment: 298 (17.5) Epilepsy: 427 (25.1) ID: 361 (21.2) Dementia: 19 (1.1)	Frequency (categories) of GP visits per year, n: mean (%) - 0-2 per year: 133 (7.8) - 2.1-11.9 per year: 1177 (69.1) - ≥12 per year: 393 (23.1)	Frequency (categories) of GP visits per year for matched controls, n: mean (%) - 0-2 per year: (14.01) - 2.1-11.9 per year: (78.86) - ≥12 per year: (7.12)
Shrader, M. (2021)	Chronic pain: Self-report (47.1) Proxy-report (53.7) Joint/muscle pain: Self-report (72) Proxy-report (61)	Proportion accessing GP per year %[d] Self-report 97.6 Proxy-report 100.0	NR
Törnbom, M. (2013)	Not specified	Proportion accessing GP per year: n (%)[b] - Group A CP (n = 25): 5 (20) - Group B CP (n = 15): 5 (33)	NR
Young, N. (2005)	Not specified	Frequency of GP visits per year/100 individuals: 1169 (11.7 visit/year)	NR
Young, N. (2007)	Not specified	Frequency of GP visits per year (excluding annual physicals)/1000 individuals: Female: 3865 visits (3.9 visit/year) Male: 2869 visits (2.9 visit/year) Annual physical GP visits/1000 individuals: Female 324 visits (0.3 visit/year) Male 282 visits (0.3 visit/year) Total frequency of GP visits per year: Female: 4.1 Male: 3.2	NR

Abbreviations: Amb, ambulatory; CP, Cerebral palsy; GERD, gastroesophageal disease; GMFCS, gross motor function classification system; GP, General practitioner, NR, not reported; ID, intellectual disability; IQR, interquartile range; Md, median; non-Amb, non ambulatory; STI, sexually transmitted illness.

[a]Demographic data reported for Time I (<18year); no significant difference in subset of 42/74 who participated in Time II.

[b]Time period not specified; assumption of at least annual contact.

[c]Author interpretation that "physician" refers to primary care provider.

[d]assumed per year; not specified by author.

[e]Ryan 2019, Smith 2019, and Smith 2021 accessed the same data from the CPRD database with different analyses; note some slight variation in data reported.

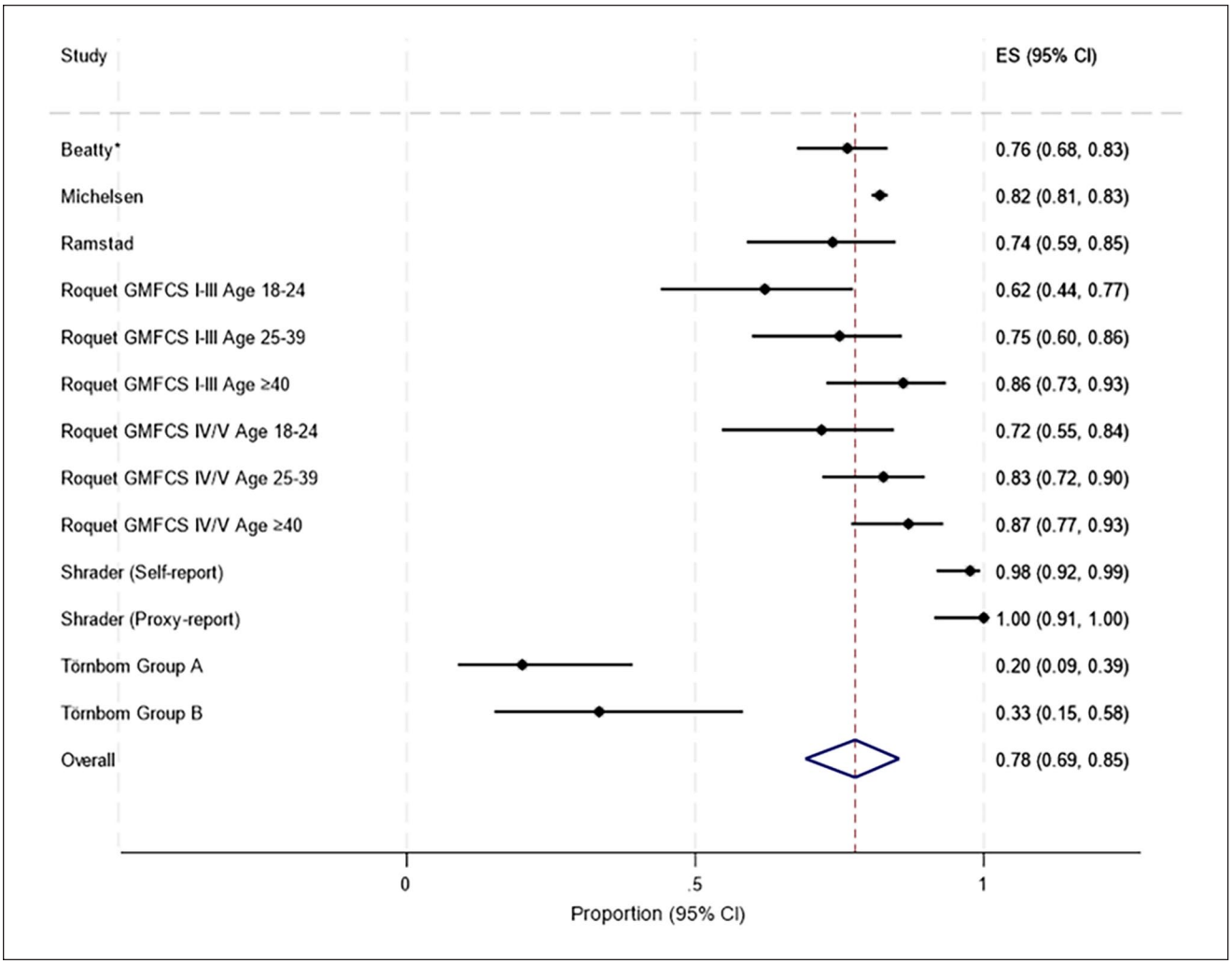

Figure 2. Proportion of adults with cerebral palsy accessing a GP at least annually.
*Those who reported they needed a GP and received GP service in the prior six months.

In Figure 3, the mean frequency of visits ranged from a low of 1.76 visits per year (mean age 19.8 years[26] to a high of 11.7 visits per year,[32] or 13.5 visits per year for people with at least 1 annual visit (ie, those with zero visits excluded).[24] Young 2007 reported that the frequency of visits was significantly more for females than males in their sample (4.1/visits per year females; 3.2/visits per year males; $P < 0.01$).[31]

Three studies reported mean annual or 2-year GP visits categorically, for example, proportion recording 0 visits, 1 to 2 visits, ≥3 visits, or 0 to 2 visits, 2.1 to 11.9 visits.[19,20,23] Smith et al[19,20] reported the proportion visiting a GP on 0 to 2 occasions within a 1-year period (ie, infrequently), ranged from a low of 2.8% (people with CP and ID) to 7.8% (people with CP and no ID, or total cohort with and without ID). Although Fortuna's data was calculated on the proportion visiting a GP within a 2-year period,[23] much higher proportions of 50% to 60% of the cohort aged 18 to 49 years visited their GP on 0 to 2 occasions (ie, infrequently).

Eight studies listed participant comorbidities as a proportion of participants, for example, epilepsy or seizure disorder was identified by Fortuna (30%-56%),[23] Ng (34%),[26] and Smith (21%-25%).[19,20] Two studies reported that comorbid ID was associated with an increased frequency of GP access compared to no comorbid ID—for example, 35.9% of those with comorbid ID attended a GP ≥12 times a year versus 19.3% with no comorbid ID.[18,19] A further 4 studies reported ID as a comorbidity in participants, but no analysis provided on how this might have impacted GP visit frequency.[20,21,23,24] Exhibiting moderate to severe pain was also associated with greater GP frequency of access (mean 3.6 visits/6 months) compared to those reporting current or

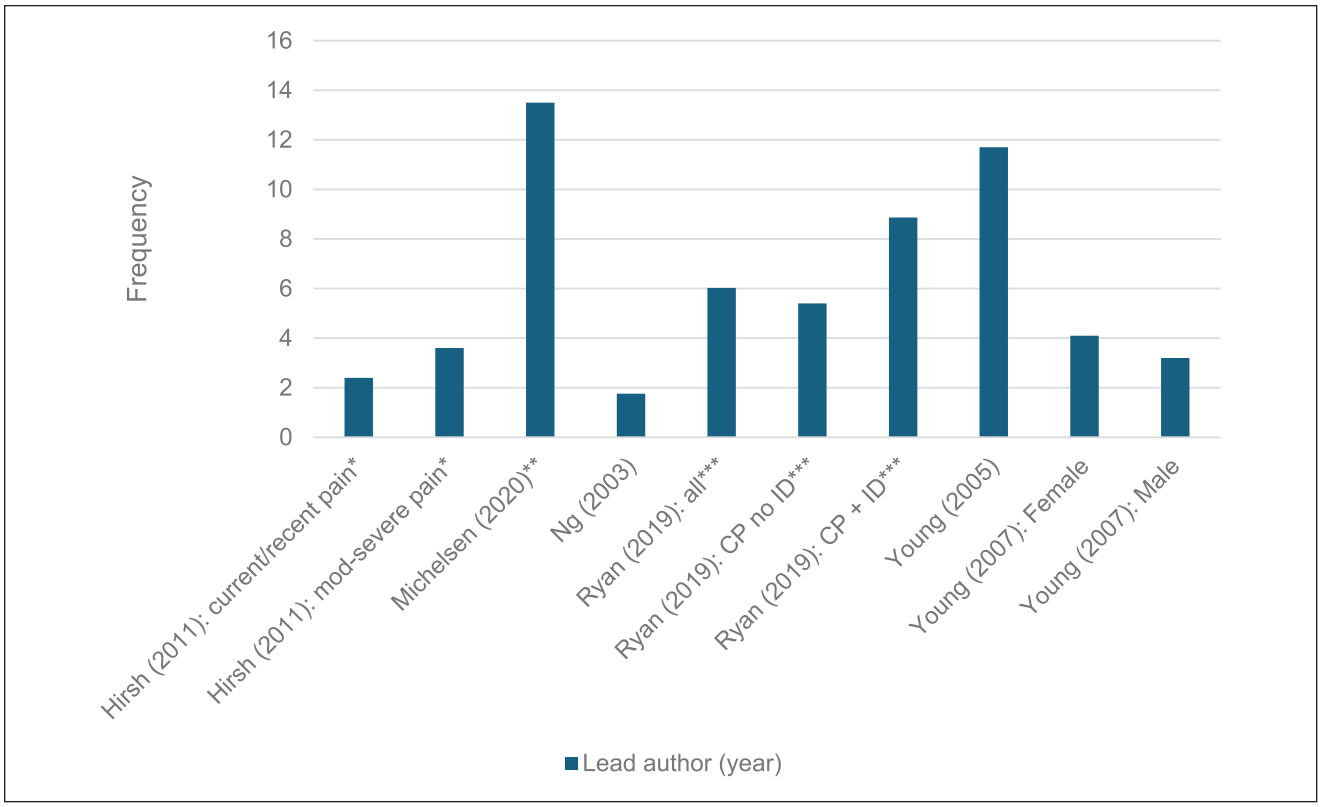

Figure 3. Mean annual frequency of GP visits.
Abbreviations: CP, cerebral palsy; ID, intellectual disability.
*Hirsh: 6-month data converted to 12-month.
**Michelsen: subset of participants with at least 1 visit/year.
***Ryan: median data.

recent pain (mean 2.4 visits/6 months) in 1 study focused on the pain experience.[29] A further 3 studies reported pain as a comorbidity in participants, but no information relating pain to GP frequency was reported.[19,28,30]

Three studies reported frequency of participants taking medications.[21,22,28,29] For example, Roquet et al[22] reported the percentage of participants taking at least 1 medication (non-ambulatory age 25-39 years: 83%) however no studies specifically linked medication use to frequency of GP access.

No studies specifically reported the healthcare reason for seeking to consult a GP or described the interventions provided specifically by the GP to this population, other than Young (2007) who reported the frequency of visits to conduct an "annual physical" (0.3 visits per year/individual).[31] One study listed treatments accessed by people with CP for pain management such as massage or acupuncture,[29] and other studies summarized interventions such as gait aids or orthoses prescribed,[21,22] however the health provider of these treatments was not specifically identified and a GP was considered unlikely.

Discussion

This review aimed to investigate the profile of GP access and interventions by adults with CP. For studies where data was able to be pooled, results suggest 78% (95% CI = 69%-85%) of adults with CP access a GP at least annually. For studies that provided comparison GP visit data of people without CP, people with CP generally accessed their GP more frequently. This result of 78% is only slightly lower than the findings of a previous review which suggested 84% attended a GP annually.[9] This minor discrepancy may be attributed to a more recent change in patterns of health care access changes in primary care availability or funding, greater proportions of adults with CP seeking alternative providers/sources,[33] or merely due to different study samples.

Review results also suggest that the frequency of access to a GP generally increases with age in adults with CP. An increase in primary care access with age has previously been noted in the general population without disabilities,[34] and hence this finding may not be surprising. Interestingly, the

young adult age group (18-29 years old) in Fortuna's study[23] was the only age group to access GP services more frequently than those older (aged 30-50 years). The reason for this may reflect young adults completing their transition from pediatric to adult services, prompted by pediatric health care providers. Nevertheless, it is likely that people with CP access their GP more frequently as they age, in line with the broader population. Gender bias influencing GP attendance, suggesting that women with CP access GP services more than males (as also documented in the general population), was also evident in the 1 study that reported this data.[31,34]

Only the study by Roquet et al[22] (and cohort also reported by Pons et al[21]) investigated any variation in access to a family physician relative to motor impairment, with findings suggesting that GP visits were generally more frequent among participants who were non-ambulatory compared to those who were ambulatory. Evidence suggests that individuals classified as GMFCS IV or V are more likely to have an increased prevalence of multimorbidity.[35] Premature aging and mobility decline has also been reported in young-middle aged adults with CP.[36] This may drive increased requirement of access to all health care services, including primary care, however the reason for GP attendance, whether for health issue management or preventive care, remains largely speculative.

Intellectual disability (ID) is a commonly occurring comorbidity, with the estimated frequency varying from 38 to 52% in individuals with CP.[37] Two studies in this review[18,19] that interrogated the same data set, observed that participants with comorbid ID accessed a GP more frequently in comparison to those without ID. As ID is more prevalent in adults with CP who have greater disability,[6] and those with greater disability typically have more comorbidities[38] this finding may not be unexpected. However, evidence that has explored access to GPs for people with ID (as a primary diagnosis) has suggested people with ID access their GP less frequently than those without ID (due to a range of supply and demand factors).[39] Furthermore, individuals with CP and comorbid ID may have worse health outcomes due to challenging behaviors associated with ID, an increased reliance on carers to identify health problems on their behalf, and they exhibit lower participation in health promoting practices and preventive care.[37] It will be important to explore further the impact of ID on GP attendance in other countries to confirm how ID as a comorbidity in CP impacts the frequency of GP attendance.

The only other comorbidity specifically identified as impacting GP frequency in this review was pain.[29] This study demonstrated that access to a GP was greater among a subset of participants experiencing moderate-severe pain (rated $\geq$5/10) in comparison to a wider group of participants reporting any pain. Mean pain prevalence has been estimated at 70% in adults with CP,[40] and consultations on chronic pain account for 22% of all primary practice visits by the general population.[41] As such, pain intensity understandably drives an increased frequency of GP access by people with CP, possibly for medication review or referral to other health practitioners such as physiotherapists, however this is an assumption.

This review additionally sought to explore any interventions provided by a GP. However little, if any, data was able to be identified. It could be argued the reason for attending a GP may be implied, for eample, those with severe pain may seek GP treatment for analgesia prescription, however no studies specifically provided this information. Older studies have described adults with CP receiving unspecified "disability" or "medical" check-ups[42,43] and 1 study in this review reported "annual physical" as a reason for GP access.[31] Thus there remain gaps in our knowledge particularly relating to the interventions that are provided to adults with CP by primary care providers, including preventive care such as health checks and cancer screening.

It is important also to consider that health service access by an individual may not represent service need, suitability, or adequacy.[9] This uncertainty in primary care management of adults with CP exists in a climate where concerns have been expressed by adults with CP regarding the skills, accessibility, and knowledge of primary care providers in managing their health needs.[44,45] It could be that adults with CP, particularly those with more complexity, seek care from emergency departments rather than attend a GP for care. For example, only 9% of 1586 presentations by adults with CP to an emergency department were classified as "low urgency," suggesting they could have been managed in a primary care setting.[46] Alternatively, adults with CP may have the majority of their healthcare needs provided by specialists such as neurologists, physiatrists, or rehabilitation teams. This is considered unlikely given evidence describing a lack of comprehensive adult services in most countries.[44,45] Characteristics of primary care provided to adults with GP warrants further investigation.

Limitations

Access to a primary care physician may be impacted by different models of health service provision. Health service access, design, and funding models thus likely impact an individual's decision to access primary care, and study findings may not be applicable in another jurisdiction. Although meta analyses suggested 78% of adults with CP visited a GP at least annually, this finding arose from 6 studies, and significant heterogeneity was evident, likely due to differences in population, methodology, or local healthcare systems.

A further challenge encountered was the broad definition of "primary care" as this term potentially could relate not only to general practice but to dental or allied health roles. Every effort was made to carefully review publications to ensure that this term was correctly interpreted. It is possible that some GP services may have been provided in part by a nurse practitioner or physician assistant (in some countries),

however this still represents the general practice environment. However if there was any uncertainty regarding the practice setting, for example studies describing provision of a "medical check-up" within a hospital setting, or healthcare services provided within ambulatory care or a specialized outpatient clinic, these were excluded.

Future Research Directions

Despite an initial focus of this review, no publications specifically identified interventions provided to adults with CP suggesting a significant knowledge gap. This evidence is important in informing guidelines for GPs and wider primary care multidisciplinary teams, allowing them to become better equipped with skills required to safely meet the primary care needs of adults with CP. Some qualitative studies have described the experience of individuals with CP in accessing a GP as part of navigating the adult healthcare system. Example reasons for seeking GP care have been identified in this qualitative data such as to facilitate a specialist referral, or medication management.[47] However robust quantitative data confirming these findings is difficult to locate, and evidence describing interventions provided by a GP, or reasons which may make a person with CP more likely to access primary care is not readily available in either quantitative or qualitative data. Future data linkage processes may enable this, by linking not only characteristics of the person with CP to GP attendance, but details of the reason for attendance and interventions provided (in categories). Knowledge regarding reasons for seeking primary care by children with CP is expanding using such data linkage processes,[48] but interventions provided by a GP remain undocumented. Data linkage of primary care outputs, as well as inputs, would enable determination of primary care interventions provided such as diabetes or cancer screening rates, immunizations offered, or mental health service referrals against best practice.

Conclusions

This systematic review indicated that around 78% of adults with CP access a GP annually. Frequency of access may increase with advancing age, severity of disability, comorbid intellectual disability, and pain. Despite the presence of multiple comorbidities and polypharmacy in adults with CP in included studies, specific reasons driving primary care access as well as interventions provided were unable to confidently be identified. This needs to be a focus of future research best addressed through data linkage studies.

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Supplemental Material

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