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Incidence of falls among adults with cerebral palsy: a cohort study using primary care data

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ABBREVIATION

CPRD Clinical Practice Research Datalink

AIM To compare the rate of falls between adults with and without cerebral palsy (CP).

METHOD We used primary care data on 1705 adults with CP and 5115 adults without CP matched for age, sex, and general practice attended. We compared odds of experiencing a fall between adults with and without CP using conditional logistic regression. We compared the rate of falls using a negative binomial model.

RESULTS Participants were 3628 males (53%), 3192 females (47%) (median age 29y, interquartile range 20–42y) at the start of follow-up. Follow-up was 14 617 person-years for adults with CP and 56 816 person-years for adults without CP. Of adults with CP, 15.3% experienced at least one fall compared to 5.7% of adults without CP. Adults with CP had 3.64 times (95% confidence interval [CI] 2.98–4.45) the odds of experiencing a fall compared to adults without CP. The rate of falls was 30.5 per 1000 person-years and 6.7 per 1000 person-years for adults with and without CP respectively (rate ratio 5.83, 95% CI 4.84–7.02)

INTERPRETATION Adults with CP are more likely to fall, and fall more often, than adults without CP. The causes and consequences of falls in adults with CP need examination.

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Falls in Cerebral Palsy *Jennifer M Ryan et al.*

What this paper adds

- Twenty adults with CP and 5.3 adults without CP experienced at least one fall per 1000 person-years.
- Adults with CP experienced 30.5 falls per 1000 person-years compared to 6.7 falls per 1000 person-years among adults without CP.
- Adults with CP had 3.64 times the odds of experiencing a fall compared to adults without CP.
- Adults with CP experienced 5.83 times more falls than adults without CP.

[main text]

Cerebral palsy (CP) is a neurodevelopmental condition that occurs in childhood and persists throughout the lifespan.[1] Most people with CP will survive to at least 60 years of age.[2] Although adults with CP consistently report poor balance, which may contribute to reduced mobility,[3,4] few studies have evaluated the frequency of falls among adults with CP.

Falls are associated with injury, disability, and death.[5,6] Fall-related injuries include fractures, which can contribute to long-term exacerbation of disability through persistent weakness and deconditioning after the immobilization required for bone healing.[7] As adults with CP present with a high relative risk of musculoskeletal disorders, such as osteoporosis,[8] the consequences of a fall for a person with CP may be magnified. In addition to the physical consequences, people who experience a fall may develop fear of falling and reduced confidence to avoid falls, which, consequently, limit participation.[6]

Two small studies have examined the prevalence of falls among adults with CP. In a study of 25 ambulatory adults with CP in Australia, 68% reported at least one fall in the past year, with the annual number of self-reported falls ranging from 1 to 500.[4] A second study of 17 ambulatory adults with CP in Australia found that 53% had experienced at least one fall in the past year.[9] This sample was slightly younger than that in the previous study, which may explain the lower prevalence of falls. While these studies suggest that the prevalence of falls is high among adults with CP, they are limited by their small size, lack of precision, use of retrospective self-reported falls as the outcome, and a relatively short duration of follow-up. Further, they do not provide information regarding the relative prevalence or rate of falls among adults with CP compared to adults without CP. More robust and precise estimates of the burden of falls among adults with CP may help to establish the need for clinical services targeted at falls prevention. The aim of this study was to compare the rate of falls between adults with and without CP.

METHOD

We conducted a matched, cohort study using primary care data obtained from the Clinical Practice Research Datalink (CPRD). The CPRD collects data from over 600 general practices in the UK. Data encompasses all routine data that general practitioners (GPs) record electronically during patient visits. These include data on clinical diagnoses, test results, prescriptions, demographics, and referrals. In the UK, approximately 99% of the population is registered with a GP. GPs are gatekeepers of care and are free to access. Data from the CPRD are largely representative of the UK population in terms of age and sex.[10] The CPRD began data collection in 1987 and we used data obtained during the period 1st January 1987 to 30th November 2015. The CPRD has obtained research ethics approval from a National Research Ethics Service

Committee for purely observational research using anonymized data. The protocol was approved by the Independent Scientific Advisory Committee for the Medicines and Healthcare Products Regulatory Agency Database Research (protocol no. 16_077R2A).

Participants

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We obtained data on adults with CP aged 18 years and older and adults without CP, matched on age (±3y), sex, and general practice attended. We matched adults with and without CP on general practice attended to control for practice-level socio-economic status and between practice variations in GP diagnostic behaviours. We used Read Codes, which are alphanumeric codes used to record clinical diagnoses in primary care in the UK, to identify patients with CP. We developed a list of 23 possible Read Codes to identify a person with CP. The list was verified by individuals with expert knowledge of CP. We included all patients, aged 18 years and older, with at least one Read Code for CP occurring within the study period and within their up-to-standard follow-up period. The up-to-standard follow-up period is the period within which a practice is considered to have continuous high-quality data that is suitable for use in research. The CPRD also performs quality checks on individual patient data to identify and exclude patients with non-continuous follow-up or poor data recording. Only patients whose data were deemed acceptable for use in research were included. We set start of follow-up (i.e. 'index date') for patients with CP as the latest of either: the date the patient registered with the general practice, the date the data were considered up-to-standard, or the 1st January of the year in which the patient turned 18 years of age. The index date for control patients was set to the index date of their matched patient with CP.

Outcomes

Outcomes were: (1) the number of adults experiencing at least one fall during follow-up and (2) the number of falls experienced during follow-up. We identified falls in primary care data and thus, only captured falls that were reported to and recorded electronically by a GP. The absence of a record of a fall in patient records assumes the absence of a fall. We developed a list of Read Codes to identify a fall by searching a dictionary of Read Codes for codes relating to a fall. A neurologist with expertise in falls research (MHC) reviewed the list of codes identified through the search and removed all terms not directly referring to a fall (e.g. 'falls risk assessment

referral'). We used this final list of codes to identify a fall in patient records (see Appendix S1, online supporting information). Where a Read Code for a fall was recorded more than once on the same date for a patient, we counted this as one fall.

Statistical analysis

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We aimed to compare: (1) the proportion of adults with and without CP experiencing at least one fall; (2) the rate of adults with and without CP experiencing a fall, accounting for differing lengths of follow-up between patients; and (3) the rate of falls between adults with and without CP, also accounting for differing lengths of follow-up between patients. Where the outcome was the number of adults experiencing at least one fall during follow-up, we identified follow-up time as the index date (i.e. start of follow-up) to the earliest of: (1) transfer out of CPRD; (2) the end of the study period; (3) general practice last collection date; (4) death; or (5) first event of a fall. Where the outcome was the number of falls experienced during follow-up, we identified follow-up time as the index date to the earliest of: (1) transfer out of CPRD; (2) the end of the study period; (3) general practice last collection date; or (4) death.

We described patient characteristics at start of follow-up using mean, standard deviation (SD), median, interquartile range (IQR), range, frequency, and percentage, where appropriate. We initially conducted a conditional logistic regression to compare the odds of adults with and without CP experiencing a fall. We calculated the incidence rate of adults with and without CP experiencing a fall by dividing the number of adults with a fall by the total person-years of follow-up. We used Lexis expansions to expand each patient's data so that they had several observations of different age-at-risk bands before calculating the incidence rate of at least one fall according to age-at-risk bands. We calculated rate ratios by age-at-risk bands and overall using the Mantel-Haenszel method. We fitted a Cox proportional hazard model adjusted for age, sex, and general practice to compare the hazard rate of adults with and without CP experiencing a fall. Finally, we fitted a negative binomial model, which included an offset for follow-up time and adjusted for age, sex, and practice, to compare the incidence rate of falls between adults with and without CP. Analysis was conducted using Stata, version 15.0 (StataCorp, College Station, TX, USA).

Sensitivity analyses and model checking

In a sensitivity analysis, we removed adults with less than 1-year follow-up time to first fall or censoring. After removing these adults, we: (1) performed conditional logistic regression to compare the odds of adults with and without CP experiencing at least one fall; (2) fitted a Cox proportional hazard models adjusted for age, sex, and practice to compare the hazard rate of adults with and without CP experiencing at least one fall; and (3) fitted a negative binomial model adjusted for age, sex, and practice, and including an offset for follow-up time, to compare the incidence rate of falls between adults with and without CP. We assessed the proportional hazards assumption for Cox models by examining plots of scaled Schoenfeld residuals against time. There was no evidence that the assumption of proportional hazards was not appropriate.

RESULTS

We identified 1705 adults with at least one record of CP occurring within the study period and within their up-to-standard follow-up period. We matched these adults to 5115 adults without CP. Patient characteristics at the start of follow-up are described in Table 1. Fifty-three per cent of the participants were male (median age 29y, IQR 20–42y). Patients with CP had 14 617 total person-years of follow-up (median 7y 1mo, IQR 0.5mo–27y 11mo). Patients without CP had 56 816 total person-years of follow-up (median 11y, range 2mo–28y). The number of people experiencing at least one fall, person-years of follow-up, and the incidence rate of at least one fall, by age-at-risk band and CP status are presented in Table 2. During follow-up, 260 (15.3%) adults with CP experienced at least one fall compared to 291 (5.7%) adults without CP. Females were more likely to fall than males; 17.8% of females with CP experienced a fall compared to 13.0% of males with CP and 7.9% of females without CP compared to 3.4% of males without CP. Twenty adults with CP (95% confidence interval [CI] 17.7–22.6) experienced a fall per 1000 person-years and 5.3 adults without CP (95% CI 4.7–5.9) experienced a fall per 1000 person-years; rate ratio 3.79 (95% CI 3.21–4.48). There was no evidence of effect modification by age-at-risk band (p=0.435). In total, 827 falls were experienced during follow-up. Adults with CP experienced 446 falls and adults without CP experienced 381 falls. Among those who experienced a fall, the median (IQR) number of falls was 1 (1–2) in adults with CP and 1 (1–1) in adults without CP; with a range of 1 to 8 for both adults with and without CP. The incidence rate of falls was 30.5 per 1000 person-years for adults with CP and 6.7 per 1000 person-years for adults without CP (Table 3).

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Adults with CP had 3.64 times the odds of a fall compared to adults without CP (odds ratio [OR]: 3.64, 95% CI 2.98–4.45, $p<0.001$). Adults with CP had 4.52 times the hazard of experiencing a fall compared to adults without CP (adjusted hazard ratio [HR]: 4.52, 95% CI 3.81–5.35, $p<0.001$). The rate of falls was also higher among adults with CP compared to those without CP (adjusted incidence rate ratio [IRR]: 5.83, 95% CI 4.84–7.02, $p<0.001$; Table 3).

Sensitivity analysis

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We removed 335 adults with less than 1-year follow-up in sensitivity analysis (181 adults with CP and 154 adults without CP). After removal of these individuals, 222 (14.6%) adults with CP and 266 (5.4%) adults without CP experienced at least one fall. Adults with CP experienced 377 falls and adults without CP experienced 338 falls. Adults with CP had 3.50 higher odds of a fall compared to adults without CP (OR: 3.50, 95% CI 2.82–4.33, $p<0.001$). Adults with CP had 4.35 times the hazard of experiencing a fall compared to adults without CP (adjusted HR: 4.35, 95% CI 3.63–5.21, $p<0.001$). The rate of falls was also higher among adults with CP compared to those without CP (adjusted IRR: 5.46, 95% CI 4.50–6.64, $p<0.001$).

DISCUSSION

In summary, we found that adults with CP are approximately four times more likely to fall compared to adults without CP. They also experience more falls than adults without CP. The rate of a first fall among adults with CP was similar in the 18 to 29 year, 30 to 39 year, and 40 to 49 year age-at-risk band, at approximately 20 per 1000 person-years of follow-up. This was much higher than the rate of a first fall in adults without CP at the same age but was particularly higher in the young to middle aged.

Fifteen per cent of adults with CP had at least one fall recorded in the medical record during follow-up. This was much lower than the prevalence of falls reported in two previous studies of adults with CP.[4,9] The prevalence of at least one fall in the past year was 68% and 53% respectively, among small samples of adults with CP in Australia. When we removed adults who had less than 1 year of follow-up the prevalence did not change substantially. As we used primary care data to identify falls, we only captured falls that were sufficiently serious for the adult to report it to their GP. Falls recorded in this study are, therefore, likely to be the most

serious falls experienced by adults with and without CP. The high prevalence of self-reported falls in previous studies suggests that many adults with CP may not report falls to their GP.

Similarly, in this study, adults with CP had a maximum of eight falls recorded during a median of 7 years of follow-up compared to the maximum of 500 retrospectively self-reported falls in one year reported by Morgan and McGinley.[4] However, 500 falls may be an extreme value as only 18% of adults reported experiencing more than 10 falls, while 41% reported experiencing 3 to 10 falls and 1 to 2 falls respectively. The lower prevalence of falls observed in this study in comparison to previous studies of ambulatory people with CP may, potentially, be explained by the inclusion of people with CP who use wheeled mobility. As we did not have information on mobility status, by including both ambulatory and non-ambulatory adults with CP we may have underestimated the burden of falls in ambulatory adults. A study of 93 ambulatory and non-ambulatory children with CP found the prevalence of falls during an in-patient hospital stay was 27%, with the number of falls reported to nursing staff ranging from 1 to 6 per child.[11] While these results are more similar to our findings, the mean length of hospital stay was just 40.3 days.

Impaired balance, progressive loss of muscle strength, and deterioration in mobility may contribute to the increased risk of falls observed in adults with CP.[3,12] However, there is a lack of research examining causes of falls in people with CP. Although a cross-sectional study found stride length was shorter among fallers (defined as ≥1 self-reported fall in the past year) compared to non-fallers,[9] it is not clear if shorter stride length is a cause or consequence of falls. Balance, gait speed, and other temporal-spatial gait parameters such as step width, cadence, and double support time did not differ between fallers and non-fallers.[9] Among ambulatory and non-ambulatory children with CP, parent-reported behavioural problems, a history of frequent falls, the ability to balance on knees without support, and not having a contracture of the hip were risk factors for falls during an in-patient hospital stay.[11] The latter two factors suggest that mobility is associated with falls, with those being more mobile having a higher risk of a fall. However, a study of adults with CP found that 0 out of 2 adults in Gross Motor Function Classification System (GMFCS) level I, 5 out of 10 adults in GMFCS level II, and 4 out of 5 adults in GMFCS level III reported a fall in the past year.[9] Another study found that 2 out of 4 adults in GMFCS level I, 12 out of 16 in GMFCS level II, and 3 out of 5 in GMFCS level III reported experiencing

at least one fall in the past year.[4] It is difficult to determine if an association between GMFCS level and falls exists from these data given the small sample sizes.

Although we were unable to examine the association between GMFCS level and falls in this study, we did observe that female sex was associated with falls. Our finding that females with CP were approximately twice as likely to fall as males is consistent with findings in older adults.[13] The reasons for this need to be explored further. It is possible that females are more likely to fall than males, or females may be more likely to seek medical care for falls than males. It is also not clear from our analysis if sex is a risk factor for falls among people with CP, independently of other known risk factors such as sarcopenia, deterioration in mobility, and comorbidities.[14]

A fall may have several consequences for adults with CP, and there is a lack of research understanding the consequences of falls in this population. Adults with CP have a high risk of osteoporosis,[8] which increases with age.[15] The combination of osteoporosis and falls is likely to contribute to a high prevalence of fractures.[16] Falls may also contribute to the deterioration in mobility commonly reported by young adults with CP.[17] Adults report that impaired balance is the main reason for decline in mobility.[3] However, a cross-sectional study of adults with CP found that self-reported gait decline was not associated with self-reported falls.[4] There is probably a complex relationship between impaired balance, decline in mobility, deconditioning, and falls, where these factors may be both a cause and consequence of a falls, which need to be examined longitudinally in order to determine the direction of association.

Limitations of this study include a lack of information on the severity of motor impairment, for example as classified by the GMFCS, and use of primary care data to identify falls. We were unable to stratify our analysis according to severity of motor impairment, which may mediate the association between CP and falls. As discussed previously, the use of primary care data to identify falls may have underestimated the rate of falls among adults with CP. GPs are not obliged to ask about or record presence/absence of falls during consultations with patients. Therefore, the assumption that the absence of a record of a fall indicates absence of a fall may be incorrect. People with CP may have reported only the most serious falls to their GP. However, our estimate of the relative rate of falls between adults with and without CP may only be biased if reporting of falls differs between these groups.

This study also had several strengths. First, this is the first cohort study to compare the rate of falls between adults with and without CP. Previous studies have used a cross-sectional design and asked small samples of adults with CP to self-report falls in previous years. Although we used historical data, the data were prospectively recorded, which reduces the potential for measurement or recall bias in comparison to self-report data. We used a robust analytical approach to account for varying lengths of follow-up when comparing rates of at least one fall and multiple falls between adults with and without CP. Last, we conducted a sensitivity analysis wherein we removed adults with less than 1-year follow-up.

In conclusion, we found that adults with CP are more likely to fall and experience more falls than adults without CP. Results from these analyses may be used to better inform clinicians, caregivers, and individuals with CP about the risk of falls in this population. Early identification of adults with CP at high risk of falls, including those who have experienced a previous fall, and provision of interventions to prevent falls, should be explored to reduce the burden of falls in this population.

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SUPPORTING INFORMATION

The following additional material may be found online:

Appendix S1: Read Codes relating to a fall.

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Variable	Adults with CP (*n*=1705)	Adults without CP (*n*=5115)	Total (*n*=6820)
Sex			
Males	907 (53.2)	2721 (53.2)	3628 (53.2)
Age, y			
Median (IQR)	29 (20–42)	29 (20–42)	29 (20–42)
<30	877 (51.4)	2631 (51.4)	3508 (51.4)
30-39	336 (19.7)	1008 (19.7)	1344 (19.7)
40-49	223 (13.1)	669 (13.1)	892 (13.1)
50-59	135 (7.9)	405 (7.9)	540 (7.9)
≥60	134 (7.9)	402 (7.9)	536 (7.9)
Practice region[a]			
North England and Scotland	473 (27.7)	1419 (27.7)	1892 (27.7)
Midlands and Wales	603 (35.4)	1809 (35.4)	2412 (35.4)
South England	587 (34.4)	1761 (34.4)	2348 (34.4)
Northern Ireland	42 (2.5)	126 (2.5)	168 (2.5)

Table 1: Patient characteristics at start of follow-up

Data are *n* (%) unless stated otherwise. [a]North England and Scotland: North East England, North West England, Yorkshire, Scotland; Midlands and Wales: East Midlands, West Midlands, East of England, Wales; South England: South West England, South Central England, London, South East England. CP, cerebral palsy; IQR, interquartile range.

Table 2: Number of adults with at least one fall, follow-up time to censoring or first fall, and incidence rate of adults experiencing a fall, according to cerebral palsy (CP) status and age-at-risk

	Adults with CP (*n*=1705)			Adults without CP (*n*=5115)			Rate ratio (95% CI)
Age-at-risk band, y	*n*[a]	Follow-up time (per 1000 person-years)	Incidence rate per 1000 person-years (95% CI)	*n*[a]	Follow-up time (per 1000 person-years)	Incidence rate per 1000 person-years (95% CI)	
18–29	22	1.04	21.1 (13.9–32.1)	13	3.52	3.7 (2.1–6.4)	5.71 (2.88–11.34)
30–39	97	4.88	19.9 (16.3–24.3)	102	18.73	5.4 (4.5–6.6)	3.65 (2.7–4.82)
40–49	139	6.86	20.3 (17.2–23.9)	169	31.68	5.3 (4.6–6.2)	3.80 (3.03–4.75)
≥50	2	0.20	9.9 (2.5–39.5)	7	1.12	6.2 (3.0–13.1)	1.58 (0.33–7.61)
Total	260	12.98	20.0 (17.7–22.6)	291	55.05	5.3 (4.7–5.9)	3.79 (3.21–4.48)

[a]Number of adults with at least one fall.

Table 3: Number of falls, incidence rate, and incidence rate ratio of falls

	n[a]	Follow-up time (per 1000 person-years)	Incidence rate (per 1000 person-years)	Unadjusted incidence rate ratio (95% CI)	Adjusted incidence rate ratio[b] (95% CI)
Adults with CP (*n*=1705)	446	14.62	30.5	4.68 (3.86–5.66)	5.83 (4.84–7.02)
Adults without CP (*n*=5115)	381	56.82	6.7	-	-

[a]Number of falls; [b]adjusted for age, sex, and general practice. CI, confidence interval; CP, cerebral palsy.