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Karen McConnell ,[1] Emma Livingstone,[2] Oliver Perra,[1] C Kerr[1]

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[1]School of Nursing and Midwifery, Queen's University Belfast, Belfast, UK
[2]Adult Cerebral Palsy Hub, London, UK

Correspondence to
Dr C Kerr; c.kerr@qub.ac.uk

ABSTRACT

Objectives This study aimed to report the prevalence and clinical characteristics of adults with cerebral palsy (CP) in a geographically defined region of the UK.

Design and setting Cross-sectional study using the Northern Ireland Cerebral Palsy Register (NICPR).

Participants All validated cases known to the NICPR, born 1981–2001 and alive and resident in Northern Ireland at age 19 years were included.

Results The study included 1218 persons with CP aged 19–39 years, 46 of whom died in adulthood. The prevalence of CP was 2.38 per 1000. The majority of cases had spastic CP (n=1132/1218, 93%) and could walk (n=949/1218, 78%). Those that died in adulthood typically had bilateral spastic CP (n=39/46) and used a wheelchair (n=40/46).

Conclusion The prevalence of CP in adults is similar to other common neurological conditions such as multiple sclerosis and Parkinson's disease. The needs of adults with CP vary widely with almost half having two or more associated impairments that may require multiprofessional and multiagency coordination. Results from this study can be used to inform transformation of health and care services for adults with CP.

Strengths and limitations of this study

- This study used a population-based cerebral palsy register that uses multiple sources of ascertainment.
- Northern Ireland Cerebral Palsy Register data are collected during childhood and thus results are an estimate of the condition in adulthood.
- Data were only available for those aged under 40 years.

INTRODUCTION

Cerebral palsy (CP) is a complex condition that requires access to a range of health and social care services across the lifespan. While CP is not progressive,[1] clinical features of the condition can change over time. Recent research has demonstrated that adults with CP experience secondary comorbidities and quicker declining mobility when compared with the general population.[2 3] In addition, many adults with CP experience pain,[2–5] depression and anxiety,[6] and are more likely to develop other chronic conditions, such as asthma, stroke, heart disease and arthritis.[7 8] Coupled with this, an increasing number of severely impaired young people with CP are now surviving and transitioning to adult services.[9] This highlights the importance of providing comprehensive health and social care services that address the many and varying needs of adults with CP.

Research in CP has primarily focused on management of children with the condition, but there is now an increased focus on adults with CP. In 2019, the National Institute for Health and Care Excellence (NICE) published clinical guidelines for adults with CP.[10] More recently NICE published quality standards, setting out five key areas for quality improvement in health services for adults with CP.[11] Implementation of such guidelines and quality standards is expected to increase quality of life and functional independence, decrease pain, improve participation and reduce unplanned hospital admissions.[11] However, current services in the UK fall short of these standards, with NICE recently reporting that service provision for adults with CP is insufficient and lacks continuity of care.[10] In order to develop and transform services for adults with CP, it is important to quantify the number and needs of the population that will use such services.

The Northern Ireland Cerebral Palsy Register (NICPR) is a cross-sectional, population-based register of people with CP in Northern Ireland born since 1977. Data are collected in childhood. The NICPR aims to monitor trends in the prevalence of the condition, provide a framework for research and provide reliable information for service planners and providers regarding the needs of people living with CP in Northern Ireland.[12] Jonsson *et al* recently demonstrated that more severe CP types such as spastic tetraplegia and dyskinesia are less common in adults

than children.[13] While the profile of the CP population in adulthood may be different to that of childhood, data from the NICPR provides population-based estimates of numbers and abilities of persons with CP and thus are useful for planning care and services.

The purpose of this study was to provide information on the prevalence and functional abilities of adults with CP born from 1981 to 2001, who were alive and resident in Northern Ireland at the time of transitioning to adult services, that is, at 19 years of age. Specifically, this study aimed to report the prevalence and clinical characteristics of adults aged 19–39 years with CP in one region of the UK to help inform health and social care services planning and delivery more generally.

METHOD

Study design and eligibility

This population-based cross-sectional study included all validated cases of CP (congenital and acquired) known to the NICPR born between 1981 and 2001 and alive and resident in Northern Ireland at age 19 years. The sample thus constitutes all adults known to the NICPR from the register's first fully ascertained birth year (1981 birth cohort, aged 39 years old) through to those who have just moved from paediatric services (2001 birth cohort, aged 19 years). Those who died, or moved out of the region before the age of 19 years, were excluded from the sample.

Method of the NICPR

At inception, the NICPR used Mutch *et al*'s definition of CP.[14] The definition by Rosenbaum *et al* has been employed since 2007.[1] The NICPR adheres to Surveillance of Cerebral Palsy in Europe (SCPE) guidelines and processes regarding eligibility and classification of cases.[15] Reliability of the NICPR is demonstrated by multiple ascertainment and notification of cases by healthcare professionals including paediatricians, physiotherapists, occupational therapists and families. In addition, routine searches of special education schools and hospital inpatient admission lists help to maximise case ascertainment. Each notified case is followed up with a standardised assessment booklet, completed by a clinician well known to the child, detailing the birth history, clinical characteristics of the child's condition and any additional medical conditions.[16] After the child's fourth birthday, all assessment booklets are reviewed by the Register's paediatrician to confirm or refute diagnosis of CP. Children who die before the age of 2 years, or who emigrate before the age of 3 years, are excluded from the NICPR. Annual information on deaths and emigration is received from the Northern Ireland Health and Social Care Business Services Organisation.

Study variables

CP subtype was classified according to the SCPE definitions as spastic bilateral, spastic unilateral, dyskinetic, ataxic and unclassifiable.[15] Gross motor function was classified using the Gross Motor Function Classification System (GMFCS).[17] For cases predating publication of the GMFCS an algorithm was applied to registry data, the validity of which was found to be satisfactory.[18] Upper limb function was rated using a 4-level system from I (no problem) to IV (incapable of eating/dressing). Hearing, visual, communication and intellectual impairments were reported as being present, not present or uncertain. Feeding problems were coded from free-text comments as present (eg, being fed via nasogastric tube, percutaneous endoscopic gastrostomy in situ, fed orally with difficulties or gastro-oesophageal reflux) or not present. Seizures, excluding neonatal and febrile seizures, were reported as ever having occurred, never having occurred or uncertain.

Statistical analysis

The prevalence rate of CP for those born from 1981 to 2001 was calculated per 1000 population of the same age using the Northern Ireland Statistics and Research Agency's midyear population estimates. Descriptive statistics were used to summarise clinical characteristics and functional ability of the sample. All statistical analyses were performed using STATA (V.12.0; StataCorp). In order to identify and summarise definite clinical needs, associated impairments were dichotomised as present or not present/uncertain.

Patient and public involvement

Mrs Emma Livingstone (Adult CP Hub) was involved at all stages of the study and is coauthor of the paper.

RESULTS

Of the 1369 cases born 1981–2001 (ie, aged 19–39) and known to the NICPR, 151 were excluded because they had died (n=113) or moved out (n=38) before the age of accessing adult services (19 years old). Of those who died before transitioning to adult services, 93% (n=105/113) were classified as GMFCS levels IV–V and 86% (n=97/113) had experienced seizures in the past. Mean age of death was 10 years (range 2–19 years). Those who moved out of the region prior to transitioning were comparable to the sample included in this study, with more than two-thirds (68%, 26/38) classified as GMFCS levels I–III. A total of 1218 persons with CP aged 19–39 years were thus included, 93% (n=1137/1218) of whom were still alive and resident in Northern Ireland at the time of this study. The remaining 7% (n=81/1218) either died (n=46) or moved out (n=35) after accessing adult services (figure 1). Latest figures from the Northern Ireland Statistics and Research Agency estimated the total population of persons aged 19–39 years old, living in Northern Ireland in 2019, to be 511 261.

Prevalence and clinical characteristics of persons with CP born 1981–2001 (aged 19–39 years)

The period prevalence of CP (1981–2001) was 2.38 per 1000 population born during the same period. This rate

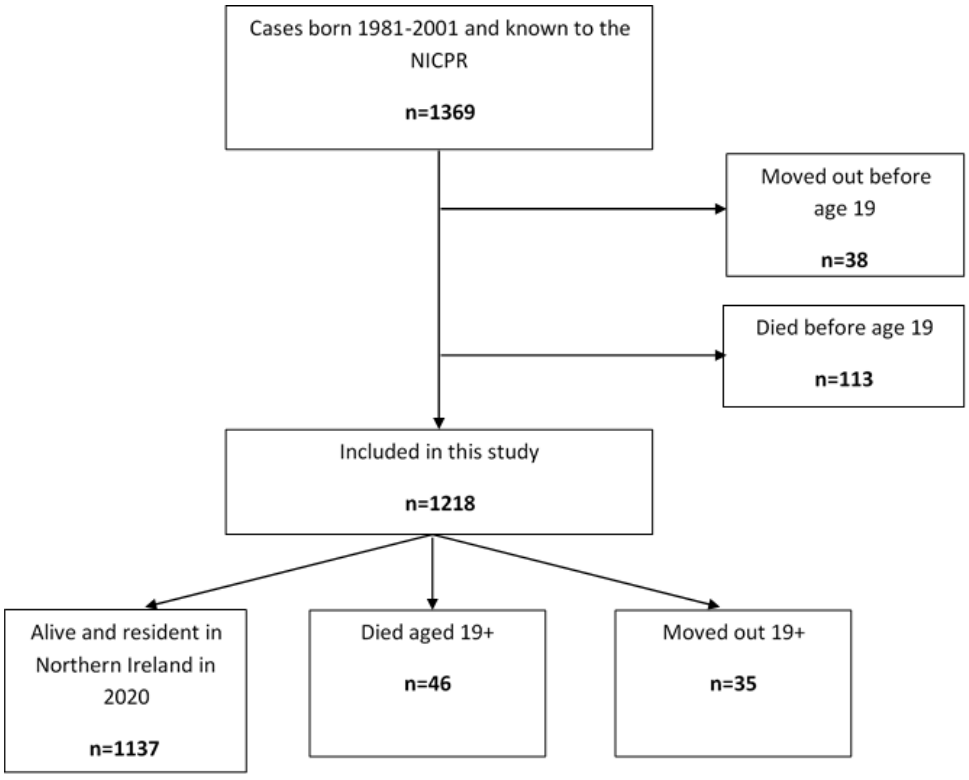

Figure 1 Flow diagram showing inclusion of participants born during 1981–2001. NICPR, Northern Ireland Cerebral Palsy Register.

includes those who transitioned to adult services but have since died or emigrated.

This population-based sample of adults with CP aged 19–39 years, were 56% male (n=683/1218). The majority of cases had spastic CP (n=1132/1218, 93%), with 47% of those being unilaterally affected (n=535/1132) and 53% having bilateral involvement (n=597/1132). More than three-quarters of the sample could walk independently or with the use of a walking aid (GMFCS levels I–III, n=949/1218, 78%). The majority of the sample (n=833/1218, 68%) had at least one reported associated impairment and almost 15% (n=177/1218) had four or more reported associated impairments. Additional information relating to upper limb function and associated impairments can be found in table 1.

Of the 46 cases with CP that died after transitioning to adult services, the majority were male (n=30/46, 65%). All cases died between 19 and 35 years (n=24 aged <25 years, n=22 aged 25–35 years), the majority had bilateral spastic CP (n=39/46, 85%) and were classified as GMFCS levels IV–V (n=40/46, 87%). Underlying cause of death (International Classification of Diseases 10th Revision (ICD-10 version): 2019)[19] was specified as CP in almost half of cases (21/46, 47%). In the remaining cases, cause of death was categorised from the following ICD-10 categories: malignant neoplasms, epilepsy, congenital malformations, other ill-defined and unspecified causes, surgical operation with formation of external stoma, and diseases of the circulatory, respiratory, digestive and genitourinary systems. More granular data cannot be presented as none of these ICD-10 categories were notified for more than five deaths.

DISCUSSION

This population-based study reported the prevalence and clinical characteristics of persons with CP born 1981–2001 in one region of the UK. It thus represents a cohort of younger adults (aged 19–39 years) with CP that require ongoing coordination and management of their condition within adult health and social care services. More than 90% of children with CP notified to the NICPR survived, or remained in the region and thus transitioned from paediatric to adult services. Four per cent of cases in this study died in adulthood. The period prevalence of CP for 19–39 year olds was 2.38 per 1000 population. The majority of cases had spastic CP. Almost a quarter of the population used a wheelchair (GMFCS levels IV–V) and almost one-third required assistance to eat and/or dress or were incapable of eating/dressing themselves. More than one-third of cases reported a history of seizures, or communication, or intellectual impairments. Over 25% had some form of visual impairment with smaller numbers reporting hearing impairment or feeding difficulties. However, 68% of cases experienced at least one associated impairment, with almost 15% experiencing four or more associated impairments. Those with multiple impairments were considered to have complex healthcare needs. This highlights the diverse range of services required for adults with CP.

Table 1 Characteristics of persons with CP born during 1981–2001 (n=1218)

Population characteristics	1981–2001 (n=1218) Frequency (%)
Sex	
Male	683 (56.08)
Female	535 (43.92)
CP subtype	
Spastic bilateral	597 (49.01)
Spastic unilateral	535 (43.92)
Dyskinetic	38 (3.12)
Ataxic	36 (2.96)
Unclassifiable	7 (0.57)
Missing	5 (0.41)
GMFCS level	
I	211 (17.32)
II	614 (50.41)
III	124 (10.18)
IV	87 (7.14)
V	178 (14.61)
Missing	4 (0.33)
UL function	
No problem	389 (31.94)
Some difficulty	443 (36.37)
Needs help eat/dress	208 (17.08)
Incapable eat/dress	157 (12.89)
Missing	21 (1.72)
Seizures	
Ever	426 (34.98)
Never/Uncertain	681 (55.91)
Missing	111 (9.11)
Communication	
Yes	465 (38.18)
No/uncertain	741 (60.84)
Missing	12 (0.99)
Intellectual	
Yes	490 (40.23)
No/uncertain	709 (58.21)
Missing	19 (1.56)
Hearing	
Yes	81 (6.78)
No/Uncertain	1114 (93.22)
Missing	23 (1.89)
Vision	
Yes	334 (27.42)
No/uncertain	879 (72.17)
Missing	5 (0.41)
Feeding	
Yes	196 (16.09)
No	951 (78.08)
Missing	71 (5.83)
Frequency of associated impairments*	
0	385 (31.6)
1	285 (23.40)
2	184 (15.11)
3	187 (15.35)
4 or more	177 (14.53)

Uncertain: clinician was uncertain as to whether the impairment was present or absent, proportion of cases with data coded as uncertain ranged from 1.56% for communication impairment to 7.14% for hearing impairment.
*Frequency of associated impairments included only those impairments reported in the table.
CP, cerebral palsy; GMFCS, Gross Motor Function Classification System; UL, upper limb.

The prevalence of CP in adults aged 19–39 years in this study was 2.38 per 1000 population the same age, which is considerably higher than the rate of 1.14 per 1000 population recently reported in Sweden.[13] However, the Swedish study included older adults aged 39–58 years and those who were alive and resident at the time of the study. In comparison, reliable data were not available for those older than 39 years in the current study and the prevalence rate included those who were alive and resident at 19 years, in order to estimate health and social care needs at the time of transition to adult services. This finding highlights the value of population-based CP registers in quantifying the size of the adult CP population in order to inform relevant health and social care services. While results from this study can be applied to other developed countries with similar healthcare systems, there would be added value in other long-standing CP registers estimating prevalence of CP in adults.

While the current study included all cases of CP that were alive and resident at the time of transition, that is, 19 years, almost 4% of cases died after transition to adult services. Not surprisingly, the majority of those who died after the age of 19 years had bilateral spastic CP and were classified as GMFCS levels IV–V, thus necessitating significant resources and services during their time in adult services. This finding is supported by a recent Australian study that demonstrated an increase over time in the number of severely impaired young people with CP surviving and transitioning to adult services.[9] Data from population-based registers can be used to help plan for future health and social care services for those with more severe CP that may require a broad range of specialised services.

Findings from this study estimated the clinical profile of adults with CP aged 19–39 years. Comparable to previous population-based reports, the majority of cases had spastic CP.[13 20] Almost a quarter of cases were classified as requiring a wheelchair, considerably more than the 12%–15% of adults with CP reported in previous studies.[13 20] This is potentially due to differences in registry methods for classifying gross motor function. In addition, the current study reported seizures in more than one third of cases while previous reports ranged from 14% to 19%.[13 20] Again, this can be explained by differences in defining seizures, whereby we included any history of seizures whereas others included only those cases having treatment or recurring seizures at the time of inclusion on the Register. Alternatively, examination of cases that died before transitioning to adult services revealed that the majority (n=93/113) had experienced seizures in the past 12 months, suggesting epilepsy may be a risk factor for mortality. Our findings highlight the importance of using consistent terminology and definitions to facilitate comparisons between countries and regions.

Recent NICE guidelines[10] identified the need for the development of pathways that allow adults with CP to access a comprehensive local network of care. Results from this study inform service commissioners and providers about the varied healthcare needs of this population as almost half of cases reported at least two associated impairments. CP is a common neurological condition that requires access to services similar to other neurological conditions. The prevalence of CP in adulthood reported here (2.38 per 1000) is not dissimilar to that reported for multiple sclerosis (1.90 per 1000 population)[21] or Parkinson's disease (2.85 per 1000 population),[22] yet health and care services for adults with CP are less well established than those for other neurological conditions, not equitable across regions and fall short of the provision recommended in current guidelines[10] and standards.[11]

The needs of people with CP are diverse and, like the general population, will change with age, and thus childhood data may not accurately reflect characteristics of adults with CP. For example, adults with the condition experience a decline in mobility earlier than their non-disabled peers[23] and have increased risk of noncommunicable disease, such as cardiac and respiratory diseases.[24] The NICE guidelines committee suggests that, dependent on local pathways of care, support for adults with CP may be adequately provided in primary care settings, with regular review.[25] Specialist input is required if the clinical impact of the condition becomes more challenging for the individual with CP or if a procedure is being considered that will impact on the execution of usual daily activities. Ensuring that a local pathway is in place will enable access to services for adults with CP at a local level.[10] This may help reduce loss of function, morbidity and mortality,[13] and thus may be more cost-efficient for service providers in the long term. Similarly, a clear pathway for specialist referral, when required, would be of benefit to both general practitioners, who may be the first point of contact, and adults with CP.

Given that findings from this study are based on clinical assessment in childhood, future population-based research is required to more accurately establish functional ability, as well as educational attainment and employment status in adults with CP. In tandem with this, research is needed to further understand current provision of services for adults with CP and satisfaction with such services. Finally, given that the needs of adults with CP are not well understood,[9] research is warranted to quantify unmet needs in this population. Research in these areas is urgently required and would further support transformation of care in adults with CP.

The main strength of this study was its use of the population-based register. Reliability of the NICPR is demonstrated by multiple ascertainment of cases, including healthcare professionals and secondary searches of routine health and education systems. However, the NICPR is cross-sectional in nature and provides a snapshot of the condition in childhood. Adults with CP experience quicker declining mobility compared with the general population,[2 3] and those able to walk independently as a child may require a wheelchair as an adult. Therefore, these results only provide an estimate of the clinical profile of adults with CP and may overestimate the functional status of adults with CP. In addition, data were not available for adults with CP over the age of 39 years as the earliest reliable birth cohort available on the NICPR is 1981. Several variables included in this study, namely seizures and feeding, had missing information for more than 5% of cases. Further, the reliability of clinician reported data on associated impairments is not known, however, this is method is typically used internationally across registry research programmes.[15] Finally, results of this study are specific to a geographical region of the UK and thus may not be comparable to other regions.

CONCLUSIONS

Findings from this study highlight that population-based registers can be used to quantify the number and needs of adults with CP. The prevalence of CP in adults is comparable to other common neurological conditions. Adults with CP have complex and varied needs that can change over time, and thus require access to a diverse range of health and care services. Results from this study can be used to inform and transform health and care services for adults with CP.

Twitter Karen McConnell @KMcConnellQUB and Oliver Perra @oliver_perra

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Contributors KM developed the paper proposal, carried out data analysis and interpretation of findings and drafted the manuscript. EL assisted with development of the paper proposal and critically reviewed the manuscript. OP co-manages the Northern Ireland Cerebral Palsy Register, assisted with development of the paper proposal and critically reviewed the manuscript. CK co-manages the Northern Ireland Cerebral Palsy Register, assisted with development of the paper proposal, contributed to interpretation of findings and drafting the manuscript. All authors approved the final version of the manuscript.

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Competing interests None declared.

Patient consent for publication Not required.

Ethics approval The NICPR has been approved by the Office for Regional Ethics Committee in Northern Ireland (REC reference 18/NI/0180). The NICPR is governed by an Advisory Committee with representatives from all Health and Social Care Trusts in Northern Ireland, a voluntary sector organisation, an adult with CP and parent representative. The NICPR has a Public Involvement Group, made up of people with CP, their families and carers, which aims to involve the public in all aspects of NICPR activities.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request. The data used and/or analysed during the current study are available from the corresponding author on reasonable request.

ORCID iD

Karen McConnell http://orcid.org/0000-0002-5221-9800

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