

## Health Care Usage among Children and Adults with Cerebral Palsy

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**Received:** December 19, 2019; **Accepted:** February 24, 2020

### Abstract

**Objective** – This paper aims to quantify and compare health care usage among children and adults with and without cerebral palsy (CP). **Materials and Methods** – A population-based study using public registries with follow-up of children and adults. Persons with CP born from 1950 to 2003 were identified in the Danish Cerebral Palsy Registry (4235 persons). Persons without CP were selected randomly from the Danish Civil Registration System and matched by birth year and gender (22,351 persons). Hospitalizations, visits to specialists, general practitioners and emergency health services were analysed. Children were born 1995-2003 and monitored until 2012 (1996-2012). Adults were born 1950-1985 and monitored for ten years (2003-2012). **Results** – Significantly fewer adults with CP visited specialists compared with children with CP. At the same time, the differences in use of general practitioners and between persons with and without CP were smaller in adulthood compared to childhood. Persons with CP and the most severe impairments had an unexpected low frequency of acute admissions compared with children with CP. We did not find a high use of acute contact with the health care system among adults with CP. **Conclusion** – If acute contacts with the health care system could be assumed to be a direct measurement of serious illness, this study does not identify a larger risk of serious illness in adults with CP, but other factors, such as reduced access to the acute health care system may, however, also be a reason for the lower use in adulthood.

**Key Words:** Cerebral Palsy ■ Health Care ■ Child ■ Adult ■ Registry.

### Introduction

The diagnosis of cerebral palsy (CP) results in a life-long condition affecting health and function. Traditionally, the health sector has had a strong focus on children with CP, but most children with CP live into adulthood (1-3). CP is associated with a range of disorders, such as seizures, intellectual disability and communication difficulties. In addition, persons with CP might experience pain, physical

fatigue and functional decline with age, along with an increased risk of a range of diseases directly and indirectly related to CP (4-8). Consequently, CP requires a lifetime of health care support (9).

Nearly all children with CP are monitored by paediatricians, but some young people with CP may experience barriers to accessing health care, and it is likely that adults with CP experience difficulties accessing the same health care treatments and services after they have left paediatric care (10-

12). During childhood the choice of contact with the health care system is taken by the parents and often facilitated by existing paediatric follow-up systems, where children are allocated regular visits. Among adults, attending health care services is, however, a matter of personal choice. Most adults with CP in Denmark live independently in society, except adults with severe CP who often live in group homes (13). Adults with intellectual disabilities thus rely on family or professionals in group homes to guide them to and within the health system. Group homes for adults with disabilities in Denmark are homes where people in need of support can live together. Professionals in these group homes have a pedagogic and/or medical background.

Existing studies reveal concerns about the decreasing use of specialists and the increasing use of emergency departments as young people with CP reach adulthood (14, 15). It has been concluded that adults with CP continue to have complex health care needs, and comprehensive services are essential to support their health (14, 15). In general, there is a call for increased awareness of common medical, physical, psychological and functional needs associated with normal aging among people with an early life disability (6). For example, disparities in health care related to disability severity and in comparison to non-disabled populations are inadequately understood (16).

This paper aims to quantify and compare health care usage among persons in Denmark with and without CP, in childhood and adulthood. Specifically, we studied whether the frequency of visits to outpatient specialists, general practitioners, acute hospitalization and visits to emergency doctors changes after the age of 18 years, comparing persons with CP to persons without CP.

## Methods

### *Study Design and Population*

This is a population-based study using public registries in Denmark. The Danish Cerebral Palsy Registry contains 4863 persons with congenital CP, born

between 1950 and 2003 (17). Of these, 4624 were identified in Statistics Denmark, comprising the study population. Drop-out is mainly attributable to deaths that occurred before the introduction of the Danish Civil Registration System in 1968 and other registries in 1980 (18). For each person with CP, five persons without CP were randomly sampled from the Danish Civil Registration System, matched by birth year and gender. The Danish Cerebral Palsy Registry covers the entire country from birth year 1995; prior to 1995, the registry only included birth cohorts from East Denmark (half of the Danish population). Accordingly, persons without CP born between 1995 and 2003 were sampled from the whole country; persons without CP born between 1950 and 1994 were sampled from only East Denmark. Persons without CP were excluded from the sample if they had a parent or child with CP. Participants who died or emigrated and did not return prior to 1 January 2004 were also excluded from this study. Children are diagnosed with CP at varying ages, but all children in the CP register were included in this study from birth. Consequently, we measured the use of health care for some children who did not yet have a diagnosis. The median diagnostic age in the registry is 11 months (19). In total, 4235 persons with CP and 22,351 persons without CP were alive and registered in 2003, and consequently included in this study.

### *Health Care in Denmark*

All persons have a free access to a general practitioner (GP), who refers patients further to specialists if needed, without any costs to the patient. Physiotherapy is free-of-charge for all persons with CP after referral from a GP or a specialist. Children with CP were traditionally monitored by annual visits to a paediatric outpatient clinic in hospitals before the start of a national CP Follow-up Programme for children born in 2008 and later. No systematic follow-up exists for adults with CP. They are expected to identify and attend health care services when needed.

### **Registers**

The Danish Cerebral Palsy Registry is a population-based registry that includes children with congenital CP. Details on data collection and validity are described elsewhere (17). Information in the Cerebral Palsy Registry is obtained from medical records. Personal data are linked to public social and health registries in Denmark via unique personal identifiers assigned through the Danish Civil Registration System. Data sources include hospitals and primary health care facilities that are obligated by law to deliver this information.

Information on the number of days and type of hospitalization, outpatient visits, orthopaedic operations as consequences of CP and botulinum toxin procedures were obtained from the National Patient Registry (20) and the Danish Psychiatric Central Research Register (21). The frequency of acute somatic hospitalization and the frequency of visits to emergency doctors were included as indicators of serious illness. Information about living independently or in group home was obtained via postal addresses, and included further exploration of the results of acute admissions of persons with severe impairments. An orthopaedic survey measured registered orthopaedic procedures during a specific age period. The number of orthopaedic operations was counted as the number of days with planned orthopaedic procedures.

Information on the number of visits to general practitioners, psychologists and specialized doctors outside the hospital system were obtained from The Danish National Health Service Registry (22). In Denmark, children's visits to psychologists are mainly directed through the school system and municipalities - these consultations are not registered centrally. Consequently, we have no data regarding psychologist visits in childhood. Treatment with botulinum toxin and a baclofen pump has only recently been recorded; therefore, results based on specific calendar years are reported in the text. The frequency of persons with a baclofen pump is measured by the frequency of persons requesting a refill of the baclofen pump. Visits to a neuro-paediatrician, neurologist, orthopaedic surgeon, psychiatrist

or child-psychiatrist (reported in Tables 1-2) include visits to outpatient clinics, as well as sessions with a private specialist. Contact with a psychiatrist or child-psychiatrist also includes hospitalization in a psychiatric department.

### **Definition of Cerebral Palsy and Severity of Impairment**

The definition of CP is based on the version agreed upon by the European collaboration of CP registries, Surveillance of Cerebral Palsy in Europe, SCPE (8). Children with CP are classified into four groups of severity based on walking ability and intellectual impairment at the age of 6. Gross Motor Function Classification System (GMFCS) levels are only included in the Cerebral Palsy Registry for children born in 1997 or later. To be consistent across all birth years, we used the old classification based on the ability to walk with or without aids. The level of intellectual impairment was available in the registry in three categories: IQ<50, IQ=50-85 and IQ>85. Few medical files included the results of psychological evaluation. If the level of cognitive development was not recorded, it was estimated by a neuro-paediatrician from the clinical assessment available in the files.

The four classification groups in this paper are "slight impairment", which comprised children with an estimated IQ>85 and the ability to walk without an aid; "mainly motor impairment", which comprised children with an estimated IQ>85 who walked with an aid or did not walk; "mainly intellectual impairment", which comprised children with an estimated IQ<85 and the ability to walk without an aid; and "motor and intellectual impairment", which comprised children with an estimated IQ<85 who walked with an aid or did not walk. The level of CP severity was unknown for 9% of children and adults. These were primarily older adults with less information available from their medical files. Persons with unknown severity of CP were excluded from analyses on hospitalization and outpatient visits, which are analysed according to the severity of CP. Motor and intellectual impairment within the group with a combination of both

impairments was more often severe, compared with the groups having mainly motor or mainly intellectual impairment. Consequently, most persons with mainly motor impairment were able to walk with aids, while most persons with both motor and intellectual impairment had no walking ability. Likewise, most children with mainly intellectual impairment had an estimated IQ of 50-85, while most children and adults with motor and intellectual impairment had an estimated IQ below 50.

### **Ethics Statement**

According to the law in Denmark, scientific studies of significant public health importance may be carried out using register data without obtaining informed consent from individual subjects. The data were handled online through Statistics Denmark with no access to personal identification numbers. The study was approved by the Danish Data Protection Agency, registration number 2013-54-0441/10.757.

### **Statistical Analyses**

The percentage followed-up by various specialists and treated with various treatments is reported in age-groups, as well as in groups according to the severity of impairment. The percentage of persons visiting or treated during specific age periods in life are based on data from 1999-2012 (Table 2). We included persons with CP with relevant birth years in the different age-groups to ensure longitudinal data on all persons included in each group (for details see Table 2). Persons who died or emigrated during the specific follow-up periods were excluded from the analyses. Use of health services in childhood was analysed for persons born 1995-2003 monitored from birth to 2012, while use in adulthood was analysed among persons born 1950-1985 monitored over the last ten years (year 2003-2012). Persons who died or emigrated before 2012 were excluded from the analyses. Groups with fewer than 10 persons were not reported.

The probability of at least one yearly visit to a general practitioner and emergency doctor was ana-

lysed using logistic regression according to age, allowing for repeated measurements, and adjusted for gender and calendar year. The probability of yearly hospitalization (e.g. outcome is at least one admission per year) and outpatient hospital visits was analysed using logistic regression according to age and severity of CP, allowing for repeated measurements, and adjusted for gender and calendar year. The number of days of hospitalization annually and the number of general practitioner and emergency visits were analysed with Poisson regression (only among persons with actual hospitalizations, outpatient visits or general practitioner visits), which allowed for repeated measurements. All outcomes in relation to health services were recorded using the personal identification number of each person. If an outcome (for example an outpatient visit or use of oral baclofen) was not registered, we considered the outcome to be negative. Consequently, we do not have missing data on outcomes. Analyses were performed in SAS 9.4 with a significance level of 0.05.

### **Results**

Table 1 gives data on birth years, the number of persons and years analysed for the total population, as well as the nine age groups and four groups of severity of CP included in Fig. 1-3.

#### **Somatic Hospitalizations**

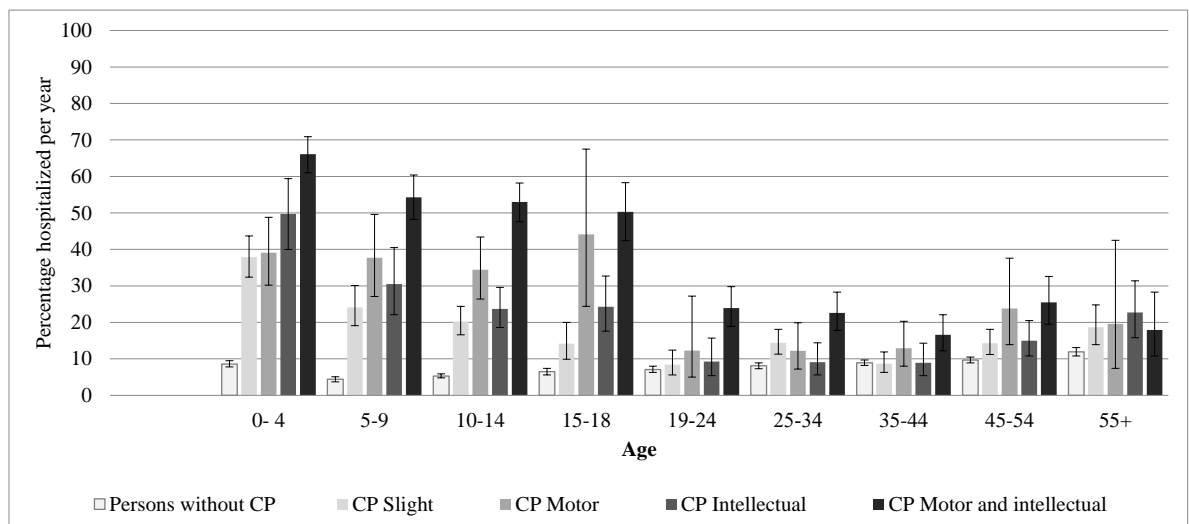
Children with CP were hospitalized in somatic departments considerably more often than children without CP. Adults with CP were hospitalized more often than adults without CP (Fig. 1).

Persons with both motor and intellectual impairment were more often hospitalized during both childhood and adulthood, compared to other groups of persons with CP. Adults with CP had a much lower frequency of hospitalization than children with CP (Fig. 1). Studying only acute admissions and thereby excluding orthopaedic corrections, we still found that persons with CP were more often hospitalized, compared to persons without CP (Fig. 2).

**Table 1. Birth Year, Year Analysed and the Number of Persons in the Total Population and in Each Group of the Population Analysed in Fig. 1-3**

Birth year	Age	Year analysed	No CP	All CP	CP Slight*	CP Motor†	CP Intellectual‡	CP Motor and Intellectual§	CP Unknown severity
			N	N	N (%)	N (%)	N (%)	N (%)	N
Total population (1950-2003)*			22351	4235	1608 (38)	326 (8)	788 (19)	1135 (27)	378 (9)
1999-2003**	0-4	2004-2005	3345	660	209 (33)	74 (12)	80 (13)	261 (42)	36
1997-2002**	5-9	2007-2008	4298	823	282 (35)	90 (11)	117 (15)	312(39)	22
1995-2000**	10-14	2010-2011	4550	854	326 (39)	72 (9)	172 (20)	272 (32)	12
1991-1995**	15-18	2010-2011	2125	396	147 (37)	15 (4)	106 (26)	134 (33)	6
1985-1991**	19-24	2010-2011	2574	451	180 (38)	29 (6)	96 (20)	168 (36)	3
1975-1985**	25-34	2010-2011	3598	623	272 (44)	7 (11)	113 (18)	162 (26)	6
1965-1975**	35-44	2010-2011	3771	675	284 (44)	85 (13)	123 (19)	151 (23)	32
1955-1965**	45-54	2010-2011	4281	781	280 (49)	27 (5)	153 (27)	108 (19)	212
1950-1955**	>=55	2010-2011	2174	376	162 (56)	16 (6)	73 (25)	38 (13)	87

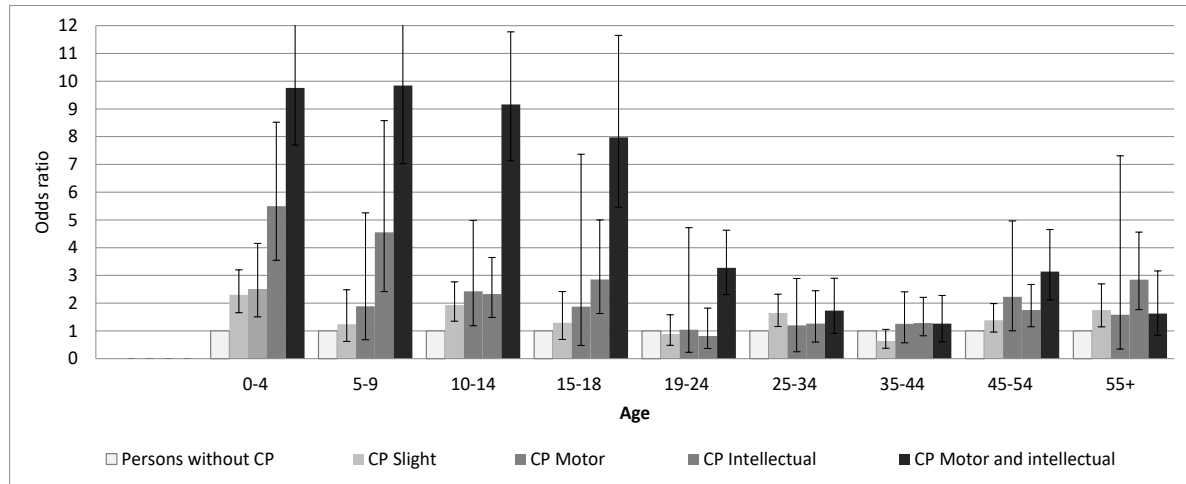
\* “Slight” comprised children with an estimated IQ>85 and the ability to walk without an aid; † “Motor” comprised children with an estimated IQ>85 who walked with an aid or did not walk; ‡ “Intellectual” comprised children with an estimated IQ<85 and the ability to walk without an aid; § “Motor and intellectual” comprised children with an estimated IQ<85 who walked with an aid or did not walk; || “Unknown severity” comprised children with an unknown level of severity of cerebral palsy; \*The percentages in different groups of severity of cerebral palsy are calculated for all persons with cerebral palsy; \*\*The percentages in different groups of severity of cerebral palsy are calculated for persons with known severity of cerebral palsy according to age group.



CP=Cerebral Palsy, CP Slight=Comprised children with an estimated IQ>85 and the ability to walk without an aid; CP Motor=Comprised children with an estimated IQ>85 who walked with an aid or did not walk; CP Intellectual=Comprised children with an estimated IQ<85 and the ability to walk without an aid; CP Motor and intellectual=Comprised children with an estimated IQ<85 who walked with an aid or did not walk.

**Fig. 1. Somatic Hospitalization in Children and Adults with and without Cerebral Palsy, Percentage Hospitalized per Year (95% CI).**

The differences in acute hospitalization between persons with motor and intellectual impairment and persons without CP were smaller in adulthood compared to childhood. In total 65% of adults



CP=Cerebral Palsy, CP Slight=Comprised children with an estimated IQ>85 and the ability to walk without an aid; CP Motor=Comprised children with an estimated IQ>85 who walked with an aid or did not walk; CP Intellectual=Comprised children with an estimated IQ<85 and the ability to walk without an aid; CP Motor and intellectual=Comprised children with an estimated IQ<85 who walked with an aid or did not walk.

**Fig. 2.** *Acute Somatic Hospitalization in Children and Adults with and without Cerebral Palsy, Odds of Acute Hospitalization of Persons with Cerebral Palsy Compared with Persons without Cerebral Palsy (95% CI).*

with motor and intellectual impairment lived in group homes. Excluding persons living in group homes did not change the results (data not shown).

Children - but not adults - with intellectual and motor impairment had longer hospital stays due to acute hospitalizations compared with children without CP. For example, the mean number of days in hospital for children under 5 years with intellectual and motor impairment (among those hospitalized) was 12.9 (8.5-17.4) versus 3.5 (3.0-4.0) in children without CP, and in children from 5 to 18 years with intellectual and motor impairment 6.7 (5.3-8.1) versus 3.5 (3.0-3.9) in children without CP. Among adults with intellectual and motor impairment, the mean number of days hospitalized was 6.7 (5.3-8.), versus 6.0 (5.5-6.6) in adults without CP.

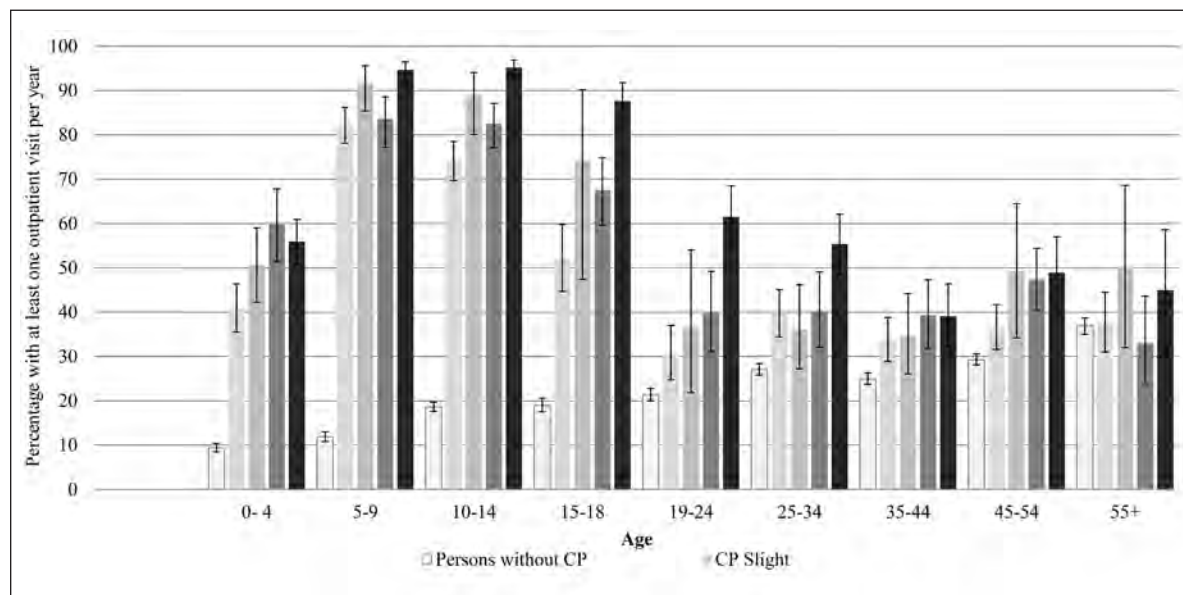
### ***Somatic Outpatient Visits and Specialist Visits***

As expected, persons with CP visited somatic outpatient clinics at the hospital more often throughout life than persons without CP (Fig. 3). Substantially more children with CP had visits compared with adults with CP.

Table 2 shows follow-up and treatment by specialists of children and adults with CP, according to six age intervals. Table 3 shows specialist visits for children and adults according to the level of severity, compared with children and adults without CP in 2012. Approximately 10% of children with CP visited a neurologist, most likely to receive EEGs or other examinations while they were still being monitored by a neuro-paediatric department (Table 2). Less than one-third of adults with CP were seen by neurologists (Table 3), most often at an outpatient clinic in a neurological hospital department. However, especially among adults without intellectual impairment, a large proportion of those seen were monitored by a neurologist not associated with a hospital (data not shown).

### ***Psychiatrist and Psychologist Visits***

More adults with CP visited a psychiatrist compared to children with CP, and in both groups more persons with CP did so than those without (Tables 2 and 3). Children and adults with mainly intellectual impairment were seen by far the most often. More young adults without intellectual impairment were



CP=Cerebral Palsy, CP Slight=Comprised children with an estimated IQ>85 and the ability to walk without an aid; CP Motor=Comprised children with an estimated IQ>85 who walked with an aid or did not walk; CP Intellectual=Comprised children with an estimated IQ<85 and the ability to walk without an aid; CP Motor and intellectual=Comprised children with an estimated IQ<85 who walked with an aid or did not walk.

**Fig. 3.** Somatic Outpatient Visits in Children and Adults with and without Cerebral Palsy, Percentage with at Least One Outpatient Visit per Year (95% CI).

Follow-up and treatment	Persons with cerebral palsy according to age (Year)					
	0 to 9	10 to 17	18 to 29	30 to 39	40 to 49	50 to 59
	N=631	N=396	N=311	N=277*	N=322*	N=229*
<b>Specialist visits</b>						
Paediatrician (%)	97	82	33	-	-	-
Neurologist (%)	9	11	30	18	30	21
Epilepsy hospital (%)	6	7	5	-	-	-
Orthopaedic (%)	64	66	55	35	35	37
Psychiatrist (%)	7	10	21	19	20	18
Psychologist (%)	-	-	12	7	8	-
<b>Treatment</b>						
Orthopaedic surgery (%)	40	61	33	9	8	10
Orthopaedic surgery <sup>†</sup> (N)	4.0	7.5	11.8	8.7	7.2	6.9
Oral baclofen (%)	27	20	14	8	11	9
Muscle relaxants <sup>‡</sup> (%)	46	38	35	29	31	31

\* Percentages greater than 10 are reported; <sup>†</sup>Mean number of days with orthopaedic surgery among those undergoing surgery; <sup>‡</sup>Including baclofen and selected anxiolytics and antipsychotics.

Table 3. Treatment and Follow-up according to the Severity of Cerebral Palsy

Treatment and follow-up	No CP	All CP	CP Slight*	CP† Motor	CP‡ Intellectual	CP§ Motor and intellectual	CP   Unknown severity
Childhood (born 1995-2003) §	N=6331**	N=1195	N=439**	N=112**	N=206**	N=396**	N=42**
Specialist Visits							
Paediatrician (%)	39	98	96	99	98	100	95
Neurologist (%)	2	13	8	11	16	18	-
Epilepsy hospital (%)	<1	6	-	-	8	12	-
Orthopaedic (%)	21	77	71	80	74	85	62
Psychiatrist (%)	8	11	11	-	18	9	-
Treatment							
Orthopaedic surgery (%)	1	51	41	63	47	64	38
Oral baclofen (%)	<1	27	9	27	10	56	29
Muscle relaxants†† (%)	4	48	25	41	38	80	48
Adulthood (born 1950-1985) ††	N=12053	N=2221	N=908	N=178	N=419	N=419	N=297
Specialist Visits							
Paediatric (%)	<1	4	4	5	4	8	-
Neurologist (%)	11	25	21	20	28	31	29
Epilepsy hospital (%)	<1	3%	2	-	4	7	-
Orthopaedic (%)	26	36	37	34	35	39	35
Psychiatrist (%)	11	18	17	14	27	15	18
Psychologist (%)	9.	9	11	17	6	5	5
Treatment							
Orthopaedic surgery (%)	2	15	15	21	12	23	8
Oral baclofen (%)	<1	12	6	16	5	30	10
Muscle relaxants†† (%)	10	32	20	31	31	59	36

CP=Cerebral Palsy; \* "Slight" comprised children with an estimated IQ>85 and the ability to walk without aid; † "Motor" comprised children with an estimated IQ>85 who walked with an aid or did not walk; ‡ "Intellectual" comprised children with an estimated IQ<85 and the ability to walk without an aid; § "Motor and intellectual" comprised children with an estimated IQ<85 who walked with an aid or did not walk; || "Unknown severity" comprised children with an unknown level of severity of cerebral palsy; § Children were monitored from birth to 2012; \*\* Only percentages based on at least 10 observations are reported; †† Including baclofen and selected anxiolytics and antipsychotics; †† Adults were monitored for the past ten years of life (2003-2012).

seen by a psychologist, compared to young adults with intellectual impairment (Tables 2 and 3).

### Treatment

The majority of children with CP, and approximately one-third of adults with CP were seen by orthopaedic surgeons (Table 3). Depending on the severity of motor impairment, in total 41-64% of children with CP underwent at least one orthopaedic operation during childhood. Children aged 10 to 17 years undergoing surgery had a mean num-

ber of eight operations in this time period, while children aged 0 to 9 had a mean number of 4 operations. Since children below the age of 5 seldom have orthopaedic surgery (results not shown), on average, children who underwent surgery did so once every year (Table 2) from the age of 5. The number of operations varied greatly between children (data not shown). Approximately one-third of young adults (aged 18-29 years) with CP had had orthopaedic surgery. In each birth cohort in 10-year age ranges - in their 30s, 40s and 50s - 10% of adults with CP had had orthopaedic surgery (Table



2). Surgery after fractures was the most frequent type of operation in adults with CP (not shown).

From 2007 to 2011, 50.3% of children with only slight impairment (N=165, born 2000-2003) received botulinum toxin. The percentages were 54.6% among children with mainly motor impairment (N=55), 30.2% among children with mainly intellectual impairment (N=53), 55.1% among children with motor and intellectual impairment (N=187) and 60.6% (N=33) among children with an unknown severity of CP (P=0.0177). In total, 46% of children aged 0 to 9 years and 38% of children aged 10-17 years received oral muscle relaxant, during the first ten years of life (Table 2). Less than one third of adults with CP did so. While Baclofen accounted for nearly half of the total use of muscle relaxants in children, the proportion was only around one third in adults.

Few persons with CP had a baclofen pump (data not shown). In 2011, the prevalence of use of a baclofen pump was 12.1% in 8-17-year-old

children with a combined motor and intellectual impairment, and 2.7% of adults in the same group.

### General Practitioner and Emergency Health Services

Table 4 shows the use of general practitioners in childhood and adulthood. A larger number of persons with CP, compared with persons without CP, consulted their general practitioner yearly, and they did so more often. The differences between persons with and without CP were smaller in adulthood compared to childhood, both regarding the proportion of persons who consulted a GP, and the number of visits per person.

The use of emergency health services was almost the same in children under 5 years with and without CP (Table 3). A significantly higher proportion of older children (5-18 years) and adults with CP used emergency doctors yearly compared to persons without CP. Studying only persons with emer-

**Table 4. Visits to General Practitioners and Emergency Doctors for Persons with and without Cerebral Palsy, in Childhood and Adulthood**

Visits to general practitioners and emergency doctors	Persons with cerebral palsy according to age (Year)					
	0-4 <sup>†</sup>		5-18 <sup>‡</sup>		19 <sup>§</sup>	
Number	No CP	CP	No CP	CP	No CP	CP
	3345	624	8269	1574	14897	2443
<b>General practitioner</b>						
Percentage with at least a yearly visit	96	98	72	86	76	82
Odds Ratio for at least a yearly visit	1	1.56 (1.05-2.31)	1	1.85 (1.63-2.11)	1	1.39 (1.24-1.57)
Mean number of visits a year (among those with visits)	9.3 (9.3-9.4)	13.8 (13.6-14.0)	5.5 (5.6-5.7)	10.7 (10.6-10.8)	9.8 (9.7-10.0)	13.5 (12.8-14.1)
Ratio of at least a yearly visit	1	1.48 (1.45-1.50)	1	1.89 (1.87-1.92)	1	1.37 (1.30-1.44)
<b>Emergency doctor</b>						
Percentage with at least a yearly visit	23	25	13	17	17	25
Odds Ratio for at least a yearly visit	1	1.14 (0.95-1.36)	1	1.44 (1.27-1.63)	1	1.57 (1.45-1.70)
Mean number of visits a year (among those with visits)	3.6 (3.5-3.7)	4.1 (3.8-4.3)	3.1 (3.0-3.2)	7.4 (7.2-7.7)	10.9 (9.1-13.0)	12.0 (9.2-15.8)
Ratio of at least a yearly visit	1	1.12 (1.05-1.20)	1	2.42 (2.33-2.53)	1	1.10 (0.79-1.53)

CP=Cerebral Palsy; <sup>†</sup>Born 1999-2003, observation period 2004-2005; <sup>‡</sup>Born 1991-2002, observation period 2007-2008; <sup>§</sup>Born 1950-1991, observation period 2010-2011; CP= Cerebral Palsy.

gency health services visits, we found that children (5-18 years), but not adults with CP, had a higher number of visits than persons without CP.

## Discussion

More children with CP visited specialists in outpatient clinics and were admitted to hospitals, compared to adults with CP. Additionally, somewhat more children with CP visited a general practitioner compared to adults with CP. We did not find a statistically significant difference between the use of emergency health services by children and adults with CP. If acute admissions and use of emergency health services can be used to monitor health, this study did not identify a larger risk of serious illness in adults with CP, compared with children with CP. However, our results, showing markedly fewer adults with severe CP admitted acute compared to children with severe CP, warrant further investigation. We discuss the possible explanations and consequences of the results in detail below.

### *Differences in Somatic Outpatient Visits between Childhood and Adulthood*

Our finding that adults with CP visited specialists in somatic hospital departments less often than adolescents with CP is in accordance with the findings of a Canadian study (14). The Canadian study proposed that this might result in more emergency department visits, but our study did not confirm this. Traditionally, the general practitioner is the gatekeeper in the Danish health care system; this could explain the differences between Canada and Denmark. However, the ratio of visits to general practitioners between persons with and without CP was smaller in adulthood compared to adolescence. This might be at least partly due to the relatively high mortality in persons with CP, and the consequently fewer impaired adults compared with children with CP, as seen in Table 1.

In addition, the choice to visit a general practitioner is driven by various factors, including symptoms, the expectation of adequate help and

accessibility. The gatekeeper function means that a person gains access to specialists, hospitalization and physiotherapy only through contact with their general practitioner. This study does not include information about the reasons for the relatively low frequency of contacts with general practitioners in adults with CP, and thereby further contact to the health system. Studies are needed to explore the relatively low use of health care especially in adults with severe CP, to ensure optimal monitoring and treatment of the known multiple health problems in this group.

While nearly all children with CP in our study were monitored by neuro-paediatricians, only a minority of adults were monitored by neurologists. This is in line with other studies indicating no systematic follow up of adults with CP (12). Some of the known issues surrounding the transition from paediatric- to adult-based health care are the local availability of appropriate services, management by multiple professionals, and coordination and management of comorbidities (10, 23). Parents and adolescents with CP find it challenging to move from multidisciplinary paediatric services to specialty visits only addressing single complaints (23). Also, specific therapy, for example orthopaedic, might be unavailable or unexperienced (23). This knowledge, combined with the relatively low frequency of visits to general practitioners in our study, might indicate that adults with CP in Denmark would benefit from a multidisciplinary adult service. In addition, a longitudinal study of the transition of adolescents with CP in the UK found that an appropriate level of parent involvement, promotion of health self-efficacy, and meeting the adult team before transfer were the three most important factors associated with improved outcomes (24).

### *Psychiatric and Psychological Services for Children*

Children with CP were more often seen by psychiatrists than children without CP. This is in accordance with the literature indicating that behavioural problems and psychiatric disorders are com-

mon and perhaps underestimated in children with CP (25-29). Unfortunately, we do not have data on psychological services in childhood, and only 9.6% of children with CP aged 10-17 years were seen by psychiatrists. This number seems low when considering the high likelihood of an increased frequency of psychiatric disorders such as Attention Deficit Hyperactivity Disorder (ADHD) (27, 30) and a three-fold increased risk of positive screening for severe emotional and behavioural problems in Danish 8- to 15 year old children with CP (28). Therefore, our findings indicate a need for better recognition of and focus on emotional and behavioural difficulties in children with CP.

More adults than children with CP had seen a psychiatrist in our study. Some of this difference is explained by psychiatric illness commencing later in life, but the lack of child psychiatric services in Denmark could be another explanation.

#### ***Differences in Somatic Hospitalizations between Childhood and Adulthood***

As expected, persons with CP were more often hospitalized compared with persons without CP. The differences were generally largest among children. Our result of a lower use of hospitals in adults with CP compared to children with CP is in line with existing, mainly cross-sectional studies (31). Our result of fewer hospitalizations among adults with CP compared with children with CP is in accordance with a Canadian study (14). At least some of the large difference in the frequency of hospitalizations between childhood and adulthood seems to be due to fewer surgical procedures in adulthood. Our findings of a simultaneously lower frequency of orthopaedic consultations in adults with CP support this explanation, which was also suggested by the Canadian authors.

#### ***Differences in Treatment Between Childhood and Adulthood***

Considerably fewer adults with CP than children with CP were seen by orthopaedic surgeons. The

children's extremities and backs are deformed by growth, hence most orthopaedic contacts are made during childhood. This is in line with other studies indicating the low use of orthopaedists in young adults with CP (12).

Children with CP who underwent orthopaedic surgery had operations almost every year. In order to reduce the number of yearly operations, multi-level surgery has been introduced. Our results do, however, show steady surgical activity which might reflect a change from mainly soft tissue surgery to a combined soft tissue and joint stabilizing surgery (osteotomies and arthrodesis), which often requires an additional operation to remove stabilizing material. Dislocation of hips has been eradicated and feet are stabilized. The reason for the fewer adults than children with CP being treated with baclofen could be the reduction in spasticity during their lifetime, or less access to medicine after discontinuing yearly follow-ups in childhood.

#### ***Persons with Severe Cerebral Palsy***

Among persons with CP and combined motor and intellectual impairment, the frequency of acute admissions and outpatient visits was much lower in all age groups above 18 years compared with children and adolescents with CP. Paediatric services end at 18 years in Denmark. Structurally, the higher number of acute admissions in childhood could be partly explained by the fact that children with CP more often have direct access to the paediatric department, in contrast to adults with CP, who need to consult a primary health care provider before hospital admission. Another explanation could be that persons surviving into adulthood are healthier and need fewer hospitalizations. On the other hand, it does not seem likely that mortality drops suddenly from the age of 18 years, which would explain the large difference in acute hospitalizations between children with CP aged 15-18 years and children with CP aged 19-24 years. The environment and culture at the hospital or other health care services might also play a role in whether a person with CP visits the service or is admitted (32). An Australian study indicated that adults with CP often do

not feel that they are asked about their needs or that their needs are met when hospitalized (33). In Denmark, no such data are available, but a possible explanation of the very low frequency of acute hospitalization in adults with combined motor and intellectual impairment are the physical and emotional difficulties involved in being moved from the home environment in this vulnerable group.

The low proportion of adults who had used advanced treatment methods, such as a baclofen pump, compared to children with the same severity of CP, may also indicate that their needs were not evaluated to the same extent after the treatment became available in Denmark. Another explanation for the differences in the frequency of baclofen pump use between children and adults may be a diminishing proportion of survivors with the most severe forms of CP.

Nearly two thirds of adults with combined motor and intellectual impairment live in group homes in Denmark, but excluding these did not change the result of decreasing acute admissions in adulthood. Consequently, differences in how professional caretakers of adults in group homes and the parents of children with CP notice symptoms and/or initiate admission cannot explain the results.

A longitudinal study from Israel suggests the under-treatment of adults with CP, and special concern was expressed about the lack of preventive services (31). Targeted health check-ups for people with intellectual disabilities, but not general health checks, are advised (34, 35). Further studies are needed to explore the access to health care and its effect on the quality of life in this group.

### ***Information and Selection Bias***

Information from registries is considered valid, with no risk of recall bias, although most registries were not built with the aim of research; thus, the information may be insufficient depending on the study aim. The Danish Cerebral Palsy Registry, as well as other included public registries in Denmark, are considered valid and fairly complete. This is mainly due to the long tradition of maintaining

registers, and to the legal obligations of the health, employment and social sectors to deliver data (20, 22, 36, 37)

Nearly all persons from the Cerebral Palsy Registry were included in the sample and persons without CP were randomly sampled, which eliminated the risk of bias. However, the often crude clinical estimation of intellectual impairment unfortunately does not take into account specific cognitive difficulties. Consequently, our estimation of IQ does not give a completely adequate description of intellectual impairment.

In the analyses of hospitalization, and visits to outpatient departments, general practitioners and emergency health services, all children were included. We mainly analysed health care usage in the last ten years to avoid results based on out-dated information. However, we did not have very recent information about health care usage for the youngest children, because the CP registry had not been completed for children born after 2003 at the time of data extraction.

Trends in use of health care over time were eliminated by using relative measurements, such as the odds ratio between persons without CP and persons with CP during the same observation period. The time trend could not be fully eliminated in the comparison of the youngest age groups, where observation periods differed. It did not change the main result regarding diminished use after the age of 18 years, because the observation period was identical for 10-to-18 year olds and adults.

### **Conclusions**

We found a lower frequency of visits to specialists among adults with CP, compared to children with CP. However, we did not find a high frequency of acute contacts with the health care system among adults with CP, compared to children with CP. This could be positive, if acute contacts with the health care system are assumed to be a direct measurement of serious illness, but other factors, such as reduced access to the acute health care system may, however, also be the reason for the lower use in adulthood.

Analyses according to the severity of CP indicate that the difference in acute admission is the largest when children and adults with the most severe form of CP are compared. This is the group with the highest mortality. Therefore, further studies are needed to gain more knowledge about whether medical problems in this vulnerable group with high mortality are handled optimally in social and health care system.

**Acknowledgement:** The study was conducted at the National Institute of Public Health, National Institute of Public Health, University of Southern Denmark, Studiestraede 6, 1455 Copenhagen K, Denmark. This work was supported by a research grant from the Elsass Foundation.

**Authors' contributions:** Conception and design: SM, EF and PU; Acquisition, analysis and interpretation of data: EF, BL, SM, PU, GR, NE, SR, AA, and LJ; Drafting the article: SM; Revising the article critically for intellectual content: EF, BL, PU, GR, NE, SR, AA, LJ, and SM; Approved final version of the manuscript: EF, BL, PU, GR, NE, SR, AA, LJ, and SM.

**Conflict of Interest:** The authors declare that they have no conflict of interest.

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