Lifetime costs of cerebral palsy

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This study quantified the lifetime costs of cerebral palsy (CP) in a register-based setting. It was the first study outside the US to assess the lifetime costs of CP. The lifetime costs attributable to CP were divided into three categories: health care costs, productivity costs, and social costs. The population analysed was retrieved from the Danish Cerebral Palsy Register, which covers the eastern part of the country and has registered about half of the Danish population of individuals with CP since 1950. For this study we analysed 2367 individuals with CP, who were born in 1930 to 2000 and were alive in 2000. The prevalence of CP in eastern Denmark was approximately 1.7 per 1000. Information on productivity and the use of health care was retrieved from registers. The lifetime cost of CP was about €860 000 for men and about €800 000 for women. The largest component was social care costs, particularly during childhood. A sensitivity analysis found that alterations in social care costs had a small effect, whereas lowering the discount rate from 5 to 3 per cent markedly increased total lifetime costs. Discounting decreases the value of costs in the future compared with the present. The high social care costs and productivity costs associated with CP point to a potential gain from labour market interventions that benefit individuals with CP.

In eastern Denmark, 2.4 children per 1000 live births were diagnosed with cerebral palsy (CP) during 1987 to 1990.[1] A more recent prevalence figure was obtained from the data underlying this analysis: among the population aged 0 to 70 years, it was estimated that 1.8 individuals per 1000 were diagnosed with CP (Table I). The challenge of estimating the lifetime costs of CP has not been taken up by many analysts. In the 1990s, the attributable lifetime costs of CP were assessed twice in the US: in 1992 they were estimated to be $375 000,[2] and in 1995 to be somewhat higher at $503 000.[3] The discrepancy between the results was caused by differences in the discount rate and the inclusion of productivity costs. A relatively recent assessment by the Centers for Disease Control (CDC) estimated the lifetime costs of CP to be US $921 000 in 2003.[4] These assessments were based on a survey of individuals with CP. Few social-cost components were included.[5] Outside the US, no lifetime cost computations for CP have been found.

The few European studies in the field have focused on components such as hospital unit costs. Beecham et al. calculated average costs per annum for young adults with hemiplegia in the UK to be £12500, of which 43 per cent (£5600) was attributable to the impairment.[6] A recent Dutch study focused on children with severe CP and found the annual costs to be €40265 per child.[7]

CP is a neurodevelopmental condition, occurring at birth or in early childhood and persisting throughout the individual's life.[8] It is a non-progressive motor impairment affecting the patient's physical and often intellectual performance. CP causes limitation of activity to varying degrees as well as disturbance of sensation, cognition, communication, perception, and behaviour.[8] The clinical type of CP is categorized as spastic, ataxic, or dyskinetic and the

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Table I: Prevalence of cerebral palsy in Eastern Denmark, 1999

Age group	Men	Per 1000 population	Women	Per 1000 population	Both sexes	Per 1000 population
0–4	172	1.7	119	1.2	291	1.5
5–9	194	2.0	146	1.6	340	1.8
10–14	213	2.6	142	1.8	355	2.2
15–19	207	2.6	141	1.8	348	2.2
20–24	149	1.5	104	1.0	253	1.3
25–29	165	1.4	127	1.1	292	1.3
30–34	214	1.6	152	1.2	366	1.4
35–39	210	1.8	149	1.3	359	1.6
40–44	207	1.9	148	1.4	355	1.7
45–49	233	2.2	169	1.6	402	1.9
50–54	214	1.7	157	1.3	371	1.5
55–59	201	2.1	148	1.6	349	1.8
60–64	175	2.4	134	1.8	309	2.1
65–69	142	2.4	117	1.8	259	2.1
Total	2 696	1.9	1 953	1.4	4649	1.7

Note: the population of Eastern Denmark constitutes approximately 49 per cent of the entire Danish population.

distribution categorized as bilateral or unilateral. Learning disability* may be present and ranges from mild to severe. Some individuals with CP suffer mild physical impairment and have an IQ in the normal range; these persons are usually able to lead an average life, including participation in education and the labour market, although their participation in the labour market is significantly lower than that of individuals without CP.[9] Other individuals with CP are dependent on wheelchairs and numerous other aids because of their physical impairment. Some also have major learning disabilities (defined as an IQ of less than 70), a fact likely to result in higher social costs. Lifetime costs appear to be related to the degree of physical impairment and intellectual capacity; probably they are also related to comorbidity (notably seizure disorders).

The aim of this study was to quantify the average cost of CP per individual in a lifetime, societal context. Since CP is a condition which can be alleviated but not cured, a prime aim of a cost-of-illness assessment is to inform planning decisions. The magnitude and breakdown of costs incurred by a person with CP are relevant for planning health and social policy. Additionally, the choice of lifetime costs as the unit analysed broadens the focus towards prevention and provides a measure of the societal benefit of preventing one case of CP. Consequently, this study provides a figure for the societal benefit from preventing one case of CP.

*North American usage: mental retardation.

METHOD

Data

The cases in this study were identified in the Danish Cerebral Palsy Register. The register contains records of individuals with CP born in Denmark since about 1900. All those with CP born since 1965 in the eastern part of Denmark are registered in the electronic database,[10] whereas information on individuals with CP born before 1965 are stored in paper records. The Danish Cerebral Palsy Register comprises the electronic database as well as the paper records. The register is assumed to be representative of Danish individuals with CP from 1950 onwards.[11] The register is updated regularly with new cases of CP.

Before inclusion on the register, a specialist in paediatric neurology verifies cases, assigns diagnoses, and provides a score of physical and intellectual impairment and epilepsy. Only persons with congenital CP are registered, and cases are included in the register at the age of 5 years. Children with CP who die during their first year of life and those with non-congenital CP are not included.

A control group was randomly selected from the Centralised Civil Register. The control group comprises 47 055 individuals born between 1930 and 2000 in eastern Denmark. Individuals with CP were excluded from the group.

For the cost assessment, the following registers were consulted: the National Patient Register, including information on all hospital discharges and outpatient visits as well as DRG (diagnosis-related group) prices for all hospital contacts; the health insurance register, covering information on all patient contacts in the primary health care sector; the pharmaceuticals database, including information on prescription medicine; the Integrated Database for Labour Market Research, comprising information on socioeconomic groups, labour market affiliation, employment status, etc.; and the register on income and the register on labour market measures, such as subsidized employment, unemployment benefits, sickness benefits, etc.

Prevalence

For persons with CP born in 1965 or later, the number of individuals alive is known from the Danish Cerebral Palsy register. The prevalence of CP in older age groups is estimated on the basis of information on excess mortality due to CP, combined with age- and sex-specific mortality for the entire Danish population, and a historic assessment of CP incidence.[12] International studies provide little information about prevalence of CP over the age of 40, as most studies of life expectancy for those with CP focus on ages up to 30 years.[13–15] The estimated excess mortality for individuals with CP is based on the Danish Cerebral Palsy Register for individuals born after 1964, and an additional

sample of 170 individuals born between 1950 and 1964, which allowed estimation of survival until the age of 56 years. Survival after the age of 56 had to be extrapolated. For the Danish population matching those with CP, age- and sex-specific survival data were retrieved from the Centralised Civil Register. The sex-specific excess mortality rates in the CP group compared with the Danish population were computed for all ages less than 57 years. These showed an increase in excess mortality from birth to 25 years for men and 34 years for women, followed by a marked decline. To predict survival from 57 years onwards, we performed log-linear regression on excess mortality rates on ages 25 to 56 for men and 34 to 56 for women. For both sexes, rates were weighted according to sampling strategy. Further, we assumed that mortality of those with CP converged towards the mortality of the general population. Regression parameters were used for extrapolation of mortality of those with CP.

Measuring lifetime costs

Costs are considered from a lifetime perspective. Therefore, costs to the health care and social sectors are assessed, as well as the costs to society constituted by lost productivity.

Costs were considered to be opportunity costs: i.e. the use of resources attains the value of their best alternative use. Transfers, such as pensions and disability grants, are not costs *per se*, as they do not represent a use of resources.

Immeasurable costs, defined as the loss to individuals due to pain and grief, as well as costs due to informal care (leisure time spent on care by family and peers), were not taken into account.

The following cost components were considered: (1) health care costs (primary health care, hospitals, and pharmaceuticals); (2) social care costs (specialized education, housing, etc.); and (3) productivity costs (the cost for society when a person leaves the labour market or never enters it).

We quantified health care costs and productivity costs as well as some social care costs by means of register data, in a cross-sectional perspective. Data for the individuals in the study were linked to information in national registers by means of the unique personal identifier, allowing identification of costs attributable to CP.

We conducted the analysis by sex and 5-year age groups. We truncated data at age 70. For each age group, the average cost was computed for individuals with and without CP and divided into the three cost components mentioned above.

The attributable costs of CP were computed by an incremental approach, where the total costs of individuals without CP were deducted from the total costs of individuals with CP. Thus, attributable costs equal average costs for individuals with CP minus average costs for individuals without CPs. Costs were discounted and summed over age groups for each sex. The resulting figures express lifetime attributable costs. Health care costs and productivity costs were established at the individual level by means of register-based cost information.

The productivity costs of CP equal the productivity benefit lost by individuals with CP leaving the labour market. We used income for the value of productivity benefits. Attributable productivity costs were equal to the average wage income for individuals without CP minus the average wage income for individuals with CP. The following measures were included: the productivity loss arising from individuals with CP leaving the labour market because of their impairment or not entering the labour market at all; and the productivity loss arising from parents leaving the labour market (permanently or temporarily) to take care of their children with CP.

For social care, it was not possible to apply the register-based approach universally, as social costs on the whole are not registered on an individual basis. Estimates of the share of individuals with CP using various elements of social care were in some cases obtained from registers and in some cases from a group of experts. Register-based information was available on the use of housing and schooling. In addition, register-based information regarding the share of individuals with CP outside the labour market was used for estimation of the shares attending day centres and similar services.

Quantification of social usage shares was carried out by means of published information on average costs per user, and validated by the group of experts.

Hence, the appraisal of social expenditure was based on three sets of estimates: estimates of total expenditure (wages and other current costs) for the social services in question multiplied by estimated proportions of individuals with CP using these services and adjusted for the estimated lifetime. The cost estimates express the estimated social costs for a given person with CP, adjusted for age- and sex-specific mortality by means of the estimated prevalence in each age group.

All costs were recorded as average costs per person. We computed attributable costs by age and sex and added these up to a lifetime cost unit. Lifetime costs were discounted using a discount rate of 5 per cent and using year 2000 as baseline, thus representing the theoretical average lifetime costs of a person with CP, born in 2000. Discounting is the process of computing the present value of costs in the future. Discounting indicates that most individuals and societies prefer expenses in the future to expenses today. Thus future costs are assigned a weight less than 1,

reflecting their present value. All costs are in euros (€). Danish kroner (DKK) were converted to euros using the exchange rate €1=7.44 DKK.

Severity

For individuals with CP born after 1965, information on severity was available. Severity of CP was defined as 0 to 2 on a scale of learning disability, related to estimated IQ (less than 50, 50–85, more than 85), and 0 to 2 on a scale of motor impairment, related to the ability to walk with and without aid. To assess the impact of severity on costs, we conducted a linear regression of health care costs and productivity costs towards the two severity items. Social care costs could not be analysed because of a lack of data. Similarly, individuals with CP born before 1965 were not included in this analysis as no information on severity was available for this group. We also computed the percentage of health care costs and productivity losses attributable to the most severe cases of CP.

Sensitivity analysis

The sensitivity analysis first assessed the consequences of a higher and lower proportion respectively, of children in specialized pre-school and school. We assumed that an average of 47 per cent of children with CP were attending a specialized school. We applied a proportion of 37 per cent to obtain a low estimate[16] and 57 per cent to obtain a high estimate. The latter percentage was assumed on the basis of an assessment of completed Danish questionnaires for a multicentre study on children with CP.[17] In the second part of the analysis, we lowered the discount rate from 5 to 3 per cent.

Uncertainty

The health care costs and productivity costs due to CP were measured directly whereas social costs were estimated. Thus, confidence intervals and other statistical measures of uncertainty were not applicable, as costs are unmanageably distributed and as the results were not generated in a statistical model. Instead, the sensitivity analysis was used to generate a range for the lifetime costs of CP.

Application of a 5 per cent discount rate and the low thresholds of the social costs assumptions were used to obtain the low end of the range, while the high end of the range was computed by a 3 per cent discount rate and the high thresholds of the social costs assumptions.

RESULTS

Table I displays the prevalence of CP in eastern Denmark in 1999. The prevalence at ages 0 to 56 years was obtained from registers whereas the prevalence at older ages was estimated from historic birth incidence figures and estimated mortality. There appears to have been a sharp decline in birth incidence during the 1950s, followed by an increase in 1980 to 1990. As mortality in individuals with CP is higher than the mortality of the background population, a high prevalence in 1999 represents much higher incidence rates, especially in older age groups.

Table II describes social cost components and cost estimates per user. Other support comprises, for example,

Table II: Social cost estimates per user

Social cost component	Cost per user, €	Estimated proportion of those with CP using this service (%)	Source of estimate
Specialized pre-school	52655	47	It was assumed that the proportion of those with CP attending specialized pre-school was equal to the proportion attending specialized school. The group of experts confirmed this assumption.
Specialized school and after-school care	27364	47	A register-based analysis[9] established that 37% of those with CP attend specialized school, whereas an assessment of completed Danish questionnaires for a multicentre study[17] found 57% of those with CP attending specialized school. The group of experts approved the use of the average of these two figures.
Support to parents	7775	41	Estimate by the group of experts
Residential institutions, children	93296	2	Estimate by the group of experts
Supervized workshops	11573	5	Estimate by the group of experts
Day centre	20859	15	Estimate by the group of experts
Housing	82534	16	The estimate is register-based[18]
Other support, adults	6878	20	Estimate by the group of experts

Table III: Attributable life time costs, €, discounted

Cost component	Lifetime costs	
	Men	Women
Health care costs, total	*66155*	*65258*
Hospital costs	51968	49921
Primary health care costs	7182	8269
Pharmaceuticals costs	7005	7068
Productivity costs	332973	261597
Social costs, total	*462578*	*470386*
Specialized child care	219970	222026
Specialized education	70330	71069
Other social costs in child-age	63658	64147
Day activities for adults	21743	22605
Housing	78681	81998
Other social costs for adults	8196	8541
Total life time costs	*861706*	*797241*

short-term stay in institutions for individuals with CP living on their own.

Table III contains the lifetime costs attributable to CP. The social cost components represented the largest proportion, as they constituted more than half of total lifetime costs. Most social costs were computed from a top-down perspective, taking into consideration the difference in mortality between men and women. Productivity costs constituted about one-third of total attributable costs. Productivity costs consisted of two items. Most importantly, approximately two-thirds of individuals with CP on average never enter the labour market. Consequently, the economy is deprived of the value of their production. A lesser proportion of the productivity loss stems from mothers' leaving the labour market temporarily or permanently following the birth of a child with CP. Health care costs constituted only about 7 per cent of total lifetime costs. In total, the lifetime costs of CP were computed to be €860 000 for men and €800 000 for women.

We found that both health care costs and productivity costs were significantly ($p<0.001$) higher among the individuals with the most severe CP. In the group aged 0 to 35 years, 37 per cent had an estimated IQ of less than 50. They accounted for 52 per cent of health care costs. The age group aged 18 to 35 years represented 28 per cent of individuals with CP and 39 per cent of total productivity costs. For motor impairment, we found that the group of immobile individuals with CP constituted 30 per cent of the 0 to 35-year-olds and accounted for 44 per cent of health care costs. For productivity costs (age groups 18–35y), the immobile group represented 23 per cent of individuals with CP and 31 per cent of productivity costs.

Most uncertainty pertained to the components of the social cost analysis. The largest social cost component concerned children with CP. Assumptions regarding specialized pre-school, school, and after-school care were altered. The effects of these alterations on total lifetime costs are shown in Table IV.

It appears that the proportion of children in specialized pre-school and school had some impact on the overall lifetime costs, without, however, altering results

Table IV: Sensitivity analysis

Cost component	Assumption	Total lifetime costs			
		Men		Women	
		€	Percentage change	€	Percentage change
Social costs					
	Lower proportion of children with CP in specialized pre-school	849643	−1.4	785147	−1.5
	Higher proportion of children with CP in specialized pre-school	873769	1.4	809335	1.5
	Lower share of children with CP in specialized school	814834	−5.4	749877	−5.9
	Higher share of children with CP in specialized school	908578	5.4	844606	5.9
Total lifetime costs					
	Discount rate 3%	1190174	38.1	1097473	37.7
	Range (lowest – highest)	802771–1203232		737783–1115376	

significantly. The discount rate of 5 per cent was evaluated by assuming a lower discount rate, which increases the present value of future costs by about 38 per cent. Accordingly, the lifetime costs of CP lie within the range of €802 771 to €1 206 232 for men and €737 783 to €1 115 376 for women.

DISCUSSION

We found that the lifetime costs of CP amounted to approximately €860 000 for men and €800 000 for women. These lifetime costs are average measures per person, but vary significantly with severity. Any individual with CP can incur much higher or much lower lifetime attributable costs.

In all cost categories, individuals with CP incurred much higher costs than individuals without CP. Social costs and health care costs for children with CP were higher than for adults with CP, whereas costs increased with increasing age for those without CP. Among the most important cost drivers were neonatal care for children and specialized school and pre-school education. We assumed that about half of children with CP attended specialized school or pre-school settings. Social care activities for adults are not quite so costly and fewer individuals choose to attend these activities. We assumed that 20 to 25 per cent of adults with CP attended social care activities such as day centres.

Generally, social costs were the largest cost component, constituting about half of the total lifetime costs of CP. Apart from social costs incurred during childhood, housing also contributed somewhat to lifetime costs.

Our results are somewhat higher than the most recent US cost estimate. The CDC estimate of lifetime costs of CP in 2003 was $921 000,[4] or about €817 000 when 2003 exchange rates are applied. The CDC cost estimate is achieved by means of a 3 per cent discount rate and should thus be compared to our estimate at a 3 per cent discount rate. The CDC cost estimate includes health care costs, productivity costs, and social costs. Also, it is computed as attributable lifetime costs, rendering them comparable to our results. However, the CDC cost estimate is largely based on a survey, contrary to our figures for health care and productivity costs, which are register-based. In addition, the US cost estimates include comparable figures for health care costs and productivity costs, but the amount of social cost components included was somewhat smaller, as they included education and assistive devices only.[5]

To our knowledge, the lifetime costs of CP have not been established outside the US. As northern European countries differ from the US in several ways, among which are the cost structure and coverage of health and social care, it remains of great importance to establish a European estimate of the lifetime costs of CP.

The cost estimate in this analysis was reached by means of a register-based analysis. The unique personal identifier used in all Danish registers allows comprehensive register linkages and vast analysis opportunities. This analysis applied register-based information for health care costs and productivity costs. This is a major strength in comparison with US analyses, as it allows detailed analysis of cost components.

In addition, the Danish Cerebral Palsy Register represents a large cohort of individuals with CP, being representative from 1950 onwards. The bottom-up analysis on a register-based cohort covering a 50-year span yields very precise results in comparison with otherwise comparable assessments. Furthermore, we were able to show that the lifetime cost varies significantly with severity.

Given that the severity of CP varies greatly, it is clear that not all individuals with CP incur social costs and productivity costs as described, as the cost burden increases with severity. Further, a change in the 'severity threshold' for labour market participation would impact on social costs and productivity costs. Thus a labour market intervention aimed at higher employment for those with disabilities would have the positive side effect of decreasing the lifetime costs of CP.

Our analysis applied the attributable-cost method, as did other analysts.[2,4,6] This approach identified the additional costs attributable to CP, as opposed to the total costs. The major cost item, social care cost, was, however, not computed as an attributable cost. The main reason for this was lack of information at the individual level. We found that the bias was negligible in this context, as most social care costs, e.g. day centres and institutions, are targeted towards persons with disabilities: therefore, most other people do not incur any of these costs.

Schooling was the exception, as all children go to school, and about half of children with CP attend a specialized school. If school expenses were known at the individual level, attributable costs could be computed. Thus the costs of children with CP attending specialized schools may be overestimated, as the average cost per schoolchild without CP should have been subtracted. This bias is outweighed by an underestimate of educational costs, as we had no information on support to the other half of children with CP. About 50 per cent of children with CP attend mainstream school, with varying degrees of support. The costs of this support were not included in the analysis. Hence, education costs are both over- and underestimated, leading us to maintain the original estimate.

The data used for this analysis included a time-series break, as data from before and after 1965 are from different sources and therefore not directly comparable. It cannot be verified whether the inclusion criteria in the electronic

register (after 1964) are similar to those for the paper records (before 1965). Thus, the individuals with CP in the paper records could be more or less severe than those with CP in the register. In terms of costs, no major time-series break appeared from the data.

Computation of lifetime costs generally falls under the heading 'cost of illness'. Cost-of-illness analyses have acquired a rather mixed reputation, as results are not applicable in health care policy. However, the analysis adopts a lifetime perspective. Therefore our results can be interpreted as incidence-related: the lifetime costs represent the saving acquired by society if one incident case of CP were to be prevented.

CONCLUSION

We found that the average lifetime cost of CP was €860 000 for men and €800 000 for women. Lifetime costs consisted mostly of social costs and productivity costs. The estimated lifetime costs represent a minimum value, as a number of cost items have not been considered, including costs of care delivered by the families and adverse effects on the physical and psychological health of parents.

Active inclusion of adults with CP in the labour market would have a beneficial impact on the lifetime costs of CP. However, the measurement of lifetime costs of CP should also focus attention on the necessity of evaluating quality of life in children and adults with CP as the real goal of resource spending in this area.

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