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Systematic review of the economic impact of cerebral palsy

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ABSTRACT

Background: Cerebral palsy (CP) and its associated conditions can pose a significant economic burden on families, the health care system and the general economy. The boundary for inclusion of costs in research can vary substantially across studies. *Aims:* To summarize the evidence for burden of disease for CP including the impacts on the health system, the community and carers. *Methods:* Literature was identified from Ovid Medline, Embase, CINHAL, PsyInfo, Econlit, Health Economic Evaluation Database (HEED) and NHS Economic Evaluation Database (NHS EED) in

Economic Evaluation Database (HEED) and NHS Economic Evaluation Database (NHS EED) in the Cochrane Library. The search was restricted to articles published in English between 1970 and April 2016. All costs were converted to \$USD 2016 price.

Results: Twenty-two articles were included. Studies varied from snapshot cost descriptions to more complex lifetime estimates, from prevalence-based to incidence-based studies, and from inclusion to exclusion of non-medical costs. There was a strong positive relationship between CP severity and expenditure. Significant costs were incurred by families and the welfare system to facilitate school and community engagement.

Conclusion: Facilitating participation for people with CP involves substantial expense. The size, nature and distribution of the economic burden emphasises the importance of finding effective strategies to reduce the risk and severity of CP, together with how it is financed.

What does this paper add?

This review systematically documents and summarises the economic impacts of CP from literature that employed different analysis techniques, cost components, and settings. This review showed that there was a strong positive relationship between CP severity and expenditure. Significant costs were borne by families and the welfare system to facilitate school and community engagement. Facilitating participation for people with CP involves substantial expense. The cost burden of CP highlights the importance of effective strategies to either prevent CP or minimise impairments associated with the condition.

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1. Introduction

Rosenbaum et al. defined cerebral palsy (CP) as "a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems" (Rosenbaum et al., 2007). CP has a prevalence of approximately 1 in 500 live births, with 17 million people affected worldwide (Graham et al., 2016). The pooled prevalence of CP in high-income countries is 2.11 per 1000 live births (Oskoui et al., 2013) and 2.0–2.8 in low and middle-income countries (Gladstone, 2010). Epilepsy, intellectual disability, hearing and visual impairments co-occur among some children with CP (Novak et al., 2012). Children may develop behaviour disorders, bladder problems, poor saliva control, sleep disorders and secondary conditions such as progressive joint contractures of the upper and lower limbs, shortened muscles, degenerative arthritis, hip or foot deformities, scoliosis and hip displacement.

CP and its associated conditions can pose a significant economic burden on families, the health care system and the general economy. Cost of illness (COI) studies (Jefferson et al., 2000) are often undertaken to estimate the size and nature of these impacts which sometimes are undertaken in parallel with Burden of Disease (BoD) studies. BOD studies focus on the incidence/prevalence of the underlying illness and associated risk factors. The two main cost categories in the COI studies are "direct" and "indirect" costs. Direct costs generally refer to costs borne by care providers/funders in the health care system and by the individual patient and their family/carers. Direct costs can sometimes extend to non-health care costs, where education expenses and home modifications are relevant. "Indirect costs" in COI studies usually refer to "productivity losses" resulting from morbidity (visits to medical practitioners, hospitalisation and premature retirement), together with premature mortality. Productivity losses are based on impacts assessed for the paid workforce, but can extend to include impacts on domestic production. Sometimes indirect costs also include dollar values placed on pain and suffering. Care is required not to confuse the term indirect costs used in the context of COI studies, with indirect costs used in the context of accounting, where it refers to overheads.

The economic burden of CP can be estimated as a lifetime cost for new cases (i.e. incidence costing), as an annual cost for all existing cases of CP (i.e. prevalence costing), or sometimes as a cost for a specific time period, condition or patient subgroup (targeted costing). The target population and setting in analysis can also vary substantially from those studies that aim to estimate the economic burden at a national level utilizing national databases or multiple data sources, to randomised control trials, through to those that utilise selective or convenience samples. The boundary around which costs are included can also vary substantially from the studies that focus narrowly on costs to the funder/service provider; to those that include costs to patients and their families/carers; to those that include productivity impacts on the general economy; through to those that also try to place a dollar term on pain and suffering. The purpose of this systematic review was to summarize the economic impact of CP on the health system, the community and carers from published literature.

2. Methods

Publications on the COI/BoD of CP were identified from Ovid Medline, Embase, CINHAL, PsyInfo, Econlit, Health Economic Evaluation Database (HEED) and NHS Economic Evaluation Database (NHS EED) in the Cochrane Library, using the following search terms: costs, health care cost, cost analysis, cost estimates, economic burden, cost-effectiveness, cost-benefit or economic evaluation and CP. Note that articles associated with cost-effectiveness analysis for CP interventions were also assessed but reported elsewhere.

Table 1

Search strategies for various databases

Ovid MEDLINE	Search Terms		
1 2 3	"cerebral palsy".sh cost*.ab. or "costs and cost analysis".sh. or "cost benefit analys*".ab. or "cost-benefit analysis".sh. or "health care costs".xs 1 and 2		
Embase			Search Terms
#1 #2 #3 #4 #5 #6 #7			'cerebral palsy':ab,ti 'cost':ab,ti 'cost effectiveness analysis':ab,ti 'cost benefit analysis':ab,ti 'health care costs':ab,ti #2 OR #3 OR #4 OR #5 #1 AND #6
CINAHL, PsycINFO, HEED, EcoLit da	atabases	Search Terms	
S1 S2 S3 S4		MJ cerebral palsy or TI cerebral palsy or AB cerebral palsy TX (cost effective analysis or cost effective* or cost benefit analysis or economic evaluation) TX (randomized controlled trial or rct) S1 AND S2 AND S3	

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