The Cost of Care Questionnaire: A Caregiver Perspective

ICAM Meeting 2023 Abstract.

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Cost of care studies are an essential measurement technique in health and medical sciences with diverse types of cost components involved and fundamental to research and practice. It is aimed to itemize, value, and sum the costs of a particular problem with the aim of giving an idea of its economic impact. Arthrogryposis Multiplex Congenita, a rare musculoskeletal condition, is associated with enormous health impact, affecting patients' health, and causing direct and indirect costs for their caregivers. A recent literature review on cost of care studies in childhood disability, reports that researchers fail to mention/provide the questionnaire used, and the validation process of these questionnaires are omitted. Although the identified questionnaires collate data that include demographics, income, and direct, and indirect costs, some studies lack the psychosocial costs, and information on the questionnaires' adaptation choices posing challenges for further study replication. Hence, this study created a tool to measure the cost of caring for children with AMC from the caregivers' perspectives. An iterative design process that included a literature review, existing measures review, stakeholders' consultation, pilot testing, and translation was used with each phase contributing to its development. The following domains were covered by the questionnaire; child and caregiver's demographics, caregiver's sociodemographic, cost information (direct, indirect cost, and psychosocial costs), and child and caregivers' perceived quality of life (EUROQOL, SF-12, EQ-5D-Y). The estimation of cost in childhood disability studies aids both researchers and policy makers to make informed decisions on its impact on the healthcare system, to motivate change through prevention, early detection, and care throughout the lifespan of affected persons. Therefore, this tool will support economic evaluations of the impact of care on caregivers of children with disabilities. It will also help other researchers to adapt & develop similar questionnaires measuring and comparing the COI to society.

Keyword 1: Cost of care
Keyword 2: Childhood disabilities
Keyword 3: Caregivers
Funding acknowledgements: CRIR Doctoral Fellowship.