Non-Orthopaedic Problems in Children with Cerebral Palsy

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The definition of cerebral palsy has evolved over time to include associated problems or comorbidities. The spectrum, clinical profile, risk factors and co-morbidities in CP can vary with the level of awareness and resources for prevention, diagnosis and management. The major non-orthopedic problems associated with CP may be broadly categorized as: neurologic, cognitive/ behavioral/ psychological, visual, hearing/ speech/ language, gastrointestinal/ nutritional, respiratory and miscellaneous. The assessment of each comorbidity requires development of specific tools to address the problems of such children appropriately. This also further emphasizes the need to assess and manage each problem in a child with CP by the multidisciplinary team.

Keywords: associated problems, cerebral palsy, co-morbidities, disability, epilepsy.

Cerebral palsy (CP) is primarily a disorder of movement and posture described first in 1840 by William Little.[1] Being the most common physical disability of childhood, the extra lifetime costs associated with CP is estimated to be $921,000 per person.[2]

Recognition that CP is not limited to motor impairment has been known since long but the associated problems or comorbidities are seen in the background.[3] The awareness has now been increasing as reflected by the evolution in the definition of CP. The current definition says "Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior; by epilepsy, and by secondary musculoskeletal problems".[4]

The prevalence of CP from population-based studies worldwide is 1.5 to more than 4 per 1,000 live births.[5-8] The pooled overall prevalence is 2.11 per 1000 live births as estimated by a meta-analysis in 2013.[9] No decline has been reported in its incidence despite the recent advances in neonatal management and obstetric care. Moreover, the contribution of prematurity and its complication to the prevalence of CP is steadily increasing.[5]

A. Present Scenario:

In context of Nepal, CP still remains a highly stigmatizing condition due to lack of access to basic information and support. There is no population-based study describing the prevalence of CP in Nepal. A study by Ellis M et al at Self-Help Group for Cerebral Palsy (SGCP)-Nepal found 108 (78.26%) cases of CP amongst the 136 cases of disability over one-year period.[10] Another study by Banskota B et al at Hospital and Rehabilitation Centre for Disabled Children (HRDC) found 15% of outpatients to be cerebral palsy.[11]

Spectrum, clinical profile, risk factors and co-morbidities in CP can vary in different population and places depending on the level of awareness and resources for prevention, diagnosis and management. Yet the major non-orthopedic problems associated with CP may be broadly categorized as: neurologic, cognitive/ behavioral/ psychological, visual, hearing/ speech/ language, gastrointestinal/ nutritional, respiratory and miscellaneous.[12]

B. Common Comorbidities

Amongst the common comorbidites, epilepsy occurs in 15-55% of children with CP as compared to 3-6 per 1000 in general population.[13] Aspiration pneumonia and airway obstruction related to epilepsy are the major causes for emergency hospital admissions and sometimes unreported mortality. Thus, epilepsy in CP adds a dimension of uncertainty to the otherwise relatively static problems.[13] Similarly, intellectual disability (50%), attention-deficit hyperactivity disorder (ADHD) and learning disabilities have significant impact on academic performance and self-esteem and may lead to increased prevalence of depression.[12,14]

Cognitive disability further impairs the assessment of hearing and speech problems in CP. There are issues like oromotor dysfunction (dysarthria/ dysarticulation) which leads to feeding and swallowing difficulties and drooling (10-37%).[15] Gastroesophageal reflux, hearing impairment, constipation, dental caries, hyperactive gag, oral aversion, gingivitis & calculus deposition in gastrostomy fed and malnutrition add to these and worsen the condition. One can imagine the situation when there is inability to feed oneself and further inability to request for food due to speech problem.

Analysis of visual problems in children with CP has shown that one in 10 children with CP has a severe visual impairment or is blind.[16] More than half have some form of visual problems like refractive errors, visual-field abnormalities due to cortical injury, strabismus, amblyopia, nystagmus

or optic atrophy. Hence, the measurement of visual ability rather than visual acuity needs to be emphasized in children with cerebral palsy.[16]

The other problem in children with CP which is highly reported from developed countries is pain (20-65%), causing negative impact on their quality of life.[14] A study on sleep disorders in children with CP found 23% had sleep problems in comparison to 5% in the general population.[17] There are also urologic manifestations ranging from voiding dysfunction, recurrent UTI, incontinence to unexplained irritability.[14] Similarly, transitional problems into adult health care cannot be neglected.

C. Assessment

The assessment of each comorbidity requires development of specific tools to address the problems of such children appropriately. This being difficult, the overall assessment of comorbidities varies in different literature. In a cross-sectional, hospital-based descriptive study done at our centre - B P Koirala Institute of Health Sciences (BPKIHS), Dharan, over 1 year period, 101 children with CP were studied and the problems noted were: intellectual disability (83.2%)- severe (33%); seizure (76.2%)- generalized (75.6%)/ focal (24.4%); speech problems (65.3%)- aphasia (95.5%); feeding problems (43.6%); malnutrition (42.6%)- severe (65.1%); visual problems (7.9%); orthopedic problems (7.9%); hearing problems (5.9%). This report still underestimates the visual, orthopedic and hearing problems as compared to other studies due to lack of use of proper assessment tools during the study. This also further emphasizes the need to assess and manage each problem in a child with CP by the multidisciplinary team.

An optimal multidisciplinary approach for management of CP would require a dedicated team of professionals comprising of a pediatrician or pediatric neurologist, orthopedist, physiotherapist, audiologist, ophthalmologist, speech therapist, occupational therapist, child psychologist, special educator and social workers. Since CP cannot be cured, the goals of management should be to use appropriate combinations of interventions (eg developmental, physical, medical, surgical, chemical, technical modalities) to promote function, prevent secondary impairments and increase child's developmental capabilities. [18]

Conclusion

In our part of the world, infection and malnutrition are still leading causes of childhood mortality. Hence, we need to address more challenges in managing children with CP : 1) Disease being incurable with lifelong disability; 2) Poor socioeconomic condition, education and motivation of patient/ caregiver; 3) Lack of a well-coordinated dedicated multidisciplinary team, required equipment/supplies and funds; 4) Lack of country level special laws with inclusive environment and disability-friendly initiatives. Nevertheless, collaborative efforts from institutions like HRDC, SGCP Nepal, Humanity & Inclusion Nepal and

BPKIHS can pave the path for optimizing multidisciplinary approach and make a positive difference in lives of children with cerebral palsy.

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