Health Care Needs Across Different Age Groups in Children with Cerebral Palsy: A Survey

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Abstract

Background: Cerebral palsy (CP) is the most common chronic childhood disability of today. Health care needs are present in these children who require health services to manage their functional disability. It can change according to the age group and severity of the condition. In the current healthcare system, little is known about priorities and needs for the children with cerebral palsy especially in reference to Indian contextual situations and how these needs may differ based on the child's age and motor function.

Methods: A cross sectional survey design is used in the study. 83 parents of children with cerebral palsy and their treating physiotherapists were selected in the study based on the inclusion and exclusion criteria. Participants were divided into 3 groups based on the age of the children. Self designed questionnaire was given to the parents and the physiotherapists to select the health care needs for the children. One time data collection was done over the period of 3 months.

Conclusion: The study also shows that mostly parent's needs are considered by physiotherapists for their goal settings. Most of the time parents' needs and the physiotherapist's goals are found to be similar.

Key Words: Cerebral Palsy, Health care needs, parents, physiotherapists.

Introduction

Cerebral palsy (CP) is the most common chronic childhood disability.(1) CP is described as a group of permanent disorders of the developing movement and posture, causing activity limitation, that are attributed to nonprogressive disturbances that occur in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior by epilepsy, and by secondary musculoskeletal problems.(2) The overall prevalence of CP is 2.11 per 1000 live births.(3) In India the overall prevalence of cerebral palsy per 1000 children surveyed is 2.95.(4) Contrary to the previous studies, prenatal factors seem to be responsible for nearly 75% of CP, whereas infant and neonatal period risk factors account for 10% to 18% of all CP cases.(5) Premature birth is considered as one of the major CP incidence risk factors.(6) Impairment in CP tends to evolve and become evident as the child grows.(7) These impairment in CP have been classified as primary, secondary, or tertiary. The primary impairments are disturbance of muscle tone, strength, balance and posture that are directly related to damage in

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the CNS. Secondary impairments may present as muscle contractures and deformities that develop over time in consequence to the primary problems. Tertiary impairments are adaptive mechanisms or coping responses that the child develops, to adapt to the primary and secondary problems.(1) In infancy, the child may show symptoms like irritability, lack of alertness and irregular sleep patterns. Delayed or absence of motor developmental milestones is an early feature of CP. It includes rolling, sitting, crawling, standing and walking.(2) Additionally children may have abnormal tone, muscle weakness and also persistence of primitive reflexes.(8) The motor problems tend to be more noticeable as the baby grows. In childhood muscle tone may increase in spastic cerebral palsy and fluctuate in dyskinetic CP. Abnormal movement patterns may develop in hypertonic or hypotonic limbs and there might be delay in postural reactions, hyperreflexia which are required for balance and mobility. Sensations may also be affected, mainly the proprioceptive and movement sensation(1). The children may also demonstrate sign of intellectual disability, cognitive impairments, language dysfunction, perceptual difficulties, attention deficit, mental retardation and epilepsy(9). In adolescence, body functional and structural problems become more prominent like increased spasticity leading to contractures or deformities, excessive contraction of muscles, impaired selective motor control which create a negative impact on locomotion. There are certain problems related more to function and ADLs that hold more priority. Difficulty in performing activities of daily living, limitation in mobility in home and community and difficulty in transportation are more often quoted.(10)

Methodology

The study was conducted on 83 parents of children with cerebral palsy and their treating physiotherapist across 3 different age groups(3-7, 8-12, 13-18 years) in order to collate different health care needs of their children and to compare the health care needs between parents and physiotherapists. The participants were selected from special schools with CP children, Rehabilitation centers where parents/guardians of children with cerebral palsy and their treating physiotherapists are available. The information was collected from the Parents / guardians of the children with spastic diplegic and quadriplegic CP and physiotherapists who are treating these patients. Both male and female children between the age group of 3-18 years with level of literacy were included in the study. Physiotherapists who treated the above children for at least 3 months were included.

Procedure:

The study procedure was submitted to the ethical committee and the approval to conduct the study was obtained. Selection of the study settings and permission to conduct the study will be taken prior from the institutions from where the study is conducted. The information regarding the health care needs were gathered from various websites, literature searched through databases (PubMed, scholar), ICF, blogs and also from textbooks. Based on the above information various health care needs were identified. The questionnaire was prepared based on the various health care needs of the children with CP. The same questionnaire was given for the parents of the children with CP and the physiotherapists treating those children.

Later the questionnaire was handed over to the experts for their opinion for intense content clarity of items and incorporation of suggestions. Five experts were selected who have master's degrees in pediatric physiotherapy with 5 years of experience in treating pediatric patients. The questionnaire was then corrected and arranged according to the opinion and views of the experts.

It was then translated to local languages including kannada, hindi, tamil and malayalam for the better understanding of the parents. The answers were then back translated to english to evaluate the efficacy of translation without changing the meaning of the content. The participants were then explained about the purpose of the study. Informed consent was obtained for the approval of participants. Later the survey questionnaire was given to the participants to be filled for the study. Data collection was conducted by either directly meeting the participants or through different online methods (email, whatsapp).

Questionnaire:

Questionnaire For Measurement of Healthcare Needs in Children with Cerebral Palsy was used to collect the data. It measures 9 domains which include needs for feeding and speech, cardiovascular and physical fitness, mobility of lower limb, movement of upper limb, neurological issues, functional activities, degenerative and lifestyle issues, social and community barriers and psychological and emotional factors.

Statistical Analysis:

The data was carefully collected and calculated. The Kruskal Wallis H test was used to compare the health care needs among parents of children with CP according to their age groups. The Wilcoxon signed rank test was used to compare the health care needs between parents and physiotherapists.

Results

Table 1. Comparison of health care needs among parents according to age groups.

Parents (n = 83)	3-7		8-12		13-18		Kruskal Wallis H test	p value
	Median	IQR	Median	IQR	Median	IQR		
Feeding/speech	3	0 to 5	2	0.75 to 5	3.5	1 to 5	1.296	0.523
Cardiovascular/ physical endurance	1	0 to 3	2	0.75 to 2.25	2	1 to 2.25	1.075	0.584
Mobility	11	7 to 13	10.5	7 to 13	9.5	7 to 10.75	1.091	0.580
Upper limb	3	2 to 4	3	1.5 to 4	4	2 to 4	1.523	0.467
Neurological	1	0 to 3	1	0.75 to 3	0.5	0 to 2	3.155	0.206
Functional training	3	1 to 4	4	3 to 5	4	2.75 to 5	5.315	0.070
Degenerative	1	0 to 4	0.5	0 to 1.25	2	2 to 2	9.636	0.008*
Social & community barriers	5	3 to 5	4.5	3 to 5.25	5	4 to 7	0.898	0.638
Psychological	1	1 to 3	2	2 to 4	4	2.75 to 5	11.376	0.003*

(* Significant)

The Kruskal Wallis H test was used to compare the health care needs among parents according to age groups. There was a difference ($p < 0.05$) in the health care needs such as Degenerative and lifestyle issues and Psychological and emotional factors among parents according to age groups.

Table 2. Comparison of health care needs among parents and physiotherapists across different age groups

Age: 3 to 7 years (group A)	Parents		Physiotherapists		"Z"	p value
	Median	IQR	Median	IQR		
Feeding/speech	3	0 to 5	3	1 to 3	-0.518	0.604
Cardiovascular/ physical endurance	1	0 to 3	2	2 to 3	-2.709	0.007*
Mobility	11	7 to 13	11	9 to 13	-1.026	0.305
Upper limb	3	2 to 4	5	3 to 5	-2.507	0.012*
Neurological	1	0 to 3	3	0 to 4	-1.783	0.075
Functional training	3	1 to 4	3	2 to 4	-0.541	0.588
Degenerative	1	0 to 4	0	0 to 1	-2.142	0.032*
Social & community barriers	5	3 to 5	4	3 to 6	-0.420	0.675
Psychological	1	1 to 3	2	1 to 3	-0.998	0.318

(* Significant)

Table 3. Comparison of health care needs among parents and physiotherapists in age group 8 to 12 years

Age: 8 to 12 years (group B)	**Parents**		**Physiotherapists**		**"Z"**	**p value**
	Median	**IQR**	**Median**	**IQR**		
Feeding/speech	2	0.75 to 5	1.5	0 to 3.25	-2.763	0.006*
Cardiovascular/ physical endurance	2	0.75 to 2.25	1	1 to 2	-0.646	0.518
Mobility	10.5	7 to 13	12	9.75 to 13.25	-1.804	0.071
Upper limb	3	1.5 to 4	4	3 to 5	-2.351	0.019*
Neurological	1	0.75 to 3	2	1 to 3	-0.873	0.382
Functional training	4	3 to 5	3	3 to 4	-1.092	0.275
Degenerative	0.5	0 to 1.25	1	0 to 1	-1.153	0.249
Social & community barriers	4.5	3 to 5.25	4.5	2 to 6	-0.162	0.871
Psychological	2	2 to 4	2	1 to 3	-1.124	0.261

(* Significant)

Table 4. Comparison of health care needs among parents and physiotherapists in age group 13 to 18 years

Age: 13 to 18 years (group c)	**Parents**		**Physiotherapists**		**"Z"**	**p value**
	Median	**IQR**	**Median**	**IQR**		
Feeding/speech	3.5	1 to 5	3	2 to 425	-0.122	0.903
Cardiovascular/ physical endurance	2	1 to 2.5	2	0.75 to 2	-0.053	0.958
Mobility	9.5	7 to 10.75	11	8.75 to 12	-2.033	0.042*
Upper limb	4	2 to 4	3	2 to 5	-0.087	0.931
Neurological	0.5	0 to 2	3	2 to 4	-2.877	0.004*
Functional training	4	2.75 to 5	4	3 to 4.25	-0.366	0.715
Degenerative	2	2 to 2	1	1 to 2	-2.132	0.033*
Social Community barriers	5	4 to 7	5.5	4 to 7	-1.314	0.189
Psychological	4	2.75 to 5	2	1.75 to 3	-1.903	0.057

(* Significant)

There was a difference ($p < 0.05$) in the health care need domains such as degenerative and lifestyle issues management (p value- 0.008) and psychological and emotional support (p value- 0.003).

Discussion

The present study was conducted to collate health care needs as reported by the parents/ guardians and therapists of children with CP across 3 different age groups and also to compare agreement between the health care needs identified by the caregiver of the children and goals set by the therapist for rehabilitation. A self designed questionnaire was used to collect the data. According to current study, there is no significant difference found among the 3 age groups in most of the domains except degenerative and lifestyle issues management (H test- 9.636, p value- 0.008) and psychological and emotional support(H test- 11.376, p value- 0.003). The parents of children in the group C placed higher demand on management of degenerative and lifestyle issues and psychological and emotional factors. The parents of group C focused more on the management of degenerative diseases followed by group A as they were more concerned about the future impairment or disabilities that may affect their child. Parents in group B were more concerned about management of other issues like mobility, neurological disorder etc than the degenerative issues. Concentrating on the psychological and emotional domain, high demand was expressed by the parents of children in group C followed by group B and then by group A. This can be due to the fact that as the age progresses psychological factors like depression, anxiety may affect an individual with disability. Children in group C might consider their lives as more challenging compared to children in other age groups as they are physically and emotionally weak. Parents of children in group B might also consider this as an important factor as the disability prevents their children from being normal when compared to the children of the same age group. The health care needs identified by the caregiver of the children and goals set by the physiotherapist for rehabilitation were also compared and analyzed in different age groups. From 3 different age groups, parents and physiotherapists were in agreement in most of the domains except few. Group A showed difference in parent's and physiotherapist's view on domains cardiovascular and physical fitness (p value-0.007), movement of upper limb (p value- 0.012) and degenerative and lifestyle issues(p value 0.32). Group B showed difference only in feeding/speech (p value-0.006) and movement of upper limb(p value-0.19). Group C showed differences in mobility (p value-0.42), neurological issues (p value-0.004) and degenerative and lifestyle issues (p value-0.33). In group A, physiotherapists expressed more importance for the improvement of cardiovascular/ physical endurance and management of upper limb impairment compared to parents. In group B, parents showed management of feeding and speech problems as an important need whereas the physiotherapists focus less when compared to other domains. In group C, physiotherapists focus on management of mobility issues and movement of hand functions when parents are more focused on other domains.

Conclusion

Health care needs among the cerebral palsy remains same throughout their age except few which are noticeable during the later stages of their life. Domains such as feeding and speech, cardiovascular and physical fitness, mobility of lower limb, movement of upper limb, neurological issues, functional activities and social and community barriers are the common needs which are required for all the children irrespective of their age. Degenerative and lifestyle issues, and psychological and emotional factors are few needs which are more expressed by the parents of children at their late adolescent age group. The study also shows that mostly parent's needs are considered by physiotherapists for their goal settings. Most of the time parents' needs and the physiotherapist's goals are found to be similar.

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References

1. Berker AN, Yalçın MS. Cerebral palsy: orthopedic aspects and rehabilitation. Pediatric Clinics of North America. 2008 Oct 1;55(5):1209-25.
2. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, Dan B, Jacobsson B. A report: the definition and classification of cerebral palsy April 2006. Dev Med Child Neurol Suppl. 2007 Feb 1;109(suppl 109):8-14.
3. Oskoui M, Coutinho F, Dykeman J, Jetté N, Pringsheim T. An update on the prevalence of cerebral palsy: a systematic review and meta-analysis. Developmental Medicine & Child Neurology. 2013 June;55(6):509-19.
4. Chauhan A, Singh M, Jaiswal N, Agarwal A, Sahu JK, Singh M. Prevalence of cerebral palsy in Indian children: a systematic review and meta-analysis. The Indian Journal of Pediatrics. 2019 Dec;86(12):1124-30.
5. Reddihough DS, Collins KJ. The epidemiology and causes of cerebral palsy. Australian Journal of physiotherapy. 2003 Jan 1;49(1):7-12.
6. Linsell L, Malouf R, Morris J, Kurinczuk JJ, Marlow N. Prognostic factors for cerebral palsy and motor impairment in children born at very preterm or very low birthweight: a systematic review. Developmental Medicine & Child Neurology. 2016 Jun;58(6):554-69.
7. Quinby JM, Abraham A. Musculoskeletal problems in cerebral palsy. Current Paediatrics. 2005 Feb 1;15(1):9-14.
8. Garfinkle J, Li P, Boychuck Z, Bussières A, Majnemer A. Early clinical features of cerebral palsy in children without perinatal risk factors: a scoping review. Pediatric neurology. 2020 Jan 1;102:56-61. 49
9. Stadsklev K, Jahnsen R, Andersen GL, von Tetzchner S. Neuropsychological profiles of children with cerebral palsy. Developmental neurorehabilitation. 2018 Feb 17;21(2):108-20.
10. Graham HK, Selber P. Musculoskeletal aspects of cerebral palsy. The Journal of bone and joint surgery. British volume. 2003 Mar;85(2):157-66.