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ASSESSING PARENTAL SATISFACTION WITH INFORMATION PROVIDED POST-DIAGNOSIS OF CEREBRAL PALSY: UNDERSTANDING IMPLICATIONS AND OUTCOMES

Paediatrics

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ABSTRACT

Cerebral palsy (CP), a disorder arising before, during, or after birth, causes brain injury and motor perception issues, impacting posture, movement, sensation, cognition, communication, and behavior. This study assesses parental satisfaction with post-diagnosis information and examines the challenges parents face in caregiving alongside daily activities, including physical, familial, social, and economic impacts. Findings show most children are preschool-aged, mothers are primary caregivers, fathers work full-time, and many families face economic instability. Parental satisfaction with information is high, but there is a need for more written updates and family-wide sessions. The study underscores the importance of comprehensive support for parents, emphasizing medical, psychological, and social aspects, and calls for further research to better address their needs.

KEYWORDS

INTRODUCTION

Cerebral palsy (CP) is a group of permanent disorders that affect movement development and limit activity. Non-progressive disturbances in the developing fetal or infant brain can lead to CP, making it the most common cause of childhood disability. The degree and type of motor impairment and functional capabilities vary depending on the etiology. CP is often linked to multifactorial causes, including prenatal, perinatal, or postnatal factors. The condition is frequently associated with comorbidities such as epilepsy, musculoskeletal problems, intellectual disabilities, feeding difficulties, visual and hearing abnormalities, and communication difficulties. These characteristics necessitate a comprehensive and interdisciplinary approach to care, given the considerable burden on functional status and the quality of life of affected individuals.[1]

Comprehensive care for children with cerebral palsy (CP) involves a multidisciplinary team approach to address the complex and diverse needs of these children. This team typically includes developmental pediatricians, clinical psychologists, physio-occupational therapists, speech therapists, and special educators. Each specialist plays a crucial role in promoting the overall development and well-being of children with CP. Developmental pediatricians focus on the medical and developmental aspects, ensuring that the child's growth milestones are met and managing any associated medical conditions. Clinical psychologists provide essential support for both the child and their family, addressing emotional and behavioral issues that may arise.[2] Physio-occupational therapists work on improving the child's physical capabilities and functional independence through targeted exercises and interventions. Speech therapists address communication challenges, enhancing the child's ability to express themselves and interact with others. Special educators tailor educational programs to meet the unique learning needs of each child, ensuring they receive an appropriate and inclusive education.[3-7]

Family involvement, particularly from mothers, plays an essential role in the care of children with disabilities. Mothers are often seen as the primary caregivers, facing day-to-day struggles and experiencing significant stress, despair, and anxiety due to their child's dysfunctional behavior, educational needs, and uncertain future. This constant tension significantly affects parental well-being. The emotional and physical demands of caring for a child with CP can lead to burnout, feelings of helplessness, and social isolation. Parents, especially mothers, often have to navigate complex healthcare systems, advocate for their child's needs, and manage various therapies and medical appointments, all while balancing other family and work responsibilities. The stress level of parents was measured with the help of Parental Stress Scale (PSS), widely used tool designed to measure the levels of stress experienced by parents in their role as caregivers. Developed by Berry and Jones in 1995, the scale consists of 18 items that assess various dimensions of parenting stress, including positive aspects (e.g., emotional benefits, personal development) and negative aspects (e.g., demands on resources, feelings of restriction).[8]

Parents rate each item on a 5-point Likert scale, ranging from "Strongly Dissatisfied" to "Strongly Satisfied". The scores are then summed to provide an overall indication of parental stress, with higher scores reflecting greater stress levels. It helps identify areas where parents might need additional support and intervention, thereby contributing to better mental health and well-being for both parents and children.[9]

Improving parental satisfaction involves not only providing detailed medical information but also offering emotional support and practical resources. Healthcare providers should engage in active listening, validate parents' concerns, and involve them in the decision-making process. Educational workshops, support groups, and counseling services can also be beneficial in helping parents manage their stress and build a supportive community. By addressing the informational and emotional needs of parents, healthcare providers can enhance the overall care experience, leading to better outcomes for both the child and their family. Parents of children with CP often report extreme worry, hopelessness, remorse, and fury, feeling helpless and struggling to maintain their social structure, self-esteem, and physical and psychological stability. The high level of responsibility and time spent caring for a child with special needs adversely affect parents' health and well-being. Encouraging early use of rehabilitation programs can positively impact the potential for growth and development in children with special needs. However, there has been limited research on how and to what extent parents' attitudes and viewpoints affect the utilization of early rehabilitation services.[10]

In conclusion, this study aims to enhance the quality of care, improve parental well-being, and ensure effective utilization of rehabilitation services by addressing gaps in communication and support.

AIM

1. To measure the satisfaction levels of parents regarding the information they receive immediately after a CP diagnosis.
2. To analyze the relationship between the quality of information provided and the overall development and health outcomes of children with CP.

METHODOLOGY

This study employ a cross-sectional design to assess parental satisfaction with the information provided post-diagnosis of cerebral palsy (CP) and understand its implications on rehabilitation service

utilization and outcomes. The study involves parents or primary caregivers of children diagnosed with cerebral palsy. Participants were recruited from pediatric neurology clinics, rehabilitation centers, and support groups for children with CP.

Inclusion Criteria:
1). Parents or primary caregivers of children diagnosed with CP within the past five years.
2). Children diagnosed with CP who are under the age of 18.
3). Willingness to participate and provide informed consent.

Exclusion Criteria:
1). Parents or caregivers who were unable to comprehend the survey due to language barriers or cognitive impairments.
2). Families of children with concurrent severe medical conditions unrelated to CP.

A sample size of 60 participants was targeted to ensure adequate power for statistical analysis. The sample size was determined based on similar studies and the expected response rate. Data was collected using a structured questionnaire designed to evaluate parental satisfaction with the information provided post-diagnosis. The questionnaire includes the following sections:
1. **Demographic Information:** Age, gender, educational level, and socioeconomic status of parents; age and gender of the child with CP.
2. **Diagnosis and Information Provision:** Details about the diagnosis process, the type and amount of information provided, and the sources of information (e.g., healthcare providers, written materials, online resources).
3. **Satisfaction Levels:** A Likert scale to measure satisfaction with the information provided, ranging from very dissatisfied to very satisfy.
4. **Utilization of Rehabilitation Services**: Questions regarding the types of rehabilitation services accessed, frequency of use, and perceived effectiveness.
5**. Parental Well-being:** Assessment of parental stress, coping mechanisms, and overall well-being using validated scales such as the Parental Stress Scale (PSS).
6. **Child Outcomes:** Information on the child's developmental progress, health status, and any changes observed since the diagnosis.
Quantitative data was analyzed using descriptive and inferential statistics. Descriptive statistics summarize the demographic characteristics, satisfaction levels, and service utilization patterns. Inferential statistics, including chi-square tests and regression analysis, were used to examine the relationships between satisfaction levels, utilization of services, and outcomes for both parents and children. The analysis also explores potential confounding factors such as socioeconomic status and educational level.

RESULTS

Table 1: Distribution Of Child By Age, Gender And Residence

Variables	Category	No of children (N)	Percentage (%)
Age Category	Infants (<1 year)	2	3.5
	Toddlers (1-3 years)	22	37.9
	Preschool (3-6 years)	34	58.6
Gender	Male	23	39.6
	Female	35	60.4
Residence	Urban	30	51.7
	Rural	28	48.3
	Total	**58**	**100**

Figure 1: Distribution of child by age, gender and residence

Table 1 presents the distribution of children by age, gender and residence in a sample of 58 individuals. The mean age was 3.67±1.40. The majority of children in the sample belong to the preschool age group (3-6 years), constituting 58.6% of the total sample followed by toddlers (1-3 years) comprising 37.9% of the sample. Infants (<1 year) are the smallest group, representing only 3.5% of the total. According to age data, there are 23 males and 35 females. Males account for 39.6% of the sample, while females comprise 60.4%. There is a notable difference in the number of males and females in the sample, with females outnumbering males by approximately 20%. The data on the distribution of residence types among a surveyed population, indicating that urban residents account for 51.7% while rural residents make up 48.3%.

Table 2: Distribution Of Age In Mother And Father Of CP Child:

	Frequency (N)		Percentage (%)	
Age group	**Mothers**	**Fathers**	**Mother**	**Fathers**
21-30	23	13	39.7	22.5
31-40	22	30	37.9	51.7
41-50	11	11	18.9	18.9
>50	2	4	3.5	6.9
Total	**58**	**58**	**100**	**100**

The table 2 categorizes study participants based on the age ranges of their mothers and fathers. Mothers aged between 21 and 30 years old represent the largest proportion of participants, constituting 39.7% of the total sample. The next significant group comprises mothers aged 31 to 40, with 37.9% of participants falling into this age range. A smaller but still notable portion of the participants have mothers aged 41 to 50, comprising 18.9% of the sample. Only a small percentage of participants, 3.5%, have mothers over the age of 50. Fathers aged between 31 and 40 years old represent the largest proportion of participants, constituting 51.7% of the total sample. This indicates that a significant portion of the fathers in the study fall within this age range. Participants with fathers aged 21 to 30 make up 22.5% of the sample. While smaller than the 31-40 age group, it still represents a notable portion of the participants. The age group of fathers between 41 and 50 years old comprises 18.9% of the sample, indicating a smaller but still significant representation. Only a small percentage of participants, 6.9%, have fathers over the age of 50, suggesting that advanced paternal age is less common within this sample.

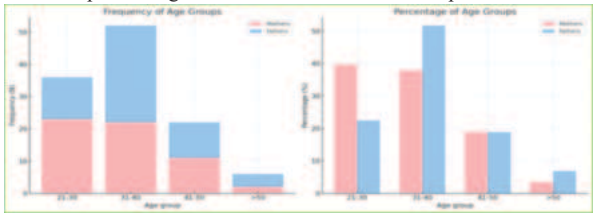


Figure 2: Distribution of age in mother and father of CP child

Table 3: Distribution Of Study Participants By The Occupation Of Parents And Care Taker At Home

		Frequency (N)		Percentage (%)	
		Mothers	**Fathers**	**Mothers**	**Fathers**
Employment status	Full time	7	49	12.1	84.5
	Part time	10	5	17.3	8.6
	Not working	41	4	70.6	6.9
	Total	**58**	**58**	**100**	**100**
		Frequency (N)		**Percentage (%)**	
Care taker at home	Mother	44		75.8	
	Father	7		12.1	
	Others	7		12.1	
	Total	**58**		**100**	

The table 3 categorizes study participants based on the employment status of their mothers and fathers; it also illustrates the distribution of primary caregivers among the study participants within their household. Majority of mothers in the sample are categorized as not working, comprising 70.6% of the total participants. 17.3% of participants have mothers who work part-time, suggesting a smaller but notable portion of mothers are engaged in part-time employment. Only a small proportion of mothers are full time working constituting about 12.1% of total. The majority of fathers in the sample are categorized as full-time employed, comprising 84.5% of the total participants. A smaller but notable portion of participants have fathers who work part-time, representing 8.6% of the sample. This suggests that some fathers balance work with other responsibilities or may have flexible work arrangements. Only a small percentage of fathers in the sample are categorized as not working, comprising 6.9% of the total participants. The majority of participants, constituting 75.8%, have their mothers as the primary caregivers at home. This high percentage reflects the traditional role of mothers in caregiving within many

households. Meanwhile, fathers serve as the primary caregiver for 12.1% of the participants, indicating their involvement in caregiving responsibilities, albeit to a lesser extent compared to mothers. Additionally, there are cases where other individuals besides the parents, such as grandparents or other family members, serve as primary caregivers for 12.1% of the participants.

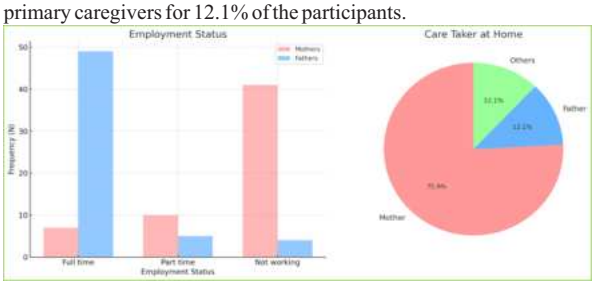
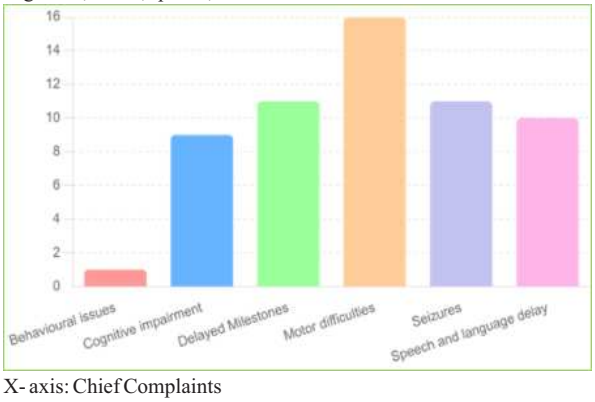


Figure 3: Distribution of study participants by the Occupation of parents and care taker at home

Table 4: Distribution Of Study Participants By Chief Complains

Chief Complains	Frequency (N)	Percentage (%)
Behavioural issues	1	1.7
Cognitive impairment	9	15.6
Delayed Milestones	11	18.9
Motor difficulties	16	27.6
Seizures	11	18.9
Speech and language delay	10	17.3
Total	**58**	**100**

The table 4 presents the distribution of study participants based on their chief complaints, categorizing them into six main categories. The data encompasses a total sample size of 58 participants. The most frequently reported chief complaint among the participants is motor difficulties, accounting for 27.6% of the total sample. Following closely behind are delayed milestones and seizures, each reported by 18.9% of the participants. Cognitive impairment and speech and language delay are also notable concerns, reported by 15.6% and 17.3% of the participants, respectively. Behavioral issues are the least commonly reported chief complaint, with only 1.7% of the participants experiencing such concerns. This distribution sheds light on the range of challenges faced by the participants, spanning cognitive, motor, speech, and behavioral domains.



X- axis: Chief Complaints
Y-axis: Frequency (N)
Figure 4: Distribution of study participants by chief complains

Table 5: Satisfaction Level Of Parents Regarding The Information Provided To Them About Cerebral Palsy And Its Implications Following The Diagnosis Confirmation.

Variable	Mean	Standard Deviation
The information provided helps me feel competent as a parent	3.98	1.000
I receive written information about my child's therapy.	3.84	0.875
The healthcare professionals provide a caring atmosphere	3.90	0.765
I have the freedom to choose when and what type of information I receive	3.98	1.000
The healthcare team addresses my child's holistic needs.	4.05	0.907
At least one team member works with us over a long period	3.91	0.756
Treatment choices are fully explained to me	3.95	0.999
I have opportunities to make decisions about treatment	3.98	1.000
Enough time is provided for discussions without feeling rushed	4.02	1.000
Plans are made collaboratively with the healthcare team.	4.07	0.856
I am treated as an equal partner in my child's care.	4.02	0.982
Information provided about my child is consistent.	4.05	0.887
I receive written updates on my child's progress.	4.00	1.012
Results from assessments are communicated to me.	3.98	1.000
Information about available services is provided.	4.07	0.835
Information about my child's disability is made available.	4.02	0.946
Opportunities are provided for the entire family to obtain information.	4.00	0.991
Advice on accessing information or contacting other parents is given.	3.98	1.000

The table 5 presents the satisfaction level of parents regarding the information provided to them about cerebral palsy and its implications following the confirmation of diagnosis. Each question was rated on a scale of 1 to 5, where 5 indicated high satisfaction and 1 indicated high dissatisfaction. The table includes variables such as the competence parents feel as caregivers, the provision of written information about therapy, the caring atmosphere provided by healthcare professionals, the freedom to choose information, addressing holistic needs, continuity of care, explanation of treatment choices, involvement in decision-making, sufficient time for discussions, collaborative planning with the healthcare team, being treated as equal partners in care, consistency of information, receiving updates on progress and assessment results, information about available services and the child's disability, opportunities for family members to obtain information, and advice on accessing information or contacting other parents. On average, parents expressed high satisfaction across all variables, with mean ratings ranging from 3.84 to 4.07. Additionally, the standard deviations, which indicate the degree of variability in responses, are relatively low, suggesting consistency in satisfaction levels among respondents. Overall, the table highlights the positive perception of parents regarding the information provided to them about cerebral palsy and its implications, indicating a supportive and informative healthcare environment that empowers parents in their caregiving role and decision-making process.

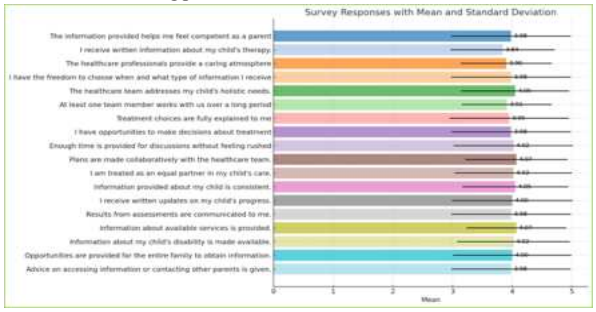
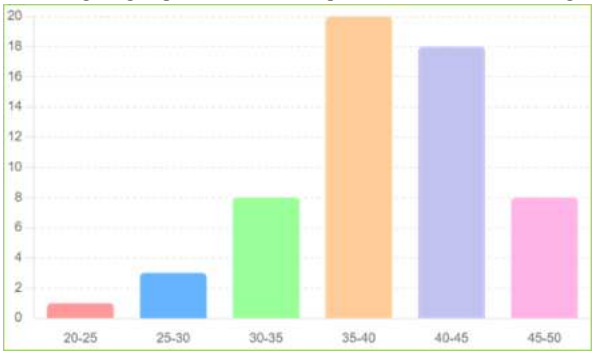


Figure 5: Satisfaction level of parents regarding the information provided to them about cerebral palsy and its implications following the diagnosis confirmation.

Table 6: Distribution Of PSS Scores According To Stress Level Of Parents:

PSS Score Interval	Frequency (N)	Percentage (%)
20-25	1	1.72
25-30	3	5.17
30-35	8	13.79
35-40	20	34.48
40-45	18	31.03
45-50	8	13.79
Total	**58**	**100**

The table 6 presents the distribution of Parental Stress Scale (PSS) scores among parents of children with cerebral palsy, reflecting their stress levels. The intervals range from 20 to 50, with higher scores indicating greater stress. The data shows that only 1.72% of parents fall into the 20-25 intervals, indicating relatively low stress. The 25-30 intervals include 5.17% of parents, suggesting slightly higher but still manageable stress levels. A notable 13.79% of parents fall into the 30-35 range, indicating moderate stress. The largest group, 34.48%, falls within the 35-40 interval, highlighting high stress levels. Similarly, 31.03% of parents are in the 40-45 range, showing very high stress. Finally, 13.79% of parents score between 45-50, representing the highest stress levels. This distribution underscores the significant stress experienced by parents of children with cerebral palsy, emphasizing the need for robust support systems to help them manage their caregiving responsibilities and improve their overall well-being.



X-axis: PSS Score Interval
Y-axis: Frequency (N)

DISCUSSION

We conducted a cross sectional study with the to evaluate the level of parental satisfaction with the information provided post-diagnosis of cerebral palsy (CP) and to understand the implications of this information on the utilization of rehabilitation services and overall outcomes for both the child and the family among 58 children diagnosed with Cerebral Palsy.

We studied the satisfaction level of parents regarding the information provided to them about cerebral palsy and its implications following the confirmation of diagnosis. We included variables such as the competence parents feel as caregivers, the provision of written information about therapy, the caring atmosphere provided by healthcare professionals, the freedom to choose information, addressing holistic needs, continuity of care, explanation of treatment choices, involvement in decision-making, sufficient time for discussions, collaborative planning with the healthcare team, being treated as equal partners in care, consistency of information, receiving updates on progress and assessment results, information about available services and the child's disability, opportunities for family members to obtain information, and advice on accessing information or contacting other parents. On average, parents expressed high satisfaction across all variables, with mean ratings ranging from 3.84 to 4.07. The current findings align with the study by Kruijsen-Terpstra et al. (5), indicating that parents require various types of information as their child grows. Following the diagnosis, parents show more interest in information regarding the causes of the disorder and potential impairments. The necessity for information remains constant in these parents' lives; however, the focus shifts along with the children's development, emphasizing ongoing changes. In 2009, Buran and colleagues found several parental information needs topics, such as services available in the community (e.g., rehabilitation centers) and emotional/physical growth and development (6). We tried to impart all these knowledge to the parents, and they were well satisfied by the knowledge given to them.

In our study we observed that 24.1% reported facing challenges related to assisting with mobility, highlighting the significant impact on mobility-related tasks. Additionally, a smaller proportion of participants reported challenges in bathing and dressing (6.9%), lifting and carrying (13.8%), feeding and swallowing (13.8%), and medication management (15.6%). Managing seizures emerged as a prominent challenge, with 25.8% of participants reporting difficulties in this area. Also, the majority, comprising 72.4%, reported experiencing social challenges. This distribution highlights the prevalence of social challenges among parents or caregivers of children with cerebral palsy, indicating the significant impact on their social well-being and support systems. These findings are consistent with the parental challenge “Additional daily parenting tasks” found by Whittingham et al. in 2011. (7) Parents of children with CP are at an increased risk of experiencing high stress, anxiety, and depression. (8) Our findings align with prior research suggesting that children with disabilities like cerebral palsy and their families often encounter social stigma and discrimination (9, 10).These challenges include difficulties in social interactions, stigma, discrimination, limited access to support networks, or strained relationships due to caregiving responsibilities. Understanding these social challenges is crucial for developing interventions and support services aimed at addressing social isolation, fostering social inclusion, and enhancing the overall quality of life for both caregivers and children with cerebral palsy.

The distribution of Parental Stress Scale (PSS) scores among parents of children with cerebral palsy highlights substantial stress levels. A significant majority, 34.48% and 31.03%, fall within the high (35-40) and very high (40-45) stress intervals, respectively. This indicates that most parents face considerable stress due to their caregiving responsibilities. Only 1.72% of parents are in the lowest stress range (20-25), suggesting minimal stress is rare in this population. Moderate stress (30-35) affects 13.79% of parents, showing that a notable group experiences significant but manageable stress. However, the high concentration of parents in the upper stress ranges underscores the need for robust support systems. These parents require substantial emotional, psychological, and practical assistance to manage their stress effectively and prevent burnout. The 13.79% of parents in the highest stress interval (45-50) further emphasizes the critical need for intensive intervention. Addressing these high stress levels is essential for improving the well-being of parents and the quality of care they provide to their children. Comprehensive support systems are crucial to help these parents cope with the demands of raising a child with cerebral palsy, ultimately promoting a healthier family environment.

CONCLUSION

In conclusion, this study sheds light on parental perspectives on caring for a child with cerebral palsy following the confirmation of diagnosis. It highlights the challenges faced by parents, the impact on economic stability, family life, and the various social and psychological challenges encountered. Despite these challenges, parents expressed high satisfaction with the information provided to them about cerebral palsy and its implications. This underscores the importance of providing comprehensive support to parents of children with cerebral palsy, not only in terms of medical care but also in terms of psychological and social support. Further research with a larger and more diverse sample, as well as longitudinal studies, are needed to better understand the needs of parents and caregivers of children with cerebral palsy.

REFERENCES

1. Guimarães A, Pereira A, Oliveira A, Lopes S, Nunes AR, Zanatta C, Rosário P. Parenting in Cerebral Palsy: Understanding the Perceived Challenges and Needs Faced by Parents of Elementary School Children. Int J Environ Res Public Health. 2023 Feb 21;20(5):3811. doi: 10.3390/ijerph20053811. PMID: 36900819; PMCID: PMC10001820.
2. Hulst RY, Gorter JW, Voorman JM, Kolk E, Van Der Vossen S, Visser-Meily JMA, Ketelaar M, Pillen S, Verschuren O. Sleep problems in children with cerebral palsy and their parents. Dev Med Child Neurol. 2021 Nov;63(11):1344-1350. doi: 10.1111/dmcn.14920. Epub 2021 May 15. PMID: 33990937; PMCID: PMC8597175.
3. Ayanniyi O, Abdulsalam K. Profile of children with cerebral palsy attending outpatient physiotherapy clinics in southwest Nigeria. African J Physiother Rehabil Sci. 2015;7(1–2):32–9. 10.4314/ajprs.v7i1-2.6. [CrossRef]
4. Kakooza-Mwesige A, Forssberg H, Eliasson AC, Tumwine JK. Cerebral palsy in children in Kampala, Uganda: clinical subtypes, motor function and co-morbidities. BMC Res Notes. 2015;8:166. 10.1186/s13104-015-1125-9. [PMC free article] [PubMed]
5. Kruijsen-Terpstra A.J.A., Verschuren O., Ketelaar M., Riedijk L., Gorter J.W., Jongmans M.J., Boeije H. Parents' experiences and needs regarding physical and occupational therapy for their young children with cerebral palsy. Res. Dev. Disabil. 2016;53:314–322. doi: 10.1016/j.ridd.2016.02.012. [PubMed] [CrossRef] [Google Scholar]
6. Buran C.F., Sawin K., Grayson P., Criss S. Family Needs Assessment in Cerebral Palsy Clinic. J. Spec. Pediatr. Nurs. 2009;14:86–93. doi: 10.1111/j.1744-6155.2008.00176.x. [PubMed] [CrossRef] [Google Scholar]
7. Whittingham K., Wee D., Sanders M.R., Boyd R. Responding to the challenges of parenting a child with cerebral palsy: A focus group. Disabil. Rehabil. 2011;33:1557–1567. doi: 10.3109/09638288.2010.535090. [PubMed] [CrossRef] [Google Scholar]
8. Sivaratnam C., Devenish B., Howells K., Chellew T., Reynolds K., Rinehart N. Risk factors for mental health difficulties in parents of children with cerebral palsy: A systematic review and meta-analysis. Clin. Psychol. 2021;25:1–18. doi: 10.1080/13284207.2020.1829945. [CrossRef] [Google Scholar]
9. Anaby D., Hand C., Bradley L., DiRezze B., Forhan M., DiGiacomo A., Law M. The effect of the environment on participation of children and youth with disabilities: A scoping review. Disabil. Rehabil. 2013;35:1589–1598. doi:

10.3109/09638288.2012.748840. [PubMed] [CrossRef] [Google Scholar]
10. Mushi D., Burton K., Mtuya C., Gona J.K., Walker R., Newton C.R.J.C. Perceptions, social life, treatment and education gap of Tanzanian children with epilepsy: A community-based study. Epilepsy Behav. 2012;23:224–229. doi: 10.1016/j.yebeh.2011.12.003. [PMC free article] [PubMed] [CrossRef] [Google Scholar]