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Abstract

Despite the rising prevalence of children with medical complexity who need extensive medical care at home, the literature evaluating pediatric home healthcare has not been well summarized. Our objective was to systematically review the evidence-base of pediatric home healthcare to understand what is currently know about access and quality of home healthcare for children. Pubmed, Ovid Medline, Embase, CINAHL, Cochrane Library, Proquest Dissertations and Theses Global were searched for studies in the United States, United Kingdom, Canada, and Australia English publications (1980-2020) regarding children (≤18 years) using shift-based home healthcare services. Blinded independent review was conducted followed by extraction of study characteristics including how each study examined access and/or quality, which was categorized using the National Academy of Medicine quality dimensions. Of 9533 abstracts, 101 were included. Most were US (82%) and regional (72%) studies. Half (54%) focused on home nursing followed by home services generally (43%). The majority (77%) evaluated access and patient-family centeredness (62%); their results identified consistent limitations in access and quality resulting in negative impacts on patients and families. Less than 20% of publications addressed safety, effectiveness or equity. Bias scoring found that quantitative studies were universally weak, but qualitative studies were mostly moderate or strong. Results are limited by design heterogeneity and exclusion of training research. While research in pediatric home healthcare has increased, studies remain observational and rarely evaluate quality in reproducible ways. More rigorous measures and interventional research are needed to improve this healthcare sector for children.

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Paid Family Caregiving for Children With Medical Complexity

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abstract

OBJECTIVES: We evaluated Colorado's paid family caregiver certified nursing assistant (CNA) program by assessing stakeholders' perceptions of the model's strengths and potential areas for improvement.

METHODS: A professional bilingual research assistant conducted key informant interviews of English- and Spanish-speaking certified nursing assistant (CNA) family caregivers (FCs), primary care providers, and pediatric home health administrators of children with medical complexity in the family caregiver CNA program. Interview questions focused on the program's benefits, drawbacks, and implications for the child and caregiver's quality of life. Transcripts were coded and analyzed, and themes summarizing program benefits and disadvantages were identified.

RESULTS: Semistructured interviews were completed by phone with 25 FCs, 10 home health administrators, and 10 primary care providers between September 2020 and June 2021. Overall, the program was highly valued and uniformly recommended for prospective families. Perceived benefits included: (1) fulfilling the desire to be a good parent, (2) providing stable and high-quality home health care, (3) benefitting the child's health and wellbeing, and (4) enhancing family financial stability. Perceived drawbacks included: (1) FCs experiencing mental and physical health burdens, (2) difficult access for some community members, (3) extraneous training requirements, and (4) low program visibility.

CONCLUSIONS: Given the perceived benefits of the family CNA program, the model may be considered for future dissemination to other communities. However, additional research and program improvements are needed to help make this a more equitable and sustainable home health care model for children with medical complexity.

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Dr Brittan conceptualized and designed the study, designed the data collection instruments, coordinated and supervised data collection, conducted the initial analyses, and drafted the initial manuscript; Ms Chavez designed the data collection instruments, collected data, and conducted the initial analyses; Ms Blakely conducted the initial analyses; Dr Dorsey Holliman conceptualized and designed the study, designed the data collection instruments, supervised data analyses, and critically reviewed and revised the manuscript; Dr Jeannie Zuk conceptualized and designed the study, designed the data collection instruments, conducted the initial analyses, supervised data analyses, and drafted the initial manuscript; and all authors critically reviewed and revised the manuscript, approved the final manuscript as submitted, and agree to be accountable for all aspects of the work.

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WHAT'S KNOWN ON THE SUBJECT: Traditional pediatric home health care models staffed by nonfamily caregivers often result in inconsistent services and quality of care for children with medical complexity and associated financial distress for their parents.

WHAT THIS STUDY ADDS: We showed that a paid family caregiver model addresses these deficiencies but also has drawbacks that need to be addressed to best serve children with medical complexity and their family caregivers.

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Children with medical complexity (CMC) have high healthcare utilization and significant unmet home health service needs.[1] CMC face chronic shortages of sufficient and qualified pediatric home healthcare workers because of variable hiring, training, and reimbursement practices.[2] These issues lead to caregiver job loss, financial insecurity, unsafe workloads, and significant stress for the family caregivers of CMC.[3–6]

In a national sample of surveyed family caregivers of CMC, 57% reported health care-related financial problems, 54% where a family member stopped working because of the child's health, and 49% that the family needed additional income for medical expenses.[7] In a separate study, parents of CMC were far more likely to report failure to pay rent or mortgage than parents of children with asthma.[6] The financial toxicity can be a substantial contributor to caregiver distress.[8]

Colorado developed a model, funded by its Medicaid program, to address these systems failings by allowing parents and/or relatives to be employed certified nursing assistants (CNAs) for their own medically complex children. Details of Colorado's family CNA program, including its's origins, eligibility, training and licensing, and administration are described elsewhere.[9] Through this program, parents are trained and licensed as CNAs and then hired by home health agencies to provide CNA care for their own children. The family CNA program has largely replaced traditional CNA care for CMC in Colorado (ie, CNA care provided by external, unrelated caregivers), with local home health agency stakeholders estimating that approximately 90% of pediatric home CNA care is provided by family caregivers as of 2021.

Although the family CNA program has compelling benefits, it has not been formally studied, and therefore actual benefits and drawbacks remain unknown. To address this gap, we assessed stakeholders' perceptions of the employed family CNA program through key informant interviews. By assessing this innovative model, we hope to raise awareness, identify strengths, and find areas for improvement that might facilitate future dissemination to other underserved and disadvantaged communities beyond Colorado.

METHODS

Study reporting is guided by the Consolidated Criteria for Reporting Qualitative Health Research[10] and was conducted in partnership with Family Voices Colorado, a grassroots advocacy group run by parents of children with special healthcare needs.

Recruitment and Sample

Semistructured interviews were conducted with CNA family caregivers (FCs), primary care providers (PCPs), and home health administrators (HHAs). PCPs and HHAs were included to examine the perspectives of healthcare workers familiar with the program. The study was approved by the Colorado Multi-institutional Review Board.

FC participants were eligible if they were the parent or a relative of a child with medical complexity less than 19 years old and provided licensed CNA care to the child at home. Since Hispanic and rural families may have lower access to pediatric home health,[11,12] we aimed to include at least 5 caregivers with Spanish as their preferred language and 5 living in rural areas. The FC interview guide was piloted with 5 participants and amended with their feedback before study use. PCPs of the same children were identified through the electronic health record. HHAs were administrative leaders of Colorado-based home health agencies that provide pediatric home healthcare services, such as CNA and home nursing care. The purposive sample strategy was based on available funds and time limits associated with the study's grant funding.

Eligible FCs were recruited using a recurring electronic health record report that identified children who were discharged from our children's hospital with home CNA services in the prior 3 months. A professional bilingual research assistant experienced in qualitative interviews recruited FCs by phone. PCPs and HHAs were invited to participate via phone or e-mail. Because of the 2020 coronavirus disease 2019 (COVID-19) restrictions on in-person research, consenting and interviews were conducted over the phone by the research assistant. All participants were compensated with gift cards. Interviews lasted approximately 30 to 60 minutes.

Interview Guides

Interview guides were based on the Impact-on-Family scale,[13] a review of published literature on CMC and research team discussions. FCs were asked to describe their child's medical conditions, their daily routines, and hours worked versus paid. Interview questions focused on the program's benefits, burdens, and implications for the child's and FC's quality of life (QoL). Demographic questions included age, race or ethnicity, marital status, education, relationship of FC to child, and urban or rural home (Appendix 1 in Supplemental Infomation).

Interviews for PCPs and HHAs broached similar questions about the program's benefits, burdens, and implications for the child and FC's QoL, (Appendices 2 and 3 in

Supplemental Infomation). PCPs were asked about their clinician type (pediatric, family practice, etc.), practice setting, and the percentages of children (and CMC) in their practice. HHAs were asked about their role in the agency and number of years spent in that role.

Analysis

Semistructured interviews were recorded, professionally translated, and transcribed verbatim. Although we prompted participants with questions about positive and negative aspects of the program, we chose not to apply a preemptive conceptual framework because of the exploratory nature of the work. We used an iterative, inductive strategy, drawing on qualitative content methodology and reflexive team analysis.[14,15] The transcripts were coded and analyzed using ATLAS.ti version 8.3.20 (Scientific Software Development, GmbH, Berlin). Three study team members (M.B., C.C., J.Z.) independently reviewed and coded a subset of transcripts to identify and define inductive codes. The research team met monthly to review the coded transcripts and to reconcile any discrepancies in the code definitions until a final codebook was developed and used to code the remaining transcripts. The coded data were analyzed to identify key themes summarizing the benefits, drawbacks, and impacts on patients and caregivers QoL of the family CNA model. After a final set of themes was developed, the executive director for Family Voices Colorado facilitated a virtual presentation of results to the Children's Disability Advisory Committee to the Colorado Department of Healthcare Policy and Financing to elicit additional feedback from community advocates and policymakers.

RESULTS

Semistructured interviews were conducted with 25 English- and Spanish-speaking FCs, 10 HHAs, and 10 PCPs between September 2020 and June 2021. Children of FCs (age range: 1–18 years; 40% female) had variable chronic conditions, including congenital genetic and metabolic disease, cerebral palsy, seizures, and intellectual and developmental disabilities (Supplemental Table 2). Many relied on medical technologies such as oxygen, feeding tubes, central lines, and ventilators, and almost all had additional home health services such as skilled nursing and physical, occupational, or speech therapies.

FCs were primarily the child's mother (76%), sister (8%), brother (4%), father (4%), and grandmother (4%). Seven (28%) FCs were Spanish-speaking and 8 (32%) lived in a rural community (Table 1). PCPs were either physicians or nurse practitioners from various practice types, including a children's hospital complex care clinic and urban or rural community pediatric or family practice clinics. HHAs were administrators or managers from local home health agencies that hire FCs as CNAs. In general, FCs and HHAs were more knowledgeable about the program than PCPs, though pediatricians with a higher mix of CMC were more familiar with the program.

The following themes summarizing the benefits, drawbacks, and impacts on patients' and caregivers' QoL of the family CNA model (Fig 1; additional quotes, Supplemental Table 3).

Perceived Benefits

Fulfilling the Desire to be a Good Parent

FCs wanted to become their child's CNA because of their emotional and moral commitment to care for their child as a good parent. FCs perceived that they could provide better care for their child than a stranger, even if it meant working many more hours than compensated or sacrificing their own goals or wellbeing.

> "And we know that he's being treated correctly, and I know just like his sounds, what he needs, what he's feeling. Where if we had a private duty nurse that changes all the time, they're not going to know him like I do ... " – FC

> "So philosophically, I would much rather just be dad ... I'm glad I

TABLE 1 Self-Reported Family Caregiver Demographic Characteristics

Category	Demographic Variable	*N* (%)
Sex	Female	23 (92)
	Male	2 (8)
Race or ethnicity	American Indian or Alaskan Native	1 (4)
	Black or African American	4 (16)
	Hispanic or Latino	11 (44)
	White	9 (36)
Preferred language	Spanish	7 (28)
	English	18 (72)
Education	Less than high school	5 (20)
	GED or high school grad	7 (28)
	Some college or college	13 (52)
Marital status	Married	13 (52)
	Single or other	12 (48)
Home address	Rural	8 (32)
	Urban	17 (68)

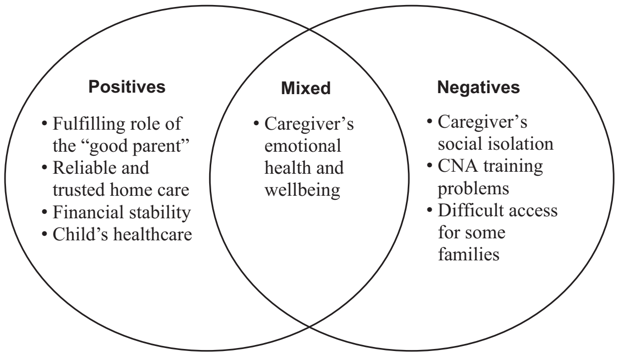

FIGURE 1
Summary of themes reflecting program positives and negatives.

> took the course. I'm glad I have these skill sets. But this was not my calling in life, right? And so, I'm just trying to be a good father ... " – FC

Providing Stable and High-quality Home Healthcare

The idea that FCs could provide higher quality care was pervasive, partly because some had poor experiences or were distrustful of outside home healthcare providers, and others did not have consistently available home CNA support

> " ... There were so many factors that just made me decide – Well, if I want this done at a good level, I might as well be the person that's doing it. Then I eliminate the in-the-house problem. I eliminate the driving problem. I eliminate quality problem. I eliminate 'I-don't-know-you' problem. And we get a little extra money every month that could be used to do something nice." – FC

Benefitting the Child's Health and Wellbeing

Interview participants regularly agreed that the program is beneficial for CMC, not only because of the consistency, superior quality, and better coordination of home healthcare, but also because the child is cared for by an emotionally invested and committed caregiver.

> "But overall, in my experience, it's a less stressful situation to have a parent consistently providing care. That patient feels a level of bond and a level of trust that really can never be reached with an external caregiver, particularly if that child has cognitive deficits ... " – HHA

Additional benefits were attributed to the FC's accumulation of expertise and confidence in managing the child's healthcare issues. Respondents determined that working within the family CNA model provided FCs with more discerning medical judgement and enhanced expertise in managing complex health and equipment issues.

> "I feel like the families who do the parent CNA program, I feel like they are very competent in doing this. I feel like they get very accustomed to how to troubleshoot the trach or the vent or the various equipment(s) that their child is using" – PCP

Enhancing Family Financial Stability

Interview participants viewed the economic benefits of the program as indispensable but also flawed in some cases because of under-compensation for hours worked or lack of pay during a child's hospitalization (particularly problematic for prolonged admissions). However, the overriding sentiment was that the program was "life-changing," and a way for families to stay afloat financially or avoid reliance on public assistance programs.

> "This is our lifeline. We cannot lose this funding. We cannot. And I take this very seriously. Really, if I was a single mom, and I didn't have my husband, to go out there and work, what would I do man? I would be destitute, on welfare, food stamps and everything. I mean, I wouldn't be able to take care of my family at all." – FC

Perceived Drawbacks

FCs Experiencing Mental and Physical Burdens

Many FCs were burdened by overwork, under-compensation for hours worked, exhaustion, and occupational injuries. For the most medically complex and chronically ill children, it was understood that around-the-clock caregiving was required.

> "It's not the CNA problems. It's being a parent of a special needs child. The basic thing is you never get a break ... They work 24/7 and can't go on a vacation either with or without your child- ... you can't leave on your own because you can't find anybody to care for them." – PCP

Because of the chronic nature of care, FCs were prone to sleep deprivation, chronic "physical and mental" exhaustion, poor self-care, injury, and social isolation. Some FCs felt that they were neglecting other family members, and a few disclosed mental health conditions such as depression and anxiety.

> "As much time as some of us parents do taking care of your child you just don't feel like you have the time to really take care of yourself in the way that you probably need to." – FC

Rarely, FCs expressed that they had little alternative because of financial needs or distrust of outside workers.

> "I feel like it makes you a prisoner because you need the money to take care of your child, but then you don't want to hire outside help because this is your income. So, it actually traps you into, 'I have to do these hours. I have to stay home with my child,' but I need to because I need the money." – FC

Nonetheless, interview participants recognized several sources of emotional benefit for FCs, including joy of caregiving, providing financially, knowing that their child was receiving good care, opportunity to spend more time with the child, and developing additional skills and competencies. The latter advantage was viewed as a direct result of the training in some cases, but also stemmed from intimate involvement in the care plans that allowed FC's to be more well-informed advocates for their children. FCs unanimously recommended the program to prospective families for several reasons, including the acquisition of new skills and correct techniques to care for their children.

> "I would tell them to do it, that it is not difficult, and they will also learn the right techniques to improve what they are already doing." -FC.

Although social isolation and loneliness were acknowledged drawbacks for some, the family CNA program was seen to add social and emotional supports through new social networks and access to agency nursing oversight or expertise.

> "I think that having that type of education and training would make me a better parent but would also really make me a better advocate for my child. And having those connections through an agency, with nurses, with physicians would also give me access to help navigate an already very complicated system so I can just better understand what opportunities, waivers, services are available for my child" – HHA

Difficult Access for Some Community Members

Respondents acknowledged that some families faced program access barriers because of immigration status, low health literacy, language barriers, or rural home location. Barriers were also attributed to bureaucratic complexities of eligibility and enrollment or to shortages of access to training and testing, particularly for rural families.

> "In taking the test, we have families where the parents' reading level was not at a level that they were able to read what they needed to do for the test. So those are kind of barriers, the language and the literacy, for our families." – PCP

Extraneous Training Requirements

There was an appreciation for the opportunity for FCs to use the training as a springboard to other employment opportunities or career growth. However, CNA training often had heavy focus on geriatric or nursing home care. Course length varied widely from 10 days to several months, and class schedules were sometimes inflexible to accommodate difficult circumstances such as health care emergencies.

> "I spent the weekend in a nursing home. My son is seizing out, dying in the hospital and I'm singing to a Down syndrome patient in a nursing home, doing my clinical [training]. I mean it was just really taxing on me." - FC

Low Program Visibility

Some of the FCs learned of the program through happenstance (eg, through a hospital nurse, family of another patient, or family friend) and stakeholders acknowledged lack of awareness for the program.

> "We talk [to family caregivers] daily. They are very, very grateful for the program. They talk about how life-changing it is. And it still surprises me that, even though this program has been around since 2001, the awareness in the public of this program still is not very good." – HHA

Response of Community Advocates and Policymakers

When study results were presented to the Children's Disability Advisory Committee to the Colorado Department of Healthcare Policy and Financing, committee members reflected on the importance of continued funding for this essential program, queried whether there were unmet needs among children with mental and behavioral health conditions, and expressed a desire to address FC respite and inequitable access. Committee members also identified the need for more pediatric specific training and better access for non-English speaking FCs (Fig 2).

DISCUSSION

This study offers a glimpse into the lives of employed family CNA

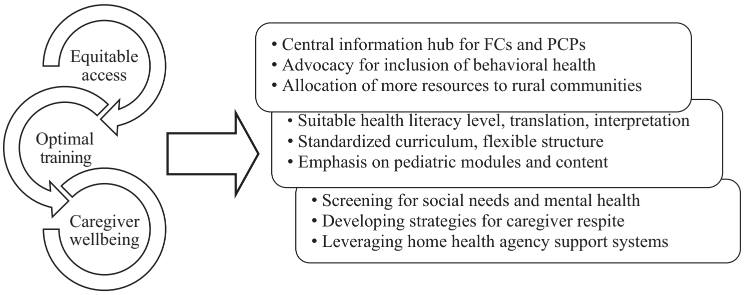

FIGURE 2

Interconnecting challenges and potential improvements to address them.

caregivers through qualitative methods. Our study indicates consensus among many local stakeholders that it is a critically needed program with many positive attributes. Yet, there are acknowledged harms that can be addressed to improve the model's effectiveness, some of which align with previously identified priority areas for research and systems improvements for children with medical complexity.[16,17]

Extant literature focuses on the demands of informal or unpaid caregiving and the implications of traditional pediatric home healthcare insufficiencies.[5,18,19] This study is novel in describing a caregiving model that addresses these deficiencies, particularly pediatric home health workforce shortages, quality problems, and associated parental job loss and financial distress. The program enhances caregiver confidence and self-efficacy, facilitates emotional bonding with the child, and provides structure for both social and professional supports. It is also seen as positive for the child's health and wellbeing and serves as an important safeguard against the exacerbating impacts of a pandemic on families of CMC.[20,21]

However, the program also poses significant emotional and physical harms to family caregivers, who are often exhausted, and is some cases, socially isolated, burned out, and experiencing deteriorating physical and mental health. Although it is hard to tease apart the effects of chronic caregiving, the program bears some influence because of the allure of financial relief and by enabling the "good parent" heuristic for these caregivers.[22] This belief system prioritizes the parent's sense of duty to ensure that the child feels loved and is well cared for, while also empowering the parent to be an informed advocate. In so doing, the program may engender overwork, social isolation, and other challenges to physical health and emotional wellbeing. This study suggests that mental health screening and corresponding interventions such as respite care are needed to alleviate social isolation, physical injury, and emotional distress.[23–25]

From the perspective of healthcare equity, the family CNA program undoubtedly improves access to high-quality home healthcare and financial security for many vulnerable and underserved patients and families. Yet, within the training process and administration of the program, there are evident disparities based on preferred language, immigration status, health literacy, and home location. Similar themes were described in a recent study of caregiver and provider experiences of home healthcare quality for children with medical complexity.[26] Community advocates reflecting on our findings also raise concerns about ineligibility for patients with severe behavioral or mental health conditions. Awareness of institutional policies, systemic biases, and funding gaps that enable these disparities should be acknowledged as a first step to designing a more equitable and accessible family CNA model of care.[27]

Finally, the CNA training would benefit from standardization, a focus on pediatric complex care, flexibility through virtual education options,[28] and appropriate health literacy and translation of course and test materials. This would help to improve client preparedness, satisfaction, and successful completion of training and licensing requirements.

LIMITATIONS

We evaluated a unique program in 1 geographic setting, and therefore, benefits, harms, and lessons learned may not be directly applicable to other paid family caregiving models in other states. Future studies comparing these programs may yield important insights. We did not assess costs associated with this program that would be of interest for future implementation.[29] COVID-19 curtailed our ability to recruit for in-person interviews, and there may be a difference between participants that interview in-person versus by phone and there is a chance that we may not have captured caregivers who were not able to access the program or had more negative views of the program (ie, selection bias). Finally, the COVID-19 pandemic may have influenced responses because of associated increases in stress and social isolation and disruptions in available home health services.

CONCLUSIONS

Given the disarray of the current pediatric home healthcare landscape[2] and the extensive home health needs of these families, it is imperative to develop and disseminate novel home healthcare models for CMC.[30] Colorado's family CNA model holds promise for replication and dissemination to other communities but requires additional research and program improvements to make it a more equitable and sustainable program.

ABBREVIATIONS

CMC: children with medical complexity
CNA: certified nursing assistant
FCs: family caregivers
HHAs: home health administrators
PCPs: primary care providers

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Psychosocial and Economic Burden on Families of Children With Cerebral Palsy: A Correlation With Locomotor Severity

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Abstract

Background: Cerebral palsy (CP) is a condition that often has significant psychosocial and economic impacts on the caregivers of affected children.

Objective: This study aimed to assess the association between the Gross Motor Function Classification System (GMFCS) level and the psychosocial and economic impact on caregivers of children with CP.

Methodology: A hospital-based cross-sectional observational study was conducted on children with CP aged 2-14 years, admitted to the Inpatient Department (IPD) or attending the District Early Intervention Center (DEIC) for physiotherapy at a teaching hospital in Odisha, from December 2020 to November 2022. In DEIC, appropriate screening and therapy as per requirement is given to the high-risk infants. Early detection of CP is done. Children with CP come here with their parents for physiotherapy, occupational therapy, hearing, vision, and development assessment. Tools used included the GMFCS - Expanded and Revised (GMFCS-ER), a five-level classification system, the Modified Updated Kuppuswamy Socioeconomic Scale (2021) for socioeconomic status (SES), and the Pai and Kapur Family Burden Interview Scale.

Results: A total of 160 children with CP were included in the study, with 98 males and 62 females, resulting in a male-to-female ratio of 1.58:1. Out of 160 children with CP, the socioeconomic distribution showed that 73 (45.6%) belonged to the upper-lower class, 68 (42.5%) to the lower-middle class, 9 (5.6%) to the lower class, and 10 (6.3%) to the upper-middle class. Regarding functional levels of 160 children with CP, 22 (13.8%) of children were in GMFCS class I, 30 (18.8%) in class II, 16 (10%) in class III, 17 (10.6%) in class IV, and 75 (46.7%) in class V. Financially, out of 160 families of children with CP, 75 (46.9%) families were moderately burdened, 84 (52.5%) were severely burdened, and only 1 (0.6%) reported no financial burden. Regarding psychosocial impact, 94 (58.8%) families experienced moderate disruption of family leisure, while 44 (27.5%) experienced severe disruption. Physical health was moderately affected in 73 (45.6%) families, and 14 (8.8%) reported a severe impact. Mental health was moderately affected in 88 (55%)of families, while 33 (20.6%) experienced severe mental health issues. There was a statistically significant association between the GMFCS level of the child and the psychosocial and economic burden on families.

Conclusions: The study concludes that higher GMFCS levels in children with CP are associated with a greater psychosocial and economic burden on their families.

Categories: Neurology, Psychiatry, Pediatrics
Keywords: cerebral palsy, economic burden, gmfcs, psychosocial stress, rehabilitation

Introduction

Cerebral palsy (CP) is recognized as the most prevalent childhood disability, affecting approximately 2 to 3 children per 1000 live births globally [1,2,3]. In India, the prevalence is slightly higher, at 2.95 per 1000 surveyed children [4]. CP encompasses a group of permanent movement disorders that result from damage to the developing brain, either during pregnancy, childbirth, or shortly after birth. These motor impairments affect the child's ability to control their muscles and body movements, often leading to lifelong challenges in mobility, posture, and coordination [5]. The disorder is associated with various degrees of severity, classified through the Gross Motor Function Classification System (GMFCS), which ranges from level I (mild impairment) to level V (severe impairment) [6].

The care and management of children with CP rely heavily on a multidisciplinary team approach, involving pediatricians, neurologists, physiotherapists, occupational therapists, and educators [7]. However, the central role in the daily care and rehabilitation of these children is often played by parents and other family members [8]. These caregivers must be actively involved in every stage of the child's treatment, including

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managing healthcare appointments and physiotherapy sessions and ensuring adherence to treatment protocols. While this involvement is crucial for the child's well-being, it places a significant psychosocial and economic burden on the family [9].

The psychosocial impact on caregivers includes emotional stress, mental health challenges, disruption of social life, and a feeling of isolation, as families may struggle to balance the needs of their child with CP and the demands of their personal and professional lives. Financially, the continuous need for medical treatments, rehabilitation, assistive devices, and specialized care can lead to substantial economic strain, particularly for families with lower socioeconomic status (SES). Additionally, the time and energy required for caregiving may limit the ability of one or both parents to engage in full-time employment, further exacerbating financial difficulties [10].

This study seeks to quantify the psychosocial and economic stress experienced by families of children with CP and identify key factors associated with these challenges. By correlating the child's functional ability, as assessed by the GMFCS, with the family's SES and the burden they experience, the study aims to provide valuable insights into the predictors of caregiver stress. Understanding these relationships can help healthcare professionals design more supportive interventions for families, improving both the quality of life for children with CP and their caregivers.

Materials And Methods

This hospital-based cross-sectional observational study was conducted at Sriram Chandra Bhanja Medical College and Hospital (SCBMCH) and Sardar Vallabhbhai Patel Post Graduate Institute of Pediatrics (SVPPGIP), Cuttack, Odisha, from December 2020 to November 2022. The study population comprised children aged 2 to 14 years diagnosed with CP. Taking CP prevalence as 2.95 children and confidence interval as 95%, our sample size was calculated as 336. As the study was done during the COVID era from December 2020 to December 2022, fewer children with CP attended our District Early Intervention Center (DEIC) for physiotherapy. A total of 160 children with CP from the Inpatient Department (IPD) and DEIC, who met the inclusion criteria, were included in the study. In the DEIC, children with physical challenges, including CP, autism, attention-deficit/hyperactivity disorder (ADHD), and other conditions, come to receive various therapies. This is a government setup available in all districts of India. It is located at the district headquarters hospital. Multidisciplinary departments such as physiotherapy, occupational therapy, psychology, ophthalmology, dentistry, and audiology are all present. Here, early intervention is done for high-risk infants to whom the pediatrician refers. Children with CP come here with their parents for physiotherapy, occupational therapy, hearing, vision, and development assessment. Parental consent was obtained before their participation. Children aged 2-14 years who were diagnosed with CP were included. Children with associated progressive neurological, metabolic, neuromuscular, neurodegenerative, rheumatological, or other chronic debilitating disorders, incomplete questionnaires, and critically ill were excluded. Tools used are the Gross Motor Function Classification System - Expanded and Revised (GMFCS-ER) [11], the Modified Updated Kuppuswamy Socioeconomic Scale 2021 [12], and the Pai and Kapur Family Burden Interview Scale (FBIS), as represented in the Appendix [10,13].

GMFCS-ER is a five-level classification system designed to assess gross motor function in children with CP. First introduced in 1997 and revised in 2008, the GMFCS-ER evaluates children's ability to perform motor activities such as sitting, walking, and mobility. Each child was classified into one of the five GMFCS levels for this study. A family's SES is based on three parameters: the head of the family's education level, occupation, and overall family income. The scale classifies families into five socioeconomic classes: upper, upper-middle, lower-middle, upper-lower, and lower, with scores ranging from 3 to 29. The FBIS is a semi-structured interview schedule comprising 24 items grouped into six dimensions: financial burden, disruption of routine family activities, disruption of family leisure, disruption of family interactions, effect on the health of others, and effect on the mental health of others. Responses are rated on a three-point Likert scale (no burden, moderate burden, severe burden). The reliability and validity of the scale were previously reported to be above 0.78, establishing it as a reliable tool for assessing family burden. In this study, the interview schedule was translated into Odia and Hindi for ease of use.

Data were collected through structured interviews with parents of children with CP attending the IPDs of SCBMCH, SVPPGIP, and DEIC at SVPPGIP. Data were collected by the researcher who was doing post-graduation in pediatrics. The pediatrics specialists posted in DEIC were also trained to collect the data in pre-designed Performa. The uniformity was done by taking the data of previously diagnosed cases of CP who had come to DEIC for physiotherapy or were admitted to IPD for any complication. Data were collected using a pre-designed proforma, and each child’s motor disability was categorized using the GMFCS. The burden on families was assessed through interviews using the Pai and Kapur FBIS, translated into regional languages. All responses were recorded and entered into an MS Excel spreadsheet, and variables were coded accordingly.

Data were analyzed using SPSS version 25 software (IBM Corp., Armonk, NY). Categorical data were expressed in percentages, and associations between two categorical variables were assessed using the chi-square test. A *P*-value of less than 0.05 was considered statistically significant. Ethical approval was obtained from the Ethical Committee of SCBMCH, Cuttack. Informed consent was secured from all participants' parents in both English and the regional Odia language.

Results

A total of 160 cases of CP were included in the study. Of these, 98 (61.3%) were males and 62 (38.8%) were females. Most of the children were aged between 6 and 14 years, with a mean age of 7 ± 3.17 years. SES, as determined by the Modified Updated Kuppuswamy Socioeconomic Scale 2021, revealed that out of 160 families, 9 (5.6%) belonged to the lower class, 73 (45.6%) to the upper-lower class, 68 (42.5%) to the lower-middle class, and 10 (6.3%) to the upper-middle class. Based on the GMFCS-ER classification, the distribution of 160 children with CP was as follows: 22 (13.8%) in level I, 30 (18.8%) in level II, 16 (10%) in level III, 17 (10.6%) in Level IV, and 75 (46.9%) in Level V. The mean age of fathers was 37.1 ± 5.97 years, while the mean age of mothers was 31.78 ± 5.45 years. In terms of CP types, 83 children (52%) had spastic quadriplegia, with all four limbs equally affected by hypertonia; 31 children (19.3%) had diplegia, with hypertonia predominantly affecting the lower limbs more than the upper limbs; 32 children (20%) had hemiplegic CP, primarily affecting the right upper and lower limbs; 12 children (8%) had a mixed type of CP, presenting as spastic-dyskinetic; and 2 children (1%) had the hypotonic variety. Mostly spastic quadriplegia and diplegia children belonged to GMFCS levels IV and V.

The majority of families reported the disruption of routine family activities. Specifically, 13 (8.1%) of families experienced no disruption, 106 (66.3%) reported moderate disruption, and 41 (25.6%) indicated severe disruption. The primary reason for the disruption of routine family life was the frequent need for hospital visits. Additionally, caring for the dependent child, such as feeding, bathing, dressing, managing the child not attending school, or the inability to assist with household chores, also contributed significantly to the disruption. This results in negligence of other family members, especially siblings. The GMFCS groups IV and V experienced more disruption. In terms of family leisure, 22 (13.8%) families experienced no disruption, while 94 (58.8%) faced moderate disruption and 44 (27.5%) reported severe disruption. Many families noted that their usual recreational activities had ceased, family holidays were affected, and other leisure activities had been postponed due to their child’s illness (Table *1*).

Type of financial burden (*n* = 160)	No burden	Moderate burden	Severe burden
A. Financial burden as a whole	1 (0.6%)	75 (46.9%)	84 (52.5%)
A1. Loss of patient's income and its effect on family income	153 (95.6%)	7 (4.4%)	0 (0.0%)
A2. Loss of income of any other member due to patient	36 (22.5%)	65 (40.6%)	59 (36.9%)
A3. Expenditure incurred due to patients and treatment and its effect on family finances	3 (1.9%)	61 (38.1%)	96 (60.0%)
A4. Expenditure incurred due to extra arrangements	12 (7.5%)	81 (50.6%)	67 (41.9%)
A5. Loans taken, its effect on family finances and savings spent	58 (36.3%)	49 (30.6%)	53 (33.1%)
A6. Any other planned activity was put off because of financial pressure owing to the patient's illness	26 (16.3%)	81 (50.6%)	53 (33.1%)
Frequency distribution of Disruption of Routine Family Activities			
B. Disruption of routine family activities	13 (8.1%)	106 (66.3%)	41 (25.6%)
B7. The patient not going to school, college, work, etc.	65 (40.6%)	34 (21.3%)	61 (38.1%)
B8. The patient not helping with the household work	55 (34.4%)	48 (30.0%)	57 (35.6%)
B9. Disruption of activities of other family members	45 (28.7%)	60 (38.2%)	52 (33.1%)
B10. The patient's behavior disrupting activities	65 (40.6%)	60 (37.5%)	35 (21.9%)
B11. Neglect of the rest of the family due to the patient's illness	58 (36.3%)	45 (28.1%)	57 (35.6%)
Frequency distribution of disruption of family leisure			
C. Disruption of family leisure	22 (13.8%)	94 (58.8%)	44 (27.5%)
C12. Stopping normal recreational activities	32 (20.0%)	73 (45.6%)	55 (34.4%)
C13. The patient's illness using up another person's holiday/leisure time	34 (21.3%)	70 (43.8%)	56 (35.0%)
C14. The patient's lack of attention to other members children and its effect on him/her	128 (80.0%)	29 (18.1%)	3 (1.9%)
C15. Any other leisure activity had to be abandoned due to the patient's illness	34 (21.3%)	95 (59.4%)	31 (19.4%)

TABLE 1: Frequency distribution of severity of financial burden and disruption in routine family activities and leisure among children 2 to 14 years.

Family interaction was not disrupted in 48 (30%) of cases, moderately disrupted in 77 (48.1%) of cases, and severely disrupted in 35 (21.9%) of cases. The effect on the physical health of caregivers was reported as follows: 73 (45.6%) experienced no ill effects, 73 (45.6%) were moderately affected, and 14 (8.8%) were severely affected. Regarding the mental health of family members, 33 (20.6%) reported severe mental health effects, 88 (55%) experienced moderate effects, and 39 (24.4%) reported no impact on their mental health. Caregivers, particularly parents, often reported sleep disturbances, feelings of depression, and irritability as a result of caring for their child (Table *2*).

Frequency distribution of disruption of family interaction			
Assessment question	No burden	Moderate burden	Severe burden
D. Disruption of family interaction	48 (30.0%)	77 (48.1%)	35 (21.9%)
D16. Any ill effect on the general atmosphere in the house	56 (35.0%)	46 (28.7%)	58 (36.3%)
D17. Do other members get into an argument	82 (51.2%)	44 (27.5%)	34 (21.3%)
D18. Have relatives and neighbors stopped visiting the family	128 (80.0%)	23 (14.4%)	9 (5.6%)
D19. Has the patient’s acute and chronic illness had any effect on the relationship	112 (70.0%)	27 (16.9%)	21 (13.1%)
D20. Has the family become secluded	124 (77.5%)	15 (9.4%)	21 (13.1%)
Effect on the physical and mental health of others			
E. Effects on the physical health of others	73 (45.6%)	73 (45.6%)	14 (8.8%)
E21. Have any other members suffered physical ill health	80 (50.0%)	63 (39.4%)	17 (10.6%)
E22. Has there been any other adverse effects on health	89 (55.6%)	54 (33.8%)	17 (10.6%)
F. Effects on the mental health of others	39 (24.4%)	88 (55.0%)	33 (20.6%)
F23. Have any other family members sought help for psychological illness	118 (73.8%)	27 (16.9%)	15 (9.4%)
F24. Have any other family members lost sleep, depressed, or irritable	17 (10.6%)	85 (53.1%)	58 (36.3%)

TABLE 2: Frequency of distribution of severity of family interaction and effect on physical health among children 2 to 14 years.

A significant association was found between the overall burden faced by families and the GMFCS level of the child ($P < 0.001$). As the GMFCS level increased, so did the severity of financial burdens, disruptions in routine family activities, family leisure, family interaction, and the physical and mental health of family members. These findings indicate that families with children with higher GMFCS levels face greater psychosocial and economic burdens. Detailed results are presented in Tables *3*-*4*.

Type of burden, family activities, and leisure	GMFCS level	Mildly severe	Moderately severe	Very severe	*P*-value
Overall burden	Level I	13 (59.1%)	0 (0.0%)	9 (40.9%)	<0.001
	Level II	7 (23.3%)	10 (33.3%)	13 (43.3%)	
	Level III	0 (0.0%)	7 (43.8%)	9 (56.3%)	
	Level IV	0 (0.0%)	0 (0.0%)	17 (100.0%)	
	Level V	0 (0.0%)	11 (14.7%)	64 (85.3%)	
Economic burden	Level I	1 (4.5%)	21 (95.5%)	0 (0.0%)	<0.001
	Level II	0 (0.0%)	22 (73.3%)	8 (26.7%)	
	Level III	0 (0.0%)	13 (81.3%)	3 (18.8%)	
	Level IV	0 (0.0%)	8 (47.1%)	9 (52.9%)	
	Level V	0 (0.0%)	11 (14.7%)	64 (85.3%)	
Disruption of routine family activities	Level I	6 (27.3%)	16 (72.7%)	0 (0.0%)	<0.001
	Level II	7 (23.3%)	20 (66.7%)	3 (10.0%)	
	Level III	0 (0.0%)	12 (75.0%)	4 (25.0%)	
	Level IV	0 (0.0%)	6 (35.3%)	11 (64.7%)	
	Level V	0 (0.0%)	52 (69.3%)	23 (30.7%)	
Disruption of family leisure	Level I	9 (40.9%)	13 (59.1%)	0 (0.0%)	<0.001
	Level II	7 (23.3%)	23 (76.7%)	0 (0.0%)	
	Level III	0 (0.0%)	13 (81.3%)	3 (18.8%)	
	Level IV	0 (0.0%)	12 (70.6%)	5 (29.4%)	
	Level V	6 (8.0%)	33 (44.0%)	36 (48.0%)	

TABLE 3: Association of overall burden, economic burden, disruption of routine family activities, and leisure with GMFCS level.

GMFCS, Gross Motor Function Classification System

Disruption in family	GMFCS level	Mildly severe	Moderately severe	Very severe	*P*-value
Disruption of family interaction	Level I	16 (72.7%)	6 (27.3%)	0 (0.0%)	<0.001
	Level II	10 (33.3%)	20 (66.7%)	0 (0.0%)	
	Level III	7 (43.8%)	6 (37.5%)	3 (18.8%)	
	Level IV	6 (35.3%)	8 (47.1%)	3 (17.6%)	
	Level V	9 (12.0%)	37 (49.3%)	29 (38.7%)	
Effects on the physical health of others	Level I	22 (100.0%)	0 (0.0%)	0 (0.0%)	<0.001
	Level II	17 (56.7%)	13 (43.3%)	0 (0.0%)	
	Level III	12 (75.0%)	4 (25.0%)	0 (0.0%)	
	Level IV	0 (0.0%)	17 (100.0%)	0 (0.0%)	
	Level V	22 (29.3%)	39 (52.0%)	14 (18.7%)	
Effects on the mental health of others	Level I	8 (36.4%)	14 (63.6%)	0 (0.0%)	<0.001
	Level II	13 (43.3%)	14 (46.7%)	3 (10.0%)	
	Level III	3 (18.8%)	13 (81.3%)	0 (0.0%)	
	Level IV	3 (17.6%)	7 (41.2%)	7 (41.2%)	
	Level V	12 (16.0%)	40 (53.3%)	23 (30.7%)	

TABLE 4: Association of disruption in family interaction and effects on the physical and mental health of others with GMFCS level.

GMFCS, Gross Motor Function Classification System

Discussion

The significance of this study lies in its comprehensive analysis of the psychosocial and economic impact on families of children with CP, specifically on the child's locomotor ability as classified by the GMFCS. Understanding these associations is crucial for clinicians and healthcare systems in designing effective family support strategies. CP is the most common childhood disability, and its impact on caregivers is profound, affecting multiple dimensions of life, including financial stability, family interactions, and physical and mental health. This study aims to provide detailed insights into the burden experienced by families and the correlation between the severity of the child's motor impairment and the magnitude of the burden. The major finding was the loss of income of the parents due to absence from work during working days. Adverse effects on the physical and mental health of parents in handling the dependent child. By identifying these associations, this study highlights the need for targeted interventions and holistic care models that address the medical and psychosocial needs of families dealing with CP. It emphasizes educating parents to visit DEIC at the appropriate times for early stimulation therapy for their child by physiotherapists, occupational therapists, and others, as well as the early recognition of hearing and vision loss with appropriate intervention therapy. Another targeted intervention by psychologists and physiotherapists is to recognize their family members or parents' mental and physical health illnesses and also treat them appropriately.

In the present study of 160 children with CP, males outnumbered females, with 61.3% of the children being boys and a male-to-female ratio of 1.58:1. A study by Najar et al. in Srinagar reported a male preponderance in their cohorts of children with CP [14]. The motor dysfunction, as classified by the GMFCS, showed that most children (46.9%) were in level V, the most severe category. Comparatively, a study by Dobhal et al. reported a higher distribution in level V [15]. In terms of CP types, the majority of children (52%) had spastic quadriplegia, which aligns with the findings from a study by Singhi et al. that report spastic CP as the most common form [16]. Our study also found similar results, with parents of children in GMFCS levels IV and V experiencing more difficulty and suffering.

The financial burden on caregivers was significant, with 52.5% of participants reporting severe financial strain and 46.9% experiencing moderate strain. Only 0.6% reported no financial burden. This financial hardship was mainly due to medical expenses, frequent hospital visits, and loss of income from work absences. Similar findings were reported by Laskar et al., where 69% of parents experienced severe financial difficulties, some even selling assets to cover their child’s medical expenses [17,18]. Our study showed a strong association between the GMFCS class and the severity of financial burden, indicating that families of children with more severe motor impairments are more likely to face significant financial challenges ($P < 0.001$). The government of Odisha with the help of the Indian government has a scheme called Rashtriya Bal Swasthya Karyakram (RBSK) where the paramedical teams visit rural areas to identify children with CP and bring them in government vehicles to the nearest DEIC for physiotherapy and drop back to their respective house. This helps the parents to save on the extra cost of transport.

Regarding the disruption of family activities, 66.3% of caregivers were moderately affected, while 25% experienced severe disruption. This disruption included difficulties managing daily household tasks, neglect of other family members, and decreased recreation or personal care time. Similar results were reported by Laskar et al., who found that nearly half of the families experienced moderate disruption [17]. Our study also found that the disruption of family leisure activities, such as attending social gatherings or engaging in recreational outings, was significantly associated with the GMFCS level ($P < 0.001$), with higher GMFCS levels correlating with more severe disruptions.

Physical and mental health effects on caregivers were also notable [19,20]. While 45.6% of caregivers experienced no physical health issues, 45.6% reported moderate effects, and 8.8% reported severe physical health problems. Caregivers of children with higher GMFCS levels were more likely to report physical health issues ($P < 0.001$). Additionally, 55% of caregivers reported moderate effects on their mental health, while 20.6% experienced severe mental health challenges, such as depression, irritability, and sleep disturbances. Gignac reported similar findings, noting that economic constraints often prevented caregivers from seeking mental health support, despite high levels of psychological distress [21]. The overall psychosocial and economic burden faced by families was significantly correlated with the GMFCS level of the child, reinforcing the need for comprehensive support systems for families dealing with severe CP.

So our recommendation is parents should be aware of government programs like RBSK and other facilities related to disability from time to time. Parents and families should be aware of that to take advantage. The parents and families should also consult physicians and mental health professionals from time to time for their well-being. A robust information education communication (IEC) program requires the awareness of the parents to take advantage of government welfare schemes to relieve their stress.

Limitations

This study is a single-center, hospital-based study. A multicenter study with a larger number of cases from different geographic locations or a community-based study would provide a better representation of a study population and additional insight into the topic. Not only the degree of a child's disability, but several other factors may be affecting caregiver stress. A more comprehensive study is required for a better understanding of the same.

Conclusions

The results of this study demonstrate a clear and significant association between the degree of a child’s motor impairment, as classified by GMFCS, and the psychosocial and economic burden on their families. Higher GMFCS levels were correlated with increased disruption in family routines, greater financial strain, and more severe physical and mental health challenges for caregivers. These findings underscore the importance of tailored support systems for families, addressing both the medical needs of children with CP and the broad range of psychosocial and economic challenges faced by their caregivers. So the different government schemes regarding children with CP must be conveyed to each parent to take the benefit and relieve their stress. The system should include proper referral of children with CP to higher centers for their medical emergencies. Additionally, the RBSK team should screen family members to identify early signs of mental or physical illness and refer them to the district headquarters hospital or medical college for better treatment.

Appendices

Appendix

A. Financial burden	No Burden Score-0	Moderate Burden Score-1	Severe Burden Score-2
A1. Loss of patient’s income and its effect on family income			
A2. Loss of income of any other member due to patient			
A3. Expenditure incurred due to patients and treatment and its effect on family finances			
A4. Expenditure incurred due to extra arrangements			

A5. Loans taken, its effect on family finances and savings spent			
A6. Any other planned activity put off because of financial pressure owing to patient’s illness			
Frequency distribution of Disruption of Routine Family Activities			
B. Disruption of routine family activities			
B7. Patient not going to school, college, work etc.			
B8. Patient not helping household work			
B9. Disruption of activities of other family members			
B10. Patient’s behaviour disrupting activities			
B11. Neglect of rest of the family due to patients’ illness			
Frequency distribution of Disruption of Family Leisure			
C. Disruption of family leisure			
C12. Stopping of normal recreational activities			
C13. Patient’s illness using up another person’s holiday/leisure time			
C14. Patient’s lack of attention to other members children and its effect on him			
C15. Any other leisure activity had to be abandoned due to patient’s illness			
Frequency distribution of Disruption of Family Interaction			
D. Disruption of family interaction			
D16. Any ill effect on the general atmosphere in the house			
D17. Do other members gets into argument			
D18. Have relatives and neighbours stopped visiting the family			
D19. Has the patient’s illness had any effect on relationship			
D20. Has the family become secluded			
Effect on Physical Health of others			
E. Effects on physical health of others			
E21. Have any other members suffered physical ill health			
E22. Has there been any other adverse effects on health			
F. Effects on mental health of others			
F23. Have any other family members sought help for pshychological illness			
F24. Has any other family members lost sleep, depressed, irritable			

TABLE 5: Interview of the relatives on guidelines and note the ratings of each general category as well as each individual item in three point category

Family Burden Interview Schedule (Pai and Kapur) [10]

Additional Information

Author Contributions

All authors have reviewed the final version to be published and agreed to be accountable for all aspects of the work.

Acquisition, analysis, or interpretation of data: Sumanta Panigrahi, Falak Naaz, Nirmal Kumar Mohakud

Drafting of the manuscript: Sumanta Panigrahi, Bibhu Prasad Nayak, Nirmal Kumar Mohakud

Critical review of the manuscript for important intellectual content: Sumanta Panigrahi, Falak Naaz, Bibhu Prasad Nayak, Nirmal Kumar Mohakud

Supervision: Sumanta Panigrahi, Nirmal Kumar Mohakud

Concept and design: Falak Naaz, Bibhu Prasad Nayak

Disclosures

Human subjects: Consent for treatment and open access publication was obtained or waived by all participants in this study. Sriram Chandra Bhanja Medical College and Hospital, Cuttack, India issued approval 1112. IEC Application. No. - 1112 Date. 25.08.202 Communication of Decision of the Institutional Ethics Committee (IEC) To Dr. Falak Naaz, P.G. Pediatrics, SCBMCH, Cuttack Protocol title: Study of the Psychosocial and Economical Impact on Family of Children With Cerebral Palsy and Its Correlation with Degree of Child's Locomotor Ability Investigators: Dr. Falak Naaz, P.G. Pediatrics, Dr. Sumanta Panigrahi. Associate Professor, Pediatrics. This decision was made during the 48th IEC meeting held on 25.08.2022. **Animal subjects:** All authors have confirmed that this study did not involve animal subjects or tissue. **Conflicts of interest:** In compliance with the ICMJE uniform disclosure form, all authors declare the following: **Payment/services info:** All authors have declared that no financial support was received from any organization for the submitted work. **Financial relationships:** All authors have declared that they have no financial relationships at present or within the previous three years with any organizations that might have an interest in the submitted work. **Other relationships:** All authors have declared that there are no other relationships or activities that could appear to have influenced the submitted work.

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