Parental Distress: A Result of Functional and Behavioral Difficulties in Children with Cerebral palsy

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ABSTRACT

Background: Children with cerebral palsy (CP) may have risk factors of Functional and Behavioral difficulties. Aims: To determine the parental distress as a result of functional and behavioral difficulties of children with C.P. Methodology: The population was based in Pakistan, cross sectional survey was conducted in which caregivers of 40 children with CP aged 3-8 Years were involved by online “Survey System” software and completed the Agitated Behavior Scale (ABS), The Gillette Functional Assessment Questionnaire and Parental Stress Scale to determine the child’s behavior, functional difficulties and parental distress. Correlation paired 2-tail and Linear regression were used to analyze the data. Data was analyzed using IBM SPSS 20. Results: The demographic data (Age and Gender), non-significant regression equation f=2 (37), P > 0.01 with a Power calculation r² = 0.45. Functional difficulties (F.A and L.A), not-significant regression equation was found df=4(35) , P > 0.01 with an Power calculation r² = 0.07 while, not-significant regression equation was found df=5(34) , P > 0.01 with an Power calculation r² = 0.03 and findings indicate that parental distress has no statistically significant relationship (|r| n=40, p > 0.05) to Functional Abilities, Locomotors Abilities and Behavior Difficulties. Conclusion and Implications: Evidences show that psychological, behavioral, emotional and communicating problems are frequent in children with CP. It’s not compulsory to have highly rated parental stress in case of children having any disability and child’s effect agitated behaviors. Effective rehabilitation programs should provide not only sufficient opportunities for the children’s disabilities but also psychological support for the mothers.

Keywords: Cerebral Palsy, Children, Stress, Behavior, Parental Distress, Functional Difficulties, Locomotor Abilities
1. INTRODUCTION

Cerebral palsy is a non-progressive neurodevelopment syndrome arising in the early stages of child development. It is associated with many deficits such as motor problems, mental retardation, speech and language deficiencies (Sankar & Mundkur, 2005). Cerebral palsy has the physical cause of disability with a prevalence of 2 to 3 per in 1000 live births and coexisting disorders affect the child's quality of life such as gross, fine motor functioning and cognitive abilities (Parisi et al., 2016). Physical impairment is the most common symptom in children with CP and it further affects their behavioral, functional and cognitive abilities. It narrows down the circle of everyday activities and social participation for the children and not only they but also their families suffer (Horwood et al., 2019).

Children with cerebral palsy show the early signs of epilepsy, motor dysfunctioning and intellectuall disability. However, all types of CP children have the speech and language problems but with the varying level of motor disability. Where CP has neuropsychological deficits affecting primarily executive functioning, visuospatial and attention deficit, these problems also affect the academic performance and social participation (Fluss & Lidzba, 2020).

Cerebral palsy has multiple etiologies resulting in brain injury that affects movement, balance and posture. The movement disorders associated with cerebral palsy are categorized as dyskinesia, spasticity, ataxia, or mixed. Spasticity is the most common movement disorder which occurs in 80% of children with cerebral palsy. Diagnosis of cerebral palsy is primarily clinical, but if there is no clear cause for the patient's symptoms Magnetic Resonance Imaging (MRI) is helpful to confirm brain injury. If it diagnoses the cerebral palsy, an instrument such as the Gross Motor Function Classification System can be used to evaluate severity and treatment response. If the Patient with cerebral palsy experience the problems unrelated to movement that need to be managed into adulthood, including cognitive dysfunction behavioral or emotional problems, seizures, pressure ulcers, osteoporosis, speech and hearing impairment, he needs a therapy which is long lasting (Vitrikas, Dalton, & Breish, 2020).

Akins & Robinson investigated 77% cases of cerebral palsy (CP). Myriads of them represent the most common physical disability in children with the spastic and most cases occur between 24 weeks gestation or at birth and arises with a disturbance in the brain sickness. Early intervention is necessary but early diagnosis is very testing and diagnosis is often delayed for several months or even years. However, blood biomarkers preferably collected at the time of birth may allow for earlier diagnosis, intervention, and the development of novel therapeutics Biomarkers identify CP patient’s severity level and the types of blood biomarkers being investigated in individuals with CP (Akins & Robinson, 2020).
Children with CP have the problem of sensory processing. It is dysfunction interference with motor and functional abilities (Pavão & Rocha, 2017). However, impaired motor function is the hallmark of the cerebral palsy (CP) syndromes. So many children experience communicating problems, sensory processing, intellectual impairments along with the problems of taking care of themselves properly (Raina et al., 2005).

Parents of children with cerebral palsy come across many challenges. CP parents engage themselves in better quality parenting than others (Dieleman, Soenens, Prinzie, De Clercq, & De Pauw, 2021).

In families of children with CP, to improve the caregiver’s physical and psychological health many techniques like support for behavioral management and daily functional activities as well as stress management and self-efficacy were used. Whereas, parents with cognitive and behavioral strategies to manage their child’s behaviors may have the potential to change caregiver health outcomes (Raina et al., 2005).

Parenting stress is defined as a perceived stress. it is negative psychological feelings associated with anxiety, frustration and self-blame that affect parenting behaviors and functions (Wang, Huang, & Kong, 2017).

External environmental demands rise the stress of caregivers (Basaran, Karadavut, Uneri, Balbaloglu, & Atasoy, 2013). Central nervous system of the children with CP is at a greater risk that results into the behavioral attention deficit, emotional problems, increased dependence, withdrawal, obstinacy and anti-social characteristics reported by parents. Children with cerebral palsy have the behavioral problems five times more than the healthy children. Parents are told about the fact that in the near time their children living with the cerebral palsy would face emotional, social, and physical problems (Fritz & Sewell-Roberts, 2018).

In 2021, researchers examined the contributions of child behavior and parents’ psychological needs to explanation of yearly variations in responsive, autonomy-supportive and psychologically controlling parenting. In the research method, parents (N = 117) of children with cerebral palsy (Mage = 10.98 years) participated in a three-wave longitudinal study. Results showed the yearly variations in parents need satisfaction and frustration related to yearly fluctuations in, respectively, autonomy-supportive and psychologically controlling parenting. However, Parents autonomous motivation was associated with better overall quality of parenting (Dieleman et al., 2021).

In 2019, researchers evaluated the prevalence of behavioral difficulties, sleep problems and night time pain in 113 children with CP aged between 4 to 12 years and completed the Sleep Disturbance Scale, Strengths and Difficulties Questionnaire for Children. By the results 25% of children with cerebral palsy (CP) had behavioral difficulties. However, in CP behavioral difficulties were described in one out of four children, along with night time pain and sleep problems (Horwood et al., 2019).

In 2018, another research determined the relationship between parental attitudes towards their children with cerebral palsy. In the method of study, 70 parents of CP children
with the age of 6 to 13 years were examined and completed the questionnaire measuring parental attitudes, Social and Emotional Behavioral problematic scale. The results showed that most of the parents had moderate attitudes towards their children with CP (Al-Dababneh & Al-Zboon, 2018).

In 2018 Hidecker and his colleagues investigated early predictors and correlate of communication function in children with cerebral palsy. In the study, design sample size were 215 cerebral Pasly children with the age range 2 to 17 years. Data was taken from parents through interview and child's Communication Function Classification System (CFCS) level was taken from parents. Results indicated less functional communication contained within gestational age less than 32 weeks, number of comorbidities such as first word pronounce after 2 years of birth and use of gestures for communication than speech. In the conclusion, these physical characteristics referrals for communication evaluations with speech, language, augmentative alternative communicate and hearing dysfunction were predicted (Hidecker et al., 2018).

In 2018 Lazarijeva, Kushchenko, Muszkieta and Zukow investigated behavioral problems. In the research study, 88 children were taken and the scale of Strengths and Difficulties Questionnaire (SDQ) , Vineland emotional problems in children and adults with cerebral palsy were analysed. In the study caregivers of 121 adults Adaptive Behavior Scale II (VABS) and Child Behavior Checklist (CBCL) were taken. Questionnaires were returned from 43 adults and 39 children. By the results both groups had same anomalies in social interaction and attention problems in (CBCL) while children showed abnormal communication, prosocial behavior and disturbed daily living skills. However, anomalies among both groups in these dimensions of VABS was markedly high (Lazarijeva, Kushchenko, Muszkieta, & Zukow, 2018).

In Pakistan Shah, Syed Faizan Ali described the health status of cerebral palsy children, in which 100 children were selected through convenient sampling and completed the Child Health Questionnaire (CHQ PQ-50) through the responses taken from primary caretaker and used the descriptive statistical analysis. By the results 65% parents rated child’s behavior unsatisfactory while 3% rated healthy behavior and 32% were satisfactory about their child behavior. In the conclusion CP children with the poor quality of life suggested dysfunctional activities with self-efficacy techniques (Shah, Sahre, Feroz, Shaikh, & Memon, 2016).

In the 2016, researchers investigated the level of depression in parents of Cerebral Palsy (CP). In the cross-sectional study, sample was taken from 148 parents and Beck Inventory scale was used to assess the parents’ depression level. The study concluded that most of the parents of children having cerebral palsy experienced moderate level of depression (Malik et al., 2019).

In 2020, researchers investigated the beliefs of mothers of children with CP in which fine and gross motor functioning of child were documented and open-ended questions were asked to examine the expectations and views of the mothers of CP children about the physiotherapy and rehabilitation programs for the children. A total of 100 mothers were
Researchers investigated the behavioral problems in school age children with cerebral palsy and they determined the nature of the relationships between children and family characteristics. In methodology researcher took CP children with the age of 6 to 12 years old and used the Gross Motor Function Measure, Vineland Adaptive Behavior Scale, Strengths and Difficulties Questionnaire (SDQ) and measured the parent’s stress level with the Parenting Stress index. Results showed that high parental stress was consistently associated with behavioral problems across all domains of the SDQ while better socialization skills and a lower parental stress were correlated with more positive behaviors. Behavioral difficulties were common in children with CP (Brossard-Racine et al., 2012).

In 2017, researchers evaluated the quality of life of cerebral palsy children. In the methodology qualitative semi-structured interviews were conducted with 18 parents. The children (9 males) had a median age of 12 (range 7 to 17) years at interview and two thirds were classified as Gross Motor Function Classification System IV or V. A grounded theory approach was used to identify domains of QOL. Results showed that 11 domains were important for quality of life such as physical health, communication, body comfort, behavior and emotion, daily activity, fine and motor activities, social connectedness (Davis et al., 2017).

In the research study, motor and functional Skills for Children with Cerebral Palsy were measured. By the systematic review, research study used the bias checklist and the updated criteria for good measurement properties was applied to assess the quality. Results identified the Gross Motor Function Measure, Pediatric evaluation of Disability Inventory, Gross Motor Performance Measure and Functional Independence Measure for Children. Whereas, evidence levels for validity, reliability and responsiveness varied among measures (Ferre-Fernández, Murcia-González, Espinosa, & Rios-Díaz, 2020).

Our study aimed to describe that the parental distress would be at a greater risk because of the functional and behavioral difficulties in their children with CP. It was hypothesized that functional and behavioral difficulties of children with cerebral palsy to be predictor of parental distress. Second, hypothesis was made to determine the positive
relationship between functional and behavioral difficulties in children with cerebral palsy and parental distress. Third, hypothesis was made to determine the behavioral and functional problems in the CP children of the age between 3-8 years and parental distress.

**RATIONAL**

The purpose of the present study was to explore the relation between parental distress and limitations in functional skills and behavioral difficulties of children with CP. This study was helpful for doctors and rehab to know morbidity in children with cerebral palsy Disorder.

**OBJECTIVE**

- To investigate the prevalence of functional and behavioral difficulties in children with Cerebral palsy
- To assess parental distress in mother of children with cerebral palsy
- To find out the relationship between functional and behavioral difficulties in children with cerebral palsy and parental distress
- To find out functional and behavioral difficulties of children with cerebral palsy as a predictor of parental distress

**HYPOTHESIS**

- There will be a positive relationship between functional and behavioral difficulties in children with cerebral palsy and parental distress
- Functional and behavioral difficulties of children with cerebral palsy will be predictor of parental distress

**2. METHODOLOGY**

**Participants and Procedure**

A cross sectional study investigated the functional and behavioral difficulties of children with cerebral palsy to be predictor of parental distress. Non probability purposive sampling was used in this study, total number of participants selected by 95% confidence interval and 10% significance interval were calculated by using data recorded during study and used “the Survey System” software around the prevalence of Cerebral Palsy 764,000. Data was taken from caregivers of CP children. N=40 children were prospectively requited in Pakistan Society Rehabilitation Disability (PSRD) hospital, facilitated to collected research data. Inclusion criteria for this study were: Participants with the caregivers in the age group 3-8 years diagnosis with CP by neurologist. Both males and females, living at home with guardian or caregiver were able to read the questionnaire and those who were willing to participate in the process were included. For the current study, researchers excluded those children who were <3 years children of age, children with vision or hearing impairment and children with autism.
INSTRUMENT:

Behavioral Difficulties:

Behavioral difficulties were reported by caregivers faced by the parents. However, in this Agitated behavior scale (ABS) was used to measure (A. Bogner, Corrigan, Stange, & Rabold, 1999) the behavioral aspects of agitation during the acute phase of recovery from acquired brain injury including aspects of aggression, disinhibition and liability. Behavior screening tool with reliable measuring agitation in persons with traumatic brain injury, as well as with long-term-care facility residents experiencing dementia was used. Agitation as measured by the ABS is best represented as a unitary construct, thus results provide additional support for the reliability and validity of the ABS (A. Bogner, Corrigan, Bode, & Heinemann, 2000).

Functional Difficulties

Researchers administered an additional questionnaire on Gillette Functional Assessment Questionnaire (14). Good test-retest reliability among parents and good interpreter reliability between parents and community caregivers were demonstrated. Content and concurrent validity were also high, as assessed by correlation to standardized functional outcome measures, energy expenditure, and gait-analysis information. A reliable and valid scale specific to the task of walking such as the FAQ can assist clinicians in documenting functional change in children with chronic neuromuscular conditions (Novacheck, Stout, & Tervo, 2000).

Parental Distress

Parental Stress Scale (Berry & Jones, 1995) scores was supported by predicted correlations with measures of relevant emotions. Role of satisfaction and significant discrimination between mothers of children in treatment for emotional/behavioral problems and developmental disabilities vs. mothers of children not receiving treatment and the Factor analysis suggested that a 4-factor structure underlies responses to the Parental Stress Scale, despite its high internal reliability.

ETHICAL CONSIDERATION

In order to conduct this research following ethical consideration are:

a. The participants were briefed about the objectives and procedures which involved in the research and assurance of the information confidentiality.

b. A consent form was filled by each participant and it showed their agreement to fulfill the questionnaire.

DATA ANALYSIS
To assess the cerebral Palsy children’s functional abilities and behavior on the Parenting Stress (n = 40). Descriptive statistics and Demographic data were measured. Linear regression analysis to test the association between two variables and correlation paired 2-tail were analyzed, reported parental stress and \( P < 0.05 \) was considered statistically significant. However, all statistical analyses were performed using IBM SPSS Statistics 24.0 for Windows.

3. RESULTS

A total of 40 CP children in this were included. However, the demographic characteristics of our study sample are detailed in Table 1 and parental distress of CP children, behavior and functional difficulties detailed in another table.

Figure 1: The percentage of demographic with Cerebral palsy children (n=40)

Note: The result shows diagnosed male and female distribution of children of Cerebral Palsy (CP).
Fig. 2: Descriptive statistics of age of children with Cerebral palsy

Note: The result shows diagnosed children of CP with the age group of 6 - 8 years.
Table 1: Pearson correlation between parental Distress, Functional Abilities, Locomotors Abilities and Behavioral Difficulties of children with Cerebral palsy

<table>
<thead>
<tr>
<th>Variables</th>
<th>Parental Distress</th>
<th>Functional Abilities</th>
<th>Locomotors Abilities</th>
<th>Behavioural</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parental Distress</td>
<td>---</td>
<td>0.18</td>
<td>0.97</td>
<td>0.36</td>
</tr>
<tr>
<td>Functional Abilities</td>
<td>---</td>
<td>---</td>
<td>0.75**</td>
<td>0.28</td>
</tr>
<tr>
<td>Locomotors Abilities</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>-0.04</td>
</tr>
<tr>
<td>Behavioural</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Mean</td>
<td>67.28</td>
<td>29.23</td>
<td>7.14</td>
<td>28.6</td>
</tr>
<tr>
<td>SD</td>
<td>11.6</td>
<td>9.2</td>
<td>16.7</td>
<td>7.4</td>
</tr>
</tbody>
</table>

Note: N=40, *P < 0.01; **P < 0.001 Parental Distress, Functional Abilities, Locomotors Abilities and Behavior Difficulties.

Table 1. Findings indicates that Functional Abilities and Locomotors Abilities has positive correlation (r= .75**, n=40, p<0.001) while behavioral difficulties shows negative correlation (r= -0.03, n=40, P > 0.05) to Functional Abilities and Locomotors Abilities.

Table 2: Pearson correlation between parental Distress, Functional Abilities, Locomotors Abilities and Behavioral Difficulties of children with Cerebral palsy

<table>
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<tr>
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Note: N=40, *P < 0.01; **P < 0.001 Parental Distress, Functional Abilities, Locomotors Abilities and Behavior Difficulties

Table 2 The findings indicates that parental distress has no statistically significant relationship (|r| n=40, p > 0.05) to Functional Abilities, Locomotors Abilities and Behavior Difficulties.
Table 3: Regression analysis of cerebral Palsy children’s functional abilities and behaviour on the Parenting Stress (n = 40).

<table>
<thead>
<tr>
<th>Dependent variable</th>
<th>B</th>
<th>SEB</th>
<th>B</th>
<th>t</th>
<th>Df</th>
<th>F</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Model R=ΔR² 0.45</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-3.4</td>
<td>3.63</td>
<td>-0.15</td>
<td>-0.95</td>
<td>2</td>
<td>1.19</td>
<td>0.16</td>
</tr>
<tr>
<td>Gender</td>
<td>5.6</td>
<td>3.64</td>
<td>0.24</td>
<td>1.55</td>
<td>---</td>
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</tr>
<tr>
<td>2 Model R=ΔR² -0.07</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Functional ability</td>
<td>-0.00</td>
<td>0.32</td>
<td>0.00</td>
<td>-0.01</td>
<td>4</td>
<td>0.93</td>
<td>0.04</td>
</tr>
<tr>
<td>Locomotors Ability</td>
<td>0.06</td>
<td>0.19</td>
<td>0.98</td>
<td>0.34</td>
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<tr>
<td>3 Model R=ΔR² -0.03</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavior</td>
<td>0.12</td>
<td>0.30</td>
<td>0.07</td>
<td>0.42</td>
<td>5</td>
<td>0.76</td>
<td>0.58</td>
</tr>
</tbody>
</table>

*P < 0.01; **P < 0.001

3.1 The simple liner regression analysis predicts Parenting Stress based on cerebral Palsy children’s functional abilities and behavior difficulties. Table shows demographic section in model one (Age and Gender), $\beta = -0.15$ and $0.24$, SEB= 3.63 and 3.64, $t=-0.95$ and 1.55, $P < 0.01$. A non-significant regression equation was found $F=1.19$, df=2 (37), $P > 0.01$ with an Power calculation $r^2 = 0.45$.

3.2 Table shows Functional difficulties (Functional Ability and Locomotors Ability) in model two, $\beta = 0.00$ and $0.98$, SEB= 0.32 and 0.19, $t=-0.01$ and 0.34, $P < 0.001$. A not significant regression equation was found $F=0.93$, df=4(35), $P > 0.01$ with an Power calculation $r^2 = 0.07$.

3.3 Table shows Behavioral difficulties in model three $\beta = 0.12$, SEB= 0.30, $t=0.42$, $P < 0.001$. A not significant regression equation was found $F=0.76$, df=5(34), $P > 0.01$ with an Power calculation $r^2 = 0.03$.

4. DISCUSSION

In 2019 Whitney, Peterson & Warschausky determine the health disorders, participation and bullying in children with cerebral palsy. Results showed that the odds of anxiety, behavior or conduct problems and multimorbidity remained increased in children with CP (Whitney, Peterson, & Warschausky, 2019). It was revealed in present study, behavioral difficulties show negative and non-significant correlation to Functional and Locomotors Abilities.

In 2019 Whitney, Peterson, & Warschausky investigated the health disorders, participation and bullying in children with cerebral palsy. Results showed the odds of anxiety, behavior or conduct problems and multimorbidity remained increased in children
with CP (Whitney et al., 2019). It was revealed in present study, behavioral difficulties show negative and not significant correlation to Functional Abilities and Locomotors Abilities.

In 2017 Garip and his colleagues evaluated fatigue in the mothers of children with cerebral palsy (CP) and determine its associations with clinical parameters of CP, depression and quality of life (QoL). Findings of the research showed that fatigue levels of mothers with CP children is higher than those with healthy children and connected with depression and deterioration in QoL in terms of physical, social and emotional functioning (Garip et al., 2017). Findings of present study show that parents of Cerebral palsy children have not any significant relationship between parental distress.

In 2017, Researchers investigated emotional availability, functional ability and parent distress Results showed the there was no relationship between child functional abilities and either parent distress or parent-child emotional availability (Barfoot, Meredith, Ziviani, & Whittingham, 2017). Results of present study supported the literature review that there is not significant relationship between Functional abilities and parental distress.

de Albuquerque Botura and his colleagues in 2017 examined presence of pain in patients diagnosed with severe cerebral palsy (CP) according to the degree of motor function impairment. The results showed that pain is prevalent in individuals with severe CP and patients have higher degree of locomotor impairment (GMFCS – level V). (de Albuquerque Botura et al., 2017). However, results of present study revealed there is positive relationship between Functional Abilities and Locomotors Abilities among CP children.

In 2015, researchers examined the relationships between activities of daily living (ADL) motor and process skills, unimanual capacity, bimanual performance and visual perception in children with unilateral cerebral palsy (CP). Results indicated that bimanual performance and unimanual capacity of the dominant upper limb are significantly associated with ADL motor skills in children with unilateral CP, which may reflect motor planning required to perform daily tasks (James, Ziviani, Ware, & Boyd, 2015). However, results of present study revealed that there is positive and significant relationship between Functional Abilities and Locomotors Abilities in cerebral palsy children.

**Recommendations**

1. If the parents with cognitive and behavioral strategies can manage their child’s behaviors, it may have the potential to change child health outcome.
2. There should be a norm-based test (Urdu Language) for assessing child’s functional, behavioral difficulties and parental distress.
3. Another study must be conducted longitudinally on CP children, preschool

And school going children side to side through which we can better understand and mange child ‘s abilities and behavioral difficulties.

1. Various parenting approaches and coping strategies need to be recommended and taught to mothers to decrease their stress.
2. Effective rehabilitation programs should provide sufficient opportunities for repeated follow-up interviews which offer not only information on the children’s disabilities but also psychological support for the mothers.

**LIMITATION**

1. Due to shortage of time researcher decreased sample size.
2. Researcher faced difficulties from parents because most of parents in data collection did not give right information about the children.
3. Many parents were reluctant in providing information regarding their children
4. Indeed, there are difficulties in establishing objective criteria for the severity of CP
5. The study findings are limited by the inclusion of children within a restricted age range (3-8-year-olds).
6. There was less discussion with the caregiver due to close ended questions in the scale.

**CONCLUSION**

Findings suggest that Psychological, behavioral, emotional, and communicating problems are frequent in children with Cerebral Palsy (CP). These difficulties are also correlated with parental distress. The current study informs about the behavioral difficulties which are common in children with CP are not related to physical and cognitive dysfunctioning, and to child’s psychological problems to improve family adaptation. This study emphasizes the need to recognize and address behavioral difficulties that may arise to optimize the health and well-being of children with CP and their families. Parent’s mental health as well as that of their children may prove to be an important intervention in helping to improve the quality of life of the children who have been diagnosed with CP. However, the effect of parental distress on acceptance of child was not significant.


