

***“***Assessment of direct cost of cerebral palsy management and its effects on family, Bangladesh perspective***”***

A dissertation submitted by:

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ID: 191- **0044-011**

In partial fulfillment of the requirement for the degree of Masters of public health (MPH)

**UNIVERSITY OF SOUTHASIA (USA)**

Date of submission:

*Dedicated*

*“To*

*My Beloved Parents and Respectful Teachers*

*For their deep love, support and inspiration to do this works”*

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Submitted by Asma Akter for the partial fulfillment of the requirement for the degree of Masters of public Health (MPH).

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| **Acronyms** |
| UniSA University of South Asia |
| CP Cerebral Palsy |
|  |
|  |

**Abstract**

**Objective**

Complications and Cost of Cerebral Palsy (CP) has a negative impact on family which has a negative effect on the management of CP children that ultimately increases the cost again . In our country we have not enough research on the cost of CP or other disability. In countries like Bangladesh it might cause more burden on the family and Countries economy. Other related impact that we mentioned here (physical. economical, psychological, and social, education, etc.) might have negative impact that was described by the family members or parents of CP children in our regular practice. Here in this small study we try to find out the cost and its impact on the family due to this cost.

**Methods**

This was a descriptive cross-sectional study to find out the direct cost of the cerebral palsy management and the effects on the family due to the cost. Sampling was purposive sampling method. Participants were from all over the country. A total of 41 parents were interviewed face to face through a semi structured questionnaire. The findings of this study may assist the researcher for further research on the cost of cp management in Bangladesh.

**Result**

Among 41 participants 53.86 %were male and 46.34% were female. Based on our samples, the most CP child age was came from three age groups, 24.39% were 2 years old, 21.95% were 3 years old, and 17.07% at 4 years.A large number of children (61%) came from urban area.Most of the CP children came with their mother as a respondents and respondent’s educational status was secondary level for almost 50 % respondents. A few number of mothers were from higher education. Direct medicine costs are the highest burden (11521.54 BDT) of the children aged 0-4 years, over the all types of cost., families of 0-4 years of children with CP spend highest 7138.46 BDT for test/diagnostic costs. Followed by, 4773.08 BDT for admission costs, 4215.38 for food and transport costs. However, children age greater than 4 years families had to spend highest (2846.67 BDT) cost for assisted devices.Among 41 children, a large number of children 36.6% (n=15) were face illness one times in last three months and the mean cost for treatment was 208600 BDT. However, the mean cost was highest for children face illness with three times in last three months.A large number of children 46.3% (n=19) were Quadriplegic and the mean cost for treatment was highest (34405.26 BDT) among all other limb involvement. Among 41 children, a large number of children 48.8% (n=20) domain affected greater than three and the mean cost for treatment was highest (40715. BDT.We found a significant mean difference between frequency of illness and total cost. We also found some significant relation between age of child, place of residence and father’s economic status which effects in the family due to the treatment costs.

**Conclusion**

The study confirmed that cost to Cerebral Palsy (CP) treatment is significantly related to frequency of illness and effect in family due to treatment cost significantly associated with age, place of residence and father’s income. Understanding the cost behind CP from various background can assist policy makers to identify useful and cost-effective interventions is warranted to optimize expenditure related to CP. Cerebral Palsy child from lowest income family have to pay more attention to support them to overcome this situations.

**Keywords** Cerebral palsy, Cost of CP, effects of CP management

**Chapter-One: Introduction**

##### INTRODUCTION

Cerebral Palsy is a long-term chronic medical condition that requires long-term supportive care services. Those with Cerebral Palsy often have other associative and co-mitigating medical conditions, including cognitive challenges, vision loss, hearing impairment, and seizures. These conditions require diagnosis, treatment and maintenance - all at significant cost. Cost of Cerebral Palsy (CP) has a negative impact on family which has a negative effect on the management of CP children that ultimately increases the cost again.

The cost of care for children with CP in this study, when considered by the economic situations during the study, was high. However, we took 3 months direct cost for the management of CP. the total annual cost when compared with what was reported from developed countries shows that our figure was much lower when compared to the cost of raising a child with CP from the USA, the UK, and the Netherlands (Beecham et al., 2001; Hoving et al., 2007). This could possibly be explained by the unavailability of cost-intensive diagnostic tools for CP, sophisticated medical therapy, and other long-term supportive services in this part of the world (Umar et al., 2020)

Cerebral Palsy (CP) is a permanent disorder that causes the movement and posture of an individual’s body to be limited1,2 . Limited movements and comorbid issues require individuals with CP to undergo rehabilitation and treatment services for long period of time In 1998, the Bangladesh Bureau of Statistics (BBS) estimated that 1.6 per cent of the country’s population suffers from disabilities. Action Aid Bangladesh estimated that 8.8 per cent of people (in 1996) require disability related services

**Justification of the study:**

* In our country we have not enough study on the cost of CP or other disability. According to the Bangladesh Bureau of Statistics (BBS) estimated that 1.6 per cent of the country’s population suffers from disabilities. Action Aid Bangladesh estimated that 8.8 per cent of people (in 1996) require disability related services.In countries like Bangladesh it might cause more burden on the family and Countries economy. Effect due to the treatment cost that we mentioned here might also have negative impact that was described by the family members or parents of CP children in our regular practice. In this small study we try to find out the cost and its impact on the family due to this cost.

**Research Question:**

What are the Prevalence of dental caries and permanent first molar among 9-12 years old school going children**?**

**Chapter two-Literature review**

##### Literature review

Oral health as a component of general health is essential to lead good quality of life. Oral diseases are major public health problems owing to their high prevalence and incidence. Dental caries is a major public health issue and it is the most widespread chronic disease. According to Global Burden of Disease Study 2015, deciduous tooth decay was ranked as the 12th most prevalent condition, Worldwide affecting 560 million children. Dental caries is a multifactorial disease, which can affect any age. It is highly related to and influenced by the patient’s dietary habits, sugar intake, salivary flow, salivary fluoride level and preventive behaviors. These factors, together with time, promote the microbial residence in the accumulated dental plaque to initiate dental caries. In children, dental caries pattern depends on the timing of tooth eruption as well as harmful dietary habit. Therefore, age is considered as an important factor that affects dental caries prevalence in children. Although caries is common, parents are infrequently concerned about oral health measures and usually poor oral health is linked with low socio-economic status. Dental caries could only be prevented through addressing and changing the underlying etiological factors. It has been estimated that about 60% to 90% of children at school age suffer from this chronic ailment. This percentage varies greatly in different population, with the incidence of dental caries in developing countries, including the Middle East, being much higher than its incidence in developed countries.

 Dental caries restrict activities in school and at home causing millions of school hours to be lost annually worldwide. Moreover, the psychosocial impact of this disease often significantly diminishes quality of life. For children in particular, dental caries not only causes pain and discomfort, it interferes with food intake affecting physical development in the form of malnutrition. It also affects ability to communicate and learn; school attendance and academic performance; and places a financial burden on the parents.

**1.1. Dental caries**

Dental caries is defined as a multi-factorial infectious disease caused by plaque bacteria. When food enters the mouth, bacteria metabolize fermentable carbohydrates, producing acids, which diffuse into hard dental tissue, and demineralize tooth enamel (17). In the absence of proper denial hygiene, this process has an increased likelihood of resulting in dental caries. Dental caries currently represents the most common chronic disease among children; it is five times more common than asthma, and seven times more common than seasonal allergies (18). Reported in third world countries, dental caries is the fourth most expensive disease to treat. For children of most low-income countries, treating dental caries is estimated at US $3513 per 1000 children, which would exceed the country’s total health budget (19). Dental treatment costs could easily exhaust a low-income country’s entire health budget, a budget that is already extended to its capacity, or simply does not exist. However, no country claims to have caries free children (20), and the explanation for why young children develop dental caries is complex.

**1.2. Dental caries indicators**

Dental caries is commonly measured by the sum of decayed, missing, and filled number of teeth (DMFT index) (21). This value has been widely applied to assess the dental caries status at the population level for public health planning and policy-making purposes [22]. The DMFT index, first introduced by [23], is a cumulative caries measure, which indicates caries occurrence, including past and present dental caries. The DMFT index has been in use for more than 76 years, and it remains the most commonly employed epidemiological index for assessing dental caries [24].

WHO and Federation Dentaire International (FDI) established the first global oral health goal, as follows: by the year 2000, children reaching the age of 12 will not possess an average of more than three decayed, missing, and filled permanent teeth (DMFT) [25]. During the following decades, most high-income countries reached or even exceeded these goals, but for many low-income countries, this remains a remote aspiration (26).

In 2003, the FDI, WHO, and International Association for Dental Research (IADR) issued “Global Goals for Oral Health 2020” (27). These goals provided guidance for local, regional, and national planners and policy makers to improve the oral health status of their populations. The new oral health goals were not numerically specific. Instead, each country could specify its own targets based on current disease prevalence and severity, local priorities, and oral health systems. Based on DMFT values, WHO generated a scale to classify caries severity: DMFT values between 0.0 and 1.1 were very low; 1.2–2.6 were low; 2.7–4.4 were moderate, 4.5–6.5 were high, and values exceeding 6.6 were very high (28).

**1.3. Different study context**

In 2003, Hobdell *et al*. developed the new global goal for oral health 2020 for the promotion of oral health globally. One of its targets for dental caries is to reduce the Decayed Missing Filled Teeth (DMFT), particularly the D component at age 12 years by a defined percent with special attention to high-risk groups within populations. Different Studies confirm that low social class increases the risk of developing high levels of dental caries. Parents' low educational level and professional situation (employed/unemployed) also play an important role in the child/adolescent oral health status. A study conducted among school children aged 8–12 years in Pakistan reported a caries prevalence of 90%.The prevalence of dental caries was higher between students belonging to family having less income and lower between students belonging to family having high income. A report from the United Arab Emirates on 12-year-old age group found DMFT ranging from 1.6 to 3.24.National Oral Health Survey in India reported caries prevalence of 51.9% at the age of 5 years, 53.8% at 12 years, and 63.1% at 15 years, respectively.

**Chapter Three-Research Methodology**

##### 3.1 Study Objectives

**General objectives:**

* We want to know the cost of CP management or treatment
* How it affects the lifestyle or livelihood to the other family members grossly.

**Specific objectives:**

1. To know the cost (direct) of CP
   1. Doctors consultation fee
   2. Medicine cost
   3. Cost of other rehabilitative services
   4. Cost of diagnostics/ test
   5. Cost of hospital admission
   6. Cost of others
2. How family gets affected because of this cost?

* income,
* treatment of the other family members,
* education of the children,
* food,
* housing and
* entertainment

1. For the benefit of the further research.

**3.2. Conceptual Framework**

Outcome Variables

Independent Variables

**Socio-demographic Variables**

* Age
* Gender
* Residence
* parents education

* cost
* Effect due to the cost

Income of parents

Frequency of illness

Domain affected

##### 3.3 Study design:-

This was a cross-sectional study.

##### 3.4 Study Location

Dr. MR Khan Shishu Hospital and Institute of Child Health. And children from all over the country.

##### 3.5 Study population

The target populations were the parents or caregiver of the Cerebral palsy children from all over the country

##### 3.6 Sample population

* The sample size was 95 but due to COVID it was reduced into 41. The Parents of CP children.

Who are willing to participate were included for the study. Parents of others disability were excluded from the study.

##### 3.7 Study Period

The study period was 6 months

##### 3.8 Inclusion Criteria

* Parents of CP children.
* Who are willing to participate?

##### Exclusion Criteria:

* Parents of CP who are not interested
* Parents of others disability.

##### 3.8 Sampling Technique

##### Three places was selected but due to COVID situation Data was collected from only one place.

##### 3.9 Sample Size

The sample size was determined using following formula

n= z2pq/d2

= (1.96)2 × (0.306) (1-0.306)/ 0.062

= 226

Here,

**n** = desired sample size (when the population>10,000)

**Z** = standard normal deviate; usually set at 1.96, which correspond to 95% confidence level.

**p** = Prevalence of study among adolescent population is performs study 30.6% (0.306). (Khan, Mahjabeen. (2013). Prevalence of Dental Caries in the first permanent molars in children between 8-12 years. Journal

**q** = 1-p

**d** = degree of accuracy required, usually set at 0.06 level

That is too difficult to fulfill the participants within 6 months because there was a pandemic of COVID-19. And limited time, I need to reduce the sample size.

##### 3.10 Data collection technique:-

A pretested semi-structured questionnaire was used for the respondents to be interviewed. This questionnaire was developed by using selected variables according to the study objectives.

##### 3.11 Data Collection Tools

**Socio-Demographic variables:** Following socio-demographic variables were collected by using a semi-structured questionnaire, such as: age, sex, residence, education, occupation and income of parents.

**Procedure:** selection of the Cerebral palsy , direct interview of the parents or caregivers.

**3.12 Interview Schedule ( Data)**

Non clinical data was collected before the diagnosis part. Non clinical information were socio-demographic background, clinical data was collected during the treatment or diagnostic part**.**

**3.13 Data management and analysis plan:**

Data was collected from the respondents by face to face interview followed by inclusion and exclusion criteria.seperate questionnaire was used for each respondent. The collected data was edited by checking and rechecking. The data was analyzed by using the software SPSS-20.

* Descriptive statistics were calculated for all of the variables, including continuous variables and categorical variables.
* The association between dental disease and smoking were estimated by doing Chi square test.
* The association between dental caries and hygiene practices and dietary history were estimated by doing Chi square test.
* The P-value less than 0.05 was regarded as significant for this study. The data was presented by table, graphs and charts.

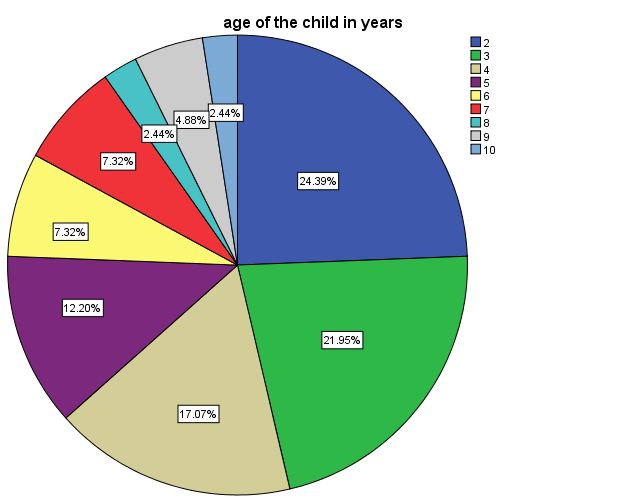
**3.14 Ethical Considerations: -**

As researcher aimed was to benefit the society hence the researchers did not force anyone to respond to the questionnaire and also make sure that all the individual information was confidential. The study protocol was approved by the authorities of the South Asia University.

* A detailed consent form was also given to the study participants.
* Confidentiality and privacy was maintained throughout the study.
* Any participant was at liberty to refuse to participate in the study or withdraw from it.

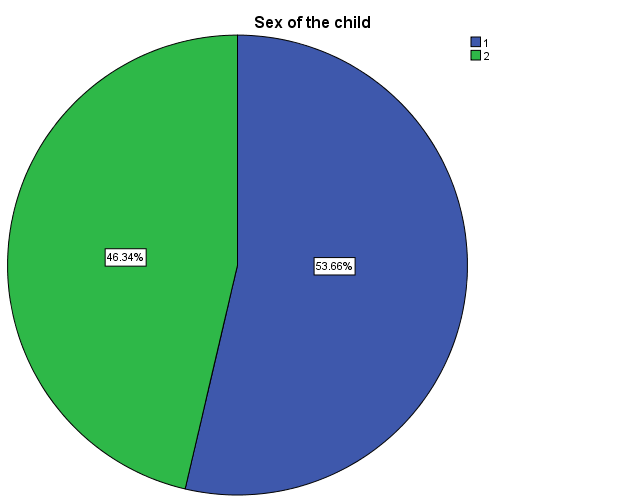
**Chapter-Four: Results**

**Figure 1: Distribution of children with** **cerebral palsy based on age (n=41)**



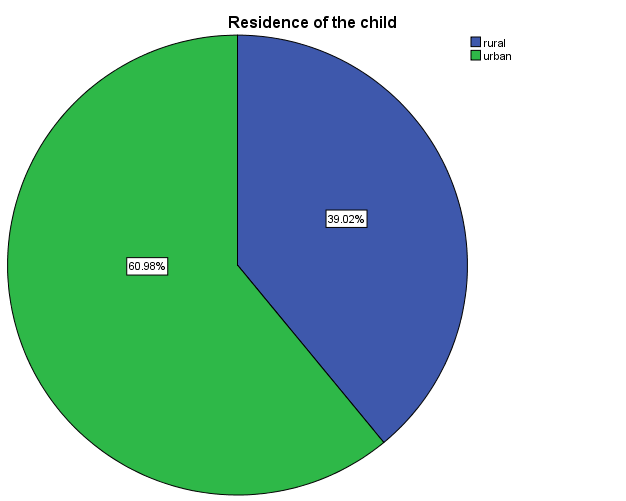
Pie chart represents the percentage of age of 41 children with cerebral palsy. Among 41 children, a large number 24.39% were 2 years old, 21.95% were 3 years old, and 17.07% at 4 years, 12.20 were 5 years old. And the rest were among 6-10 years old.

**Figure 2 : Distribution of children with** **cerebral palsy based on sex (n=41)**



represents the percentage of 41 children with cerebral palsy. Among 41 children, a large number 53.7% (n=22) were male and a small number of children 46.3% (n=19) were female.

**Figure 3 : Distribution of children with** **cerebral palsy based on Residence (n=41)**



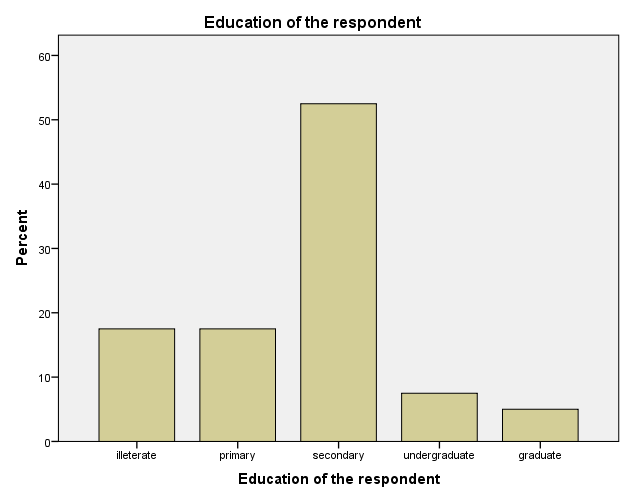
Represents the percentage of 41 children with cerebral palsy. Among 41 children, a large number 61.0% (n=25) came from urban areas and a small number of children 39.0% (n=16) were came from rural areas.

**Table 1: Distribution of children with** **cerebral palsy based on respondent’s age (n=41)**

|  |  |  |
| --- | --- | --- |
| Respondent’s age | Frequency | Percentage |
| 15-30 | 24 | 58.5 |
| 30+ | 17 | 41.5 |
| Total | 41 | 100.0 |

Table 4 represents the percentage of 41 children with cerebral palsy. Among 41 children, a large number 58.5% (n=24 have 15-30 years respondents and a small number of children 41.5% (n=17) of children have respondents greater than 30 years.

**Bar chart: Distribution of the respondent’s education (n=41)**



Bar chart represents the percentage of educational level of the respondents of the cerebral palsy children. Most of the respondents were mother and mong 41 respondents, Above 50% is with secondary education status, illiterate and primary education status almost at the same percentage, and less number of respondents are graduate and undergraduate level. In simple, large number 63.4% (n=26) have respondents with secondary or higher education status and a small number of children 36.6% (n=15) of children have respondents with below secondary educational status.

**Table 8: Distribution of children with** **cerebral palsy based on age father’s income (n=41)**

|  |  |  |
| --- | --- | --- |
| Father’s income | Frequency | Percentage |
| Below 20000 | 30 | 73.2 |
| 20000+ | 11 | 26.8 |
| Total | 41 | 100.0 |

Table 8 represents the percentage of 41 children with cerebral palsy. Among 41 children, a large number 73.2% (n=30) child father income below 20000 and a small number of children 26.8% (n=11) of child father earn more than 20000.

**Table 1: Distribution of cost type with children with cerebral palsy (n=36) in the last 3 months:**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Cost Type | Mean | SD | Min | Max |
| **Direct cost(medical)** |  |  |  |  |
| Doctors Consultation Fee | 967.07 | 925.99 | 0 | 5000 |
| Admission fee | 3785.37 | 8829.40 | 0 | 50000 |
| Medicine cost | 7842.93 | 38805.50 | 0 | 250000 |
| Test / diagnostic fee | 5223.17 | 10981.87 | 0 | 64000 |
| Rehabilitation services | 1708.54 | 3018.44 | 0 | 19000 |
| Cost for Assisted Devices | 2017.07 | 3252.43 | 0 | 15000 |
| **Direct cost (non-medical but treatment related)** |  |  |  |  |
| Food and transport cost | 3259.76 | 6353.69 | 100 | 35000 |
| Others cost | 1121.95 | 1286.37 | 0 | 5000 |
| Total cost | 25925.85 | 52619.24 | 150 | 335950 |

Based on Table 1, average cost incurred by families of children with CP was 25925.85 BDT. Overall, direct medicine costs are the highest burden (7842.93 BDT) of the Bangladeshi family over the all types of cost. Rather than medicine cost, on average, families of children with CP spend highest 5223.17 for direct test/diagnostic costs. Followed by, 3785.37 BDT for admission costs, 3259.76 for indirect food and transport costs.

**Table 2:** **Mean difference of total cost by condition of children with** **cerebral palsy**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | n (%) | Total cost | | P-Value |
|  | Mean | SD |  |
| **Frequency of illness** |  |  |  |  |
| No illness | 9 (22.0) | 6477.78 | 3659.76 | .085 |
| One times | 15 (36.6) | 20260.00 | 20791.64 |  |
| Two times | 10 (24.4) | 20860.00 | 17388.02 |  |
| Three times | 7 (17.1) | 70307.14 | 118280.08 |  |
| **Limb involvement** |  |  |  |  |
| Monoplegic | 3 (7.3) | 10583.33 | 5385.24 | 0.791 |
| Hemiplegic | 18 (43.9) | 20761.67 | 20310.78 |  |
| Diaplegic | 1 (2.4) | 3800.00 | - |  |
| Quadriplegic | 19 (46.3) | 34405.26 | 74773.19 |  |
| **Domain affected** |  |  |  |  |
| Less than two | 5 (12.2) | 15540.00 | 19972.56 | 0.381 |
| Two | 6 (14.6) | 7875.00 | 1835.14 |  |
| Three | 10 (24.4) | 12370.00 | 10032.81 |  |
| Greater than three | 20 (48.8) | 40715.50 | 72375.63 |  |
| Total | 41 (100) | 25925.85 | 52619.24 |  |

Table represents the percentage of 41 children with cerebral palsy. Among 41 children, a large number of children 36.6% (n=15) were face illness one times in last three months and the mean cost for treatment was 208600 BDT. However, the mean cost was highest for children face illness with three times in last three months.

Among 41 children, a large number of children 46.3% (n=19) were face Quadriplegic limb involvement and the mean cost for treatment was highest (34405.26 BDT) among other limb involvement. Among 41 children, a large number of children 48.8% (n=20) were face domain affected greater than three and the mean cost for treatment was highest (40715. BDT) among all other domain.

**Table 3: Comparison of CP economic burden according to age group**

|  |  |  |  |
| --- | --- | --- | --- |
| Cost Type | 0-4 years old | 4+ years old | P-value |
| **Direct cost(medical)** |  |  |  |
| Doctors Consultation Fee | 1011.54 | 890.00 | 0.691 |
| Admission fee | 4773.08 | 2073.33 | 0.352 |
| Medicine cost | 11521.54 | 1466.67 | 0.431 |
| Test / diagnostic fee | 7138.46 | 1903.33 | 0.144 |
| Others (Services like physiotherapy, occupational therapy, speech therapy, counselling, nutritional counselling etc.) | 1446.15 | 2163.33 | 0.471 |
| Cost for Assisted Devices | 1538.46 | 2846.67 | 0.219 |
| **Direct cost (non-medical but treatment related)** |  |  |  |
| Food and transport cost | 4215.38 | 1603.33 | 0.209 |
| Others cost | 1084.62 | 1186.67 | 0.810 |

Based on Table, direct medicine costs are the highest burden (11521.54 BDT) of the children aged 0-4 years, over the all types of cost. Rather than medicine cost, on average, families of 0-4 years of children with CP spend highest 7138.46 for direct test/diagnostic costs. Followed by, 4773.08 BDT for admission costs, 4215.38 for indirect food and transport costs. However, children age greater than 4 years families spend highest (2846.67 BDT) for direct cost for assisted devices.

**Table 4: Comparison of CP economic burden according to education of mother (respondents)**

|  |  |  |  |
| --- | --- | --- | --- |
| Cost Type | Below secondary | Secondary or higher | P-value |
| **Direct cost(medical)** |  |  |  |
| Doctors Consultation Fee | 830.00 | 1046.15 | 0.479 |
| Admission fee | 1633.33 | 5026.92 | 0.241 |
| Medicine cost | 1506.67 | 11498.46 | 0.434 |
| Test / diagnostic fee | 2136.67 | 7003.85 | 0.175 |
| Others (Services like physiotherapy, occupational therapy, speech therapy, counselling, nutritional counselling etc.) | 2140.00 | 1459.62 | 0.494 |
| Cost for Assisted Devices | 2300.00 | 1853.85 | 0.678 |
| **Direct cost (non-medical but treatment related)** |  |  |  |
| Food and transport cost | 1950.00 | 4015.38 | 0.322 |
| Others cost | 986.67 | 1200.00 | 0.615 |

Based on Table, direct cost for assisted devices is the highest burden (2300.00 BDT) of the children with below secondary respondents, over the all types of cost. Rather than cost for assisted devices, on average, below secondary respondents with CP children spend highest 2140 for direct others costs. Followed by, 2136.67 BDT for test/diagnostic costs, 1950.00 for Direct cost non-medical but treatment related food and transport costs. However, children with secondary or higher educational respondents spend highest (11498.46 BDT) for direct medicine cost.

**Table 5: Mean difference of total cost by socio-economic characteristics of children with** **cerebral palsy (Two sample T-test)**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Total cost | | P-Value |
| **Age in months** | Mean | SD |  |
| 0-4 | 32729.23 | 65092.74 | 0.281 |
| 4+ | 14133.33 | 10472.32 |  |
| **Sex of child** |  |  |  |
| Male | 18159.09 | 18865.61 | 0.315 |
| Female | 34918.95 | 74689.55 |  |
| **Place of residence** |  |  |  |
| Rural | 38943.75 | 81138.25 | 0.209 |
| Urban | 17594.40 | 17740.45 |  |
| **Father’s Income** |  |  |  |
| Below 20000 | 26775.00 | 60109.46 | 0.867 |
| 20000+ | 23610.00 | 24268.29 |  |
| **Mother’s Age** |  |  |  |
| 15-30 | 18242.08 | 18474.51 | 0.272 |
| 30+ | 36773.53 | 78852.68 |  |
| **Sex of respondent** |  |  |  |
| Male | 46100.00 | 15908.49 | 0.497 |
| Female | 24333.16 | 54258.60 |  |
| **Respondents education** |  |  |  |
| Below secondary | 13483.33 | 9359.31 | 0.255 |
| Secondary or higher | 33104.23 | 65073.20 |  |
| **Relation with child** |  |  |  |
| Mother | 24819.19 | 54923.10 | 0.687 |
| Others | 36162.50 | 23743.12 |  |
| **Cost contributors** |  |  |  |
| Father | 29691.94 | 59957.99 | 0.427 |
| Others | 14251.00 | 11054.55 |  |

The mean cost of age 0-4 years and greater than 4 year of children with CP is 32729.23 and 14133.33, respectively. The mean cost of male and female children with CP is 18159.09 and 34918.95, respectively. The mean cost of rural and urban children with CP is 38943.75and 17594.40, respectively.

**Table 6: Effects on family due to the cost of CP treatment (N=41)**

|  |  |  |
| --- | --- | --- |
| Variable | percent | Frequency |
| 1Effects on treatment of the other family members   * Does not do anything/ no treatment * Visit a quack * Went to a doctor and get proper treatment * Others like home remedy or traditional treatment | 39  53.7  39.5  10.5 | 16  22  16  6 |
| 2.Effects on Income of the family members( mainly father and mother)   * Due to frequent visit to doctors * Due to take care of the child | 41.5  14.6 | 17  18 |
| 3.Effects on Education of the other children   * Late school fee * Effects on tuition fee * Withdrawn from school | 19.5  34.1  0 | 8  14  0 |
| 4.Effects on food for the family member   * Reduce the number of meal * Reduce number of good food * Reduce number of favourite food | 31.7  56.1  61 | 13  23  25 |
| 5. effects on entertainment of the family member   * Attending social program * Visiting family members and relatives/tour * Children amassment like go to park, zoo etc. | 48.8  46.3  29.3 | 20  19  12 |

Table 6 shows the effect on the family due to due to the treatment cost of the CP, We only count the number who has a problem, who had no problem we did not count them.

Effect on the treatment of the other family member’s shows, 53.7% (n=22)visit a quake to save the money for the treatment of the CP child, 39% does not do any treatment and 10.5% received treatment from traditional healer or home remedy.

Effects on Income of the family members (mainly father and mother): 41.5 % (n=17) stated that due to frequent visit of doctors their income reduced. 14.6% (18) complained due to take care of the child.

Effects on Education of the other children, mainly effects on the tuitions fee of the other children 34.1% (n=14), late school fee was complained by 19.5% (8), no one complained about withdrawn from school.

Effects on food for the family member, 61% (25) told they do not take favorite food, 56.1% (23) stated about reducing number of balanced or good food, 31.7% (13) said that had to reduce the number of food due to the treatment cost.

Effects on entertainment of the family member, almost half 48.8% (20) of the mother said they usually don’t attend social program. Visiting family members and relatives/tour 46.3 %( 19) had face problem, and 29.3% (12) did not consider or take Children amassment like go to park, zoo etc.

**Table 7: Association between effects in the family due to the treatment cost of children with** **cerebral palsy with socio-economic characteristics**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Effect | | P-Value |
| **Age in months** | **Low** | **High** |  |
| 0-4 | 11 (42.3) | 15 (57.7) | 0.281 |
| 4+ | 4 (26.7) | 11 (73.3) |  |
| **Sex of child** |  |  |  |
| Male | 9 (40.9) | 13 (59.1) | 0.536 |
| Female | 6 (31.6) | 13 (68.4) |  |
| **Place of residence** |  |  |  |
| Rural | 5 (31.3) | 11 (68.8) | 0.209 |
| Urban | 10 (40.0) | 15 (60.0) |  |
| **Father’s Income** |  |  |  |
| Below 20000 | 10 (33.3) | 20 (66.7) | 0.067 |
| 20000+ | 5 (45.5) | 6 (54.5) |  |
| **Mother’s Age** |  |  |  |
| 15-30 | 6 (25.0) | 18 (75.0) | 0.272 |
| 30+ | 9 (52.9) | 8 (47.1) |  |
| **Sex of respondent** |  |  |  |
| Male | 2 (66.7) | 1 (33.3) | 0.261 |
| Female | 13 (34.2) | 25 (65.8) |  |
| **Respondents education** |  |  |  |
| Below secondary | 6 (40.0) | 9 (60.0) | 0.730 |
| Secondary or higher | 9 (34.6) | 17 (65.4) |  |
| **Relation with child** |  |  |  |
| Mother | 13 (35.1) | 24 (64.9) | 0.558 |
| Others | 2 (50.0) | 2 (50.0) |  |
| **Cost contributors** |  |  |  |
| Father | 10 (33.3) | 20 (66.7) | 0.427 |
| Others | 5 (45.5) | 6 (54.5) |  |
| **Total** | 15 (36.6) | 26 (63.4) |  |

there was significant relationship between age of child, place of residence and father’s economic status with effects in the family due to the treatment costs. We didn’t find any association with child sex, mothers age and respondents education that may effects in the family due to the treatment cost. In our study, higher aged child showed higher effect (73.3%) in the family due to the treatment cost compare to the low effect (26.7%). Most of the rural family (68.8%) faced high effects in the family due to the treatment cost. Fathers who income less than 20000 faced high effect on family due to the treat cost of CP.

**Chapter Five**

**Discussion, Conclusion, Recommendations**

**Discussion:**

CP is a developmental disability with a relatively high incidence. Affected individuals are among the most handicapped in our society. The huge challenges in dealing with CP include a lack of etiologic understanding of this condition, and consequently lack of effective means of prevention or treatment other than symptomatic approaches. CP usually originates in the pre- or perinatal period. However, it can be brought on in childhood by infection, trauma, and other causes, and it may develop in the absence of any identifiable risk factors. Our findings reveal its burden in Bangladesh in economic terms in order to address policy-makers’ concerns and provide them with input to future decisions on CP prevention and care.

It was a small study with a population size of 41 and due to COVID situation we did not get varieties of population, although they came from all over Bangladesh. We receive information from a group of people who were from a certain socio- economic status. We get cost information of last 3 months which did not represent all treatment cost of the patient, but due to limitations we had to do. Effect we just count the effect that respondents mention mainly and not in details.

The cost of care for children with CP in this study, when considered by the economic situations during the study, was high. However, the total annual cost when compared with what was reported from developed countries shows that our figure was much lower when compared to the cost of raising a child with CP from the USA, the UK, and the Netherlands (Beecham et al., 2001; Hoving et al., 2007). This could possibly be explained by the unavailability of cost-intensive diagnostic tools for CP, sophisticated medical therapy, and other long-term supportive services in this part of the world (Umar et al., 2020).

Based on the information obtained from interviews with 41 CP patients’ caregivers in Bangladesh, from the societal perspective, the total lifespan economic burden caused by a new CP case mean was BDT 25925.85 in 2020. The economic burden is heavy both for the family and society. There are several factors which contribute to this high economic burden, such as long-life expectancy, life-long and high dependency on caregivers’ support, progressive deterioration of motor function, and recurrent use of rehabilitation services.

It is noteworthy, however, that indirect mean cost in this study contributed BDT 4381.71 to the total cost. This is in keeping with reports from Europe and the US that showed indirect costs as the predominant cost driver (Kancherla et al., 2012; Kruse et al., 2009). However, their indirect cost is much higher than our finding; the reason being that we only considered productivity losses by parents or caregivers, while other related studies on developed countries considered productivity losses by both caregivers and the patient and other financial forfeitures related to the disorder. The difference may also be attributed to the higher cost of labour and services in such developed societies when compared to our resource-challenged settings.

Our study also showed that transport and lodging costs spent during each clinic visit per month were quite insignificant as most of the patients reside within the metropolis. There is no significant difference in the average cost per patient per month across gender, age group, ethnicity, type of CP, perceived cause of CP, and a number of associated problems. By sociodemographic characteristics, our study showed that the majority of the patients in the study belong to the middle and lower socioeconomic classes based on a validated scoring tool in a resource-challenged setting. This finding is consistent with the previous association of CP with poor education and poverty (Eide et al., 2014; Odding et al., 2006). Furthermore, our finding is similar to previous reports from developing countries (Frank-Briggs & Alikor, 2011; Singhi et al., 2002).

**Conclusions**

Understanding of the economic impact of CP can assist decision makers in their day-to-day decisions. The applicability of the economic impact research findings would be greatly enhanced through greater consistency of reporting methods across studies. Although analysis techniques and cost components employed in the included studies were varied, the results showed a strong positive relationship between CP severity and costs. Costs covered substantial expenditure related to medical services, costs borne by families, as well as the welfare system to facilitate social participation and engagement. The results also confirm that research to identify useful and cost-effective interventions is warranted to optimise expenditure related to CP care.

**Recommendations**

The findings of this study have important implications for the practice of public health in the country. The fact that the caregivers of children with developmental disabilities most likely are highly vulnerable persons places a great responsibility on the public health system to provide support systems and take measures to ensure the wellbeing of these caregivers This study also provides important information that the financial support provided by the government as a welfare measure to children with disabilities is perceived to be insufficient. There is a need to revise the financial support. The government must take appropriate measures to improve urban and rural planning to make public spaces inclusive. Public transport must also have special provisions for caregivers traveling with children with special needs.

* Need to conduct more study with a large group of population.
* Need more study on the cost induced effect in our context?
* Need more support or help from the government for the treatment of the Cerebral palsy

**Limitations of the study**

* We were supposed to collect data from three different organizations but due to corona related lockdown we couldn’t collect, instead of three we collect from one organization.
* Our sample size needed to reduce due to COVID-19, we couldn’t collect data as required.
* Most of the population were from a certain socioeconomic condition, so we did not know the cost and effect of the people with other socioeconomic condition.

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* [NIH – Medical expenditures attributable to cerebral palsy and intellectual disability among Medicaid-enrolled children](https://www.ncbi.nlm.nih.gov/pubmed/22245730)
* [CDC – (MMWR)](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5303a4.htm)
* [United Cerebral Palsy](http://ucp.org/wp-content/uploads/2013/02/cp-fact-sheet.pdf)

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**Annexes**

INFORMED CONSENT

University of South Asia



Name of the Respondent: Date:

I am Asma Akter, student of MPH program, University of South Asia. As a course requirement I am doing a research on **“*Direct cost of cerebral palsy management (medical) and its effects on family, Bangladesh perspective”.*** I am inviting you to participate in this research study.

I need Some Valuable Information from you as a part of my academic purpose. Your cooperation will be highly appreciable. You can refuse to answer any questions or may leave at any time you feel like. If you refuse or leave you will not face any problem.

All the information given by you will be kept confidential also will not be shared it with anyone. Your identity will not be disclosed. Only study related personnel will be allowed to see the information.

I would appreciate your cooperation. If you agree to join the study please sign at the space indicated below.

Interviewers Signature & Date

Respondents Signature/ Thumb impression & Date

## Topic: Direct cost of cerebral palsy management (medical) and its effects on family, Bangladesh perspective.

**Questionnaire**

Id no:

* Affected domain of CP child: 1.Gross Motor 2.Fine Motor 3.visual

4. Hearing 5.speech and communication 6.cognition 7. Epilepsy.

* Age of the CP child: Sex 1. Male 2. Female
* Respondents name: age sex 1. Male 2. Female
* Residence 1. Dhaka 2. Outside Dhaka
* Respondents Relation with the CP children: 1. Father 2. Mother 3. Caregiver 4.others
* Education of the respondent: 1. Illiterate 2. Primary 3. Secondary

4. Undergraduate 5. Post graduate

* Income of the respondent (main incoming member of the family monthly: 1.below 20,000

2. 20,000- 50,000 3. Above 50,000

* Main contributing member for child’s treatment: 1. Father 2. Mother 3. others

***Cost Related***

* How many time does your child get sick in a month? / Frequency of child’s illness?
* What type of sickness he/she usually get?

**Answer last 3 months cost of your child’s treatment:**

|  |  |  |  |
| --- | --- | --- | --- |
| SL. no | Cost details | Cost of treatment of last 3 months | Frequency  / time of visit |
|  | Doctors consultation fee( medical, GP) |  |  |
|  | Specialist consultation, like (medicine, neurologist, (orthopedics, dentist, ophthalmologist, ENT, others. |  |  |
|  | Diagnosis or investigations cost( like blood test, x ray, EEG, MRI ETC ) |  |  |
|  | Drugs/ medicine cost |  |  |
|  | Hospitalization( admission) |  |  |
|  | Physiotherapy |  |  |
|  | Occupational therapy |  |  |
|  | Speech therapy |  |  |
|  | Dietician consultation fee |  |  |
|  | Cost of surgery If any |  |  |
|  | Transportation fee( from home to the hospital/ center-hospital /center to home |  |  |
|  | Cost of assisted device (special chair, walking aids, braces or orthoses etc.) |  |  |
|  | Cost for food( during admission/ travel/ for the child including parents/ attendance |  |  |
|  | Hotel /resident cost for the attendance ( father/ relatives) |  |  |
|  | Others(Telephone / other communication cost, Entertainment( z00, museum, visit to relatives, shopping Contingency for consulting doctors, diagnosis etc. etc. |  |  |

Where do you get money for this cost?

1. From monthly income 2. From deposited money 3. Loan from Bank

4. Loan from others 5. Selling household, ornaments 6. Others

**Effects on the family (grossly) due to the treatment cost of CP child.**

**(last 3 months)**

* Family members get sick but

1. Does not go doctors 2. Visit a quake / alternative doctors to reduce fee

3. Others 4.no effect

* Reduce income of the family members

1. To visit of doctor (frequently) 2. To take care of the child (mother/father/ other family member) 3. Others 4. No effect

* Education of other child

1. Late school fee 2. Effect on tuition due to extra treatment cost 3.withdrawn from the school 4. Others 5. no effect

* Food of the family members

1. Reduce the number of meal 2. Reduce the number of favorite food/ balanced food 3. No effect

* Extra Problems stated by the family members: write here)