Health Related Quality of Life of Children with Cerebral Palsy among 3-12 Years Old

Mohammad Mohinul Islam, Arifa Sultana, Md. Zahid Hossain, and Sharmila Jahan

ABSTRACT

Introduction: Health-related Quality of Life (HRQOL) refers to a set of characteristics that may have an effect on health because they are related with an increased risk of chronic diseases related to low levels of physical activity. HRQOL is especially appropriate to conditions that are continuing and disabling such as cerebral palsy (CP). This study aims to determine the quality of life of children with cerebral palsy.

Methods: Cross sectional prospective survey under a quantitative study design was conducted for six months. Data was collected from the outdoor and indoor Paediatric physiotherapy unit of the Centre for the Rehabilitation of the Paralysed (CRP), Bangladesh. 100 cerebral palsy children were taken as the sample based on eligibility criteria, LAQ-CP questionnaire was used to assess the effect of disability in children with CP and their families.

Results: From the analysis, found that cerebral palsy most commonly limits the schooling of the cerebral palsy child. Also, it limits the ability of mobility, physical independence, and social integration. Besides it causes economic and clinical burden for the family members of the child with CP. Overall, the QOL severely affected 40% (n=40) cerebral palsy children, moderately 29% (n=29), mildly 20% (n=20) children. Only 11% (n=11) was found with good QOL in this study.

Conclusion: HRQOL is pointedly affected in most of the children suffering from cerebral palsy. Measurement of HRQOL should be include with other type of assessment, to specify the areas in which a patient is most suffering and help the expert in making suitable decisions for patient management. The present finding indicates that cerebral palsy has a negative impact on health status and quality of life of children with cerebral palsy, as reported by the respondent parent.

Keywords: Cerebral palsy, health related quality of life, LAQ-CP.

I. INTRODUCTION

Health-related Quality of Life states to a set of characteristics that may affect health as they are linked with an increased risk of chronic diseases associated to lower level of physical activity [1]. HRQOL is particularly related to situations that are continuing and disabling such as cerebral palsy (CP) [2]. Cerebral Palsy (CP) defines a group of conditions, arising from an injury to the developing brain and occurs in 2.0 children per 1000 live births. In addition to the disturbances of movement and posture including spasticity, muscle weakness and reduced coordination, common impairments of children with CP include disturbances of sensation, perception, cognition, communication, behaviour, epilepsy, and secondary musculoskeletal problems; Reduced activity levels and participation restrictions due to these impairments may lead to a reduced quality of life (QOL), compared to their typically developing peers [3]. Nevertheless, little is known about health professionals’ estimations of pain and HRQOL in children with CP, despite its importance on treatment choices, patient-doctor relationship, and psychosocial status management during healthcare-related procedures [4]. Quality of life is not only the concept of illness, functional status, mental health, and comfort but also parental impact and family functioning. Due to their challenging behaviour and interest, those children always need high supervision and care-giving. It is important to conduct the study because it will provide a better awareness about the impact on the mother or career’s life of having a cerebral palsy child. This awareness is very necessary to understand their problems and their needs. It will also help therapists to provide effective family education to mothers and careers by increasing their knowledge about cerebral palsy and changing their attitudes towards CP. This study will be helpful for physiotherapists to make awareness about children with cerebral palsy. The primary objective of this research is to determine the health-related quality of life of children with cerebral palsy and the secondary objectives are to explore the socio-demographic (age, gender, residential area) information, level of physical independence, level of mobility, clinical and economic burden level, ability to manage schooling and social integration.
II. MATERIALS AND METHODS

A. Study Settings and Participants

Cross sectional prospective survey under a quantitative study design was conducted for 6 months. Data was collected from the outdoor and indoor Paediatric physiotherapy unit of the Centre for the Rehabilitation of the Paralysed (CRP), Bangladesh. 100 cerebral palsy children were taken as the sample based on eligibility criteria. Children with a diagnosis of cerebral palsy, age range between 3-12 years, both boys and girls, [5], getting regular (minimum 1 visit for 1 week) physiotherapy/occupational therapy, were included in the study by purposive sampling technique. Participants were excluded in case of non-availability of the principal caregiver, complain other continuing illnesses that are not associated with cerebral palsy, families who have other child with cerebral palsy, autism spectrum disorder, severe spasticity according to Modified Ashworth scale among CP were excluded.

B. Questionnaire

A structured Life Assessment Questionnaire (LAQ) and demographic information chart was used to collect the data. LAQ-CP questionnaire assesses the influence of disability in children with CP, also it assesses the difficulties of their family members. It consists of 46 items, ordered into six dimensions: physical independence, mobility, clinical burden, schooling, economic burden, and social integration. Total Lifestyle Assessment Score (LAS) is obtained, founded on scores of each item, scores of each dimension and a final score which is standard score of measurement of this scale These are uttered as a percentage (%) score. Dimensions are named to reflect elements of the International Classification of Impairment, Disabilities and Handicaps [6].

C. Data Analysis

Descriptive statistics were used to analyze data. Descriptive statistics refers to methods of describing a set of results in terms of their most interesting characteristics [7]. Data was analyzed with the software named Statistical Package for the Social Science (SPSS). The variables were labelled in a list and the researcher established a computer-based data definition record file that consists of a list of variables in order. The researcher put the name of the variables in the variable view of SPSS and defined the types, values, decimal, label alignment and measurement level of data. The next step was cleaning new data files to check the inputted data set to ensure that all data has been accurately transcribed from the questionnaire sheet to the SPSS data view. Then the raw data was ready for analysis in SPSS. Data was analysed by descriptive statistics and calculated as percentages and presented by using table, bar graph, pie charts etc. Microsoft office Excel 2010 was used to decorate the bar graph and pie charts. The result of this study consisted of quantitative data. By this study a lot of information was collected.

III. RESULTS

An exploratory data analysis was conducted among 100 children to have a preliminary idea about the trends of data. The average age of the participants was 7.8 ±2.93years (Table I). Majority of the children (52%) were between 8-12years old, followed by 48% were 3-8 years. Most of them were boys (Fig. 1) and results showed that 37% of children's mothers' education level were SSC (Fig. 2). None of the mothers has a history of cousin marriage and most of the women told their age during the birth of their child was between 18-22 years (45%) followed by 26-30 years (25%), 22-26years (19%) and 30-35 years (11%). This study also shows that most of the children were from rural areas (67%). Besides mothers report that most of the children have a history of Jaundice (9%), Pneumonia (6%), Epilepsy (19%), Dehydration (4%), Seizure (25%) after birth. During birth 45% had a history of birth injury and 39% had a history of birth asphyxia.

<table>
<thead>
<tr>
<th>TABLE I: CHARACTERISTICS OF CHILDREN AGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total, N=100</td>
</tr>
<tr>
<td>Age (mean ± SD)</td>
</tr>
<tr>
<td>3-8 years</td>
</tr>
<tr>
<td>48 (48%)</td>
</tr>
<tr>
<td>8-12 years</td>
</tr>
<tr>
<td>52 (52%)</td>
</tr>
</tbody>
</table>

Fig. 1. Gender.

Fig. 2. Mothers educational level.

Quality of life of cerebral palsy children was measured by using the Lifestyle assessment questionnaire (LAQ-CP) in this study. Mean score was calculated for six dimensions. From the analysis, found that cerebral palsy most commonly limits the schooling of the cerebral palsy child. Also, it limits the ability of mobility, physical independence, and social integration. Besides it causes economic and clinical burden for the family members of the child with CP (Table II). Overall, the QOL severely affected 40% (n=40) cerebral palsy children, moderately 29% (n=29), mildly 20%(n=20)

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children. Only 11% (n=11) was found with good QOL in this study (Table III).

### TABLE II: DIMENSIONAL SCORE

<table>
<thead>
<tr>
<th>Dimensions</th>
<th>Average Score (%)</th>
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<tbody>
<tr>
<td>Mobility</td>
<td>50.4%</td>
</tr>
<tr>
<td>Schooling</td>
<td>70.1%</td>
</tr>
<tr>
<td>Physical independence</td>
<td>69.2%</td>
</tr>
<tr>
<td>Social integration</td>
<td>39.1%</td>
</tr>
<tr>
<td>Economic burden</td>
<td>41.6%</td>
</tr>
<tr>
<td>Clinical burden</td>
<td>30.2%</td>
</tr>
</tbody>
</table>

### TABLE III: STATUS OF HRQOL BASED ON QOL SCORE

<table>
<thead>
<tr>
<th>Status of HRQOL</th>
<th>Frequency (N=100)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>11 (11%)</td>
</tr>
<tr>
<td>Moderately affected</td>
<td>29 (29%)</td>
</tr>
<tr>
<td>Severely affected</td>
<td>40 (40%)</td>
</tr>
</tbody>
</table>

IV. DISCUSSION

The study was aimed to see the quality of life of cerebral palsy children among 3-12 years. After analysis shows that most of the children under this study maximum age was 12 and minimum age was 7. Study also explores the ages of mothers when their CP child was born. Maximum age of mothers was between 18-22 years. For CP children maternal age is an important causative factor, because study found that causative factors of CP may depend on mother age [8]. Diseases after birth like Jaundice, Pneumonia, Dehydration and Seizure are also important for CP children. Over this study most of the children suffered from dehydration, Pneumonia, Jaundice, Seizure after birth which are responsible for CP. According to [9] at least one or two comorbid conditions present in 95% children with CP. These are basic points to analyse the CP child birth, which is related to this study.

QOL is a wide-ranging idea which focuses not only on positive side of life but also the negative aspect. It explains a person's overall life experiences. For the child with CP, QOL is a very related and significant matter because it can affect the child's overall life status, including physical, psychological and functions [10]. Children having cerebral palsy needs different care and healthcare services in compare with healthy one [11]. Various factors induce the life status of CP child and their family members including their inability to works, limitation in participations and emotional stress and need of support from others. Identification of status of QOL is important to choose appropriate treatment [12]. This study analyse this.

After analysis the quality of a CP child study found that most of them are affected in schooling. That includes - type of school, duration of school attendance, distance between home and school in those activities’ children do not complete daily tasks without support. That way mobility like opening doors, carrying a drink, walking unassisted, picking an object etc., in those activities most of the children need assistance that means they do not complete these by moderate or without assistance. One of the important issues is physical independence that includes cleaning hands, eating, putting on dress, getting in/out of bed and toilet, climbing stairs etc. is also compromised in CP child. After completing this study, it indicates that most of the children completed their daily physical activities by moderate to minimum support. Similar study was conducted by [13], that study found more limitation in physical independence (63%) rather than mobility (60%) and schooling (29%).

Social integration, clinical burden, economic burden are also important for quality-of-life measurement. But in this study children need minimum to moderate support to accomplish these activities. Reference [14] found almost similar results like the present study. Overall study found that only 11% of CP children have good QOL. 40% reported severely affected quality of life, 29% moderately and 20% mildly affected QOL which was reported by their families [14]. Their study uses the same questionnaire. On the other hand, [15] found nearly 48% of CP children had a good quality of life, which is not similar to present study. May be due to age difference of the participants and different types of questionnaires is the cause of this dissimilar result. Many studies were conducted about the health-related quality of cerebral palsy children, but due to dissimilarity of age and way of outcome measurement findings of those studies could not compare with present study.

V. CONCLUSION & RECOMMENDATIONS

HRQOL is pointedly affected in most of the children suffering from cerebral palsy. Measurement of HRQOL should be include with other type of assessment, to specify the areas in which a patient is most suffering and help the expert in making suitable decisions for patient management. The present finding directs that cerebral palsy has a negative impact on health status and quality of life of children with cerebral palsy, as reported by the defendant parent. Children with cerebral palsy have a reduced HRQol and the degree to which it is reduced is directly related to the age and severity of the cerebral palsy. Increasing age and severity of the cerebral palsy have a negative impact on physical function, social role/behaviour, parenting impact (time/emotion), children’s health and their psychosocial function.

Although the study results explore important aspects about CP child, the sample size was very small and the study area was not appropriate to generalize the results of the study. In future this study is recommended to conduct with a large sample and if possible, study should conduct with those who can report their QOL on their own, so that the nature of their problems will be clearer to all. Also, it will be easy to take appropriate care for them.

CONFLICT OF INTEREST

Authors declare that they do not have any conflict of interest.

REFERENCES


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