Children with Cerebral Palsy and Their Quality of Life in Nepal

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Abstract

Introduction: Cerebral Palsy (CP) may affect individual's everyday life and it may have significant impact on quality of life (QOL). The objective of this study was to assess the quality of life of children with Cerebral Palsy in Nepal. **Material and Methods:** This is a descriptive cross sectional study that involved 42 children between 4 and 12 years of age. The Socio-demographic variables were obtained from interviews and CP related factors were obtained from medical reports. Validated CP-QOL child self-report and parent proxy version of questionnaire was used for data collection. Severity was assessed using Gross Motor Function Classification System (GMFCS), Manual Ability Classification System (MACS), Communication function Classification System (CFCS) and ICD-10 Classification System. Data were summarized using descriptive statistics. Kruskal Wallis and Man Whitney was used to find out association between Cerebral Palsy related factors and Quality of Life. **Results:** 57.1% (n=24) were between 8 and12 years of age and 42.9% (n=18) were between 4 and 8 years of age. Overall QOL was reported to be fairly good. Both the child and Caregiver gave highest score on "Social wellbeing and acceptance" and "Emotional wellbeing and self-esteem domain" and Lowest Point in "Pain and Impact of disability". This implies that Psychosocial Quality of Life is good in children with CP. Quality of Life as reported by child was better than Quality of Life reported by Caregiver. **Conclusion:** Overall QOL is fairly good in children with CP. However, Pain and impact of disability impairs QOL.

Key words: Cerebral Palsy, Quality of life

Introduction

Cerebral Palsy is defined as the permanent non-progressive disorders of movement and posture that results in restriction of activities occurring in the developing foetal or infant brain. It is the most common cause of chronic disability restricting the children to participate in their daily activities of life[1]. Thus, it compromises quality of life of children[2]. It is the most significant motor impairment in childhood which occurs in 2.5 children per 1000 live births[3].

Quality of Life (QOL) can be defined as the individual's own perception of overall wellbeing and contentment in life, including both

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psychosocial and health-related domains[4]. 'Quality of Life' is referred as broad and multi-dimensional concept that involves subjective evaluation of both the positive and negative aspects of life of children[5]. It can provide a comprehensive picture of the overall impact of a health condition on a child's social, emotional, and physical well-being and therefore provides essential information for decision making in clinical practice[6] The Neurological disability can affect different aspects of children's Quality of life including Physical, Psychological and psychosocial levels[7] There are many influencing factors that influence the QOL of children including the child's level of disability, environmental and social influences, stressors and level of support[4].

Research indicates that patients with CP have impaired functional and Psychosocial QOL when compared with their normative peers[2]. Paediatric CP literature suggests that the co morbidity of many of the impairments i.e. Visual, hearing and feeding impairments, language delay and epilepsy may be associated with decreased QOL[8].Children with CP can self-report their Quality of reliability in absence of emotional distortion, cognitive impairment and learning disabilities. However, it may be difficult to obtain reliable information from those who have mild to significant intellectual impairment and communication difficulties. Therefore, Parents usually mothers should be interviewed to get reliable information regarding Quality of Life[9]. The Cerebral Palsy Quality of Life Questionnaire for children (CP QOL-child) is an international CP-specific instrument based on the International Classification of Functioning, Disability and Health (ICF) Framework. It was developed by an international multidisciplinary team of clinical and child health researchers, in collaboration with parents and children with cerebral palsy[10].

According to Centre for disease control and prevention (CDC) the prevalence of CP is about one in 323 children[11]. Children with cerebral Palsy not only have to live with a range of Physical problems such as muscle weakness, stiffness, and clumsiness, but they are also four times more likely to experience emotional and behavioural problems in compare to their peer group[12]. Quality of life is a very relevant and important construct in the context of children with cerebral palsy. It provides a subjective indication of their well-being across several life domains such as physical health and social and emotional well-being[13]. Many of the children with CP also had at least one co-occurring condition (41%) had co-occurring epilepsy and 6.9% had co-occurring ASD[14].

A study was done in 13 to 14 centres in Europe including 6502 children born between 1976 and 1990 showed that among the various types of CP 85.7% (95% CI 84.8 to 86.7) were spastic, 6.5% (95% CI 5.8 to 7.2) were dyskinetic and 4.3% (95% CI 3.8 to 4.9) were Ataxic while 3.7% were classified as unknown type of CP. The most common subtype in this data set was bilateral spastic CP[15]. A retrospective cohort study of all infants who were born in California including Asian and white births during an 11-year period (1991 to 2001) reported that the overall prevalence of CP was found to be 1.40 per 1000. Among them, the prevalence of CP was 1.09 per 1000 in Asian Children and 1.36 per 1000 in whites. Overall the risk of CP was 20% lower in Asians than Whites. According to national origin subgroup, the prevalence of CP, significantly lower CP rates than whites included Japanese (RR = 0.62, 95% CI = 0.42–0.89), Indian (RR = 0.65, 95% CI = 0.49–0.87), Chinese (RR = 0.72, 95% CI = 0.60–0.86), and Vietnamese (RR = 0.79, 95% CI = 0.64–0.97)[16].

There is already a paucity of study of CP in Nepal. A study conducted in Cerebral Palsy Rehabilitation Centre Nepal from April 2010 to April 2014 suggests that 68.9 % (228) children suffered from spastic CP, 29 % (96) from dyskinetic CP and 2.1 % (7) from ataxic CP and the sex ratio of males to females was two in the study population of children with CP. Both of these are much higher than data from developed countries [17]. Though many studies have been carried out in other countries regarding QOL of children with CP, no such studies had been conducted in Nepal. The aim of this study is to assess the quality of life of children with CP. These study findings would be helpful to identify the areas of impairment that affects the quality of life of Children with CP in context of Nepal.

Material and Methods

This is descriptive cross-sectional study design was used to assess the Quality of Life(QOL) of children with CP. The study was conducted at Self-help Group for Cerebral Palsy (SGCP), Nepal.The study population comprised of children aged 4-12 years diagnosed with CP. Only the children and parents willing to participate in the study able to give informed consent were included in the study. While the children who were not present during course of study or who suffered from severe Mental Retardation along with CP and whose respondents who were not willing or didn't consent to participate in the study were excluded. Data were collected from eligible children during 15th to 31st May 2016 using purposive consecutive sampling technique. A total of 12 children aged 9-12 years and 39 caregivers of children aged 4-12 years were interviewed. Data was collected from the primary caregiver amongst the children above 9-12 years who were not able to complete the CP-QOL questionnaire due to cognitive and communication limitations.

In this study, QOL is defined as individual's perception of well-being in all the domains physical, psychological, and social wellbeing.Structured Questionnaire;CP QOL-child was used to assess Quality of Life of Children with CP. Permission was obtained from the concerned authorities for the use of CP QOL-child. The tool is a rating scale containing 65 questions in seven domains in parent-proxy version and 53 questions in 5 domains in child-self report version. The CP QOL-child measures the following seven domains of child's life: Social wellbeing and acceptance; Participation and physical health; Feelings about functioning; Emotional wellbeing and self-esteem; Pain and Impact of disability; Access to services and Family health. Each question has a maximum score of 100 and minimum score of 0. The higher the score; the better is the quality of life.

The validity and reliability has been measured by many researches and found to be high. It had good test-retest reliability, construct validity and internal consistency and Cronbach's alphas of 0.74 to 0.91[23,24]. The content validity had not been established in Nepalese context, so the content validity of CP QOL-child was obtained by subject experts of concerned areas and review of related literature. It was first translated to Nepali language. Opinion from language expert was obtained for simplicity during Nepali translation. The tool was again back translated to ensure that the meanings have been retained.

As non-probability sampling technique was used in the study and hence the study may not be generalized. Another limitation of this study is that children were required to be of a certain age group and to have sufficient cognitive ability to complete the questionnaire.

Socio-demographic variables here include age, sex, education level and occupation that are influenced by CP related factors such as the type and severity of CP, age of diagnosis and co-morbidities. For severity of various capacities of CP children, objective parameters as Gross Motor Function Classification System (GMFCS), CFL (Cognition Function Level), Communication Function Classification System (CFCS) and Manual Ability Classification System (MACS) were used.Same doctor classified the MACS, GMFCS, CFL and CFCS.

The collected data were checked each day for completeness and accuracy and was compiled for data analysis. It was then entered, edited, organized and coded using SPSS version 20. The data was then analyzed by using appropriate statistical techniques as frequency, percentage, mean and standard deviation. Non-parametric test Man Whitney U test and Kruskal Wallis H test were used for inferential statistics. The level of significance was considered at 5% with $p \leq 0.05$.

Results

This presents findings of quality of life of children with Cerebral Palsy and its association with Cerebral Palsy related factors. Out of a total of 42 children with Cerebral Palsy, 12(n=12) aged 9-12 years completed the child self-report version and 30 caregivers (n=30) of children aged 4-12 years completed parent-proxy report.

Table 1 represents distribution of children and their caregiver according to socio-demographic variables. More than half of the children (57.1%) were under age group 8-12. The mean age of children was 8.3 with Standard deviation of 2.85. More than half of the children (59.5%) were male. Nearly, half of the children (45.2%) of children were uneducated. Majority of caregiver of children (88.1%) were biological mother. Half of the caregiver i.e. 50% has completed Secondary Level of education and majority of them (78.8%) were unemployed.

Table 2 Shows types, severity, age of diagnosis and co-morbidities of children with Cerebral Palsy. According to the medical report more than half (61.9%) of children has Spastic cerebral Palsy. In GMFCS more than 1\4th (31%) were under GMFCS II. In MACS more than 1\4th (35.7%) were under MACS II. In CFCS almost half (40.5%) were under CFCS II. According to ICD-10 classification almost half (42.9%) were under CFL II. Majority of children (83.3%) were diagnosed with cerebral Palsy within age group (0-5).The mean age of diagnosis was 2.9 with standard deviation 2.8. Majority of respondents (85.7%) had Speech impairment. More than 1\4th (33.3%) had epilepsy and less than 1\4th (21.4%) had drooling. Very few (9.5%) had knee contracture and only 2.4% had hip dislocation and ankle contracture.

Table 3 represents overall Quality of Life of children of both child and Parent Proxy version. Out of five considered domains of QOL both child and caregiver gave highest point for Social wellbeing and Acceptance (72.09±10.17) and (73.45±6.76) respectively. The domain that was rated lowest by child was Pain and Impact of Disability (56.62±24.43) and the domain that was rated lowest by caregiver was Access to services (54.32±13.65) followed by Family Health (58.49±16.12) and Pain and Impact of disability (58.94±22.63). Quality of life reported by child was better than Quality of life reported by caregiver.

There was no significant association between quality of life of children with regard to Type, Severity and co-morbidities in 3 domains i.e. Social wellbeing and acceptance, emotional wellbeing and acceptance and Pain and impact of disability (Table 5). However, significant association was seen between GMFCS and Participation and health and MACS and feelings about functioning. Table 5 represents the association between the two domains .i.e. Access to services and Family health with regard to type, severity and co-morbidities of cerebral palsy. It shows that there is significant association between MACS and CFL with access to services. However, type of CP, GMFCS, Age of diagnosis and co-morbidities, was not found to be associated with both access to services and Family health.

Table 1: Analysis related to Socio Demographic Characteristics (n=42)

Characteristics	Frequency	Percentage %
Age of child (years)		
4-8	18	42.9
8-12	24	57.1
Mean±SD:8.35±2.85		
Sex		
Male	25	59.5
Female	17	40.5
Education		
Uneducated	19	45.2
Playgroup	11	26.2
Primary	12	28.6
Age of caregivers		
20-30	15	35.7
30-40	21	50.0
40-50	3	7.1
50 and above	3	7.1
Sex of caregivers		
Male	5	11.9
Female	37	88.1
Education of Caregivers		
Uneducated	9	21.4
Primary	1	2.4
Secondary	21	50
High School	8	19
Bachelor	3	7.1
Occupation of caregivers		
Unemployed	31	78.8
Service	5	11.9
Businessmen	5	11.9
Labour	1	2.4

Table 2: Analysis related to Cerebral Palsy related Factors of Respondents(n=42)

Variables	Frequency	Percentage%
Type of CP		
Spastic	26	61.9
Dyskinetic	13	31
Ataxic	1	2.4
Mixed	2	4.8
GMFCS		
GMFCS I	10	23.8
GMFCS II	13	31
GMFCS III	7	16.7
GMFCS IV	9	21.4
GMFCS V	3	7.1
MACS		
MACS I	6	14.3
MACS II	15	35.7
MACS III	8	19
MACS IV	8	19
MACS V	5	11.9
CFCS		
CFCS I	5	11.9
CFCS II	17	40.5
CFCS III	11	26.2
CFCS IV	4	9.5
CFCS V	5	11.9
ICD 10 Classification		
CFL I	7	16.7
CFL II	18	42.9
CFL III	9	21.4
CFL IV	8	19
Age of diagnosis		
0-5	35	83.3
5-10	3	7.1
10-15	4	9.5
Mean±SD:2.9±2.8		
Co-morbidities		
Speech	36	85.7
Visual	2	4.8
Epilepsy	14	33.3
Drooling	9	21.4
Hip dislocation	1	2.4
Ankle Contracture	1	2.4
Knee Contracture	4	9.5

Abbreviations; GMFCS: Gross Motor Function Classification System, MACS: Manual Ability Classification System, CFCS: Communication Function Classification System, CFL: Cognition Function Level

Table 3: Analysis related to Quality of Life in Child and Parent Proxy Version

Characteristics	Child version (n=12) Mean ±SD	Parent Version (n=39) Mean ± SD
Social-wellbeing and Acceptance	72.09±10.17	73.45±6.76
Functioning	64.58±11.16	64.27±8.49
Participation and Physical Health	66.28±10.61	63.0±7.8
Emotional wellbeing and Self-esteem	66.31±15.63	64.85±10.8
Access to services		54.32±13.65
Pain and Impact of Disability	56.62±24.43	58.94±22.63
Family Health		58.49±16.12
Mean QOL	65.176	62.47

Discussion

Regarding severity, highest percentage of children were less GMFCS Level II (31%) and least GMFCS Level V (7.1%), which was consistent with studies conducted in various countries[20,24,25]. The reason behind higher percentage among GMFCS II (less severe) and least among GMFCS V (most severe) could be that it is easierfor lesser severe children to access specialized centre and the parents are also hopeful as there is apparently more potential for improvement for a less severe child. Whereas, in a severely affected child, it is difficult to bring the child to healthcare facilities due to the difficult geography and poor transportation system of Nepal. A similar study done in US revealed that GMFCS was not associated but co-morbidities were strongly co-related with social wellbeing and acceptance and emotional well-being and self-esteem[27].

Regarding co-morbidities, majority of respondents 85.7% had Speech impairment, 33.3% had epilepsy and 21.4% had drooling. Very few (9.5%) had knee contracture and only 2.4% had hip dislocation and ankle contracture. Similar to this finding Speech impairment was more common and hearing impairment was less common in comparative study done in Australia and Bangladesh[20]. However, in a study conducted in Uganda, epilepsy was more common (45.2%) and least common was Hearing impairment (15.6%)[22]. Moreover, a study conducted in turkey showed that none of the children had epilepsy, hearing, feeding and communication problems. But visual problem and pain was dominant[26]. This shows that the overall co-morbidities in among the children in this study was better than under-developed countries but not as good as the developed ones. This maybe reflecting better situation than it actually is because this was a specialized centre based study and to know the true picture a community based survey is needed.

The overall Quality of life is fairly good especially in domains “Social wellbeing and Acceptance” and “Emotional well-being and self-esteem” in both child self-report and parent proxy-report version. However, Pain and Impact of Disability (56.62±24.43), access to services (54.32±13.65) and Family Health (58.49±16.12) impairs QOL in children with CP. This result implies that Psychosocial Quality of life is good in children with CP. But, Physical Quality of life is affected. “Pain and Impact of disability” was perceived as the least satisfactory domain from children’s point of view in this study. This indicates the need for pain management to uplift the QOL of children with CP. Similarly, from caregiver’s perspective “access to services” was rated lowest. This may be due to the poor economic condition, poor access to Health Care and lack of specialized experts to handle these problems in Nepal. Similar finding was seen in a study in Finland where Social wellbeing and Acceptance, emotional well-being and self-esteem were given highest point in both questionnaire versions while Pain and Impact of disability (75±17) was rated lowest in child version and Participation and Physical health (65.2±15.6) was rated lowest in Parent-proxy report[19]. Study conducted in USA also reveals that Psychosocial QOL is better in CP children[27] compared to other aspects of QOL.

The association of selected variable and 7 domains of QOL did not yield any significant differences in this study. Among the five domains i.e. Social well-being and acceptance, feeling about functioning, participation and physical health, Emotional wellbeing and self-esteem and Pain and impact of disability, association was seen only between GMFCS with Participation and Health, MACS with feeling about functioning. Similarly, in two domains of Parent proxy report association was seen only between access to services with GMFCS and MACS.

QOL reported by child was better than QOL reported by caregiver which was consistent with the study conducted in Finland[19]. Perhaps caregivers perceive more problems in QOL than that reported by children alone since they might perceive the child's QOL magnified in view of their own difficulties increased by the burden of a disabled family member. Also, almost half (45.2%) of children were found to be uneducated reflecting the lack of access to school or other educational facilities for disabled children in Nepal. Also a markedly delayed symptom recognition and late age of diagnosis of CP is reported from Nepal[28] which may further impede timely intervention in CP that further detoriates the QOL and functional outcome in children with CP.

Conclusion

Children with cerebral palsy have good psychosocial QOL while they have reduced Physical QOL. Severity and Co-morbidities are strongly associated with impairment of QOL. Whereas, specific parameters pertaining to functional capacity such as MACS and GMFCS may not influence the overall QOL of children with CP but influences certain domains viz. functioning, participation and physical health.

Recommendations: There is little study conducted in Nepal regarding CP and till date no study has been published regarding QOL. Therefore, further studies can take into consideration the findings and limitations of this study for a more elaborate result. Also, to get a broader view, community based studies should be done. Since, QOL scored low in health and co-morbidities related domains, health service providers can therefore play a major role in this aspect to uplift the QOL of children suffering from CP. Also,not only healthcare and rehabilitative facilities but educational opportunity as well should be made more abundant and accessible for children with CP since there is only one organization registered for rehabilitation and pedagogy for CP and only a handful of organizations that tries to address the problems of children and adults with CP.

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