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ORIGINAL PAPER

Assessment of proxy quality of life in children with cerebral palsy: a cross-sectional study

Kanniappan Vadivelan[1], Pasupathy Sekar[2]

[1]Department of Physiotherapy, S.R.M. College of Physiotherapy, S.R.M. Institute of Science and Technology, S.R.M. Nagar, Kattankulathur – 603203, Kanchipuram, Chennai, Tamilnadu, India
[2]Department of Pediatrics, S.R.M. Medical College Hospital, and Research Centre, S.R.M. Institute of Science and Technology, S.R.M. Nagar, Kattankulathur – 603203, Kanchipuram, Chennai, Tamilnadu, India

ABSTRACT

Introduction: Cerebral palsy (CP) is a non-progressive brain disorder in the developing fetal or infant brain that reduces the quality of life of children with cerebral palsy. Every child with CP may have individual experiences and problems that restrict participation in daily life activities. Quality of life (QOL) in children with CP needs to be measured by CP-specific questionnaire, Cerebral palsy – Quality of life (CP-QOL). CP-QOL questionnaire is being used for this purpose. Hence, we aimed to study the proxy QOL of children with CP from the primary caregivers.
Material and methods: One hundred and twenty-one primary caregivers (parent) of children with CP in the age group of 4 to 12 years were recruited by convenience sampling technique for the cross-sectional descriptive study. The parents of the children attending the Physiotherapy Outpatient Department, Occupational Therapy Outpatient Department, and Pediatric Outpatient Department were asked to complete the CP-QOL questionnaire. Collected data were analyzed and reported in frequency.
Results: CP-QOL questionnaire was completed by 121 primary caregivers of CP children. The overall QOL score obtained was 37.67 ±4.57. The seven domains of the questionnaire were taken into consideration, and QOL was found to be compromised. The domains of pain, access to services and impact of disability family health were severely compromised and less reliable when compared to other domains. The CP-QOL score among the children with CP in the age groups 4 to 6 years, 7 to 9 years, and 10 to 12 years were 37.44 ±12.52; 39.95 ±4.74 and 39.64 ±1.65, respectively.
Conclusions: The proxy QOL of children with CP was compromised, and the CP-QOL can be used to assess the QOL in children among the developing countries.

KEY WORDS:
quality of life, cerebral palsy, caregiver, proxy.

INTRODUCTION

Cerebral palsy (CP) is a group of conditions that are characterized by chronic disorder of movement or postures; it is cortical in origin, manifests itself early in life, and is not the outcome of progressive disease, which is collectively defined as "developmental disabilities" [1]. CP is a syndrome with a combination of motor, sensory, intellectual, language, perceptual, balance [2], and behavioral problems. CP has a prevalence of 1.5 to 2.5 per 1000 live births [3]. Worldwide, CP has an incidence of 1 in 500 births [4]. The impact of such children in the

ADDRESS FOR CORRESPONDENCE:
Kanniappan Vadivelan, Department of Physiotherapy, S.R.M. College of Physiotherapy, S.R.M. Institute of Science and Technology, S.R.M. Nagar, Kattankulathur – 603203, Kanchipuram, Chennai 603203, Tamil Nadu, India, ORCID: 0000-0003-2088-9874, e-mail: vadivelk@srmist.edu.in

families is intense, which greatly affects the quality of life of such children [5, 6]. Quality of life (QOL) of children with CP can be assessed using a validated tool such as Cerebral palsy – Quality of life (CP-QOL) questionnaire, which helps in addressing the several domains of life both by children themselves and by the caregivers also. CP-QOL is a CP specified questionnaire designed in accordance with the International Classification of Function (ICF) and definition of quality of life by the World Health Organization [7, 8]. CP-QOL basically assess the well-being of children with CP, rather than ill-being [7].

There are other Qualities of Life questionnaires for children like Pediatric QOL Questionnaire CP Module (PedsQL), KIDSCREEN, Kid-KINDL, health-related quality of life (HRQOL) and, CHQ. For CP-QOL there are two versions available, one for the children and the other for the primary caregivers [9]. The validity and reliability have already been established in different countries by using the questionnaire in several languages besides the English language [10]. The primary caregiver version for ages 4 to 12 years old has seven domains like social well-being and acceptance, functioning, physical health, pain and impact of disability, participation, emotional well-being, access to services, and family health. The other version for self -report by children is available for children ages 9 to 12 years old [10]. But children with CP who are younger than nine years of old were not able to report their QOL. Hence, their parents were asked to report QOL, and so, the word 'proxy' – the concept was introduced. Here, we aimed to assess the proxy QOL of children with CP in the South Indian population using the CP-QOL parent proxy version.

MATERIAL AND METHODS

The study protocol was approved by the institutional ethics committee of recognized tertiary care teaching hospital with unique reference no. 1505/IEC/2018 dated 25.10.2018. The study was performed according to the principles laid by, declaration of Helsinki (Revised 2013), Council for international organizations of medical sciences (CIOMS) guidelines, International ethical guidelines for health-related research involving humans (2016), and National guidelines for biomedical and health research involving human participants (2017).

A convenient sampling method was adapted to select 121 primary caregivers of children with CP with ages 4 to 12 years who were recruited as participants for this study. The sample was recruited during the period December 2017 to January 2019 from the Physiotherapy, Occupational therapy and Pediatric outpatient department of Sri Ramaswamy Memorial (SRM) Medical College Hospital and Research Centre by the memorandum of understanding (MoU) established with the regional Empowerment center, National Institute for Empowerment of Persons with Multiple Disabilities. The inclusion criteria being the primary caregivers of children with CP between 4 and 12 years of age with the GMFCS (Gross Motor Functional Classification Scale) of level IV and V and who are willing to spend their time to report the QOL about their children with CP. GMFCS stratifies motor function of child with CP under five classification system through self-initiated movement [11]. It has excellent interrater reliability (κ) of 0.75 among children aged 2 and 12 years of age [12]. The questionnaire version 2 was used in the English language for this study. Permission to use the questionnaire in English for the Indian population was taken from the author. The language barrier was minimized for those who did not understand English well by translating the questionnaire by the same individual in a face to face interview. The interviews were performed by the same person to reduce the risk of information bias. The researcher did not intervene in between the interview sessions. Informed consent was taken from all the parents/caregivers and was explained about the questionnaire and its interpretation to be used for research before the beginning of the interview.

The CP-QOL questionnaire used has seven domains, with a total of 66 items, which are to be marked by the caregivers at the time of the interview [9]. The questions are provided with a 9- pointer scale to mark how happy or unhappy your child is regarding the particular question being asked. The scoring was done as per instructions by the author of the questionnaire by converting the values of the score as 1 = 0, 2 = 12.5, and 3 = 25, so on till 9 = 100. The average mean was also calculated as an overall QOL score and score for each domain individually [9]. The CP-QOL questionnaire has the internal consistency between 0.74 and 0.92, with test-retest reliability ranged from 0.76 to 0.89. The moderate construct validity ($r > 0.50$) has been established with KIDSCREEN [7].

DATA ANALYSIS

The collected demographic and outcome measures were assessed for their normality using the Kolmogorov-Smirnov test. As the data follow the normal distribution, all the descriptive were expressed in mean ±standard deviation. The Independent t-test was adopted to find out the differences between boys' and girls' CP-QOL scores. The internal consistency of CP-QOL scores was established by Cronbach's α. The data were analyzed using statistical software, International Business Machines Corporation (IBM) Statistical Package for the Social Sciences (SPSS) version 20.0 (Armonk, NY: IBM Corp.). The p-value ≤ 0.05 was considered to be statistically significant.

RESULTS

In this study, we gathered information from 121 caregivers by using the CP-QOL questionnaire. Among these children, 72 (59%) were male and were 49 (41%) female,

TABLE 1. Quality of life (QoL) among the south Indian children with cerebral palsy

QoL parameters	Mean ±SD	Cronbach's α
Social wellbeing and acceptance	33.44 ±3.31	0.96
Functioning	31.84 ±0.81	0.97
Participation	34.37 ±1.30	0.93
Physical health	32.40 ±0.85	0.85
Emotional well being	68.00 ±25.9	0.80
Access to services	39.40 ±9.33	0.88
Pain, impact of disability and family health	40.12 ±10.55	0.74
Overall QoL score	37.67 ±4.57	

TABLE 2. Quality of life (QoL) among the south Indian children with cerebral palsy with different Gross Motor Function Classification System (GMFCS) level

GMFCS level	QoL
Level-II ($n = 71$)	36.51 ±3.51
Level-III ($n = 24$)	40.4 ±4.66
Level-IV ($n = 18$)	42.02 ±6.59
Level-V ($n = 8$)	31.75 ±2.22
Overall QoL score	37.67 ±4.57

who were aged into three categories of 4–6 years (n = 72 children), 7–9 years (n = 38 children), and 10–12 years (n = 11 children). The mean age of these 121 children with CP was 6.85 ±2.43 years. They were categorized according to GMFCS (Gross Motor Functional Classification Scale) levels in which there were n = 71 children in GMFCS level II, n = 24 children in level III, n = 18 children in level IV, and n = 8 children in level V. Table 1 displayed CP-QOL scores along with Cronbach's alpha of the seven domains of the questionnaire. The CP-QOL score among different GFCS level was tabulated in Table 2. There exists a significant difference (p = 0.013) in CP-QOL scores among males (37.27 ±0.32) and female (42.32 ±7.46). The CP-QOL score among the children with CP in the age groups 4 to 6 years, 7 to 9 years, and 10 to 12 years were 37.44 ±12.52; 39.95 ±4.74 and 39.64 ±1.65, respectively.

DISCUSSION

The incidence of CP in India is estimated to be around 3 per 1000 live births which is higher when compared to the developed countries [13]. The QOL in children with CP is lower than the typically developing children [14]. This ultimately results in increasing the caregiver's burden by lowering their participation in daily life [15]. Hence, there is a definite need to determine the QOL in children with CP living in India. Questionnaires are an important research tool in identifying the need for assessing the QOL of children with different disabilities worldwide. The CP-QOL, a CP-specific tool for assessing QOL in children with CP, is a valid and reliable tool used in many studies in the different parts of the world. CP is a life prolonged condition impacting the life of the children and their parents. The quality of life is therefore needed to be assessed as in our study; we tried to calculate it on the basis of an overall QOL score of 37.67 ±4.57. In the studies carried out in Malaysian children with the use of the Lifestyle assessment questionnaire (LAQ) to find the quality of life of children with CP, which classified the children into mild, moderate, and severely affected children. So every questionnaire has its own aspects of assessing a condition or disease which could not be generalized [16].

A similar type of study in north India was conducted using the same CP-QOL questionnaire in the Hindi language for a better understanding of the caregivers that showed that there was no significant difference in the gender, but there was a significant difference in parental education and age [9]. A study in Iran assessed the association between Gross Motor Function (GMF) and the QOL domains for children with CP using the same questionnaire. They reported an increase in GMF in children with CP has a considerable effect on their QOL [17]. The QOL score obtained from the study was much affected by the pain, the impact of disability, and the family health domain of the questionnaire. The gender difference between the samples also led to a statistical difference in this study. CP-QOL Child primary caregiver questionnaire or CP-QOL parent proxy version has been validated to be used in the children with CP aged 4 to 12 years of age. Hence, we have used in the questionnaire in similar age group [9, 17–20].

When comparing the overall QOL with that of demographic data like sex, age, and type of GMF levels, the results did not vary much, although to generalize the result, more samples should be included in further studies. As the sampling technique adopted was a convenient sample, and all the samples were recruited from a single-center could have led to the risk of selection bias. The language barrier for some caregivers, as they did not have sufficient schooling to understand the questions, could act as the potential confounders; interviewer approach and interview settings in gathering information from the primary caregivers were the limitations of this study. This could act as the potential-bias in interpreting the results. Another important limitation was a less sample size that led to the result to be interpreted with caution and could not be generalized to the wider population.

CONCLUSIONS

The proxy quality of life among CP children in the south Indian population was found to be compromised. The CP-QOL for primary caregivers can be used to find the QOL of Indian children by the use of this validated tool in the English language.

DISCLOSURE

The authors declare no conflict of interest.

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