Health-related Quality of Life of Nigerian Children with Cerebral Palsy

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ABSTRACT

Purpose: *To assess the impact of cerebral palsy on health-related quality of life (HRQoL) of Nigerian children.*

Method: *This is a cross-sectional survey. The study involved 54 children (33 males and 21 females), between 1 and 12 years of age, with cerebral palsy. They were consecutively recruited from two tertiary health institutions in Lagos, Nigeria.*

The socio-demographic details of the participants were obtained through interviews. Their HRQoL was assessed using the Child Health Questionnaire-Parent Form-28 (CHQ-PF 28). The questionnaire was completed by their parents, guardians or primary care-givers. Severity of motor disability was assessed and classified using the Gross Motor Function Classification System (GMFCS). Data were summarised using descriptive statistics. Chi-square was used to find the association between each of the selected socio-demographic variables and motor disability, and HRQoL.

Results: *Thirty-eight children (70.3%) were between 1 and 6 years of age, and 16 (29.7%) were between 7 and 12 years. The participants' overall scores and scores on each domain of CHQ-PF 28 were very low. Majority (69.5%) were in GMFCS classification-level 1, 7 (13.0%) were in level 2, 12 (22.2%) were in level 3, 14 (25.9%) were in level 4, and 16 (29.6%) were in level 5. Age had significant effect (CI = 95%) on HRQoL of children with cerebral palsy. Severity of disability had negative impact (CI = 95%) on HRQoL of children with cerebral palsy.*

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Vol 22, No.1, 2011; doi 10.5463/DCID.v22i2.24

Conclusions: *The health-related quality of life of Nigerian children with cerebral palsy is low, and is negatively affected by age and severity of disability.*

Key words: *Quality of life, cerebral palsy, children, Nigeria*

INTRODUCTION

Quality of life is a person's subjective well-being and physical health, material well-being, interpersonal relationships within and outside the family, work and other activities in the community, personal development and fulfillment, and active reaction (Niemi et al, 1988). It is also an individual's perception of his or her position in life, taken in the context of the culture and value systems in which he or she lives, in relation to his or her goals, expectations, standards and concerns (World Health Organisation, 1999).

Although quality of life has emerged as an important concept in childhood, little is known about the quality of life of children with disabilities, especially those with early onset of disability, and is represented along a continuum or spectrum throughout life. There is consensus that children can self-report their quality of life reliably in the absence of emotional distortion, cognitive impairment and learning disabilities (Eiser and Morse, 2001a; Raven-Sieberer, 2001; Riley, 2004). However, it may be difficult to obtain reliable information from children with cerebral palsy who may have mild to significant intellectual impairment or communication difficulties. Therefore, it has been suggested that the use of proxies (usually mothers) may provide better objective assessment of quality of life for these children (Eiser and Morse, 2001b). The Child Health Questionnaire-Parent Format 28 (CHQ-PF 28) is one of the validated generic health-related quality of life measures that are used to quantify health and well-being in children with various chronic health conditions, including cerebral palsy (Landgraf et al, 2000).

Cerebral palsy is a group of permanent disorders in the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain (Surveillance of Cerebral Palsy in Europe, 2000). Cerebral palsy is the most common cause of significant motor impairment in childhood, occurring in 2.5 children per 1000 live births (Eiser and Morse, 2001b). The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy and by secondary musculoskeletal problems (Bax et al, 2005; Rosenbaum et al, 2007). These are some of the many potential causes of poor health related quality of life (HRQoL) in children with cerebral palsy. The impact of sensation, perception, cognition, communication and behaviour on the health and well-being of children with cerebral palsy, is a topic of increasing research interest.

Chronic illnesses have been shown to have negative impact on the quality of life in adult populations, but with little focus on children, especially those from developing countries. A study that reveals the impact of chronic illness on the quality of life of children is important, as it will provide information to enable better management of this part of the population. In children, health-related quality of life includes not only concepts of illness, functional status, mental health and comfort, but also parental impact and family functioning. Despite the wide-spread prevalence of cerebral palsy, researchers are just beginning to focus on its impact on children's health status and quality of life (Kennes, 2002). There are increasing data from the Western countries, with less focus on the developing countries where there could be less sophisticated gynaecological and paediatric care. Therefore, this study evaluated health-related quality of life of Nigerian children with cerebral palsy who attend tertiary health institutions in Lagos.

METHOD

This study was approved by the Ethical Review Committee of the Lagos University Teaching Hospital, Lagos. Permission from the authorities of the Lagos State University Teaching Hospital was also obtained. The informed consent of the mothers (the respondents) of the participants (children with cerebral palsy) was obtained, after the objective of the study was explained to them. They were assured of the confidentiality of the information that they would be providing. They were also informed that they reserved the right not to participate in the study or to withdraw their participation at any time, without any consequences to the management of their children. This study involved 54 children (33 males and 21 females) with cerebral palsy, between 1 and 12 years of age. They were consecutively recruited from two tertiary health institutions in Lagos, Nigeria. Their socio-demographic details and health-related QoL were assessed using the Child Health Questionnaire-Parent Form 28 (CHQ-PF 28). The CHQ-PF 28 is one of the validated generic health-related quality of life measures that are used to quantify health and well-being in children with various chronic health conditions, including cerebral palsy (Landgraf, 2000). It is a proxy assessment of health-related quality of life in children and has demonstrated good relationship with self-rating of quality of life among them (Landgraf, 2000). The questionnaire was self-rated by the mothers, or by primary care-givers in case of orphans. The severity of motor disability was assessed and classified using the Gross Motor Function Classification System (GMFCS). Data were summarised using descriptive statistics. They were also assessed for associated health problems. Chi-square was used to find the association between each of the selected socio-demographic variables and motor disability and QoL.

RESULTS

Thirty-eight children (70.3%) were between 1 and 6 years of age, and 29.7% were between 7 and 12 years (Table 1). The participants' overall scores and scores on each domain of CHQ-PF 28 were very low. The majority (69.5%) was in GMFCS classification-level 1, 13.0% in level 2, and 29.6% in level 5 (Figure 1). The majority (92.6%) of the respondents were biological mothers (Table 1). The older the children were, the poorer was their HRQoL (CI = 95%). Severity of disability had a significantly negative impact on HRQoL of children with cerebral palsy. Age had a significant effect on health-related quality of life of children with cerebral palsy. There was no significant difference between age and physical function. Children with cerebral palsy had associated health problems like attention deficit (2.2%), orthopaedic problems (11.1%), behaviour problems (13.2%), and cognitive problems (2.2%). The number of reported medical problems and deformities were higher in children with more severe cerebral palsy. There was significant association between severity of cerebral palsy and each of physical disability, parenting impact, social and psychological functions. Majority (77.8%) had a lot of limitations in activities that took a lot of energy, while only 1.9% had no limitations. Twenty four (44.4%) could ambulate with mild or little limitation, while 55.6% could not ambulate and were severely limited. Three (5.7%) felt pain very often, 18.9% fairly often, 37.7% once or twice, and 18.9% did not feel any pain (Table 2). Comparing their children's health with health of other children, most parents (79.2%) agreed that children with cerebral palsy were less healthy, 13.2% disagreed and 7.5% were indifferent (Table 2). Eleven (20.4%) of the children did not relate well to their parents and other children, 66.7% related quite well and 13.0% did not relate at all. Two (3.7%) performed social roles expected of his/her age quite well, 25.9% performed well and 70.4% did not perform well. The behaviour of three of the children (5.6%) was very good, 9.3% was good, 31.5% was fair, and 53.7% was poor (Table 2).

Table 1: Socio-Demographics of Participants and Disability Data

VARIABLES	N	%
Age of the Children (years)		
1-3	23	42.6
4-6	15	27.8
7-9	15	27.8
10-12	1	1.8
Relationship of Respondents to children (n=54)		
Biological parent	50	92.6
Close relative	1	1.9
Grandparent	3	5.5

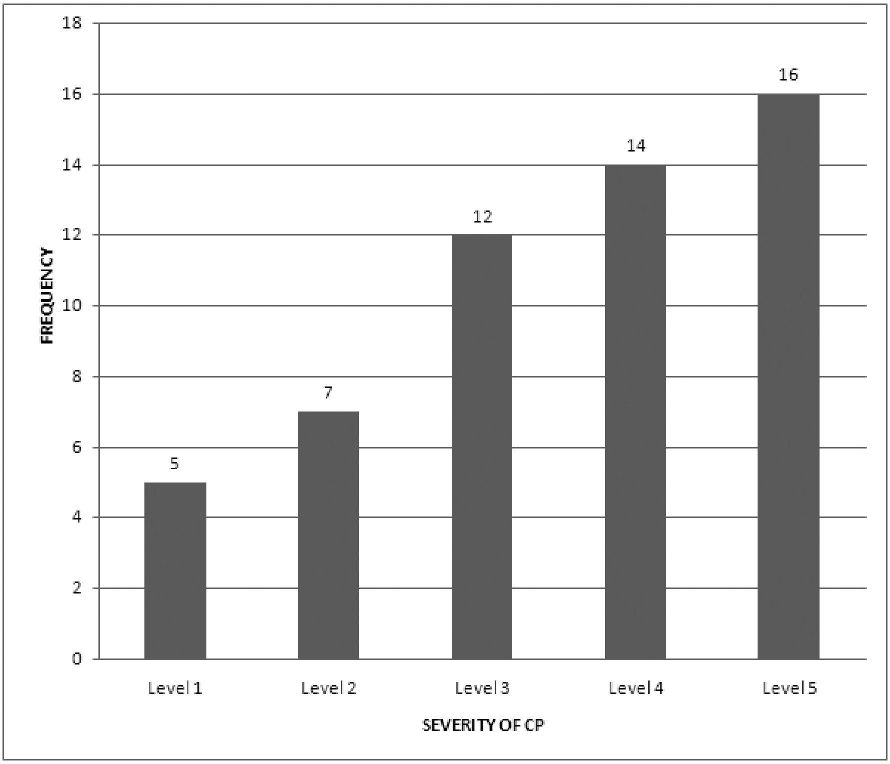

Figure 1: Distribution of Cerebral Palsy children according to severity of cerebral palsy

Table 2 : Physical and Social Attributes

VARIABLES	N	%
Pain/discomfort		
A few times	20	37.6
Fairly often	10	18.9
None	10	18.9
Once or twice	10	18.9
Very often	3	5.7
Mobility		
Ambulatory (level 1-3)	24	44.5
Non ambulatory (level 4-5)	30	55.5
Doing things that take little energy		
No, not limited	3	5.6
Yes, limited some	28	51.8
Yes, limited a lot	23	42.6
Does your child relate to other children?		
Not at all	7	13.0
Not well	36	66.7
Quite well	5	9.2
Well	6	11.1
Child's behaviour compared to other children?		
Fair	17	31.5
Good	5	9.3
Poor	29	53.6
Very good	3	5.6
Social role expected of his/her age?		
No	14	25.9
Not quite well	38	70.4
Yes	2	3.7

DISCUSSION

This study was carried out to evaluate the Health-Related Quality of Life (HRQoL) of children with cerebral palsy. It evaluated variables that impact health status and quality of life, and determine the severity of motor disability in children with cerebral palsy. The higher incidence of cerebral palsy among males in this study shows that more male children are susceptible to non-progressive injury to the brain at infancy. This result corroborates those of previous studies, that male children have higher incidence of cerebral palsy (Johnson, 2002). The fact that the number of reported medical problems and deformities were higher in children with more severe cerebral palsy shows that the prevalence of common medical problems increase with an increasing severity of motor disability. This has also been previously observed (Adams, 2005).

The significant association between severity of cerebral palsy and physical disability shows that severity of disability is associated with poorer general health and physical disability. This finding is in agreement with several previous studies which concluded that the health-related quality of life of children with cerebral palsy has an interdependent relationship with their functional status (Wake et al, 2003; Adams, 2005). The strong influence of severity of disability on physical functioning was anticipated because cerebral palsy is a motor disorder, and therefore affects movement and mobility. Furthermore, the GMFCS which was used to assess severity reflected the impact of physical disability on daily activity.

The influence of severity of cerebral palsy on health-related quality of life among children with cerebral palsy might be due to the subjects' physical condition interfering with their personal and social activities. This may indicate limitations in school work, social activities, and friendships. This observation is in agreement with the report of some previous authors, that there is significant association between social activity and severity of cerebral palsy among children with cerebral palsy (Wake et al, 2003; Adams, 2005; Vitale et al, 2005).

The negative influence of severity of cerebral palsy on psychosocial function shows the negative impact of cerebral palsy on the emotional well-being of children living with it. This finding is in agreement with the report of McCarthy et al (2002), which noted that severe cerebral palsy is associated with reductions in health and functional status of the subjects. However, it is in contrast with the findings of Wake et al (2003) that psychosocial aspects of HRQoL do not vary with differences in severity of motor disability, in the case of health and well-being of Australian children with cerebral palsy.

The negative impact of severity of motor disability on parenting, in the areas of emotional worries/concern and time, shows that parents have many emotional worries about their children's health and motor disability. This may be because these parents are required to spend more time with their children, and this could have a negative impact on their social activities. They may not want to carry children like these for social functions. This is not only because it would require a lot of effort to carry them, but also because of the social stigma. This observation is in agreement with the report of Vitale et al (2005) which stated that severity of cerebral palsy was significantly associated with parent impact-time, parent impact-emotional and family.

The finding that age is associated with reduced HRQoL in children with cerebral palsy is not surprising. This is because the older the child is, the more he/she will feel the impact of social isolation from peers. There will be more participation restriction coupled with significant activities limitation. This result is in close agreement with the opinion of Melisa and Chee (2002) that physical challenges of cerebral palsy may intensify with age (such as increased spasticity, fatigue, loss of strength and declining mobility). However, it was observed in this study that there was no significant difference between age and physical function, which is in contrast with the observation of Melisa and Chee (2002). The lack of association between age and physical function might be attributed to the proxy reporters. Self-report information from children themselves might have been more suitable and reliable, to fully understand the impact of age on physical activities of children with cerebral palsy (Livingston et al, 2007).

CONCLUSION

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 parents. 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.

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