Title: Relationship between caregiver related factors and their proxy report of quality of life of children with cerebral palsy in Kano City, Nigeria

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Abstract

Background: Caregivers of children with Cerebral Palsy (CP) have intimate knowledge of the children and can provide reliable information on their Quality of Life (QoL).

Objective: This study assessed the factors that could influence caregiver proxy report of QoL of children with CP.

Methods: The cross-sectional survey recruited 30 caregivers and 30 children diagnosed with CP using purposive sampling technique. QoL in the children with CP and functional level were assessed with CP-QoL questionnaire caregiver proxy version and Gross Motor Function Classification System (GMFCS) respectively. Depression in the caregiver, socio-demographic data and perceived stress were assessed with Patient Health Questionnaire (PHQ-9) and a pro-forma respectively. The data were summarised with descriptive statistics and analysed with Spearman rank order correlation at alpha level of $P<0.05$.

Results: The mean age of caregivers and that of children with CP were 34.40 ± 7.02 years and 7.23 ± 2.08 years respectively. The mean QoL score was 60.06±4.27. The 'social well-being and acceptance' (75.07 ± 9.52) and 'Access to services' (66.65±7.87) domains have the highest mean scores. Marital status of the caregivers had significant relationship with their proxy report of the children's overall QoL (Rho=0.40; $P<0.05$) and caregivers' depression (Rho=-0.414; $P<0.05$).

Conclusion: Children with CP in Kano city have moderate QoL. Proxy report of the overall QoL of children with CP was significantly related to marital status of the caregivers with married caregivers more likely to report better QoL. Researchers should always endeavor to compare parents' and children's reports in order to obtain a more accurate measure of children's QoL.

Key words: Cerebral palsy, Caregiver, Quality of life, Proxy report

Introduction

Cerebral palsy (CP) is a motor disorder resulting from a non- progressive insult to the developing brain, before, during or shortly after birth (Shevell and Bodensteiner, 2004). In many cases of CP, motor and associated disorders cannot be alleviated completely. Over time, parents' hopes of complete recovery for their child may be changed into hopes for the child's happiness and improved quality of life (QoL) (Shikako-Thomas et al, 2013). Typically it is the parents' perceptions of their children's wellbeing that influences healthcare utilization (Varni et al, 2007). Though studies have shown that children were able to self-report their own QoL (Feeny et al, 1995; Varni et al, 2005), self-report of QoL among some children with CP may not be reliable especially in situations of severe cognitive impairments or fatigue (Varni et al, 2007). Accuracy of the report may also be compromised by the severity of the disability (Goodwin et al, 1994) or reluctance to report for themselves (Cremeens et al, 2006). In these situations, parents' proxy report of a child's QoL could be more reliable (Erhart et al, 2009). Therefore, caregivers' proxy report is often used because it is believed that they have intimate knowledge of their children and they can provide reliable information (Cremeens et al, 2006). A problem with proxy report however is that caregivers usually under report their children's QoL (Cremeens et al, 2006; White-Koning, et al, 2008) and this is more likely to be influenced by the severity of the impairment (Arnaud et al, 2008), high levels of parenting stress (Arnaud et al, 2008; White-Koning, et al, 2008) or caregivers' own QoL (Cremeens et al, 2006). Furthermore, Panepinto et al, (2013) reported that worsening mental health in the parents is associated with worse under reporting of child's QoL. There is a dearth of published studies on factors that could influence caregivers' proxy reports of QoL of the children with CP in the African community. In this study, caregivers refer to parents taking care of their own children who had CP. The study therefore examined the factors related to caregivers' proxy report of QoL of children with CP in Kano city, North Western Nigeria.

Methods

A cross-sectional survey design was employed and participants were recruited using purposive sampling technique. The participants in this study were children diagnosed with CP and their parents (caregivers) who were attending paediatric units of physiotherapy departments in Aminu Kano Teaching hospital and Murtala Mohammed Specialists Hospitals in Kano city.

Inclusion Criteria

In this study caregiver was defined as a person who is most closely involved in taking care of the child with CP and this includes the mother or father of the child. Only those caregivers that gave consent of participation and those whose children were aged between 4 to 12 years (for eligibility to use the parent proxy version of Cerebral Palsy QoL questionnaire, CP-QOL) were recruited.

Exclusion Criteria

Paid caregivers such as nannies were excluded

The Informed Consent

The consent in this study included statements of voluntariness anonymity and confidentiality which were duly observed. All the research participants were informed of the research procedure before they all signed the informed consent form.

Ethical Approvals

Approvals for the study were obtained from the ethics committees of Aminu Kano Teaching Hospital and Kano State Hospitals Management Board.

Sample Size Determination

The sample size for the study was obtained from the formula:

$$N=\frac{Z^2 P(1-P)}{d^2}$$ (Naing et al, 2006)

N=sample size;

P=expected prevalence or proportion

Z is a constant =1.96 at 95% Confidence Interval (CI)

d= precision (width of CI/2)

According to the result of a systematic review and meta-analysis, by Oskoui et al, (2013) the prevalence of CP worldwide was 2.11 per 1000 live births (95% CI = 1.98-2.25).

CI=1.98 - 2.25, width of CI= 2.25-1.98=0.27

d=CI/2 = 0.27/2 = 0.135=0.14

Prevalence = 2.11 per 1,000. This equals 0.211 per 100 live births. Hence P=0.21

$$N= \frac{1.96^2 X\, 0.21(1-0.21)}{0.14^2} = 33 \text{ participants}$$

This study was able to recruit 30 children with CP and 30 caregivers

Procedure of Data Collection

The CP-QoL questionnaire caregiver proxy version was used to collect data on the children’s QoL. Patient Health Questionnaire (PHQ-9) was used to assess the level of depression of the caregiver. Gross Motor Function Classification System (GMFCS) was used to assess the level of function of the children. A pro-forma was used to collect the socio-demographic data of the caregivers, their level of income and level of perceived stress.

Assessment of QoL of Children with CP

The CP-QoL child (a disease specific instrument) was self-administered to the caregivers. The instrument has internal consistency of α = 0.74-0.91. It has moderate concurrent validity with kidscreen-10 and child health questionnaire (Davis et al, 2009a). It has seven domains and sixty-five items. Most of the items begin with 'How do you think your child feels about…' with the exception of the items in domain 6 (pain and impact of disability) that have a different leading question.

Scoring of the CP-QoL Child

Each of the items was scored using a 9-point scale ranging from 1 to 9. Score of 1 =very unhappy, 3=unhappy, 5=neither happy nor unhappy, 7=happy, and score of 9=very happy. However, item number 4 of domain 6 "Does your child worry about who will take care of them in the future?" was rated on a 5 point scale ranging from 1to 5. For this item, score of 1 =very unhappy, 2=unhappy, 3=neither happy nor unhappy, 4=happy, and score of 5=very happy.

Items Transformation

Items were transformed to a scale with a range of 0-100 using the following formula:

A score of 1 was recorded as 0; the score of 2 was changed to 12.5; 3 to 25; 4 to 37.5; 5 to 50; 6 to 62.5; 7 to 75; 8 to 87.5 and the score of 9 was recorded as 100. For the item that was rated on a 5 point scale, a score of 1 was transformed to 0; 2 to 25; 3 to 50; 4 to 75 and the score of 5 was recorded as 100. The mean score of each domain was calculated. Higher mean score means higher QoL and vice versa (Waters et al, 2013)

Assessment of Depression of the Caregivers

The PHQ-9 was self-administered to the participants. It is a 9 item questionnaire scored on a 4 point Likert scale ranging from 0 to 3 (not at all = 0; several days = 1; more than half the days =

2 and nearly every day = 3). The least score was 0 and highest score was 27. A score of 1−4 was rated as minimal depression, 5−9 mild depression, 10−14 moderate depression 15−19, moderately severe depression and 20−27 severe depression (Badaru et al, 2013). The PHQ-9 has an internal consistency of 0.86 (Cronbach's coefficient) and a test-retest reliability of 0.94 (Bian et al, 2011).

Assessment of Level of Function

The GMFCS rates the functional level of children with CP on a 5 point ordinal scale ranging from I – V. The ratings of the children's functional abilities were adopted from Palisano et al (2009) as follows:

I. Walks without restrictions; limitations in more advanced gross motor skills
II. Walks without assistive devices; limitations walking outdoors and in the community
III. Walks with assistive mobility devices; limitations walking outdoors and in the community
IV. Self-mobility with limitations; children are transported or use power mobility outdoors and in the community
V. Self-mobility is severely limited even with the use of assistive technology (Palisano et al, 2009)

Assessment of Levels of Income and Perceived Stress

A pro-forma was used to rate the participants' income level. Monthly income less than ₦50,000 was rated as low income, ₦50,000-₦100,000 average income and income above ₦100,000 was rated as high income. Similarly the caregivers were asked to rate their level of perceived stress by choosing low, moderate or high options.

Data Analysis

The data obtained were summarized with descriptive statistics of mean, standard deviation, frequency and percentage; and illustrated using tables. Spearman rank order correlation was used to find the relationship between categorical variables at a level of significance of 0.05. The correlation analysis was conducted with SPSS version 16.0.

Results

Characteristics of the Caregivers

In this study, the mean age of 30 caregivers of children with CP was 34.40 ± 7.02 years, age range 25 – 50 years. Eleven (36.7%) of the caregivers had minimal depression, 9(30%) mild depression and 10(33.3%) moderate depression. Also 15 (50%) of the caregivers perceived high levels of parenting stress and 15(50%) had moderate perceived stress. Most of the caregivers 24(80%) were married and employed 26 (86.6%) and only 6 (20%) were not married. About 12(40%) had secondary education and only 5 (16.7%) belonged to the high income category (Table 1).

Characteristics of the Children with CP

Mean age of children with CP was 7.23 ± 2.08 years, age range 4 -11.5 years. The range of their GMFCS Score was I – IV and about 16 (53.3%) of the children were non-ambulant (GMFCS IV) (Table 2). Twenty-two children (73.3%) had spastic CP and in majority of cases (46.7%) it was due to birth asphyxia (table 1)

Table 1: Characteristics of the study participants

Variables	Frequency
Occupation	**n (%)**
Unemployed	4(13.30)
Self-employed	16(53.30)
Civil servants	10(33.30)
Level of education	
Non	4(13.30)
Primary education	5(16.70)
Secondary education	12(40.00)
Higher education	9(30.00)
Level of income	
Low	14(46.70)
Average	11(36.70)
High	5(16.70)
Characteristics of children with CP	
Sex	**n (%)**
Male	18 (60)
Female	12 (40)
Type of CP	
Quadriplegic	12(40)
Diplegic	4 (13.3)
Hemiplegic	6(20)
Athetoid	3 (10)
Mixed	5(16.7)
Gmfcs score	**n (%)**
I	2 (6.7)
II	5 (16.7)
III	7(23.3)
IV	16 (53.3)
Aetiology	
Birth asphyxia	14(46.7)
Prematurity	3(10)
Neonatal Jaundice	2(6.7)
Unknown	6(20)
Neonatal infections	5(16.7)

Key: n = frequency, % = percent; SD = standard deviation

QoL of Children with CP

The overall QoL score of children with CP in this study is 60.06±4.27 as presented in table 2. It was further observed that the 'social well-being and acceptance' domain of CP-QoL child has the highest mean score (75.07 ± 9.52) followed by 'Access to services' (66.65±7.87), however, 'Pain and impact of disability' domain has the lowest mean score (50.50±10.73) (table 2).

Table 2: QoL of children with cerebral palsy

QoL	Mean ± SD	95% CI
The overall QoL score	60.06±4.27	56.87-62.34
Domains of CP-QoL		
Social wellbeing and acceptance	75.07±9.52	71.51-78.62
Participation and physical health	58.33±10.54	54.40-62.27
Feelings about functioning	58.89±13.78	53.74-64.04
Emotional wellbeing and self esteem	52.98±14.86	47.43-58.53
Access to services	66.65±7.87	63.71-69.58
Pain and impact of disability	50.50±10.76	46.47-54.51
Family health	58.47±12.93	53.64-63.30

Key: SD=Standard Deviation CI =Confidence Interval; QoL= Quality of Life

Correlation between Proxy Report of QoL and Caregiver and Child Characteristics

Spearman rank order correlation found that, the only caregiver factor that significantly correlated with the overall proxy report of QoL was marital status (Rho=0.40; P=0.027) (Table3). Analysis into the individual domains of CP-QoL child showed that proxy report of 'pain and impact of disability domain was significantly correlated with caregivers' age (Rho=0.41; P=0.025).

Table 3: Correlation between proxy QOL reports and participants' characteristics

Participants' characteristics	**Domains of CP-QoL Questionnaire**							**Overall QoL**
	EWB	**PID**	**ATS**	**SWBA**	**PPH**	**FAF**	**FH**	
Age (CG)	Rho= -0.11 P=0.56	Rho=0.41 P=0.025*	Rho= -0.14 P=0.47	Rho= -0.09 P= 0.64	Rho= -0.43 P=0.017*	Rho= -0.09 P=0.64	Rho= -0.28 P=0.13	Rho= -0.16 P=0.39
Marital Status (CG)	Rho=0.35 P=0.06	Rho= -0.18 P=0.33	Rho=0.28 P=0.14	Rho=0.47 P=0.009*	Rho=0.45 P=0.012*	Rho= -0.14 P=0.46	Rho= -0.12 P=0.54	Rho=0.40 P=0.027*
Occupation Level (CG)	Rho=0.05 P=0.81	Rho=0.01 P=0.96	Rho=-0.19 P=0.32	Rho=-0.04 P=0.86	Rho=0.15 P=0.44	Rho=-0.22 P=0.25	Rho=-0.26 P=0.16	Rho= -0.06 P=0.75
Education Level (CG)	Rho=0.17 P=0.36	Rho=-0.01 P=0.95	Rho=0.09 P=0.65	Rho=0.15 P=0.434	Rho=0.14 P=0.45	Rho=-0.27 P=0.16	Rho=-0.14 P=0.09	Rho= 0.05 P=0.78
Perceived Stress (CG)	Rho= -0.20 P=0.29	Rho=0.123 P=0.52	Rho=0.05 P=0.79	Rho= -0.12 P=0.52	Rho= -2.05 P=0.28	Rho=0.05 P=0.79	Rho=-0.02 P=0.90	Rho=-0.08 P=0.67
Income level (CG)	Rho=0.04 P=0.85	Rho=0.2 P=0.30	Rho=0.027 P=0.89	Rho= -0.06 P=0.77	Rho=-0.05 P=0.80	Rho= -0.48 P=0.007*	Rho= -0.44 P=0.015*	Rho= -0.17 P=0.36
Depression level (CG)	Rho= -0.13 P=0.49	Rho=-0.12 P=0.52	Rho=0.08 P=0.67	Rho= -0.25 P=0.19	Rho= -0.13 P=0.51	Rho= 0.28 P=0.14	Rho= -0.14 P=0.47	Rho= 0.09 P=0.65
GMFCS (CP)	Rho=0.17 P=0.383	Rho=0.25 P=0.181	Rho=-0.19 P=0.316	Rho=-0.12 P=0.531	Rho=0.05 P=0.802	Rho= -0.46 P=0.01*	Rho=-0.32 P=0.089	Rho=-0.28 P=0.129

Key: CG=Caregivers; CP= cerebral palsy; EWB= Emotional wellbeing and self-esteem; PID= Pain and impact of disability; ATS= Access to services; SWBA= Social wellbeing and acceptance; PPH= Participation and physical health; FAF= Feelings about functioning; FH= Family health; QoL=quality of life; Rho = Spearman Rank order correlation; P=p-value; *significant (P< 0.05)

'Participation and physical health' domain correlated negatively with caregivers age (Rho=-0.43; P=0.017), 'feeling about functioning' domain correlated negatively with level of caregiver income (Rho=-0.48; P=0.007) and child's GMFCS level (Rho=-0.46; P=0.01) (table 3).

It was further discovered that marital status of the caregivers correlated significantly negatively with depression (Rho=-0.414; P=0.023) as presented in table 4.

Table 4: Correlation among socio-demographic characteristic of participants

Variables		**Rho**	**p-value**
Marital status	Perceived stress	-0.167	0.379
	Level of income	-0.241	0.200
	Depression	**-0.414**	**0 .023***
	Education level	0.243	0.195
	occupation	0.193	0.308
	Caregivers' Age	-0.314	0.091
Depression	Perceived stress	0.360	0.05
	Level of income	-0.016	0.932
	Education level	-0.176	0.353
	occupation	-0.170	0.371
	Caregivers' Age	0.041	0.830

Key: Rho = Spearman Rank order correlation; P=P-value; *significant (P< 0.05)

Discussion

The overall QoL of the children is 60.06%. This implies that the QoL of children with CP in Kano city is not severely affected. The QoL scores are comparable to that of Chulliyil et al, (2014) who found that proxy report of children's QoL is slightly above 60%. This result is a further confirmation of the research finding of Cremeens et al, (2006) and Erhart et al, (2009) that parents usually report moderate QoL of children with CP. In this study, 'social wellbeing and acceptance' domain was rated high by the caregivers, which implies that majority of the children were happy with the way they associate with their parents, siblings, and people in general both at home and school. It also suggests that most of the children have been accepted by their families, other adults and people in general. This result is similar to that of Davies et al (2009a) where the 'social wellbeing and acceptance' domain was rated high by the caregivers of children with CP. Also, in the study by Davis et al (2009b), the caregivers proxy report of children's QoL showed that the baseline ratings of the 'social wellbeing and acceptance' domain were high for children in both the experimental and control groups.

Furthermore, the observation that ‘access to services’ domain of children’s QoL was rated very high by the caregivers, signified that children with CP in Kano city were very happy to have good access to medical, surgical and allied health services. It was observed however, that ‘Pain and impact of disability’ domain was rated low by caregivers, implies that most of the children were not bothered about having CP, many do not experienced much pain and discomfort or worried by frequent hospital visits.

In this study, the only caregiver factor that significantly positively influenced the proxy report of the children’s QoL was marital status. Most of the caregivers who are married tend to report higher QoL. The implication of significant negative correlations between marital status and depression could be that caregivers who are happily married with caring spouses may experience low levels of psychological stress and this could positively influence their report of children’s QoL.

Additionally the result that proxy report of ‘pain and impact of disability’ domain was significantly positively related to caregivers’ age means that older caregivers reported higher scores of children’s ‘pain and disability’ domain. Furthermore the result that ‘participation and physical health’ domain was negatively influenced by caregivers age implies that older caregivers significantly reported lower levels of children’s ability to play with friends, do things they want to do and participate in social events and recreational activities. The implication of the finding above is that older caregiver reported higher scores of pain and disability and lower scores of children’s participation.

Furthermore, significant negative relationship between family income and ‘feeling about functioning’ domain implies that caregivers who earn higher income are more likely to report low level of physical functioning of the children with CP. The observation that higher score of children's GMFCS (or lower functional ability) resulted in significantly lower proxy scoring of 'feeling about functioning' domain implies that caregivers tend to report lower 'feeling about functioning' domain when their children are physically dependent. This finding is similar to that of Arnaud et al (2008) and Chulliyil et al (2014) who found that parent proxy report of QoL of children with CP is associated strongly with their level of function.

The insignificant relationship between the caregivers' proxy report of the overall QoL and each of 'caregivers' depression' and 'caregivers' perceived stress' means that the aforementioned factors did not directly influence the proxy report given by caregivers' about their children's QoL. The finding on stress is different from that of White-Koning et al (2008) who reported that that high levels of parenting stress influences proxy report of children's QoL. The possible reason for the difference in finding between this study and that of White-Koning et al (2008) could be because this study only assessed the caregivers feeling of being stressed using a pro-forma. The caregivers stress was not assessed with a standardized instrument. This is therefore a limitation of this study. The finding that most caregiver in this study had minimal to mild depression is similar to previous finding from Nigeria (Badaru et al, 2013) but different from that of Panepinto et al, (2013) who found that worsening of the mental health in the parents is associated with worse parent proxy report of the child's QoL.

Conclusion

The QoL of the children with CP in Kano City is moderate. The proxy report of overall QoL of children with CP was significantly influenced by marital status of the caregivers with married caregivers more likely to report better QoL. Depending on the domain investigated, factors such as child functional status, caregivers' age and their level of income could significantly influence proxy report of some QoL domains. Older caregivers tend to report higher scores of 'pain and disability' domain and lower scores of participation. The 'feeling about functioning' domain is influenced by children's level of function.

Key messages

Caregivers who are widows or have marital challenges may experience significant depression and this could negatively influence their report of children's overall QoL. In such cases the parents' proxy report of children's QoL may be unreliable. When such cases are identified, both the parents' and children's reports should be compared to obtain a more accurate measure of QoL of children with CP.

References

Arnaud C, White-Koning M, Michelsen SI, Parkes J, Parkinson K, Thyen U, Beckung E, Dickinson Ho, Fauconnier J, Marcelli M, Mcmanus V, Colver, A. 2008. Parent-Reported Quality of Life of Children With Cerebral Palsy in Europe**.** *Paediatrics*, 121(1): 54-64.
Badaru UM, OGwumike OO, Adeniyi AF, Kaka B. 2013. Psychosocial adversities and depression in mothers of children with cerebral palsy in Nigeria. *Journal of Pediatric Neurology*, 11 (1): 1-7.

Bian C, Li C, Duan Q, Wu H. 2011. Reliability and validity of patient health questionnaire: Depressive syndrome module for outpatients. *Scientific Research and Essays,* 6(2): 278-82.

Chulliyil SC, Diwan SJ, Sheth MS, Vyas NJ. 2014. Correlation of functional independence and quality of life in school aged children with cerebral palsy. *International Journal of Contemporary Pediatrics* 1(1):32-36.

Cremeens J, Eiser C, Blades M. 2006. Factors influencing agreement between child self-report and caregiver proxy-reports on the Pediatric Quality of Life Inventory 4.0 (PedsQL) generic core scales. *Health Qual Life Outcomes,* 4: 58.

Davis E, Davies B, Wolfe R, Raadsveld R, Heine B, Thomason P, Dobson F, Graham H.K. 2009b. A randomized controlled trial of the impact of therapeutic horse riding on the quality of life, health, and function of children with cerebral palsy. *Developmental Medicine and Child Neurology*, 51: 111–119.

Davis, E., Shelly, A., Waters, E., Davern, M. 2009a. Measuring the quality of life of children with cerebral palsy: comparing the conceptual differences and psychometric properties of three instruments. *Developmental Medicine and Child Neurology,* 52(2): 174-80.

Erhart M, Ellert U, Kurth B, Ravens-Sieberer U. (2009) Measuring adolescents' HRQoL via self-reports and parent proxy reports: an evaluation of the psychometric properties of both /versions of the KINDL-R instrument. *Health and Quality of Life Outcomes*, 7: 77 http://www.hqlo.com/content/7/1/77.

Feeny D, Furlong W, Boyle M, Torrance GW. 1995. Multi-attribute health status classification systems: Health Utilities Index. *Pharmacoeconomics,* 7: 490–502.

Goodwin DA, Boggs SR, Graham-Pole J. 1994. Development and validation of the Pediatric Oncology Quality of Life Scale. *Psychological Assessment*, 6: 321–328.

Naing, L. Winn, T. Rusli B.N. 2006. Practical Issues in Calculating the Sample Size for Prevalence Studies. *Archives of Orofacial Sciences,* 1: 9-14.

Oskoui M, Coutinho F, Dykeman J, Jetté N, Pringsheim T. 2013. An update on the prevalence of cerebral palsy: a systematic review and meta-analysis. *Developmental Medicine and Child Neurology*, 55(6): 509-519.

Palisano RJ, Almarsi N, Chiarello LA, Orlin, M N, Bagley A, Maggs J. 2009. Family needs of parents of children and youth with cerebral palsy. Child: Care, Health and Development, 36(1): 85–92.

Panepinto JA Hoffmann RG And Pajewski NM. 2010. The Effect of Parental Mental Health on Proxy reports of Health-related Quality of Life in Children with Sickle Cell Disease. *Pediatric Blood and Cancer,* 55(4); 1-17.

Shevell MI, Bodensteiner JB. 2004. Cerebral palsy: defining the problem. *Seminars in Pediatric Neurology,* 11(1): 2-4.

Shikako-Thomas K, Bogossian A, Lach LM, Shevell M, Majnemer A. 2013. Parents' perspectives on the quality of life of adolescents with cerebral palsy: trajectory, choices and hope. *Disability and Rehabilitation,* 35(25): 2113-2122.

Varni JW, Burwinkle TM, Sherman SA, Hanna K, Berrin SJ, Malcarne VL, Chambers H.G. 2005. Health-related quality of life of children and adolescents with cerebral palsy: hearing the voices of the children. *Developmental Medicine and Child Neurology,* 47(9): 592-597.

Varni JW, Limbers CA, Burwinkle TM. 2007. Parent proxy-report of their children's health-related quality of life: an analysis of 13,878 parents' reliability and validity across age subgroups using the PedsQL™ 4.0 Generic Core Scales. *Health and Qual of Life Outcomes,* 5(2): 1-10.

Waters E, Davis E, Boyd, Reddihough D, Mackinnon A, Graham Hk, Lo Sk, Wolfe R, Stevenson R, Bjornson K, Blair E, Ravens-Sieberer U. 2013. Cerebral Palsy Quality of Life Questionnaire for Children Manual.; Melbourne: University of Melbourne

White-Koning M, Grandjean H, Colver A, Arnaud C. 2008. parent and professional reports of the quality of life of children with cerebral palsy and associated intellectual impairment. *Developmental Medicine and Child Neurology,* 50: 618–624.