A SURVEY OF HEALTH RELATED QUALITY OF LIFE (HRQL) IN CHILDREN WITH CEREBRAL PALSY

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Summary

Introduction. Assessing the quality of life forms a vital part of the complex process of therapeutic-rehabilitation in children. This enables specific domains of functioning to be defined and subsequently targeted for therapy in those areas most affected by Cerebral Palsy (CP) in order to minimise the impact of this illness.

Aims. To assess HRQL in children with CP depending on the type, the severity of CP, mental development and the comorbidity of epilepsy and defining those aspects of life on which CP has the strongest negative influence.

Material and methods. The study group consisted of 83 children aged 5-18 years. Data were obtained both from a questionnaire, (CHQ-PF 50), completed by parents and from clinical records.

Results. Scores ranged from 36.542 to 66.637 in the CHQ-PF 50 scales. The lowest parental ratings were for their children's health status and capacity for future improvement. The greatest influence on the quality of life was the limited degree of personal time for the parents. The most severe CP was related to the lowest ratings for quality of life, but the family functions were unrelated to the type of CP and on severity of the symptoms. No statistically significant differences were found in any of the evaluated HRQL areas between children of normal intelligence and those with slight or moderate intellectual impairment.

Conclusions. CP decreases the quality of life in all of the analysed domains. This condition, regardless of the clinical type or severity, negatively affects the quality of life of the whole family mainly through limiting the amount of personal time for the parents.

Key words: quality of life, child, cerebral palsy

INTRODUCTION

Cerebral palsy occurs in 2-2.5 per 1000 births and constitutes the most frequent cause of disability in children. Treatment is long-term, costly and requires a constant commitment to be made by the child's family. In the planning of complex medical-rehabilitation treatment regimes, it is vital to understand the influence of this illness on the patient's quality of life as well on the family (1). The concept of health-related quality of life (HRQL), was introduced by Schipper in 1990 recognising the functional effects of the illness and its treatment from the patient's viewpoint (2) An assessment on the quality of life should therefore take into account both an objective evaluation of the child's functional state and a subjective one of the patient's well being and that of their closest caregivers (3). Despite many attempts, HRQL has not yet been precisely defined but those generally used in studies are reduced to a listing of the components on the quality of life. According to most authors there are 3 fundamental factors; physical, psychological, and social. Up to now, there haven't been any assessments in Poland on the effect of CP on various areas of the functioning of the child nor on the family. By thus assessing the quality of life in children with CP, a broader view on the child's family life with a chronic illness can so be achieved which can therefore indicate the direction in which treatment and any help proceed.

AIM

The aim of the study was to assess the health-related quality of life in the children with CP into dependence on the CP types, severity, the stage of mental development, coexisting of epilepsy and defining those areas of life that are most negatively affected by this illness.

MATERIAL AND METHODS

The study was undertaken at the rehabilitation clinic of the Child Health Memorial Hospital, in Warsaw. It covered children and teenagers aged 5-18 years receiving treatment at this institute. A package was sent to the

parents of 148 children with CP, including a study questionnaire and a letter which explained the purpose and study methods. A stamp addressed envelope for postal return was attached. Replies were received from 86 questionnaires out of which 83 were taken for further analysis (56.1%), where 3 questionnaires were rejected for not having been properly filled in. Hospital records provided information on age, gender, living address, CP type and the disease severity based on the GMFCS scale levels; (level I- child can independently walk, corresponding to GMFCS levels I and II; level II – child walks with assistance, corresponding to GMFCS levels II and III; level III – child requires an wheelchair for moving, corresponding to GMFCS levels IV and V). Data also included the degree of mental development according to ICD-10, the co-morbidity of epilepsy and other accompanying syndromes. The assessment of HRQL was based on 12 domains of the child's life covering physical, psychological and social aspects based on the CHQ-PF 50 questionnaire concerning child health.

CHQ-PF 50 (The Child Health Questionnaire – Parent Form 50) was constructed to measure the physical and psychosocial well-being in children aged 5-18, in the USA in 1994 by Landgraf and Ware as a tool to measure HRQL in children that are healthy or suffering from chronic illnesses. The CHQ-PF 50 is filled in by the parent or caregiver. In giving answers to most of the questions, account is taken of the preceding 4 week period (4). A Polish version of the CHQ-PF 50 was used for the present work which previously had been successfully tested in a children's study on Juvenile Idiopathic Arthritis (5). The measurement of the HRQL was undertaken in 12 categories covering; physical functioning (PF), limitations in social interactions caused by the child's health (RP), general perception of health (GH), bodily pain and discomfort (BP), limitations to parent's personal time due to the child's condition; parent impact time – PT, influence of the child's condition on the feelings of the parents; parental impact-emotional – PE, role/social limitations as a result of emotional-behavioural problems (REB), self esteem (SE), mental health (MH) and general behavior (BE), limitations in family activities (FA) and family cohesion (FC). The measurement results were numbered on a scale of 0-100, where the higher the number the better is the child's welfare status. The overall HRQL assessment, is the total of all the 12 measurements. Statistical analysis was performed to investigate the significant associations between variables expressed as interval estimates by using Pearson's Correlation Coefficient, Spearman's Rank Correlation and Kendall Tau Rank Correlation Coefficient. For variables expressed in other ways the Kruskall-Wallace and Scheffe Multiple Comparison tests were used. Significance levels were taken as $p \leq 0.05$.

RESULTS

The study group (83 children) consisted 45 boys and 38 girls with CP. The mean age was 11 years. The characteristics of the sample are shown in table 1.

Table 1. The characteristics of the sample n = (83).

		Numbers of children (%)
Type of CP	Diplegia	34 (40.96%)
	Tetraplegia	25 (30.12%)
	Hemiplegia	14 (16.87%)
	Dyskinetisia	6 (7.23%)
	Atalia	4 (4.82%)
Severity of CP	Level I	46 (55.42%)
	Level II	23 (27.71%)
	Level III	14 (16.87%)
Degree of mental retardation	None	41 (49.40%)
	Mild	16 (19.28%)
	Limited	11 (13.25%)
	Significant	11 (13.25%)
	Deep	4 (4.82%)
Epilepsy	Yes	37 (44.58%)
	No	46 (55.42%)

Individual questionnaire scales

In all the studied domains, parents gave the lowest scores for the child's state of health and possibility of future improvement (GH); (mean 36.542). A somewhat higher score, (mean 45.762), was obtained in the child's physical functioning (PF). Distress concerning the child's health (PE) and limitations in social functioning arising from physical disabilities (RP) were reflected in the mid scale scores with means ranging 49.344-52.04. The remaining areas were rated somewhat higher by the parents, (ranging from 60.299 to 66.63). A parental rating of their children's behaviour (BE) received the highest score (66.637).

The effect of individual domains on the whole HRQL assessment

The dominating feature of the overall quality of life assessment was the illness's limitations on the child impacting on family life especially on decreasing personal parental time. Further important areas were seen to be those concerning the social functioning of the child. However the influences of the child's physical and emotional health were not that significant. Results are shown in table 2.

Place of residence and HRQL

Statistically significant differences were seen in two categories between children from the countryside and towns/cities. Parents from the latter gave higher scores for the child's general health perceptions and the possibilities for future improvement (GH) as well as for the child's self esteem (SE). According to the opinion of parents from this group their children are more self-contented with their lives than their counterparts from the countryside. Results are shown in table 3.

Table 2. The effect of the studied domains, on the overall HRQL assessment in order of decreasing significance.

	HRQL
1.	Parental Impact Time
2. 3. 4.	Distress suffered by the parents Limitations to joint family activities Role/social limitations as a result of emotional-behavioural problems
5.	Limitations in social interactions caused by the child's state of health
6.	Overall perceptron of Heath
7. 8. 9.	Pain Self-esteem Physical fitness
10.	Mental Heath
11.	Behaviour
12.	Family coherence

CP Type and HRQL

Because of the small numbers of CP children with ataxia and dyskinesia, the statistical analysis was performed on those children groups with diplegic, hemiplegic and tetraplegic type of CP. Statistically significant differences were seen in the 2 categories: PF and SE. According to the parents, children with hemiplegia were physically more fit than those with diplegia or tetraplegia as well as being more self-content than children with tetrapegia. Results are shown in table 4.

Disease severity and HRQL

The majority of domains gave worse results the greater the disease severity. Statistically significant differences were seen in the overall HRQL assessment and in the scores of; general health (GH); physical functioning (PF); limitations in social interactions caused by the child's state of health (RP); and general behavior (BE). Nevertheless, this degree of severity did not affect the level of self esteem (SE) nor did it limit joint family activity (FA). Results are shown in table 5.

Table 3. Mean results of HRQL measures amongst children living in the countrywide and towns/cities.

Domain	Mean		p
	Place of residence		
	Countryside (n = 35)	Town/city (n = 48)	
PF	41.39	48.95	p > 0.05
RP	45.55	56.77	p > 0.05
GH	**31.56**	**40.18**	**p < 0.05**
BP	63.71	62.92	p > 0.05
FA	65.83	62.79	p > 0.05
REB	59.68	67.70	p > 0.05
PT	65.16	60.88	p > 0.05
PE	51.43	47.83	p > 0.05
SE	**55.28**	**63.96**	**p < 0.05**
MH	63.14	58.38	p > 0.05
BE	66.40	66.81	p > 0.05
FC	63.29	61.77	p > 0.05
Overall	672.42	698.93	p > 0.05

Mental state and HRQL

Because of the children's frequency distribution, a statistical analysis was performed between the following children groups; those with normal mental development, those with a mild and limited retardation (group 1), as

Table 4. Mean results of HRQL measures amongst children with Diplegia, Hemiplegia, Tetraplegia, Cerebral type and pyramidal/extra-pyramidal of CP.

Domain	Mean			p	Mean	
	diplegia (n = 34)	hemiplegia (n = 14)	tetraplegia (n = 25)		ataxia (n = 4)	dyskinesia (n = 6)
PF	**41.34**	**72.22**	**45.33**	**p < 0.05**	**16.32**	**30.55**
RP	60.05	67.86	39.78	p > 0.05	29.16	36.11
GH	41.16	35.12	34.01	p > 0.05	31.04	27.91
BP	62.35	68.57	52.20	p > 0.05	55.00	86.67
FA	69.66	58.93	59.83	p > 0.05	67.71	59.72
REB	76.63	73.80	49.33	p > 0.05	33.33	55.55
PT	69.36	58.73	55.55	p > 0.05	63.88	62.96
PE	**53.06**	**48.21**	**44.33**	**p > 0.05**	**56.25**	**47.22**
SE	65.10	61.55	53.53	p < 0.05	61.46	57.64
MH	60.63	60.00	60.60	p > 0.05	61.25	58.47
BE	70.90	62.46	62.32	p > 0.05	72.92	66.00
FC	61.76	64.29	62.00	p > 0.05	76.25	54.17
Overall	731.99	731.72	623.81	p > 0.05	624.55	642.96

Table 5. Mean results of HRQL measures in I, II and III severity grades of Paralysis.

Domain	Mean			p
	Severity grades of paralysis			
	I (n = 46)	II (n = 23)	III (n = 14)	
PF	**65.09**	**32.06**	**4.76**	**p < 0.001**
RP	**66.18**	**43.84**	**19.05**	**p < 0.001**
GH	**38.36**	**40.79**	**23.59**	**p < 0.01**
BP	63.91	61.74	63.57	p > 0.05
FA	63.84	68.66	57.32	p > 0.05
REB	71.74	62.07	43.65	p > 0.05
PT	66.60	60.38	53.57	p > 0.05
PE	48.55	54.53	43.45	p > 0.05
SE	60.16	63.95	54.76	p > 0.05
MH	57.39	62.05	67.50	p > 0.05
BE	**63.86**	**67.00**	**75.18**	**p < 0.05**
FC	60.76	69.13	56.79	p > 0.05
Overall	**726.44**	**686.19**	**563.18**	**p < 0.05**

well as children with significant and deep retardation (group 2). The Kruskal-Wallis test shows the uniformity of such linked groups. Statistically significant differences were seen in the majority of domains. Despite this, a mild or limited degree of mental disability did not affect the scores in any of the domains compared to those children with a normal mental capacity. Results are shown in table 6.

Table 6. Mean results of HRQL measures amongst children with normal mental development, mild and limited retardation and those with significant and deep retardation.

Domain	Mean		p
	Mental state		
	normal development, mild and limited retardation (n = 68)	significant and deep retardation (n = 15)	
PF	**54.33**	**6.94**	**p < 0.001**
RP	**60.82**	**12.22**	**p < 0.001**
GH	**40.69**	**17.72**	**p < 0.001**
BP	**67.65**	**43.33**	**p < 0.05**
FA	**66.87**	**51.39**	**p < 0.05**
REB	**72.63**	**26.67**	**p < 0.001**
PT	**66.95**	**43.33**	**p < 0.05**
PE	**51.65**	**38.89**	**p < 0.05**
SE	**62.33**	**51.11**	**p < 0.05**
MH	59.81	63.00	p > 0.05
BE	65.79	70.50	p > 0.05
FC	63.24	58.67	p > 0.05
Overall	**732.75**	**483.76**	**p < 0.001**

Comorbidity of epilepsy and HRQL

This is significantly related to a lower overall HRQL assessment. Parents of epileptic children gave lower ratings and were more anxious about their child's health (GH, PE). The epilepsy also limited joint family activities (FA); but participation in school lessons and contacts with their peers (REB) were unaffected. Results are shown in table 7.

Table 7. Mean results of HRQL measures related to the comorbidity of epilepsy.

Domain	Mean		p
	Comorbidity of epilepsy		
	yes (n = 37)	no (n = 46)	
PF	45.45	46.01	p < 0.05
RP	47.15	55.98	p < 0.05
GH	**29.71**	**42.03**	**p < 0.05**
BP	60.27	65.65	p < 0.05
FA	**57.20**	**69.60**	**p < 0.05**
REB	58.86	68.72	p < 0.05
PT	56.75	67.45	p < 0.05
PE	**42.56**	**54.80**	**p < 0.01**
SE	59.26	61.14	p < 0.05
MH	60.73	60.11	p < 0.05
BE	63.87	68.86	p < 0.05
FC	60.00	64.35	p < 0.05
Overall	**641.82**	**724.69**	**p < 0.05**

RESULTS REVIEW AND DISCUSSION

Health is one of the most important factors on which a good quality of life depends. It is therefore vital to measure the influence of health on the well-being of the sick child especially in cases of chronic illness. Because the effect of the child's illness severity on HRQL was required for assessment, a questionnaire was used for parents so as not to exclude children with severe forms of CP. Parents were observed to score all their children's domains significantly lower than those seen in healthy children. Studies in this subject area from the USA conducted by Langraf gave results of 72.3-96.1 (4). In Poland a study by Romicka on a small group of children demonstrated similar results of 81.9-100; apart from GH at a 67.5 score (5) A token of just how much a burden CP is on patients and their family is shown by such parents not assessing the quality of their children's lives compared to those parents with children that have asthma or psychological disturbances (6, 7). A study by Liptak also showed lower parameters in children with CP compared to healthy children; physical functioning and parent's personal time being decreased the most (8). Furthermore, a worse quality of life is demonstrated in a study by Samson-Fang (9) as likewise by McCarthy (10), who showed a lowered score for physical and social functioning; however areas concerned with

family functioning were not studied. This parameter would however seem to be a key one in assessing the quality of life; the study of Wake showed that parents of children with CP give scores lower than those with healthy children in all domains studied, especially those regarding physical and family functioning (11).

Our results lead us to believe that, from the domains studied concerned with HRQL, the most affected areas are the physical limitations due to CP and the functioning of the whole family. The domain scores and the overall quality of life assessment is unaffected by the CP type. The diplegic form is considered the mildest and is linked to higher scores in only two areas – physical functioning (PF) and child self esteem (SE). McCarthy and Vitale also observed differences in parental ratings of PF (10, 12). As can be expected the majority of the studied domains, important for the quality of life, demonstrated worse results the greater the disease severity. It is interesting to note that, together with the increase in severity, parents give higher scores of their child's behaviour. This is surely related to the way the question was constructed in the CHQ questionnaire which included assessing pathological behaviour such as stealing. However there were no significant differences seen in self esteem scoring.

Both the type and severity of CP did not modify the functioning of the family (PT, FA and PE). However even a small disease severity is large burden for the family to bear. This can be linked to the co-existence of numerous neurological disorders; 2/3 of parents state in the survey that their children have difficulty concentrating, over half the parents indicate problems with learning as well as frequent problems with the child's behaviour (40% parents): this all imposing a large burden on the parents and decreases their well-being even cases with mild severity of CP. A deeper severity is linked to a lower rating of physical and social functioning of the child. Wake also showed higher scores for behaviour in patients with such deeper severities. Children that used a wheelchair were found to have a more limited social life than those walking (11). The negative influence of the disease severity on quality of life was also shown by Liptak, however this study only included children with a high disease progression (8).

Studies by Schneider reported equivocal results, however the publication did not provide data yet it claimed that, even though the majority of children possessed significant disabilities, the quality of life scores did not correlate with their functioning state (13). It is not surprising that with a deeper severity the quality of life decreases but it brings to attention that mild and limited severities do not worsen HRQL assessment rating compared to the normal mental state. Although McCarthy and Wake did not find any significant differences in HRQL domain scores between children with CP and average child intelligence to those children with CP and mental retardation (10, 11), they however did not relate this to the degree of mental retardation.

Although the coexistence of epilepsy is linked to a lower quality of life rating, it nonetheless does not lead to a decrease in self-esteem nor limits participation in school lessons and contacts with peers. Wake when studying the influence of epilepsy on quality of life did not demonstrate significant differences when comparing CP without an accompanying epilepsy (11). This is most certainly related to good pharmacological control over the seizures. The largest influence on the quality of life measures are exerted in the area of the functioning of the whole family. It is known that chronic illness disrupts the whole family life. Parents often feel guilty or have low self-worth which requires support for the whole family of the sick child. The decrease in personal parental time especially influences the HRQL ratings. It seems that this can be related to various problems concerned with the illness's course such as difficulties with coping by oneself or problems with mobility.

In the questionnaire footnotes, parents emphasise the time-consuming nature of care and child rehabilitation; 74% give the children exercises in movement. It is also noteworthy that 48.2% of mothers are not professionally employed; citing the child's health status as a reason. Our results confirm the significant time burden in child upbringing with CP already pointed out earlier (14). A large influence on the quality of life is the degree by which the ability to participate in school lessons and games with their peers is limited due to the illness. A bigger problem in this instance is the emotional and psychological disruption rather than the physical. The period of school education is very significant in adapting to a life with someone suffering from CP.

Some children can only meet their peers at school; as shown from our own studies where 20% of children with CP don't have any contacts with their peers outside school and 80% don't take advantage of any extra-school activities. Our results demonstrate wide areas of discomforting inconveniences associated with a serious illness which decreases not only the patient's well being but those of the whole family; especially the mothers, (in fact this survey was 96.4% completed by the mothers), irrespective of the CP severity. In the comments enclosed with the questionnaire, parents complained about the lack of sufficient social help and feelings of being abandoned. It therefore seems necessary to expand the range of social care – rehabilitation facilities so that mothers can be relieved from a constant regime of 24-hour care. Increasing the mother's personal time would thereby help bring about a better quality of life for the child and members of the family. The issue of organising family help for children with CP therefore requires further debate with the aim of increasing help for those afflicted and their families.

CONCLUSIONS

1. Cerebral palsy in children decreases the quality of life for all the domains (areas) studied, amongst which the parents gave the lowest ratings for

the child's state of health and the possibility for future improvement.
2. Regardless of its clinical form and severity, cerebral palsy in children negatively affects on the quality of life for the whole family through limiting the parent's personal time.
3. Parents of children with cerebral palsy living in the countryside give a lower rating for the child's state of health and the possibility for future improvement as well as child self esteem compared to those living in towns/cities.
4. In the studied domains, mild and limited mental retardation do not affect the quality of life in children with cerebral palsy.
5. The comorbidity of epilepsy with child cerebral palsy decreases the quality of life. □

References

1. Eiser C: Childrens quality of life measures. Arch Dis Child 1997; 77(4): 350-354. **2.** Schipper H, Clinch J, Powell V: Definitions and conceptual issues. [In:] Spilker B (ed.): Quality of life assessments in clinical trials. Raven Press, New York 1990; 11-24. **3.** Koman LA, Smith B, Shilt JS: Cerebral palsy. Lancet 2004; 363: 1619-1631. **4.** Landgraf JM, Ware JE Jr: Child Health Questionnaire (CHQ): A User's Mannual. Health Act, Boston, MA 1999. **5.** Romicka AM, Ruperto N, Gutowska-Grzegorczyk G et al.: The Polish version of the Childhood Health Assessment Questionnaire (CHAQ) and the Child Health Questionnaire (CHQ). Clin Exper Rheumatol 2001; 19 (Suppl. 23): 121-125. **6.** Sawyer MG, Spurrier N, Kennedy D, Martin J: The relationship between asthma severity, family functioning and health-related quality of life of children with asthma. Qual Life Res 2000; 9: 1105-1115. **7.** Sawyer MG, Whaites L, Rey JM et al.: Health-related quality of life of children and adolescents with mental disorders. Am Acad Child Adolesc Psychiatry 2002; 41: 530-537. **8.** Liptak GS, O'Donnell M, Conaway M: Health status of children with moderate to severe cerebral palsy. Dev Med Child Neurol 2001; 43(6): 364-370. **9.** Samson-Fang L, Fung E, Stallings V: Relationship of nutritional status and societal participation in children with cerebral palsy. J Pediatrics 2002; 141(5): 637-643. **10.** McCarthy M, Silberstein C, Atkins E: Comparing reliability and validity of pediatric instruments for measuring health and well-being of children with spastic cerebral palsy. Dev Med Child Neurol 2002; 44: 468-476. **11.** Wake M, Salmon L, Reddihough: Health status of Australian children with mild to severe cerebral palsy: cross-sectional survey using the Child Health Questionnaire. Dev Med Child Neurol 2003; 45: 194-199. **12.** Vitale MG, Roye D, Levy DE et al.: An exploration of quality of life outcomes measures in scoliosis and cerebral palsy. Pediatrics 1999; 104 (Suppl. 716). **13.** Schneider J, Gurucharri L, Gutierrez A, Gabler-Spira D: Health-related quality of life and functional outcome measures for children with cerebral palsy. Dev Med Child Neurol 2001; 43: 601-608. **14.** Pisula E: Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju. Wydawnictwa Uniwersytetu Warszawskiego, Warszawa 1998.

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