

THE QUALITY OF LIFE IN CHILDREN WITH CEREBRAL PALSY

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ABSTRACT

Background: Cerebral palsy (CP) is the most common pediatric disability causing long-term functional limitations. CP remarkably influences the life of those affected and their families. For this reason it is important and necessary to direct attention not only type of the CP, but also the impact the disorder has on the child, parents, siblings and the entire family as a whole. The aim of this study was to assess the impact of CP on the child's quality of life, considering parents' perceptions about their child's illness, in order to underline the impact the illness has not only on the child but also his/her family.

Methods: The study included both parents of the 36 subjects enrolled (19 males and 17 females), with established CP diagnosis. The effect of CP on the families was assessed using the Impact of Childhood Illness Scale. This questionnaire assesses the quality of life in children with epilepsy and other chronic pathologies and in their families. All questions refer to effect to the illness family. The scale comprises 30 questions divided into four sections: impact of illness and its treatment; impact on development and child's adjustment; impact on parents and impact on the family. Descriptive analyses were used for data analysis and it is also calculated the rank correlation coefficient Spearman's rho.

Results and conclusion: The mothers' group presents little higher average scores than the group of fathers in two four subscales or in the basement "Impact on the child" and "Family impact on the organization". This could be due to the fact that mothers are concerned most of the child's caregiver, living most of all the difficulties that entails; mothers show greater concerns than fathers. In subscale "Impact on parents" the average score of the answers of the group of mothers coincide with that of the fathers; the experience and the experience of his son's illness is analogous for both parents. No significant differences were found from the correlational analysis between the individual items of the subscales and the different forms of CP. In families of children with CP, strategies for optimizing caregiver physical and psychological health include supports for behavioral management and daily functional activities as well as stress management and self-efficacy techniques.

Keywords: cerebral palsy - quality of life - pediatric disability, parenting.

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Introduction

Cerebral palsy (CP) is the most common pediatric disability causing long-term functional limitations⁽¹⁻³⁾.

Children with CP most often present with multiple impairments, activity limitations and participation restrictions; most children require lifetime

extensive assistance in functional day to day activities^(1, 4-5). The level of required assistance depends on the severity of impairments, activity limitations and participation restrictions^(1,6).

Although impaired motor function is the hallmark of the cerebral palsy (CP) syndromes, many children with this development disorder also experience sensory, communicative, and intellectual

impairments and may have complex limitations in self-care functions^(1,7). Although caregiving is a normal part of being the parent of a young child, this role takes on an entirely different significance when a child experiences functional limitations and possible long-term dependence⁽⁹⁾. One of the main challenges for parents is to manage their child's chronic health problems effectively and juggle this role with the requirements of everyday living⁽⁷⁾.

Although it is expected that caring for a child with cerebral palsy (CP) can impact on the quality of life (QOL) of caregivers, the QOL of caregivers' has yet to be adequately examined^(1-3, 7, 8).

Caring for a child with CP can both positively and negatively impact on a parent's life. There is value for both parents and children if parental concerns and determinants of QOL are considered in overall program planning and service delivery for children and their families⁽⁸⁾.

The aim of this study was to assess the impact of CP on the child's quality of life, considering parents' perceptions about their child's illness, in order to underline the impact the illness has not only on the child but also his/her family.

Materials and methods

Research study included both parents of 36 (19 males and 17 females) subjects enrolled affected by CP; age ranged from 6 to 18 years (mean age of 13.4 ± 3.8) recruited in Sicilia Region. Specifically, among the CP diagnoses in our sample were the following: 50% spastic quadriplegia, 13.88% spastic diplegia, 11.11% spastic hemiplegia, 8.33 ataxic form, 8.33 athetoid/dyskinetic form, 8.33 mixed type. Moreover, 25% presented associated speech disorders, 16.66% epilepsy, 11.11% sensory disturbances and 5.56% behavioral disorders.

Eighteen subjects (50%) were inpatients in two of the Italian Associations for the Spastic Subjects Support (ASSS) of Palermo, fourteen subjects (38.88%) at ASSS of Agrigento and four subjects (11.11%) at Department of Neuropsychiatry Hospital "Aiuto Materno" of Palermo.

Fathers age ranging from 36 to 62 years, while mothers from 33 to 57 years. The education level was the follow: 8.3% University degree, 54.1% high school grade, 36.1% middle school grade and 1.3% primary school grade. Besides, 47.2% of the mothers were housewives and most of them gave up a job for illness of their sons.

In order to evaluate CP effects on familiar management, the Impact of Childhood Illness Scale test has been used⁽⁹⁾. The test assesses quality of life in children and their families affected by epilepsy and other chronic pathologies.

The test comprises 30 questions divided into four sections:

- impact of illness and its treatment (questions 1-5);
- impact on development and child's adjustment (questions 6-15);
- impact on parents (questions 16-20) and 4) family impact (questions 21-30).

For each question, parents were asked to rate two variables: frequency (how often a particular problem or situations arose) and impact (amount of concern it produced). The two variables for each question were scored 0, 1 or 2. The questionnaire also contains a brief preliminary section that explains to parents the aim of the assessment procedure.

Statistical analysis

Descriptive analyses were used for data analysis and it was also calculated the rank correlation coefficient Spearman's rho.

Results

The most frequent problems linked to CP for both parents (who answered "sometimes" or "often, very often" according to frequency parameter and "some" or "very important" according to the importance parameter) were: the risk that can stop breathing, you get hurt, it may suffer brain damage or die (these data were measured in all forms of CP) (Tables 1-4).

Spearman's rho coefficient rank correlation analysis showed a significant correlation between variables (0.8 in the group of mothers and 0.6 in fathers) (Tables 5 and 6).

In Figure 1 and Figure 2 the mean scores of the four subscales of the questionnaire for the group of mothers and fathers were showed, respectively, according to the parameter of the frequency and importance.

Discussion

In general caring child affected by disabling illness may lead to increase parental stress^(6, 10-20).

Consequently, long-term caregiving for a child with CP may negatively affect the well-being of

caregivers^(21, 22) inducing caregiver burden⁽²³⁾, a multi-factorial complex, subjective and dynamic as envisaged in different conceptual models which have been developed to explain this construct^(23, 24).

Questions	Answers					
	0 = Never or rarely true		1 = Sometimes true		2 = Often or really true	
	N.	%	N.	%	N.	%
1. Because of his/her illness he/she may stop breathing	10	27.9	12	33.3	14	38.8
2. There is a risk he/she may injure himself/herself	5	13.8	21	58.4	10	27.8
3. There is a risk he/she may be brain damaged or even die	8	22.2	16	44.5	12	33.3
4. The drugs my child takes makes him/her less alert	20	55.6	15	41.7	1	2.7
5. The drugs worsen his/her behavior	21	58.4	13	36.1	2	5.5
6. My child is more moody because of his/her illness	11	30.6	19	52.8	6	16.6
7. He/she is shy and more easily embarrassed	17	47.3	14	38.9	5	13.8
8. Because of his/her illness, he /she is teased and bullied	9	25.0	11	30.5	16	44.5
9. Because of his/her illness, he/she has few friends	6	16.8	15	41.6	15	41.6
10. Because of his/her illness, he/she has fewer interests	5	13.8	13	36.2	18	50.0
11. Because of his/her illness, my child has problems in reading or maths	2	5.6	17	47.2	17	47.2
12. My child is less clever because of his/her illness	22	61.2	9	25.0	5	13.8
13. My child may not find a job when he/she has leaves school	15	41.7	13	36.1	8	22.2
14. My child may have to take drugs for years	10	27.7	17	47.3	9	25.0
15. My child may not marry or have a family	17	47.3	12	33.3	7	19.4
16. My child makes a fuss about taking his/her drugs	18	50.0	17	47.3	1	2.7
17. Because of his/her illness, It difficult for him/her to use public transport	1	2.8	6	16.7	29	80.5
18. He/she is less able to care for him/herself	1	2.8	18	50.0	17	47.2
19. It is difficult to explain my child's illness to others	3	8.3	11	30.5	22	61.2
20. It is difficult to explain my child his/her own illness	5	13.8	13	36.2	18	50.0
21. Because of his/her illness, my child must be more closely watched than other children	1	2.8	12	33.3	23	63.9
22. It is difficult to give my other children enough attention	6	16.6	16	44.5	14	38.9
23. My child illness limits what his/her brothers and sisters can do	19	52.8	12	33.3	5	13.9
24. We have to limit our holidays	9	25.0	19	52.8	8	22.2
25. His /her illness means we have fewer friends around	14	38.4	18	50.0	4	11.6
26. My child illness influence how often we go out as a family	12	33.3	17	47.3	7	19.4
27. We have more arguments at home	13	36.1	15	41.7	8	22.2
28. We go out less often in the evening as a couple	9	25.0	17	47.3	10	27.7
29. My child is more difficult to manage because of his/her illness	3	8.3	13	36.2	20	55.5
30. Because of his/her illness we turn down opportunities at work	10	27.9	12	33.3	14	38.8

Table 1: Answers of mothers on frequency.

Questions	Answers					
	0 = Never or rarely true		1 = Sometimes true		2 = Often or really true	
	N.	%	N.	%	N.	%
1. Because of his/her illness he/she may stop breathing	12	33.3	15	41.7	9	25.0
2. There is a risk he/she may injure himself/herself	9	25.0	16	44.4	11	30.6
3. There is a risk he/she may be brain damaged or even die	14	38.8	13	36.2	9	25.0
4. The drugs my child takes makes him/her less alert	3	8.4	9	25.0	24	66.6
5. The drugs worsen his/her behavior	3	8.4	5	13.9	28	77.7
6. My child is more moody because of his/her illness	7	19.4	10	27.8	19	52.8
7. He/she is shy and more easily embarrassed	5	13.6	4	11.4	27	75.0
8. Because of his/her illness, he /she is teased and bullied	18	50.0	7	19.5	11	30.5
9. Because of his/her illness, he/she has few friends	16	44.5	9	25.0	11	30.6
10. Because of his/her illness, he/she has fewer interests	12	33.3	11	30.5	13	36.2
11. Because of his/her illness, my child has problems in reading or maths	15	41.6	8	22.2	13	36.2
12. My child is less clever because of his/her illness	3	8.3	3	8.3	30	83.3
13. My child may not find a job when he/she has leaves school	4	11.2	1	2.7	31	86.1
14. My child may have to take drugs for years	4	11.2	17	22.2	24	66.6
15. My child may not marry or have a family	3	8.3	5	13.9	28	77.8
16. My child makes a fuss about taking his/her drugs	-	-	8	22.2	28	77.8
17. Because of his/her illness, It difficult for him/her to use public transport	21	58.3	11	30.5	4	11.6
18. He/she is less able to care for him/herself	14	38.9	12	33.3	10	27.8
19. It is difficult to explain my child's illness to others	21	58.4	5	13.8	10	27.8
20. It is difficult to explain my child his/her own illness	15	41.7	10	27.7	11	30.6
21. Because of his/her illness, my child must be more closely watched than other children	13	36.1	15	41.7	8	22.2
22. It is difficult to give my other children enough attention	10	27.8	13	36.1	13	36.1
23. My child illness limits what his/her brothers and sisters can do	6	16.6	7	19.5	23	63.9
24. We have to limit our holidays	4	11.2	12	33.3	20	55.5
25. His /her illness means we have fewer friends around	4	11.2	5	13.8	27	75.0
26. My child illness influence how often we go out as a family	3	8.3	7	19.5	26	72.2
27. We have more arguments at home	5	13.9	8	22.2	23	63.9
28. We go out less often in the evening as a couple	4	11.2	5	13.8	27	75.0
29. My child is more difficult to manage because of his/her illness	8	22.2	12	33.3	16	44.5
30. Because of his/her illness we turn down opportunities at work	4	11.2	21	58.3	11	30.5

Table 2: Answers of mothers on importance.

Questions	Answers					
	0 = Never or rarely true		1 = Sometimes true		2 = Often or really true	
	N.	%	N.	%	N.	%
1. Because of his/her illness he/she may stop breathing	7	19.4	11	30.5	18	50.0
2. There is a risk he/she may injure himself/herself	5	13.8	22	61.2	9	25.0
3. There is a risk he/she may be brain damaged or even die	6	16.6	10	27.9	20	55.5
4. The drugs my child takes makes him/her less alert	18	50.0	16	44.5	2	5.5
5. The drugs worsen his/her behavior	18	50.0	17	47.2	1	2.8
6. My child is more moody because of his/her illness	24	66.7	12	33.3	-	-
7. He/she is shy and more easily embarrassed	10	27.8	23	63.9	3	8.3
8. Because of his/her illness, he /she is teased and bullied	10	27.8	12	33.3	14	38.8
9. Because of his/her illness, he/she has few friends	7	19.4	18	50.0	11	30.6
10. Because of his/her illness, he/she has fewer interests	3	8.3	17	47.2	16	44.5
11. Because of his/her illness, my child has problems in reading or maths	1	2.7	19	52.8	16	44.5
12. My child is less clever because of his/her illness	29	80.6	5	13.9	2	5.5
13. My child may not find a job when he/she has leaves school	13	36.1	19	52.8	4	11.1
14. My child may have to take drugs for years	13	36.1	17	47.3	6	16.6
15. My child may not marry or have a family	17	47.3	12	33.3	7	19.4
16. My child makes a fuss about taking his/her drugs	21	58.4	14	38.9	1	2.7
17. Because of his/her illness, It difficult for him/her to use public transport	1	2.8	8	22.2	29	75.0
18. He/she is less able to care for him/herself	3	8.3	18	50.0	15	41.7
19. It is difficult to explain my child's illness to others	-	-	9	25.0	27	75.0
20. It is difficult to explain my child his/her own illness	3	8.3	17	47.2	16	44.5
21. Because of his/her illness, my child must be more closely watched than other children	1	2.8	13	36.1	22	61.1
22. It is difficult to give my other children enough attention	2	5.5	25	69.5	9	25.0
23. My child illness limits what his/her brothers and sisters can do	11	30.6	23	63.9	2	5.5
24. We have to limit our holidays	6	16.6	27	75.0	3	8.3
25. His /her illness means we have fewer friends around	11	30.6	22	61.1	3	8.4
26. My child illness influence how often we go out as a family	14	38.9	21	58.3	1	2.8
27. We have more arguments at home	5	13.9	28	77.8	3	8.3
28. We go out less often in the evening as a couple	13	36.2	18	50.0	5	13.8
29. My child is more difficult to manage because of his/her illness	2	5.5	22	61.2	12	33.3
30. Because of his/her illness we turn down opportunities at work	5	13.8	22	61.1	9	25.0

Table 3: Answers of fathers on frequency.

Questions	Answers					
	0 = Never or rarely true		1 = Sometimes true		2 = Often or really true	
	N.	%	N.	%	N.	%
1. Because of his/her illness he/she may stop breathing	13	36.1	16	44.5	7	19.4
2. There is a risk he/she may injure himself/herself	4	11.1	21	58.3	11	30.6
3. There is a risk he/she may be brain damaged or even die	14	38.9	14	38.9	8	22.2
4. The drugs my child takes makes him/her less alert	5	13.9	7	19.5	24	66.6
5. The drugs worsen his/her behavior	4	11.1	7	19.5	25	69.4
6. My child is more moody because of his/her illness	9	25.0	9	25.0	18	50.0
7. He/she is shy and more easily embarrassed	2	5.5	11	30.6	23	63.9
8. Because of his/her illness, he /she is teased and bullied	11	30.6	15	41.6	10	27.8
9. Because of his/her illness, he/she has few friends	8	22.2	12	33.3	16	44.5
10. Because of his/her illness, he/she has fewer interests	10	27.8	19	52.7	7	19.5
11. Because of his/her illness, my child has problems in reading or maths	11	30.6	13	36.1	12	33.3
12. My child is less clever because of his/her illness	1	2.8	5	13.9	30	83.3
13. My child may not find a job when he/she has leaves school	2	5.5	7	19.5	27	75.0
14. My child may have to take drugs for years	3	8.3	8	22.2	25	69.5
15. My child may not marry or have a family	2	5.5	6	16.7	28	77.8
16. My child makes a fuss about taking his/her drugs	-	-	7	19.5	29	80.5
17. Because of his/her illness, It difficult for him/her to use public transport	19	52.8	14	38.9	3	8.3
18. He/she is less able to care for him/herself	14	38.9	12	33.3	10	27.8
19. It is difficult to explain my child's illness to others	28	77.6	4	11.2	4	11.2
20. It is difficult to explain my child his/her own illness	14	38.9	10	27.8	12	33.3
21. Because of his/her illness, my child must be more closely watched than other children	9	25.0	17	47.3	10	27.7
22. It is difficult to give my other children enough attention	2	5.5	19	52.9	15	41.6
23. My child illness limits what his/her brothers and sisters can do	1	2.8	9	25.0	26	72.2
24. We have to limit our holidays	1	2.8	6	16.8	29	80.5
25. His /her illness means we have fewer friends around	2	5.5	8	22.2	26	72.3
26. My child illness influence how often we go out as a family	2	5.5	4	11.2	30	83.3
27. We have more arguments at home	1	2.8	12	33.3	23	63.9
28. We go out less often in the evening as a couple	1	2.8	4	11.2	31	86.0
29. My child is more difficult to manage because of his/her illness	5	13.9	11	30.6	20	55.5
30. Because of his/her illness we turn down opportunities at work	5	13.9	10	27.8	21	58.3

Table 4: Answers of fathers on importance.

Although impaired motor function is hallmark in CP, many children may experience also sensory, communicative, and intellectual impairments and may have complex limitations in self-care func-

tions as in many other neurodevelopmental pathologies^(7; 25-29).

Questions	RX	RY	(RX-RY) ²
1	2	6.5	20.25
2	2	6.5	20.25
3	2	6.5	20.25
4	7	6.5	0.25
5	7	6.5	0.25
6	7	6.5	0.25
7	7	6.5	0.25
8	7	6.5	0.25
9	7	6.5	0.25
10	7	6.5	0.25
11	21.57	6.5	227.10
12	21.57	6.5	227.10
13	21.57	15	43.16
14	21.57	15	43.16
15	21.57	15	43.16
16	21.57	15	43.16
17	21.57	15	43.16
18	21.57	24	5.90
19	21.57	24	5.90
20	21.57	24	5.90
21	21.57	24	5.90
22	21.57	24	5.90
23	21.57	24	5.90
24	21.57	24	5.90
25	21.57	24	5.90
26	21.57	24	5.90
27	21.57	24	5.90
28	21.57	24	5.90
29	21.57	24	5.90
30	21.57	24	5.90
Total	-	-	809.20
Rho	-	-	0.8

Table 5: Determination of Coefficient of rank correlation Spearman’s rho of mothers.

Questions	RX	RY	(RX-RY) ²
1	1.5	6	20.25
2	1.5	6	20.25
3	7.5	6	20.25
4	7.5	6	20.25
5	7.5	6	20.25
6	7.5	6	20.25
7	7.5	6	20.25
8	7.5	6	20.25
9	7.5	6	20.25
10	7.5	6	20.25
11	7.5	6	20.25
12	7.5	16.5	81.00
13	21.5	16.5	25.00
14	21.5	16.5	25.00
15	21.5	16.5	25.00
16	21.5	16.5	25.00
17	21.5	16.5	25.00
18	21.5	16.5	25.00
19	21.5	16.5	25.00
20	21.5	16.5	25.00
21	21.5	16.5	25.00
22	21.5	26	20.25
23	21.5	26	20.25
24	21.5	26	20.25
25	21.5	26	20.25
26	21.5	26	20.25
27	21.5	26	20.25
28	21.5	26	20.25
29	21.5	26	20.25
30	21.5	26	20.25
Total	-	-	711
Rho	-	-	0.6

Table 6: Determination Coefficient of rank correlation Spearman’s rho of fathers.

Although caregiving is a normal part of being the parent of a young child, this role takes on an entirely different significance when a child experiences functional limitations and possible long-term dependence⁽⁷⁾.

On the other hand, our findings show a higher average scores in mothers than fathers in subscales 2 and 4 or in the “Impact on the child” and “Family

impact on the organization” sub-items. This could be due to the fact that mothers are often the principal caregiver, particularly in Southern Italy Regions. In subscale “Impact on parents” the average score in mothers was the same with fathers; pinpointing that the experience of own son’s illness was analogous.

CP remarkably impact life of those affected and their families. For this reason it is important and necessary to direct attention not only type of the CP, but also the impact the disorder has on the child, parents, siblings and the entire family as a whole. Studies using the Impact of Childhood Illness Scale to investigate the effect of a child’s chronic and invalidating pathology on his/her parents have pointed out that these illnesses can influence not only the child’s development, but also the life of the entire family^(30,31).

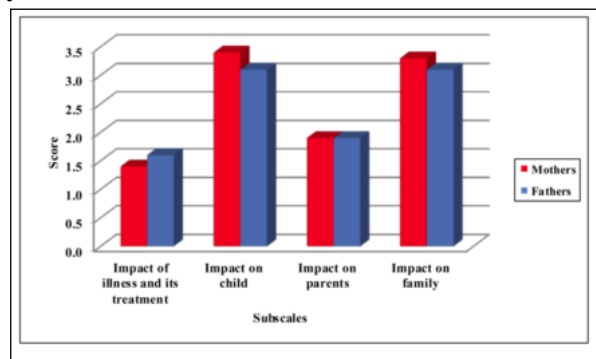


Figure 1: Average scores of the four subscales for the parameter of frequency.

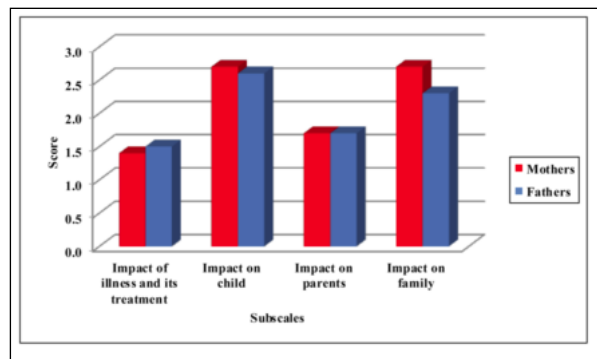


Figure 2: Average scores of the four subscales for the parameter of importance.

On the other hand, reported findings about the quality of life in children with CP are conflicting and different from Countries. In fact Bowling et al. in 2016, showed that children with CP QOL is quite good in Finland. However, barriers to participation and the impact of disability and pain impair QOL, greatly⁽³²⁾.

A study by Davis et al. (2010) showed that there was no difference in parental QOL among sub-groups (i.e. mothers and fathers, age groups, varying

levels of impairment). Caring for a child with CP affects a parent's physical well-being, social well-being, freedom and independence, family well-being and financial stability⁽⁸⁾. Parents indicated That Often they feel unsupported by the services they access⁽⁸⁾.

That fatigue levels of mothers with CP children are higher than those with healthy children and associated with depression and deterioration in QOL in terms of physical, social and emotional functioning⁽²²⁾. This should be considered while designing a family centered rehabilitation program for children affected by CP^(22,33).

Depression and anxiety mothers levels are higher than those with ones' healthy children such as in other disabling condition⁽³⁴⁻³⁶⁾.

The quality of life profile in mothers of children with CP is different from those who have a child with minor health problems. Different coping strategies and psychosocial programs must be designed and implemented to decrease the burden of care⁽³⁷⁾.

An analysis of the data showed that the child's illness and treatment weigh further on his/her development and adaptation. No significant differences emerged in the impact of the various different case histories or between fathers' and mothers' evaluations. The higher frequency of anxiety and level of concern among the mothers might be due to the fact that they look after their children more often than the fathers do^(25, 36, 38, 39).

In conclusion, results of the present study seem to support clinical required of biopsychosocial approach family/patients centered, not simply technical and short-term rehabilitation interventions focused on the child. In terms of prevention, providing parents with cognitive and behavioral strategies to manage their child's behaviors may have the potential to change caregiver health outcomes.

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