



Being adults with cerebral palsy: results of a multicenter Italian study on quality of life and participation

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Abstract

Cerebral palsy (CP) is still the most common cause of disability developing in infancy. How such a complex disorder affects adult life raises important questions on the critical issues to consider and the most appropriate care pathway right from early childhood. We conducted a multicenter study on a sample of 109 individuals with CP followed up from infancy and recalled for an assessment at ages ranging between 18 and 50 years (mean age 26 years). Semi-structured interviews and specific questionnaires (SF36, LIFE-H and Hollingshead Index) were conducted to assess general psychological state, quality of life, and socio-economic conditions. Our findings showed a globally positive perception of quality of life, albeit with lower scores for physical than for mental health. Our cases generally showed good scores on participation scales, though those with more severe forms scored lower on parameters such as mobility, autonomy, and self-care. These findings were investigated in more depth in interviews, in which our participants painted a picture showing that gradual improvements have been made in several aspects over the years, in the academic attainment and employment, for instance. On the downside, our sample reported persistent limitations on autonomy in daily life. As for the more profound psychological domain, there was evidence of suffering due to isolation and relational difficulties in most cases that had not emerged from the questionnaires. Our data have possible implications for the management of CP during childhood, suggesting the need to avoid an exclusive focus on motor function goals, and to promote strategies to facilitate communication, participation, autonomy, and social relations.

Keywords Cerebral palsy · Adulthood · Quality of life and participation

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Introduction

With a prevalence of approximately 2 per 1000 population, cerebral palsy (CP) is the most common cause of disability developing in infancy. Improvements in its treatment have generally meant that patients have nearly the same life expectancy as normal, and this raises crucial issues with the transition from childhood to adulthood [1, 2]. These issues concern various aspects of patient management [2, 3]. The available research has tended to focus exclusively on neuromotor skills [4], and on specific age groups or specific forms of CP, but there is clear evidence of individual profiles varying considerably [5].

It may be that we have yet to see the effects of the “latest” definition of outcome, based on the bio-psycho-social model promoted by the WHO’s International Classification of Functioning, Disability and Health [6, 7]. Such outcome definition is no longer confined to the context of a single function, but it is seen as the influence of various functions on the achievement of a greater autonomy, quality of life (QoL), and participation. Analyzing QoL can prove difficult, however, because of the diverse criteria used to define and measure it [8]. Moreover, there are no guidelines to facilitate the planning, continuity, and integration of the care provided for adults with CP [1].

An awareness of these shortcomings coincides with the need to investigate the natural history of CP and the effects of rehabilitation measures as fundamental links connecting patients’ initial assessment at an early age with studies on the most effective ways to assure them a continuity of care.

Despite these limitations, the few available studies seem to show that individuals with CP remain largely stable in terms of their various adaptive functioning and QoL over the years, despite a possible decline in some motor skills, especially in the more severe forms [4, 5]. The substantial continuity of problems with pain, fatigue, and psychological issues (especially depression [2, 9]) identified in childhood and adolescence has been acknowledged as important, but still little analyzed in any depth. There is a lack of data on patients’ personal and environmental features [10], and particularly on their family dynamics [10], which confirms yet again the need for a more holistic approach to their care already from childhood. In the light of these considerations, we report a multicenter study financed by Mariani Foundation conducted by sections of the Italian Network for Cerebral Palsy (ITA-NET-CP) on a sample of more than a hundred individuals with CP.

Methods

This multicenter observational study enrolled adults who had been diagnosed with spastic CP in infancy and followed up at Brescia, Firenze, Genova, Milano (3 centers), Napoli, Torino, and Viterbo sections of the ITA-NET-CP.

The study was approved by the Ethics Committee of all the centres involved.

The inclusion criteria were as follows:

- A confirmed diagnosis of spastic CP (according to the current definition, developed by Rosenbaum and an international team of experts) [11].
- Intelligence quotient (IQ) ≥ 70 .

For each participant, we collected the following:

- Principal clinical details.
- Level of severity (I best–V worst) according to the Gross Motor Function Classification System (GMFCS) [12] Manual Ability Classification System (MACS) [13], the Communication Function Classification System (CFCS) [14].
- Neuroradiological documentation classified in accordance with the Surveillance of Cerebral Palsy in Europe working group [15].

After receiving written informed consent, participants completed the following protocol:

- Specific questionnaires to assess:
 - (a) Quality of life: the SF-36 [16] measures 8 different aspects of quality of life (physical functioning, role-physical, pain index, general health perceptions, vitality, social functioning, role-emotional, mental health index) with standardized scores ranging from 0-worst to 100-best; two indexes measuring physical (Standardized Physical Component Scale) and mental (Standardized Mental Component Scale) health-related QoL, ranging from 0 to 100, can also be calculated.
 - (b) Participation: LIFE-H [17] measures participation in 11 different domains (nutrition, fitness, personal care, communication, housing, mobility, responsibilities, interpersonal relationships, community life, education/employment, recreation/leisure): the score ranges from 1 for maximum participation to 3 for no participation
 - (c) Socio-economic status (SES, Hollingshead index [18]) which incorporates parental educational attainment and occupational status (5 level in ascending orders).
- A semi-structured interview based on parameters agreed between the various centers and designed to obtain information concerning
 - (a) General state of health and aspects of daily life relating to their occupation, free time, and autonomy;
 - (b) Affective relations and capacity for self-observation of their inner world, investigating emotions, affections, and

feelings, such as anger, sadness, and happiness; in particular, questions were asked about whether participants experienced each of these three emotions in daily life, with what frequency (never, sometimes, often, always), and the main causes that triggered them.

The statistical analysis was performed on an anonymized dataset. The sample was described using mean with standard deviation for continuous variables, and counts and percentages for categorical variables. Continuous variables were compared between groups using the *t* test. Categorical variable was compared between groups using the chi-squared or the Fisher's exact test. All tests were two-tailed with a 5% significance level. Analyses were performed using the SAS statistical package (version 9.4, SAS Institute Inc, Cary, NC, USA).

Results

Features of the sample

The sample consisted of 109 subjects with CP (53 females) followed up since childhood and recalled for an assessment at an age between 18 and 50 (mean age 26 years; SD 7). The sample was classified according to the international classification [18] in unilateral (32%), and bilateral (68%: diplegic 34% and tetraplegic 34%).

Regarding clinical complications, 33% of participants had epilepsy which however was well controlled by therapy, 38% had cerebral visual impairments, and 84% had complications involving bone and joint, treated with orthosis, botulinum toxin injection, and pharmacological therapy but over the years necessitating surgery in 62% of the cases.

Neuroradiological findings were available for 85 cases (78%) and revealed subcortical lesions in 71% of cases (mainly periventricular leukomalacia), cortical-subcortical lesions or middle cerebral artery infarcts in 19%, non-specific signs in 6%, a normal picture in 3%, and one patient had an impaired neuronal proliferation/migration.

All socio-economic levels measured with the Hollingshead index were represented (Table 1).

From the neurofunctional standpoint, all patients were classified according to GMFCS, MACS, and CFCS (Graph 1). According to the GMFCS, 40 patients (36.7%) were level I, 21 (19.3%) were level II, 24 (22.0%) were level III, 11 (10.1%) were level IV, and 13 (11.9%) were level V.

Using the MACS, the level assigned was I for 33 patients (30.3%), II for 42 (38.5%), III for 21 (19.3%), IV for 7 (6.4%), and V for 6 (5.5%). As for the CFCS, 81 patients (74.3%) were level I, 14 (12.8%) were level II, 6 (5.5%) were level III, 3 (2.8%) were level IV, and 5 were level V (4.6%).

Table 1 Clinical details of the sample

Hemiplegia		32%
Forms	Diplegia	34%
	Tetraplegia	34%
Clinical details	Cerebral visual impairment	38%
	Epilepsy	33%
	Bone and joint problems	84%
	Orthopedic surgery	62%
Neuroradiological findings	(a) Malfomation	1%
	(b) White matter lesions	71%
	(c) Gray matter lesions	19%
	(d) Miscellaneous	6%
	(e) Normal	3%
Hollingshead Index	Level I	11%
	Level II	23%
	Level III	30%
	Level IV	21%
	Level V	15%

Our study findings confirmed generally good scores for participation (LIFE-H mean total score 1.3) (Table 2). The domain in which patients reported the greatest difficulty was mobility (mean 1.8), followed by self-care (mean 1.5). When participation was considered separately for unilateral and bilateral forms of CP, the latter were associated with worse scores for parameters such as mobility, autonomy, and self-care, while the two groups did not differ significantly in aspects such as communication, responsibility, community life, and interpersonal relations. A lesser participation was seen in the more severe forms (GMFCS and MACS levels IV–V), and interpersonal relations were most difficult for subjects with CFCS IV–V. Similarly, our participants seemed to have a globally positive perception of their QoL, as measured with the SF-36 questionnaire (Table 2). Mean scores for the items relating to role limitations due to poor physical health, pain, perceived state of general health, social activity, role limitations in the emotional sphere, and mental health were higher than 70, while the scores were lower for physical health (mean 55.4).

When unilateral and bilateral forms were compared, there were significant differences for “physical functioning” (mean scores of 41.1 for bilateral forms, and 82.2 for unilateral forms; $p < 0.0001$), and for perception of general health (mean 68.3 and 77.9, respectively; $p < 0.05$). There were differences in the perception of health in terms of the two summary scores for the physical and mental components (PCS and MCS): patients with bilateral CP scored lower on the PCS than on the MCS, while the MCS was lower than the PCS for patients with unilateral CP. This was despite no significant differences between the two group levels of GMFCS, MACS, or CFCS.

Table 2 LIFE-H and SF-36

	Mean	SD
LIFE-H domains		
1. Nutrition	1.4	0.6
2. Fitness	1.3	0.6
3. Personal care	1.5	0.7
4. Communication	1.3	0.6
5. Housing	1.4	0.7
6. Mobility	1.8	0.6
7. Responsibilities	1.3	0.6
8. Interpersonal relationships	1.1	0.3
9. Community life	1.1	0.8
10. Education/employment	1.4	0.7
11. Recreation/leisure	1.4	0.6
Total	1.3	0.5
SF-36 factor		
Physical functioning	55.4	35.8
Role-physical	83.7	30.3
Pain index	76.6	26.8
General health perceptions	71.6	22.2
Vitality	62.4	18.2
Social functioning	76.8	22.9
Role-emotional	78.0	36.1
Mental health index	71.8	17.8
Standardized physical component scale	45.6	11.9
Standardized mental component scale	50.9	11.0

The physical functioning factor was scored lowest by patients with the most severe gross motor dysfunction (GMFCS IV–V), and the important influence of pain on QoL was confirmed (Table 3).

Among clinical features, epilepsy or visual impairments were associated with a more limited participation, while complications affecting bone and joint and necessitating surgery were inversely associated with perceived QoL (Table 4).

The interviews were designed to enable a more “qualitative” investigation within a relational setting (Graph 1). In our sample, 32 participants (29.4%) had completed their schooling up to grade 8, while 55 (50.4%) had completed secondary school (up to grade 13), and 22 (20.2%) had a university degree.

As for their occupational status, 35 (32.1%) were employed, 37 (33.9%) were still studying, and 5 (4.6%) were attending socio-educational day centers. Most of the participants in employment had a milder clinical picture (GMFCS, MACS, and CFCS levels I–III). There was no significant difference between cases with unilateral as opposed to bilateral forms of CP, but there was a trend towards more individuals in employment having unilateral forms. In addition, no correlation with familiar SES was found.

In terms of their affective-relational life situations, 21 participants (19.3%) were in a stable affective relationship, and 4 of them (3.66%) were living with significant others. The remaining 88 (81.7%) were unattached. Almost all of our participants (96.33%) still lived with their family of origin, while 2 (1.83%) lived alone, and another 2 (1.83%) lived with friends.

The fundamental emotions investigated were anger, sadness, and happiness. Concerning anger, all reported experiencing this emotion to some degree, with the following distribution: 90 (82%) did so “sometimes,” 12 (11%) “often,” 4 (4%) “never,” (1) 1% “always,” and 2 (2%) gave no answer. Feelings of sadness were similarly distributed: 81 (74%) felt sad sometimes, 11 (10%) often, 11 (10%) never, 1 (1%) “rarely,” and 4 (4%) did not answer. As for happiness, this emotion was more evenly distributed: 48 participants (44%) were reportedly happy sometimes, and 50 (46%) often; the remainder were happy always in 7 cases (6%), never in 2 (2%), and 2 (2%) gave no answer.

Further analysis of answers revealed that anger and sadness mainly concerned the relational sphere, and particularly the scarcity of interpersonal relations. Anger was mainly associated with the sphere of disability in 37% of cases, and with that of relations in 53%. Sadness was mainly associated with the sphere of disability for 37% of participants, and with the relational sphere for 47%. Feelings of happiness were generally associated with a sense of physical and psychological well-being, and therefore more focused on the individual sphere. Happiness was experienced regarding the sphere of physical and psychological well-being in 50% of cases, and the relational sphere in 43%.

As for LIFE-H and SF-36 scores in relation to frequency of different feelings, most subjects reported feelings of sadness, anger, and happiness as sometimes present. As a consequence, statistical tests made to compare LIFE-H and SF-36 scores between different categories of frequency of each feeling were not sufficiently powered. In spite of this, a significant difference in the SF-36 standardized mental component was observed between subjects reporting different frequencies of happiness: the score was higher in those reporting to be always happy, followed by those reporting to be often happy and then by those who claimed to be sometimes happy. The worst score regarded those who said they were never happy. No other significant differences were observed.

Discussion

The use of an assessment that includes standardized questionnaires and semi-structured clinical interviews has contributed to a characterization of QoL and participation of Italian adults with CP.

Table 3 LIFE-H and SF-36: differences between bilateral and unilateral forms

	Bilateral		Unilateral		<i>p</i> value
	Media	Std. dev.	Media	Std. dev.	
Item LIFE-H					
1. Nutrition	1.5	0.6	1.1	0.4	< 0.0001
2. Fitness	1.4	0.6	1.1	0.3	0.0007
3. Personal care	1.7	0.8	1.2	0.5	0.0006
4. Communication	1.4	0.6	1.2	0.5	0.1287
5. Housing	1.6	0.7	1.2	0.4	< 0.0001
6. Mobility	2.0	0.6	1.4	0.5	< 0.0001
7. Responsibilities	1.4	0.7	1.2	0.4	0.0611
8. Interpersonal relationships	1.2	0.3	1.1	0.3	0.4724
9. Community life	1.2	0.8	0.8	0.7	0.0228
10. Education/employment	1.5	0.7	1.1	0.4	0.0026
11. Recreation/leisure	1.5	0.6	1.2	0.4	0.0007
Total	1.4	0.6	1.2	0.3	0.0038
Item SF-36					
Physical functioning	41.1	33.9	82.2	21.0	< 0.0001
Role-physical	82.0	34.1	86.8	21.5	0.3716
Pain index	73.9	28.9	81.5	22.1	0.1624
General health perceptions	68.3	24.3	77.9	16.2	0.0153
Vitality	63.0	17.8	61.1	19.2	0.6165
Social functioning	78.9	24.0	73.0	20.7	0.2062
Role-emotional	78.9	36.6	76.3	35.4	0.7260
Mental health index	71.5	17.2	72.2	18.4	0.8524
Physical component scale	41.9	12.0	52.3	8.0	< 0.0001
Mental component scale	52.9	10.8	47.1	10.5	0.0088

As for the SF-36 questionnaire

The influence of the severity of a motor impairment on QoL, and even what we mean by QoL, is an issue that is still the object of debate [8]. According to some, a severely limited

motor function is associated with a poor QoL [2], but others have found QoL only partially influenced by motor impairments [19, 20]. The literature is consistent, on the other hand, as concerns the role of pain, which has a negative effect on all aspects of QoL [2, 19, 20].

Table 4 Clinical features, LIFE-H, and SF-36 questionnaires

Clinical features	LIFE-H		SF-36		<i>p</i> value (difference between groups)
	Total score	<i>p</i> value (difference between groups)	Physical component scale	Mental component scale	
No epilepsy	1.2	0.006	46.7	50.5	0.144*
Epilepsy	1.5		43.2	51.7	0.590**
Not surgery	1.3	0.313	49.3	48.1	0.014*
Surgery	1.4		43.5	52.4	0.053**
No visual impairment	1.2	0.0007	47.1	49.8	0.236*
Cerebral visual impairment	1.5		42.2	51.8	0.878**

*Physical component scale

**Mental component scale

The results of SF-36 in our study generally indicated good scores, lower on the items relating to physical health, however, confirming the negative influence that physical disability can have in adult life.

One of the aspects not previously described in the literature and highlighted in our study is the difference between unilateral and bilateral forms: the individuals with bilateral forms of CP experienced a more severe impairment in their physical rather than in their mental health, whereas those with unilateral forms suffered more in terms of their mental health. This distinction persisted between the groups of subjects with higher and lower levels of GMFCS, MACS, and CFCS. A possible explanation for this picture lies in that individuals with bilateral forms of CP are likely to suffer to such an extent for their physical symptoms that they are not even conscious of their mental suffering. The significant difference identified between unilateral and bilateral forms for physical functioning and perception of general health was greater for the more severe forms, and was associated with the amount of pain experienced.

In confirmation of this, complications affecting bone and joint, severe enough to necessitate surgery, were inversely associated with perceived QoL (Table 4).

As for LIFE-H questionnaire

There is no general consensus on how much participation is influenced by more or less severe motor function impairment. There is a greater homogeneity of the data concerning the association between participation and intellectual disability or epilepsy [10, 21, 22].

The results in relation to LIFE-H questionnaire in our sample indicated that the level of participation was generally good but with lower scores in the case of epilepsy and more severe forms of CP, with greater difficulties in the areas of mobility and self-care.

We have also highlighted a reduced level of participation in patients with cerebral visual impairment confirming that these disorders must be integrated in a rehabilitation treatment in early childhood. In adult life, when educational supports come to an end, patients require specific social care.

As for the semi-structured interview

Our study showed a significant improvement in educational level over previous reports in Italy [23], in which any formal education had stopped at the end of primary school (grade 5) for a fairly high proportion of individuals with CP, and a small proportion had not been to school at all. In our sample, most participants had completed secondary school, a few had graduated from university, and a few had stopped going to school after completing grade 8. This improvement is presumably due to a greater attention to the inclusion of school-aged

children with disabilities in mainstream schools and to more personalized teaching programs.

Anyway, we could not confirm the same positive evolutions in relation to employment and autonomy of life. Among participants who had completed their studies, there was only a slightly higher proportion of those with a job than those who were unemployed. Individuals with a milder clinical picture (GMFCS, MACS, and CFCS levels I–III) were more likely to have a job. Some participants also reported, in line with literature data [24], that the jobs they were offered were not suited to their needs, or to their capabilities.

Moreover, almost all of our participants were still living with their families.

These findings highlighted the need to integrate rehabilitation efforts with the institutional, environmental, and social support to reduce those barriers that in Italy can prevent equal opportunities and full integration.

As concerns emotional domain, few studies have investigated the implications on QoL [25]. Recent research has shown, however, that adults with CP are at greater risk not only of anxiety and depression [9] but also of behavioral problems and difficult social relations [26].

Our semi-structured interview was designed as an attempt to shed light on the complexity of the human emotional experience of our participants. Our investigation concentrated on three fundamental emotions: anger, sadness, and happiness. The analysis of our results showed that anger and sadness were mostly associated with difficult and/or lack of interpersonal relations, rather than with physical disability, while happiness with perceived physical and psychological well-being. These results suggest that happiness is related to a more personal dimension of well-being, sadness and anger with difficulties in the interpersonal sphere.

The discrepancy in our results between questionnaire and the interviews on the topic of satisfactory interpersonal relationships can be explained by the fact that questionnaires often fail to grasp the complexity of relational-affective experience. They may also elicit more evasive responses in patients who are defensive or suffering. Our interviews, on the other hand, gave participants an opportunity to talk about their experiences related to the relational dimension, and their participation in a broader sense. The interviews also better captured the need of the participants to be heard, and the complexities of a time of life when partialized support interventions do not tend to consider the individual as a whole.

Conclusions

We think that the data offered by tools as questionnaires should always be associated with a deeper analysis of psychological and emotional dimensions. This could also guarantee a space where people could feel more cared for and understood.

As for our semi-structured interview, future studies could use more sensitive tools to assess the psychological factors and complexities of the inner world, as a step towards a better quality of care and to sustain a real social integration.

Moreover, the rehabilitative approach cannot but be multi-dimensional. Not only motor aspects must be taken into consideration, but also all the activities and strategies that can facilitate communication, participation, autonomy, and social relations, closely related aspects of a patient's overall well-being.

To ensure this, current rehabilitative practice in Italy is oriented to satisfy the immediate inclusion of the emotional dimension of the children and their parents. The rehabilitation program is the result of the continuous collaboration of the team of neurologists, therapists, and psychologists with the family and the child in line with a family-centered therapy [27].

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Compliance with ethical standards

Ethics approval and consent to participate

We confirm that we have given due consideration to the protection of intellectual property associated with this work and that there are no impediments to publication, including the timing of publication, with respect to intellectual property. In so doing we confirm that we have followed the regulations of our institutions concerning intellectual property. We confirm that we obtained consent by all the participants. We confirm that the manuscript has been read and approved by all named authors.

Conflict of interest The authors declare that they have no conflict of interest.

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