ORIGINALES

Quality of life in institutionalized adults with cerebral palsy
Calidad de vida en adultos institucionalizados con parálisis cerebral infantil

Laura Martínez-Traver[1]
Águeda Cervera Gasch[2]

[1] ASPROPACE Foundation, ASPROPACE day and residence center. Castellón de la Plana.Spain.
[2] Department of Nursing. Faculty of Health Sciences. Jaume I University. Castellón de la Plana. Spain.
cerveraa@uji.es

ABSTRACT:
Introduction: Cerebral palsy is considered a group of permanent developmental disorders that cause limitations in daily activity. One of the complications in people with cerebral palsy is the decrease in quality of life.
Objective: The objective of this study is to know the quality of life for institutionalized adults with infantile cerebral palsy and to know if there are differences in the quality of life index based on functional characteristics.
Method: Cross-sectional descriptive observational study in institutionalized adults with infantile cerebral palsy performed in the APCA and ASPROPACE centers between March and September 2017. The San Martín questionnaire was administered to measure the Quality of Life, Gross motor classification system, Barthel questionnaire, Scale CFCS to measure motor function, physical dependence, level of communication and relate them with sociodemographic and clinical variables. The selection of the participants was carried out by random stratified sampling. It was approved by the centers' addresses.
Results: Participants were 39 people with an average age of 32.54 years. The overall average score of the San Martin questionnaire was 102.97 points. The most affected dimensions were material well-being, personal development and social incluison. No statistical significance was obtained in the overall score of the questionnaire based on the secondary variables.
Conclusions: The results of this study have shown that the quality of life of adults with cerebral palsy in the subjects studied is good.

Key words: cerebral palsy, quality of life, motor skills, activities of daily living communication.

RESUMEN:
Introduccion: La parálisis cerebral es considerada como un grupo de trastornos permanentes del desarrollo que originan limitaciones en la actividad diaria. Una de las complicaciones en las personas con parálisis cerebral es la disminución de la calidad de vida.
Objetivo: El objetivo de este estudio es conocer la calidad de vida de las personas adultas institucionalizadas con parálisis cerebral infantil y conocer si existen diferencias en el índice de calidad de vida en función de las características funcionales.
Método: Estudio observacional descriptivo trasversal en personas adultas institucionalizas con parálisis cerebral infantil realizado en los centros APCA y ASPROPACE entre marzo y septiembre de 2017. Se

administró el cuestionario San Martín para medir la Calidad de Vida, Gross motor classification system, cuestionario Barthel, Escala CFCS para medir función motora, dependencia física, nivel de comunicación y relacionarlas con variables sociodemográficas y clínicas. La selección de los pariticipantes se llevó a cabo mediante un muestreo estratificado aleatorio. Se contó con la aprobación de las direcciones de los centros.

Resultados: Participaron 39 personas con edad media de 32,54 años. La puntuación media global del cuestionario San Martin fue de 102,97 puntos. Las dimensiones mas afectadas fueron bienestar material, desarrollo personal e incluison social. No se obtuvo significación estadística en la puntuación global del cuestionario en función de las variables secundarias.

Conclusiones: Los resultados de este estudio han demostrado que la Calidad de vida de adultos con parálisis cerebral en los sujetos estudiados es buena.

Palabras clave: Parálisis cerebral, calidad de vida destreza motora, actividades cotidianas, comunicación.

.

INTRODUCTION

Infant cerebral palsy (ICP) is no specific disease, but it is preferred to consider it a descriptive term for a group of motor disorders of brain origin that form part of development disabilities[1]. It is currently described as a group of permanent disorders in movement and postural development that lead to limitations in activity and can be attributed to nonprogressive alterations taking place in fetal brain development[2].

No unique criteria exist to define quality of life (QoL), but a general definition describes it as the perceived level of well-being that derives from evaluating what each person does with objective and subjective elements in their different life dimensions[3]. The World Health Organization (WHO) defines QoL as "*individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns*"[4].

People with significant disabilities form a heterogenous group and share different aspects, like depending on others to perform most of their activities of daily life (ADL). When communicating, they find that using self-report scales is very difficult. Therefore, QoL is measured mainly by reports provided by other people who know people with a significant disability very well [5].

Despite being a nonprogressive lesion, symptoms remain in adulthood, which implies consequences for functions and activities during growth[6]. In fact between 5 and 15 years after reaching adolescence or early adulthood, mobility notably diminishes, which implies reduced functional capacity[7], and changes occur that impact patients' QoL[2]. This impact means worse QoL due to physical problems, speech pathologies and mobility problems related to ADL [8].

The present study objectives were to know the QoL of adults with ICP using the San Martin Scale, and how it affects their level of dependence, and their level of communication and motor function, and to determine which aspects need to be promoted for adults with ICP to enjoy a better QoL.

Method

This observational descriptive study is based on analyzing QoL using the San Martin Scale.

The object study population comprised adults with ICP from the day centers and residential homes of the Foundations APCA and ASPROPACE in the Valencian Community (Spain). The study was conducted between March and September 2017.

Participants were selected by random stratified sampling, where strata corresponded to each center. Those people who did not wish to be included in the study and were periodically hospitalized in both day centers and residential homes did not form part of this study.

Sample size was calculated according to the total number of patients in the participating centers who met the inclusion criteria (N=59). According to the GRANMO program results, a random sample of 39 subjects was considered sufficient by taking into account a 95% confidence interval (95%CI), accuracy of +/-3 points and a standard deviation of 15 points over the overall San Martin questionnaire score. A 20% replacement percentage was considered.

In order to measure the main study variable, namely QoL, the validated San Martin scale was used(5). This scale allows the QoL of people with significant disabilities to be evaluated via informants who know these people well (for at least 3 months), and who have had the chance to observe them over long periods of time and in different contexts. The scale comprises 95 items written in the third person whose dimensions, number of items, score range and validity results are provided in Table 1.

Table 1. Dimensions and psychometric property of the questionnaire.

Dimension	No. items	Score range	Mean correlation
Self-determination	12	2-17	0.552
Emotional well-being	12	2-15	0.549
Physical well-being	12	2-15	0.444
Material well-being	12	2-14	0.515
Rights	12	2-15	0.448
Personal development	12	2-15	0.640
Social inclusion	12	2-16	0.544
Interpersonal relations	11	2-15	0.591
Overall	95	16-122	------

The secondary study variables were: level of physical dependence, level of communication, motor function. The included socio-demographic and clinical variables were: gender (man/woman), type of cerebral palsy (spastic/ataxic/dyskinetic/mixed), user type (day center/residential home), province (Castellón or Alicante) and age in years, followed by the classification by Martin. J.F. Subjects were classified as young adults aged 20-39 years/middle-aged adults aged 40-49 years/and mature adults as of the age of 50 years[9].

Physical dependence was measured by the Barthel Index,[10] a test with interobserver reliability and Kappa indices between 0.47 and 1.00, and intraobserver reliability with a Kappa index between 0.84 and 0.97. This index contains 10 domains that evaluate differently, and 0. 5. 10 or 15 points can be assigned. The total scale score may vary between 0 (completely dependent) and 100 (completely

The communication skill was measured with the Functional Communication Classification System (FCCS), which was designed to evaluate the skill of people with

cerebral palsy to communicate in different environments[11]. This scale has to be used by a professional who is familiar with someone's communication by selecting a communication performance level. This scale uses five levels to classify this skill.

Motor function was measured by nursing teams using the Gross Motor Function Classification System (GMFCS) scale, which comprises five levels [12]. It was initially created for infant populations but, with time, has also proven valid to classify adults. A Kappa coefficient of 0.75 was obtained in its validation study. This scale employs five levels to classify people, where level 1 represents greater independence in gross motor function, and level 5 indicates less independence.
All these scales were handed out by nursing staff.

A descriptive analysis was done of all the variables according to their nature. A distribution of frequencies and proportions was used for the categorical variables, while the analysis for the continuous variables was done by calculating the mean, median, standard deviation, and the minimum/maximum for all the variables and dimensions.

A bivariate analysis was done to determine if any differences existed in the means of the QoL index (QoLI) and its dimensions according to the secondary variables. For the main variable (QoLI) and its dimensions, a normality study was run using the Kolmogorov-Smirnov test. In those results in which no normal distribution of the variable was obtained, nonparametric tests were used (the Wilcoxon test to compare two means, and the Kruskal Wallis test to compare more than three means). In those variables in which normal distribution was obtained, the Levenne test was run to verify the equality or lack of equality of variances according to the secondary variable to be studied. Depending on the results, a t-test was run for the independent samples, or an ANOVA to compare three groups or more by taking equal or unequal variances depending on the Levenne test results.
The R Commander Statistical Package was used, and statistical significance was set at $p < 0.05$.

The project was designed in line with Organic Law 3/2018, of 5 December, [13] on Personal Data Protection, and the ethical considerations of the Declaration of Helsinki were respected.

Ethical principles of biomedical scientific research were respected according to Spanish law on data protection. The questionnaire did not include any personal data. To ensure that data remained confidential, all the information was coded using passwords. The project was authorized by the management of the APCA and ASPROPACE centers.

RESULTS

The sample included 39 participants (24 males, 15 females) aged between 20 and 56 years, whose mean age was 32.54 years (SD=8.61). Of all the participants, 16 belonged to a day center and 23 lived in a residential home. Regarding provinces, 14 came from Castellón and 25 from Alicante. For all the other secondary variables, the sample mean obtained for the Barthel Index was 16.41 (SD: ± 20.83; 95%CI: 0-70) points, with higher frequency (n=28) in the completely dependent group. Higher frequencies for the motor function and communication levels were obtained at levels 5

(n=27) and 3 (n=11), respectively (Table 2).

Table 2. Socio-demographic and clinical variables

Variable	Frequency	Percentage
Gender		
Male	24	61.54
Female	15	38.46
Paralysis type		
Spastic	2	5.13
Ataxic	0	0
Dyskinetic	0	0
Mixed	3	7.69
Not specified	34	87.18
User type		
Day centre	16	41.03
Residential home	23	58.97
Province		
Castellón	14	35.9
Alicante	25	64.1
Age (grouped)		
Young adult	31	79.49
Middle-aged adult	2	15.38
Mature adult	6	5.13
Barthel		
Complete dependence	28	71.79
Severe dependence	9	23.08
Moderate dependence	2	5.13
Motor function		
Level 1	1	2.56
Level 2	1	2.56
Level 3	4	10.26
Level 4	6	15.38
Level 5	27	69.23
Level of communication		
Level 1	3	7.69
Level 2	7	17.95
Level 3	11	28.21
Level 4	8	20.51
Level 5	10	25.64

The mean overall questionnaire score was 102.97 (SD± 9.07; 95%CI: 85-120) points. The worse scoring dimensions were: material well-being, with a mean of 9.53 (SD: ± 2.22; 95%CI: 4-14) points, personal development 9.79 (SD: ± 2.39; 95%CI: 5-15) and social inclusion 9.79 (SD: ± 2.51; 95%CI 5-18). Table 3 offers the analysis of each dimension.

Table 3. Descriptive analysis of the results obtained with the questionnaire.

	N	Mean	SD	Min.	Max.
QUALITY OF LIFE INDEX	39	102.97	9.07	85	120
Self-determination	39	11.58	2.73	6	15
Emotional well-being	39	10.84	1.78	6	15
Physical well-being	39	11.05	1.94	8	15
Material well-being	39	9.53	2.22	4	14
Rights	39	11.03	2.06	6	15
Personal development	39	9.79	2.39	5	15
Social inclusion	39	9.79	2.51	5	18
Interpersonal relations	39	10.51	2.21	6	15

Reading:
N= Number of surveyed people
SD= Standard deviation
Min= Minimum response value
Max= Maximum response value

Table 4 shows the comparison of the overall questionnaire means and all the dimensions according to the secondary variables.

Table 4. The statistical significance obtained when running the statistical QoLI tests and their dimensions according to the secondary variables

Variable	QoLI	Self-determination	Emotional well-being	Pysical well-being	Material well-being	Rights	Personal development	Social inclusion	Interpersonal relations
Gender	0.345[1]	0.114[1]	0.466[3]	0.872[3]	0.893[1]	0.755[3]	0.678[1]	0.403[3]	0.340[3]
Paralysis type	0.401[2]	0.954[2]	0.384[4]	0.384[4]	0.328[2]	0.384[4]	0.775[2]	0.644[4]	0.644[4]
User type	0.539[1]	0.593[1]	0.325[3]	0.284[3]	0.437[1]	0.311[3]	0.717[1]	0.212[3]	0.771[3]
Province	0.069[5]	0.070[1]	0.416[3]	**0.025**[3]	**0.036**[5]	0.071[3]	0.224[5]	0.030[3]	0.087[3]
Age group	0.376[2]	0.747[2]	0.402[4]	0.402[4]	0.608[6]	0.402[4]	0.061[2]	0,676[4]	0.676[4]
Barthel Group	0.698[2]	0.626[2]	0.712[4]	0.712[4]	0.945[2]	0.712[4]	0.115[2]	0,139[4]	0.435[4]
Motor function level	0.586[2]	0.574[2]	0.839[4]	0.999[4]	0.882[2]	0.274[4]	0.368[2]	0,163[4]	0.204[4]
Communication level	0.051[2]	**0.007**[2]	0.181[4]	0.181[4]	0.153[2]	0.181[4]	0.059[2]	0,241[4]	0.241[4]

Reading:

[1] T-test for independent samples by taking variances to be equal

[2] ANOVA by taking variances to be equal

[3] Wilcoxon test for two samples

4 Kruskal-Wallis test

[5] T-test for independent samples by taking variances to be unequal

[6] ANOVA by taking variances to be unequal

No statistical significance was found to state that there were any differences in the average overall questionnaire level according to the secondary variables. When all the questionnaire dimensions were analyzed according to the secondary variables, no statistical significance was observed to state that differences existed at the mean QoLI level and its dimensions depending on the physical dependence and motor function levels. The level of communication analysis found statistical evidence to confirm differences in the average self-determination level according to this variable (p value=0.00794) and when comparing the means by the ANOVA. A pairwise comparison of the means indicated that the differences in the self-determination mean were found among levels 1-2-3 or in relation to levels 4-5. Statistical significance was also observed to confirm that there were differences in the mean of physical well-being for province (p value=0.025). When the unilateral hypothesis verification was made, the mean obtained for physical well-being in the province of Alicante was lower than that obtained in the province of Castellón. In this variable, differences were also found for social inclusion depending on province (p value=0.030). For this aspect, a unilateral hypothesis verification was also made and the obtained mean for social inclusion in the province of Alicante was higher than that obtained in the province of Castellón.

DISCUSSION

The obtained results coincided with those reported by M. Badia-Corbella et al.,[4] who concluded that the QoL of patients with CP during the aging process was generally good. The results of the comparison made according to gender coincided with the results obtained in the study by Ross et al. [14] which compared QoL in adults with CP and found no statistically significant differences between males and females.

No statistically significant differences were found for the levels of QoL and physical dependence on the QoLI and its dimensions according to the obtained Barthel level and the motor function level. The present work demonstrated that, according to the GMFCS scale, no different scores were obtained for the QoLI and QoL dimensions.

This finding contrasted with the study carried out by Braccialli et al.,[15] who indicated that the severity of a motor disability affected the QoL of people with CP, but coincided with another study that found no statistical evidence for motor function affecting the QoLI in a sample of children with CP[16]

Statisically significant differences were found in QoL according to the communication level with the FCCS, which allowed us to state that the communication level on the FCCS affected the self- determination dimension because, for the people with communication levels I and II, there was sufficient statistical evidence to indicate that their self-determination results were better than those with communication levels III, IV and V according to the FCCS. Authors like M. Hickey and P. Moore concluded that one of the most affected QoL dimensions in adolescents with CP was social inclusion[17]. Another study by A. Colver, M. Rap et al.[18] also determined that the most affected dimensions in adolescents with CP were self-determination and social inclusion. The results of both these studies agree with those obtained herein.

The QoL dimensions on which the lowest mean scores were obtained were

personal development, social inclusion and material well-being. The study conducted by Park et al.[19] also found lower means for social inclusion, but the interpersonal relations dimension obtained a lower mean than the rest.

As this is a cross-sectional study, limitations appeared when recruiting samples, such as some centers not wishing to participate in the study. Moreover, its wide geographic distribution entails traveling far and making thorough follow-ups of data very difficult. We should also consider these results cautiously because the frequencies for some secondary variables were small with values with fewer than five people.

CONCLUSION

The results in this study demonstrate that QoL in adults with CP from APCA and ASPROPACE centers is generally good.

Some differences were found on the physical well-being and the social inclusion dimensions between provinces, and the self-determination dimension was affected in communication levels terms. The mean ages shows that the adult population with CP is young. One need emerged, that of improving communication in people who obtained higher FCCS levels in an attempt to increase their self-determination levels. Another observation was that the centers in the province of Castellón must focus part of their work on enhancing social inclusion, while those in the province of Alicante must work the emotional well-being dimension more.

REFERENCES

1. Gulati S, Sondhi V. Cerebral Palsy: An Overview. Indian J Pediatr. 2018 Nov;85(11):1006-1016. doi: 10.1007/s12098-017-2475-1. Disponible en: https://link.springer.com/article/10.1007%2Fs12098-017-2475-1
2. Wimalasundera N, Stevenson VL. Cerebral palsy. Pract Neurol. 2016 Jun;16(3):184-94. doi: 10.1136/practneurol-2015-001184. Disponible en: https://pn.bmj.com/content/16/3/184.long
3. Colver A, Rapp M, Eisemann N, Ehlinger V, Thyen U, Dickinson HO, Parkes J, Parkinson K, Nystrand M, Fauconnier J, Marcelli M, Michelsen SI, Arnaud C. Self-reported quality of life of adolescents with cerebral palsy: a cross-sectional and longitudinal analysis. Lancet. 2015 Feb 21;385(9969):705-16. doi: 10.1016/S0140-6736(14)61229-0. Disponible en https://www.sciencedirect.com/science/article/pii/S0140673614612290?via%3Dihub
4. Badía Corbella, M., Carrasco Trenado, J., Orgaz Baz, M. B., & Escalonilla García, J. M. (2018). Calidad de vida percibida por personas adultas con discapacidades del desarrollo versus la informada por profesionales Siglo Cero Rev Española sobre Discapac Intelect. 2016;47(1):7. Disponible en: http://revistas.usal.es/index.php/0210-1696/article/view/scero20161721
5. Verdugo MA, Gómez LE, Arias B, Navas P, Schalock RL. Measuring quality of life in people with intellectual and multiple disabilities: validation of the San Martín scale. Res Dev Disabil. 2014 Jan;35(1):75-86. doi:10.1016/j.ridd.2013.10.025. Disponible en: https://www.sciencedirect.com/science/article/pii/ S0891422213004691?via%3Dihub

6. Fabricio Espinoza Ortiz. Aproximacion Teorica Al Concepto De Calidad De Vida.2014;No14,2014:331–47. Disponible en: https://revistaselectronicas.ujaen.es/index.php/rae/article/view/1801/1559

7. Jiang B, Walstab J, Reid SM, Davis E, Reddihough D. Quality of life in Young adults with cerebral palsy. Disabil Health J. 2016 Oct;9(4):673-81. doi: 10.1016/j.dhjo.2016.04.006. Disponible en: https://www.sciencedirect.com/science/article/pii/S1936657416300450?via%3Dihub

8. Scherer R, Billinger M, Wagner J, Schwarz A, Hettich DT, Bolinger E, Lloria Garcia M, Navarro J, Müller-Putz G. Thought-based row-column scanning communication board for individuals with cerebral palsy. Ann Phys Rehabil Med. 2015 Feb;58(1):14-22. doi: 10.1016/j.rehab.2014.11.005. Disponible en: https://www.sciencedirect.com/science/article/pii/S1877065714018430?via%3Dihub

9. Martin J-F. Los factores definitorios de los grandes grupos de edad de la población: tipos, subgrupos y umbrales. Geo Crítica / Scripta Nova. Revista electrónica de geografía y ciencias sociales. Barcelona: Universidad de Barcelona. p. vol. IX, núm. 190. Disponible en: http://www.ub.edu/geocrit/sn/sn-190.htm

10. Cid-Ruzafa J, Damián-Moreno J. Valoración de la discapacidad física: el indice de Barthel. Rev Esp Salud Publica. 1997;71(1):127–37. Available from: http://scielo.isciii.es/scielo.php?script=sci_arttext&pid=S1135-57271997000200004

11. Compagnone E, Maniglio J, Camposeo S, Vespino T, Losito L, De Rinaldis M, et al. Functional classifications for cerebral palsy: Correlations between the gross motor function classification system (GMFCS), the manual ability classification system (MACS) and the communication function classification system (CFCS). Res Dev Disabil. 2014;35(11):2651–7. Disponible en: http://dx.doi.org/10.1016/j.ridd.2014.07.005.

12. Andrea E, Mejía C, Cristina A, Ávila Q, Milena D, Vidal D. Escala Gross Motor Function Measure . Una revisión de la literatura. 2014;2(8):11–21. Disponible en: https://www.researchgate.net/publication/304662448_Escala_Gross_Motor_Function_Measure_Una_revision_de_la_literatura

13. Ley Orgánica 3/2018, de 5 de diciembre, de Proteccion de Dato Personales y garantia de los derechos digitales. Disponible en: https://boe.es/diario_boe/txt.php?id=BOE-A-2018-16673

14. Ross SM, MacDonald M, Bigouette JP. Effects of strength training on mobility in adults with cerebral palsy: A systematic review. Disabil Health J. 2016 Jul;9(3):375-84. doi: 10.1016/j.dhjo.2016.04.005. Disponible en: https://www.sciencedirect.com/science/article/pii/S1936657416300449?via%3Dihub

15. Braccialli, L. M., Almeida, V. S., Sankako, A. N., Silva, M. Z., Braccialli, A. C., Carvalho, S. M., & Magalhães, A. T. (2016). Translation and validation of the Brazilian version of the Cerebral Palsy Quality of Life Questionnaire for Children–child report. *Jornal de pediatria*, *92*(2), 143-148. Disponible en: https://www.sciencedirect.com/science/article/pii/S0021755715001722?via%3Dihub

16. Pashmdarfard M, Amini M, Badv RS, Namazi NG, Rassafiani M. Does parent report gross motor function level of cerebral palsy children impact on the quality of life in these children? Iran J Child Neurol. 2017;11(4):52–7. Available from: https://www.ncbi.nlm.nih.gov/pubmed/29201124

17. Hickey M, Moore P. Quality of life in adolescents with cerebral palsy. Lancet [Internet]. 2015;385(9969):670–2. Available from: http://dx.doi.org/10.1016/S0140-6736(14)61599-3

18. Colver, A., Rapp, M., Eisemann, N., Ehlinger, V., Thyen, U., Dickinson, H. O., ... & Marcelli, M. (2015). Self-reported quality of life of adolescents with cerebral palsy: a cross-sectional and longitudinal analysis. *The Lancet*, *385*(9969), 705-716. Disponible

en:
https://www.sciencedirect.com/science/article/pii/S0140673614612290?via%3Dihub

19. Park TS, Dobbs MB, Cho J. Evidence Supporting Selective Dorsal Rhizotomy for Treatment of Spastic Cerebral Palsy. Cureus. 2018 Oct 19;10(10):e3466. doi:10.7759/cureus.3466. Disponible en: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6300384/