Revista Española de Cirugía Ortopédica y Traumatología 68 (2024) 57–63

Revista Española de Cirugía Ortopédica y Traumatología

www.elsevier.es/rot

ORIGINAL PAPER

Improving health-related quality of life in middle-age children with cerebral palsy following selective percutaneous myofascial lengthening and functional physiotherapy

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Received 3 June 2023; accepted 16 August 2023
Available online 7 September 2023

KEYWORDS
Cerebral palsy;
Functional physiotherapy;
Health-related quality of life;
Selective percutaneous myofascial lengthening

Abstract
Introduction and objectives: Children with cerebral palsy (CP) experience decreased health-related quality of life (HRQOL). This study aimed to assess the HRQOL of children with CP before versus after a combined program of minimally invasive selective percutaneous myofascial lengthening (SPML) and functional physiotherapy.
Material and methods: A single-group pre–posttest design was used. Twenty-six middle childhood children with spastic CP, aged 5–7 years, with Gross Motor Function Classification System levels II–IV underwent SPML surgery and 9 months of postoperative functional strength training therapy. The proxy version of the DISABKIDS-Smiley questionnaire was completed by one parent of each child. Dependent *t*-tests were used to compare mean pre- and post-measurement scores.

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https://doi.org/10.1016/j.recot.2023.08.018

Results: After the 9-month intervention, the children with CP had significantly higher quality of life scores (mean difference, 11.06 ± 9.05; 95% confidence interval [CI], 7.40–14.71; $p < 0.001$).
Conclusions: This study demonstrated that children with CP had better HRQOL after a combined program of minimally invasive SPML surgery and functional physiotherapy (ACTRN12618001535268).

PALABRAS CLAVE
Parálisis cerebral;
Fisioterapia funcional;
Calidad de vida relacionada con la salud;
Alargamiento miofascial percutáneo selectivo

Mejora de la calidad de vida relacionada con la salud en niños de mediana edad con parálisis cerebral después de un alargamiento miofascial percutáneo selectivo y fisioterapia funcional

Resumen
Introducción y objetivos: Los niños con parálisis cerebral (PC) experimentan una disminución de la calidad de vida relacionada con la salud (CVRS). El objetivo de este estudio fue evaluar la CVRS de niños con PC antes y después de un programa combinado de alargamiento miofascial percutáneo selectivo (SPML) y fisioterapia funcional.
Material y métodos: Se utilizó un diseño de un solo grupo con pretest y postest. Veintiséis niños de mediana edad (5 a 7 años) con PC espástica, niveles II-IV del sistema de la clasificación de la función motora gruesa se sometieron a cirugía SPML y fisioterapia de funcional posquirúrgica durante 9 meses. La versión proxy del cuestionario DISABKIDS-Smiley fue completada por uno de los padres de cada niño. Se realizaron pruebas t dependientes para comparar las puntuaciones medias previas y posteriores a la medición.
Resultados: Después de 9 meses de intervención, los niños con PC tenían puntuaciones de calidad de vida significativamente más altas desde el punto de vista estadístico (diferencia de medias: $11{,}06 \pm 9{,}05$; intervalo de confianza del 95%: 7,40-14,71; $p < 0{,}001$).
Conclusión: Este estudio demostró que los niños con PC presentaron una mejor CVRS después de un programa combinado de cirugía SPML y fisioterapia funcional.

Introduction

Cerebral palsy (CP), the most common cause of serious childhood physical disability and motor dysfunction, has a prevalence of around 1.6 per 1000 live births in high-income countries, including Greece.[1] Children with CP have a reduced health-related quality of life (HRQOL) secondary to neuromusculoskeletal and movement-related impairments, activity limitations, and participation restrictions.[2] HRQOL in childhood can be a multidimensional effect of a health condition and its treatment on a child's physical, mental, social, and behavioral components (well-being and function).[3,4]

HRQOL is increasingly used as a tool to provide an overview of a child's life, recognize every positive and negative aspect, monitor changes, and respond to treatment.[5] Although no theoretical framework exists to assess children's quality of life,[6] researchers[7] have investigated the suitability of the International Classification of Functioning, Disability, and Health (ICF) model for HRQOL. The ICF offers a conceptual framework that describes the dynamic interactions between body functions and structures, activities and participation, and personal and environmental factors, with each having an equal influence on health and function. All ICF components can potentially affect and contribute to changes in a child's HRQOL as the child grows and develops.[7] However, there is sufficient evidence that an individual's psychosocial–emotional well-being is not associated with their function[8,9] as defined by body function, structure, activity, and participation. Children with CP may have good psychosocial and emotional well-being despite poor function.[9] Therefore, HRQOL instruments should focus on psychosocial well-being and feelings rather than function or symptoms.[6,10]

Although quality of life, as a subjective concept, should be self-reported by an individual,[6] some children are unable to complete self-reported HRQOL questionnaires for a variety of reasons, such as young age (<8 years), developmental immaturity, condition severity, low cognitive ability, and limited communication skills.[6,11] In such cases, parent proxy questionnaires are valuable.[6,11]

There is little evidence to support the notion that multilevel orthopedic surgery improves HRQOL in children with CP, as they reported no clinically meaningful benefits.[12] Selective percutaneous myofascial lengthening (SPML) is a current minimally invasive trend in surgery that corrects shortness of the musculotendinous unit in children with CP.[13,14] SPML is a quick surgical technique, involving very small incisions without scarring, allowing a few hours hospital stay, immediate mobilization and full weight-bearing activities.[14] Besides, a key component for a successful multilevel orthopedic surgery is the implementation of a functional strengthening physiotherapy program rather than a child-passive intervention (e.g. original passive form of Bobath/NDT approach).[14,15]

Some evidence suggests the positive effects of SPML combined with functional physiotherapy on the gross motor ability of children with CP.[13,14] However, little is known about how minimally invasive SPML surgery affects the HRQOL of children with CP.[16] Therefore, this study aimed to assess the effectiveness of minimally invasive SPML surgery combined with 9 months of postoperative functional physiotherapy on the HRQOL of children with CP.

Material and methods

Study design

This was a single-group pre–posttest study of children enrolled in a non-randomized controlled trial protocol as the investigation group.[14] HRQOL measurements were collected before and 9 months after the SPML procedure and postoperative functional physiotherapy. The study was registered in a clinical trial registry and received approval from the authors' Institutional Review Board in accordance with the Declaration of Helsinki. Written informed consent was obtained from the parents of all children included in the study.

Participants

Twenty-six children with spastic CP were included in this study. All inclusion and exclusion criteria were previously published.[14] In summary, all children were 5–7 years of age with Gross Motor Function Classification (GMFCS) levels II–IV, with soft-tissue contractures and without or non-significant bony deformities (with no need for concomitant osteotomy). One child's parents was randomly selected and asked to complete a parent-reported version of the DISABKIDS-Smiley questionnaire. The same parents completed the baseline (pre-surgery) and 9-month (post-physiotherapy) follow-up questionnaires.

Intervention

The intervention was described in detail elsewhere[14] and is summarized here. Minimally invasive SPML surgery consisted of lengthening the medial hamstrings, hip adductors, and/or gastrocnemius muscles as indicated. Alcohol blocks (obturators and/or femoral nerves) were an essential part of minimally invasive SPML surgery in cases of excessive reflex-mediated stiffness during passive and active movement of the lower limbs. The alcohol blocks were done on 73% of participants ($n = 19$).[14] There was a specific orthotic protocol (solid ankle foot orthoses, knee immobilizers) following short-leg casting (if applied), which is described in detail in a previous paper.[14] Physiotherapy was started on an as-tolerated basis within a few hours after minimally invasive SPML surgery based on an intensive functional strength training program. The functional exercises and activities performed during a well-defined training protocol[14] were developed and adapted according to each child's individual needs and GMFCS level. The training frequency was 5–6 times per week for the first 6 weeks and then 2–3 times per week until the end of the 9-month postoperative period. The parents played an active role during physiotherapy to increase their child's ability to perform repetitive varied exercises and activities.

Instrument

The DISABKIDS-Smiley questionnaire (proxy version) was used with permission from the European DISABKIDS Group to assess HRQOL. It was developed as a part of the European DISABKIDS Research Program to create a cross-culturally valid tool to assess general health and well-being in children aged 4–7 years with chronic health conditions, including CP.[3] The questionnaire was developed and validated in seven European countries, including Greece, and is available in parental and self-reported forms.[4,17] The term ''smiley'' refers to the graphical distribution of the five-point Likert-like rating scale using facial icons (emoticons). Each facial icon represents a possible emotional status, ranging from an extremely sad face meaning ''very unhappy'' (score of 1) to the most smiley face meaning ''very happy'' (score of 5). The questionnaire includes six emotional statuses: (1) ''My child/I feel(s)...''; (2) ''When my child/I/go(es) to the doctor, he/she/I feel(s)...''; (3) ''When my child/I do(es) things on their/my own they/I feel...''; (4) ''About/him-/her-/myself my child/I feel(s)...''; (5) ''Kindergarten or school makes my child/me feel...''; and (6) ''When my child/I compare(s) him-/her-/myself to others, he/she/I feel(s)...''.[4]

The six emotional statuses explored the fluctuation of emotions regarding self-feeling (item 1), self-confidence (item 3), self-esteem (item 4), self-concept (item 6), and daily activities such as consulting with the doctor (item 2) and school attendance (item 5). The six items of the DISABKIDS-Smiley questionnaire identified three dimensions of physical, mental, and social well-being by covering the ICF categories related to (a) mental function in terms of temperament, energy, and drive; (b) execution of a task or action at school; and (c) environmental factors in terms of physical, social, and attitudinal environments.[18]

The DISABKIDS-Smiley questionnaire was scored by summing the items to compute a raw score (minimum, 6; maximum, 30) and converting it to a range of 0–100. Higher values indicate better functioning and well-being.[17] The completion time of the questionnaire is 2 min.[19] Parent- and child-reported DISABKIDS-Smiley questionnaires have been shown to be valid and reliable HRQOL measures for children with chronic diseases, including CP.[17] Compared to other HRQOL instruments, the DISABKIDS questionnaires provide more evidence of their psychometric properties in children with neurodisabilities.[20]

Statistical analysis

Dependent *t*-tests were conducted to compare the pre- and post-treatment total scores on the DISABKIDS-Smiley questionnaire. The non-parametric Wilcoxon signed-rank test

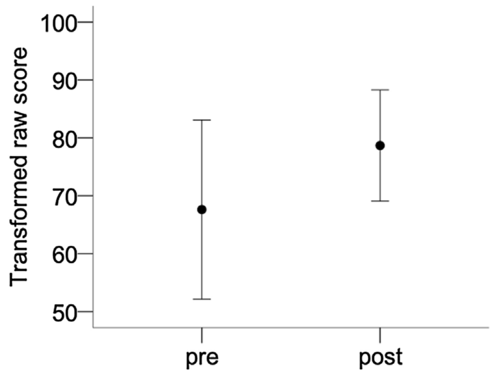

Figure 1 Parent-reported health-related quality of life in 5–7-year-old children with cerebral palsy before and 9 months after SPML surgery and functional physiotherapy, according to the DISABKIDS-Smiley questionnaire. Error-plot with means and standard deviations of the DISABKIDS-Smiley total 100-point scale scores.

was used to compare the pre- and post-treatment scores for each questionnaire item. The effects were considered significant at $p < 0.05$. All statistical analyses were performed using SPSS Statistics for Windows (version 26.0; IBM Corp., Armonk, NY, USA).

Results

Parents of all children with spastic CP (10 females, 16 males; mean age 6.15 ± 0.73 years; tetraplegia, $n = 11$; diplegia, $n = 13$; hemiplegia, $n = 2$; GMFCS level II, $n = 6$; GMFCS level III, $n = 12$; GMFCS level IV, $n = 8$) completed the DISABKIDS-Smiley questionnaire before and 9 months after their children received a combined program of SPML procedure and functional physiotherapy. Most questionnaires were completed by mothers ($n = 21$, 80%), while fathers completed 20% ($n = 5$).

A dependent t-test showed significantly higher quality of life scores on the DISABKIDS-Smiley questionnaire with the rate increasing from 67.63% to 78.69% ($p < 0.001$) (Fig. 1, Table 1). The quality of life scores were also significantly higher ($p < 0.05$) for each GMFCS level group as shown in Table 1.

By analyzing the values of each item of the DISABKIDS-Smiley questionnaire using the Wilcoxon signed-rank test, all the children had significantly better self-feeling (item 1, $p < 0.001$), higher self-concept (item 6, $p = 0.012$), greater self-esteem (item 4, $p = 0.002$), higher self-confidence (item 3, $p = 0.021$), better emotional status regarding consultation with the doctor (item 2, $p = 0.004$), and better school attendance (item 5, $p = 0.008$) (Table 2). An analysis of items in each GMFCS group revealed a blend of statistically significant and non-significant improvements among GMFCS groups for each item. In particular, children in each GMFCS level (II–IV) had significantly better self-feeling (item 1, $p < 0.05$); level III had significantly greater self-esteem (item 4, $p = 0.011$) and better emotional status regarding consultation with the doctor (item 2, $p = 0.025$); level IV had significantly higher self-confidence (item 3, $p = 0.025$).

Discussion

HRQOL instruments are increasingly being used as health outcome measures in relation to psychosocial–emotional well-being to evaluate treatment interventions for children with CP.[5,6] At the time of this writing, only one published abstract examined the HRQOL of 28 children with CP aged 4–12 years and 12 months after minimally invasive SPML surgery.[16] Using the Cerebral Palsy Quality of Life Questionnaire for Children answered by caregivers, Isidro et al.[16] reported statistically significant improvements ($p < 0.05$) in the ''Emotional well-being and self-esteem,'' ''Feelings about functioning,'' and ''Participation and physical health,'' domains but no significant changes in the ''Social well-being and acceptance,'' ''Access to services'' and ''Pain and impact of disability'' domains.

In the present study, the Greek parent proxy version of the DISABKIDS-Smiley questionnaire was used to examine the general health status and psychosocial–emotional well-being in young children aged 4–7 years with chronic health conditions, including CP. The DISABKIDS-Smiley questionnaire is among the most widely used instruments for evaluating HRQOL in young children as perceived by their parents.[21]

This study demonstrated that 5–7-year-old children with CP and GMFCS levels II–IV had significantly higher scores on the DISABKIDS-Smiley scale following minimally invasive SPML surgery combined with 9 months of functional physiotherapy. These results revealed the positive effect of this minimally invasive orthopedic surgery and rehabilitation protocol on general quality of life, reflecting the degrees of improvement in physical, psychosocial, and emotional well-being. Following the intervention, children demonstrated lower levels of psychological distress, more positive self-feelings, greater self-esteem, higher self-concept, and greater self-confidence. This psychological euphoria allows children to experience more emotions of joy about school, increasing their energy, driving actions, and activities. This improvement in quality of life seems to be related to the positive effects of this intervention on gross motor function in children with spastic CP,[14] as gross motor function has been shown to be a causal factor of HRQOL in school-aged children with spastic CP.[22]

The questionnaire in this study was completed by one of the parents of the participating children, with the largest percentage being mothers (80%), since mothers are, the researches show,[21,23–25] likely to be more available and willing to answer questions about their children. The use of a parent proxy questionnaire is considered the most appropriate and reliable option for evaluating HRQOL in children < 8 years of age.[11,21] Children aged 5–7 years do not yet have the linguistic and cognitive skills[11] to understand basic health-related concepts and terms.[26] Furthermore, children in this age group perceive time differently, have difficulty expressing their feeling, and tend to provide extreme answers, i.e. responding only with ''very happy'' or ''very unhappy'' on a series of five-point Likert-type scale of emoticons.[21,26] According to a validation study of the Japanese DISABKIDS-Smiley questionnaire, the parent-reported version had better reliability and validity than the

Table 1 Quality of life scores on the DISABKIDS-Smiley questionnaire by Gross Motor Function Classification System level.

GMFCS	*n*	Mean ± SD		Mean difference and 95% CI of the difference			
		Pre	Post	MD ± SD	LCL	UCL	*P*-value
II	6	65.97 ± 13.54	77.08 ± 12.00	−11.11 ± 8.19	−19.71	−2.51	0.021
III	12	65.28 ± 19.73	77.78 ± 10.71	−12.50 ± 11.65	−19.90	−5.10	0.003
IV	8	72.40 ± 8.60	81.25 ± 5.89	−8.85 ± 4.69	−12.78	−4.93	0.001
Total	26	67.63 ± 15.47	78.69 ± 9.60	−11.06 ± 9.05	−14.71	−7.40	<0.001

The values of scores are in the range of 0–100.
CI, confidence interval; GMFCS, Gross Motor Function Classification System; L/UCL, lower/upper confidence limit; *n*, number of participants; MD, mean difference between pre- and post-experimental measurements; SD, standard deviation.

Table 2 Pre-test and post-test changes in the 5-point Likert-scaled score of the parent-reported DISABKIDS-Smiley questionnaire for each item separately.

	Very happy	Happy	Ok	Unhappy	Very unhappy
1.	*My child feels...*				
Pre	6	11	7	2	
Post	14	10	2		
2.	*When my child goes to the doctor he/she feels...*				
Pre	1	1	23	1	
Post	2	8	16		
3.	*When my child does things on their own the feel...*				
Pre	12	10	3	1	
Post	18	5	3		
4.	*About him-/herself my child feels...*				
Pre	5	13	6	2	
Post	10	14	2		
5.	*School makes my child feel...*				
Pre	7	12	5	2	
Post	12	11	2	1	
6.	*When my child compared him-/herself to others he/she feels...*				
Pre	1	11	9	4	1
Post	3	14	9		

child-reported version.[24] There is also sufficient evidence to support the idea that parents and children agree well when reporting children's HRQOL.[23] This agreement was greatest between parents and children with chronic diseases compared to a healthy control group.[23] In a study of 12 children with CP (GMFCS levels I–III) aged 11–18 years (mean age, 14 years), Stephan-Carlier et al.[25] found a satisfactory correlation between parents' perceptions and their children's HRQOL (DISABKIDS CP Module, 8–16 years) following multilevel surgery.

Furthermore, only a few pre–posttest studies assessed HRQOL in children with CP following multilevel surgery. In 2007, Cuomo et al.[27] studied the effect of multilevel surgery on HRQOL progression in 57 ambulatory children with CP aged 4–18 years (mean age, 9.5 years) for the first time. The authors[27] reported a 17.6% improvement ($p < 0.001$) in the total HRQOL score on the parent version of the Pediatric Quality of Life Inventory (PedsQL).

Two years later, Gorton et al.[28] also using the parent-reported PedsQL, arrived at similar results when they compared surgical ($n = 75$) and non-surgical ($n = 75$) children with CP (GMFCS levels I–III) aged 4–18 years. In a randomized controlled trial, Thomason et al.[29] published in 2011, no significant ($p > 0.05$) intergroup differences were noted in the physical functioning and family cohesion domains of the Child Health Questionnaire Parent-Form 50 (CHQ-PF50) at 12 months after a multilevel surgery and physiotherapy strengthening program in children 6–12 years of age with spastic CP (GMFCS levels II–III). However, the authors found a significant ($p < 0.05$) intergroup difference in the psychosocial–emotional well-being of the CHQ-PF50 with a small deterioration of 5.8% in the surgical group ($n = 11$) and a 9% increase in the control group ($n = 8$) who underwent only the physiotherapy strengthening program.[29] This significant difference might seem attributable to the stresses of multilevel surgery and subsequent rehabilitation as well as to enhance self-esteem resulting from participation in a strength training program.[29] Hence, functional physiotherapy appears to promote HRQOL as shown in the conclusions of a recent study that demonstrated that

HRQOL (KIDSCREEN-52 Quality of Life Measure) significantly improved in the physical well-being ($p = 0.01$) and school environment ($p = 0.006$) domains after a 3-month intensive functional physiotherapy program among 31 children and adolescents with CP aged 12–18 years (mean age, 14.13 years).[30]

One possible limitation of this study is that the DISABKIDS-Smiley questionnaire assesses the general quality of life and well-being of young children aged 4–7 years and is not a specific CP quality of life outcome measure. However, the fact that this HRQOL measure focuses on well-being and feelings[17] rather than function and symptoms is an additional key criterion for confirming its suitability for use.[6] Another possible methodological limitation is the use of a single experimental group. Nevertheless, previous studies reported that measures of HRQOL remain fairly stable over many years among individuals with CP aged 1–24 years with a downward trend among children aged 5–8 years.[2] Therefore, this evidence explains and justifies the choice to use a single-group pre–posttest design.

Conclusions

In conclusion, this study demonstrated that middle-age children with CP and GMFCS levels II–IV presented better HRQOL after a combined minimally invasive SPML surgery and functional physiotherapy program. The children appeared to have better psychosomatic function and well-being, critical aspects of their participation in life situations. Future studies with larger sample sizes and follow-up measures for long-term outcomes could aid the further validation of our findings.

Level of evidence

Level of evidence IV.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Conflict of interest

The authors of article declare no conflict of interest.

Ethics Committee approval

Ethical Council of the 'Attikon' University General Hospital, Chaidari, Attica, Greece (EBΔ 2199/14-03-2017).

Acknowledgements

The authors gratefully acknowledge the parents and their children for their willingness to participate.

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