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# Quality of life and satisfaction after multilevel surgery in cerebral palsy: Confronting the experience of children and their parents

*Comparaison de la satisfaction et qualité de vie de l'enfant paralysé cérébral marchant et de sa famille après chirurgie multi-étagée*

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## Abstract

**Objectives.** – If the benefits of single-event multilevel surgery (SEMS) in ambulatory children with cerebral palsy have already been validated, especially in terms of functional outcomes, fewer studies have evaluated SEMS in terms of quality of life and satisfaction with surgical outcomes, especially pertaining to the opinions of children and their family. The objectives of this study were to confront the perceptions of parents and the experience of their operated children in terms of quality of life and surgical outcomes.

**Materials and methods.** – This was an observational, descriptive, single-center study conducted in a regional Pediatric Physical Medicine and Rehabilitation (PM&R) center, which is considered a reference center in this region of France. The subjects recruited were ambulatory children with cerebral palsy (CP) who had SEMS between 2009 and 2011, and one of their parents. The specific “child” and “parent” CP-related modules of the DISABKIDS questionnaire were used to assess these children’s quality of life post-surgery. Perceptions of parents and children regarding gait evolution and satisfaction with surgical outcomes were analyzed via a questionnaire developed by the author. Regarding quality of life and surgical outcomes, the correlation between the perception of parents and experience of children was estimated using the intraclass correlation coefficient (ICC) or prevalence-adjusted bias-adjusted kappa values (PABAK).

**Results.** – Twelve children (83% of them boys) and their parents participated in the study. For the DISABKIDS questionnaire, a moderate correlation was found regarding functional impact (ICC = 0.58;  $P < 0.0178$ ) but a high correlation was reported for the communication item of the questionnaire (ICC = 0.73;  $P = 0.0025$ ). Regarding satisfaction with surgical outcomes, results showed a good correlation (PABAK = 0.64).

**Conclusion.** – Concerning quality of life and satisfaction with surgical outcomes, our study showed a good or even high correlation between parents’ perceptions and their child’s experience. It is however essential to privilege the child’s opinion whenever possible.

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**Keywords:** Health-related quality of life; Satisfaction; Cerebral Palsy (CP); Ambulatory children; Single-event multilevel surgery (SEMS)

## Résumé

**Objectif.** – Alors que les bénéfices de la chirurgie multi-étagée chez l'enfant paralysé cérébral marchant sont connus notamment en termes de résultats fonctionnels, ils le sont moins en termes de qualité de vie et satisfaction vis-à-vis de ce type de chirurgie, notamment en prenant en compte à la fois le point de vue de l'enfant et du parent. L'objectif était d'évaluer le niveau de concordance entre la perception des parents et celles des enfants opérés, concernant la qualité de vie des enfants et la satisfaction après cette chirurgie.

**Matériels et méthodes.** – Étude observationnelle à visée descriptive monocentrique, réalisée dans un centre de médecine physique et de réadaptation pédiatrique de référence au niveau régional, auprès d'enfants paralysés cérébraux marchants ayant bénéficié d'une chirurgie

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multi-étagée entre 2009 et 2011, et un de leur parent. Les versions « enfant » et « parent » du module spécifique à la paralysie cérébrale (PC) du questionnaire DISABKIDS ont été utilisées pour évaluer la qualité de vie des enfants. La perception de l'évolution de la marche et la satisfaction après chirurgie a été évaluée par un questionnaire rédigé par l'auteur. La concordance parent–enfant a été estimée par le coefficient de corrélation intraclasse (CCI) ou le coefficient de kappa ajusté sur la prévalence (PABAK).

**Résultats.** – Douze enfants (83 % de garçons) et leur parent ont participé. Une concordance modérée entre les réponses des parents et des enfants au DISABKIDS était retrouvée pour le domaine impact fonctionnel (CCI = 0,58 ;  $p < 0,0178$ ) et importante pour le domaine communication (CCI = 0,73 ;  $p = 0,0025$ ). Concernant la satisfaction, la concordance était jugée bonne (PABAK = 0,64).

**Conclusion.** – En ce qui concerne l'évaluation de la qualité de vie et la satisfaction, un bon, voire excellent niveau de concordance parent–enfant était observé. Il est important de considérer l'avis des enfants aussi souvent que possible.

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**Mots clés :** Qualité de vie ; Satisfaction ; Paralysie cérébrale (PC) ; Enfants marchants ; Chirurgie multi-étagée

## 1. English version

### 1.1. Introduction

The prevalence of cerebral palsy (CP) ranges between 1.7 and 2.5 per 1000 live births in European and North American countries [1]. This chronic pathology leads to frequent motor disabilities, especially severe gait impairments.

Initially, the child presents with a normal musculoskeletal system and non-progressive but irreversible brain damage. The consequences of this brain damage, called “primary impairments”, consist of several symptoms, such as loss of muscle tone, motor control and balance disorders, as well as spasticity (in most types of CP). Later on, muscle and tendon contractions and impairments of the musculoskeletal system appear. “Secondary impairments” are caused by abnormal mechanical stimulations imposed on a growing musculoskeletal system [2,3]. Children try to walk in spite of their primary and/or secondary structural and dynamic impairments. The prevention and treatment of these impairments are based on physical therapy, medical treatment, orthotics, injections of botulinum toxin and surgery.

Surgical management for CP, including tendon lengthening and/or transfers, derotational osteotomy or joint stabilization, has always had a functional improvement objective. For a long time, it has been performed in a limited and successive manner in fear of doing too many surgical procedures that would yield to irreversible consequences [4].

Recently, single-level surgery has been replaced by the concept of multilevel surgery consisting of two teams operating simultaneously on both of the patient's lower limbs during one single surgical procedure; thus, requiring only one hospitalization and one post-surgical rehabilitation stay.

The effectiveness of multilevel surgery has been validated in several studies, which have underlined the reduced number and total duration of hospitalizations during childhood, improvement in gait parameters, joint range of movement, decreased energy cost when walking, as well as improvement in functional abilities evaluated via the Gross Motor Function Measure (GMFM) [5–12].

Numerous studies lately have been focusing on assessing the functional results of this surgery, however, very few studies

have evaluated the quality of life and satisfaction after this type of surgery. One should underline that the opinion of children is rarely studied in today's literature.

The main objective of this study was to evaluate the correlation between the perception of parents and experience of children regarding quality of life and satisfaction with multilevel surgical outcomes. The secondary objective was to describe the perception of children regarding the evolution of their general state and most specifically gait abilities.

### 1.2. Material and methods

#### 1.2.1. Study design

Descriptive, observational, single-center study conducted in a Pediatric Physical Medicine and Rehabilitation (PM&R) center of reference. Recruited subjects were ambulatory children with cerebral palsy who had multilevel surgery. The evaluation was done based on self-assessment questionnaire and semi-directed interviews. This study was approved by the local Ethics committee and all parents signed an informed consent form before study inclusion.

#### 1.2.2. Characteristics of the studied population

The following inclusion criteria for the study were:

- children diagnosed with cerebral palsy and ambulatory capacities [Gross Motor Function Classification Scale (GMFCS) I to III];
- children aged < 18 years old at the time of surgery;
- children who had multilevel surgery in the Lorraine regional university hospital center between 2009 and 2011. To be defined as multilevel surgery, the procedure had to include in a single surgical procedure at least two muscle–tendon (lengthening or transfer) or bone surgical gestures on one or two limbs;
- children who spent their post-surgical rehabilitation in the regional reference PM&R center of Lorraine, France.

Exclusion criteria were children with mild intellectual disability (intelligence quotient below 70), as well as children and/or parents who refused to participate to the study.

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