



# Impact of Orthopedic Surgery on Parents of Children Affected by Cerebral Palsy: a Preliminary Study in Greece

Assimina Tsibidaki<sup>1</sup>, Haridimos Tsibidakis<sup>2</sup>, Anastasia Tsamparli<sup>1</sup>, Doxa Kotzia<sup>3</sup>, Artemisia Panou<sup>4</sup>

<sup>1</sup> Department of Primary Education, University of the Aegean, Greece

<sup>2</sup> Department of Orthopaedics and Ilizarov Unit, A. Manzoni Hospital, Lecco, Italy

<sup>3</sup> Department of Paediatric Respiratory Medicine and Lung Transplantation, Great Ormond Street Hospital, United Kingdom

<sup>4</sup> Department of Orthopaedics, Pediatrics and Neuro-orthopaedics, Humanitas Research Hospital, Rozzano (Milan), Italy

**Corresponding author:** Artemisia Panou, Department of Orthopaedics, Pediatrics and Neuro-orthopaedics, Humanitas Research Hospital, 56 Manzoni St., 20089 Rozzano (Milan), Italy; E-mail: artemisia.panou@humanitas.it; Tel: 00393453304077

**Received:** 25 Jan 2019 ♦ **Accepted:** 27 Feb 2019 ♦ **Published:** 30 Sep 2019

**Citation:** Tsibidaki A, Tsibidakis H, Tsamparli A, Kotzia D, Panou A. The impact of orthopedic surgery on parents of children affected by cerebral palsy: a preliminary study in Greece. *Folia Med (Plovdiv)* 2019;61(3):384-8. doi: 10.3897/folmed.61.e39344

**Background:** Cerebral palsy (CP) is a serious disorder with an important impact not only on the affected person but also on parents and the entire family. CP children often undergo surgery with long stay hospitalization.

**Aim:** The aim of the study was to highlight the impact of orthopedic surgery on parents of children affected by cerebral palsy in Greece.

**Materials and methods:** The semi-structured interviews of 80 parents (40 fathers and 40 mothers) of nuclear and intact families were collected. All parents were of Greek nationality, belonged to the middle socio-economic class and had at least one child affected by CP candidate to orthopedic surgery.

**Results:** The majority of parents' perception was that CP is a condition requiring special education, need for specialized services and a medical problem that affects the entire family. Their expectations after orthopedic surgery were focused mainly on child's healing and hope to have a "healthy" child, while expectations from future surgery were focused on improving child's quality of life, movement and gait.

**Conclusions:** Parents of CP children have different perceptions of the clinical condition and a variety of expectations about orthopedic surgery and its outcomes.

## Key words:

cerebral palsy, parents, Greece, orthopedic surgery

## INTRODUCTION

Cerebral palsy (CP) is the most common chronic disorder. Although great effort was made by different Greek researchers to determine its prevalence, no evidence has still been found. However, prevalence in Greece seems to range between 1.7 and 2.5 per 1000 live births as reported

in North America and Europe.<sup>1</sup> Severe gait impairments are the main characteristics associated to sensory, intellectual and communication deficits and complex limitations in self-care functions. CP is a serious disorder with a great impact on affected person's life, family's life, society and public services as represents a chronic and complex condition associated to high economical healthcare costs.<sup>2-6</sup> Be-

ing parents of CP child constitutes an additional challenge in family's daily life and requires further skills to effectively deal with all daily issues.<sup>4,5</sup>

CP children are often hospitalized during growth with necessity of longer stays and higher levels of care than other children without disabilities.<sup>6-9</sup> Having a child with disability in the hospital is a major source of stress for a family, and the child's disease and hospitalization increase the level of anxiety and insecurity on parents.<sup>10,11</sup> Immobility in a non-familiar and uncomfortable environment makes parents more vulnerable and the preoperative period may lead to anxiety associated with type of surgery, potential risks and outcomes.<sup>11</sup> However, parents discover that they are able to adapt and to adjust to new conditions, especially in situations where they are well supported.<sup>5</sup>

Different orthopedic surgical treatments are usually performed during growth in CP children to correct musculo-skeletal deformities, improving gait, functional abilities, sitting balance and perineal care and the perioperative period can be very challenging.

The aim of our pilot study was to highlight the impact of orthopedic surgery on parents of children affected by cerebral palsy in Greece.

## MATERIALS AND METHODS

Interviews of 80 parents of CP children belonging to nuclear and intact families were included in the study. Mean age for fathers was 44.2 yrs (SD =7.6; range: 30-58 yrs) and 40 yrs for mothers (SD=7; range: 25-55 yrs). All parents were Greek and belonged to the middle social-economic class. Each family had at least one CP child candidate for orthopedic surgery. Of 40 CP children, 24 were males (65%) and 16 females (35%), with a mean age at surgery of 8.3 yrs (SD=2.6; range 4-12 yrs). According to the GMFCS<sup>12</sup> all patients were classified as GMFCS V and underwent bilateral multilevel muscle tendon lengthening of the lower limbs at the same hospital. GMFCS V children were included in the study as disability is greater with other concomitant diseases that make their management extremely challenging for the entire family.

Voluntary participation, anonymity and informed written consent were obtained and the regional Hospital's Committee for Medical Research Ethics approved the pilot study.

Individual semi-structured but focused interviews were conducted orally during recovery for orthopedic surgery, to ensure that all parents had the same opportunity to express their individual perspectives and answer questions without any distraction and/or interruption, allowing better evaluation of their emotional status. Parents provided basic descriptive information about themselves, their child and their family. Interviews were conducted using an interview guide (constructed by researchers) that contained questions addressing on how parents describe the CP condition, their perceptions/expectations for each type of surgery and for further and future need of orthopedic surgery. Examples of

questions included: "How would you describe your family?", "Could you describe a typical day of your family?", "According to your opinion, how would you characterize the condition of CP?", "What are your expectations after your child's operation?", "What do you expect from the on-going orthopaedic surgery?"

The interviews lasted from 1.5 to 2 hours and were tape-recorded. The first author transcribed verbatim and wrote down the themes arising after reading each interview text. The key phrases were obtained counting their frequency from the transcribed interviews and then, collected and formulated into categories: representation/perception of CP, perception/expectation for orthopedic surgery's outcome, and their expectations for further, future need of orthopedic surgery.

Reliability was established by an independent researcher (family therapist) that reviewed the scripts again and re-evaluated the themes formulated by the researchers to ensure coherence with the scripts and to identify possible inconsistencies and/or omissions.

The frequency of parents' answers was recorded using the SPSS17 software and a descriptive interpretive approach within a pragmatic perspective was used during analysis to obtain results.

## RESULTS

**Table 1** shows the parents' perception/representation of CP results. The majority of the parents (40%,) reported that CP requires special education and supportive services. Characteristically, a father said: "Basically, it's a condition requiring constant monitoring, both medical and educational, social supportive services, which are not available in Greece". Other parents described CP predominately as a medical problem that affects the entire family (28.8%) or mainly the child (6.3%). Moreover, a mother said: "What does CP means? It is clearly a medical problem in which you must constantly see doctors and be in and out of hospitals and treatments". Furthermore, 28.7% of parents reported that CP is a very difficult social and cultural condition created by unfriendly environments and by the attitudes of other people outside the family

Results of parents' perceptions after orthopedic surgery outcomes are reported in **Table 2**. The majority of these (57.5%) perceived that surgery would change child's life bringing to healing and consequent change to a "healthier" child. Additionally, 22.5% of parents reported that the aim of surgery was to improve child's daily living conditions, while 17.5% considered orthopedic surgery as palliative treatment to prevent future child's deterioration. Only the 2.5% of the parents reported that orthopedic surgery represents one medical problem less for their child.

Results of parents' expectations on further, future need of orthopedic surgery are reported in **Table 3**. Seventy percent reported that future orthopedic surgery is focused mainly on improving child's quality of life, movement and gait. A

**Table 1.** Parents' representation/perception of cerebral palsy (n: number)

Representation of cerebral palsy	Father		Mother		Total	
	n	%	n	%	n	%
A condition requiring special education and support services	16	20	16	20	32	40
A medical problem that affects the whole family	11	13.8	12	15	23	28.8
A social and cultural condition created by unfriendly environments or the attitudes of other people outside the family	10	12.5	10	12.5	20	25
A medical problem that mainly affects the child	3	3.8	2	2.5	5	6.3

**Table 2.** Parents' expectations after orthopedic surgery (n: number)

Expectations after each operation	Father		Mother		Total	
	n	%	n	%	n	%
An operation will change the child's life and stimulate other children	22	27.5	24	30	46	57.5
An operation will improve the daily living conditions of the child with CP	10	12.5	8	10	18	22.5
An operation constitutes a palliative care	7	8.75	7	8.75	14	17.5
An operation represents one medical problem less for the child	1	1.25	1	1.25	2	2.5

**Table 3.** Parents' expectations on further, future need of orthopedic surgery outcomes (n: number)

	Father		Mother		Total	
	n	%	n	%	n	%
Orthopedic surgery will improve the child's quality of life and their movement and gait.	28	35	28	35	56	70
Orthopedic surgery will improve the conditions of child's daily care	8	10	8	10	16	20
Orthopedic surgery is only one of the many surgeries which a child with CP needs	4	5	4	5	8	10

mother said characteristically: "We hope that our child's life will change. We expect to see him improving his movement and gait.... I believe this is the main thing". A lower percentage (20%) reported that orthopedic surgery would improve child's daily care, while 10% affirmed that orthopedic surgery is only one of the various types of surgery necessary to be performed during child's life.

## DISCUSSION

Cerebral palsy is the most common cause of motor impairment in children and, often, surgery is necessary to adjust not only muscle-skeletal deformities caused by spasticity, but, also other health problem requiring different professional figures of different specializations.<sup>13-15</sup> CP children are continuously under medical treatment and often sur-

gery is necessary during their growth and medicine, nursing and rehabilitation have an important role on CP children management.<sup>14,15</sup>

The long-term family impact after the birth of a disabled child has been already described, but research on the impact of orthopedic surgery on parents of cerebral palsy is scanty. The aim of the study was to highlight the impact of orthopedic surgery on parents of CP children in Greece using data obtained by interviews which are a rich means of gathering information from families<sup>16</sup> containing questions addressing how parents describe CP, their perception and their expectations after orthopedic surgery.

Cerebral palsy is a unique condition experienced by the entire family and the affected child. Our data showed that parents mainly perceive CP as a condition that requires special education and supportive services.

Expectations after orthopedic surgery are focused most-

ly on the child's healing hoping that the child would become "healthy", focusing on how surgery "changes his/her life ... to become just like all other children", improving child's quality of life, movement and gait. Surgery gives families the hope of a "healthy child" which represents the main CP parents' desire. Parents often demonstrate unrealistic expectations expressing their hope/desire to achieve full rehabilitation on all children's lives levels after surgery. This hope/desire may help parents to handle better anxiety<sup>17</sup>, but on the other hand increases hope and expectations for surgery outcomes, which always include high risks and complications. On the other hand, some parents seem to have more realistic hopes and expectations considering orthopedic surgery as a palliative care, aiming to prevent child's future deterioration.

According to the expectations after orthopedic surgery our results highlighted the finding that the majority of parent's expectations are focused basically on improving child's quality of life, improving his/her movements and gait. Parents raising a child with CP have moderate hopes and many concerns about surgical complications and functional outcomes. However, the hope of functional outcome is higher and they still expect that their child will become "normal". Our results suggest that child's age at surgery seems to influence CP parent's expectations as higher expectations regarding surgical outcomes are present when CP child is young, while in the case of older children, parents expectations seem to be limited to a functional child's mobility improvement. Parents' adjustment to child's care and their expectations during growth has already been reported in other studies.<sup>18</sup> Probably, over time, integration of the moaning process caused by being parents of a CP child occurs and parents begin to accept reality, focusing on the real clinical picture, limiting their expectations on child's functional mobility improvement for his/her everyday needs.

Nowadays, parents are more familiar with orthopedic surgical procedures and they are well informed about child's medical conditions and surgical procedures. Moreover, parents show positive and optimistic attitudes in all medical figures involved with the care and treatment of a CP child.<sup>19,20</sup> In addition, positive perception can also be considered as a factor that improves the effect of a child's disability on family balance.<sup>21</sup>

## CONCLUSION

Knowledge of the impact of orthopedic surgery on parents of CP can provide useful recommendations/information which can facilitate family-provider collaboration for goal setting and intervention planning and management. Further research is mandatory to better understand the impact of different types of surgery (orthopedic and not) on parents' of CP children, their perception/expectations after surgery, its outcomes and for future need of surgery.

## REFERENCES

1. Rosenbaum P. Cerebral palsy: What parents and doctors want to know. *BMJ* 2003; 326(7396): 970-4.
2. O'Shea TM. Diagnosis, treatment, and prevention of cerebral palsy. *Clin Obstet Gynecol* 2008; 51: 816-28.
3. Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl* 2007; 109: 8-14.
4. Magill-Evans J, Darrah J, Pain K, et al. Are families with adolescents and young adults with cerebral palsy the same as other families? *Dev Med Child Neurol Suppl* 2001; 43(7): 466-72.
5. Iversen AS, Graue M, Clare J. Parents' perspectives of surgery for a child who has cerebral palsy. *J Pediatr Health Care* 2009; 23: 165-72.
6. Murphy NA, Hoff C, Jorgensen T, et al. Costs and complications of hospitalization for children with cerebral palsy. *Pediatr Rehabil* 2006; 9: 47-52.
7. Newacheck PW, Inkelas M, Kim SE. Health services use and health care expenditures for children with disabilities. *Pediatrics* 2004; 114: 79-85.
8. Young NL, Gilbert TK, McCormick A, et al. Youth and young adults with cerebral palsy: Their use of physician and hospital services. *Arch Phys Med Rehabil* 2007; 88: 696-702.
9. Young NL, McCormick AM, Gilbert T, et al. Reasons for hospital admissions among youth and young adults with cerebral palsy. *Arch Phys Med Rehabil* 2011; 92: 46-50.
10. Kerper, LF, Spies, CD, Löbner M, et al. Persistence of psychological distress in surgical patients with interest in psychotherapy: Results of a 6-month follow-up. *PLoSOne* 2012; 7: e51167.
11. Hopia H, Tomlinson P, Paavilainen E, et al. Child in hospital: Family experiences and expectations of how nurses can promote family health. *JCN* 2005; 4(2): 212-22.
12. Morris C, Bartlett D. Gross motor function classification system: impact and utility. *Dev Med Child Neurol*. 2004; 46(1): 60-5.
13. Almasri NA, O'Neil M, Palisano RJ. Predictors of needs for families of children with cerebral palsy. *Disabil Rehabilitation* 2014; 36(3): 210-9.
14. Rentinck ICM, Ketelaar M, Jongmans MJ, et al. Parents of children with cerebral palsy: A review of factors related to the process of adaptation. *Child Care Health Dev* 2007; 33: 161-9.
15. Rentinck ICM. Parental adaptation in families of young children with cerebral palsy. Utrecht University; 2009.
16. Beitin, B. Qualitative research in marriage and family therapy: Who is in the interview? *Contemp Fam Ther* 2008; 30: 48-58.
17. Horton-Vensters T, Wallander JL. Hope and social support as resilience factors against psychological distress of mothers who care for children with chronic physical conditions. *Rehabil Psychol* 2001; 46: 382-99.
18. Whittingham K, Sheffield J, Boyd RN. Parenting acceptance and commitment therapy: A randomised controlled trial of an innovative online course for families of children with cerebral palsy. *Child Care Health Dev* 2016; 33(2): 161-9.
19. Guyard A, Michelsen SI, Arnaud C, et al. Family adaptation to cerebral palsy in adolescents: A European multicenter study. *Res Dev Disabil* 2017; 61: 138-50.
20. Lin S. Coping and adaptation in families of children with cerebral palsy. *J Except Child* 2000; 66(2): 201-18.
21. Folkman S, Moskowitz JT. Positive affect and the other side of coping. *Am Psychol* 2000; 55(6): 647-54.

## Воздействие ортопедических операций на родителей детей, страдающих церебральным параличом: предварительное исследование в Греции

Асимина Тсибидаки<sup>1</sup>, Харидимос Тсибидакис<sup>2</sup>, Анастасия Тсампарли<sup>1</sup>, Докса Котзиа<sup>3</sup>, Артемизия Пану<sup>4</sup>

<sup>1</sup>Кафедра начального образования, Эгейский университет, Греция

<sup>2</sup>Кафедра ортопедии и клиника „Илизаров“, Больница „А. Мандзони“, Лекко, Италия

<sup>3</sup>Кафедра детской респираторной медицины и трансплантации лёгких, Больница „Грейт Ормонд стрит“, Объединённое Королевство

<sup>4</sup>Кафедра ортопедии, педиатрии и нейро-ортопедии, Научно-исследовательская больница „Хуманитас“, Розано (Милан), Италия

### Адрес для корреспонденции:

Артемизия Пану, Кафедра ортопедии, педиатрии и нейро-ортопедии, Научно-исследовательская больница „Хуманитас“, ул. „Мандзони“ № 56, 20089, Розано (Милан), Италия ;

Email: artemisia.panou@humanitas.it;

Tel: 00393453304077

**Дата получения:** 25 января 2019

**Дата приемки:** 27 февраля 2019

**Дата публикации:** 30 сентября 2019

**Ключевые слова:** церебральный паралич, родители, Греция, ортопедическая хирургия

### Образец цитирования:

Tsibidaki A, Tsibidakis H, Tsamparli A, Kotzia D, Panou A. The impact of orthopedic surgery on parents of children affected by cerebral palsy: a preliminary study in Greece. Folia Med (Plovdiv); 2019;61(3):384-8.

doi: 10.3897/folmed.61.e39344.

**Введение:** Церебральный паралич (ЦП) - серьёзное заболевание, которое оказывает важнейшее воздействие не только на пострадавшего человека, но и на родителей и всю семью. Дети с ЦП часто подвергаются операции с длительной госпитализацией.

**Цель:** Цель исследования состояла в том, чтобы осветить воздействие ортопедической хирургии на родителей детей, страдающих церебральным параличом в Греции.

**Материалы и методы:** Было проведено полуструктурированное интервью с 80 родителями (40 отцами и 40 матерями) из базовых и здоровых семей. Все родители были греческого происхождения, принадлежали к среднему социально-экономическому классу и имели по крайней мере одного ребёнка, страдающего ЦП, который являлся кандидатом на ортопедическую операцию.

**Результаты:** Большинство родителей понимали, что ЦП - это состояние, требующее специальной подготовки, необходимость специальных услуг и медицинская проблема, затрагивающая всю семью. Их ожидания после ортопедической операции были сосредоточены главным образом на исцелении ребёнка и на надежде иметь «здорового ребёнка», в то время как ожидания в отношении будущей операции были сосредоточены на улучшении качества жизни, двигательных функций и походки ребёнка.

**Выводы:** Родители детей с ЦП имеют разные представления о клиническом состоянии и разные ожидания в отношении ортопедической хирургии и её результатов.