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

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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. 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.
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.4,5

CP children are often hospitalized during growth with necessity of longer stays and higher levels of care than other children without disabilities.6-9 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.10,11 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.11 However, parents discover that they are able to adapt and to adjust to new conditions, especially in situations where they are well supported.5

Different orthopedic surgical treatments are usually performed during growth in CP children to correct musculoskeletal 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. Off 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 GMFCS12 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 orthopedic 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/expectation 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
A 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. CP children are continuously under medical treatment and often surgery is necessary during their growth and medicine, nursing and rehabilitation have an important role on CP children management.

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 using data obtained by interviews which are a rich means of gathering information from families containing questions addressing how parents describe CP, their perception and their expectations after orthopedic surgery.

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<tr>
<th>Table 1. Parents’ representation/perception of cerebral palsy (n: number)</th>
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<td><strong>Representation of cerebral palsy</strong></td>
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<tr>
<td>A condition requiring special education and support services</td>
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<td>A medical problem that affects the whole family</td>
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<td>A social and cultural condition created by unfriendly</td>
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<th>Table 2. Parents’ expectations after orthopedic surgery (n: number)</th>
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<td><strong>Expectations after each operation</strong></td>
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<td>An operation will change the child’s life and stimulate other</td>
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<td>children</td>
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<td>An operation will improve the daily living conditions of the</td>
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<td>child with CP</td>
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<td>An operation constitutes a palliative care</td>
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<td>An operation represents one medical problem less for the</td>
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<td>and their movement and gait.</td>
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impact 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 after surgery. This hope/desire may help parents to handle better anxiety, 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 parents’ 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. 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. In addition, positive perception can also be considered as a factor that improves the effect of a child's disability on family balance.

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

Воз действие ортопедических операций на родителей детей, страдающих церебральным параличом: предварительное исследование в Греции

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


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.