

# Children with Cerebral Palsy Across the Gross Motor Function Classification System Requiring Orthopaedic Surgery: The Lived Experiences of Parents

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## Objectives

1. To describe the role of orthopaedic surgery for children with cerebral palsy (CP)
2. To present the findings of a study exploring the experience of parents during their child's orthopaedic surgery
3. To suggest considerations for practice and service delivery.



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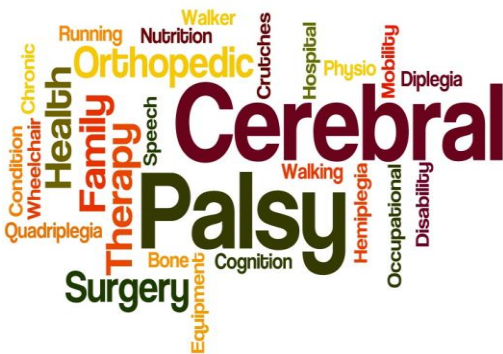
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## Orthopedic Surgery

- Range of dose
- Functional mobility
- Multiple procedures
- Ongoing process




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## GMFCS

### Gross Motor Function Classification System

[www.canchild.ca](http://www.canchild.ca)

Palisano et al., *Dev Med Child Neurol.* 1997, 39: 214-223



GMFCS E & R between 6 <sup>th</sup> and 12 <sup>th</sup> birthday: Descriptors and illustrations	
	<b>GMFCS Level I</b> Children walk or crawl, adjust, sidestep and in the community. They can walk across uneven terrain on all of walking. Children perform gross motor skills such as running and jumping, tag games, balance and coordination are limited.
	<b>GMFCS Level II</b> Children walk on most level and smooth terrain. Walking on a walking. They have experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a walker or handrails and/or with limited mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.
	<b>GMFCS Level III</b> Children walk using a hand-held mobility device in most indoor settings. They can stand alone holding onto a wall with supervision or assistance. Children can ascend mobility using standard leg devices and may self-propel for shorter distances.
	<b>GMFCS Level IV</b> Children use method of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances in areas with physical assistance or powered mobility. A child subject matter when performed. At school, outdoors and in the community children are transported by manual wheelchair or use powered mobility.
	<b>GMFCS Level V</b> Children are transported in a manual wheelchair in all settings. Children are limited to bare ability to maneuver themselves in wheelchairs, posture and control leg and arm movements.

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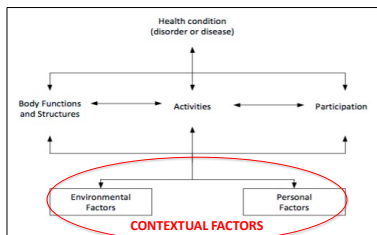
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## Family as environment



(Adapted from: WHO, 2013, p. 7)

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## Research Question

What is the lived experience of parents of children with CP across the GMFCS levels who require orthopaedic surgery?




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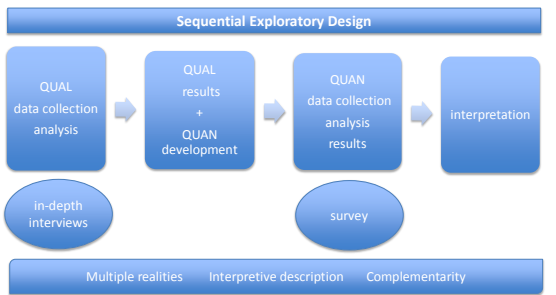
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## Mixed Methods



(Adapted from O'Neill, 2009; Rauscher & Greenfield, 2009)

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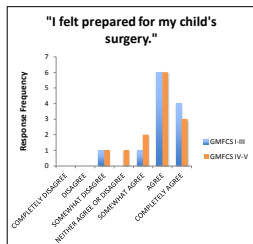
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## Theme #1: Preparing & being prepared

*"You don't want to be in a situation where it's Saturday night, every store's closed and you're trying to figure out how to manage... your child that is helpless at this point, in a cast. So, yeah, that was I think the most beneficial."*




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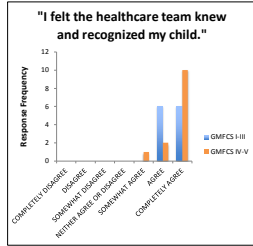
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**Theme #2: Feeling known & recognized**

*"You guys all include [him] and talk to [him], and he is the patient, and it is being done for him, and it's not just that he's a chair, you know, like just a fixture in the room."*




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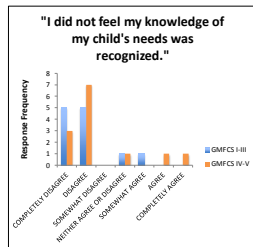
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**Theme #3: Knowing & advocating for your child**

*"We were the ones that, we kept saying... his legs are at different lengths and no one seemed to listen to us... and I'm like, but look, like look! They're not the same! And it was his... physiotherapist... who finally was like, no, like when he's laying, when he's sitting, when we look I see what, like, the parents aren't just making this up."*




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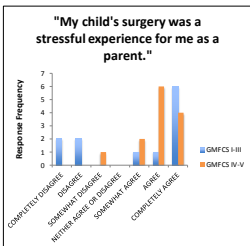
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**Theme #4: Feeling stressed & coping**



*"I sort of feel... [our child] is here to help me learn and our family learn about, you know, living a happier, better life. But he's also helping all the team, the people around him and so... if his presence is to, you know, help other people feel more comfortable around kids like that, or help the doctors try new techniques, or you know, it's just, I feel like he's helping everybody in their development and their learning too"*

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## The Parent Experience

- Vulnerability, helplessness  
*(Iversen et al., 2009)*
- Ambivalence  
*(Iversen et al., 2013)*
- Parent partnership  
*(Hayles et al., 2015)*
- Very high stress 5x higher  
*(Parkes et al., 2011)*



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## Implications for Practice



- Family-centered care  
*(Rosenbaum et al., 1998)*
- Multidisciplinary care  
*(Fairhurst, 2012)*
- Individualized care  
*(Almasri et al., 2011)*



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## Conclusions

- Surgery can be stressful for parents
- Experience is multifactorial
- Parents rely on health care practitioners
- Parents want to be known and heard
- Parents have expertise and find ways to cope



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- BCCH Orthopaedic CP Clinic
- BCCH Orthopaedic Department
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