



## Parents' experiences and needs regarding physical and occupational therapy for their young children with cerebral palsy



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### ABSTRACT

**Objective:** To explore the experiences and needs of parents of young children (aged 2–4 years) with cerebral palsy (CP) regarding their child's physical and occupational therapy process in a rehabilitation setting.

**Methods:** A qualitative design was used involving semi-structured interviews with 21 parents of young children with CP. Interviews were conducted until informational redundancy was achieved.

**Results:** Three major themes were identified: Information, communication and partnership. A fourth, overarching theme emerged: The process of parent empowerment. Experiences and needs differed between parents and changed over time.

**Conclusion:** This study suggests that various themes play a key role in the experiences and needs of parents of young children with CP. The identified themes provide important insights into how and why service providers might change their approach.

**Practice implications:** Becoming empowered is a dynamic process for parents, in which both parents and service providers play a role. Service providers should continually adapt their role to parents' needs of information, communication and partnership, and they should support and facilitate parents in becoming empowered.

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For that, service providers should be educated on the process of parent empowerment, on ways to facilitate this process and on the importance of involving and interacting with parents.

This allows families of young children with CP to be provided with services that best suit their needs.

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## 1. Introduction

The most common physical disability affecting children is cerebral palsy (CP), with a prevalence of 2 to 2.5 per 1000 live births (Dolk, Parkes, & Hill, 2006; Hutton & Pharoah, 2006; Oskoui, Joseph, Dagenais, & Shevell, 2013). CP is the general term for a number of neurological conditions that affect movement and co-ordination. Children with CP often receive physical and occupational therapy to optimize their development. A key concept in the treatment of children with CP is Family-Centered Care (King & Chiarello, 2014). Family-Centered Care comprises listening to families and being responsive to their priorities and needs, and developing an equal partnership between service providers and parents, in order to promote the families' engagement (King & Chiarello, 2014). Parental engagement in children's therapy is essential, since it has been suggested that parents' early beliefs regarding their child's therapy might have consequences for treatment participation, and potentially also for treatment outcomes (Nock, Ferriter, & Holmberg, 2007). Furthermore, Family-Centered Care is also believed to facilitate the process of empowerment (King & Chiarello, 2014), referring to the process of families gaining control over their lives (Singh et al., 1995). Parents of young children with CP not only have to adapt to raising a child, but are also engaged in a process of adapting to having a child with a disability (Piggot, Paterson, & Hocking, 2002; Rentinck, Ketelaar, Jongmans, & Gorter, 2007). This adaptation process might involve parents of younger children having different experiences and needs than parents of older children, so in examining the experiences and needs of parents, it is important to distinguish between parents of younger children and those of older children.

Based on a recent literature review on parents' experiences with physical and occupational therapy for their young child with CP (Kruijzen-Terpstra et al., 2013), a framework was constructed to describe the experiences of parents of young children with CP regarding the interventions their child receives (Kruijzen-Terpstra et al., 2013). However, only three of the thirteen studies included in the review explicitly focused on parents of young children (Hinojosa, 1990; Hinojosa & Anderson, 1991; Øien, Fallang, & Østensjø, 2010). Most studies failed to describe in detail the roles of parents in the children's interventions. The extent of parental involvement may have influenced parents' experiences. In addition, since the experiences and needs of parents of young children might be affected by the parents' process of adapting to having a child with a disability, there is a need for more studies explicitly focusing on the experiences of parents with young children with CP (Kruijzen-Terpstra et al., 2013).

Greater understanding of the perspectives of parents of young children might facilitate therapists in providing services that suit the family's needs, maximizing opportunities for parental engagement in their child's therapy and, ultimately, optimizing the health outcomes of the child with CP and the family. The objective of the present qualitative study was to explore the experiences and needs of parents of young children (aged 2–4 years) with CP regarding their child's physical and occupational therapy process in a rehabilitation setting.

## 2. Methods

### 2.1. Design and study sample

The experiences of parents of young children (aged 2–4 years) with CP were explored using qualitative semi-structured interviews. This study was done in the context of a larger study (LEARN 2 MOVE 2-3 Study) in which parents and their children participated. The LEARN 2 MOVE 2-3 Study evaluated the efficacy and working mechanisms of two intervention approaches, compared to regular care (Ketelaar et al., 2010). During the LEARN 2 MOVE 2-3 Study all children received physical and/or occupational therapy in a rehabilitation setting in the Netherlands. Additionally, the context of the LEARN 2 MOVE 2-3 Study allowed us to examine parental involvement in the intervention procedures in the three intervention groups (child-focused, context-focused and regular care). Parents often reported that they did not notice any differences in the content or process of their child's therapy before or during the LEARN 2 MOVE 2-3 Study. Therefore, parents' experiences and needs regarding their child's therapy are reported for the whole group of interviewed parents.

Once a child had completed the LEARN 2 MOVE 2-3 intervention, his or her parents were recruited to participate in this qualitative study. A purposive sampling approach was used to ensure that parents of all three intervention groups were included. Recruitment of parents continued until the interviewers indicated that informational redundancy had been achieved. In total, 23 of the 68 families were invited to take part in this qualitative study. Two of the 23 invited families did

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