Family Needs of Parents of Children and Youth with Cerebral Palsy: Determinants and Unique Profiles

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DEDICATIONS

It is my pleasure to dedicate this work to my great parents who taught me that with hope and persistence nothing is impossible as well as to my teachers who have entrenched the love of knowledge in my heart and encouraged me to seek it all through my life.
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ABSTRACT

Family Needs of Parents of Children and Youth with Cerebral Palsy: Determinants and Unique Profiles
Nihad A. Almasri
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It is important for professionals who provide medical, rehabilitation, educational, and community services for children and youth with cerebral palsy to provide a quality medical home, family-centered, and needs-based services to address their needs and improve child and family well-being. Knowledge regarding determinants and unique profiles of needs for families of children and youth with cerebral palsy is limited. The aims of this research were to (1) test structural equation models of determinants of three types of family needs of parents of children and youth with cerebral palsy; (2) identify and describe unique profiles of family needs; and (3) examine whether profiles of needs are differentiated based on child, family, and service characteristics. Participants were 579 parents of children and youth with cerebral palsy. Children/youth, and their parents completed a modified version of the Family Needs Survey, Family Environment Scale, Coping Inventory, Children’s Assessment of Participation and Enjoyment, Measure of Processes of Care, and Services questionnaire. Research assistants determined the Gross Motor Function Classification System levels of the children. The structural models explained 23% of variance in needs related to child condition, 43% of variance in needs related to community and financial resources, and 33% of variance in needs related to family functioning. The determinants of the three models included different combinations of services (accessibility, coordination, processes), family (relationships, income), and child
(gross motor function, adaptive behavior, communication problems) characteristics. K-means cluster analysis indicated four unique profiles of needs: Low Needs, Needs Related to Child Health Condition, Needs Related to Community and Financial Resources, and High Needs. Profile membership was differentiated based on child gross motor function and adaptive behavior, family relationships and income, and access to and coordination of services. Families who were included in the profile of low needs commonly reported accessible, coordinated, and family-centered care. The results emphasize the importance of providing medical and family-centered services to address the unique needs of families of children and youth with cerebral palsy. Service providers are encouraged to engage families in expressing their needs, collaborate with families in identifying resources to meet needs, and guide families in navigating complex service systems to address needs.
CHAPTER 1
RESEARCH PROPOSAL
1.1. Specific Aims

Although addressing the needs of children and youth with disabilities in the context of their families is essential for providing family-centered services (Baird & Peterson, 1997; King, Teplicky, King, & Rosenbaum, 2004; King et al., 2002), knowledge about the needs of families of children and youth with cerebral palsy is limited. The need for information about a child’s condition, intervention options, and available services are the most frequently expressed needs for families of children with disabilities (Bailey & Simeonsson, 1988; Dragone, 1990; Ellis et al., 2002; Sloper & Turner, 1992; Walker, Epstein, Taylor, Crocker, & Tuttle, 1989). Children with cerebral palsy vary considerably in severity of limitations in motor function and associated problems in communication and learning (Rosenbaum et al., 2007). The needs of families of children with cerebral palsy may differ compared to families of children with other types of disabilities. Among families of children with cerebral palsy, needs may depend not only on the child’s age and abilities, but also on environmental and personal characteristics. Knowledge of the child, family, and service characteristics that are determinants of amount and type of needs should enhance the provision of family-centered services that support children, youth, and their families at different stages of their lives and in turn optimize children’s activity and participation.

The long-term goal of the research described in this dissertation is to improve the outcomes of rehabilitation services for children and youth with cerebral palsy by providing services that best meet families’ expressed needs. The overall objectives of this proposal are: (1) test a model that identifies
determinants of family needs of parents of children and youth with cerebral palsy; (2) describe unique patterns (profiles) of needs expressed by parents; and (3) examine whether profiles of needs are differentially related to child and family characteristics. As part of my Doctoral work during the past two years, I have participated as a research assistant in a study of Activity and Participation of Children with Cerebral Palsy (CAPS). The objectives of this proposal were achieved by conducting secondary data analysis of the CAPS data. I also presented preliminary findings at an international conference. These findings examined the effect of children's age and motor abilities on the needs of their families. My work thus far has prepared me to conduct this research.

The overall objective was accomplished by the following specific aims:

**Aim# 1:** Identify the child, family, and service characteristics that are determinants of the amount and type of family needs.

**Aim# 2:** Identify and describe unique profiles of family needs for families of children and youth with cerebral palsy.

**Aim# 3:** Determine whether profile membership is differentially related to child and family characteristics.

The proposed research is innovative because it constitutes a systematic and comprehensive approach for understanding the determinants of family needs of families of children and youth with cerebral palsy. The study is also novel because of its focus on the identification of profiles of family needs in this population. I expect the results will yield the following expected outcomes: (1) a model that will enhance knowledge and understanding of expressed family needs of parents of children and youth with cerebral palsy; (2) profiles of needs that
reflect unique needs of families of children and youth with cerebral palsy; and (3) a better understanding of the differences between profiles of needs based on personal and environmental characteristics of children and families. The findings will inform collaboration and partnership among service providers and families, and assist health care providers, including physical therapists, to develop and implement service plans that are flexible, culturally competent, and responsive to families’ needs.

Figure 1.1 shows a logic model for the proposal analyses that includes the inputs, activities that will lead to outputs, short and long-term outcomes, individuals who will be influenced by outcomes, and the impact of the proposed research. In the proposed research, input from the scientific literature, CAPS data, and committee members informed model development and profile identification. The short and the long-term outcomes included in the logic model are expected to influence the outcomes of children and youth with cerebral palsy and their families, and promote services that are specific and responsive to child and family needs.
Figure 1.1: Logic model of the proposed research.
1.2. Significance

Family-centered care represents a practice of choice when providing services for children with cerebral palsy and their families (King et al., 2004c). Provision of family-centered services involves partnership, collaboration, and coordination with families to empower family members based on comprehensive assessment of their needs (Bailey & Blasco, 1990; Bamm & Rosenbaum, 2008; Dunst, Trivette, & Hamby, 2008). Based on an ecological perspective of human development (Bronfenbrenner, 2005), a combination of child, family, and service characteristics potentially determine the amount and type of family needs (Perrin, Lewkowicz, & Young, 2000). Therefore, knowledge of the child, family, and service characteristics that are determinants of the amount and type of needs should enhance provision of family-centered services that support children, youth, and their families at different stages of their lives. Professionals’ consideration of child, family, and service characteristics and functioning may result in improved processes and outcomes of services, and in turn optimize children’s activity and participation.

Cerebral palsy is the most common diagnosis for which pediatric physical therapy services are sought (Hayes, McEwen, Lovett, Sheldon, & Smith, 1999). Despite the high prevalence rate for cerebral palsy, there is a lack of strong evidence that child-focused physical therapy interventions either identify or address family need. It is, therefore, critical that more rigorous research be conducted to address this gap in knowledge. The proposed research is important because it informs our understanding of determinants and profiles of needs of families of children and youth with cerebral palsy, where knowledge is limited. Knowledge about determinants
and unique profiles of needs is expected to have direct implications for family-centered services. Service providers can apply the knowledge obtained through this study to best assess, understand, anticipate, and address different types of family needs; also, to provide more accessible, coordinated, flexible, and culturally competent services.

1.3. Background

Cerebral palsy is “a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems” (Rosenbaum et al., 2007, p. 9). Approximately, 100,000 people under 18 years of age in the United States have cerebral palsy (Kuban & Leviton, 1994; Schaefer, 2008), which causes substantial financial and social costs to families, children, and health systems (Heymann, Penrose, & Earle, 2006).

The support of families of children with cerebral palsy emerges as a vital part of providing services for their children. Parents of children and youth with cerebral palsy have additional caregiving responsibilities and spend substantial time and effort arranging everyday care for their children (Raina et al., 2005). In addition, cerebral palsy is a life-long condition where the needs of children might extend beyond childhood into adulthood, which will lead the majority of youth with cerebral palsy to continue to live with their families longer than their peers without disabilities (Freedman & Boyer, 2000).
Family-Centered Services

Family-centered services describe how professionals engage families in interventions to address their needs and achieve desirable outcomes (Dunst et al., 2008). This reflects a primary change in the ways that professionals typically provide services for families of children with disabilities (Bailey & Simeonsson, 1988; Dunst, Boyd, Trivette, & Hamby, 2002). Family-centered services have been widely implemented in early intervention (Duwa, Wells, & Lalinde, 1993; Keyser, 2006), family support programs (Weissbourd, 1990), human services (Shelton, Jeppson, & Johnson, 1987), education (Keyser, 2006), and in many health care fields including pediatric rehabilitation (Bamm & Rosenbaum, 2008; Rosenbaum, King, Law, King, & Evans, 1998; Law et al., 2005). According to the Can Child Centre for Childhood Disability Research, family-centered services are defined as: “A set of values, attitudes, and approaches to services for children with special needs and their families. Family-centered service recognizes that each family is unique; that the family is the constant in the child’s life; and that they are the experts on the child’s abilities and needs. The family works with service providers to make informed decisions about the services and supports the child and family receives. In family-centered service, the strengths and needs of all family members are considered” (Law et al., 2003, p. 2).

Accordingly, families, children, and youth with disabilities should be actively engaged in decision-making regarding services (Palisano, 1994). Dunst and Trivette (1996) identified two components of family-centered practices: relational and participatory. The relational component includes good clinical practice such as active listening and respecting the families, while the participatory component includes providing interventions that are
individualized and responsive to families’ concerns and needs. Both relational and participatory elements are critical to providing effective family-centered services (Dunst et al., 2008).

Many authors have described family-centered practices in the past 30 years (Briar-Lawson, Lawson, Hennon, & Jones, 2001; Dunst, 1997; Rosenbaum et al., 1998; Shelton et al., 1987). Common principles and key elements arise from these descriptions. First, families are the primary people in children’s lives. Second, families are best able to identify priorities and needs of their children. Third, the relationship between health care providers and families is anchored in partnership and collaboration. Fourth, families should be empowered to make their own decisions and health care providers are accountable for providing families with complete and unbiased information. Fifth, services for children with disabilities and their families should be accessible, individualized, comprehensive, and flexible. Finally, health care providers should respect the families’ choices and demonstrate sensitivity to the families’ culture and beliefs.

Children who received comprehensive, family-centered services have been reported to make better gains in motor and skill development (Law et al., 1998; Moxley-Haegert & Serbin, 1983). Improved psychological adjustment was found with children who have chronic illness after a comprehensive program focusing on families and their needs (Stein & Jessop, 1984). Parents’ satisfaction with services is higher when services are family-centered (Brehaut et al., 2004; King, King, & Rosenbaum, 2004; Raina, et al., 2005; Mah, Tough, Fung, Douglas-England, & Verhoef, 2006). Parents’ satisfaction with services is associated with lower levels of stress and more commitment to services because of the parents’ increased feeling of being partners in decision-making,
having their views understood, and receiving coordinated services (King et al., 2004c). Parents who receive family-centered services have been found to experience better psychological well-being (Ireys, Chernoff, DeVet, & Kim., 2001; King at al., 1999; VanRiper, 1999), increase in knowledge about their children's conditions, improvement in child participation (Moxley-Haegert & Serbin, 1983), and feelings of competence and self-efficacy (Dunst & Dempsey, 2007; Law et al., 2003).

In a research synthesis and meta-analysis of 43 research reports about family-centered practices, Dunst et al. (2008) found significant relationships between family-centered help giving and parents' satisfaction, self-efficacy beliefs, program helpfulness, child functioning, parent-family functioning, and parenting behavior. The results show that family-centered services are strongly associated with positive family and child behavior and functioning. The positive influence of parents’ self-efficacy beliefs and satisfaction with services on child and family behaviors and functioning was highlighted. The indirect effect of family-centered practices on family and child outcomes mediated by parents' beliefs appraisals was reported. The researchers identified the moderating effects of “contextual, situational, and personal factors” (Dunst et al., 2008, p. 28) on relationships between family-centered practices and family and child outcomes. Multidimensional complex relationships between family-centered practices and the outcomes of children and families are recognized in the current research. Thus, further research is warranted to understand these relationships.

The translation of knowledge about the elements and principles of family-centered services from research to practice has been a challenge for many health professionals (Lawlor & Mattlingly, 1998; Leiter, 2004;
MacKean, Thurston, & Scott, 2005; Shelton, 1999). For instance, professionals often raise questions related to when and how to provide families with information, when to listen and when to guide families, and how to work in partnership with families (Bamm & Rosenbaum, 2008). Knowledge of determinants of family needs and profiles for families of children and youth with cerebral palsy should improve understanding of how family and environmental factors contribute to expressed family needs and consequently enhance the ability of health care professionals to provide family-centered services.

Based on available research, I grouped the current research about family-centered services into four research areas that aim to: (1) develop a theoretical framework for providing services; (2) translate knowledge from theory into practice; (3) evaluate the process and outcomes of practice; and (4) improve quality of services. Figure 1.2 shows the sequence relationships among these four areas. Research related to the principles, assumptions, and behaviors of family-centered services has been extensive and theory-based frameworks have been proposed.

Dunst (2002) provided integrated evidence from research and experience that professionals in education, health, and other fields are not as family-centered as they often claim. Professionals in early intervention and preschool programs have been using family-centered principles longer than primary and elementary schools and therefore their practice were found to be more family-centered. Other practitioners, depending on their area of specialty, were found to implement the relational component of family centered services more than the participatory component or sometimes they were less family-centered in both components (Dunst, 2002). The findings by
Dunst (2002) might therefore reflect limited knowledge about family-centered care practices or a lack of ability to translate knowledge into practice.

**Figure 1.2:** Sequential relationship among areas of research on family-centered services.

**Needs of Families of Children and Youth with Cerebral Palsy**

Knowledge about the needs of families of children with cerebral palsy is limited because most studies that investigated family needs often included children with different diagnoses and health conditions (e.g. Bailey & Simeonsson, 1988; Perrin et al., 2000; Sloper & Turner, 1992). A literature search identified one study by Nitta et al. (2005) of 297 mothers of school-aged children with cerebral palsy. The results of this study showed that there is a relationship between the child's disability and two major areas of needs: social support and community services. Services that enhance social networking with formal and informal resources of support, as well as services that increase knowledge about community resources and opportunities of participation, were identified as key elements of effective plans of services.

Needs for information are the most commonly expressed needs of families of children with a wide range of disabilities and health conditions (Bailey & Simeonsson, 1988; Dragone, 1990; Ellis et al., 2002; Sloper & Turner, 1992; Nitta et al., 2005). Fifty-nine percent of the families who participated in a study conducted by Sloper et al. (1992) expressed needs
related to provision of information about services and 43% of participants reported needs for information about child’s condition. Forty percent of the participants were families of children with cerebral palsy. Walker et al. (1989) found that 91% of the parents expressed needs for obtaining information about their child’s condition, treatment, and long-term outcomes. In addition to their needs for more information, families expressed needs for integrated and coordinated service plans for the child and family (Perrin et al., 2000; Farmer, Marien, Clark, Sherman, & Selva, 2004; Kanthor, Pless, Satterwhite, & Myers, 1974). Another area of major concern for families of children with chronic health conditions and disabilities is the need for formal and informal support and community services (Bailey et al., 1999). In a study conducted by Farmer et al. (2004), over half of the participants reported the need for support and community services.

On the other hand, family support was the least expressed need by parents of children with motor disabilities (Hendriks et al., 2000). Some studies found that more often than not parents of children with disabilities tend to underestimate their needs for family support (Graves & Hayes, 1996; Perrin et al., 2000) because they focus more on needs related to their children. Researchers expected the needs of family support to increase when children grow and environmental demands increase on the families (Hendriks et al., 2000).

Families of children with cerebral palsy may share similar needs with families of children with other health conditions such as their needs for information regarding their child’s diagnosis (Bailey, Blasco, & Simeonsson, 1992; Ellis et al., 2002; Mitchell & Sloper, 2002), social participation (Hendriks et al., 2000; Fisher, 2001), respite care (Hendriks et al., 2000;
Murry, Maslany, & Jeffery, 2006), and social support (Bailey et al., 1992; Farmer et al., 2004). The needs of families of children and youth with cerebral palsy might also be unique because of the nature of cerebral palsy condition (Hendriks et al., 2000). Children with cerebral palsy have a variety of motor disorders and associated health problems (Rosenbaum et al., 2007) that are different from children with other developmental conditions. In addition, cerebral palsy is identified in childhood and persists throughout the lifespan, which requires families to adjust to a life-long child disability. Needs may change as the child ages and matures. However, service providers can develop and implement effective service plans that target specific needs of families of children with cerebral palsy when they recognize the unique needs of this population. The proposed research will identify unique profiles of needs for families of children and youth with cerebral palsy and will examine the effect of children and family characteristics on differences among identified profiles.
Determinants of Family Needs

Several child, family, and service characteristics have been identified as potential determinants of needs of families who have children with disabilities (e.g. Bailey & Simeonsson, 1988; Bailey et al., 1992; Bailey et al., 1999; Ellis et al., 2002; Farmer et al., 2004; Graves & Hayes, 1996; Hendriks et al., 2000; Hinden, Bieble, Nicholson, & Mehnert, 2005; Mcgill, Papachristoforou, & Cooper, 2006; Rahi, Manaras, Tuomainen, & Lewando-Hundt, 2004; Nitta et al., 2005; Sloper & Turner, 1992). Figure 1.3 shows these characteristics according to the framework of International Classification of Functioning, Disability and Health model (ICF; WHO, 2001).

Figure 1.3: Summary of determinants of family needs that are examined by research in the framework of the ICF model.