Family needs of parents of children and youth with cerebral palsy

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Abstract

Background  Understanding the needs of families of children and youth with cerebral palsy (CP) is important for family-centred services. The aims of this study were to identify: (1) differences in the number and types of family needs expressed by parents based on the age and gross motor function level of their children with CP; (2) the most frequent family needs; and (3) needs that differ on gross motor function level.

Methods  A total of 501 parents (77.6% mothers) of children and youth with CP completed a modified version of a Family Needs Survey and a demographic questionnaire. Children's gross motor function level was classified using the Gross Motor Function Classification System.

Results  Total number of family needs differed based on gross motor function level (P < 0.001) but not age. Parents of children/youth who use wheeled mobility expressed the highest number of family needs, while parents of children/youth who walk without restrictions expressed the fewest needs. Family needs for Information (P = 0.001), Support (P = 0.001), Community Services (P < 0.001) and Finances (P < 0.001) differed based on children's gross motor function level. Over 50% of parents expressed family needs for information on current and future services, planning for the future, help in locating community activities and more personal time. Parents of children and youth who use wheeled mobility were more likely to express the need for help in paying for home modifications, equipment, services and locating sitters, respite care providers and community activities.

Conclusions  The gross motor function of children/youth with CP has implications for collaboration with families to identify needs and co-ordinate services. Health professionals have a role to assist families with information needs and locating community services and leisure activities. Family needs for future planning suggest that health professionals should assist families to prepare for key periods in the lives of their children with CP.

Keywords  cerebral palsy, children, family-centred services, family needs, needs assessment, youth

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Introduction

Parents of children and youth with cerebral palsy (CP) encounter daily challenges in care giving, advocacy and co-ordinating services. Knowledge of the priorities and needs of families of children and youth with CP is essential for providing family-centred services. Family-centred service is considered best practice in pediatric rehabilitation (King et al. 2004). A family-centred approach embodies the belief that processes and outcomes of health care are optimized through services that encompass the child, family and the environments where the child lives, learns and plays (Law et al. 1998; King et al. 2002; Palisano et al. 2004). Within a family-centred approach, assessment of family needs is a collaborative process. The family shares concerns and priorities and professionals provide information to make informed decisions about services and supports for desired outcomes (King et al. 2004).

Research involving families of children with disabilities or special healthcare needs has identified several types of family needs. Families of children with physical disabilities most often expressed needs for information about services (59%) and their child’s condition (43%) (Sloper & Turner 1992). Walker and colleagues (1989) found that 91% of parents of children with chronic health conditions expressed needs for information about their child’s condition, treatment and long-term implications of the child’s health condition. Forty-seven percent of families of children with a diagnosis of autism, pervasive developmental disorder or mental retardation had needs for information and 21–32% of the parents had needs for support, community services, family functioning and explaining their child’s condition to others (Ellis et al. 2002). Families of children with special healthcare needs have reported needs for co-ordinated service plans (Farmer et al. 2004), their child’s social participation (Hendriks et al. 2000; Fisher 2001; Farmer et al. 2004) and respite care (Hendriks et al. 2000; Murray et al. 2006).

Based on lifespan development, we propose that there are differences in family needs based on the age of the child with CP. Needs of families or infants and toddlers are often assessed in early intervention. Less is known about the needs of families of children and youth with disabilities. This knowledge would be useful for supporting families as their children transition from primary to secondary education and then to adulthood. Transition to adulthood presents many challenges for youth with CP, including finding an adult medical home, independent living, post-secondary education, work and community inclusion (Blomquist 2006; Stewart et al. 2006). Findings on the influence of age varied for three studies that used the Family Needs Survey (Bailey & Simeonsson 1988). Among families of children 3–16 years of age with developmental disabilities, families of younger children reported more needs than families of older children (Ellis et al. 2002). In studies by Bailey and colleagues (1992) and Farmer and colleagues (2004), however, child’s age was not related to family needs.

Knowledge of the needs of families of children and youth with CP is limited. Children with CP vary considerably in gross motor function (Rosenbaum et al. 2002). Family needs may differ depending on whether the child is self-sufficient or requires physical assistance and assistive technology for mobility. Mothers of children with CP identified needs for formal and informal supports and information about community resources (Nitta et al. 2005). Limited awareness of resources and uncoordinated services were associated with restricted participation opportunities for children with CP (Mihaylov et al. 2004).

The aims of this study were to identify: (1) differences in the number and types of family needs expressed by parents of children and youth with CP based on children’s age and gross motor function level; (2) the most frequently expressed family needs; and (3) needs that differ based on gross motor function level. Knowledge of common family needs and whether the number and types of needs differ for children and youth with CP depending on their age and gross motor function should assist families and health professionals to identify goals and co-ordinate services.

Methods

Participants

A cross-sectional analytical design was used. Families were part of a larger multisite study of activity and participation of children with CP sponsored by Shriners Hospitals for Children. Children and youth were receiving services from one of six Shriners Hospitals: Chicago, Illinois; Erie, Pennsylvania; Lexington, Kentucky; Northern California (Sacramento), California; Philadelphia, Pennsylvania; Springfield, Massachusetts; or Kluge Children’s Rehabilitation Center, Charlottesville, Virginia. Families of children with a primary diagnosis of CP without a concomitant illness or health condition that may impact quality of life, such as cystic fibrosis, cancer or a mental health condition, were eligible for the study. The study was approved by all local Institutional Review Boards. A parent or legal guardian and youth age 18 and older provided informed consent. Informed assent was provided by children 7 years of age and older.
A convenience sample of 501 parents of children and youth with CP participated in the study. Parents were primarily mothers (77.6%) with a mean age 40.3 years (SD = 9.3). Their children/youth were 2–21 years of age (M = 10.8 years, SD = 4.5). Children/youth were grouped by age (<6 years, 6–12 years, 13–21 years) and Gross Motor Function Classification System (GMFCS) level (I, II/III, IV/V) (Palisano et al. 1997). The decision to group children/youth into three levels of gross motor function was based on previous research (Palisano et al. 2007). Eighty-one children were <6-year-old, 257 were 6–12-year-old and 163 youth were 13–21-year-old. In total, 112 children and youth were in Level I (walk without restrictions), 229 in Levels II & III (walk with limitations) and 160 in Levels IV & V (wheeled mobility and physical assistance). The demographics of the parents, their families and children are presented in Tables 1 and 2.

**Measures**

**Family needs survey** (Bailey & Simeonsson 1988)

The Family Needs Survey (FNS) is a 35 item parent-completed questionnaire developed to assess current needs of families of young children with developmental disabilities irrespective of services. Items are grouped by type of need: 1) Needs for information; 2) Needs for supports; 3) Explaining to others; 4) Community Services; 5) Financial Needs; and 6) Family Functioning. Family functioning refers to the whole family and includes needs for problem solving, support systems and role allocation. The three response options are: 1 'I definitely do not need help'; 2 'Not sure'; 3 'I definitely need help'. In an effort to identify needs of families of older children and youth, three items were modified and four items added with permission of the authors, for a total of 39 items. Items were modified to include needs for locating a school, vocational training, job, paying for equipment and paying for home modifications. The additional items addressed needs for help in: (1) getting transportation services; (2) locating camps, sports, recreational, social and leisure activities; (3) co-ordinating medical, developmental, educational and other community services; and (4) finding information about planning for the child’s future well-being including guardianship, trust funds and transition to adulthood. Internal consistency of all 39 items and internal consistency of items for each of the six types of needs were examined for the participants in our study. Cronbach’s alpha coefficient for all items was 93 and coefficients varied from 76 to 83 for each type of need. Our findings compare favourably with the internal consistency of the FNS reported for a sample of 53 children with disabilities (overall alpha coefficient of 91 and coefficients of 65–86 for each type of need) (Sexton et al. 1992). Test-retest reliability (Bailey & Simeonsson 1988) and acceptability (Bailey & Blasco 1990) of the FNS has been reported.

**GMFCS** (Palisano et al. 1997)

The GMFCS is a five-level system developed for children with CP to classify gross motor function based on usual performance in home, school and community settings. Distinctions between GMFCS levels are based on functional abilities and limitations, the need for assistive mobility devices (walkers, crutches, canes), wheeled mobility and, to a lesser extent, quality of movement. Table 3 summarizes the functional abilities and limitations for

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**Table 1. Characteristics of participants and their families**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship to the child (n = 501)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>389</td>
<td>77.6</td>
</tr>
<tr>
<td>Father</td>
<td>59</td>
<td>11.8</td>
</tr>
<tr>
<td>Grandmother</td>
<td>25</td>
<td>5.0</td>
</tr>
<tr>
<td>Others</td>
<td>28</td>
<td>5.6</td>
</tr>
<tr>
<td>Education (n = 482)</td>
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<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>30</td>
<td>6.2</td>
</tr>
<tr>
<td>High school</td>
<td>216</td>
<td>44.8</td>
</tr>
<tr>
<td>Some college/associates degree</td>
<td>112</td>
<td>23.2</td>
</tr>
<tr>
<td>Bachelor degree</td>
<td>89</td>
<td>18.5</td>
</tr>
<tr>
<td>Graduate degrees</td>
<td>35</td>
<td>7.3</td>
</tr>
<tr>
<td>Employment (n = 473)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not employed</td>
<td>180</td>
<td>38.1</td>
</tr>
<tr>
<td>Part time</td>
<td>98</td>
<td>20.7</td>
</tr>
<tr>
<td>Full time</td>
<td>195</td>
<td>41.2</td>
</tr>
<tr>
<td>Adults in household (n = 484)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>104</td>
<td>21.5</td>
</tr>
<tr>
<td>Two</td>
<td>333</td>
<td>68.8</td>
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<tr>
<td>Three</td>
<td>38</td>
<td>7.9</td>
</tr>
<tr>
<td>Four or five</td>
<td>9</td>
<td>1.9</td>
</tr>
<tr>
<td>Children (&lt;21) in household (n = 485)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>132</td>
<td>27.2</td>
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<tr>
<td>Two</td>
<td>182</td>
<td>37.5</td>
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<tr>
<td>Three</td>
<td>96</td>
<td>19.8</td>
</tr>
<tr>
<td>Four to nine</td>
<td>75</td>
<td>15.5</td>
</tr>
<tr>
<td>Other children with special needs (n = 492)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>395</td>
<td>80.3</td>
</tr>
<tr>
<td>Yes</td>
<td>97</td>
<td>19.7</td>
</tr>
<tr>
<td>Family income (n = 442) ($)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 15 000</td>
<td>53</td>
<td>11.9</td>
</tr>
<tr>
<td>15 000–29 999</td>
<td>64</td>
<td>14.5</td>
</tr>
<tr>
<td>30 000–44 999</td>
<td>85</td>
<td>19.2</td>
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<tr>
<td>45 000–59 999</td>
<td>58</td>
<td>13.1</td>
</tr>
<tr>
<td>60 000–74 999</td>
<td>68</td>
<td>15.4</td>
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<tr>
<td>75 000–99 999</td>
<td>61</td>
<td>13.8</td>
</tr>
<tr>
<td>100 000–199 999</td>
<td>45</td>
<td>10.2</td>
</tr>
<tr>
<td>200 000 and over</td>
<td>8</td>
<td>1.8</td>
</tr>
</tbody>
</table>
the 6–12-year age band. A classification is made by interview with the child and parents and observation of the child's gross motor abilities.

The GMFCS has evidence of content, construct and discriminative validity, and inter-rater reliability (Palisano et al. 1997, 2000; Wood & Rosenbaum, 2000). The preliminary version of the 12–18-year age band of the expanded and revised GMFCS was used to classify participants over 12 years of age (Palisano et al. 2008). Prior to data collection, each research assistant classified a minimum of 11 children and demonstrated a percent agreement of >80% with the criterion levels.

Procedures

Research assistants classified children's GMFCS levels. Research assistants represented nursing, occupational therapy, physical therapy, psychology and social work. Parents completed the modified FNS (Bailey & Simeonsson 1988) and a demographic questionnaire. Parents had the option to complete the questionnaire electronically on a laptop computer or complete a paper copy. Research assistants were available to address questions regarding the modified FNS or demographic questionnaire.

Data analysis

Statistical analysis was performed using SPSS for Windows (Version 16).* Expressed family need was defined as a rating of 3 'I definitely need help' for an item. The total number of family needs and the number of each type of need were tabulated by age (<6 years, 6–12 years, 13–21 years) and GMFCS level (I, II & III, IV & V). The effect of age and GMFCS level on the total number of family needs was examined by two-way analysis of variance (ANOVA). The interactions between age, GMFCS level and type of family needs were examined by repeated measures ANOVA. The mean percentage of each type of need was compared as the numbers of items differ for types of needs. Significant interactions were examined by one-way ANOVA. Paired comparisons were performed using the Bonferroni test.

Items for which at least 50% of parents expressed a need were identified. Items where parent needs differed by more than 20% were analysed using logistic regression to determine if the odds of having the need differed based on GMFCS level. The probability level for all analyses was $P \leq 0.05$.

Results

The total numbers of expressed family needs are presented in Table 4. The average number of needs for each group varied from 5.1 to 12.1. Fifteen parents expressed no family needs at all while two parents expressed a definite need for all items. The effect of GMFCS level on total number of family needs was

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* SPSS Inc., Chicago, IL 60606.
significant \( F(2, 492) = 12.38, P < 0.001 \). The effect of age \( F(2, 492) = 0.33, P = 0.72 \) and the interaction between age and GMFCS level were not significant \( F(4, 492) = 1.21, P = 0.31 \). Post-hoc comparisons indicated that the total number of family needs was highest for parents of children/youth in Levels IV & V \( (P < 0.01) \) and lowest for parents of children/youth in Level I \( (P < 0.01) \). For the entire sample, the average for each type of family need by GMFCS level is presented in Table 5. The interaction between GMFCS level and type of need was significant \( F(10, 976) = 1.16, P = 0.32 \) and the interaction between GMFCS level, age and type of need \( F(10, 1960) = 2.72, P = 0.05 \). The effect of age differed based on GMFCS level (Fig. 1). Logistic regression indicated that the odds of expressing the need for help paying for home modifications, equipment or toys were 25 times higher [95% confidence interval (CI) 11.8–53.8] for parents of children/youth in Levels IV & V than parents of children/youth in Level I \( (P < 0.01) \) and six times higher (95% CI 2.9–12.6) than parents of children/youth in Levels II & III \( (P < 0.01) \). The odds of expressing the need for locating babysitters or respite care providers was 10.9 times higher (95% CI 5.2–23.0) for parents of children/youth in Levels IV & V than parents of children/youth in Level I \( (P < 0.001) \) and 2.9 times higher (95% CI 1.4–6.1) than parents of children/youth in Levels II & III \( (P < 0.01) \). The odds of expressing the need for

<table>
<thead>
<tr>
<th>Type</th>
<th>Items</th>
<th>Mean (SD)</th>
<th>Mean (SD)</th>
<th>Mean (SD)</th>
<th>Significant* paired comparisons</th>
</tr>
</thead>
</table>
| Information | 8 | 2.5 (2.3) | 3.3 (2.4) | 3.6 (2.4) | II & III > I  
| Support | 8 | 1.6 (1.8) | 2.1 (1.9) | 2.3 (2.2) | IV & V > I  
| Community services | 8 | 1.0 (1.4) | 1.6 (1.7) | 2.6 (1.9) | IV & V > I  
| Financial | 5 | 0.6 (1.0) | 1.1 (1.4) | 2.0 (1.5) | II & III > I  
| Explaining to others | 6 | 0.6 (1.0) | 0.7 (1.3) | 0.8 (1.3) | None  
| Family functioning | 4 | 0.4 (0.9) | 0.6 (1.1) | 0.7 (1.1) | None  

*P ≤ 0.05.

![Figure 1](link)

Table 5. Mean number of each type of family need by children’s Gross Motor Function Classification System level and results of paired comparisons

- At least 50% of parents expressed the need for five items. The need for information about services their child might receive in the future and services that are presently available was expressed by 68% and 59.6% of parents respectively. The need for information about planning for their child’s future well-being was expressed by 57.7% of parents. The need for help in locating community camps, sports, recreational, social and leisure activities was expressed by 51.5% of parents. The need to have more personal time was expressed by 50.8% of parents. Less than 20% of parents expressed needs for items pertaining to Family Functioning and Explaining to Others.

Four items were notable for differences based on GMFCS level (Fig. 1). Logistic regression indicated that the odds of expressing the need for help paying for home modifications, equipment or toys were 25 times higher [95% confidence interval (CI) 11.8–53.8] for parents of children/youth in Levels IV & V than parents of children/youth in Level I \( (P < 0.01) \) and six times higher (95% CI 2.9–12.6) than parents of children/youth in Levels II & III \( (P < 0.01) \). The odds of expressing the need for locating babysitters or respite care providers was 10.9 times higher (95% CI 5.2–23.0) for parents of children/youth in Levels IV & V than parents of children/youth in Level I \( (P < 0.001) \) and 2.9 times higher (95% CI 1.4–6.1) than parents of children/youth in Levels II & III \( (P < 0.01) \). The odds of expressing the need for

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help in paying for therapy, child care or other services were 2.7 times higher (95% CI 1.6–4.8) for parents of children/youth in Levels IV & V than parents of children/youth in Level I (P < 0.001). The odds of expressing the need for help in paying for therapy, child care or other services did not differ between parents of children/youth in Levels IV & V and parents of children in Levels II & III (odds ratio = 1.2, 95% CI 0.7–2.1, P = 0.48). The odds of expressing the need for help locating camps, sports, recreational, social and leisure activities were 3.3 times higher (95% CI 2.0–5.5) for parents of children/youth in Levels IV & V than parents of children/youth in Level I (P < 0.001) and 2.1 times higher (95% CI 1.3–3.4) than parents of children/youth in Levels II & III (P < 0.01).

Discussion

Parents differed in the number and types of expressed family needs based on the gross motor function but not on the age of their children/youth with CP. Parents of children/youth who use wheeled mobility expressed the most family needs while parents of children/youth who walk without restrictions expressed the fewest needs. We did not control for problems in communication and learning that are associated with CP (Rosenbaum et al. 2007). Parents reported that between 9% and 34% of children/youth had an attention deficit, an intellectual disability or a learning disability. Consequently factors in addition to gross motor function may have contributed to differences in family needs. Parents of children/youth who use wheeled mobility were more likely to express needs for help paying for home modifications, equipment, toys and services, and locating babysitting, respite care and community activities. This finding has implications for social services to assist families in accessing resources to support their child’s care.

The number and types of family needs did not differ based on children’s age, findings that consistent with those of Bailey and colleagues (1992) and Farmer and colleagues (2004) but not Ellis and colleagues (2002) who reported families of younger children expressed more needs. CP is a lifelong condition and we anticipated that types of family needs would differ based on age. In retrospect, our methods were not optimal to examine the potential effect of age. The FNS was developed for families of young children. Our effort to adapt the FNS for families of older children may not have been successful. Items are general and do not reflect the context for a need. For example, one item asks about the need for help in locating a child care centre, preschool, school, vocational training or job. Locating a pre-school programme for a 4-year-old child with CP versus a job for a 20-year-old youth with CP is an age-related distinction that is not differentiated by the FNS but is likely to have implications for services. Further research using mixed methods (quantitative and qualitative) approaches is recommended to investigate age-related differences in the needs of families of children/youth with CP.

The results suggest that a role of health professionals is to assist families to prepare for key periods in their children’s lives. This perspective is supported by the finding that a high percentage of parents expressed a need for information on future planning and needs were expressed regardless of their children’s age. Families may have needs specific to their children’s transition to preschool, elementary education, secondary education and adulthood. Gall and colleagues (2006) recommend that the transition process should involve a gradual shift in responsibilities from parents to the youth. Our study does not reflect this process, as only the family needs of parents were measured.

The high percentage of parents who expressed needs for information about current services, community resources and supports is consistent with previous findings for families of children with disabilities (Sloper & Turner 1992; Ellis et al. 2002), including mothers of children with CP (Nitta et al. 2005). Our findings may partly reflect a parental attitude that it is impossible to have too much information. Comments from parents when completing these items indicated that many felt they were very well informed but that it is ‘always good to know more’.

The need for leisure, recreational and social activities was highest among parents of children/youth who use wheeled mobility. This suggests that finding community activities is especially challenging for parents of children/youth who require physical assistance for motor function, especially those who also have problems in communication, learning or both. Our results, coupled with the findings that limited knowledge of community resources was associated with fewer opportunities for participation (Mihaylov et al. 2004) and youth with CP had low satisfaction with recreational services (Magill-Evans et al. 2003), suggest health professionals have a role in assisting families to find community activities for their children/youth. Direct consultation with community organizations, instructors and coaches is recommended to facilitate successful participation.

At face value, the low percentage of parents who expressed needs for family and social supports and explaining their child’s condition is encouraging. Others have cautioned that parents of children with disabilities are more focused on needs related to their children’s development than needs for the whole family (Graves & Hayes 1996; Perrin et al. 2000). Physical therapists, occupational therapists, speech therapists, developmenta1 pediatricians, neurologists and orthopedic surgeons are among the health professionals who provide services to children/youth.
with CP. Interventions provided by professionals from these disciplines traditionally have focused on the child’s impairments in body functions and structures. The perceptions and beliefs of families and health professionals about family functioning are topics for further research.

Conclusions

The results have implications for collaboration of families and health professionals to identify needs and co-ordinate services. Family needs may differ depending on whether their child/youth with CP is self-sufficient or requires physical assistance and assistive technology for mobility. Needs for information, supports, community services and financial needs were highest among parents of children/youth who use wheeled mobility. For the entire sample, the most frequently expressed needs were for information about current and future services, planning for the future, help in locating community activities and the parent’s need to have more personal time. We recommend application of the results within a family-centred approach in which services build on the strengths of children, youth, families and communities.

Key messages

- Parents of children and youth with CP who walk without restrictions expressed fewer family needs compared with parents of children who walk with limitations or use wheeled mobility.
- Parents of children and youth with CP who use wheeled mobility expressed more total family needs and more needs for information, supports, community services and financial needs.
- The total number and types of family needs did not differ among parents of children and youth with CP <6 years, 6–12 years and 13–21 years.
- Over 50% of parents of children and youth with CP expressed needs for information about current and future services, planning for the future, help in locating community activities and the need to have more personal time.
- Parents of children/youth who use wheeled mobility were more likely to express a need for help paying for home modifications, equipment, toys, services and help locating sitters, respite care providers and community activities compared with parents of children and youth who walk.

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References


