Available online at www.sciencedirect.com

ScienceDirect

journal homepage: http://www.elsevier.com/locate/medici

Original Research Article

The family needs of parents of preschool children with cerebral palsy: The impact of child's gross motor and communications functions

Dace Bertule *, *Anita Vetra*

Department of Rehabilitation, Riga Stradins University, Riga, Latvia

ARTICLE INFO

Article history:
Received 10 January 2014
Accepted 20 November 2014
Available online 27 November 2014

Keywords:
Children
Cerebral palsy
Family needs

ABSTRACT

Background and objective: An understanding of the needs of families of preschool children with cerebral palsy (CP) is of essential importance if efficient and cost-effective services are to be provided to them. The aims of this study were to identify the most frequently expressed needs of families with preschool children with CP; differences in the amount and types of family needs based on the child's gross motor function and communication function level; and the impact of the child's gross motor function and communication function level on the type and amount of family needs.

Materials and methods: A total of 227 parents of preschool children with CP completed a modified version of the Family Needs Survey and a demographic questionnaire. Children's gross motor function level and communication function level was classified using the Gross Motor Function Classification System (GMFCS) and the Communication Function Classification System (CFCS), respectively.

Results: The total number of family needs differed based on GMFCS and CFCS levels. Children's GMFCS and CFCS level were not significant predictors of overall family needs (adjusted $R^2 = 0.163$). In this model the GMFCS level of children did not account for the total number of family needs, while the CFCS level did.

Conclusions: Child's limitations in terms of communication and gross motor functions must be taken into consideration when planning services for families with preschool children with CP.

© 2014 Lithuanian University of Health Sciences. Production and hosting by Elsevier Urban & Partner Sp. z o.o. All rights reserved.

* *Corresponding author at*: Department of Rehabilitation, Riga Stradins University, Dzirciema 16, 1007 Riga, Latvia.
E-mail address: dace.bertule@rsu.lv (D. Bertule).

Peer review under responsibility of Lithuanian University of Health Sciences.

Production and hosting by Elsevier

http://dx.doi.org/10.1016/j.medici.2014.11.005

1010-660X/© 2014 Lithuanian University of Health Sciences. Production and hosting by Elsevier Urban & Partner Sp. z o.o. All rights reserved.

1. Introduction

Although some researchers have reported that having a child with developmental disability may have a positive impact on family functioning [1–3], the fact is that parents of children with disabilities are more likely to need information about the condition of their children, treatment options, and available services [4–7]. Such families also require additional support, community services [6,8], and respite care [9].

Children with cerebral palsy (CP) experience different levels of disability. Some children have minor motor and cognitive impairments, while others experience more severe limitations [10]. Recent studies show that family needs vary because of multiple factors, such as the child's functional limitations. Parents of children and youth who are severely disabled are more likely to express a higher number of family needs [6,8,11]. Others have found, however, that severity of the child's disability is not a strong determinant of family needs [12,13]. There have been studies on how a child's mobility restrictions affect family needs, but there has been no proper examination of whether the child's communication abilities impact family needs and to what extent they do so. The findings on the influence of the child's age are also controversial. Carpenter [14] and Ellis et al. [15] have reported that families with younger children express more needs than families with older children do, while Farmer et al. [13] and Palisano et al. [6] indicate that the child's age is not related to family needs.

Researches into the needs of families with children who suffer from CP have been conducted in the United States, Western Europe, China, and Japan [6–8,14,15]. We assume that socioeconomic and historical differences might have an impact on the type of needs faced by families with children who suffer from CP in our region.

The aims of this study were to identify the most frequently expressed needs of families with preschool children with cerebral palsy; differences in the amount and types of family needs based on the child's gross motor function and communication function level; and the impact of the child's gross motor function and communication function level on the type and amount of family needs.

2. Materials and methods

2.1. Participants

This descriptive study involved a survey of families with preschool-aged children (aged 2–7 years) with a primary diagnosis of CP, with the children receiving services from two rehabilitation centers and one hospital in Latvia. The study was approved by local institutional ethics committees. A total of 241 families were invited to take part in the study. Potential participants were contacted in person during a visit to a clinic or by telephone.

2.2. Measures

2.2.1. Family Needs Survey

The Family Needs Survey (FNS) is a 35-item questionnaire to measure the specific and current needs of families with young children who suffer chronic conditions and disabilities [16]. Items are grouped in 6 subscales according to the type of needs: Needs for Information; Needs for Support; Explaining to Others; Community Services; Financial Needs; Family Functioning. The response options are: 1 = *I definitely do not need help with this*, 2 = *Not sure*, 3 = *I definitely need help with this*.

For the present study we used a translated (into the Latvian language) and modified version of FNS. In terms of the needs that might be more specific in our country, one item was removed and six items were added with the written permission of the authors, for a total of 41 items. The item removed: ''Getting child care in church/synagogue''. The items included the following: ''Finding information about planning for child's wellbeing in future,'' ''Finding information about future education,'' ''Explaining my child's condition to professionals,'' ''Locating rehabilitation services,'' ''Coordinating medical, developmental, educational, and other community services,'' and ''Paying for home modification.''

The internal consistency (Cronbach alpha) and test–retest reliability (ICC 2.1) of the translated and modified version of FNS were tested in advance of the original study. The Cronbach alpha coefficient for all 41 items was 0.82 and ranged between 0.71 and 0.89 for each type of need. ICC 2.1 for all items was 0.89 and the coefficient varied from 0.72 to 0.98.

For the purposes of this study, only the items that were scored with number 3 (I definitely need help with this) were considered to be unmet family needs and were scored for getting the total number of family needs and the number of each type of need for data analysis.

2.2.2. The Gross Motor Function Classification System

The Gross Motor Function Classification System (GMFCS) is a 5-level classification system developed for children with CP to classify gross motor function on the basis of causal performance [17]. Particular emphasis is on sitting, walking, and wheeled mobility (Table 1).

Table 1 – The level description of Gross Motor Function Classification System (GMFCS) and Communication Function Classification System (CFCS).

Level	GMFCS	CFCS
I	Walks without limitation	Sends and receives information with familiar and unfamiliar partner effectively
II	Walks with limitation	Sends and receives information with familiar and unfamiliar partner – may need extra time
III	Walks with assistive mobility devices	Sends and receives information with familiar partner but not with unfamiliar partners
IV	Self-mobility with limitation, children are transported or use wheeled mobility	Inconsistently effectively sends and receives information even with familiar partner
V	Self-mobility is severely limited, children are transported	Seldom effectively sends and receives information even with familiar partner

2.2.3. *Communication Function Classification System*

The Communication Function Classification System (CFCS) is a 5-level classification system developed to classify the everyday communication performance of an individual with CP [18]. The CFCS groups children in terms of the effectiveness of their current communication performance and regardless of the communication method that is used (speech, gestures, eye gaze, alternative communication, etc.) (Table 1).

2.3. *Procedure*

Parents who agreed to participate in the study completed a demographic questionnaire and the modified FNS. The children's GMFCS and CFCS levels were classified on the basis of consensus between parents and professionals (physiotherapists and speech therapists, respectively) during clinic visits.

2.4. *Data analysis*

Statistical analysis was performed using SPSS for Windows (version 17). The total number of family needs and the number of each type of need were tabulated by GMFCS and CFCS level. Interactions between the total number of family needs, the number of each type of need and GMFCS and CFCS level were examined by one-way analysis of variance (ANOVA). Bonferroni correction was used to perform paired comparisons. Multivariate linear regression was used to identify the importance of child's GMFCS and CFCS level in terms of the type and amount of family needs. P value of <0.05 was considered to be statistically significant for all tests.

3. Results

A total of 227 parents or legal guardians of children with CP participated in the study, with 14 families refusing to take part for various reasons. Parents or legal guardians provided informed consent. Most (93.4%) of participants were mothers with a mean age of 34.9 years (SD, 7.9). The mean age of their children was 4.8 (SD, 1.7). More than 91.2% of respondents had a higher education, and almost half (48.9%) were unemployed. The majority (82.4%) had a spouse, and for one-half (49.3%) of participants, the child with CP was their only child. Children were mostly classified with the spastic form of CP (80.1%). At least one form of comorbidity was reported in 153 (61.4%) children. The demographics of the parents, families and children, as well as the classification of children in accordance with GMFCS and CFCS are presented in Table 2.

The most frequently cited unmet needs included information about services available now (88.5%) and services that children might receive in future (89%). Information about the child's education now and in future was of concern to 85% of

Table 2 – Characteristics of parents, families and children; children classification according Gross Motor Function Classification System level (GMFCS) and Communication Function Classification System level (CFCS).

Family characteristics	*n* (%)	Child characteristics	*n* (%)
Relationship to the child		Gender	
Mother	212 (93.4)	Male	128 (56.4)
Father	4 (1.8)	Female	99 (43.6)
Grandmother	7 (3.1)	Comorbidities[a]	
Guardian	4 (1.8)	Visual impairment	90 (36.6)
Education		Hearing impairment	27 (11.9)
Bachelor's/Master's degree	89 (39.2)	Cognitive impairment	153 (61.4)
Secondary school	118 (52.0)	Seizure	56 (24.7)
Lower than secondary school	20 (8.8)	Child health[a]	
Employment		Good	91 (40.1)
Full-time	79 (34.8)	Fair	123 (54.2)
Part-time	33 (14.5)	Poor	13 (5.7)
Not employed	111 (48.9)	Type of cerebral palsy	
Studying	4 (1.8)	Spastic unilateral	75 (33.0)
Marital status		Spastic bilateral	107 (47.1)
Married or living with partner	187 (82.4)	Dyskinetic	24 (10.6)
Widowed	3 (1.3)	Ataxic	9 (4.0)
Divorced or separated	19 (8.4)	Not specified/mixed	12 (5.3)
Single	18 (7.9)	GMFCS level	
Children in household		I	76 (33.5)
One	112 (49.3)	II	43 (18.9)
Two	78 (34.4)	III	42 (18.5)
Three or more	37 (16.3)	IV	46 (20.3)
Family income (EUR per month)		V	20 (8.8)
Less than 419	37 (16.3)	CFCS level	
420–839	132 (58.1)	I	54 (23.8)
840–1119	38 (16.7)	II	41 (18.1)
More than 1120	17 (7.5)	III	40 (17.6)
No answer	3 (1.3)	IV	54 (23.8)
		V	38 (16.7)

[a] Parent-reported.

Table 3 – Mean number of family needs by children's Gross Motor Function Classification System level (ANOVA and paired comparisons).

Type of needs (subscales and total)	Items[a]	Level I	Level II	Level III	Level IV	Level V	ANOVA		
		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	*F*	*P* value	Significant paired comparisons
Information	9	6.08 (2.23)	6.12 (2.35)	6.67 (1.98)	7.07 (1.55)	7.30 (1.52)	2.917	0.022	None
Support	8	3.13 (2.06)	3.23 (2.14)	3.95 (2.19)	3.89 (2.28)	4.15 (1.66)	2.055	0.088	None
Explaining to others	6	1.14 (1.64)	1.26 (1.52)	1.50 (1.56)	1.26 (1.37)	1.25 (1.51)	0.358	0.838	None
Community services	6	1.62 (1.44)	2.37 (1.63)	2.62 (1.62)	3.37 (1.30)	3.70 (1.12)	14.421	0.000	I < III–V II < IV and V
Financial	7	1.83 (1.22)	2.40 (1.46)	3.02 (1.85)	3.63 (1.69)	3.65 (1.56)	13.238	0.000	I < III–V II < IV and V
Family functioning	5	0.55 (0.82)	0.72 (1.07)	0.76 (1.05)	0.74 (0.90)	0.55 (0.82)	0.570	0.685	None
Total family needs	41	14.03 (6.53)	16.09 (7.36)	18.52 (7.38)	19.96 (6.15)	20.60 (5.16)	7.385	0.000	I < III–V

[a] Number of items in subscale/total.

parents. In the area of social support, parents would like to have greater opportunities to meet and talk to other families of children with disabilities (59%), or to read about others who have similar children (73.6%). Participants indicated that they need help with co-ordination of care (72.7%) and with the location of rehabilitation services (61.2%). Most parents need financial aid to pay for therapy, childcare, or other services for their children (77.1%), and more than one-half (57.7%) need help in paying for the special equipment that their children need. The least frequently cited unmet needs related to explaining the situation to others (9.3%–33.5%) and family functioning (1.3%–17.2%).

The mean number of the total and type of family needs in accordance with the children's GMFCS and CFCS level, as well as significant paired comparisons, are presented in Tables 3 and 4, respectively. The interaction between the GMFCS level and the total number of family needs was significant ($F(4, 222) = 7.38$, $P < 0.001$). Bonferroni post hoc comparisons of the five groups indicated that parents with children at Level I expressed fewer family needs than those with children at level III ($M = -4.16$; 95% CI: −7.81 to −0.52), Level IV ($M = 5.60$; 95% CI: −9.14 to −2.06), and Level V ($M = -6.24$; 95% CI: −11.01 to −1.48). The differences between the total number of family needs and other GMFCS levels were not statistically significant.

The mean number of needs for information, community services and finances differed on the basis of the GMFCS level ($P < 0.05$). There were no statistically significant interactions between the GMFCS level and family needs in the areas of support, explaining the situation to others, and family functioning.

The interaction between the CFCS level and the total number of family needs was significant ($F(4, 222) = 11.18$, $P < 0.001$). Bonferroni post hoc comparisons showed that the parents with children at Level I expressed fewer family needs than those with children at Level III ($M = -4.38$; 95% CI: −8.23 to −0.55), Level IV ($M = -4.98$; 95% CI: −8.53 to −1.44), and Level V ($M = -8.48$; 95% CI: −12.38 to −4.59). Parents of children at Level II had fewer family needs than parents of children at Level V ($P < 0.001$). The differences between the total number of family needs and other CFCS levels were not statistically significant.

Table 4 – Mean number of family needs by children's Communication Function Classification System level (ANOVA and paired comparisons).

Type of needs (subscales and total)	Items[a]	Level I	Level II	Level III	Level IV	Level V	ANOVA		
		Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	*F*	*P* value	Significant paired comparisons
Information	9	5.59 (2.15)	5.93 (2.19)	6.83 (1.86)	6.81 (2.01)	7.63 (1.34)	7.544	0.000	I < III–V II < V
Support	8	2.85 (2.11)	3.02 (2.34)	3.73 (1.78)	3.83 (2.17)	4.50 (1.85)	4.486	0.002	I and II < V
Explaining to others	6	0.78 (1.32)	1.59 (1.87)	1.53 (1.69)	1.19 (1.33)	1.45 (1.40)	2.309	0.059	None
Community services	6	1.56 (1.72)	1.95 (1.41)	2.58 (1.41)	2.78 (1.44)	3.87 (1.01)	16.244	0.000	I–IV < V I < III–V
Financial	7	2.07 (1.52)	2.12 (1.45)	2.53 (1.30)	3.04 (1.84)	3.82 (1.64)	8.967	0.000	I–III < IV I < IV
Family functioning	5	0.61 (0.89)	0.51 (0.81)	0.68 (0.85)	0.80 (0.89)	0.68 (1.21)	0.587	0.673	None
Total family needs	41	13.46 (7.30)	15.12 (6.76)	17.85 (5.53)	18.44 (6.57)	21.95 (5.75)	11.186	0.000	I < III–V II < V

[a] Number of items in subscale/total.

The mean number of needs for information, finances, community services ($P < 0.001$) and support ($P < 0.05$) differed on the basis of CFCS levels. There were no statistically significant interactions between the CFCS level and family needs in relation to explaining the situation to others and family functioning.

Multiple regression analysis showed that the children's GMFCS and CFCS levels were not significant predictors of overall family needs (adjusted $R^2 = 0.163$). In this model, the GMFCS level of children did not account for a total number of family needs ($\beta = 0.127$, $P = 0.122$), while the CFCS level did do ($\beta = 0.317$, $P = 0.000$). Nevertheless, the GMFCS level was a predictor of needs for community services and finances ($\beta = 0.254$, $P = 0.001$ and $\beta = 0.348$, $P = 0.000$). The CFCS level was also found to be a predictor of family needs in the areas of information ($\beta = 0.344$, $P = 0.000$), support ($\beta = 0.268$, $P = 002$), and community services ($\beta = 0.0292$, $P = 0.000$).

4. Discussion

Consistently with previous findings [6–8,15], a higher percentage of parents in our study said that they need information about present and future services, as well as about ways to promote their children's education. The desire for information was at an extremely high level: at least 6 (out of 9) information-related needs were reported as unmet by each respondent. We assume that the high percentage of parents with unsatisfied family needs in this area might be influenced by the age of the children. Our sample included parents with children aged 2–7 years – an age during which caregivers are still very confused and insecure about their children's development and are thus seeking out all available information to facilitate it.

Under the category of support, families indicated a desire to meet with others who have a child with CP and to read materials about families with such children. This suggests that parents are largely isolated from other families with children who are suffering from disabilities. Co-ordination of services and the location of rehabilitation services for children were also strong concerns among parents. It must be mentioned that rehabilitation and educational services for children with developmental disabilities are still developing in our country. Despite recent and positive changes in policies that relate to community support systems and funding, parents still seek financial aid to pay for therapy or to buy the special equipment that their children need. These findings might also be explained by the fact that nearly one-half of surveyed parents were unemployed, and most families live in rural areas where community services are poorly developed. A low average level of family income may also have an impact on the high number of unmet family needs in the area of finances.

Although a child's gross motor and communication function abilities relate significantly to the total number of family needs, these factors were not considered to be a strong predictor of family needs. King et al. [12] and Farmer et al. [13] have also reported that the severity of a child's disability is not necessarily a key determinant of family outcomes. On the other hand, others [6,8,11] have found the child's functional limitations to be a strong determinant of overall family needs. Unmet family needs appear to vary by the complexity of the child's functional limitations and the various types of family needs. In our study, the parents of children with more severe gross motor function limitations stated greater needs for community services and finances. This supports findings by Palisano et al. [6] and Almasri et al. [11], who have argued that the needs of families with children who have CP for community services and finances vary on the basis of the children's gross motor function. In our study, the child's inability to communicate effectively proved to be a more important factor in terms of the number of unmet family needs than was the case with the child's gross motor function limitations. In addition to the need for community services and finances, parents of children with more severe communication limitation need more information and social support. Almasri et al. [11] also report that the adaptive behaviors and communication of children are directly associated with family needs. The ability to communicate allows children to interact more effectively with family members in terms of expressing their needs and desires. Serious problems with communication may lead to social exclusion, and parents who cannot understand their children often feel helpless, frustrated and isolated themselves [19].

Parents of children with minor gross motor and communication limitations seem to have significantly fewer unmet family needs than is the case with parents of children with more severe disabilities. This should be taken into account when planning social, educational and rehabilitation services, particularly in a situation of limited financial resources. Service providers, thus, must be familiar with the real needs of each family so as to provide the necessary support and services in an effective, but also economical way.

Families that took part in this study did not mention the need for help in explaining the child's condition to other people involved in the situation (teachers, neighbors, physicians, other children); parents believe that they can do this themselves. They also did not mention the need for help in terms of resolving internal family functioning issues such as the taking of decisions about who will take care of the child, who will be the wage earner, who will help to resolve discrepancies, etc. These results may be based on our historical background. In the past, families did not seek professional help to solve their internal problems. The tendency to focus on needs related to the child's development, as opposed to the needs of the whole family [20] may also help to account for our findings.

The strength of our study is a very high response rate (94%) of invited caregivers for preschool aged children with CP agreed to participate. According to official data from the Latvian State Medical Commission for the Assessment of Health Condition and Working Ability, there are currently 264 children diagnosed with CP who are between two and seven years old. This means that our sample covered 86% of the whole population.

Children's functional abilities (GMFSC and CFCS) were classified on the basis of a consensus between parents and professionals. This approach can be seen as both a strength and a limitation in this study.

5. Conclusions

The most frequently endorsed needs in our sample of families with preschool children with CP were for information about

the current and future services, children's teaching and future education, helping in locating rehabilitation services and care coordination. Parents of preschool aged children with CP who walk independently and can communicate with familiar and unfamiliar partner have significantly less unmet family needs than parents of children with more severe disabilities. The children's GMFCS (representing gross motor ability) level did not appear to be a strong determinant for the total number of unmet family needs in families with preschool children with CP, while the CFCS (representing communication ability) level did. Nonetheless, the children's GMFCS level was found to be predictor for the needs for community services and finances.

Conflict of interest

The authors state no conflict of interest.

Acknowledgments

The authors wish to thank the families and services that participated in this study. In addition, the first author would like to send special thanks to her colleagues – physiotherapists and speech therapists – involved in the evaluation of children.

REFERENCES

[1] Hassall R, Rose J, McDonald J. Parenting stress in mothers of children with an intellectual disability: the effects of parental cognitions in relation to child characteristics and family support. J Intellectual Disabil Res 2005;49:405–18.
[2] Hastings RP, Beck A, Hill C. Positive contributions made by children with an intellectual disability in the family mothers' and fathers' perceptions. J Intellectual Disabil Res 2005;9(2):155–65.
[3] Olsson MB, Larsman P, Hwang PC. Relationships among risk, sense of coherence, and well-being in parents of children with and without intellectual disabilities. J Policy Pract Intellect Disabil 2008;5(4):227–36.
[4] Walker DK, Epstein SG, Taylor AB, Crocker AC, Tuttle GA. Perceived needs of families with children who have chronic health conditions. Child Health Care 1989;18:196–201.
[5] Sloper P, Turner S. Service needs of families of children with severe physical disability. Child Care Health Dev 1992;18:259–82.
[6] Palisano R, Almasri N, Chiarello L, Orlin M, Maggs J. Needs of families of children and youth with cerebral palsy. Child Care Health Dev 2010;36:85–92.
[7] Wang P, Michaels CA. Chinese families of children with severe disabilities: family needs and available support. Res Pract Pers Sev Disabil 2010;34(2):21–32.
[8] Nitta O, Taneda A, Nakajima K, Surya J. The relationship between the disabilities of school-aged children with cerebral palsy and their family needs. J Phys Ther Sci 2005;7:103–7.
[9] Murray HM, Maslany GW, Jeffery B. Assessment of family needs following acquired brain injury in Saskatchewan. Brain Inj 2006;20:575–85.
[10] Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, et al. A report: the definition and classification of cerebral palsy. Dev Med Child Neurol Suppl 2007;109:8–14.
[11] Almasri NA, Palisano RJ, Dunst CJ, Chiarello LA, O'Neil ME, Polansky M. Determinants of needs of families of children and youth with cerebral palsy. Child Care Health Dev 2011;40(2):130–54.
[12] King G, King S, Rosenbaum P, Goffin R. Family-centered caregiving and well-being of parents of children with disabilities: linking process with outcome. J Pediatr Psychol 1999;24(1):41–53.
[13] Farmer JE, Marien WE, Clark MJ, Sherman A, Selva TJ. Primary care supports for children with chronic health conditions: identifying and predicting unmet family needs. J Pediatr Psychol 2004;29(5):355–67.
[14] Carpenter B. Sustaining the family: meeting the needs of families of children with disabilities. Br J Spec Educ 2003;27 (3):135–44.
[15] Ellis JT, Luiselli JK, Amirault D, Byrne S, O'Malley-Cannon B, Taras M, et al. Families of children with developmental disabilities: assessment and comparison of self-reported needs in relation to situational variables. J Dev Phys Disabil 2002;14(2):191–202.
[16] Bailey Jr DB, Simeonsson RJ. Assessing needs of families with handicapped infants. J Spec Educ 1988;22(1):117–27.
[17] Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. Dev Med Child Neurol 1997;39(4):214–23.
[18] Hidecker MJC, Paneth N, Rosenbaum PL, Kent RD, Lillie J, Eulenberg JB, et al. Developing and validating the Communication Function Classification System for individuals with cerebral palsy. Dev Med Child Neurol 2011;53(8):704–10.
[19] Pennington L. Cerebral palsy and communication. Paediatr Child Health 2008;18(9):405–9.
[20] Perrin EC, Lewkowicz C, Young MH. Shared vision: concordance among fathers, mothers, and pediatricians about unmet needs of children with chronic health conditions. Am Acad Pediatr 2000;105(Suppl. 2):277–85.