Family Priorities for Activity and Participation of Children and Youth With Cerebral Palsy

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Background. Understanding family priorities for children and youth with cerebral palsy is essential for family-centered service.

Objective. The purposes of this study were: (1) to identify family priorities for activity and participation in children and youth with cerebral palsy and (2) to determine differences based on age and Gross Motor Functional Classification System (GMFCS) level.

Design. Five hundred eighty-five children and youth with cerebral palsy and their caregivers participated at regional children's hospitals. The children and youth were 2 to 21 years of age; 56% were male, and 44% were female. Their caregivers, predominantly mothers (80%), had a mean age of 40.3 years (SD=9.3). The Canadian Occupational Performance Measure was administered to caregivers to identify their priorities for their children. The priorities were coded into 3 categories (daily activities, productivity, and leisure) and 13 subcategories. The GMFCS levels were determined by assessors who met the criterion for reliability. Friedman and Kruskal-Wallis one-way analyses of variance were used to examine differences in priorities.

Results. Parents of children in all age groups and GMFCS levels II to V identified more priorities for daily activities. Parents of school-aged children and youth had more priorities for productivity than parents of younger children. For parents of children in all age groups and motor function levels, self-care was the most frequent priority subcategory. Sixty-one percent of parents identified at least one priority related to mobility.

Limitations. The study did not include qualitative analysis of priorities of parents.

Conclusions. Parents' priorities for their children and youth with cerebral palsy differed depending on age and gross motor function level; however, the most frequent priority for all age groups was daily activities. Interviews with families are recommended for identifying outcomes for activity and participation and developing an intervention plan.

Understanding the priorities and needs of children and youth with cerebral palsy and their families is essential for family-centered service. A family-centered approach embodies the belief that processes and outcomes of health care are optimized through services that encompass the child, family, and environmental settings in which the child lives, learns, and plays.[1–3] *Cerebral palsy* describes a group of disorders of posture and movement that occur as a result of a nonprogressive disturbance in the developing fetal or infant brain and that often are accompanied by impairments in sensation, perception, cognition, and communication.[4] For children with cerebral palsy, an interdisciplinary, family-centered rehabilitation approach is recommended to address child and family needs.[5] In the current health care system, services need to be efficient and goal-directed. Yet, little is known about priorities and needs for activity and participation among families of children with cerebral palsy and how these needs may differ based on the child's age and motor function.

Most studies exploring parents' priorities for their children have included a heterogeneous sample of children with various physical disabilities and have not examined whether priorities differ based on the child's age and severity of the child's condition. Parents of children under 8 years of age referred for occupational therapy identified personal care, functional mobility, play, and socializing most frequently as their priorities.[6] Pollock and Stewart[7] examined the needs of 92 young school-aged children with physical disabilities at school and in the community. Parents identified mobility most often as a priority and expressed concerns about dressing, toileting, socialization, play, and written work. In a sample of 14 adolescents with physical disabilities, parents expressed the highest percentage of priorities for self-care, followed by household management and socialization.[8] Parents also were particularly concerned about implications for the future. A qualitative study with 15 families of adolescents with physical disabilities showed that parents were concerned about nutrition and physical activity, social life, future productivity, daily routines, and balancing their adolescents' need for independence with safety and energy conservation.[9]

Three studies have examined parents' priorities for their children with cerebral palsy. Through an interview, parents of 12 young children with cerebral palsy, 1 to 4 years of age, identified self-care, mobility, sitting and standing, and play as focused tasks for physical therapy and occupational therapy intervention.[3] Similarly, parents of 13 young children with cerebral palsy, 2 to 4 years of age, identified self-care, mobility, play, socialization, strength, coordination, and balance as priorities for rehabilitation.[10] These studies did not explore priorities based on the child's motor ability. Knox[11] performed a retrospective chart review of parent concerns at the start of rehabilitation therapy for 121 children with cerebral palsy (with 57% of the children having a poor prognosis for independent walking). Parents most often expressed priorities for standing and walking, except for parents of children with limited motor ability, whose most frequent priorities were sitting, communication, and floor mobility. Parents' priorities for standing and walking were most prevalent when children were between 2 and 4 years of age or 6 years of age and older; whereas floor mobility was most prevalent when children were under the age of 2 years.

It is difficult to generalize priorities of families of children with physical disabilities to families of children with cerebral palsy. In addition, knowledge of whether family priorities for their children with cerebral palsy differ depending on the children's ages and gross motor abilities has implications for family-centered services. Most important, to reflect contemporary frameworks for rehabilitation practice such as the *International Classification of Functioning, Disability and Health*,[12] there is a need to understand family priorities related to their children's activity and participation in daily life. Research has focused primarily on identifying parents' goals for their children's therapy programs. These findings may reflect parents' perceptions of and experiences with rehabilitation services but may not fully reflect their priorities for their children's activity and participation at home, in school, and in the community.

The primary purpose of this study was to categorize parents' priorities for activity and participation of children and youth with cerebral palsy and identify differences based on children's age and gross motor function level. A secondary purpose of the study was to examine whether priorities for activity and participation are related to mobility. Mobility is a primary focus of rehabilitation services for children with cerebral palsy, and information on the extent to which priorities are related to mobility will inform efforts to meet the comprehensive needs of children with cerebral palsy and their families.

Method

A cross-sectional analytic design was used. The participants were part of a larger study of determinants of activity and participation of children with cerebral palsy. Parents or guardians and young people aged 18 to 21 years provided consent; children and adolescents aged 7 to 17 years provided informed assent.

Participants

A sample of 585 parents or guardians of children with cerebral palsy was recruited from 6 Shriners Hospitals for Children (Philadelphia, Pennsylvania; Chicago, Illinois; Erie, Pennsylvania; Lexington, Kentucky; Sacramento, California; Springfield, Massachusetts) and Kluge Children's Rehabilitation Center, Charlottesville, Virginia. All children with cerebral palsy receiving services at 1 of the 7 sites were eligible for the study if they did not have a concomitant illness or health condition (eg, cystic fibrosis, cancer, a mental health disorder) that might affect participation.

Table 1 provides demographic information on the participants and their children. The participants were primarily mothers (80%) and fathers (11%). Other participants included stepparents, foster parents, grandparents, and guardians. All will be referred to as parents throughout the article. Parents had a mean age of 40.3 years (SD=9.3), 50% had education beyond high school, and 61% were employed. The children and youth were 2 to 21 years of age, with a mean age of 11.0 years (SD=4.5); 56% were male, and 44% were female. Table 1 provides demographic information of the children and youth grouped by age: under 6 years, 6 to 12 years, and 13 to 21 years. Gross motor function varied across Gross Motor Function Classification System (GMFCS) levels.

The Bottom Line

What do we already know about this topic?

Parents of young children with cerebral palsy have identified self-care, mobility, standing or walking, and play as priorities for their children's rehabilitation programs.

What new information does this study offer?

Parents' priorities for activity and participation differ based on age and gross motor function level of the child. Priorities for daily activities, particularly self-care, were identified more often than productivity or leisure for children of all ages. Parents of school-aged children had more priorities for productivity than parents of younger children. Parents of children who were able to walk without limitations had a similar amount of priorities for daily activities, productivity, and leisure.

If you're a patient, what might these findings mean for you?

It is important for parents and children to share their priorities with their therapist and advocate for support and resources for daily activities. Physical therapists are encouraged to explore children's interests in participation in home, school, and community life.

Measures

The Canadian Occupational Performance Measure (COPM), 3rd edition,[13] is an individualized, client-centered measure designed to identify and quantify a client's priorities related to self-care, productivity, and leisure. *Occupational performance* refers to an individual's experiences in performing activities in daily life. *Self-care* includes personal care, functional mobility, and community management. *Productivity* includes paid or unpaid work, household management, school, and play. *Leisure* includes quiet recreation, active recreation, and socialization. The COPM is completed through a semi-structured interview with a client or caregiver. The COPM has been widely used in research with children with disabilities and demonstrates sound reliability and validity.[6,13,14]

As the COPM is an individualized measure, resulting in narrative statements, for this study we developed a coding system to categorize the priorities identified by the parents. The coding system was based on the coding scheme developed by Pollock and Stewart[7] and was refined through literature review of studies using the COPM and analysis of our pilot data. The coding system consisted of 3 categories and 13 subcategories: daily activities (self-care, mobility, communication, and other daily activities), productivity (household, school, community, and other productivity), and leisure (socialization, community entertainment, quiet recreation, physical recreation, and other leisure). Self-care priorities were further categorized into specific activities: eating, dressing, bathing, toileting, and hygiene. Operational definitions of the categories were developed to ensure reliable use of the coding system. Because the intent of the study was to identify the parents' priorities related to activity and participation of their children, priorities were coded based

Table 1.
Demographic Information on Children and Caregivers by Age Group (%)

Variable	Age Group			
	<6 y (n=91)	6–12 y (n=296)	13–21 y (n=198)	Total (N=585)
Child age (y)				
$\bar{X}$	4.4	9.6	16.2	11.0
SD	1.0	2.0	2.2	4.5
Range	1.9–5.9	6–12.9	13–20.9	1.9–20.9
Child sex				
Male	57 (63%)	171 (58%)	100 (50.5%)	328 (56%)
Female	34 (37%)	125 (42%)	98 (49.5%)	257 (44%)
Child race/ethnicity				
White (not of Hispanic origin)	66 (73%)	235 (79%)	135 (68%)	436 (74%)
African American or black (not of Hispanic origin)	8 (9%)	19 (6%)	19 (10%)	46 (8%)
Hispanic/Latino	4 (4%)	22 (8%)	20 (10%)	46 (8%)
Other	13 (14%)	20 (7%)	24 (12%)	57 (10%)
Caregiver age[a] (y) (n=506)				
$\bar{X}$	34.7	39.1	44.7	40.3
SD	9.3	8.1	9.0	9.3
Range	20–74	23–64	24–72	20–74
Caregiver's relationship to the child[a] (n=579)				
Mother	78 (87%)	230 (79%)	152 (77%)	460 (80%)
Father	5 (5%)	36 (12%)	25 (13%)	66 (11%)
Other	7 (8%)	25 (9%)	19 (10%)	51 (9%)
Caregiver's educational background[a] (n=551)				
Less than high school	5 (6%)	16 (6%)	11 (6%)	32 (6%)
High school	29 (35%)	132 (47%)	83 (44%)	244 (44%)
Associate's/technical degree	23 (27%)	53 (19%)	55 (29%)	131 (24%)
Bachelor's degree	17 (20%)	59 (21%)	29 (15%)	105 (19%)
Graduate degree	10 (12%)	18 (7%)	11 (6%)	39 (7%)
Caregiver's employment status[a] (n=543)				
Not employed	44 (53%)	99 (36%)	68 (37%)	211 (39%)
Part-time	13 (16%)	59 (22%)	38 (20%)	110 (20%)
Full-time	26 (31%)	116 (42%)	80 (43%)	222 (41%)
Caregiver's family income[a] (n=509)				
<$15,000	9 (12%)	30 (12%)	21 (12%)	60 (10%)
$15,000–$29,999	13 (17%)	30 (12%)	28 (16%)	71 (12%)
$30,000–$44,999	12 (16%)	60 (23%)	33 (19%)	105 (18%)
$45,000–$59,999	14 (18%)	37 (14%)	18 (10%)	69 (12%)
$60,000–$74,999	12 (16%)	38 (15%)	28 (16%)	78 (13%)
$75,000–$99,999	9 (12%)	37 (14%)	18 (10%)	64 (11%)
$100,000–$199,999	8 (10%)	26 (10%)	20 (12%)	54 (9%)
≥$200,000	0 (0%)	1 (0%)	7 (4%)	8 (1%)

[a] Caregiver demographic information not available for the complete sample.

on the expressed functional activity. As an example, "I would like my child to have better motor skills so that she can play an instrument" would be coded as "Leisure, quiet recreation."

The GMFCS[15] is a 5-level system to classify gross motor function of children with cerebral palsy 12 years of age and younger. The preliminary version of the 12- to 18-year-old age band of the expanded and revised GMFCS was used to classify participants over 12 years of age.[16] The classification of a child's gross motor function is based on current performance during daily activities and routines, with emphasis on sitting, transfers, and mobility. The GMFCS has evidence of content validity, construct validity, and interrater reliability.[15,16]

Preparation of Research Assistants

At each hospital, data were collected by 1 to 3 research assistants. The majority of research assistants were health care professionals experienced in serving children and families with cerebral palsy, and all were selected to collect data based on their positive interpersonal and communication skills. Prior to data collection, the research assistants received a procedural manual, including training videos, for the administration of the COPM, and attended a 2-day training workshop. Following instruction in the GMFCS, interrater reliability was examined using a videotape. Each assessor classified a minimum of 11 children and demonstrated a percentage of agreement of greater than 80% with the criterion levels. Following instruction and role playing in administration of the COPM, the research assistants completed a trial interview that was audiotaped and reviewed for procedural accuracy by one of the authors (L.A.C. or J.M.M.). Throughout the study, an additional onsite meeting, group teleconferences, and e-mail and telephone communications were used to provide additional guidance and direction for the administration and coding of the COPM. The primary issue requiring additional guidance related to the challenge of framing parent priorities for children with significant motor and cognitive impairments, especially when priorities were focused on health and educational systems of care as opposed to direct priorities for their children.

Procedure

As part of the larger study on activity and participation of children with cerebral palsy, the research assistants observed the motor abilities of the children and youth and determined their GMFCS level. The COPM was completed with the parent using the procedure described in the manual. The interview process consisted of the following steps. First, the parent was asked a series of open-ended questions and prompts to encourage identification of current priorities and needs. Sample questions included: Are you pleased with what your child is able to do now at home? and Are there activities that are difficult for your child that you would like her or him to be able to do better? Next, the parent rated the priorities for their importance on a scale of 1 ("not important at all") to 10 ("extremely important") and selected up to 5 top priorities. The length of the interviews ranged from 5 to 60 minutes, with a typical length of 20 minutes. Length of the interviews varied based on the number of priorities expressed by the parents and the depth of the discussion. The research assistants coded the priorities and entered the data into a computer software program.

Data Analysis

The coding of the statements was reviewed by the first author (L.A.C.). The author concurred with the coding of 95% of the statements. The author consulted with the research assistants to modify the coding of 3.5% of the statements, and the consensus of the first 2 authors (L.A.C., R.J.P.) was used to finalize coding of the remaining 1.5% of the statements.

Statistical analyses were performed using the SPSS for Windows software program (version 15.0).* Descriptive statistics were conducted to describe the demographic characteristics of the participants and to summarize parents' priorities for their children by categories and subcategories. Priorities of parents were grouped based on their children's age group (<6, 6–12, and 13–21 years) and GMFCS levels (I, II/III, and IV/V). Forty-six parents (8%) did not report any priorities and were excluded from the analyses. A higher percentage of parents of children in GMFCS level I (13%) reported no priorities compared with parents of children in GMFCS levels II/III (6%) and IV/V (7%).

In addition to general mobility priorities that were coded as "Daily activities, mobility," such as "I want my child to be able to walk longer distances," priorities were coded for functional activities, such as "bathing." We were interested in examining whether parents' priorities for their children included an issue related to mobility, such as transferring into the bathtub. To determine whether parents' priorities for their children were related to mobility, 2 investigators (N.A. and L.-J.K.) independently reviewed all the priorities for each child to determine whether mobility was an issue for at least one of the priority activities. The 2 investigators achieved interrater reliability of 98.7%. When disagreements were present, consensus was reached through discussion with the primary investigator (L.A.C.).

* SPSS Inc, 233 S Wacker Dr, Chicago, IL 60606.

For each age group (<6, 6–12, 13–21 years) and GMFCS level subgroup (I, II/III, and IV/V), differences in the number of priorities for each category were examined using Friedman one-way analyses of variances (ANOVAs). *Post hoc* analysis of significant effects was performed using the Wilcoxon signed rank test. For each category, differences in the number of priorities between age groups and GMFCS level subgroups were analyzed using Kruskal-Wallis one-way ANOVAs. *Post hoc* analysis of significant effects was performed using the Mann-Whitney *U* test. Chi-square tests were used to determine whether the proportion of parents with at least one priority related to mobility differed by age group and GMFCS level subgroup. A probability of $P \leq .01$ was used for all analyses. For each age group and GMFCS level subgroup, the percentage of the number of priorities among the total number of priorities for each subcategory was calculated. Differences were not analyzed statistically.

Role of the Funding Source

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Results

Effect of Children's Age on Parents' Priorities

Table 2 presents the number of priorities, percentage of the number of priorities among the total number of priorities, and median number of priorities for each category by age group. Parents' priorities for each category differed for each age group (for the <6 years age group, $\chi^2=104.04$, $P<.001$; for the 6–12 years age group, $\chi^2=182.91$, $P<.001$; and for the 13–21 year age group, $\chi^2=25.01$, $P<.001$). Table 3 presents the *z* scores for *post hoc* analyses of significant effects. Parents of children aged <6 years identified the most priorities for daily activities (70%, median number=3) and the least for productivity (8%, median number=0). Parents of children aged 6 to 12 years (59%, median number=2) and youth aged 13 to 21 years (44%, median number=1) also expressed the most priorities for daily activities, but the number of priorities for leisure and productivity did not differ for either age group.

Parents' priorities for daily activity ($\chi^2=50.50$, $df=2$, $P<.001$) and productivity ($\chi^2=45.93$, $df=2$, $P<.001$) differed by age group (Tab. 2). Parents of youth aged 13 to 21 years had fewer priorities in daily activities (44%, median number=1) than parents of children aged 6 to 12 years (59%, median number=2) and <6 years (70%, median number=3). Parents of children aged 6 to 12 years had more priorities in productivity (20%, median number=1) than parents of children aged <6 years (8%, median number=0). Parents' priorities for leisure did not differ by age group.

Table 4 presents the number and percentage of the number of priorities among the total number of priorities for each subcategory by age group. Parents expressed 25% to 42% of priorities for self-care and 11% to 17% of priorities for mobility depending on their children's age. Parents of youth aged 13 to 21 years expressed 14% of priorities for socialization.

Table 5 presents the number and percentage of the number of priorities among the total number of self-care priorities for each area of self-care by age group. Parents expressed 30% to 39% of priorities for dressing depending on their children's age. Parents of children aged <6 years

Table 2.
Parents' Priorities for Each Category by Age of Their Children and Youth

Category	Age Group								
	<6 y (n=85)			6–12 y (n=276)			13–21 y (n=178)		
	n	%	Median	n	%	Median	n	%	Median
Daily activities	220	70	3	649	59	2	284	44	1
Productivity	25	8	0	217	20	1	197	31	1
Leisure	68	22	1	228	21	1	161	25	1

Table 3.
Effect of Age: *z* Scores for *Post Hoc* Analyses of Significant Effect[a]

Category	Age Group		
	<6 y	6–12 y	13–21 y
Productivity and daily activity	−7.68	−11.23	−3.53
Productivity and leisure	−4.41	NS	NS
Leisure and daily activity	−6.96	−11.32	−5.24
Age Group	**Daily Activity**	**Productivity**	**Leisure**
<6 and 6–12 y	NS	−4.96	NS
<6 and 13–21 y	−5.73	−6.56	NS
6–12 and 13–21 y	−6.26	−3.24	NS

[a] $P<.001$ for all reported *z* scores. NS=not significant.

Table 4.
Parents' Priorities for Each Subcategory by Age of Their Children and Youth

Category	Age Group					
	<6 y (n=85)		6–12y (n=276)		13–21y (n=178)	
	n	%	n	%	n	%
Daily activities						
Self-care	132	42	389	36	158	25
Mobility	52	17	138	13	69	11
Communication	14	4	40	4	18	3
Other	22	7	82	7	39	6
Productivity						
Household	2	1	61	6	67	10
School	17	5	123	11	62	10
Community	3	1	11	1	58	9
Other	3	1	22	2	10	2
Leisure						
Socialization	20	6	71	6	87	14
Community entertainment	1	1	8	1	4	1
Quiet recreation	14	4	28	3	14	2
Physical recreation	33	11	117	11	54	8
Other	0	0	4	1	2	0

Table 5.
Parents' Priorities for Self-Care by Age and Gross Motor Functional Classification System (GMFCS) Level of Their Children and Youth

Activity	Age Group					
	<6 y (n=85)		6–12 y (n=276)		13–21 y (n=178)	
	n	%	n	%	n	%
Eating	37	28	55	14	20	13
Hygiene	10	8	41	11	38	24
Toileting	29	22	85	22	22	14
Bathing	8	6	58	15	31	20
Dressing	48	36	150	39	47	30
Activity	**GMFCS Level**					
	I (n=118)		II/III (n=105)		IV/V (n=172)	
	n	%	n	%	n	%
Eating	8	7	36	11	68	31
Hygiene	18	15	49	14	22	10
Toileting	16	14	74	22	46	21
Bathing	14	12	59	17	24	11
Dressing	61	52	124	36	60	27

expressed 28% of priorities for eating and 22% for toileting. Parents of children aged 6 to 12 years expressed 22% of priorities for toileting. Parents of youth aged 13 to 21 years expressed 24% of priorities for hygiene and 20% for bathing.

Effect of Gross Motor Function Level of Children and Youth on Parents' Priorities

Table 6 presents the number of priorities, percentage of the number of priorities among the total number of priorities, and median number of priorities for each category by children's gross motor function level. The number of priorities for each category differed for parents of children and youth in levels II/III (χ^2=132.42, P<.001) and IV/V (χ^2=167.23, P<.001) but not for parents of children in level I. Table 7 presents the z scores for the *post hoc* analyses of significant effects. Parents of children and youth in levels II/III expressed more priorities for daily activities (56%, median number=2) than for productivity or leisure (22%, median number=1). Parents of children and youth in levels IV/V also expressed more priorities for daily activities (65%, median number=2) than for productivity (16%, median number=0) or leisure (19%, median number=1). There was no difference in the number of priorities for productivity and leisure expressed by parents of children and youth in levels II/III or IV/V.

Parents' priorities for daily activity (χ^2=35.27, df=2, P<.001), productivity (χ^2=13.05, df=2, P =.001), and leisure (χ^2=11.86, df=2, P<.01) differed based on their children's gross motor function levels (Tab. 6). Parents of children and youth in level I had fewer priorities in daily activities (44%, median number=1) than parents of children and youth in levels II/III (56%, median number=2) and IV/V (65%, median number=2). Parents of children and

youth in levels IV/V had fewer priorities for productivity (16%, median number=0) and leisure (19%, median number=1) than parents of children and youth in level I.

Table 8 presents the number and percentage of the number of priorities among the total number of priorities for each subcategory by gross motor function level. Parents expressed 28% to 35% of priorities for self-care depending on their children's gross motor function level. Parents of children and youth in levels II/III and IV/V each expressed 14% of priorities for mobility. Parents of children and youth in levels II/III expressed 11% of priorities for physical recreation. Parents of children and youth in level I expressed 16% of priorities for physical recreation, 13% for school, and 11% for socialization.

Table 5 presents the number of parent priorities for each area of self-care by GMFCS level subgroup. Parents' expressed 27% to 52% of priorities for dressing. Parents of children in level IV/V expressed 31% of priorities for eating. Parents expressed 10% to 22% of priorities for hygiene, toileting, and bathing depending on their children's GMFCS level subgroup.

Priorities Related to Mobility

Mobility was a component of at least one priority activity for 358 parents (61.2%). The percentage of parents with priority activities related to mobility did not differ by age group. A greater percentage of parents of children and youth in levels II/III (68.7%) had priorities related to mobility than parents of children and youth in level I (54.2%, $\chi^2=7.25$, $df=1$, $P<.01$) and levels IV/V (55.2%, $\chi^2=7.90$, $df=1$, $P<.01$).

Discussion

Parents' priorities for their children with cerebral palsy differed depending on their child's age and gross motor function level; however, the most frequent priority for all children was daily activities. This finding is consistent with psychological theories that purport that individuals focus on meeting their basic daily needs before pursuing personal achievements and leisure.[17] Families of children with cerebral palsy want their children to gain independence and efficiency in self-care and mobility. Dressing was a frequent self-care priority of parents. Dressing is a complex task that requires considerable time and for older children particularly relates to their self-expression. Eating was a self-care priority for parents of children under 6 years of age and the highest priority for parents of children and youth in levels IV/V. Self-feeding and nutrition were concerns of families of young children and children with severe motor limitations and may reflect parents' concern for their children's growth and health status.[18] These concerns are consistent with literature that has identified problems with growth and nutrition of children with cerebral palsy who have significant motor impairments.[19] Previous investigators also have reported that self-care is a high priority for parents of young children with cerebral palsy[3,10] and for young and school-aged children with physical disabilities.[6-7] A focus on self-care for young children reflects developmental expectations. The continued focus for older children may reflect parents' desire for their children to be able to meet self-care needs that not only would reduce the amount of caregiver assistance but also enable socialization with peers, participation in community activities, and transition to independent living.

Table 6.
Parents' Priorities for Each Category by the Gross Motor Functional Classification System (GMFCS) Level of Their Children and Youth

Category	GMFCS Level								
	I (n=118)			II/III (n=249)			IV/V (n=172)		
	n	%	Median	n	%	Median	n	%	Median
Daily activities	183	44	1	548	56	2	422	65	2
Productivity	114	27	1	220	22	1	105	16	0
Leisure	120	29	1	214	22	1	123	19	1

Table 7.
Effect of Gross Motor Functional Classification System (GMFCS) Level: *z* Scores for *Post Hoc* Analyses of Significant Effect[a]

Category	GMFCS Level		
	I	II/III	IV/V
Productivity and daily activity	NS	−9.12 ($P<.001$)	−9.91 ($P<.001$)
Productivity and leisure	NS	NS	NS
Leisure and daily activity	NS	−9.79 ($P<.001$)	−9.59 ($P<.001$)
GMFCS Level Groups	**Category**		
	Daily Activity	**Productivity**	**Leisure**
I and II/III	−4.46 ($P<.001$)	NS	NS
I and IV/V	−5.85 ($P<.001$)	−3.36 ($P=.001$)	−3.37 ($P=.001$)
II/III and IV/V	NS	NS	NS

[a] NS=not significant.

Table 8.
Parent's Priorities for Each Subcategory by the Gross Motor Functional Classification System (GMFCS) Level of Their Children and Youth

Category	GMFCS Level					
	I (n=118)		II/III (n=249)		IV/V (n=172)	
	n	%	n	%	n	%
Daily activities						
Self-care	117	28	342	35	220	34
Mobility	31	7	137	14	91	14
Communication	3	1	16	2	53	8
Other	32	8	53	5	58	9
Productivity						
Household	30	7	78	8	22	3
School	55	13	92	9	55	8
Community	13	3	36	4	23	4
Other	16	4	14	1	5	1
Leisure						
Socialization	45	11	78	8	55	8
Community entertainment	4	1	3	0	6	1
Quiet recreation	5	1	22	2	29	4
Physical recreation	65	16	108	11	31	5
Other	1	0	3	0	2	0

Mobility was a priority for parents of children 12 years of age and younger and parents of children and youth who have limitations in mobility (levels II/II and IV/V), signifying the value parents place on their children being able to move from place to place in order to be active and participate in daily activities. Parents' priorities for mobility are consistent with the perspectives of youth with cerebral palsy. Self-sufficiency was a theme that emerged from a qualitative study of mobility experiences of youth with cerebral palsy.[20] Youth viewed mobility as important for getting from place to place without relying on other people.

The greater focus on productivity by parents of school-aged children and youth is consistent with developmental expectations. Parenting can be characterized by 2 main tasks: nurturing to promote the child's health, function, and well-being and facilitating the child's development to become an adult.[21] Priorities for productivity reflect parental concerns regarding school performance and, for youth, transition to postsecondary education or work. Parents of school-aged children and youth had similar numbers of priorities for productivity and leisure, suggesting that both are equally valued and important. For parents of adolescents and young adults, the focus on socialization most likely reflects awareness of the need for their children to separate from the family and engage in age-appropriate activities with peers. Parents want their adolescents and young adults to engage with their peers, establish relationships, and have friends. Parents of children and youth, particularly those in levels IV/V, who have priorities for daily activities may be at risk for spending less time on their children's needs for productivity and leisure.

For parents of children who walked independently or with assistance, physical recreation was another priority, suggesting that parents want their children to participate in physical activities. Parents expressed that it was important to them for their children to play and be physically active. Information about community recreation programs is a common need expressed by families.[22] Fifty-two percent of parents who participated in the current study reported a need for help in locating community camps, sports, and recreational, social, and leisure activities for their children.[23]

Implications for Practice

The parents' priorities in daily activities, productivity, and leisure for their children with cerebral palsy have clinical implications for routines-based intervention. Routines-based intervention is an approach where intervention methods are embedded during children's naturally occurring learning opportunities.[24] Therapists implement strategies during the activities and routines that are meaningful to the child and part of daily life. Interventions can be provided during mealtimes to support parents' ability to nourish their children, teach young children self-feeding skills, and assist families with adaptations and strategies for ease of caregiving for children with significant motor limitations. Physical therapists have an important role in addressing a variety of self-care tasks, including dressing, toileting, and hygiene, through their expertise in motor function, positioning, transfers, and assistive technology. It also is important for physical therapists to collaborate with other health care professionals, teachers, child care providers, and durable medical equipment providers to ensure that children with cerebral palsy have comprehensive supports for self-care.

The finding that mobility was related to at least one priority for 61.2% of the parents has implications for physical therapists. It is important for therapists to support mobility needs within the environments where activity and participation occur. Interventions to support mobility will be different if the priority is to be a member of the school band versus being able to move around at home. Physical therapists' expertise may be particularly needed for children and youth in levels II and III who are capable of walking but often experience difficulty keeping up with peers, moving in crowds and confined areas, and navigating uneven or slippery terrain when outdoors.

To promote physical activity, fitness, and socialization with peers, physical therapists have a critical role to advocate for sports and recreational programs for children with cerebral palsy. For children in level I, it is important to examine and evaluate endurance and gross motor skills such as running, jumping, and balancing to support the competencies they need to fully participate with their peers in physical recreational activities. For children who are unable to walk, therapists can address needs pertaining to participation in adapted wheelchair sports or physical recreation activities. Supporting client priorities for socialization also has implications for how physical therapy services are provided. Group therapy sessions and consultation with community leisure, recreational, sports, and social programs may provide children and youth with opportunities to interact with their peers. Therapists are encouraged to engage children and youth in conversations to explore their preferences for social participation and to identify physical barriers to socialization that therapists can address.

We believe that interviewing families, listening to their priorities for their children, and exploring the meaning of these priorities for their children's participation in home, school, and community life are essential to guide service delivery plans. Physical therapists need to be responsive to family priorities and support children's self-care needs, as well as promote opportunities for productive leisure and social life experiences. It is important for therapists to engage parents and children in stories and conversations, provide families with options, and explore possibilities to ensure that priorities or opportunities are fully identified. Additional research using qualitative research methods may provide further insights into our understanding of parents' priorities for their children.

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