

# Facilitators and Barriers to Performing Activities and Participation in Children With Cerebral Palsy: Caregivers' Perspective

Pinailug Tantilipikorn Earde, PT, PhD; Aina Praipruk, PT, BSc; Phanlerd Rodpradit, PT, BSc; Parichad Seanjumla, PT, BSc

Department of Physical Therapy, Faculty of Allied Health Sciences, Thammasat University, Thailand.

**Purpose:** To investigate contextual factors that were facilitators and barriers to performing activity and participation for children with cerebral palsy from the caregivers' perspective.

**Methods:** Qualitative in-depth interview with primary caregivers of children with cerebral palsy aged 4 to 12 years was conducted in the metropolitan area of Thailand. Semistructured questions related to environmental and personal factors were recorded. Interviews were transcribed verbatim and analyzed for main themes on the basis of the International Classification of Functioning, Disability, and Health—Children and Youth Version (ICF-CY) classification.

**Results:** Twenty-seven caregivers participated. Facilitators were appropriateness of assistive devices, support and acceptance from family, friends, and society, health services, willingness, and self-acceptance. Barriers were inappropriate design and facilities, overprotection of family, nonacceptance from family, friends, and society, inconvenient transportation, financial problems, limited health services, limited access to education, frustration, and being an introvert.

**Conclusions:** Contextual factors that can be facilitators and barriers to perform activities and participation should be considered for improving lives of children with cerebral palsy. (*Pediatr Phys Ther* 2018;30:27–32)

**Key words:** cerebral palsy, children, developing country, environmental factors, ICF, personal factors

## INTRODUCTION

Cerebral palsy (CP), the most common disability in childhood, is a non-progressive motor disorder with co-morbidities such as epilepsy, secondary musculoskeletal problems, disturbances of sensation, perception, cognition, and behavior.<sup>1</sup> Motor ability in children with CP can be classified into 5 levels from level I, independent ambulation without restriction, to level V, severely limited self-mobility by the Gross Motor Function Classification System (GMFCS).<sup>2</sup> Motor deficits of children with CP can limit their activities and participation. Regarding framework of the International Classification of Functioning, Disability, and Health—Children and Youth Version (ICF-CY),<sup>3</sup>

contextual factors including environmental and personal factors can play important roles in performing activities and participation. The ICF-CY supports that environmental factors are categorized into 5 chapters: chapter 1, product and technology; chapter 2, natural environment and human-made changes to the environment; chapter 3, support and relationships; chapter 4, attitude; and chapter 5, services, systems, and policies.<sup>3</sup> Each chapter of environmental factors contains branching levels.<sup>3</sup> There is no classification for personal factors because social and cultural aspects can impact personal factors.<sup>3</sup>

Previous studies reported that contextual factors, both environmental and personal, can be either facilitators or barriers to perform activities and participation in children with CP.<sup>4-11</sup> Mobility devices, support from family and others, and family/others attitude were reported as environmental facilitators.<sup>6,7,10</sup> Environmental barriers were inappropriate building, access to information, health services, recreational program, and attitudes of strangers.<sup>6,7,10</sup> Apart from environmental factors, personal factors of the children such as motivation, self-efficacy, and interest may result in enhancing the performance of children with CP.<sup>7,10</sup> However, there are no studies of facilitators and barriers in children with CP in developing countries.

There are many differences between developed and developing countries including the structure of health policies and services. Cultural belief for people with disabilities in developing countries especially Thailand tends to reflect differently. Social attitudes in Thailand discourage people with disabilities

0898-5669/110/3001-0027

Pediatric Physical Therapy

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Correspondence: Pinailug Tantilipikorn Earde, PT, PhD, Department of Physical Therapy, Faculty of Allied Health Sciences, Thammasat University, 99 Moo 18, Klong Luang, Pathumthani 12120, Thailand (pinailug.e@allied.tu.ac.th).

Grant Support: This study was supported by Thammasat University Research Funding, Thailand. Funding was not involved in study design, data collection, analysis, manuscript preparation, and publication decisions.

The authors declare no conflicts of interest.

DOI: 10.1097/PEP.0000000000000459

from independence or to reach their highest potential. In contrast, independent living is an ultimate goal for people with disabilities in developed countries. Health services in most developing countries are available more in metropolitan than in rural areas because of the limited supply of health professionals and equipment in rural areas. Assistive technology, even basic equipment for children with CP such as ankle-foot orthosis and adaptive/power wheelchair, is limited in low-resource countries including Thailand. Furthermore, infrastructure in low-resource countries is sometimes inappropriate for wheelchair users because of the absence of a ramp or elevator in buildings and steep wheelchair ramps that lack accessible handrails. As a consequence, children who do not walk may face more difficulties accessing public areas. The educational system for children with disabilities in Thailand is different from a developed country. There is limited availability of schools for children with special needs, and children with CP who can walk may be more likely to get into school than children who cannot walk.

The ICF framework has been used to identify assessment and management in children with CP in Thailand, mostly for body structures and functions.<sup>12,13</sup> Activities and participation are less likely to be included.<sup>12,13</sup> Identifying facilitators and barriers to performing activities and participation in children with CP facilitates the recommendations for adaptive environments to improve the effectiveness of interventions. There are limited instruments to measure contextual factors that impact activities and participation in children with CP.<sup>8</sup> Evidence suggests that qualitative studies can provide details and better understanding.<sup>8</sup> Primary caregivers can provide relevant information for children with CP who may have difficulty communicating.

The purpose of this study was to investigate contextual factors that were perceived as facilitators and barriers to performing activities and participation by primary caregivers of children with CP in Thailand. We hypothesized that the environmental factors influencing activities and participation might be different between children with CP who can walk and those who cannot walk.

## METHODS

Semistructured in-depth interviews (phenomenology method) were conducted with primary caregivers of the children with CP. Ethical approval was obtained from Thammasat University, Thailand (approval number: 113/2557). Informed consent was received from all participants.

### Participants

Purposive sampling was used. Participants were recruited from foundations for children with disabilities in the metropolitan area of Thailand. Inclusion criteria were primary caregivers of children with CP aged 4 to 12 years at all GMFCS levels. Caregivers reported GMFCS levels of their children using the translated version of the GMFCS family report, which has shown good reliability.<sup>14,15</sup> The caregivers were excluded if they could not communicate in the local language. Caregivers were grouped into 2 groups: primary caregivers of children who could walk (GMFCS I-III) and caregivers of

children who could not walk (GMFCS IV-V). Data collection was conducted concurrently with data analysis, and this was discontinued once data saturation was reached in each group,<sup>16</sup> that is when no new themes emerged from the interviews.

## Procedure

The semistructured in-depth interview was conducted in a quiet area at the foundations by 1 researcher. Open-ended questions developed by researchers on the basis of the ICF-CY included facilitators and barriers—both environmental and personal factors—that might affect activities and participation. Before data collection, questions had been tested with caregivers for clarity and understanding. The definitions of “activity” and “participation” according to the ICF-CY were explained to each participant at the beginning of the interview. The questions were: (1) “What makes activities and participation easier or better for your child? (at home or school or other places)”, (2) “What makes more difficult for your child to engage in activities and/or participate? (at home or school or other places)”, (3) “Does your child have characteristics that positively affect activities and participation?”, and (4) “Does your child have characteristics that negatively affect activities and participation?” Further questions were asked if clarification was required. The caregivers could also discuss relevant issues beyond the researchers’ questions. Participants were not pressured and the interviews were audio recorded.

## Data Analysis

Audio records from the interviews were transcribed verbatim. Transcripts were read several times, and thematic analyses (framework analysis)<sup>17</sup> on the basis of the ICF-CY chapters were performed independently by 3 researchers. Themes, ICF-CY chapters, and ICF-CY codes were identified after discussion and consensus were reached among researchers. Ages of caregivers and children with CP between the groups were compared using the Mann-Whitney *U* test.

## RESULTS

Twenty-seven participants were recruited: 14 caregivers in group 1 had children who were at GMFCS levels I to III and 13 caregivers in the group 2 had children who were at GMFCS levels IV to V. Characteristics of participants and their children are shown in Table 1. All primary caregivers were female. Ages of participants were between 27 and 62 years in group 1, and 29 and 67 years in group 2, with no statistically significant difference between groups. Ages of children were not significantly different between the 2 groups and was 4.9 to 12.2 years in group 1 and 4.9 to 12.7 years in group 2. The average duration of the interview was 34.5 (standard deviation = 18.1) minutes.

### Facilitators to Perform Activities and Participation

Facilitators were reported in all ranges of the ICF-CY environmental factors. Themes for environmental facilitators that emerged were the appropriateness of assistive devices, appropriate weather, family/society support and acceptance, and

**TABLE 1**

Characteristics of Children With Cerebral Palsy and Their Primary Caregivers

Characteristics of Children	Ambulatory (n = 14)	Nonambulatory (n = 13)
Mean age (SD), y	7.7 (2.6)	9.3 (2.6)
Gender, n (%)		
Boys	7 (50)	10 (77)
Girls	7 (50)	3 (23)
GMFCS levels, n (%)		
I	1 (7)	–
II	7 (50)	–
III	6 (43)	–
IV	–	3 (23)
V	–	10 (77)
Education, n (%)		
Attending school	11 (79)	5 (62)
Not attending school	3 (21)	8 (38)
Characteristics of primary caregivers		
Mean age (SD), y	42.4 (9.8)	42.9 (11.8)
Relationship, n (%)		
Mother	11 (79)	11 (85)
Grandmother	3 (21)	2 (2)
Education, n (%)		
Less than high school level	2 (14)	2 (15)
High school level	3 (21)	3 (23)
Diploma	2 (14)	3 (23)
College/higher education level	7 (50)	5 (38)

Abbreviations: GMFCS, Gross Motor Function Classification System; SD, standard deviation.

health services from the government (Table 2). For personal factors, willingness and self-acceptance were identified as a major drive for children with CP to facilitate activities and participation.

The ICF-CY code mapping and responses are shown in Table 3. Product and technology for personal use in daily living and indoor/outdoor mobility/transportation (e115 and e120) including orthopedic shoes, ankle-foot orthosis, walker, and wheelchair were frequently reported as facilitators in chapter 1: product and technology. An example of answers was: “Assistive and mobility devices make him can do various activities.

If he does not have these devices, he will face difficulties with his stiff legs to do activities. When he sits properly in this proper wheelchair, he can do activities better” (GMFCS III). Design construction and building products and technology of public/private use (e150 and e155), which were handrail at school/home, ramp, and smooth surface, can facilitate activities and participations of children with CP.

Cool weather (e225) was a facilitator in chapter 2: natural environment and human-made changes to the environment. Facilitators reported in chapter 3 (support and relationships) were support from family, friends, and society and adequate family time of health care for children with CP (e310, e320, and e325). Caregiver acceptance (e410) was reported as a facilitator in chapter 4: attitudes. Regarding chapter 5 (services, systems and policies), health services, systems, and policies (e580) were reported as facilitators. All participants reported that physical therapy facilitated their children to perform activities and participation including improved postural control, walking, and playing. In addition, medical treatment funded by the government for children who registered as children with disabilities was a facilitator. Attending school or group training (e585) was reported as facilitators because friends could induce children with CP to participate in activities. Examples of answers were: “Government funds all medical expenses. It is really good.” (GMFCS IV); “Group training is good. It helps a lot, helps parents to relax and a child to relax. She has got friends and get along with them.” (GMFCS II).

### Barriers to Performing Activities and Participation

Themes for environmental barriers were inappropriate design facilities and weather, overprotection of family, nonacceptance from society, inconvenient transportation, financial problems, limited health services, and education services. Frustration and characteristics of introversion for children with CP were personal barriers (Table 2).

The ICF-CY code mapping found that the e150, design, construction, and building products and technology of buildings for public use were primarily reported as barriers in chapter 1. Answers were related to uneven surface, no ramp, no handrail in the community, and no playground at school. Examples of

**TABLE 2**

Theme for Facilitators and Barriers on the Basis of the ICF-CY Chapters Reported by Primary Caregivers

Environmental Factors	Facilitators	Barriers
Chapter 1: products and technology	Appropriateness of assistive devices	Inappropriateness of design and facilities
Chapter 2: natural environment and human-made changes to environment	Cool weather	Hot weather Loudness
Chapter 3: support and relationships	Support from primary caregivers, friends, and society Adequate family time	Overprotection of family Inadequate family time
Chapter 4: attitudes	Caregiver acceptance	Nonacceptance from family, friends, and society
Chapter 5: services, systems, and policies	Health services from government	Inconvenient transportation Financial problems Limited health services Limited accessibility to education
Personal factors	Willingness Self-acceptance	Frustration Being an introvert

Abbreviation: ICF-CY, International Classification of Functioning, Disability, and Health—Children and Youth Version.

**TABLE 3**  
Responses According to the ICF-CY Codes of Environmental Factors<sup>a</sup>

ICF-CY Chapter	ICF-CY Codes	Facilitators, n (%)		Barriers, n (%)	
		Ambulator (n = 14)	Nonambulator (n = 13)	Ambulator (n = 14)	Nonambulator (n = 13)
Chapter 1	e115: Products and technology for personal use in daily living	10 (71)	11 (85)	3 (21)	1 (8)
	e120: Products and technology for personal indoor and outdoor mobility and transportation	10 (71)	11 (85)	2 (14)	2 (15)
	e150: Design, construction, and building products and technology of buildings for public use	6 (43)	6 (46)	12 (86)	9 (69)
	e155: Design, construction, and building products and technology of buildings for private use	3 (21)	1 (8)	8 (57)	5 (39)
Chapter 2	e225: Climate	–	2 (15)	–	2 (15)
	e250: Sound	–	–	1 (8)	2 (15)
Chapter 3	e310: Immediate family	12 (86)	13 (100)	7 (50)	4 (29)
	e320: Friends	9 (64)	5 (39)	1 (7)	–
	e325: Acquaintances, peers, colleagues, neighbors, and community members	3 (21)	1 (8)	1 (7)	–
Chapter 4	e410: Individual attitudes of immediate family members	7 (50)	8 (62)	1 (7)	4 (31)
	e420: Individual attitudes of friends	1 (7)	3 (23)	2 (14)	2 (15)
	e425: Individual attitudes of acquaintances, peers, colleague, neighbors, and community members	1 (7)	3 (23)	1 (7)	3 (23)
	e445: Individual attitudes of strangers	–	2 (15)	4 (29)	5 (38)
Chapter 5	e540: Transportation services, systems, and policies	–	–	7 (50)	11 (85)
	e565: Economic services, systems, and policies	–	–	6 (43)	10 (77)
	e570: Social security services, systems, and policies	–	2 (15)	7 (50)	8 (62)
	e580: Health services, systems, and policies	14 (100)	13 (100)	5 (36)	10 (77)
	e585: Education and training services, systems, and policies	4 (29)	6 (46)	6 (43)	6 (46)

Abbreviation: ICF-CY, International Classification of Functioning, Disability, and Health—Children and Youth Version.

<sup>a</sup>Chapter 1, products and technology; chapter 2, natural environment and human-made changes to environment; chapter 3, support and relationships; chapter 4, attitudes; chapter 5, services, systems, and policies.

answers were: “We will not go to a place that is inaccessible for wheelchair and walker users. When we are going out, we have to check if there are any available area for wheelchair/walker users, smooth surface, and accessible toilet. We will only go to a place that is convenient for him.” (GMFCS III); “Footpath is rough. It limits him to participate in activities.” (GMFCS IV).

Hot weather (e225) and loudness (e250) were barriers in chapter 2. Overprotection and inadequate family time of health care (e310) in chapter 3 limited children participation in activities. Nonacceptance from friends and society (e420, e425, and e455) was barriers in chapter 4. In addition, nonacceptance of the family at the beginning of diagnosis of CP (e410) was reported as a barrier. Regarding chapter 5, transportation, finance, and limited health services (e540, e565, and e580) were barriers in both groups, with higher responses in the group of children who could not walk. Answers in the e540 (transportation services, system, and policies) were related to high cost of transportation, inappropriate public transport for wheelchair users, and refusing to pick up from a taxi driver. The e565

(economic services, system, and policies) was connected with family income from one person and unavailable work for a primary caregiver who needs to look after a child with CP. The e580 (health services, system, and policies) was associated with limited and centralized hospitals, limited health care provider, and long-awaited health services. The e570 (social security services, systems, and policies) was a potential limitation because of insufficient financial support, difficulty in accessing to government support, inaccessible information, and unemployment. Furthermore, limited accessibility to the education system (e585) was a barrier to perform activities and participation. Examples of answers were: “I drive her to school. Gasoline is expensive. Only her father has paid work. There is no work that allows me to do while I have to look after her.” (GMFCS II); “Carrying him to get on and off a public bus is difficult and dangerous. The hospital is far. Sometimes, I decided not to go to the hospital for the physical therapy session.” (GMFCS IV); “Government said regular school should accept children with disabilities but when we go there ... the school refused him.”

## DISCUSSION

Caregivers' perspective reported on facilitators and barriers to performing activities and participation covered all environmental chapters and personal factors of the ICF-CY. Children in both groups reported similar contextual factors. Transportation, economic and health services system, and policies were more reported as barriers in the group of children who could not walk. This is similar to our hypothesis that infrastructure of a developing country, including Thailand, is inappropriate for wheelchair users. Children who depend on wheelchairs have difficulties using public transportation (eg, buses and trains) and need to use cars or private transportation. Not only is the cost of transport by a car/taxi higher, but a taxi driver may refuse to take a wheelchair. Participants reported that health services, especially physical therapy, could facilitate their children to participate in activities, but there are limited hospitals and physical therapists. Hospitals and physical therapy services for children with CP are mostly located in the metropolitan areas. Some participants moved their family from the rural to urban areas especially for treatment. When they moved, their cost of living was higher because of house rental and transportation. The results suggest that expansion of the hospitals to the rural area may resolve the difficulty of limited health services, family finances, and transportation. In addition, increasing the number of community-based physical therapists is another possible solution to expand physical therapy services to the countryside.

Regarding personal factors, willingness was a facilitator whereas frustration was a barrier. Thai cultural belief is that parents could instruct their child to do any activities and a child has to follow it without choice. If the orders correspond to a child's needs, a child will be willing to do so. If the order and the willingness are not correspondent, a child with CP who may have difficulties communicating may be easily frustrated. The previous study reported that *not* offering choices or opportunities to speak was one of the barriers affecting activities and participation in children with CP.<sup>7</sup> It is suggested that offering choices to participate in activities would prevent a child with CP from being frustrated.

Findings of this study were similar to previous studies in developed countries<sup>6,7,10</sup>; however, some barriers were different. Children with CP in Thailand can register to be people with disabilities and can then access government support including financial support (500 baht/month) and free health services. Nevertheless, it is a challenge to access the government support because of the complicated process and inaccessible information. Although children with CP can access free health services, there are difficulties getting appropriate assistive devices in a low-resource country. A power wheelchair or an adapted wheelchair is not included in the free health services. Children with CP can get only a standard wheelchair, which might be oversized. Another difference between low-resource and high-resource countries is access to the education system. Not only are there limited special schools for children with CP, but also schools require self-reliance. Many children with CP, especially who cannot walk, cannot access the education system, both regular and special schools. Furthermore, there is limited employment for people with CP in Thailand.

Although employment of persons with disabilities is a government policy, some companies refuse to employ individuals with disabilities. Interestingly, products and technology for communication, which should be considered for CP population at all ages,<sup>18</sup> were not often mentioned in our findings, and this might be due to unconcern. Caregivers might have more expectation of gross motor functions for children with CP rather than communication.

The strength of this study included caregivers of children with CP in all GMFCS levels. There were some differences in facilitators and barriers between groups. A potential limitation of this study was that participants were recruited from 2 rehabilitation centers funded by a nongovernment organization in the metropolitan area. The findings of this study might not represent the population of children with CP in other regions. Furthermore, all primary caregivers in our study were females, which may be less likely to generalize to male caregivers' perspective. Children with CP were not interviewed in this study; therefore, another possible limitation might occur if caregivers and their children perceive barriers and facilitators differently.

## ACKNOWLEDGMENTS

We thank all caregivers who participated in this study. We also thank all staffs at Foundation for Children with Disability (Bangkok) and Foundation for the Welfare of the Crippled under the Royal Patronage of Her Royal highness the Princess Mother (Nonthaburi) for recruitment of participants.

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