Children’s and Parents’ Perspectives About Activity Performance and Participation After Spinal Cord Injury: Initial Development of a Patient-Reported Outcome Measure

M. J. Mulcahey, Nicole DiGiovanni, Christina Calhoun, Erica Homko, Ann Riley, Stephen M. Haley

KEY WORDS
- activities of daily living
- human activities
- interpersonal relations
- pediatrics
- outcome assessment (health care)
- spinal cord injuries

OBJECTIVE. To report on a cognitive testing study on newly constructed items designed to evaluate client-reported outcomes of activity performance and participation after spinal cord injury (SCI).

METHOD. Thirty-three children with SCI and 13 caregivers participated in cognitive testing interviews. Open-ended questions were used to gain a better understanding of activity performance and participation. The interviews were transcribed verbatim. A thematic analysis was carried out independently by 2 researchers, and key sentences and phrases from both analyses were merged.

RESULTS. Four themes were defined: (1) apprehension related to activity performance and participation, (2) reference point, (3) missing out, and (4) autonomy.

CONCLUSION. Insight into children’s and caregivers’ perspectives provided important information that helped refine the wording of test items and response scales. The theme of autonomy provided a stronger catalyst to solidify items for both child- and parent-reported outcomes. This study further validated the complexity of the construct of participation.
with less physical functioning are less likely to participate in typical childhood activities (Law, Petrenchik, King, & Hurley, 2007; Law et al., 2004; King et al., 2004; Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004) and children with disabilities receive more enjoyment while engaging in activities that they are physically capable of doing (King et al., 2007). Despite the associations between degree of physical impairment and participation, a stronger relationship between participation and the environment (Heah, Case, McGuire, & Law, 2007), financial status (Mactavish, Schlieren, & Tabourne, 1997), and family support (Heah et al., 2007; Law, Petrenchik, King, & Hurley, 2007) exists.

One of the greatest challenges to understanding activity performance and participation among children with SCI is the lack of a valid SCI-specific outcomes measure. Notable measures are available. The Craig Handicap Assessment and Reporting Technique (CHART; Whitenack, Tate, & Charlfinte, 1999) and the Children’s Assessment of Participation and Enjoyment (CAPE; King et al., 2004) have limitations when applied to children with SCI. The CHART is a SCI-specific measure but contains items designed entirely for adults, and its use with children has been ill advised (Hall, Bushnik, Lakisic-Kazacic, Wright, & Cantagallo, 2001). The CAPE evaluates children’s involvement in leisure and recreation activities and how frequently and with whom those activities are performed. No specific work on the CAPE with children with SCI has been reported, and important activity and participation patterns associated with one’s own self-care and school involvement are excluded from the CAPE (King et al., 2003).

The Canadian Occupational Performance Measure (Law et al., 1990), a tool that measures changes in client-perceived performance of self-identified goals, does not produce a composite score of activity performance that is comparable longitudinally and across populations but can provide an understanding of activity performance at a point in time in a child’s life (Duffy & Mulcahey, 2004). The Craig Hospital Inventory of Environmental Factors (CHIEF; Craig Hospital Research Department, 2001) evaluates the degree to which environmental characteristics (accessibility, accommodation, resource availability, social support, and equality) facilitate or impede participation. The CHIEF was developed for use with adults and has been used as a parent report of environmental barriers to children’s participation (Law et al., 2007). Evidence of adequate reliability and validity (Whitenect et al., 2004) exists for adults, but no psychometric work on the CHIEF when used as a child-reported outcome measure has been done.

As a direct response to the limitations of current outcome measures for use with children with SCI, our research group is developing a patient-reported outcomes measure of activity performance and participation for children and youths with SCI. We have operationally defined activity performance as “children’s execution of complex functions—these functions represent specific tasks that are typically done in isolation of others; activity considers ease, level of independence, and quality of execution of tasks. Activity represents the individual perspective of function.” Examples of activity include dressing, bathing, writing, and pushing a manual wheelchair. Participation is operationally defined as “children’s involvement in life situations across physical, social, spiritual, and virtual environments including home, school, and the larger community. Participation involves the accomplishment of a variety of tasks to engage in solitary or group activity that is socially and culturally recognized.” Examples of participation include completing homework, going to sleepovers at a friend’s house, taking lessons for a special talent such as playing a musical instrument, and going to the movies. The definitions and concepts reflect the positions of the International Classification of Functioning, Disability and Health (World Health Organization, 2001) and the Occupational Therapy Practice Framework: Domain and Process (American Occupational Therapy Association, 2008).

The patient-reported outcome measure is being developed in the form of computer adaptive testing (CAT). As part of CAT’s development, an item bank (Bode, Lai, Cella, & Heinemann, 2003) containing a comprehensive set of items from multiple instruments and ones that are newly developed is being created; once the item bank is solidified, CAT uses a simple form of artificial intelligence that selects questions from the item bank that are directly tailored to an individual child, shortens or lengthens the test to achieve the desired precision, and scores each test on a standard metric so that results can be compared across time points and across groups of children. CAT applications require a large set of items in any one domain (e.g., the domain of self-care or the domain of participation); items that consistently scale along a construct of low to high; and rules guiding starting, stopping, and scoring procedures (Wainer, 2000).

In practice, most therapists intuitively adapt histories and tests to a child’s apparent functional level. For example, a child with a C5 SCI and the inability to ambulate is usually not asked about community ambulation, whereas a child with an incomplete SCI who is currently walking up and down three flights of stairs is not asked
about the ability to negotiate three to five steps. Administering items that are either too easy or too hard provides little information and places a burden on those responding. In a dynamic test, such as CAT, each administration is adapted uniquely to the child’s level of functioning at that time.

As part of our work on the development of item banks for eventual CAT platforms of both caregiver-reported outcomes and child-reported outcomes, >800 test items were identified or written by content experts and were exposed to formal cognitive testing methodology (Willis, 2005) with children with SCI and their caregivers. Cognitive testing is a process used to evaluate the readability and comprehensibility of newly developed test items. The purpose of cognitive testing is to ensure that the item is written in a way that conveys the item’s intent to children and parents in a consistent way and in a way that minimizes or eliminates interpretation of the item’s meaning. Cognitive testing identifies phrases, items, response scales, and words that are not understood by younger children and those that are difficult despite age.

Although it is recognized that children as young as age 6 can report on their own health (Rebok et al., 2001), we considered formal cognitive testing to be pivotal to the solidification of items for three reasons. First, a lack of knowledge exists about how well children with SCI are able to report their capacity for activity performance and involvement in participation patterns. Through cognitive testing methodology, we hoped to gain a better understanding of children’s interpretation of the meaning of the items and to ask children for recommendations for wording more suited to children’s understanding. We also wanted to determine whether children were able to respond about their own engagement in activity and participation. Finally, we were keenly aware that achieving unidimensional scales needed for CAT work in the domains of activity performance and participation may be more difficult than in other content areas, such as physical functioning; thus, items needed to be written as clearly as possible to avoid misfit. Cognitive testing methodology was developed to achieve such precision. Our purpose in this article is to describe the outcomes of the cognitive testing study with respect to children’s and caregivers’ perspectives, experiences, and reasoning about activity performance and participation.

Method

We developed a standardized cognitive testing protocol containing the new and revised SCI items, response scales, and probes on the basis of the work by Willis (2005) and carried out under a formal research protocol. The child and parent were interviewed separately in a private room, and neither was present during the other’s interview. For each item, the child and caregiver were asked to read each item aloud and answer the item aloud using the response scale choices (examples shown in Figure 1). Participants were asked to verbalize all of their thoughts while responding to test items. This technique, known as think-aloud methodology (Van Someren, Barnard, & Sandberg, 1994), provides detailed information about how respondents understand and interpret items and why they select a given response. Semistructured and open-ended questions were used to probe further regarding comments made about participation and reasoning behind choices of participation. All of the interviews were audiotaped and transcribed verbatim.

Before the interviews, each investigator was provided with three formal training sessions: one focused on cognitive aspects of survey methodology, one focused on cognitive testing technique in children, and one focused on interview techniques using open-ended questions. After the formal training sessions and before cognitive testing with study participants, each investigator performed at least two cognitive testing practice sessions with children.

![Figure 1. Example participation items and response scale.](image-url)
The study protocol consent, assent, and Health Insurance Portability and Accountability Act forms were all approved by the institutional review board, and children and parents provided written informed assent and consent, respectively, before enrollment in the study.

Sample
Purposeful sampling was used to identify children ages 7–18 with a chronic SCI and their primary caregivers. At the time of the study, all participants were being seen for initial or routine follow-up care related to their SCI. Children were excluded from participation if English was not their primary language and if they were on mechanical ventilation and unable to communicate using verbal expression, had not yet been discharged from their initial (acute) rehabilitation, or were unwilling to participate as evidenced by parental refusal to provide written informed consent or child refusal to provide written informed assent.

Thematic Analysis
The transcribed interviews were thematically analyzed to reveal recurrent themes about how children and caregivers think about participation and what considerations occur when making decisions about participation. Initially, Nicole DiGiovanni, a research assistant trained in this methodology, completed thematic analysis. She read and reread the interviews multiple times and coded key sentences and phrases related to participation. The senior investigator (Mulcahey) conducted a separate thematic analysis using a similar approach. Finally, key sentences and phrases from both analyses were merged.

Results
Thirty-three children or youths between ages 7 and 18 with traumatic SCI and 13 caregivers were enrolled in this study; provided written informed assent and consent, respectively; and completed cognitive interviews. Of the children or youths, 21 had paraplegia; the remaining 12 had tetraplegia. Eleven child–caregiver dyads participated; two additional caregivers whose child did not participate completed the interviews.

Although open-ended questioning and probing elicited varied responses about activity performance and participation, four themes important to activity performance and participation as understood or perceived by children with SCI and their caregivers emerged: apprehension related to activity performance and participation, reference point for participation, missing out, and autonomy. An underlying construct among all themes was accessibility.

Apprehension Related to Activity Performance and Participation
During the interviews, almost all of the children and their caregivers described feelings of apprehension related to participation. Apprehension was most commonly associated with the perception by both children and caregivers that participation beyond structured activities would likely result in getting hurt either physically or socially. For example, when asked to discuss participation in sports, an 8-yr-old with paraplegia responded, “It [playing ball] was really hard.” When probed as to why participating in sport activities was really hard, he stated, “Cause they’re [the soccer ball and basketball] really big and they can hit you and hurt.” This response would generally not be anticipated by an 8-yr-old boy who, before his injury, participated as a member of his community little league team. Similarly, when the mother of a 14-yr-old was asked to elaborate on her child’s ability to participate in his own self-care regimens (e.g., cut his own fingernails), she replied, “He’s too afraid to cut himself. So, he’s unable to do [it],” which was followed by “I don’t know if he’s unable. . . . I’ve never let him try. I’m afraid he’s going to clip himself, so I’ve been doing them; he has been through enough!” Another mother described her anxiety about her daughter’s community participation by saying, “She will do it [pop her chair up a curb], but she’s petrified of falling off [out of her chair].” The 14-yr-old daughter further clarified this statement; when asked to explain her fear of falling out of her chair while in the community, she said, “I want my mother to stand behind so that I never [will] fall.”

Feelings of apprehension related to participation were also illustrated by one mother, a substitute teacher at her son’s high school, who reported,

A lot of times kids don’t pay attention to the boy . . . the kids in wheelchairs. They’re doing their own thing. A couple [kids] have hit his headrest on accident, running into him sideways, and that kind of thing—crowded places are not a good place to go.

Crowded school hallways were not the only environment that provoked apprehension among parents. For example, one mother, when probed why her child never leaves home, explained,

[When sitting] in the chair, his head is about to where our hands are and, so when we are walking around, people hit his head with cigarettes that they are holding in their hands, and they do not even know it! That is
why we do not go out too much and why I am very nervous when we do decide to go to crowded places like a strip mall or amusement park.

While exploring the same issue, another mother bluntly pointed out,

Um, his level [while sitting in the wheelchair], because he is down at people’s butts and hands. Cigarettes because they’ll poke him in the eyeball. They’re right at that level. He is so low that a lot of grown-ups, their eyes seem to be up here and don’t see him down there. He has a lot of problems with bumping into people, and it’s their fault. It’s not him, we try to clear them and they change their movement and he hits ankles; it is not a pleasant or calming experience to go out.

Children, particularly adolescents, expressed apprehension about social participation and the implications of their SCI. For example, when describing what she thinks about when deciding to participate in activities such as dances or trips to the mall, one teenage girl explained,

I go to school and I will maybe go out with my friends for a little while, but I will not go places in my friends’ cars in case I need to get home to cath [self-catheterize to empty bladder], and I will not sleep [at my friend’s house], even though they [my friends] want me to. I will not sleep at their house . . . they [my friends] know that I got hurt in the wreck and I cannot walk, but I did not tell them that I cannot go to the bathroom on my own anymore, and they do not know that I need to cath and do a bowel program . . . [silence] . . . I just cannot imagine them knowing I have accidents and sometimes wet myself . . . it is so embarrassing and stressful, I hate myself for that part of it.

Another adolescent with an incomplete SCI was asked to describe what it was like for her to walk in a busy place like a school hallway with a lot of people or a mall; she said, “That’s hard; it bothers me to walk into . . . to let people see how I walk now—like slow and with braces and crutches like yeah.” When she was asked what would make it easier to walk around the mall, she responded, “If I walked like my other friends.”

Reference Point

During the interviews, it became quite clear that after an SCI, children had a personal reference point that determined, to a large extent, whether they decided to participate or refrain from participation. For example, children and youths tended to have an internal reference point for what they believed participation looks like, as evidenced by a 10-yr-old’s explanation for why he does not play baseball anymore—“I barely do it [swing a baseball bat] because it’s no fun doing it in a wheelchair and it is not really baseball if you cannot run”—and by an adolescent’s explanation for why she does not go to school dances anymore—“Are you kidding, a dance? [pause] I am not ever going to dance again—either actually dance or go to a dance, I don’t walk, I am done dancing.” One 10-yr-old could not see beyond her reference point for what “playing on the playground” meant as illustrated by her reasoning as to why she does not play on the playground: “I cannot play anymore because I cannot walk.”

In contrast to those who had a reference point for participation as done before their injury, other children seem to embrace new reference points after their injury. One father described his 10-yr-old son’s participation in community sports with an interesting and inquisitive perspective:

We basically made him choose between [flag football and wheelchair basketball, and he’s going to do basketball instead . . . and I gotta say we probably coached him to go that route . . . because we feel that, um, pretty quick down the road, here, there’s gonna be a separation between what kids are doing and what he’s probably going to be able to do.

Although he misses “what it used to be like,” one 11-yr-old still enjoys physical activities, claiming that for fun he likes to “play basketball, [ride his] four wheeler, and play baseball.” An 8-yr-old and a 16-yr-old girl explained, “I can do anything I want, like horseback riding” and “I am very much participating as an active volleyball player who enjoys cyber-bowling and going to school dances,” respectively.

Missing Out

Each of the interviews made reference to changed social habits that indicated children felt as though they were missing out. One 13-yr-old reflected on the amount of time that he spends with his friends and explained,

They [his friends] have, like two-a-days for football and track and wrestling and basketball, but they don’t have time to come to my house. I really kind of miss that. If I wasn’t hurt, I’d be right there with them.

He further revealed,

They told me, you know, even though I’m hurt, I’m still part of the team—but I am not—I do go with them but I am not active with them, I stay at home—maybe I am still a member in their minds.

Children shared that they no longer participated as members of community sports teams because “I am not
allowed to play in a chair,” “I cannot do gymnastics in a chair,” and “they don’t take kids like me”; others simply stated, “I will never be able to be on a team.”

The theme of missing out is further clarified by one boy’s explanation about why he does not participate in field trips: “I miss school trips because they go on charter buses, and charter buses aren’t wheelchair accessible.” Other children provided additional clarity on the theme of missing out; a 10-yr-old explained, “I really can’t hang out at my friend’s house . . . because I can’t get into my friend’s house.” When responding that he never goes to parties, another boy pointed out, “I cannot get in houses where [my] friends’ parties are at.” A 14-yr-old girl explained that she never plays or hangs out at her friends’ houses “because I can’t get into my friend’s house” and that she goes to dances less often than her friends “because since my accident I can’t dance yet.”

**Autonomy**

During the interviews, both the children and the caregivers implied that after SCI, parents treated their children differently, had fewer expectations for participation, and made decisions for their child about activity performance and participation to a greater degree than before the injury. Some caregivers felt responsible for carrying out activities for their child, even when it was physically unnecessary. For example, when asked to describe how her young son gets into a Jeep from his wheelchair, one mother replied, “His dad will pick him up and put him into it [the Jeep]; he doesn’t have him do anything himself—nothing, nothing.” When one mother was asked why her 15-yr-old child with paraplegia does not participate in his own self-care, she replied,

Yeah . . . I know it is important for him to participate in his own care and exercise, and he is very able to do it [pause], but look at it from my point of view—if everything is going to get done, I just better do it rather than have him participate [pause], there is just too much to do—get him dressed, feed him, get him to school, make sure his medications and cathing supplies are packed [pause], and I have two other kids and then the normal stuff we do, not about the SCI, just stuff we need to do each day . . . participation in his own care is a nice thought and he really can do it without a problem, but I can’t give it the time.

When questioned about sleeping over at her friends’ houses, one young girl exclaimed, “I never do it now, before I did . . . because now my mom won’t let me.” Likewise, when this 9-yr-old girl was asked where she goes when her friends’ parents are driving, she responded, “I never go . . . because sometimes my mom thinks that they’ll take me somewhere that I don’t want to go.” Another 10-yr-old child had a similar message: “Ever since my injury my mom will not let me do anything; I would love to do the things on these pages but I am just not allowed [pause] ever since my accident.”

Somewhat similarly, one adolescent explained that after his injury, his parents gave him fewer rules than before. When he was further asked about following rules in his house, he explained, “I probably do [follow rules] less than my friends, because their parents have more rules for them than I do, right now. I really don’t have any rules, my parents decided after my injury I have no rules.” Parallel to this, when asked what expectations were placed on him to help out at home, he replied, “Uh . . . nothing, really, even if I wanted to [help] it would not be left up to me.” After she was asked about participating in meal preparation and chores, another 16-yr-old participant responded, “I can do everything like before but my mom does not let me do anything—I do not have a choice.”

**Discussion of and Implication for Development of CAT Platform of Participation for Children With SCI**

As part of a cognitive interview study on newly constructed items for eventual CAT platforms of activity performance and participation, we explored the experiences with and perceptions of activity and participation of children with SCI and their caregivers.

The theme of apprehension about activity performance and participation is related to the interaction within the environment and perceived barriers to participation. Consistent with the understanding of environment, in this study, environment was not restricted to structural designs but also involved the personal, social, and cultural milieus in which participation occurs. Fears—both perceived and based on actual experiences—about activity performance and participation emerged as a theme defined as “apprehension about activity performance and participation.” Fear of physical hurt, such as falling out of a wheelchair or being hit by a ball, reflected perceptions about the consequences of participation that limit involvement in activities despite the physical ability to engage. Fear of emotional or social hurt, such as peers’ negative reactions to bladder incontinence, also reflects a personal belief about the consequence of participation that adversely affects participation.

Little is known about fears among children with SCI, especially fears about sustaining additional physical injuries when participating in sports, games, and
community outings. The traumatic nature of most SCIs may influence children to choose more sedentary activities to avoid additional injuries or pain. Alternatively, as noted by Heah et al. (2007), a combination of unsupported environments, parental apprehension, and limited physical abilities may limit children’s participation in active play. Before this study, we did not fully appreciate the apprehension associated with actual consequences of participation, particularly in crowded environments. The descriptions of cigarette burns and bumping or being bumped by others provide a deeper appreciation for why some children and youths with SCI simply choose to participate in more sedentary and solitary activities than in activities occurring in places with crowds. Although these findings are important to the understanding of participation and measurement of activity performance and participation, they also have implications for the measurement of quality of life.

Others have recognized how perceptions and attitudes act as strong barriers to participation (Law et al., 1999; Pivik, McComas, & Laflamme, 2002). In our study, children and caregivers described real and perceived attitudes of other people as barriers to participation. Consistent with the findings of Law et al. (2007), in our study, adolescent participants more frequently described perceived attitudinal barriers. Although the beliefs, experiences, perceptions, and subjective reality of participation of people with disabilities have been recognized as important aspects of health outcomes, their influence on activity performance and participation makes the measurement of these constructs, especially using CAT, particularly challenging. For the eventual CAT platform of participation for children with SCI, we have developed a response scale with the realization that a variety of reasons for why one chooses to participate or refrain from participation exist (see Figure 1). Calibration work will evaluate the dimensionality of participation, as defined by the item bank, and confirm the degree to which the construct of participation is synergistic with CAT methodologies.

The think-aloud technique and open-ended questions used in this study provided tremendous insight into children’s mental images or reference points for activity performance and participation. Clearly, some children framed participation items on the basis of past experience as an able-bodied person, and others reframed participation on the basis of mobility impairments and other consequences of SCI. To establish a common reference point so that all children were interpreting the item similarly, we added preambles to many questions, shortened and simplified other questions, and removed several questions. For example, when asked why she does not play on the playground, a child initially responded “because I can’t walk.” This child’s reference point for “play on the playground” was how she ran and played ball before her injury and how other children ran and played on the playground. We reworded the item to read “Playing on the playground means playing games with other kids. I play on the playground.” Likewise, when responding to the item “I dance,” an adolescent explained that she cannot dance because she is in a wheelchair. The item was revised to read “Dance means to move any part of your body or to move your wheelchair to music. I dance.” Other items were simplified. For example, varied responses to and descriptions of participation in physical education class emerged; these varied responses were based largely on children’s reference point for what encompassed participation while in gym class. We finally simplified the item to read, “In gym class, I do the same thing as the other kids.” Feedback from other children, who described themselves as very participatory, prompted us to expand the breadth of items to avoid ceiling effects on the eventual CAT.

**Mobility impairments** were identified as barriers to participation in community and school sports and on community teams. Most children who participated as members of an organized school or community sports team before their injury described feelings of missing out. Likewise, children who had never engaged in organized sport teams also implied that they miss out on the chance to be a team member. In addition to children’s mobility impairments, transportation and the physical and structural environments were impediments to participation. Accessibility issues were discussed throughout the interviews, particularly in reference to being able to go to friends’ homes. These findings contribute to the building evidence in support of participation as a complex and multifactorial construct. The structure of our item bank recognizes significant mobility impairments, transportation, and ill-equipped environments as variables that adversely influence participation.

The concept of autonomy refers to the ability to make one’s own decisions about what one is able and willing to do (Chan, 2002). Unlike adults with SCI who achieved autonomy before sustaining SCI, children and youths with SCI are at varying stages of autonomy partly because of typical development and, as evidenced in this study, partly as a result of their SCI. Typically, parents of young children make most of the decisions concerning their child (decisional autonomy), whereas older children begin to assume responsibility for their own choices. This study’s findings suggest that parents assume a greater role.
in making decisions for their children after SCI—even for youths who, before SCI, developed decisional autonomy for many aspects of their lives. Recognizing this, we have developed items and response scales for both child-reported outcomes and parent-reported outcomes. We will conduct future work to evaluate the disparity between parents’ reports of their child’s participation and children’s reports of their own participation.

This study has limitations. First, the number of children and caregivers interviewed was small, and their collective experiences may not represent the experiences of other children with SCI and their caregivers. We did not use formal qualitative research methodologies to ensure rigor and trustworthiness of the data; rather, we used formal cognitive interviewing methodology to better understand children’s and caregivers’ perceptions and thought processes about items written to measure activity performance and participation.

Conclusion

As part of a cognitive testing study, 33 children and 13 caregivers were engaged in interviews using open-ended questions to gain insight into perceptions of and experiences with participation after childhood SCI. Insight into children’s and caregivers’ perspectives provided important information that helped refine the wording of test items and response scales. Although the intent was always to develop both a child- and parent-report outcome measure, the theme of autonomy for participation provides an even stronger catalyst to solidify item banks for both children and parents. This study further validated the complexity of the construct of participation. ▲

Acknowledgments

We acknowledge Louis Hunter, Ross Chafetz, Diane Barus, and Carolyn Hendrix for their assistance with the study. The study was funded by Shriners Hospitals for Children Research Grant 9146 (M. J. Mulcahey, Principal Investigator).

References


