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# Item Selection in Self-Report Measures for Children and Adolescents with Disabilities: Lessons from Cognitive Interviews

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Self-report measures;  
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The aim of the study was to evaluate children's and adolescents' understanding of items from self-report measures. Cognitive interviews were conducted as part of a larger study on pain and fatigue in children with disabilities. A list of guiding questions was used to encourage participants to talk about words or concepts in the scale that they found difficult. The sample included 32 children and adolescents with physical disabilities. Participants had difficulty with words such as *intense*, *severe*, and *anxiety*. They had more difficulty with abstract ideas, such as *average*, than they did with more concrete ideas, such as naming a recreational or social activity. Because poor outcome measurement hinders symptom evaluation, findings support the need to put greater emphasis on the child perspective when developing and using self-report measures. Suggestions for increasing accuracy of these measures are offered for clinicians and researchers.

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## Background

PAIN AND EMOTIONAL distress are primary symptoms in conditions that affect children with disabilities, such as cerebral palsy (CP), spina bifida (SB), neuromuscular disease (NMD), spinal cord injury (SCI), limb deficiency (LD), and amputation (AMP; Engel, Jensen, & Schwartz, 2006; Engel, Kartin, & Jaffe, 2005; Jan & Wilson, 2004; Oddson, Clancey, & McGrath, 2006; Wilkins, McGrath, Finley, & Katz, 2004). Despite advances in understanding the consequences of these diseases and conditions, pain and emotional distress in children are often poorly managed (Eccleston, Crombez, Scotford, Clinch, & Connell, 2004; Finley, McGrath, & Chambers, 2006; Sakolsky & Birmaher, 2008).

There is little known about pain, fatigue, depression, and related symptoms in children with disabilities. Although there are a number of strategies to evaluate pain in children, there is little evidence to support their use in children with disabilities (Engel & Kartin, 2004). Fatigue in children with cancer has been found to be a significant problem (Hinds et al., 1999; Hockenberry-Eaton et al., 1998; Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002), but fatigue in children with disabilities has not been well studied (Eddy & Cruz, 2007). Little is known about the prevalence of depression in children with the particular disabilities we studied, but given the relationship between pain, depression, and fatigue described in adults with similar disabilities (Benony et al., 2002), there is reason to believe that these children and adolescents are at high risk. Measurement of participation among children with disabilities has been limited to the Community Activities Questionnaire (CAQ; Ehrmann, Aeschleman, & Svanum, 1995). Advances in the management of these symptoms and research on effective

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treatments depend on the existence of measures that function well in pediatric populations.

Although there is increasing evidence that, given age-appropriate measures, children as young as 5 years can reliably and validly self-report aspects of their health status, challenges in assessment of outcomes in children remain, including inadequate construct definition and lack of consistent terminology (Jan & Wilson, 2004; Varni, Limbers, & Burwinkle, 2007; von Baeyer, 2006). In addition, many of the scales that target pediatric populations were developed for use in adult populations and later adapted for use with children. For example, the Brief Pain Inventory (BPI) was used to assess pain in children with CP (Engel, Petrina, Dudgeon, & McKearnan, 2005), and Srisaeng (2003) used the Multidimensional Scale of Perceived Social Support (MSPSS) to assess social support in adolescent mothers in Thailand. The CAQ (Ehrmann et al., 1995), the primary measure of participation in children with disabilities, was derived from an adult measure, the Activity Pattern Indicator (Brown & Gordon, 1987). There is little research investigating the validity of these adapted measures in pediatric populations. Many studies claim that selected measures function reliably in pediatric populations because children provide responses. However, for the most part, these same studies have not investigated children's understanding of these measures (Canty-Mitchell & Zimet, 2000; Imms, 2008). In a comprehensive review of quality of life measures in childhood (Eiser & Morse, 2001), the authors found that instruments based primarily or entirely on adult measures imposed considerable response burden for children in terms of length, reading skills, and response scale. These authors stressed that item and scale wording and format need to be modified for children's cognitive and language skills and that more research are needed to determine the level of response burden that children of different ages can manage.

The purpose of this study was to learn how items from self-report measures used with adults and children were interpreted by children with disabilities. Words and concepts presented in the BPI, the Short Form Health Survey (SF-8), and the MSPSS were analyzed by participants during cognitive interviews (CIs).

## Cognitive Interviewing

Cognitive interviewing has emerged as a promising method for obtaining respondent feedback on potential items for inclusion in self-report questionnaires (Christodoulou, Junghaenel, DeWalt, Rothrock, & Stone, 2008) and for correcting problems with existing self-report items (Beatty & Willis, 2007). Cognitive interviewing is defined as "administering draft survey questions while collecting additional verbal information about the survey responses that is used to help determine whether the question is generating the information that its author intends" (Beatty & Willis, 2007, p. 287). Its purpose is to identify and correct problems with survey questions in an effort to minimize response error

(Drennan, 2003). CIs have been shown to contribute to both the reliability and validity of measures by providing data on the clarity and meaning of questionnaire items to participants (Beatty & Willis, 2007; Clarke, 2004; Knafl et al., 2007).

## CIs With Children

Although the literature on cognitive interviewing with children is sparse (de Leeuw, Borgers, & Smits, 2004), researchers stress the importance of this step in the development of child self-report instruments because of differences between children and adults in social, emotional, and cognitive skills (Drennan, 2003; Levine, Huberman, Allen, & Dubois, 2001; Woolley, Bowen, & Bowen, 2004). For example, in a study of the validity of child-report data from the Elementary School Success Profile, Bowen (2008) found that children had issues with word recognition, misunderstanding content, response option incongruence, and misapplying response options to content. These authors suggested strategies to address these problems, including deletion of problem words or items, item simplification, reordering of scale items, and adding content as needed.

Irwin, Varni, Yeatts, and DeWalt (2009) used CIs successfully with children and adolescents from the general pediatric population to gain feedback on items from patient-reported outcome measures, and Stewart, Lynn, and Mishel (2005) were able to demonstrate the validity of using children with cancer as content experts in a self-report instrument content validity assessment. This study extends that research to include children with a variety of physical disabilities.

## Method

CIs were conducted as part of a larger study ( $N = 119$ ) on pain and fatigue in children with disabilities. The two most frequently used CI techniques are "think aloud" (where the respondent articulates what he or she is thinking as he or she answers the question) or "retrospective probing" (where the researcher asks specific, direct questions to illuminate how the respondent went about answering the question; Bell, 2010). The retrospective probing method was utilized in this study. After training in CI methodology, CIs were conducted by research staff using a list of guiding questions to encourage participants to talk about any words or concepts they found troublesome. For this study, researchers were most interested in two of Bowen's (2008) categories of issues with self-report items: misunderstanding content and misapplying response options to content. Therefore, CI questions were developed based on those categories (Irwin et al., 2009). Terms used in the BPI, the SF-8, and the MSPSS and questions designed to elicit understanding of time frames were presented during CIs, and only children who responded to items from the BPI, the SF-8, and the MSPSS during the larger study were included in this part of the study.

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