Refining the Pediatric Evaluation of Disability Inventory–Patient-Reported Outcome (PEDI-PRO) item candidates: interpretation of a self-reported outcome measure of functional performance by young people with neurodevelopmental disabilities

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AIM This study examined the item interpretability and rating scale use of the Pediatric Evaluation of Disability Inventory–Patient-Reported Outcome (PEDI-PRO) by young people with developmental disabilities. The PEDI-PRO assesses the functional performance of discrete functional tasks in the context of everyday life situations.

METHOD A two-phase cognitive interview design was implemented with a convenience sample of 37 young people (mean age 19y, SD 2y 5mo; 13 males and 24 females; 68% with intellectual disability) with developmental disabilities. In phase I, 182 item candidates were each reviewed by an average of four young people. In phase II, 103 items were carried forward or revised and each reviewed by an average of seven additional young people. Two raters coded responses for intended item interpretation and performance quality; codes were analysed using descriptive statistics. Qualitative analysis explored young people’s self-evaluation process.

RESULTS Items were interpreted as intended by most young people (mean 86%). Young people can use PEDI-PRO response categories appropriately to describe their performance: 94% of positive performance descriptions coincided with a positive response category choice; 73% of negative descriptions coincided with a negative response category choice. Young people interpreted items in a literal manner, and their self-evaluation incorporated the use of supports that facilitate functional performance.

INTERPRETATION The PEDI-PRO’s measurement framework appears to support the self-evaluation of functional performance of young people with developmental disabilities.

Patient-reported outcomes of functional performance are increasingly recognized as important indicators of health care outcomes in research and practice.1 While there are several high-quality paediatric patient-reported outcome measures (PROMs) available to evaluate young people’s functional performance, many measures do not include young people with developmental disabilities during development and subsequent validation.2,3 The adoption of these PROMs in neurorehabilitation may not be appropriate because the meaning of the measured construct may be different for young people with developmental disabilities, who may have cognitive and physical impairments that shape their everyday experiences.4,5 These differences may affect the way young people with developmental disabilities interpret and respond to PROM items and threaten the validity of the scores obtained.6,7 Therefore, there is a need for a PROM of functional performance designed specifically for young people with developmental disabilities.

The Pediatric Evaluation of Disability Inventory–Patient-Reported Outcome (PEDI-PRO) was developed in partnership with young people with developmental disabilities and with input from professionals working with young people with developmental disabilities. The PEDI-PRO uses a unique measurement framework to assess the functional performance of discrete tasks. In most available PROMs, items are administered in sets organized around professionally defined constructs – for example, activities of daily living. Alternatively, when responding to the PEDI-PRO, young people with developmental disabilities first select one of 11 familiar and important everyday life situations, such as working or getting ready in the morning. Young people then answer items about various functional tasks related to these everyday life situations that represent the three PEDI-PRO functional domains: Daily Activities, Mobility, and Social/Cognitive. These functional domains are aligned with the parent report, PEDI-CAT.8
We hypothesized that the PEDI-PRO’s measurement framework facilitates comprehension of items and generalization to everyday life, to improve the validity of self-reports gathered from young people with developmental disabilities. The PEDI-PRO is computer administered and incorporates accessibility features such as images depicting the item, text-to-speech, and practice items, to support comprehension for young people with developmental disabilities.

This article illustrates the use of an adapted cognitive interviewing methodology with young people with developmental disabilities to evaluate young people’s interpretation of PEDI-PRO item candidates. Research questions included the following: (1) Do young people with developmental disabilities interpret the PEDI-PRO item candidates in the intended manner? (2) Can young people with developmental disabilities use a Likert response scale to report their functional performance in a manner consistent with their self-described performance? (3) What factors influence the interpretation of PROM items and self-evaluation of performance of functional tasks by young people with developmental disabilities?

**Method**

**Design**

All activities were reviewed and approved by an institutional review board. This study used an iterative, two-phase cognitive interview methodology (Fig. S1, online supporting information). Prior to the cognitive interviews, we developed item candidates in the Daily Activities (74 item candidates), Social/Cognitive (63 item candidates), and Mobility (45 item candidates) domains for 11 everyday life situations in partnership with eight young adult co-researchers with developmental disabilities and with input from 67 additional young people with developmental disabilities and 26 professionals (these development activities are not the focus of this manuscript). Phase I cognitive interviews explored the wording, relevance, and potential ability of item candidates to discriminate performance differences among young people. Phase I results informed item revisions. Phase II cognitive interviews used a larger sample to evaluate comprehension of refined item candidates.

**Participants**

Participants were recruited through professional contacts and sites serving young people with developmental disabilities. We over-recruited young people with cognitive impairments aged 16 to 21 years, as this is a transition period during which young people are encouraged to identify needs and goals. We assumed young people with cognitive impairments would be most likely to identify problematic content and administrative features. Inclusion criteria were the ability to communicate simple ideas in English and maintain attention to a task for 5 minutes. Thirty-seven participants, aged 8 to 21 years, completed cognitive interviews (Table I). All participants and parents provided informed assent/consent and permission to participate.

**Procedures**

Cognitive interviewing places cognitive and communication demands on young people with developmental disabilities. To engage in this method, respondents must have knowledge of vocabulary and grammar, the ability to generalize questions to one’s everyday experiences, and the ability to communicate abstract ideas. We used a modified approach to reduce the demands of the interview process for young people with developmental disabilities. To reduce attention and communication demands, we developed smaller item sets of approximately 25 items for each everyday life situation; each item set contained items from all three functional domains. For each item, the interviewer asked a question about item comprehension (‘Tell me in your own words what this sentence is about’), rating decision-making (‘What were you thinking about when you chose [response]?’), or personal performance (‘How do you do [item]?’). This approach requires fewer cognitive demands than answering questions after all items are administered. Administrators could customize these questions to facilitate young people’s understanding of the

**Table I: Participants**

<table>
<thead>
<tr>
<th>Participant characteristics</th>
<th>n=37, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (range) age, y</td>
<td>19y (8.5–21.7)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>13 (35)</td>
</tr>
<tr>
<td>Female</td>
<td>24 (65)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>28 (76)</td>
</tr>
<tr>
<td>African-America</td>
<td>2 (5)</td>
</tr>
<tr>
<td>Other or multiple</td>
<td>7 (19)</td>
</tr>
<tr>
<td>IEP eligibility categories represented*</td>
<td></td>
</tr>
<tr>
<td>Autism spectrum disorder</td>
<td>13 (35)</td>
</tr>
<tr>
<td>Developmental disability</td>
<td>20 (54)</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>20 (54)</td>
</tr>
<tr>
<td>Sensory impairment (vision and/or hearing)</td>
<td>9 (24)</td>
</tr>
<tr>
<td>Speech or language impairment</td>
<td>8 (22)</td>
</tr>
<tr>
<td>Multiple disabilities</td>
<td>7 (19)</td>
</tr>
<tr>
<td>Specific learning disability</td>
<td>7 (19)</td>
</tr>
<tr>
<td>Orthopaedic impairment</td>
<td>6 (16)</td>
</tr>
<tr>
<td>Emotional disturbance</td>
<td>3 (8)</td>
</tr>
<tr>
<td>Neurological impairment-traumatic brain injury</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Other health impairment</td>
<td>2 (5)</td>
</tr>
<tr>
<td>Intellectual disability*</td>
<td>25 (68)</td>
</tr>
<tr>
<td>Use of mobility device</td>
<td>3 (8)</td>
</tr>
</tbody>
</table>

Data are n (%) unless otherwise indicated. *Young people may be eligible for an Individualized Education Program (IEP) under several disability categories. bParent-reported diagnosis, reported by 36/37 parents.
cognitive interviewing processes. To further support young people, six phase I interviews were co-facilitated by a young adult co-researcher. Completing the cognitive interview with a familiar peer may increase young people’s motivation and can elicit a depth of information not possible when cognitive interviews are administered only by an unfamiliar adult.\textsuperscript{13} Incorporating peer support into phase I interviews was essential, as items had not yet been refined.

To begin the cognitive interview, young people learned how to use the response categories by viewing examples and completing practice items. They then selected one of the 11 PEDI-PRO everyday life situations. Next, they answered standardized ‘who, what, when, where, how’ open-ended questions about their experiences performing the everyday life situation; these questions primed their memory and assisted with recall and reflection.\textsuperscript{14,15} An item set for that situation was then administered on a tablet using touch-activated PowerPoint (Microsoft, Redmond, WA, USA). Each participant chose a second everyday life situation and repeated this process. Individual participants answered 13 to 68 items (mean: 44); only two participants did not complete the full item set owing to difficulties with attention or communication; their available data was included in analyses.

In phase I, each item was reviewed by an average of four young people. In phase I, we also explored the acceptability of multiple response options. Based on phase I responses, we classified items into three categories: no revisions and proceed, revise and proceed, and discontinue. Items were discontinued for several reasons, including low comprehension, low relevance to young people’s everyday experiences, low content validity, or potential lack of discrimination, as evidenced by universal use of the highest response category across respondents. After phase I, we also developed 13 new item candidates in response to information shared from respondents and data gathered concurrently from professionals. Each remaining and new item was reviewed by an average of seven additional young people, to achieve saturation;\textsuperscript{11} in total, items reviewed in phase I and II were reviewed by an average of 11 young people. Phase II used the response options: ‘Very easy’, ‘A little easy’, and ‘A little hard’.

Interviews were audio-recorded and university researchers completed field notes. Participants’ qualitative responses and rating choices for each item were transcribed verbatim and entered into an Excel (Microsoft) database for coding.

**Analysis**

While most cognitive interview methodologies rely on inductive evaluation of responses,\textsuperscript{11,16,17} we used a coding approach that operationalized our research questions.\textsuperscript{6} Two researchers independently coded open-ended responses to each item for intended and unintended interpretation (1287 data points). We also coded how each young person described his or her ability to perform each item in the open-ended interview: positive, negative, or varying ability, or does not do. Raters reviewed all coding discrepancies to achieve consensus; if raters could not achieve consensus, a third coder was consulted (first author). We calculated the percentage of responses per item coded as ‘intended interpretation’, and then obtained the mean and range for all items in each domain. We used pivot tables to evaluate the consistency between young people’s open-ended descriptions of their performance and their response scale choices; we expected a pattern in which positive ratings were selected when open-ended descriptions were positive, and in which negative ratings were selected when open-ended descriptions were negative.

To identify factors influencing young people with developmental disabilities’ interpretation of PROM items and response categories, we purposefully sampled two types of open-ended responses: (1) responses coded as ‘unintended interpretation’, or (2) open-ended performance descriptions that were inconsistent with young people’s selected rating. Two coders independently generated memos of key ideas using inductive analysis.\textsuperscript{18} Memos were compared to identify common factors; these factors were then re-examined against all responses to identify confirming or negative cases. This resulted in the identification of two salient factors.

**RESULTS**

**Question 1: PEDI-PRO item interpretation**

In phase I, 60 items were interpreted in the intended manner by a majority of young people and proceeded without revision (Fig. S1; Table S1, online supporting information). An additional 43 items required revisions. Young people had difficulty interpreting items that included less familiar words, such as ‘step stool’ or ‘building directory sign’, or referenced a novel task, such as using an ‘automated phone menu’ or ‘a self-checkout machine’. Items were revised to use more familiar terms suggested by participants’ responses and young adult co-researchers. After identifying gaps in relevant item content, an additional 13 item candidates were developed for testing in phase II. Finally, 79 items were discontinued for additional testing.

Across all 116 items tested in phase II, on average, items were interpreted as intended 86% of the time (Table II). Young people rarely stated they were confused or did not know a word in the item (<2% of the time). The Daily Activities items had the highest frequency of comprehension, and Mobility items had the lowest frequency of comprehension.

**Question 2: self-reporting performance using Likert scales**

Results suggested young people with developmental disabilities could appropriately select a response category consistent with their open-ended description of task performance (Table III). As would be expected, young people were most likely to select the highest response category, ‘Very easy’, when they provided positive open-ended descriptions of their abilities. Young people who reported varying ability to complete a discrete task selected the
middle category, ‘A little easy’, most often. When young people provided negative open-ended descriptions of their abilities, they most often selected the lowest response category, ‘A little hard’, and infrequently selected the highest response category. Finally, the majority of young people who reported they did not perform the discrete task assessed in the item appropriately selected the ‘skip’ option. However, young people’s open-ended performance descriptions were mostly positive (58% of responses); they less frequently described their abilities as variable (19%) or negative (12%).

Question 3: factors influencing item interpretation and self-evaluation

Functional performance reflects use of supports and strategies

Young people’s self-reported ability to complete functional tasks incorporated the use and availability of environmental supports and strategies. Young people sometimes attributed positive performance to their active initiation of strategies and mobilization of environmental supports. Strategies included planning ahead to reduce the difficulty of the task, requesting assistance from trusted adults such as parents or teachers, or using adaptive equipment to support task completion. Their positive self-evaluation on the PEDI-PRO encompassed their active and successful use of such strategies. In other instances, young people described environmental supports implemented by others, such as the availability of accessible spaces or prompts provided by adults to scaffold activity completion. In these cases, young people still provided a positive self-evaluation on the PEDI-PRO, but less frequently attributed their performance to the provision of these supports.

Literal interpretation of item candidates

Young people in our study interpreted items in a literal manner in three ways; in all cases young people felt the item was not applicable to their experience. First, young people applied a literal interpretation of their own behaviour to items that referenced behaviours such as ‘use bad words’, ‘get angry’, or ‘hurry’. Young people who insisted they did not demonstrate these behaviours had difficulty understanding that absence of these behaviours may indicate a positive performance. Second, young people literally interpreted the methods used to complete a discrete task as depicted in the item or image. Young people’s responses to such items included caveats such as ‘That’s not how I take it off. I press it on a counter and then twist it, use my shirt’ in response to the item ‘Take the top off of a jar’, which depicted a hand directly gripping the jar lid. Third, young people literally interpreted the everyday life situation in which the discrete functional task was performed. One young person shared that she did not need to look up the doctor’s address on the Internet because ‘I know the (doctor’s) address (already)’, and another stated he did not use a calendar to remember his work schedule because his shift was the same every week. These findings suggest young people with developmental disabilities were unable to generalize the assessed functional task to an equivalent everyday life situation more familiar or relevant to their everyday experiences (e.g. entering information into a calendar for another purpose).

DISCUSSION

Herein, we have illustrated the use of an adapted cognitive interviewing methodology to evaluate the interpretation of PEDI-PRO item candidates by young people with developmental disabilities. The PEDI-PRO’s unique measurement framework and integration of accessibility features appears to support the comprehension of functional performance items by these young people. On average, items were interpreted in the intended manner 86% of the time. However, the interpretability of items varied across functional domains. Daily
Activity items were usually interpreted in the intended manner by most young people; these items assessed tasks that required only one to two familiar concrete steps or that have a restricted range of performance methods and demands. Examples include, ‘Cut my food with a knife and fork’ and ‘Use a key to unlock a door’. This type of content may be easier to generalize to one’s everyday life experiences, and thus may be easier to interpret.21,25 In contrast, young people’s unintended interpretation of Mobility items often included references to both the intended mobility task and unintended functional tasks that are concurrently performed with mobility tasks during everyday activities, such as paying attention to one’s surroundings or holding or manipulating objects while moving. It is possible that the 92% (34/37) of young people in our sample without significant mobility limitations (as indicated by infrequent use of mobility equipment) were less attuned to the discrete mobility tasks targeted in each item. Further research is needed to refine Mobility item candidates with young people with developmental disabilities and more significant mobility impairments.

Overall, young people with developmental disabilities were able to use response categories in an appropriate manner to evaluate their functional performance, as indicated by the consistency between their selected responses and open-ended descriptions. The PEDI-PRO response categories were not designed to assess independent performance, but rather functional performance. Young people’s responses suggest their perceptions of successful functional performance reflect the successful incorporation of strategies and environmental supports. This lived experience is aligned with the International Classification of Functioning, Disability and Health’s definition of performance as ‘what an individual does in his or her current environment’.21 These findings provide additional support for the meaningfulness and relevance of the PEDI-PRO’s approach to evaluating performance in the context of everyday life situations to young people with developmental disabilities.

However, some young people continued to select positive response categories even after identifying challenges completing functional tasks, which was an unexpected pattern. About 16% of the time young people described varying ability, they selected the ‘Very easy’ response category, and about 20% of the time young people described their performance negatively, they selected the ‘A little easy’ response category (Table III). This suggests response categories typically assumed to represent minor performance difficulties when used by adults, such as ‘A little easy’, may indicate moderate-to-significant performance difficulties when selected by young people with developmental disabilities. Additionally, these young people were more likely to select positive rating categories in this and other research.22,23 PROMs for young people may need to be sensitive to smaller self-reported shifts in performance at higher ends of a rating scale, for example from ‘A little easy’ to ‘Very easy’. PROMs for young people with developmental disabilities may also need to include more items assessing the most difficult functional tasks or embed tasks in more difficult contexts, for example talking with strangers instead of familiar people, or concentrating in a very noisy environment. We found in phase I that items assessing basic functional tasks were almost universally endorsed as ‘Very easy’ by young people with a range of functional abilities, as alternative supports and strategies are more readily available for such tasks. Across both phases, extremely difficult tasks were more likely to elicit more variability in responses and as a result, more frequent use of negative-rating categories. Creating a greater number of item candidates that assess tasks that are very difficult to perform even with supports and strategies may result in more discriminatory and precise functional performance PROM scores for young people with developmental disabilities, and should be explored in future research.

This study revealed a tension between the benefits and limitations of item specificity in PROMs designed for young people with developmental disabilities. The valid use of PROMs requires respondents to identify implicit cues about the intended construct of measurement.24 For example, a question about using a calendar to remember one’s work schedule intends to assess the discrete functional task of using a calendar to keep track of responsibilities. However, young people with developmental disabilities may not be aware of those implicit cues, and as our study demonstrates, may be unsure how to evaluate their performance when items reference specific activities they do not perform, or perform in different ways. Yet, our study also suggests young people with developmental disabilities are more likely to interpret items in the intended manner when they are embedded within specific, familiar everyday experiences. The PEDI-PRO measurement framework and use of everyday life situations to assess functional performance increases the likelihood young people will be familiar with the functional tasks assessed in an item. However, given the proclivity for young people with developmental disabilities to interpret items in a literal manner, young people are likely to encounter some items they feel are not applicable to their lived experience. In these instances, the availability of the ‘skip’ option may reduce measurement error resulting from unintended item interpretation or inappropriate use of response options.

This study had several limitations. Our convenience sample contained fewer young people with significant mobility impairments and young people who identify as a minority; these characteristics could impact item interpretation. Our sample under-represented males; it is possible that gatekeepers overidentified females.25 More research is necessary to ensure young people with a range of abilities and characteristics interpret the items in the intended manner, and requires a larger sample to increase generalizability. One artefact of the cognitive interview methodology was that some young people provided extensive information, some of which was off topic. We inductively determined if these responses reflected unintended item meaning, or if the young people were providing as much
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improve the interpretability of Mobility item candidates, and supports and strategies. Future research is necessary to matched their self-described performance using environmental supports and strategies. Future research is necessary to improve the interpretability of Mobility item candidates, and evaluate item interpretation with a broader clinical population.

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SUPPORTING INFORMATION

The following additional material may be found online:

Figure S1: Iterative two-phase cognitive interview process.
Table S1: Detailed information about item comprehensibility, relevance, and sensitivity across phases I and II of cognitive interview.

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