Developmental Screening and Parents’ Written Comments: An Added Dimension to the Parents’ Evaluation of Developmental Status Questionnaire

abstract

OBJECTIVE: The aim of this study was to better understand the utility of using the Parents’ Evaluation of Developmental Status (PEDS) in well-child visits by analyzing themes and patterns in parents’ written responses on the PEDS form.

METHODS: We reviewed a consecutive sample of medical records with PEDS forms for children aged 6 months to 9 years (site 1) and 3 to 5 years (site 2). We recorded the concerns that parents identified in response to the 10 PEDS questions along with demographic information. We then categorized parents’ written comments about those concerns according to comment content. We used qualitative and quantitative methods for analysis.

RESULTS: We collected 752 PEDS forms. Ninety percent of the parents endorsed at least 1 concern (94.6% on the English forms versus 69.7% on the Spanish forms; \( P < .001 \)). Parents qualified 27.5% of their concerns with a written comment. In 23.9% of cases in which parents identified a concern and provided a written comment, the content of the comment did not match the question’s intent; rates of mismatch were similar for the English and Spanish forms. Among comments regarding behavioral concerns, 12% reflected a misunderstanding of age-appropriate behavior. Medical concerns accounted for 14.1% of the comments; these concerns were more common on English forms (61.3%) than on Spanish forms (1.7%) \( (P < .08) \). More than one-fourth of the comments reported behavior or development that was on target or advanced for the child’s age.

CONCLUSIONS: Parents frequently used the PEDS forms to communicate additional concerns regarding their child or provide positive feedback on their child’s progress. The inappropriate developmental expectations, limited health literacy, and culturally distinct comments on the PEDS forms reinforce the importance of using screening tools to enhance the care provided during visits but not to replace patient-provider communication. Pediatrics 2010;126:S170–S176

AUTHORS: Joanne E. Cox, MD,a Noelle Huntington, PhD,a,b Adrianna Saada, BA,a Alexandra Epee-Bounya, MD,a and Alison D. Schonwald, MDa,b

Divisions of aGeneral Pediatrics and bDevelopmental Medicine, Children’s Hospital Boston, Boston Massachusetts

KEY WORDS
developmental screening, well-child visits

ABBREVIATIONS
WCV—well-child visit
PEDS—Parents’ Evaluation of Developmental Status
CHPCC—Children’s Hospital Primary Care Center
MEHC—Martha Eliot Health Center

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Address correspondence to Joanne E. Cox, MD, CHPCC, Children’s Hospital Boston, 300 Longwood Ave, Boston, MA 02115. E-mail: joanne.cox@childrens.harvard.edu

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The American Academy of Pediatrics recommends using a validated tool to screen children for risk of developmental delays at the 9-, 18-, and 30-month well-child visits (WCVs). In its policy statement on the subject the academy listed a variety of screeners that target language, motor skills, or a broader range of concerns. Some of these questionnaires ask parents about the child’s skills, others require direct assessment of the child by the health care professional, and only a few ask parents to identify concerns across developmental realms. Every listed tool is standardized, and their accuracy is considered adequate for a screening measure.

Schonwald et al have demonstrated that using the Parents’ Evaluation of Developmental Status (PEDS) to screen children for developmental delays during WCVs is effective and operationally feasible in a large, urban, teaching setting. They also showed that implementing the PEDS does not lay during WCVs is effective and operationally feasible in a large, urban, teaching setting. They also showed that implementing the PEDS does not stretch the visit. Other tools, such as the Ages & Stages Questionnaire, were found to be an effective and feasible addition to the WCV. Despite the known utility and feasibility of routine developmental screening in identifying children at risk of delays, little is known about other effects of this substantial practice change on the WCV.

Given provider resistance to adding this procedure to the already overfilled WCV, it is important to document other potential benefits of routine screening within real-life settings.

Our practices chose to screen children for developmental delays during WCVs by using the PEDS because of its brevity, literacy level, and ease of administration. The PEDS is a 10-item questionnaire that parents complete to identify concerns about developmental progress. The questionnaire’s 10 items address discrete developmental realms; the first and last items provide opportunities to identify more general concerns. Rather than asking about the presence of specific skills, the PEDS encourages parents to write down and discuss their concerns with the provider. In scoring the PEDS, some concerns are considered “predictive,” which means that they are more likely to be indicative of a developmental issue and, therefore, are more likely to warrant a referral for further evaluation. Other concerns are considered “nonpredictive,” which means that the concerns most likely can be addressed by counseling parents during the WCV. Whether a concern is considered predictive depends, in part, on the child’s age. However, it is the provider’s judgment, based on further conversation with the parent, that determines whether a referral is made.

In this study, we analyzed parent comments on the PEDS. By categorizing the content areas that parents addressed, the developmental knowledge they had or needed, and the patterns unique to Spanish-speaking families, we hoped to identify other ways that the PEDS could be used to better meet the needs of the families we serve.

METHODS

Setting and Participants

We collected completed PEDS forms from the Children’s Hospital Primary Care Center (CHPCC) and Martha Eliot Health Center (MEHC), both of which serve predominantly low-income families. The CHPCC is the primary care pediatric practice of Children’s Hospital Boston and serves ~13 000 children (~40 000 visits per year), mostly from the surrounding Boston neighborhoods. Forty percent of CHPC patients are black or African American, 35% are Latino, and 65% qualify for free care or have Medicaid coverage. The PEDS has been a standard part of WCVs at the CHPCC for children aged 6 months to 9 years since January 2006. The MEHC is an urban community health center operated by Children’s Hospital Boston that serves >8000 families from diverse ethnic, cultural, and linguistic backgrounds. Of the families that the MEHC serves, 24% are English-speaking, 75% are Spanish-speaking, and 1% speak other languages such as Creole and Somali. Many families served by the MEHC are recent immigrants, primarily from the Dominican Republic and other Latino countries. The PEDS became a standard part of WCVs at the MEHC for children aged 6 months to 5 years in April 2007.

Design

We reviewed all medical records of children aged 6 months to 9 years between January 2007 and February 2008 for the CHPC and of children aged 3 to 5 years between April 2007 and June 2007 for the MEHC. MEHC data were originally recorded for another study that focused on narrower age and date ranges. At both sites, our study included all completed and available PEDS responses for children within the study age ranges who had a WCV within the specified date windows. The hospital’s institutional review board approved the study.

For each of the 10 PEDS questions, we recorded whether the parent endorsed a concern (by responding “yes” or “a little”) and transcribed verbatim all of the parents’ written comments. A bilingual research assistant translated the comments that were written in Spanish to English. We also recorded the child’s age, gender, ethnicity, race, insurance status, primary care provider, and WCV date, as well as the parent’s primary language and the language used to complete the PEDS. Two investigators (Drs Schonwald and Cox) analyzed the written comments by using standard qualitative tech-
niques\textsuperscript{11,12} and generated a list of codes for classifying the comments. The study team reviewed the codes, created a hierarchy of code classes and subclasses, and refined the codes. Some code categories were based on the 8 areas of development addressed in questions 2 through 9 of the PEDS; another category included more general concerns (eg, “I am worried that he doesn’t do all the things that other kids his age do.”) We also developed codes to capture medical concerns, emotional/mental health concerns, and concerns about autism. We developed a subclass of codes for specific behavioral (eg, hyperactivity or aggression) and activities-of-daily-living (eg, sleeping or toileting) concerns. Finally, we developed codes to capture the positive and neutral information that some parents provided, such as statements that the child’s development was on target or listing services that the child was receiving.

Two investigators (Drs Schonwald and Cox) then coded all comments from the CHPCC and 2 investigators (Drs Schonwald and Epee-Bounya) did the same for the MEHC comments by using the coding system that the study team had developed. A third author (Dr Huntington) then reviewed and resolved all discrepancies, in some cases with additional discussion and clarification of codes by the study team.

We analyzed the data by using SPSS 14.0 (SPSS Inc, Chicago, IL) for frequencies, \(\chi^2\) or Fischer’s exact tests depending on cell size, and independent \(t\) tests.

RESULTS

We collected 752 PEDS forms (690 from the CHPCC and 62 from the MEHC). Of these forms, 138 (18.4%) were completed in Spanish, although 22.1% of the parents reported that their primary language was Spanish. Mean ages of the children were 3.4 ± 2.5 years (English forms) and 3.5 ± 1.9 (Spanish forms) \((P = .46)\). Approximately one-third of the children (32.6%) were Latino, 42.0% were black, and 30.2% were biracial or of another race or ethnicity. Forty-nine percent of the children were male, and 70.7% had Medicaid coverage.

Frequencies of Concerns and Comments

Table 1 summarizes the frequencies of the concerns (circled or written) and presence of written comments for each question. Ninety percent of the parents endorsed a concern (“yes” or “a little”) in response to at least 1 question, primarily questions 1 (global concerns) and 10 (other concern). Parents qualified 27.5% of their concerns across all questions with a written comment, most frequently for concerns about motor skills, behaviors, and socialization.

<table>
<thead>
<tr>
<th>PEDS Question</th>
<th>English Forms With Concerns (N = 613)</th>
<th>Spanish Forms With Concerns (N = 138)</th>
<th>(P^a)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: global</td>
<td>464 75.8</td>
<td>81 59.1</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>2: expressive language</td>
<td>93 15.6</td>
<td>18 13.1</td>
<td>.47</td>
</tr>
<tr>
<td>3: receptive language</td>
<td>59 9.7</td>
<td>10 7.3</td>
<td>.38</td>
</tr>
<tr>
<td>4: fine motor</td>
<td>32 5.2</td>
<td>0 0.0</td>
<td>.006</td>
</tr>
<tr>
<td>5: gross motor</td>
<td>26 4.3</td>
<td>3 2.2</td>
<td>.26</td>
</tr>
<tr>
<td>6: behavior</td>
<td>108 17.9</td>
<td>19 13.9</td>
<td>.26</td>
</tr>
<tr>
<td>7: socialization</td>
<td>53 8.8</td>
<td>9 6.6</td>
<td>.010</td>
</tr>
<tr>
<td>8: activities of daily living</td>
<td>46 7.6</td>
<td>2 1.5</td>
<td>.008</td>
</tr>
<tr>
<td>9: academic</td>
<td>57 10.0</td>
<td>8 6.0</td>
<td>.14</td>
</tr>
<tr>
<td>10: other</td>
<td>559 91.2</td>
<td>70 50.7</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

* Based on \(\chi^2\) analysis or Fisher’s exact test.

Of parents who completed the forms in English, 94.6% indicated a concern on at least 1 question, compared with 69.6% of parents who completed the forms in Spanish \((\chi^2 = 78.64; P < .001)\) (Table 2). English forms also showed significantly more concerns, on average, than Spanish forms (2.4 vs 1.6; \(t_{49} = 5.5; P < .001\)). Concern rates were significantly higher on the English forms for questions 1, 4, 8, and 10. Parents who completed the forms in English or Spanish were equally likely to qualify their concerns with written comments, although those who completed the forms in English were more likely to provide a written comment about a behavioral concern, and parents who filled out the forms in
Spanish were more likely to offer written comments about an "other" concern (Table 3).

**Types of Comments**

Parents provided a total of 740 comments on the PEDS forms. Table 4 summarizes the content of parent comments. More than half of all comments addressed concerns about the child’s expressive language, behavior, activities of daily living, or medical issues. More than one-fourth of the comments were in response to PEDS questions to which parents had responded by indicating no concern; in these cases, the parents used the comment field to reinforce that they had "no concerns" or state that their child was "fine.”

**Question-Comment Mismatch**

We evaluated how often parents conveyed a concern about 1 area of development in response to a question intended to elicit concerns about another area of development. Of comments made in response to questions 2 through 9, 23.9% did not match the question’s intent (Table 5). For example, parents provided comments on behavioral issues in response to questions about their child’s fine or gross motor skills:

- “I have been told that he can’t keep his fingers out of his mouth.” (parent comment on question 4 [fine motor skills issues] about a 6-month-old)
- “She hits a bit and scratches all the time.” (parent comment on question 5 [gross motor skills issues] about a 2-year-old)

The rate of mismatch between comments and question intent was equal for the English and Spanish forms. The 55 known mismatches were in only 45 (6%) of all forms. On the English forms, 6.7% contained at least 1 mismatch compared with 2.9% on the Spanish forms, although this difference was not significant ($\chi^2 = 2.2; P = .11$).

For 6 of the mismatches, the question represented a nonpredictive concern for that child’s age but the text of the parent’s comment indicated that there was actually a predictive concern. For example, in response to question 6 about behavioral concerns, which are nonpredictive, a parent expressed an academic concern, which is predictive:

- “He can’t read just yet when you read to him he seems to not care less about what you’re reading.” (about an 8-year-old)

In 21 of the mismatch cases, the opposite occurred: the question was de-
signed to elicit predictive concerns, but the parent’s comment described a nonpredictive concern. For example, in response to question 3 about receptive language concerns, which are predictive, the parent expressed a behavioral concern that is nonpredictive:

“I tell him not to do something and he seems to forget what I say and does it again.” (about a 5-year-old)

**Developmentally Inappropriate Concerns**

In many cases, parent comments indicated a misunderstanding of typical development for age. In particular, 12% of all behavioral concerns seemed to be developmentally inappropriate, and the parents indicated that they expected their child to display skills beyond his or her age or developmental level. For example:

- “Crying a lot before going to sleep.” (about a 6-month-old)
- “She’s bad.” (about a 12-month-old)
- “She does not know how to play with other children.” (about an 18-month-old)

**Medical Concerns**

The PEDS was designed to capture developmental and behavioral concerns, but 14.1% of all comments addressed medical concerns, most commonly in response to question 1 (global concerns) or question 10 (other concerns). Medical concerns were more commonly expressed on the English forms (61.3%) than on the Spanish forms (41.7%) ($\chi^2 = 3.0; P < .08$). The most common medical concerns were about orthopedic issues (eg, “problems with legs”), rashes, and coughs.

**Feedback**

Some parents used the PEDS form to share additional information about their child, such as a positive description of the child, a story about the child’s developmental achievements, or information on the child’s current service use. Overall, 10.3% of the comments were informational. For example:

- “No concerns, very intelligent child. She amazes us everyday.” (positive statement about a 4-year-old child)
- “She says ‘ta,’ ‘ta’ She wants to walk. She holds her bottle. She sits up by herself. She love to grab things.” (story about developmental achievements of a 6-month-old)
- “Early intervention has come to the house twice for an evaluation.” (current service use)
- “She has been diagnosed with autism. She is currently in Early Childhood Program.” (about a 4-year-old)

**DISCUSSION**

Although the American Academy of Pediatrics recommends routine screening for effective, early, and universal identification of young children who would benefit most from timely interventions, little is known about the additional impact of routine screening on primary care. Results of our analyses confirmed that a substantial portion of PEDS forms include information that is potentially useful to providers, beyond the identification of risks of developmental and behavioral concerns. We found that when practices use the PEDS appropriately, they can collect a wealth of information beyond the development realm, including potential medical concerns and parent misunderstandings of normal child development.

To use the PEDS questionnaire appropriately, providers must discuss reported concerns with parents. Mismatches between question intent and actual parent concern can occur as well as parent misunderstanding of what is developmentally appropriate for their child. In our study, only a few mismatched written comments would have changed the risk category indicated by the PEDS score, but all of the mismatches could provide important opportunities to engage with parents who need education on developmental guidance and promotion. In fact, mismatches are probably far more common than our results showed, because the mismatches we identified were based only on what parents had written; conversations with parents might identify even more concerns that parents had incorrectly identified as being relevant to a given PEDS question. Providers may be able to use parents’ comments as a framework for guiding additional dialogue. Developmentally inappropriate concerns may afford an opportunity to learn about parents’ understanding of child development and adjust this understanding. Improving parent knowledge of child development could not only improve the parent-child relationship but also prevent misdiagnoses.13

The 90% of PEDS forms in our study with at least 1 concern endorsed as “a little” or “yes” was higher than the 56.7% rate in the PEDS-standardization study. A possible explanation could be that providers were more likely to include completed PEDS forms in medical records when parents endorsed concerns and to discard forms with no endorsed concerns. Alternatively, these differences could reflect different demographic characteristics: 74.6% of our patients were black or Latino, whereas only 35.5% of patients in the standardization group were black or Hispanic/other.

English forms were far more likely to contain comments than were Spanish forms. The similar mismatch rates on the English and Spanish forms suggest that this difference in comment rates cannot be accounted for by differences in literacy or the effects of translating the form’s questions from English to Spanish. Perhaps English and Spanish speakers have different concern thresholds for the issues raised by the PEDS questions, different interpretations of developmental milestones and expectations for their children, or dif-
different levels of comfort in communicating with medical personnel about what they might perceive as nonmedical information.

The different patterns we found in written comments on the English and Spanish forms were similar to some of those found in the PEDS-standardization study. As in our study, the standardization study revealed that Hispanic parents were less likely than white and black parents to be concerned about self-help but more likely to be concerned about medical status. The authors of previous studies have described differences in maternal developmental expectations among different cultural groups and the importance of cultural context when talking with parents, which reinforces the importance of provider cultural competency in interpreting screening tool results to ensure that dialogue with parents is reciprocal, respectful, and responsive and to establish a context for further discussion. Perhaps most intriguing are the “medical” or “feedback” comments, which provide information about parents’ medical concerns, current services that the children are receiving, diagnoses from other providers, or positive assessments of the children’s functioning. In previous work, our group showed that after our practices implemented developmental screening, parents reported talking to the provider about their concerns more often and being more likely to receive answers to their concerns than before screening became routine. The comment structure of the PEDS may empower parents to communicate unsolicited comments to their child’s medical provider, and the opportunity to convey neutral or positive information could enhance the parent-provider relationship by contributing to a strength-based, rather than a deficit-based, model of care.

CONCLUSIONS

Our study results show that parents frequently use the PEDS to communicate concerns beyond those regarding their child’s development, such as medical concerns, or to provide positive feedback on their child’s progress. The comments revealed that some parents have inappropriate developmental expectations or limited health literacy that providers should address in their discussions with these parents. Our results provide confirmation that screening tools can enhance, but should not replace, patient-provider communication. The variety of topics covered in parents’ comments can provide a framework for discussion throughout the WCV, enable health care providers and parents to use WCV time more efficiently, and enhance the partnership between parents and providers.

It is unclear whether other developmental and behavioral screeners reveal similar supplemental information on children and parents. Future studies should examine whether screeners with questions about specific skills, rather than open-ended inquiries about concerns, have the same potential to facilitate conversation between parents and providers. In addition, researchers should evaluate the influence of parent health literacy on the written feedback provided in response to developmental and behavioral screener questions.

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