

The importance of discussing parents' concerns about development

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ABSTRACT

Objective	Pediatricians are encouraged by the American Academy of Pediatrics and the Bright Futures Guidelines ² to elicit and respond to parents' psychosocial concerns. This is especially important given research showing that parents' concerns can be significant predictors of developmental problems. Still there are many unanswered questions about the implications of parent-provider discussions of concerns: How likely are parents to engage in discussions of psychosocial concerns? Do providers use parents' concerns when making decisions about which families to counsel versus refer? Do family characteristics affect which parents discuss concerns? The purpose of this study is to provide preliminary answers to these questions and to view the implications of parent-provider discussions about concerns in developmental surveillance.
Design	Survey.
Setting	Public schools and day care centers in four diverse geographic sites representing the Northern, Central, Southern and Western US.
Patients and other participants	408 children between 11/2 and 7 years of age and their parents, whose socioeconomic and demographic characteristics reflect proportions in the 1990 US Census.
Main outcome measures	Licensed psychological examiners and educational diagnosticians elicited parents' concerns, measured children's development with measures of intelligence, language, motor, and school skills, and reported on whether children were previously enrolled in special education services.
Results	220 parents had developmental concerns. Of these, 59% could identify health care providers. Those families with providers were more likely to have: multiple concerns; concerns most predictive of developmental problems and to perceive their children as having health problems. Of those with providers, 66% shared concerns. Parents were more likely to share concerns if they were fathers, when they perceived their children to have health problems, and when they had expressive language concerns.
Conclusions	Parents who seek health care for their children seem to have more developmental concerns than those without providers. Although some parents do not discuss their concerns, most do. However, parents tend to share concerns only about expressive language and only when they perceive their child to have health problems, perhaps not recognizing that more complete discussions of concerns are of interest to pediatric

Introduction

It is the recommendation of the American Academy of Pediatrics Committee on the Psychosocial Aspects of Child and Family Health¹ and the authors of Bright Futures² that at each health supervision visit, pediatricians discuss parents' psychosocial concerns. The value of this recommendation is supported, in part, by research showing that in response to a standardized protocol for eliciting and interpreting parents' concerns, parents can provide highly accurate indicators of childhood disabilities.^{3–7}

Nevertheless, little is known about how parents express concerns outside of research settings. Pediatricians may use varying methods for eliciting concerns or they may depend on parents to raise concerns spontaneously. These approaches may alter the content of discussions or affect referral decisions. For example, Sharp et al. showed that despite readily engaging parents in discussions of psychosocial issues, pediatric residents had difficulty responding appropriately to parents' concerns – often ignoring concerns or failing to explore them further.⁸ Another study showed that fewer than 50% of patients with psychiatric disturbance were referred even when parents raised concerns.⁹

Thus there are a number of research questions to be answered about the actual use and impact of parents' concerns about children's development on provider referrals. These include:

- Are parents more likely to seek health care when they have concerns about their children?
- How likely are parents to discuss concerns about development with health care providers?
- What kinds of concerns are discussed?
- Do parental socioeconomic status and other family characteristics affect the likelihood of raising concerns?
- What happens after concerns are discussed?

The goal of this study is to provide preliminary answers to these questions. The results should have implications for the use of parents' concerns in developmental surveillance and promotion as well as for future research.

Method

In order to address the goals of this study, it was necessary to have a sample of children with and without disabilities, only some of whom had been previously identified and enrolled in special programs and to have a group of parents with concerns who had or had not discussed them with providers. Above all, it was important to have a sample that was representative of overall population of parents and children in which the prevalence of disabilities was representative but still large enough to enable adequate exploration of the study questions. For this reason, a sample was selected that included children older than 18 months of age (because the incidence of disabilities is higher

in older children). Subjects were also selected from school settings rather than pediatric offices in order to assess whether parents' concerns were related to health care utilization.

Accordingly, this study was conducted in four sites designed to represent the broad geographic regions of the United States: At each site, a school was identified in which approximately one-third of students participated in the federal free/reduced lunch program. Parents of kindergarten and first grade students were sent informed consent letters recruiting the enrolled student and his or her 2–4-year-old siblings. In all sites, there were insufficient numbers of younger siblings so recruitment was extended to day-care centers and preschool programs with federal funding subsidies (in order to obtain a sample that represented a range of income levels).

A total of 408 families participated. They represented more than 80% of the children recruited. For all sociodemographic variables, distributions were similar to those found in the 1990 US Census except that there were somewhat more Hispanic participants than US averages and somewhat fewer African–American participants. Table 1 shows the characteristics of subjects.

Educational diagnosticians or psychologists employed by the public schools served as examiners for the study. They administered to children a battery of developmental tests (described in Appendix A) that included the Slossen Intelligence Test, the age appropriate form of the Brigance Screens, and the Child Development Inventory, a 300 item parent report measure. Children 21/2 years and older were administered several pre-academic and academic subtests from the Woodcock–Johnson Psychoeducational Battery. Examiners were also asked to indicate whether children were already enrolled in special programs.

Parents were not provided the results of standardized testing until the completion of the study. Prior to this, parents were asked to provide demographic information, to rate their perceptions of children's health status (as not serious, somewhat serious, or very serious) and to answer questions about their concerns. These were elicited using the Parents' Evaluations of Developmental Status (PEDS), a previously standardized and validated questionnaire consisting of two questions.^{3–7} The first is open-ended, 'Please tell me any concerns about how your child is learning, developing and behaving'. The second question probes developmental concerns in each domain. 'Do you have any concerns about how she understands what you say? ... talks? ... makes speech sounds? ... uses hands and fingers to do things? ... uses arms and legs? ... behaves? ... gets along with others? ... is learning to do things for himself/herself? ... is learning preschool and school skills?' Responses to both questions can be reliably categorized into the various developmental domains including: expressive and receptive language, self-help, socialization, behavior, gross and fine motor, academic, and global/cognitive skills. An additional category is used to capture medical or other issues (usually concerns about hearing).³

After listing their concerns, parents were asked:

1) 'Have you ever talked about your concerns with your child's medical doctor?' This question was worded so as to capture those concerns that may have been elicited in various nonstandardized ways, as well as those concerns parents may have raised spontaneously; and 2) 'How did he or she respond?' Answers to this question were grouped into two broad categories: referred versus not referred.

Results

Children were grouped according to whether or not they appeared to meet criteria for special education placement (Table 2). Of the 408 children, 86% (n=352) were found to be performing with normal limits and 14% (n=56) met the study's criteria for special education services. These figures are similar to those of other prevalence studies.^{10,11} Of the 56, 13 were previously enrolled in special education services including special classrooms, speech-language, occupational or physical therapy. Thus, the sample clearly included a large number of children with disabilities who had not been previously identified or enrolled in services.

Of the 408 parents, 220 had at least one developmental or behavioral concern. These are listed by type and frequency in Table 3. Concerns are divided into two categories: the significant concerns are those most predictive of developmental problems (identifying between 75 and 79% of children with disabilities across studies)^{3–7} while the nonsignificant concerns (or absence of any concern) are known to identify the majority of children without disabilities (72–74% across studies).

Of the 220 parents with any type of concern, 59% (n=129) identified a health care provider and the remainder did not. A t-test revealed that parents with providers had far more concerns of any type (mean=2.2) [$t(1219)=2.11$, $p,0.001$] than did parents without providers (mean=1.3). Parents with providers also had more of the significant concerns (mean=1.5) [$t(1219)=4.03$, $p,0.0001$] than parents without providers (mean=0.8). Table 3 shows the patterns of concerns between those with and without health care providers as assessed by chi-square analyses.

Logistic regression was then used to determine whether any family characteristics predicted identification of a health care provider. Predictor variables included race, parents' levels of education, employment, marital status, numbers of children in the home, children's developmental status, age, participation in school programs, whether mother versus fathers/other primary caretakers responded, and parents' perceptions of children's health status. Only two predictors were significant: parents' perceptions of children's health status (OR = 3.8; CI=1.6–9.1) and the presence or absence of developmental disabilities (OR = 2.1; CI=1.0–4.2). Fully 60% of the children found to have disabilities had parents who identified a provider.

Of the 129 families with providers, 66% (n=85) had discussed concerns and the remaining 34% (n=44) had not. Logistic regression was used to determine whether any family characteristics or types of concerns predicted which parents engaged in discussions with providers. As shown in Table 4, this revealed three significant predictors including: concerns about expressive language (OR = 3.2; CI= 1.5–6.9), perceptions that children had serious or somewhat serious health problems (OR=3.43, CI=1.2–9.7), and if the father or primary caretaker other than the mother discussed concerns (OR=1.8, CI=0.47–7.0).

Of the 129 children with providers, 25% (n=33) were found to have disabilities. Of the 33, 67% (n=22) had parents who had discussed concerns. Ten of the 33 (30%) had been referred by providers for special education services and all ten had parents who had discussed concerns. Thus, children with disabilities whose parents had discussed concerns were almost four times as likely to be enrolled in special services (OR=3.8, CI=0.6–21.5) as compared to children whose parents had not shared concerns. The probabilities are even more striking when comparing the enrollment in special programs of children whose parents had discussed concerns to that of all children in the study sample. Those with providers whose parents discussed concerns were almost 11 times more likely to be enrolled in special programs (OR=10.8, CI=5.1–22.7) as compared with those whose parents had either not talked to a provider or could not identify a provider.

Discussion

When elicited with two standardized questions, more than 50% of parents had concerns about their child's development. Although many parents with concerns could not identify health care providers, more than half did. Families with providers were more likely to have children who met criteria for developmental disabilities and to perceive their children as having health problems. These parents also had far more concerns and far more of the significant concerns – those highly predictive of disabilities.³⁻⁷ From other research, it is known that children with developmental and behavioral problems have increased health care utilization and that their parents view providers as a critical source of information about their child's difficulties.¹² Thus it appears that children with disabilities (both diagnosed and undiagnosed) and parents' with developmental concerns are heavily represented in pediatric offices. How this actually affects the incidence of parental concerns and childhood disabilities in pediatric offices is not clear from the current data since parents without concerns were not asked to identify health care providers. Nevertheless, a viable hypothesis is that there is a higher incidence of both because studies of childhood disabilities conducted in pediatric settings generally find incidences of 20–25%; figures quite similar to the 26% (33 of 129) found in this study.

It is clear that providers cannot depend on parents to initiate discussions of concerns. More than one-third of parents with concerns did not discuss them with health care providers. When parents did discuss concerns, they were less motivated by children's overall developmental status and more by perceptions that children had health problems or by concerns about expressive language. Further, fathers appeared more likely than mothers to discuss concerns. These findings illustrate that parents need encouragement to discuss concerns and also imply that in the absence of such encouragement, parents may present a restricted set of developmental concerns to providers, perhaps even couching them within medical issues. If so, this may obfuscate providers' efforts to detect children with undiagnosed disabilities. In either case, it appears essential not only to ask all parents about developmental concerns, but also to prompt parents to discuss the full range of their concerns, particularly if relying on parents' concerns to identify children with and without likely disabilities.

Parental concerns appeared to have a tremendous impact on provider referrals. Children of parents who discussed concerns with providers were far more likely to be enrolled in special education programs as compared with parents who did not discuss concerns. This suggests that providers value parents' concerns and rely on them, at least in part, to help identify children with developmental difficulties. At the same time, the findings illustrate the powerful role of pediatric providers in ensuring that children with developmental problems obtain services. Children with providers (whether parents discussed concerns or not) were almost 11 times more likely to be enrolled in services than were children whose parents could not identify providers.

There are several limitations in the current study that suggest needs for further research. First, discussions with providers and indeed even the existence of a provider were viewed through the filter of parents' perceptions. There exists the possibility that providers engaged in more discussions of parental concerns than parents reported. Further research might involve interviewing parents before or after pediatric encounters and matching their perceived discussions of concerns with the actual content of the encounter. More importantly and more challenging would be to compare the identification and referral rates of providers who use standardized questions and interpretations of parental concerns to those using informal approaches. Additionally, the impact of parent-provider discussions was restricted to referrals versus nonreferrals for special education services. A broader focus in future research is recommended and should address other appropriate responses such as watchful waiting, counseling,

and referrals to non-special education services (such as parenting classes, audiological evaluations, or mental health services, etc.). Finally, future research should identify the various types of pediatric providers (e.g. public health departments, community pediatricians, family practice physicians, versus residents) to determine whether they differ in the exploration and use of parents' concerns.

Implications for practice

Although parents with concerns about development and behavior appear more likely to seek health care services, many do not discuss their concerns. Because providers seem to rely heavily on parents' concerns to help identify children with undiagnosed disabilities, the consequences of either partial or omitted discussions may result in limited detection of children with disabilities. In contrast, when parents and providers discussed concerns, children with disabilities were far more likely to have been enrolled in special education services. Thus, both parents and providers need to be encouraged to discuss more fully psychosocial concerns. Parents may not realize that these issues are important to providers and within the scope of their expertise. Providers, in turn, cannot depend on parents to raise concerns spontaneously.

One obvious way to encourage parents to discuss concerns is to routinely use trigger questions. Although discussing concerns with parents is already a routine part of any pediatric encounter, this study showed that standardized questions such as PEDS, clearly facilitated discussions of concerns: far more parents reported concerns to researchers than to pediatric providers. An additional advantage of PEDS as compared to informal questioning is that it offers a validated interpretation of concerns. This leads to clear and helpful evidence on when to refer, as well as when to counsel, offer reassurance, and watchfully wait.³⁻⁷ Those interested in viewing PEDS can view scored copies from the online at <http://www.pedstest.com>

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Biosketch

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