

## The Relationship Between Parental Concerns and Professional Assessment in Developmental Delay in Infants and Children — A Hospital-based Study

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### Key Words

developmental delay;  
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**Background.** Developmental delay (DD) in infants and children is one of the chief complaints of parents. It has been established that the concerns of parents are as accurate as quality screening tests. Some kinds of concerns are particularly useful in the early detection of associated developmental problems. The purpose of this study was to investigate the relationship between the main parental concerns and the final diagnosis based on professional assessment of children who are suspected to have DD.

**Methods.** One-hundred and 1 infants or children were recruited into this study. The major concerns of parents were elicited and categorized by various developmental domains: speech, motor, behavioral, cognitive, global, and non-specific developmental problems. All children underwent comprehensive combined assessments by professionals in the hospital, and were classified into 6 subtypes: speech, motor, behavioral, cognitive, and global DD, and normal development.

**Results.** Our results revealed that parental concerns about speech, motor, and behavioral development yielded a high sensitivity to the final diagnosis of the same developmental domain (77-89%). However, concerns about cognitive and global DD had limited sensitivity (15-36%). On the other hand, concerns about global, speech, and motor DD had relatively higher positive predictive values (55-77%). Comparatively, cognitive or behavioral concerns had lower positive predictive values (25-33%).

**Conclusions.** Such results indicate that parents play an important role in detecting speech, motor and behavioral DD in children. Parental concerns about cognition and behavior should be questioned in terms of their association with the real problem. This information may be useful in establishing trends in understanding the discrepancy or relationship between parental concerns and professional assessments in DD.

The term developmental delay (DD) is frequently used to identify children who demonstrate a delay in meeting developmental milestones in one or more streams of development. It has been suggested that a child suspected of having DD should always be assessed in each of the major streams of development: expressive and receptive language; nonverbal cognition; motor development; and neurobehavioral and social-emotional development.<sup>1</sup> Early intervention indicates early detection, diagnosis, and rehabilitation training for children with DD. It is beneficial to determine at an early stage whether a developmental problem really exists in children with suspected DD, and to clarify the range of asso-

ciated deficits. Then a complete service system is offered for early intervention.<sup>2</sup> A series of steps should be included: a thorough evaluation, such as medical assessment and psychological testing; a rehabilitation program with physical, occupational, and speech therapy for positioning, handling, feeding, language, and cognitive stimulation; and an educational plan to instruct families in proper functioning.<sup>3</sup>

However, DD is best viewed as a chief complaint rather than a diagnosis. Normally, parents describe their major concern or anxiety with more concrete and definitive statements such as "He cannot speak." or "She cannot sit alone, even up till now." It has been gradually es-

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established that concerns from parents are as accurate as quality screening tests, and they are meaningful indicators for the true developmental status of the children.<sup>4-10</sup> At the same time, investigators have also recognized that concerns span a range of developmental areas, and that some kinds of concerns are more useful than others for early detection.<sup>7-9</sup> The purpose of this study was to investigate the relationship between the types of parental main concerns and the final diagnosis after professional assessment, for children who were suspected of having DD. The results may help clinicians to understand more about parental domain-specific concerns, and serve more significantly to help determine whether clinicians should assess multiple developmental domains in response to a specific parental concern. Furthermore, the results may be beneficial in assisting in the developmental promotion and counseling of clinical target families.

## METHODS

One-hundred and 1 infants or young children, aged from 6 to 77 months, median 38.7 months, suspected of having DD were recruited into this study. Major parental concerns were probed and elicited after detailed interviews. The concerns were categorized into various developmental domains by the same observer: speech, motor, behavioral, cognitive, and global developmental problems.

Global concern was coded when parents made statements such as "He is behind other kids." or "She cannot perform well in many skills, including motor and verbal expression." The children were categorized into a non-specific group when the parents did not mention special complaints and had no insights into their child's delay.

Children were comprehensively assessed by experts from various departments of the hospital: the pediatric neurologist, psychiatrist, rehabilitation physician, physical therapist, occupational therapist, speech therapist, psychologist, social worker, and other associated specialists. Aspects of the evaluation included the confirmation of DD, the specific classification of the apparent delay, determination of possible underlying diseases, identification and management of intercurrent medical or behavioral problems, and the arrangement or referral to

appropriate rehabilitation, support, and community resources.

To determine any related diseases, children underwent detailed birth history-taking, chart review, prospective clinical investigations of developmental milestones and laboratory examinations in specialized departments, including neurological (echography, magnetic resonance imaging, computed tomography, electroencephalography, brain auditory evoked potentials, *etc.*), genetic (chromosome, DNA, *etc.*), metabolic, hearing, and visual studies.

The Chinese Children Developmental Inventory (CCDI) was used for the assessment of 8 functional domains: gross motor, fine motor, expressive language, concept comprehension, social comprehension, self help, personal social, and general development.<sup>11</sup> Other evaluative tests were also integrated into the assessment depending on initial impression, such as the Peabody Developmental Motor Scale, Peabody Picture Vocabulary Test, Pediatric Evaluation Developmental Inventory, Gross Motor Functional Measure, Wechsler Preschool and Primary Scale of Intelligence. All children were classified into 6 subgroups, speech, motor, behavioral, cognitive, and global DD or normal development, based on clinical assessments incorporated with all evaluative tests results.

Significance was defined as 2 or more standard deviations below the mean on norm references of developmental screening or assessment tests. Speech DD indicated a significant delay restricted to speech and language skills with normal performance in other developmental domains.<sup>1</sup> Motor DD was defined as delay in gross motor or fine motor skills with a presentation of age-appropriate performance in other developmental domains.<sup>12</sup> In this study, the children with autistic spectrum disorders, with core features of observed qualitative deficits in social skills and communication, and repetitive/restrictive patterns of behavior, and those who were diagnosed as attention deficit hyperactivity disorder (ADHD), were placed into a behavioral aberration group. Cognition involves the highly integrated process of attention, perception, memory, and functional task performance. Neuropsychological and intelligence tests were helpful in identifying children with cognitive DD. The children with developmental quotients under 80% in

multiple domains were defined as belonging to the global DD group.<sup>13</sup>

Differences in continuous data (age at first aid, birih body weight, BBW; gestational age, GA) among the 6 groups (speech, motor, behavioral, cognitive, global domain delays, and normal development) were compared using ANOVA tests with Tukey HSD multiple comparisons. Differences in categorical data (gender distribution) among the groups were determined with Chi-square ratio or Fisher's exact tests. Values of  $p < 0.05$  were considered statistically significant.

Sensitivity, specificity and positive predictive value were calculated to present the relationship between parental concern and DD subtypes (sensitivity: percentage of children with problems who were correctly identified, specificity: percentage of children without problems who were correctly identified, positive predictive value: percentage of children with concerned parents who actually had a problem).

**RESULTS**

Global DD comprised the most frequent diagnosis (28%) of all infant and childhood DD, based on the hospital-based samples. Speech (19%), motor (15%) and cognitive (13%) DD followed in sequence. Only 9% (n = 9) of the children were diagnosed with a behavioral aberration, including 3 who were diagnosed as pervasive developmental disorder. It was noted that 17% (n = 17) had no significant developmental delay problems (Table 1).

The average age of the children with speech, behavioral, and cognitive DD was 44-47 months. Children with motor and global delays were below 3 years old, and the children with motor DD were about 1 year old ( $p < 0.01$ ). A male dominance was observed in the speech, behavioral, and global DD groups. The average GA and BBW were relatively low for children with motor and global delays from birth history (motor: 34 weeks, 2722 grams; global: 36 weeks, 2655 grams), although there was no significant difference compared with the other groups ( $p > 0.05$ ) (Table 1).

Our results showed that 14 children in the global DD group were defined as related diseases based on diagnoses from 6 major categories. These cases were distributed as follows: 5 with cerebral palsy, 3 with mental retardation (MR), 1 with ADHD, 1 with congenital heart disease, 1 with congenital muscle dystrophy, 1 with microcephaly, 1 with chromosome disorder, and 1 with hydrocephalus (Table 1).

Table 2 shows the relationship between the main parental concerns in each developmental domain and the

**Table 2. The relationship between parental main concerns and developmental delay subtypes**

Concerns	Sensitivity	Specificity	Positive predictive value
Speech	89	85	59
Motor	80	88	55
Behavioral	77	85	33
Cognitive	15	93	25
Global	36	96	77
Non-specific	24	95	50

**Table 1. Characteristics of 6 functional developmental delay subtypes**

Data	Groups						p value
	A n = 19	B n = 15	C n = 9	D n = 13	E n = 28	F n = 17	
Age (months old)	43.5 ± 16.6	12.1 ± 9.8	47.0 ± 16.3	45.5 ± 18.4	34.1 ± 22.0	50.5 ± 19.5	*: AB, BC, BD, BE, BF
Gender (M:F)	15:4	7:8	8:1	6:7	22:6	7:10	0.013
GA (weeks)	38.9 ± 1.3	33.9 ± 9.6	37.4 ± 4.3	38.6 ± 2.0	36.3 ± 4.3	39.4 ± 1.2	0.117
BBW (gram)	3262.9 ± 346.1	2722.9 ± 905.1	2944.9 ± 865.1	3078.1 ± 462.6	2655.7 ± 865.4	3469.8 ± 461.1	†: EF
Related disease	2	2	7	2	14	0	

A = speech developmental delay group; B = motor developmental delay group; C = behavioral developmental delay group; D = cognitive developmental delay group; E = global developmental delay group; F = normal developmental group; M:F = male versus female; GA = gestational age; BBW = birth body weight; Related disease = case number of related disease determined. \* $p < 0.01$ ; † $p < 0.05$ .

final diagnosis from professional assessments. It was found that speech, motor, and behavioral concerns could produce high levels of sensitivity to the final diagnosis in the same developmental domain (77-89%). However, concerns about cognitive and global delay had limited sensitivity (15-36%). On the other hand, concerns about global development had a 77% positive predictive value, and speech and motor concerns yielded a 55-59% positive predictive value. Comparatively, parental concerns about cognition or behavior had a lower positive predictive value (25-33%).

The results also showed that there was no significant difference between parental concerns with or without positive predictive value, when considering the children's age, gender distribution, GA, BBW, ranking of all siblings, parental education, and family economic status.

## DISCUSSION

High sensitivity was found in parental concerns about speech, motor, and behavioral developmental problems in children, whereas concerns about cognition and global delay showed relatively low sensitivity. The results indicated that parents played important roles in the early discovery of children with speech, motor and behavioral DD. Speech, motor and behavioral performance are usually distinct manifestations, and become noticeable by their caregivers in the developmental phase of the children. Furthermore, parental concerns about motor delay at an early age reflected parental awareness and sensitivity to the performance of early motor milestones.<sup>14</sup> On the other hand, cognitive representation was not discernable easily to parents; learning achievements perceived by schoolteachers are sometimes more helpful. Nevertheless, since the definitions of cognition are obscure, the parents were inclined to express their worries in other chief concerns about speech or behavior. Besides, parents are not alert to all developmental domains, which are sometimes not well recognized. Nor do all parents possess a comprehensive concept of DD, although they are the first observers of their child's DD. Relatively few global DD concerns ( $n = 13$ , 13%) were expressed by parents in this study. Instead, only 1 issue was addressed, even with children who had global DD.

Parental concerns about global delay yielded a high positive predictive value (77%), and speech and motor DD concerns had a 55-59% positive predictive value. This shows that more than half of the children assumed by their parents to have speech or motor problems were diagnosed as speech or motor DD after professional assessments. Adversely, our results show that parental concerns about cognition and behavior had relatively low positive predictive value (25-33%). This result suggests that clinicians should retain doubts about such concerns, and investigate other developmental domains in these children. We analyzed the reasons why behavioral and cognitive concerns were not positively predictable, and found that parents are commonly overly anxious about children who are exceedingly vigorous or quiet, and consider these children to be problematic. The other possible reason is that children who have cognitive DD and are diagnosed to be associated with MR manifest behavioral problems in some cases.<sup>15,16</sup> Therefore, it is easier for professionals to make the distinction than parents or caregivers. In this study, we found that concerns about cognition only were focused on color discrimination, which was within normal limits in the general cognitive development.

A series of studies by Glascoe<sup>4,17,18</sup> reported high sensitivity and specificity ranging from 70-80% of parental concerns about children's DD. Glascoe indicated that parental concerns were as accurate as quality screening tests, and might be helpful in making other important decisions about children's developmental and behavioral needs. Regarding domain-specific concerns, the report<sup>17</sup> showed that certain concerns, e.g., motor, language, global, and school, had high levels of sensitivity, and were able to identify 79% of the children with disabilities. Moreover, the investigators also found that the absence of concerns, or concerns in other areas, such as socialization, self-help, or behavior, had reasonable specificity, and were able to identify 72% of the typically developing children. The author suggested that some parental concerns were more useful than others in early detection, and put forth examples of concerns about self-help, gross motor, and social skills that had not been shown to be associated with true problems. In contrast, concerns about speech-language development were highly associated with true speech-language problems,

while concerns about children's behavior were closely related to the presence of significant behavioral problems.<sup>17,18</sup> Glascoe<sup>4</sup> also assessed whether the parallel relationship between the types of parental concerns and the types of developmental problems continued with children with global DD, and found that concerns about speech-language and behavior were sensitive in detecting global deficits (83%), while the absence of such concerns had modest specificity in detecting normal development (47%).

As for behavioral concerns, previous studies<sup>17,18</sup> have mentioned that parents appeared to notice subtle developmental and behavior problems. Parents with inaccurate concerns raised more concerns about their children's skills in areas of self-help, socialization, and behavior. About 21% of parental concerns were non-significant predictors of DD, and thus associated with normal development; 83% of the time, these concerns focused on behavior.

In spite of the variation of conclusions in the above reports, all previous studies agreed that parents were equally able to raise important concerns regardless of their differences in education, socioeconomic status, and child-rearing experience.<sup>4,17,18</sup> The reason was that most parents derived their concerns from a comparison of their children with others. Making comparisons is a relatively simple cognitive skill, and cuts across socioeconomic strata and differences in parenting ability. Therefore parents of varying levels of experience and education are equally capable of raising important concerns.<sup>10,17-19</sup> Our results were consistent with the previous observations.

Parents play important roles in detecting children with speech, motor, and behavioral DD. Thus, parental concerns about global, speech and motor delay produced significantly positive predictive values. In contrast, concerns about cognition and behavior generated relatively low positive predictive values. The results suggested that such concerns should always be questioned and clinicians are required to investigate other developmental domains for these children.

We herein report the above conclusions, although the results may be geographically specific and reflect the existing local patterns and biases of the settings in which the study was conducted. However, the information may be useful in building up trends to help understand the dis-

crepancies and relationships between parental concerns and professional assessment in DD, from the viewpoint that the degrees of eliciting parental concerns would be helpful for clinicians in identifying families needing suggestions for developmental promotion and in-office counseling.

## REFERENCES

1. Petersen MC, Kube DA, Palmer FB. Classification of developmental delays. *Semin Pediatr Neurol* 1998;5:2-14.
2. Levy SE, Hyman SL. Pediatric assessment of the child with developmental delay. *Pediatr Clin North Am* 1993;40:465-77.
3. Allen MC. The high-risk infant. *Pediatr Clin North Am* 1993;40:479-90.
4. Glascoe FP. It's not what it seems: the relationship between parents' concerns and children with global delays. *Clin Pediatr* 1994;33:292-6.
5. Starfield B, Borkworf S. Physicians' recognition of complaints made by parents about their children's health. *Pediatrics* 1969;43:168-72.
6. Dulcan MK, Costello EJ, Costello AJ, Edelbrock C, Brent D, Janiszewski S. The pediatrician as gatekeeper to mental health care for children: Do parents' concerns open the gate? *J Am Acad Child Adolesc Psychiatr* 1990;29:453-8.
7. Glascoe FP, Altemeier WA, MacLean WE. The importance of parents' concerns about their child's development. *Am J Dis Child* 1989;143:955-8.
8. Glascoe FP. Can clinical judgment detect children with speech-language problems? *Pediatrics* 1991;87:317-22.
9. Glascoe FP, MacLean WE, Stone WL. The importance of parents' concerns about their child's behavior. *Clin Pediatr* 1991;30:8-11.
10. Glascoe FP, MacLean WE. How parents appraise their child's development. *Fam Relations* 1990;39:280-3.
11. Hsu CC, Su S, Shao SJ, Lin CC, Soong WT, Chang C. Chinese child developmental inventory: a tentative normative data. *Acta Paediatrica sinica* 1978;19:142-57.
12. Simeonsson RJ, Sharp MC. Developmental delays. In: Hoekelman RA, Friedman SB, Nelson NM, et al., eds: *Primary Pediatric Care*. St Louis: Mosby-Yearbook, 1992;867-70.
13. Shevell MI. The evaluation of the child with a global developmental delay. *Semin Pediatr Neurol* 1998;5:21-6.
14. Shevell MI, Majnemer A, Rosenbaum P, Abrahamowicz M. Profile of referrals for early childhood developmental delay to ambulatory subspecialty clinics. *J Child Neurol* 2001;16:645-50.

15. Thomas CH, Patton JR. Mild and moderate retardation. In: Patton JR, Beirne-Smith M, Payne JS, eds. *Mental retardation*. 3rd ed. New York: Merrill, 1990:197-226.
16. Stott DH. A law of multiple congenital impairment. In: Stott DH, editor. *Studies of troublesome children*. London: Routledge, 2001;119-51.
17. Glascoe FP. Parents' concerns about children's development: Prescreening technique or screening test? *Pediatr* 1997;99: 522-8.
18. Glascoe FP. Using parents' concerns to detect and address developmental and behavioral problems. *J Society of Pediatr Nurs* 1999;4:24-35.
19. Glascoe FP. Evidence-based approach to developmental and behavioral surveillance using parents' concerns. *Child Care Health Dev* 2000;26:137-49.