

Shared Vision: Concordance Among Fathers, Mothers, and Pediatricians About Unmet Needs of Children With Chronic Health Conditions

Ellen C. Perrin, MD; Corinne Lewkowicz, PhD; and Martin H. Young, PhD

Abstract. Objective. These analyses were undertaken to investigate the number and types of services and assistance believed to be useful to children with a chronic health condition and their families. The perspective of mothers, fathers, and primary care physicians were sought separately and compared.

Methods. Families that include at least 1 child with a chronic health condition were selected from pediatric practices in Central Massachusetts. All 3 respondents completed a questionnaire describing their own perspective of current needs and of the severity of the child's condition. The 3 perspectives are compared statistically and areas of agreement/disagreement are described.

Results. Mothers, fathers, and physicians described children's and families' needs with a surprising degree of concordance. On the other hand, pediatricians identified fewer needs, despite rating the severity of children's illnesses as greater than did parents. Mothers and fathers agreed substantially about the level of severity of their child's condition and about their unmet needs.

Conclusions. It is important that pediatric practice systems include effective mechanisms to assess parents' opinions regarding the unmet needs of their child/family in the face of a child with a chronic health condition. Without input from families, pediatricians are aware of only *some* of the needs that parents identify. *Pediatrics* 2000;105:277-285; *children, chronic health condition.*

ABBREVIATION. SD, standard deviation.

About 15% to 18% of children in the United States have a chronic health condition.¹⁻³ They and their families may have a large variety of health-related needs over and above those of their healthy peers. Families and their primary care physicians are centrally responsible for identifying, obtaining, coordinating, and monitoring a wide range of services for these children.⁴⁻⁶ The number and type of needs and services they identify depend in part on the particular condition(s) the child has, its manifestations and severity, the child's age, the parents' social circumstances, and the particular medical care arrangements available to the family.^{7,8}

Both *identifying* children's and families' needs and making the arrangements necessary to *meet* them have been inefficient and rarely systematic processes often associated with dissatisfaction on the parts of both parents and physicians.⁹⁻¹² Long-term needs especially may be met inadequately^{5,6} despite regular contact with health care professionals^{9,13} and physicians' interest in helping in this domain.^{14,15} Mothers and fathers may identify differing needs and desires with regard to the care of their child, and these may be different from physicians' beliefs about the child's and family's needs.^{11,16,17} Many observers have identified a few predictable clusters of children's and families' needs that are independent of the child's particular diagnosis^{4,9-11,13,18,19}: family solidarity and support, information, finances, social support, child care, and professional services.

Most frequently noted to be inadequately met has been the need for information.^{11,13,16,18,20} Ninety-one percent of the parents surveyed by Walker et al⁴ reported that they would like to obtain more information about the child's condition, its treatment, and its long-term implications. Parents also appreciated getting information about the child's medical problem directly from the child's physician. In addition to more information, families wish for help from an integrated oversight system that helps them to evaluate the child's needs and coordinate long-term care planning for the child and family.⁵ Some have construed this "supervision" function as a role for the primary care pediatrician.^{6,14,15}

Other investigators have reported that parents' primary unmet need was for family support and counseling.^{20,21} Most research suggests close to double the prevalence of emotional, developmental, and educational difficulties among children with a chronic condition as compared with healthy children.^{3,20-24} Various interventions have been tried in an effort to prevent and/or ameliorate these secondary psychosocial consequences of chronic health problems.^{25,26} Formal and informal social support as well as individual, group, and family therapy have been helpful to many families.

A study of adolescents found that their needs tended to focus on vocational and adaptive issues related to having a long-term condition, rather than issues related to the particular condition per se.¹⁸ Child care (both regular and respite) is a prevalent need for families with young children.¹⁰ Neither demographic variables such as race, socioeconomic

From the University of Massachusetts Medical Center, Department of Pediatrics, Worcester, Massachusetts.

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Reprint requests to (E.C.P.) University of Massachusetts Medical Center, Department of Pediatrics, 55 Lake Avenue North, Worcester, MA 01655.

E-mail: ellen.perrin@banyan.ummed.edu

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status, birth order, and child age, nor diagnostic classification have been found to be related to the number or types of needs expressed by parents.^{11,27,28}

Parents and health care providers have differing important perspectives on their child's needs and the services that would be beneficial for a child with a chronic condition.²⁹ Older children and adolescents also may have ideas about the services that would foster their successful adaptation.^{18,19} If parents and physicians concur regarding the child's and family's needs, long-term care plans are likely to address more fully the child's particular issues and concerns, and parents are likely to be content with the child's overall care.³⁰⁻³²

The project reported here differs from most of its predecessors in the setting, the age of the children, their health conditions, and the respondents. This study was based in a primary care context, while almost all earlier studies assessing the needs of parents have focused on children in hospitals, early intervention programs, or pediatric specialty clinics. We have included children across the pediatric age range with a wide variety of chronic health conditions, and we have solicited parallel information about each child from pediatricians, mothers, and fathers.

Abundant anecdotal reports recount insufficient communication between parents and primary care physicians regarding children's care,^{12,31,33} and generate expectations that collaborative decision-making or "family-centered care" might improve the process of their care.^{32,34,35} Nevertheless, there has been no systematic investigation of the concordance among mothers', fathers', and physicians' reports of the unmet needs of children with chronic health problems and their families.

Previous investigations of mothers' and fathers' reports about their children's *behavior* have demonstrated wide disparity in both their observations and their interpretations of the behavior.^{17,36} With regard to the identification of unmet child/family *needs*, most investigations have either asked only mothers or combined responses from mothers and fathers as "parents."^{4,5,6,9,10,13,16} The few investigations that have included fathers have focused primarily on the effect *on the father* of having a child with a chronic health condition and the extent to which fathers are *involved* in the care of their ill child—not on their perceptions of the child's or family's needs. When both parents have identified their child's unmet needs, the needs identified by mothers and fathers differed somewhat, and mothers expressed more needs than did fathers.^{11,17}

In one study Bailey et al¹¹ obtained responses from 106 mother-father pairs of children <3 years old who were involved in an early intervention program for children with developmental disabilities. They found that mothers expressed more and somewhat different needs than did fathers. Both parents expressed needs for information and for child care; mothers were more likely than fathers to identify a need for enhanced family and social sup-

port and for help with interpersonal interactions regarding their child.

Horn et al²⁹ found broad agreement between "families" and "professionals" about the stressors experienced and the coping strategies used by children during a lengthy hospitalization. In contrast, parents of children with chronic illnesses were noted by Liptak and Revell⁶ to be far more likely than physicians to identify a need for information about the child's diagnosis, treatment and prognosis, financial assistance, and social/recreational opportunities. Several studies have identified similar disparities in the priorities of parents and primary care pediatricians regarding the services needed for the care of children with a variety of chronic physical illnesses and disabilities.^{11,37}

Parents in general appreciate the opportunity to have their points of view regarding their child's condition and needs heard and understood.^{38,39} Collaboration among physician, parents, and the child/adolescent is one of the basic principles of family-centered care.^{30-32,34,35} Once overlapping and divergent perceptions are made explicit, they can be discussed, understood, and reconciled, and a joint plan agreed to by all participants.

The purposes of the present study were to: 1) determine the extent and characteristics of agreement among mothers, fathers, and physicians regarding the unmet needs of particular children with chronic health conditions and their families, and 2) investigate the factors associated with greater or lesser disparity among different participants' perceptions of these needs. Our hypotheses were that 1) parents would judge children's conditions as more severe than would physicians and than a semi-objective proxy of "intensity"; 2) mothers and fathers would differ in the amount and types of needs they identified as potentially beneficial; and 3) parents would indicate *more* needs than would physicians, especially in the categories of "information" and "support."

METHODS

Participants

Eleven pediatricians in 5 pediatric practice groups participated in a project that aimed to improve the coordination of care for children with chronic conditions in the context of community primary care settings. These pediatricians agreed to participate in the project because of their interest in improving their practice with regard to the care of children with chronic health conditions and their families. Two practiced as part of a staff model health maintenance organization, 2 as independent partners, 3 as members of a 6-member pediatric practice, and 4 in semi-rural multispecialty practices.

Pediatricians identified families who had a child with a chronic health condition, using billing records from the previous 2 years and a broad range of diagnostic codes based on the *International Classification of Diseases, Ninth Revision (ICD-9)* coding system. A chronic health condition was operationally defined as a condition that had lasted or was expected to last 1 year or more, and that could be expected to require more than the usual amount of medical supervision.

Because this project was based in primary care pediatric office settings, the children involved differed from those included in most prior investigations. Consultation with the participating pediatricians as the project developed clarified the importance of using a broadly inclusive definition of "chronic health conditions." For example, a child with a severe language

delay, attention deficit disorder, or chronic recurrent otitis media may meet the eligibility guidelines described above as thoroughly as a child with cerebral palsy, mental retardation, or asthma. The added needs these children present to conscientious health care professionals and parents are independent of their particular diagnoses. A systematic investigation of whether children with differing conditions present differing kinds or numbers of needs would be instructive. Unfortunately, the size of the sample in this project did not allow such a detailed subgroup analysis.

We have attempted a rough approximation to address this question. We created clusters of children in 4 broad diagnostic subgroups. Children who had a respiratory condition *only* (eg, asthma, chronic otitis media) or a neurologic condition *only* (eg, seizure disorder, mental retardation, cerebral palsy, attention deficit disorder) accounted for the largest condition-specific groups. A third group was made up of children with a large variety of other conditions (eg, diabetes, cardiac conditions, renal conditions, major orthopedic abnormalities). Children who had more than 1 discrete condition were combined in a separate cluster. Children with either a respiratory or a neurologic condition *in addition to* a substantially different chronic condition were included in this last group.

Parents were contacted by mail by their primary care physician and asked for permission to have a member of the research staff contact them. If they agreed, the project was explained by the project director over the phone. If parents then agreed to participate they were entered tentatively into the study sample. A subsequent mailing included a description of the project and its response requirements, a request for information about the family, and a document to be signed to verify informed consent. Once the latter 2 items were returned, the family was considered *enrolled* in the project. If more than 1 child in the family had a chronic condition, the child rated as more severely affected was selected. These procedures for sample selection and the research protocol itself were approved by the Committee for the Protection of Human Subjects at the University of Massachusetts Medical Center.

Procedure

Once enrolled, physicians and both parents provided information separately about the severity of the child's condition and their perception of the child's and family's current needs. The questionnaires were mailed separately to each parent, along with a letter requesting that they complete them independently of the other parent. This procedure was followed whether parents were living together or apart. Parents also provided demographic information and detailed information about their child's condition. Socioeconomic status was estimated using parental education and insurance information.

Unmet "Needs"

A list of 23 categories of "needs," listed in Table 2, was assembled from previous investigations^{4,5,10,11,13,18,19} and clinical experience. Each of the 3 respondents (mothers, fathers, and physicians) noted which of these 23 items/services the child/family "would benefit from." For the purposes of this publication, we have used the term "needs" to designate the items chosen from this list, but this word was not used in communications with the families because of the known reluctance of respondents to acknowledge *needing* anything.

Severity

Because of the wide range of diagnoses included, no physiologic measure of severity could be applied. All 3 respondents rated their assessment of the severity of the child's condition on a 4-point scale (slight, mild, moderate, severe). The severity of the child's condition was estimated somewhat less subjectively as well. This assessment, called "intensity," was created from parents' responses to 6 questions: in the previous year 1) the number of days their child missed from school attributable to his/her condition(s); 2) the number of days someone in the family stayed home from work because of the child's health condition(s); 3) the number of times the child was seen in the primary care doctor's office; 4) the number of doctor visits made specifically to discuss the care of the child's ongoing health

condition(s); 5) the number of different diagnoses the child had been given; and 6) the presence of any limitation of activity as a result of the child's health condition(s). All responses were converted to 4-point scales in which a higher score reflected greater presumed severity of the condition(s). If the mother's and father's responses were disparate, the higher score was used for these analyses. These 6 scores were then combined, and the *mean* used as a proxy for the "intensity" with which the child's condition(s) appeared to have been experienced by the child and family. Thus, there are 4 scores reflecting an estimate of "severity": subjective ratings by mother, father, and physician, and a more objective score or "intensity."

Analyses

Results were analyzed in 4 steps. **First**, mothers', fathers', and physicians' responses were compared with regard to both the total number and the types of needs each respondent noted. Pearson's product moment correlations, paired *t* tests, and Cohen's κ analyses were used to determine the level of agreement among them. **Second**, a factor analysis, using a principal components extraction and a varimax rotation, was conducted for 2 reasons: 1) to determine if physicians, mothers, and fathers shared similar perceptions about the services they felt were needed; and 2) to identify common groupings of items for further analyses. A factor was identified if it had an eigenvalue of at least 1.0, and an item was identified as belonging in a given factor if it had a factor loading of at least .40. **Third**, because mothers' and fathers' responses were very consistent within these clusters, they were combined, and physicians' responses were compared with this *combined* parent response. The level of concordance between parents' and physicians' views regarding the clusters of needs was assessed using Pearson's product moment correlations and paired *t* tests. **Fourth**, multiple regression analyses were used to identify some of the characteristics that predicted agreement between parents and physicians regarding current needs.

RESULTS

I. Description of the Sample

Using billing data, 234 children were identified as having a chronic health condition. Of these, 168 agreed to participate in the project and 163 provided informed consent and basic demographic information and were thus enrolled in the project, a participation rate of 70%. Responses regarding 123 children were used for these analyses: 123 from physicians, 122 from mothers, and 100 from fathers (99 mother-father pairs). Participants did not differ from nonparticipants in the gender or age of the child or the constellation of diagnoses. Further information about the nonparticipating children is not available.

Children ranged in age from 2 months to 15 years, and 48% were female. Diagnostic information is available for 119 children as noted in Table 1: 33 children (28%) had multiple conditions; 25 were identified as having a primary respiratory condition; 39 had a primary neurologic condition; and 22 had a variety of "other conditions." The socioeconomic status of the families was primarily middle class (79% class 2 or 3), with only 18% class 4 and 5.

II. Development of Subgroups of Items

Factor analyses informed the creation of discrete subgroups of items. Physicians' perceptions of families' needs clustered into 7 factors, accounting for 62.3% of the variance. One item did not load onto any factor: the family's need for advice regarding

TABLE 1. Description of the Sample

Number of children:	123
Girls:	59 (48%)
Age:	Range: 2 mo to 15 y Mean: 6.78 mo SD: 4.07 mo
Age of onset:	Range: birth to 13 y Mean: 26.65 mo SD: 36.4 mo Onset before 2 mo: 42 (34%)
Duration:	Range: 6 mo to 13 y Mean: 4.61 y SD: 3.23 y
Diagnostic clusters:	Respiratory conditions: 25 children Neurologic conditions: 39 children Other conditions: 22 children Multiple conditions: 33 children
Conditions noted by parents of 119 children (many children had more than one condition):	
Asthma, bronchopulmonary dysplasia, cystic fibrosis	37
Mental retardation, developmental delays	17
Attention deficit/hyperactivity disorder, learning disabilities	17
Cerebral palsy	14
Seizure disorders	13
Blind, deaf	11
Congenital heart disease	10
Major orthopedic abnormalities (includes arthrogyrosis, scoliosis, osteogenesis imperfecta)	9
Renal disease (includes lupus nephritis, nephrotic syndrome)	8
Endocrine conditions (includes diabetes, hypothyroidism)	7
Cleft lip/palate	6
Chronic otitis media	6
Neuropsychiatric conditions (includes autism)	5
Complex syndromes (includes Down, Kallmann, DiGeorge)	4
Arthritis	3
Leukemia	1
Neurofibromatosis	1

finances and health insurance. Similarly, mothers' assessments of needs also clustered into 7 factors, accounting for 61.7% of the variance, with 5 items not loading on any factor (information for adolescents, genetic counseling, transportation, contact with other families, and social, camp, and recreational activities). Only 6 factors were identified for fathers' assessments of family needs, including all 23 items and accounting for 60.5% of the variance.

To allow for comparisons among mothers', fathers', and physicians' responses, 4 subgroups were created based on the results of the factor analyses and theoretical expectations. These consisted of 1) parents' needs for *information and advice*; 2) the family's need for *contact with similar families*; 3) the need for *counseling*; and 4) *specific help needs*, such as child care while parents work, help with household projects, home nursing care, and legal assistance. Reliabilities were acceptable for mothers and fathers for all four subgroups ($\alpha = .70-.80$), but somewhat lower for pediatricians (see Table 2). Four items were not included in any subgroup because they did not cluster in the factor analyses: 1)

information for adolescents regarding education and sexuality, 2) job training and work opportunities, 3) genetic counseling, and 4) the child's need for information regarding his/her condition/treatment. These items were treated as individual items only.

III. Severity

Parents and physicians rated the severity of each child's condition on a 4-point scale, ranging from mild to severe. The average severity rating for physicians was 2.97 (SD = .84), for mothers was 2.53 (SD = .96), and for fathers was 2.36 (SD = .94). The difference between physicians and mothers was significant ($t(89) = 4.50; P < .001$), as was the difference between physicians and fathers ($t(65) = 4.15; P < .001$). Physicians consistently rated children's conditions as being more severe than did either mothers or fathers. The average "intensity" rating was 2.37 (SD = .77) and was highly correlated with mothers', fathers', and physicians' severity ratings. Mean severity ratings (and standard deviations) did not vary across diagnostic clusters. Thus, our hypothesis—that parents would rate the severity of their children's conditions as greater than physicians did and greater than more objective indicators would suggest—was *not* supported.

Parents' ratings of the severity of their child's condition(s) were significantly correlated with the number of unmet needs they indicated in the realm of *contact* needs, *counseling* needs, and *specific help* (Table 3). For neither mothers nor fathers was

TABLE 2. Reliabilities Among Items in Four Subgroups

Subgroup	Number of Items	Coefficient Alpha		
		Physicians	Mothers	Fathers
Information needs	4	.56	.70	.72
Contact needs	3	.66	.72	.76
Counseling needs	2	.52	.75	.76
Specific help needs	10	.72	.77	.80

TABLE 3. Correlations Among Severity Ratings and Number of Needs Identified in Each Subgroup, for Each Respondent

	Information		Contact		Counseling		Specific Help	
	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>
Mother: severity	.03	>.10	.25	<.01	.26	<.01	.35	<.001
Father: severity	.04	>.10	.23	<.05	.31	<.01	.25	<.05
Physician: severity	.26	<.01	.41	<.001	.23	<.05	.52	<.001

their perception of the severity of the child's condition(s) correlated significantly with their indication of unmet needs for *information*. Physicians' estimates of severity were moderately to strongly correlated with the number of unmet needs they indicated in each item subgroup. On the other hand, the more objective rating of "intensity" was associated with the number of *specific help* needs parents endorsed.

IV. Concordance Between Mothers and Fathers

We had hypothesized that mothers and fathers would differ in the amounts and types of needs they identified as potentially beneficial. Of the 23 individual items that were examined, mothers identified an average of 9.7 needs (SD = 4.9; range: 0–18), and fathers 9.5 (SD = 5.2; range: 0–22). Mothers and fathers endorsed similar numbers of needs both for the sample as a whole and within

each diagnostic cluster ($t(98) = .17; P > .05$). For both parents, the number of needs differed substantially according to diagnostic cluster ($F(3,117) 3.6, P < .05$ for mothers; $F(3,96) 4.4, P < .01$ for fathers). The largest number of needs was endorsed for children with "multiple" conditions and the lowest number for children with respiratory conditions.

Mothers consistently endorsed the items reflecting their need for more information about the child's health condition(s) and about the child's behavior and development. As shown in Table 4, >50% of the mothers also endorsed items pertaining to their need for support: discussion groups for parents and for children, and contact with other families who had a child with a chronic condition. Over half of the mothers indicated also that they wanted more help in identifying social and recreational opportunities for their children and in coordinating their child's overall care. Only 2 items

TABLE 4. Proportion of Physicians, Mothers, and Fathers Endorsing Each Need Item

Need	Physicians	Mothers	Fathers	<i>P</i>
	%	%	%	
Subgroup: Information needs				
Information about child's condition(s) and treatment(s)	63.4	71.3	72.0	NS
Advice about child's behavior and development	59.3	63.9	72.0	NS
Advice about what to expect as child gets older (planning and future needs)	67.5 ^b	79.5 ^{a,b}	82.0 ^a	<.05
Help in being sure child gets what is needed (coordinating care)	47.2 ^b	61.5 ^a	67.0 ^c	<.01
Subgroup: Contact needs				
Discussion groups for children and their brothers and sisters	42.3	55.7	41.0	<.05
Discussion groups for parents	46.3	57.4	48.0	NS
Contacts with other families with children with ongoing health conditions	45.5	59.0	50.0	NS
Subgroup: Counseling needs				
Counseling for parents or other family members	39.8 ^b	40.2 ^{a,b}	38.0 ^a	<.05
Counseling for child	24.4 ^b	37.7 ^{a,b}	32.0 ^a	<.08
Subgroup: Specific help needs				
Arrangements for child's school programs	52.0	44.3	47.0	NS
Care for child so parents can get away	30.9 ^b	41.0 ^{a,b}	45.0 ^a	<.08
Child care while parents work	16.3 ^b	26.2 ^{a,b}	31.0 ^a	<.05
Advice on health insurance or other financial assistance (SSI, Medicaid)	30.9	41.0	35.0	NS
Legal assistance	3.3 ^a	14.8 ^b	19.0 ^c	<.001
Modifications to home for the child's needs, professional homemaker services, help with day-to-day jobs like babysitting, shopping	13.8 ^a	28.7 ^b	39.0 ^b	<.001
Transportation to medical or other services	8.1	9.0	12.0	NS
Social, recreational and camp activities for child	44.7	54.1	48.0	NS
Home nursing care, specialized treatments (occupational therapy, speech therapy)	27.6	35.2	41.0	NS
Special equipment (wheelchairs, communication aids)	12.2	18.0	18.0	NS
Items not in a subgroup				
Education for child about the condition(s) and treatment(s)	52.0	54.9	51.0	NS
Information about the chances of child's condition occurring in other family members (genetic counseling)	11.4 ^b	31.1 ^a	28.0 ^a	<.01
Information for adolescents (eg, sexuality, future career decisions)	13.0 ^b	38.5 ^a	25.0 ^{a,b}	<.001
Job training and work opportunities for child	4.1	6.6	6.0	NS

NS indicates not significant.

Within each item, statistically significant differences exist ($P < .05$) between percentages with different superscripts^{a,b,c}.

were endorsed by <10% of mothers: career-related information for adolescents, and transportation services. Fathers showed a similar response pattern; more than half endorsed informational items, and <10% endorsed career-related information for adolescents. It is important to note that only 12.2% of the sample ($n = 15$) were ≥ 12 years old.

Cohen's κ analyses were used to investigate if a pattern existed in the specific needs that were identified by mothers and by fathers. A κ score of $< .40$ was taken to indicate *disagreement*, and the McNemar χ^2 test was then used to test the *direction* of the disagreement.⁴⁰ For 14 of the 23 items mothers and fathers *agreed* about the presence of the need. For 7 items there was a statistically significant difference between mothers and fathers ($\kappa < .40$) but the direction of the difference was not predictable, and for only 2 items did mothers consistently indicate a need that fathers did not indicate (information for adolescents regarding education and sexuality, and child/sibling discussion groups).

Mothers and fathers agreed substantially as well about the subgroups of items they thought were needed. Table 5 indicates high correlations between parents in all subgroups, and significant differences between them (using t tests) only for *contact* needs.

The hypothesis that mothers and fathers would differ in the number and types of unmet needs they identified was supported only in part. Parents agreed substantially about all but the need for increased contact for both adults and children with others dealing with similar life circumstances, which mothers identified more often than fathers.

V. Concordance Between Parents and Physicians

Physicians reported that families had, on average, 7.6 needs (SD = 4.2; range: 0–18). The difference between the number of items endorsed by mothers and physicians was statistically significant ($t(121) = -4.70$; $P < .001$), as was the difference between fathers and physicians ($t(99) = 3.57$; $P = .001$). Physicians identified the greatest number of needs for children with neurologic conditions, and the fewest for children with respiratory conditions ($F(3,118) 8.9$; $P < .001$).

As shown in Table 4, few items were endorsed by the physicians as needed by more than half of the children. Of those that were, 4 pertained to information for both the parent and the child regarding the child's condition and about behavior and de-

velopment, and 1 addressed families' need for help arranging the child's school program. Three items were endorsed by physicians for <10% of the children: information for adolescents regarding job opportunities, legal assistance, and transportation to medical services.

To investigate different patterns of needs identified by parents and physicians, parents were defined as indicating a need if *either* the mother *or* the father endorsed an item. Cohen's κ and McNemar χ^2 analyses revealed that parents identified a need more often than did physicians for 19 of the 23 items ($\kappa < .40$; $P < .01$). This difference was most striking for items that concerned assistance with child care, genetic counseling, information for parents, children, and adolescents, and help in coordinating the child's overall needs and care.

Table 5 summarizes the relationships between the physicians' and each parent's responses regarding the 4 item subgroups. Physicians' responses regarding *contact*, *counseling*, and *specific help* needs were highly correlated with *both* mothers' and fathers' ratings, but their ratings of *information* needs were correlated with *neither* parent's rating. Physicians noted significantly fewer needs with regard to both *information* and *specific help* than did either mothers or fathers, and fewer *contact* needs than did mothers. There were no differences between physicians and either parent in the numbers of items endorsed regarding the family's *counseling* needs. Both mothers and fathers endorsed a greater *total* number of needs than did physicians.

These data support the hypothesis that physicians would report fewer and different kinds of needs than parents. Physicians seemed to underestimate especially the need the parents felt for more information regarding the day-to-day management of the child's condition, and the mothers' need for help in facilitating social contact, as well as the parents' need for help in coordinating the child's overall health and developmental circumstances.

VI. Predictors of Concordance

We wondered if physicians might be in closer agreement with parents of children they considered to be most severely affected with their condition(s), as compared with more mildly involved children. Physicians' severity ratings were correlated with both mothers' and fathers' endorsements of *specific help* needs (for mothers, $r = .42$, $P < .001$; for fathers, $r = .34$, $P < .01$), as well as with mothers'

TABLE 5. Relationships Among Respondents on Four Subgroups of Items and on Estimates of Severity

Scale	Physicians-Mothers		Physicians-Fathers		Mothers-Fathers	
	r	$t(121)^a$	r	$t(99)$	r	$t(98)$
Information needs	.07	-2.50*	-.01	-2.71**	.55***	-1.45
Contact needs	.35***	-3.03**	.33***	-0.79	.52***	2.98**
Counseling needs	.35***	-1.64	.31***	-1.28	.52***	0.59
Specific help needs	.48***	-3.37**	.45***	-3.83***	.72***	-1.62
Total number of needs	.40***	-4.70***	.33***	-3.57***	.67***	0.17
Severity rating	.51***	4.50***	.46***	4.15***	.55***	1.39

^a Parentheses indicate $n-1$ degrees of freedom.

* $P < .05$; ** $P < .01$; *** $P < .001$.

ratings of *contact* needs ($r = .25$; $P < .01$). The “intensity” rating was correlated both with the number of *specific help* needs and with the *total* number of needs endorsed by each of the respondents (mothers $r = .34$ and $.24$, $P < .001$ and $< .05$; fathers $r = .32$ and $.22$, $P < .001$ and $< .05$; physicians $r = .41$ and $.31$, $P < .001$).

Multiple regression models were estimated to identify some of the variables that predicted more or less concordance between parents and physicians. The predictor variables of interest were the child’s age, the diagnostic cluster, the parents’ and physicians’ ratings of the severity of the child’s condition, and the more objective “intensity” score. An indicator variable was entered initially in the first step to control for effects attributable to individual physicians.^a Because these variables did not account for a significant amount of the variance, they were deleted from subsequent models.

The outcome variable was the level of agreement between parents and physicians about each subgroup of needs. Physicians and parents were considered to be in agreement if: 1) the physician and either the mother or the father identified an item as a need; or 2) none of the 3 respondents identified the item as a need. If the physician identified an item as a need and neither parent did, or if the physician did not identify an item as a need and at least 1 parent did, the physician and the family were considered to be *not* in agreement. The number of items on which physicians and the family agreed were then summed separately for each of the 4 subgroups and for all items together.

Table 6 contains the R^2 s and the β coefficients for all 5 regression models. The model predicting concordance regarding the need for *information* for parents, children, and adolescents about their condition(s), treatments, and their long-term implications attained statistical significance ($P < .001$). Physicians and parents were more likely to agree about these needs for children with neurologic conditions, and for children whose “intensity” was rated higher. With regard to *contact* needs, the full model approached significance, $P = .06$. Age was a significant predictor of concordance: the younger the child the more physicians and parents agreed about the need for links with other families that included a child with a chronic condition. Neither parents’ nor physicians’ ratings of severity predicted concordance in any model.

DISCUSSION

We have investigated the concordance among 3 adult observers regarding the unmet needs of children with chronic health conditions. We had expected that there would be substantial disagreement between a) mothers and fathers, and b)

physicians and parents, regarding both the severity of children’s conditions and what additional services would be helpful to children and their families. Our findings suggest instructive patterns both of concordance and of difference among observers.

Mothers and fathers reported a high level of agreement about the severity of their child’s condition(s), and about the number and type of needs that were currently insufficiently met, independent of the diagnostic category of the child’s condition(s). The only consistent discordance between them reflected mothers’ greater desire for social contact for themselves and for their children with other families that included a child with a chronic condition. Programs that address this need have evolved in many forms (eg, *Parent-to-Parent* in Vermont, *Family Ties* in Massachusetts, and the national organization *Family Voices*) and merit the support of pediatricians on behalf of the families they serve together.

Parents of children with multiple different conditions indicated a greater number of insufficiently-met needs than did parents whose children had single or similar conditions. Independent of diagnostic category, parents who rated their child’s condition(s) as more *severe* also indicated a larger number of needs.

Despite a high level of concordance as well between parents and physicians, some consistent patterns of difference are important: physicians rated the severity of children’s illnesses as greater, but the extent of their unmet needs as *lower* than did parents. This pattern did not vary by the diagnostic category of the child’s condition(s).

Physicians regularly underestimated parents’ apparently insatiable desire for information about the child’s chronic condition(s) and its implications. While parents state their desire for more information consistently and independently of severity and diagnostic categories, pediatricians seem to be more aware of this need for information among children with neurologic conditions, and those whose conditions have resulted in greater impact on the family (“intensity”), than among other children. It should be relatively easy for pediatricians to provide resources for parents to obtain appropriate information about their children’s condition(s), treatments and their family implications. Some community and regional medical centers have developed information resource centers for families. The World Wide Web has created vast new opportunities for access to information, although its unedited format can also create unanticipated new difficulties. Pediatricians will continue to be called on to provide and to interpret information that can help parents to advocate most effectively for their children’s health and development.

Pediatricians appeared to be unaware of how often parents (mothers especially) are interested in being involved in groups for their children and for themselves for the purposes of discussion, networking, and counseling. They similarly did not recognize the frequency with which parents felt a need for better understanding of the familial/

^aChildren were not distributed equally among the 11 participating physicians. These pediatricians each contributed 30 or more children to the final sample; 25 children were patients of 8 different pediatricians. Thus, 4 dummy variables were created, with the 8 pediatricians’ patients combined in one group and those of each of the 3 other pediatricians considered as separate groups.

TABLE 6. Predictors of Concordance Between Parents and Physicians ($n = 91$): hierarchical regression model, with diagnostic groups entered as a dummy variable in step 1^a

	Type of Need									
	Information		Contact		Counseling		Specific Help		Total	
	R^2 Added	β	R^2 Added	β	R^2 Added	β	R^2 Added	β	R^2 Added	β
Step 1										
Diagnosis: respiratory		-.01		.06		-.09		.06		-.05
Diagnosis: neurological		.37**		.17		.06		.10		.27*
Diagnosis: other		-.04		.09		.03		.04		.03
	.14**		.02		.01		.04		.06	
Step 2										
Age		-.04		-.30**		.02		-.13		-.19
Physician severity rating		.18		.07		-.18		-.02		.06
Family severity rating		-.08		-.10		-.21		.03		-.15
Intensity		.32*		-.03		.17		-.25		-.01
	.14**		.10		.08		.05		.06	
Total R^2	.28***		.12		.09		.09		.12	

* $P < .05$; ** $P < .01$; *** $P < .001$.

^a R^2 at step 2 represents the amount of variance accounted for above and beyond that accounted for by diagnostic group.

^aChildren were not distributed equally among the 11 participating physicians. Three pediatricians each contributed 30 or more children to the final sample; 25 children were patients of 8 different pediatricians. Thus, 4 dummy variables were created, with the 8 pediatricians' patients combined in one group and those of each of the 3 other pediatricians considered as separate groups.

genetic implications of their child's condition(s), nor the difficulty parents have in making child care arrangements. Noteworthy is that physicians were considerably less likely than parents to identify a need for care coordination. Physicians identified such a need for fewer than half of the children, while two-thirds of parents stated their need for help in this domain.

That these pediatricians consistently underestimated families' wishes with regard to these issues is particularly striking because the pediatricians who participated in this project are acknowledged to be leaders in their region with regard to their interest in and understanding of the special needs of children with chronic health conditions and their families. They have made various adaptations to their practices to be able to provide special care for these children. The discrepancy we report here is likely therefore to understate the misunderstanding of *most* pediatricians of the special stresses and desires of the parents of their patients who have chronic conditions.

Several limitations of this study should be kept in mind. First, the sample was drawn from a group of pediatricians with particular interests in the care of children with chronic health conditions. The data should not be interpreted to reflect in any way the "standard of care" evident among pediatricians in general.

Second, selection of children from these pediatric practices was done using billing and coding records and may not represent the full spectrum of children with chronic conditions who are cared for by these pediatricians. The difficulties of identifying research participants in pediatric practices underscore the need for systematic data management software that can be incorporated into practice routines in a sufficiently user-friendly fashion to encourage collaborative research.

Third, the sample for which complete data are available represents only 70% of the originally selected population. Although there is no difference between those parents who agreed to participate and those who did not with regard to the gender, age, or diagnoses of their children, more precise differences among these families could not be ascertained. Thus, it is possible that the sample for which we have data does not accurately represent the true population of children with chronic conditions and their families.

CONCLUSION

These findings have important implications for policy and practice in pediatrics. Even pediatricians who are knowledgeable about and sensitive to the special issues involved in caring for children with special health care needs and who provide a great deal of support and assistance to these families underestimate the unmet needs their patients' parents recognize.

A mechanism must be found to integrate regular communication among parents and physicians about children's and families' long-term needs into the general health care supervision of children with chronic health conditions. For example, as part of the larger project that developed from the study presented here, parents and pediatricians arrange an annual joint planning meeting. In this forum, mothers, fathers, physicians, and nurse practitioners (if involved) present their observations and concerns about the child's and family's current status and outstanding needs. Among them a strategy is formulated to address those needs that the group agrees to be both important and soluble. Arrangements for shared coordination of care often emerge out of these discussions.

Scheduling and financing considerations present a formidable challenge, but should not be allowed

to supersede the requirements of comprehensive health care for these vulnerable children. Some third-party payors acknowledge the importance of such a planning encounter by reimbursing physicians using a "care coordination" code. Systematic and universal arrangements for financial risk adjustment and modifications in the organization of practice systems will be necessary to allow primary care practices to meet the complex needs of children and families.

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