Discussion of Illness During Well-Child Care Visits With Parents of Children With and Without Special Health Care Needs

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Objective: To compare parents of children with special health care needs (CSHCN) with other parents to determine parents’ expectations and priorities for discussing concerns related to a child’s acute or chronic illness at well-child care visits, the association of unmet expectations and priorities with satisfaction, and whether discussing illness displaces prevention topics.

Design: Written, self-administered survey of parents at well-child care visits.

Setting: Two community-based pediatric practices in suburban southeast Michigan.

Participants: Five hundred parents with children aged 6 months to 12 years.

Main Exposure: Having a special health care need.

Main Outcome Measures: Expectations and priorities for discussing illness-related topics (chronic and acute illnesses, medications, specialist referrals, and effects of health on life overall), actual discussion regarding illness and preventive topics, and satisfaction.

Results: Compared with parents of children without chronic conditions, parents of CSHCN were more likely to expect to discuss their child’s illness (81% vs 92%, respectively; \( P < .001 \)); 79% of parents of CSHCN ranked illness among their top 3 priorities (vs 53% of other parents \( P < .001 \)). Parents of CSHCN reported discussing a mean of 3.2 illness topics, as compared with a mean of 2.2 illness topics for other parents \( (P < .001) \). Having more than 1 unmet expectation for discussing illness was associated with higher odds of lower satisfaction (for parents of CSHCN: odds ratio, 7.2; 95% confidence interval, 2.9-18.3; for other parents: odds ratio, 3.0; 95% confidence interval, 1.7-5.5). Discussing more illness topics was associated with discussing more preventive topics \( (P < .001) \).

Conclusions: Discussing illness is frequently expected and highly prioritized at well-child care visits, particularly for parents of CSHCN. Unmet expectations are associated with lower satisfaction. Incorporating illness concerns at well-child care visits may improve chronic disease management.

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Well-child care visits are the primary vehicle in pediatrics for delivering preventive care and promoting general health and development.\(^1\) Specific recommendations for these visits include discussing multiple anticipatory guidance topics and performing screening tests.\(^2,3\)

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Nevertheless, recommendations may not reflect topics parents feel are most important to discuss. Parents may view well-child care visits as valuable opportunities to discuss their child’s acute or chronic illness. While Bright Futures\(^4\) recommends asking about recent illnesses and discussing home management of minor illness, the guidelines do not address how best to balance therapeutically oriented goals with standard preventive care objectives, especially when the child has a chronic condition. Furthermore, incorporating parents’ preferred topics of discussion during well-child care visits, even topics unrelated to preventive care, is central to the concept of family-centered care.\(^4\)

Previous studies\(^5-7\) examining what parents value at well-child care visits have focused on what anticipatory guidance and screening parents wished to receive. It is not known how parents value discussion of illness-related topics, how often discussion of illness topics occurs, the extent to which parents of children with special health care needs (CSHCN) discuss topics related to their child’s chronic condition, or the way in which discussion of parents’ priority topics may affect parents’
satisfaction with a well-child care visit. Studies in adults suggest that patients receive less preventive care in the presence of competing demands, typically chronic conditions. Whether less anticipatory guidance is covered when spending time discussing medical issues for children—especially for CSHCN—is not known.

Accordingly, we surveyed the parents of patients immediately before and after well-child care visits to answer these questions:

1. How often do parents expect or prioritize discussion of illness during well-child care visits, how often does this discussion occur, and does discussion of illness-related topics lead to less discussion of prevention?
2. Do parents of children with chronic conditions expect and prioritize discussion of illness, and if so, how do they differ from parents of children without chronic conditions?
3. When expectations and priorities for discussing illness are unmet, how does this affect parents' satisfaction with care?

**METHODS**

**DESIGN AND SUBJECT RECRUITMENT**

We conducted a written, self-administered previsit and postvisit survey of 500 parents (or legal guardians) attending well-child care visits at 1 of 2 pediatric practices in suburban southeast Michigan. One practice employs 3 physicians, is affiliated with a tertiary hospital 12 miles away, schedules 30 minutes for a well-child care visit, and has electronic medical records. The other practice employs 5 physicians, is adjacent to a community hospital, schedules 15 minutes for a well-child care visit, and uses paper medical records. Both practices use well-child care templates, have access to social workers either on site or by telephone, and train residents from pediatric and family medicine residency programs.

Eligible participants were approached by a research assistant (Jessica Lewis, BA, Rhett Elliot, Fatima Karaki, BA, Gail Pennington, MA, and Chelsey Burt) in either the waiting room or the examination room prior to seeing the physician. Parents were eligible if the child having the visit was aged 6 months to 12 years and was an established (ie, not new) patient and if the parent spoke English. If siblings had well-child care visits on the same day, 1 child was randomly chosen for the survey. Of 617 eligible parents approached, 500 completed surveys (overall response rate, 81%). Primary reasons for not participating were lack of time before seeing the physician and uses paper medical records. Both practices use well-child care templates, have access to social workers either on site or by telephone, and train residents from pediatric and family medicine residency programs.

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Informed consent was obtained from subjects and each received a $10 gift card. Institutional review boards at the University of Michigan Medical School, Ann Arbor, and Oakwood Healthcare System, Dearborn, Michigan, approved this study.

**SURVEY INSTRUMENT**

The survey consisted of previsit and postvisit portions that were linked for each respondent. We measured these domains: what parents expected to discuss with the physician (expectations), what parents felt was most important to discuss (priorities), what parents discussed with the physician (discussion received), and satisfaction with the visit.

**PREVISIT PORTION**

To measure expectations, we modified a survey used previously in adults to measure expectations for ambulatory visits. We gave parents a list of 16 items and asked whether they expected to discuss each item with the physician. These 16 items (Table 1) included preventive care or anticipatory guidance topics (11 items) as well as illness topics that cover various aspects of assessment and management of disease (5 items). We chose the preventive topics based on recommendations by professional organizations for these visits.

Parents rated each topic on a Likert-type scale that ranged from 1 (I definitely expect this) to 5 (I definitely do not expect this). Parents were also given an option to mark if the topic did not apply to their child. To create a measure of whether parents expected to discuss the topic, we counted those who marked 1 or 2 for each item as expecting and those marking 3 to 5 or not applying to their child as not expecting to discuss the topic. To examine which topics parents prioritized, parents ranked which 3 of the topics were most important to discuss with the physician, in rank order of importance.

**POSTVISIT PORTION**

After the visit, we asked parents which of the 16 items listed on the previsit portion they had just discussed with the physician (regardless of previsit expectations). We adapted language from the Promoting Healthy Development Survey and asked parents to mark 1 of the following: (1) they had received satisfactory information on the topic, (2) they had received information but wished they had received more, (3) they had not discussed the topic but wanted to discuss it, or (4) they had not discussed the topic but it was not important for that visit. Because we aimed to capture whether topics were discussed during the visit, we designated those parents having received satisfactory discussion of the topic as having discussed it and those who did not discuss the topic or did not receive adequate discussion as not having discussed it.

We asked parents how satisfied they were with the visit using a scale containing 6 Likert-type items. We adapted the Visit Specific Questionnaire, previously used in the adult ambulatory setting. We retained 5 questions that dealt with the interaction with the physician and the visit overall. Because eliciting parental concerns is critical to the well-child care visit, we added 1 item asking parents to rate the way the physician encouraged the parent to ask questions. Parents ranked each item on a 5-point scale (excellent, very good, good, fair, or poor).

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**Table 1. List of Topics on Previsit and Postvisit Survey**

<table>
<thead>
<tr>
<th>Illness Topics</th>
<th>Preventive Topics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s recent illness</td>
<td>Growth</td>
</tr>
<tr>
<td>Chronic conditions</td>
<td>Development</td>
</tr>
<tr>
<td>Medications</td>
<td>Nutrition</td>
</tr>
<tr>
<td>Referral to a specialist or therapist</td>
<td>Injury prevention</td>
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<tr>
<td>Effect of child’s health problems on life overall</td>
<td>Behavior</td>
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<td></td>
<td>Changes in the home environment</td>
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<td>School</td>
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<td></td>
<td>Sleep (at ages 0-5 y)</td>
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<td></td>
<td>Child’s ability to make friends (at ages 6-12 y)</td>
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<tr>
<td></td>
<td>Parental smoking</td>
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<tr>
<td></td>
<td>Parental stress</td>
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<td></td>
<td>Parental depression</td>
</tr>
</tbody>
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We collected information on parent and child sociodemographic factors and health status because they represented potential confounders. We asked for the child's age, sex, insurance status (private, public, uninsured), and race/ethnicity (white, black, other) and used the CSHCN Screener\(^1\) to determine whether the child has a chronic condition. This 3-item screening tool assesses a child's ongoing (>12-month duration) need for prescription medication, need for health or education services or special therapies beyond those required by children generally, functional limitations, and emotional, behavioral, or developmental problems. We asked about the child's health status (excellent, very good, good, fair, poor). We also asked for the parent's age group, employment (full time, part time, unemployed), and education level (< high school, high school graduate, some college, college graduate).

### DATA ANALYSIS

Using our primary comparison variable of CSHCN status, we generated descriptive statistics using bivariate tests (t test, Pearson \(\chi^2\), Wilcoxon rank sum test) to explore differences in parents' expectations, priorities, and discussion of prevention and illness, both in general (combining the 5 illness topics) and for each topic. We also generated descriptive statistics to explore unmet expectations and priorities for discussing illness.

We tested whether discussing more illness topics is associated with discussing fewer prevention topics. Stratifying by CSHCN status, we examined the association between the number of preventive topics discussed and the mean number of illness topics discussed using 1-way analysis of variance.

We performed multivariate ordinal logistic regression analyses to explore associations of unmet illness expectations and priorities with 3 levels of visit satisfaction. We stratified the analyses by CSHCN status and included parent and child sociodemographic and health variables and a study site variable. We adjusted standard errors to account for clustering effects related to physician practice.\(^13,14\)

The proportion of parents who reported discussing all of the 16 topics was 12%. These parents might have reported discussing topics not actually discussed. We conducted a sensitivity analysis that excluded these parents. We used Stata version 8 statistical software (Stata Corp, College Station, Texas) for all of the analyses.

### RESULTS

#### SAMPLE CHARACTERISTICS

The respondent was the mother in 91% of cases and the father in 6% of cases. Among children, 25% had a special health care need. The CSHCN were older than other children (mean age, 5.3 years vs 3.9 years, respectively; \(P < .001\)), were more likely to have older siblings (69% vs 56%, respectively; \(P = .01\)), and reported worse health status (good, fair, or poor in 31% vs 6%, respectively; \(P < .001\)). Fifty-six percent of parents of CSHCN and 61% of other parents had attended or graduated college. Parents of CSHCN were more likely to be older than other parents (27% vs 21%, respectively, were aged > 34 years; \(P = .009\)).

#### EXPECTATIONS FOR AND PRIORITIZATION OF DISCUSSION OF ILLNESS TOPICS

Parents of CSHCN expected to discuss at least 1 illness topic 92% of the time, compared with 81% of parents of children without special health care needs (\(P < .001\) (Table 2)). Parents of CSHCN expected to discuss 1 ad-
other parents had an unmet expectation for discussing illness topics, respectively; P < .001). The most frequently expected illness topics for parents of CSHCN were medications (78%), chronic conditions (74%), and the effect of health problems on life overall (71%). In contrast, parents of children without special health care needs most commonly expected to discuss their children’s recent illness (63% of these parents).

Parents frequently prioritized illness among the top 3 most important topics. Parents of CSHCN ranked an illness topic in the top three 79% of the time (vs 53% of other parents; P < .001), and 57% ranked an illness topic as the most important (vs 27% of other parents; P < .001).

**DISCUSSION OF ILLNESS DURING THE VISIT**

On the postvisit portion of the survey, 97% of parents of CSHCN and 86% of other parents reported discussing at least 1 illness topic during well-child care visits (P = .001) (Table 3). Parents of CSHCN discussed more illness topics than parents of other children (mean, 3.8 vs 2.6 illness topics, respectively; P < .001). For parents of CSHCN, the most commonly discussed item was their child’s medication (86% of visits), compared with parents of children without chronic conditions, who most commonly discussed their child’s recent illness (68% of visits).

**BALANCE OF DISCUSSION OF PREVENTION VS ILLNESS TOPICS**

We hypothesized that if more illness topics were discussed, fewer prevention topics would be discussed. However, we found the opposite: for both parents of CSHCN and other parents, as more illness topics were discussed, more prevention topics were also discussed (Figure).

**UNMET EXPECTATIONS, UNMET PRIORITIES, AND PARENTAL SATISFACTION WITH THE VISIT**

Twenty-nine percent of parents of CSHCN and 38% of other parents had an unmet expectation for discussing at least 1 illness topic. Approximately 1 in 8 parents had an unmet priority for discussing illness (12% for parents of CSHCN and 13% for other parents).

In multivariate ordinal logistic regression (Table 4), when more than 1 expectation for discussing illness was unmet, parents were less satisfied with the visit (for parents of CSHCN: odds ratio, 7.2; 95% confidence interval, 2.9-18.3; for other parents: odds ratio, 3.0; 95% confidence interval, 1.7-5.5). Similarly, when parents prioritized an illness topic but did not discuss it, they were less satisfied with the visit (for parents of CSHCN: odds ratio, 4.8; 95% confidence interval, 1.1-21.0; for other parents: odds ratio, 2.2; 95% confidence interval, 1.4-3.4).

**SENSITIVITY ANALYSIS**

We performed all of the analyses excluding the 12% of parents who reported discussing all of the 16 items. The findings were the same as those in analyses of the full sample (data not shown).
This is the first study to our knowledge that examines the common phenomenon of discussing medical concerns during well-child care visits and compares what parents of CSHCN expect, prioritize, and receive at well-child care visits with the same for other parents. We found that parents, particularly parents of CSHCN, frequently expected, prioritized, and received discussion of many aspects of illness. Contrary to our hypothesis, broader discussion of illness topics coincided with discussion of more preventive topics. Importantly, when expectations and priorities for discussing illness were unmet, visit satisfaction was lower.

EXPECTATIONS AND DISCUSSIONS OF ILLNESS DURING WELL-CHILD CARE EXAMINATIONS

In contrast to guidelines’ emphasis on anticipatory guidance, parents frequently expected to discuss medical concerns during well-child care visits and ranked these topics higher in importance than recommended preventive topics. Most parents expected to cover more than 1 illness topic, suggesting that they expected a significant portion of the visit to be dedicated to disease management. Our findings echo those of other studies indicating parents’ primary goals for health supervision focus on the physical health of their children.

Is there a disconnect, then, between what parents consider important to cover during well-child care visits and what guidelines emphasize? In our study, many parents clearly prioritized illness over topics such as nutrition and safety. Given a few precious moments with the pediatrician, it seems that parents prefer to address their children’s medical issues, perhaps because pediatricians are a vital resource for medical information, and to interpret, explain, and apply such information to an individual child. In contrast, abundant information on safety and nutrition is available in the lay literature and through friends and family.

Differences were seen in expectations and priorities of specific illness topics between parents of CSHCN and other parents, suggesting that well-child care visits may play distinct roles in managing disease for these 2 groups of parents. Parents of children without special health care needs tended to expect, prioritize, and discuss a recent illness, whereas parents of CSHCN focused on their child’s chronic condition and the effects of health problems on life overall.

While parents of CSHCN expected and prioritized more illness discussion than parents of other children, their similar emphasis on discussion of illness appeared quite important for visit satisfaction. Failure to discuss illness topics that were expected or prioritized was associated with lower visit satisfaction, and this is consistent with studies in adults in which failing to meet patients’ expectations for aspects of ambulatory visits significantly lowered satisfaction.

DISCUSSION OF ILLNESS AND ANTICIPATORY GUIDANCE

We hypothesized that if parents discussed more illness topics, such discussion would crowd out preventive topics. Instead, when more topics related to illness were discussed, more preventive care topics were discussed. Because we accounted for the effect of clustering of subjects within physicians, this finding is not likely driven by between-physician differences in care. While parents who discussed more topics may have spent more time with the physician, this does not likely account for all of the variation. Rather, we speculate that parents who discuss multiple topics are more activated, enter the well-child visit with a prepared agenda, and are more engaged in the visit. In previous studies, it was found that patients who are more active during the visit receive more information and support from the physician, and patients who proactively request specific preventive services are more likely to receive them.

LIMITATIONS

We note several limitations. Viewing topics on the pre-visit questionnaire may have affected what parents brought up during the visit. However, studies have found that asking adult patients’ expectations did not affect care during encounters. Pediatricians may have altered visits if they knew parents were in the study (Hawthorne effect), although we blinded physicians to the specific content of the parent survey.

Topics of discussion during visits were assessed by parental report, which may not accurately reflect what transpired. We did not examine the depth of discussion of any 1 topic; thus, we could not distinguish between brief conversations and those that were extensive and perhaps more meaningful to parents. The survey was administered in 2 pediatric practices, and our findings may not be generalizable to other clinic populations.

Many parents of children without special health care needs reported expecting to discuss and actually discussing a chronic condition. These children may have had symptoms or risk factors that prompted discussion of a possible chronic condition but did not screen positive with the CSHCN Screener. This may also reflect differences in what parents consider a chronic condition vs what the CSHCN Screener measures. The estimated prevalence of special health care needs in the general pediatric population is 18%. The higher rate (25%) found in this study may reflect that CSHCN are more likely to have medical homes and attend well-child care visits than other children.

IMPLICATIONS

Findings in this study are relevant for clinical experts and policymakers who design guidelines for health supervision visits. Revising guidelines to account for the importance parents place on discussion of illness and differences between parents of CSHCN and other parents may make these visits more valuable. Also, these findings are important for third-party payers. Most parents receive more than basic well-child care; pediatricians should bill and be reimbursed accordingly. Currently, billing for an illness visit and a preventive care visit on the same date is limited by some insurers.

Several questions remain. Do parents whose expectations are fully met communicate differently with phy-
physicians as compared with parents with unmet expectations? Would parents benefit from pediatricians’ explicitly asking about expectations for discussing medical issues at well-child care visits? Would efforts to increase parent participation during well-child care visits decrease unmet expectations and priorities for discussing illness? Answers to these questions may help shape more effective well-child care visits in the future.

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Author Contributions: Dr Van Cleave had full access to all of the data in the study and takes responsibility for the integrity of the data as well as the accuracy of the data analysis. Study concept and design: Van Cleave, Heisler, and Davis. Acquisition of data: Devries. Analysis and interpretation of data: Van Cleave, Heisler, Joiner, and Davis. Drafting of the manuscript: Van Cleave and Heisler. Critical revision of the manuscript for important intellectual content: Heisler, Devries, Joiner, and Davis. Statistical analysis: Van Cleave, Heisler, and Davis. Administrative, technical, and material support: Devries and Joiner. Study supervision: Heisler, Joiner, and Davis.

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