

1 **Surveillance or engagement: children's conflicts during health maintenance visits**

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1 **Abstract**

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3 **Objective:** School-aged health maintenance visits seek to prevent or intervene early with
4 health issues of life-long importance. Little is known about engaging children in health
5 maintenance discussions and as active collaborators in care.

6 **Methods:** Visits by 30 children (53% Latino, 27% African-American and 20% White)
7 age 7-11 years were videotaped and later reviewed by children. Interview transcripts
8 were analyzed for expectations, perceptions of comfort and partnership, and
9 communication with providers.

10 **Results:** Children believed doctors were helpful, caring, and a source of important
11 information. They expected immunizations, a limited physical examination, and praise
12 for accomplishments but could be surprised by discussions about behavior, family
13 function, and lifestyle. Children trusted doctors but resented what some called ‘lies’ in
14 the service of reassurance. Feelings varied among children and during visits from
15 warmth toward providers to embarrassment, wariness, irritation and boredom. Children
16 hesitated to break into parent-provider conversations or correct perceived provider
17 misunderstandings, not wanting to be seen as inappropriate or rude. When asked
18 questions they viewed as off topic, likely to reveal sensitive information, or that could
19 lead to changes in their lifestyle, some were silent or answered evasively. Some said they
20 would have spoken more freely without their parent present but valued parental support
21 and wanted parents to make important decisions.

22 **Conclusions:** School-aged children’s limited understanding of health maintenance and
23 worry about negotiating control over their lives compete with their desire to access expert

- 1 advice and form bonds with providers. Engaging children in health promotion may
- 2 require more relationship-building and education and less surveillance.
- 3

1 **What's new:**

2

3 Health maintenance visits challenge children's evolving autonomy and self-image.

4 Distracted by immunizations and surprised by questions they see as intrusive or

5 inappropriate, children may remain silent or answer evasively. Worry about surveillance

6 and its consequences competes with children's desire to engage in their own care.

7

1 **Introduction**

2

3 Pediatrics tries to engage children in healthcare, “empowering them to discover their own
4 strengths, build confidence, and participate in making choices and decisions about their
5 health.”¹ Children’s participation improves their satisfaction^{2,3} and adherence to advice.^{3,4}
6 In randomized trials of self-management interventions for school-age children with
7 asthma and atopic dermatitis, increased child participation improved disease control,
8 knowledge, and quality of life.⁵⁻⁷

9

10 Children participate little in healthcare visits, however,⁸⁻¹⁰ speaking much less than either
11 physicians or parents.¹¹⁻¹⁶ Doctor, parent and child factors may limit children’s
12 participation. Many doctors assumed until recently that children were not
13 competent to participate and did not try to include them.¹⁷ Doctors continue to
14 address more conversation to parents than to children, though as children get older
15 doctors are more likely to address questions to them.^{11,13, 18} Parents of cancer
16 patients report limiting doctor-child communication in order to protect children
17 from troubling discussions.¹⁹

18

19 Studies find that school-aged children would like to have a more active role in their
20 own general medical care.^{8,20} In one study, a majority of children with serious
21 illnesses said they wanted to hear information from their doctor, and participate in
22 decision-making, though they especially valued doctors who could do so with
23 empathy.²¹ Children have reported voluntarily limiting participation out of
24 deference to the doctor’s expertise or when they feel that ‘serious’ decisions require

1 parental input.^{22,23} Regardless of their desire to participate, children may lack the
2 pragmatic language skills needed for effective communication.^{24, 25} For example,
3 they may still be learning the special vocabulary of medical visits, to use and
4 understand complex grammar, or to answer questions that require self-reflection.
5 When asked a question they may pause before answering, creating an opening for
6 parents to answer for them. Children may also modify their participation based on
7 their perceptions of their own and their doctor's gender, race/ethnicity, or spoken
8 language²⁶⁻³⁰ or what they believe is proper when children interact with adults.³¹

9
10 Few studies have investigated how to increase child participation in healthcare visits. In
11 an observational study, factors associated with participation included whether the child
12 sat next to the doctor, whether the doctor explicitly invited the child to participate, and
13 whether the parent had been invited to express their own concerns early in the visit.¹⁰ In
14 an experimental study, children shown a video explaining the importance of participation
15 and modeling useful skills felt more rapport with doctors and wanted a more active role,
16 but did not speak more during visits.³²

17
18 In this study, we wanted to understand children's experiences of health maintenance
19 visits and their decisions to participate. We used stimulated recall – interviews with
20 children built around viewing video recordings of their own visits.^{33,34,35} There is good
21 reason to believe that, if asked, children can provide information that cannot be deduced
22 from observing their behavior or even by asking them about it immediately after a visit.
23 Parents' reports of children's emotional states have long been noted to differ from reports

1 made by the children themselves.³⁶ In a study of shared decision making among adults,
2 observers' scoring of visit videos had limited agreement with accounts given by
3 patients' and doctors' independent review.³⁵ In over half the decision-making
4 episodes that observers rated as successful shared decisions, participant accounts
5 revealed the opposite. In many of these misjudged episodes, patients said they had
6 deliberately withheld information or only appeared to be agreeing with the doctor's
7 conclusion. A study of children's opinions about the process of medical visits found
8 that asking at a point removed from the time of the visit yielded more negative
9 assessments compared to opinions given immediately afterwards.³⁷ Issues the
10 children came to feel more negatively about included the extent to which they had
11 been brought into the conversation, been able to clarify conversations, had plans
12 explained, or had their questions answered..

13

14 Our framework for questioning children about their experiences drew from the
15 literature on therapeutic alliance and more generally from the "common factors"
16 associated with patients' engagement in care and clinical improvement in
17 psychotherapy.³⁸ While common factors have been studied mostly among adults,
18 there is evidence that they function in child therapy as well.³⁹ Common factors have
19 long been the basis of family-centered interventions for children's mental health and
20 medical problems.⁴⁰ The common factors literature posits that patients will
21 participate more in care when they have accurate and positive expectations of clinical
22 interactions, are able to form a trusting relationship with their provider, and can
23 come to agreement with the provider on the goals and means of treatment.³⁹ We thus

1 wanted to learn from school-aged children, coming for routine health maintenance
2 visits, what they had expected of the visit, the extent to which they understood its
3 purpose, their feelings of comfort and discomfort as they interacted with providers
4 and, ultimately, their decisions about the extent to which they would participate.

5

6 **Methods:**

7 The study was conducted in a general pediatric practice staffed by attending
8 physicians, nurse practitioners and residents (only attending physicians and nurse
9 practitioners were asked to participate). Ninety percent of patients are insured
10 through Medicaid and 75% are children of limited English proficiency Latino
11 parents. Health maintenance visits follow national guidelines⁴¹ and include vital
12 signs, growth measurements, medical and social histories, physical examination,
13 anticipatory guidance, and immunizations.

14

15 A bi-lingual research assistant approached families coming for a health maintenance
16 visit with a participating provider. We used stratified recruiting with the goal of
17 including patients each from the three major ethnic/racial groups seen at the
18 practice (we sought a sample that was about half Latino and a quarter each African
19 and Caucasian-American). Eligibility criteria included child age 7-12, parent-
20 reported ethnicity/race as African-American, Caucasian-American, or Latino, and
21 parent's preferred language as English or Spanish. Parents provided written consent
22 and children verbal assent. The study was approved by the Institutional Review Board
23 of the Johns Hopkins School of Public Health.

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Initially, we included only children screening positive on the Strengths and Difficulties Questionnaire (SDQ) and thus excluded 5 children rated as unlikely to have a psychosocial problem.⁴² Subsequently, to speed recruiting, child participants were not required to have a positive SDQ (though all continued to be screened).

Visit recording: A video camera filmed the provider, the patient and parent, who were encouraged to cover the lens or turn the camera off if they felt uncomfortable. During the physical examination providers pulled closed a curtain between the camera and the examining table.

Stimulated recall interview: Used widely in psychotherapy research and to a lesser extent in medical research, stimulated recall uses visit recordings to prompt reflection and increase the accuracy and completeness of recall during a subsequent interview with a participant.^{43,44,45} Following the stimulated recall method,^{35,46} one author (SL) reviewed visit videos and picked segments corresponding to a) provider behaviors likely to be associated with building child and parent engagement; b) main components of health maintenance visits (questioning, examinations, immunizations, anticipatory guidance), and c) potential conversational challenges such as when children appeared to have been excluded from conversations and when parents said something that appeared to make the child embarrassed or uncomfortable (Table 1). Interviews then took place at the child’s home within two weeks of the visit. SL asked the child to view the video alone with her, but parents

1 could observe if they wished or the child preferred. Interviews were conducted in
2 English, Spanish, or both depending on child and parent preference.

3

4 SL began by asking the child what they remembered about the visit, whether they
5 had had questions for which they had wanted help, if anything the doctor had done
6 or said was particularly helpful, and if the visit had been different from others in the
7 past. SL then taught the child how to play and stop the video to make a comment.

8 She then started the video from its beginning. If the child did not begin to make
9 comments, she paused the video at the first pre-identified segment and asked the
10 child to comment on what he or she had been thinking or feeling at that time. If the
11 child said he or she did not know or remember, questions were re-asked in a closed-
12 ended fashion, including, if needed, a range of speculations to which the child could
13 answer yes or no.⁴⁷ This continued until the entire visit had been viewed.

14 Interviews were audio recorded and transcribed without translation by SL and RH:
15 SL and LW reviewed the transcripts as they became available to monitor SL's
16 adherence to the interview process and to consider modifications for visits that
17 were particularly long or for children who had more difficulty recounting their
18 thoughts.

19

20 Analysis: Data analysis was iterative, with concepts developed over time through
21 discussions among team members. The authors involved brought diverse
22 perspectives: SP is a pediatrician, LW and RH child psychiatrists, MK and PS are
23 psychologists, and AB was an undergraduate linguistics major. AB, RH, SP, and LW

1 are able to read English and Spanish. Analysis included both deductive and
2 inductive components. First, RH and SP separately read transcripts and identified
3 passages corresponding to a template, derived from common factors concepts.^{39, 48,}
4 ⁴⁹ Template categories described children's expectations of the visit and provider,
5 experiences during the visit (positive: trust, support, validation, agreement;
6 negative: embarrassment, worry, anger), reports of provider behaviors associated
7 with these experiences, and decisions to speak or not. Emergent themes were also
8 identified⁵⁰ and along with themes from the template were organized into a
9 codebook with illustrative quotes. Once RH and SP agreed on the codebook, RH
10 coded all of the transcripts and prepared initial summaries. A third author, LW,
11 reviewed the summaries, selected key quotations within them, and went back to the
12 transcripts to a) provide a check on agreement with the coding, and b) support the
13 interpretation of the quotations by reading them in the context of the entire
14 transcript and the corresponding section of the visit video on which the child was
15 commenting. LW also re-read all of the transcripts to understand how children's
16 experiences evolved during the course of visits. A fourth author, PS, not involved in
17 the coding or analytic process until that time, read selected transcripts to check that
18 the results reported remained grounded in the original data.⁵¹

19 **Results**

20 *Participants:* Seven of the practice's eight staff clinicians, six pediatricians and one
21 nurse practitioner, agreed to participate. They had been in practice a median of 4
22 years (range 2-26) and all were female. Six of the seven spoke Spanish with a self-
23 reported Spanish proficiency of 3.5 (range 3-3.5; possible range 0-5) using the

1 International Language Roundtable scale.⁵² Forty-seven families were approached,
2 39 agreed, and 6 were ineligible (five for normal SDQ scores according to initial
3 eligibility criteria as described above, and one not self-identifying as Latino, African-
4 or Caucasian-American). Three had visits recorded but could not be contacted for
5 follow-up interviews.

6

7 The 30 children interviewed had a mean age of 9.5 years (range 7 -11) and 57%
8 were male (Table 2). For both children and parents, 53% self-reported as Latino,
9 27% as non-Latino African-American, and 20% non-Latino Caucasian-American.
10 Sixteen parents were foreign-born with a median number of years in the US of 10
11 (IQR 8-12); 69% were from Mexico. All the foreign-born parents had limited English
12 proficiency (LEP), defined as speaking English less than very well.⁵³ Of the 30
13 children, the SDQ Total Difficulties Score was abnormal for 8 (27%) participants and
14 borderline for 6 (20%) participants (Table 2). Seven of the 30 were making their
15 first visit to the provider, though some of these children had seen other providers in
16 the practice, and all had had prior medical care in the US.

17

18 Visits lasted on average 25 minutes (range 8-48). Length did not differ by
19 race/ethnicity, but boys' were longer (mean 29 minutes) than girls' (mean 20
20 minutes, $p=.013$). Stimulated recall interviews averaged 56 minutes (range 32-91),
21 correlating with actual visit length ($r = .53$, $p = .003$), but not differing significantly
22 by gender, race/ethnicity, or preferred language. Children responded "don't
23 know/don't remember" to 6% (range 0-35%) of open-ended questions; girls 7%,

1 and boys, 5%. Latino, Caucasian-American, and African-American children
2 answered, “don’t know/don’t remember,” to 5%, 7%, and 9% of open-ended
3 questions, respectively.

4

5 Overview

6 Analysis followed the “common factors” model looking for evidence that children
7 had accurate and positive expectations about their visits, that they could develop an
8 alliance with their doctors - come to feel comfortable and trusting during the visit --
9 and would choose to actively engage in conversations, sharing information and
10 taking part in making plans.

11

12 The most prominent theme to emerge from the interviews was that children had
13 mixed expectations of their visit and felt unprepared for much of what came to be
14 discussed. They had anticipated pleasant interactions, praise for accomplishments,
15 useful information, and reassurance about concerns, but also anticipated painful
16 immunizations and potentially embarrassing examinations. Subsequently, during
17 the visit children could be surprised by topics went beyond their basic medical care
18 and confused by questions and medical vocabulary. They might alternately
19 experience the doctor as supportive, validating, and reassuring or as intrusive and
20 even, for some, inappropriate, invading space that they felt belonged within their
21 family. Their feelings ranged from pride to embarrassment and from a sense of
22 agency to irritation. Despite doctors’ regularly addressing them questions, children
23 could feel excluded when parent-doctor conversations seemed to leave them out, or

1 angry when doctors turned to parents to fill in child silences or to verify answers.
2 Children's experience of the doctor's approval and reassurance competed with
3 worries about involuntary changes to their lifestyle, feeling ashamed, or "getting in
4 trouble." While children found the presence of parents to be reassuring in general
5 and necessary for major decisions, there were instances where children said they
6 would have been more comfortable if they could have spoken to the doctor out of
7 earshot of their parent.

8

9 Many children said they preferred active participation and realized its importance
10 so that "important" information would not be missed,. They felt more comfortable
11 doing so when doctors took time to establish a dialog before touching on sensitive
12 subjects, used humor, and interceded on their behalf. Children were reluctant,
13 however, to correct the doctor when they felt that advice was impractical or based
14 on an erroneous sense of their situation. As a rule, children responded to negative
15 feelings by remaining silent, though they could be disappointed that doctors did not
16 notice their discomfort and solicit their input more directly. They wanted a chance
17 to provide their reasoning rather than raw data; short answer factual questions –
18 when do you go to sleep, do you eat sweets – could often receive purposefully vague
19 or partial answers.

20

21 The following paragraphs explore these themes in more depth: themes are
22 illustrated by examples putting children's thoughts in the context of visit dialog.

1 Accompanying tables provide further examples of children’s comments related to
2 the themes.

3

4 Conflicting expectations of visit content and of providers (Table 3)

5 *Expectations of visit content:* Children anticipated that visits would include pleasant
6 exchanges about accomplishments or behaviors of which they were proud, and
7 praise for how they had grown physically, socially, or cognitively. However, they
8 also expected to experience physical discomfort, mostly from “shots.” Concern
9 about the negative aspects of the visit could be distracting. One child, an 8 year-old
10 Caucasian-American girl, commented on her persistent concerns and disbelief in the
11 doctor’s reassurances:

12 **Example 1: X26**

13 **Video of visit:** During the opening minutes the child is smiling and friendly
14 but keeps asking about “shots.” When the doctor talks to her mother about
15 dental care the child talks over that conversation, asking, “Do you have a
16 medicine to give me (for the flu) instead of a shot?” As the doctor asks about
17 car seats the child motions to her arm and asks “Would it be there?” As the
18 doctor talks about vision, the child breaks in and asks, “Does it hurt?” The
19 doctor answers:

20 **Doctor:** It actually does not hurt, when I had mine it did not hurt, when they
21 gave it to me it did not hurt at all but I was a little bit sore the next day so that
22 later today you might be a little bit sore.

23 **Child:** [makes whining sound]

1 **Doctor:** And you'll get a Band Aid, too

2 **Recall interview: Interviewer:** When you see the doctor, what kinds of
3 things do you want to hear about?

4 **Child:** How it is going to feel and I want them to be honest... she told me that
5 it wouldn't hurt on my hand but it did a little bit.

6 **Interviewer:** What was that like?

7 **Child:** I mean she said she doesn't want me to not be like, scream and run, so
8 that's why she told me a lie.

9

10 Some children were particularly perplexed by discussions of mood or behavior,
11 which they did not expect, did not believe that the doctor could help, and that they
12 thought parents should be addressing instead. In Example 2, a 10-year old Latina
13 did not expect that "talking about health and behavior problems" would occupy so
14 much of the visit.

15 **Example 2: X34**

16 **Video of visit:** The doctor has been asking the child's mother about behavior
17 problems in school.

18 **Doctor:** Are you worried that it's a problem that needs a counselor? Are you
19 getting that help?

20 **Mother:** I think it's a problem that needs a counselor – I've talked to her, that
21 she should behave well.

22 **Recall interview: Interviewer:** Were you paying attention to your mom
23 and the doctor talking?

1 **Child:** No.

2 **Interviewer:** Since you weren't paying attention, was there anything in
3 particular you were thinking about?

4 **Child:** Like, is the doctor going to do anything? Or, why did I come to the
5 doctor? They were talking more about my health and my behavior problems
6 instead of like, giving me a shot, taking my blood pressure, and then I leave...
7 I wasn't expecting that.

8

9 Children's lack of knowledge about the purpose and content of the visit made it
10 particularly difficult when doctors began with open-ended questions that the
11 children did not understand. Parents' initial statements of concerns could open up
12 sensitive areas before there had been a chance for getting settled. For example, the
13 8 year-old in Example 1 was asked, "Do you have any concerns?" After a pause she
14 answered, "No," but in the recall interview said she had been confused because, at
15 the time, she did not realize that "Do you have any concerns?" meant, "Do you have
16 any questions?" In the following example, a 9-year old Latino talked about his
17 feelings when the doctor started the visit in a similar way:

18 **Example 3: X32**

19 **Video of visit:** The boy is playing with an exam glove that he blows air into.
20 The doctor's first question is about his age, to which he responds with a
21 smile. About 25 seconds into the visit the doctor asks:

22 **Doctor:** Do you have any questions or worries today?

23 **Child:** [shakes his head 'no,' turns to mother, blows into the glove]

1 **Doctor:** [to mother] Do you have any questions or worries?

2 **Mother:** Yes, I have questions about his behavior, I have questions whether it
3 is normal.

4 [Child looking at mother, smiling.]

5 **Recall interview: Interviewer:** How did you feel at the beginning when the
6 doctor had just come in?

7 **Child:** I was upset.

8 **Interviewer:** Can you tell me more?

9 **Child:** I felt nervous.

10 **Interviewer:** What made you nervous?

11 **Child:** The questions [later he says he has difficulty with the doctor's
12 Spanish, but knows the doctor speaks in Spanish because his mother does
13 not understand English].

14 **Interviewer:** Your mother is telling the doctor that she is worried about how
15 you behave with other children, like your brother. How did you feel when
16 your mother was telling that to the doctor?

17 **Child:** Angry.

18

19 *Expectations of the doctor as beneficent and authoritarian:* Most children thought
20 that doctors had their best interests at heart and would be helpful and reassuring.
21 As one child said, "Everything [doctors] do is for you." Children also, however,
22 expected doctors to be authoritarian, telling children and parents what should be
23 done without option for discussion. As in Example 1 (above), some children

1 believed that doctors would deliberately mislead them in the name of some
2 potential benefit.

3

4 Challenges to building an alliance during the visit (Table 4)

5 *Provider behaviors that built a positive relationship:* Children appreciated time at the
6 beginning of visits to acquaint or re-acquaint themselves with their provider; talking
7 about neutral topics gave them a chance to relax. Children appreciated friendly and
8 inclusive greetings, jokes, expressions of support or empathy, and praise for
9 development or achievements. Children also appreciated cues to participate in
10 discussions and when providers seemed to be advocating for them in an interaction
11 with their parent.

12

13 Children described several situations that made them uncomfortable. Some posed
14 threats to the image they wanted the doctor to have of them, while others raised the
15 possibility of unwanted disclosures with undesirable consequences.

16

17 *Fear of losing the doctor's approval:* Children avoided admitting to behavior or
18 thoughts that might diminish them in their doctor's eyes, including divulging that
19 they had been irritable, depressed or discouraged. In Example 4, a 9 year old
20 African-American girl explains that she does not want the doctor to think that
21 anything is wrong with her:

22 **Example 4: X22**

1 **Video of visit:** The child is seated on the exam table with legs and arms
2 crossed. Her mother faces the doctor.

3 **Doctor:** (to mother) You said that she's more angry than your other
4 daughters. (turns to child) Do you notice that, too? Do you think that you get
5 angry pretty easily?

6 **Child:** (looking at floor but nods 'Yes')

7 **Doctor:** What usually makes you angry?

8 **Child:** (still looking at floor, shrugs shoulders, murmurs something that
9 could be "Don't know")

10 **Mother:** (looking at daughter) A lot of stuff?

11 **Child:** (nods 'Yes')

12 [After more discussion with mother the doctor suggests seeing a counselor.]

13 **Recall interview: Interviewer:** So how did you feel when the doctor asked
14 you about maybe being a little bit angry?

15 **Child:** I didn't like her asking that.... I do get angry but I just didn't want her
16 to question it.

17 **Interviewer:** Yeah, I can see your body language. You cross your arms.
18 You're not really looking at her very much. Can you think of anything that
19 might have made it easier for you to talk about this?

20 **Child:** Um... no.

21 **Interviewer:** How did it make you feel when your mom was telling your
22 doctor that maybe you were a little angrier than some people?

23 **Child:** I didn't want her to tell it, because I just didn't want her to tell it.

1 **Interviewer:** So, does it matter to you? Do you think about what the doctor
2 may be thinking of you?

3 **Child:** I just wonder if like, I just wonder what she thinks about me.

4 **Interviewer:** So what did you think about the doctor’s suggestion there?
5 About maybe seeing someone to talk about it?

6 **Child:** I don’t know. I don’t want to go... I didn’t want her to think that
7 something was wrong with me and I didn’t want to go.

8

9 *Wariness about surveillance:* Children were worried when asked questions for which
10 they suspected there was a “right answer,” including questions about dietary, sleep,
11 or study habits, where (they feared) a “wrong” answer could lead to limits on their
12 behavior or other consequences for themselves or their family. Similarly, they were
13 wary of open-ended questions if it was not clear where the conversation might lead
14 or to whom the information might be disclosed. A child of immigrant parents
15 worried that if he said the wrong thing his family could be deported. The child in
16 Example 2 was concerned that the doctor’s very obvious real-time documentation in
17 the electronic medical record meant that concerns about her relationship with peers
18 would be transmitted directly to her school records. In the Example 5, a 10-year old
19 Latino had a problem being bullied. A discussion, involving the doctor, the child and
20 his mother, takes place during the physical examination. He worries about how the
21 doctor will respond and who she might tell.

22 **Example 5: X21**

1 **Video of visit: Doctor:** Are there any people at school who are not nice to
2 you, who say mean things?
3 **Child:** Yes (very low).
4 **Doctor:** Really. Who do you tell when they say these things?
5 **Child:** The teacher.
6 **Doctor:** And what does the teacher say?
7 **Child:** (not audible – mother is coughing)
8 **Doctor:** Do they ever push you or hit you or make fun of you for telling the
9 teacher?
10 **Child:** (not audible but must have indicated ‘Yes’)
11 **Doctor:** And what do you do then?
12 **Child:** (long pause, um)
13 **Doctor:** (now to mother) He is saying that there are children who say bad
14 things and bother him at school and that he told the teacher...
15 **Mother:** They don’t do anything. Last year he was hit twice... and the
16 principal didn’t do anything.
17 **Doctor:** (to child) Are you afraid of these kids that beat you up?
18 **Child:** Some.
19 **Doctor:** That’s not right, and something should happen.... We are going to
20 talk to the psychologist, once we learn more we’ll talk to the teacher, what’s
21 your teacher’s name?
22 **Child:** (says and spells teacher’s name)
23 **Doctor:** OK (pause), I need to look in your private area...

1 **Recall interview: Interviewer:** How did you feel when the doctor was
2 asking you about kids and if some of them are mean to you?

3 **Child:** Like, worried... Cause they could go to the school.

4 **Interviewer:** Who could go to the school?

5 **Child:** The doctor.

6 **Interviewer:** You thought she was going to go to the school and talk to the
7 kids?

8 **Child:** (non-verbal agreement)

9 **Interviewer:** What would you have liked the doctor to do?

10 **Child:** Just talk to the principal.

11

12 *Intrusions on family prerogatives:* Children disliked and experienced as intrusive
13 discussions that seemed to be prying into family affairs or reviewing situations
14 already discussed or worked out at home. Many of these discussions involved
15 routine anticipatory guidance – bedtimes, screen time, or diet – but to children they
16 raised the fear of changing established patterns or revealing that the child had been
17 deceiving the family; children were not sure what these things had to do with
18 medical care. A 9 year-old Caucasian-American female reflected to the interviewer
19 that “family stuff” was “personal” and not why she had come to the doctor:

20 **Example 6: X39**

21 **Recall Interview: Interviewer:** If you had problems with your friends, do
22 you think the doctor would be able to help with that?

1 **Child:** No... because I came here to get my foot checked. I didn't come there
2 just to talk about things... because that's not what a doctor should do. They
3 should check what their patient came to do. They don't come to, um, come to
4 talk. They come to get what's pain and talk about what's hurting them.

5 **Interviewer:** What did you think about the doctor wanting to know about
6 your family stuff?

7 **Child:** All personal... I bet you she (the doctor) wouldn't want us to ask her
8 that question.

9

10 Genital examinations were particularly unexpected and some children did not
11 understand why the doctor should be interested in this part of their body. The 8
12 year-old girl in Example 1 made her recommendations:

13 **Interviewer:** ...you are giving advice to all the doctors in the world, what are
14 some things that they should not do that make kids feel uncomfortable?

15 **Child:** Not so many shots.

16 **Interviewer:** Okay, not so many shots, for sure.

17 **Child:** Not the spray up the nose.

18 **Interviewer:** Okay, no spray up the nose. Anything else?

19 **Child:** No messing with any of their privates.

20 **Interviewer:** No messing with any of their privates. Definitely heard that
21 one.

22 **Child:** Only their parents.

23

1 *Information overload:* Children could become overwhelmed by the amount of
2 information presented to them (or their parent), especially if they were worrying
3 about something that drew their focus away from the conversation. In the following
4 example an 11-year old African-American boy's mother has said that he cannot
5 focus in school and he must do more about that himself. The boy cannot take in all
6 of the doctor's advice, and is distracted by one part of it – the possibility that his new
7 school and grade will be significantly harder academically.

8 **Example 7: X11**

9 **Video of visit: Doctor:** (to mother) So I'm glad you have high expectations,
10 and 6th grade is different from 5th grade... [The doctor continues for almost 4
11 minutes. The child is mostly still, generally looking toward the doctor,
12 occasionally closing his eyes, not saying anything. The doctor then turns to
13 the child and asks, "Are there some nice teachers (at your new school)?"

14 **Recall interview: Interviewer:** So what did you think of the doctor's
15 response to what your mom had said there?

16 **Child:** That... I can't remember because I need to rewind it over, 'cause she
17 was like, she brought up a lot of things. I mostly heard that it's not that my
18 old school and my new school are different, but 5th grade and 6th grade are a
19 lot different than each other.

20 **Child:** And how did it make you feel to hear the doctor say this in response to
21 your mom?

22 **Interviewer:** Well, because she said that, I was scared, scared like to go back
23 to school because the work was going to get a lot harder.

1

2 *Irritation with advice without information:* Several children pointed out segments
3 where they felt the doctor was basing her advice on incomplete information. One
4 child resented being admonished for not wearing a bicycle helmet when the
5 undisclosed reason was that his helmet no longer fit. Another was frustrated to be
6 advised to eat fruit when she already ate applesauce, which she felt was equivalent.
7 As discussed below, children generally did not feel comfortable pursuing bids to
8 present additional information.

9

10 *Parents as support and challenge to feeling comfortable:* Parents' presence was
11 valued for painful procedures and important decision-making. A 7 year-old
12 Caucasian-American girl said that she liked to be asked "child stuff, but not like the
13 stuff that her (the doctor) and mommy are talking about, not like serious stuff."
14 However, children could be irritated if doctors' conversations with parents made
15 them feel left out, and they worried about what their parents might disclose. A few
16 children felt angry about being forced to reveal sensitive information in front of
17 their parent, especially if their parent seemed to join with the doctor in pressuring
18 them. The child in Example 6 reported feeling "surrounded," and others expressed a
19 desire to speak with the doctor out of earshot of their parent. The child in Example 2
20 told the interviewer that she liked it when the doctor sat closer to her rather than
21 across the room, "because, like, far away, I don't want to say it out loud because my
22 mom is right there and (if she's) closer I can be like (whispers) 'this, this, this'
23 because I don't want my mom to hear anything."

1

2 Children’s decisions about participating in the visit (Table 5)

3 Overall, children said that they preferred an active role. They enjoyed conversation
4 and disliked being bored. They knew doctors needed accurate information on which
5 to base treatment, and, especially for somatic problems, children were concerned
6 that important issues could be overlooked if they did not reply to questions or
7 volunteer information. The negative feelings described above, however, and
8 uncertainty about how to respond assertively but politely, created a conflicting
9 desire to remain silent.

10

11 *Fear of seeming rude or interrupting:* In her recall interview, the 10 year-old Latina
12 in Example 2 was asked if she would be comfortable telling the doctor that she did
13 not want to talk about a sensitive subject (her father, who was not living with the
14 family). She said she could not do so because she believed it would be rude. A 10
15 year-old African-American boy, asked if he could request that the doctor not check a
16 particular part of his body, said that perhaps he could, though he did not know how
17 to say it “in a kind, respectful way.” In the following example, an 8-year old Latino
18 discussed not telling the doctor that he didn’t think her ideas would work:

19 **Example 8: X24.**

20 **Video of visit:** The first minutes are taken up by discussion of the child’s
21 weight and ways to control it, including increased physical activity:

22 **Doctor:** (to mother) ...one option is to play outside of school, or after school,
23 because he is right, the children don’t play much from 8 to 3. Maybe he could

1 spend 30 or 45 minutes playing after school, but at school... With the bus,
2 you can say to the driver that 'he is with me and he's not going on the bus
3 today;' it's an idea... Because changing what he eats is important, and activity
4 is also important. (to child) OK, and everything's good at school?

5 **Recall interview: Interviewer:** The doctor is suggesting that you stay a
6 after school to play on the jungle gym. What do you think of that plan?

7 **Child:** It won't work because they are not going to let me miss the bus. Or
8 not let me call my mother by myself or not go on the bus and call her when
9 I've finished playing.

10 **Interviewer:** OK, so you think that the plan is unlikely to work?

11 **Child:** Yes.

12 **Interviewer:** OK, and why didn't you tell that to the doctor?

13 **Child:** It's that my mother is the one who makes the plans. I wanted to tell
14 her, but... no, because I didn't want to interrupt.

15

16 *Fear of consequences of disclosure:* as described above, children frequently found
17 themselves in discussions of subjects they did not want raised, or that seemed to be
18 leading in the direction of a disclosure they did not want to make or an intervention
19 they opposed. They might respond with silence, apparent inattention, or with an
20 evasive or partial answer. In this example, an 11 year-old Caucasian-American boy
21 pointed out where he had feared getting into trouble with his father if his soda
22 consumption and true bedtime were to be revealed. The presence of his younger
23 sister created another possibility for uncontrolled disclosure. He managed the

1 situation by giving vague answers about soda and by simply not telling when he
2 goes to sleep.

3 **Example 9: X36.**

4 **Video of visit: Doctor:** Are you good about drinking water?

5 **Child:** Yes.

6 **Doctor:** Do you drink juice or soda?

7 **Child:** No.

8 **Father:** Yes

9 **Sister:** Yes, he drinks soda.

10 **Dad:** You said you drink orange juice every day in school.

11 **Child:** Yeah.

12 **Doctor:** That's ok, but how about soda?

13 **Child:** ummmh - no.

14 **Sister:** Yes.

15 **Father:** When we go to McDonalds he'll drink a soda, not that often.

16 **Grandmother:** Not at home.

17 **Father:** (to doctor) I'm not home every day...

18 **Doctor:** Any trouble going to the bathroom?

19 **Recall interview: Child:** Well sometimes I do.

20 **Interviewer:** Sometimes you drink soda?

21 **Child:** Mhm, when they don't know.

22 **Interviewer:** When they don't know? And why didn't you tell the doctor
23 that?

1 **Child:** I didn't want to get in trouble.

2 **Later in the visit – from video:**

3 **Doctor:** What time is bedtime?

4 **Grandmother:** It's supposed to be 8:30... (she and father agree it's usually
5 more like 10 or 10:30).

6 **Recall interview:**

7 **Child:** I don't really sleep at 10 or 10:30, I sleep at like 1 o'clock in the
8 morning. That's the only time I sleep.

9 **Interviewer:** Why didn't you tell the doctor that?

10 **Child:** I really didn't want to get in trouble.

11

12 *Wish for better invitation:* An 8 year-old Latina thought it was important that
13 doctors "tell (kids) what they are doing and, sometimes, tell them (they) have to
14 care about what they're saying." Several children pointed out parts in their visits
15 where they were irritated because, had they been asked, they could have given
16 better information than their parent. In his recall interview, the child in Example 7,
17 above, was asked what he experienced when the doctor ultimately turned to him
18 with some questions. He said that he appreciated it, because, "like when she (the
19 doctor) asks the questions that are similar to the ones she's asking my mom, I feel
20 like that when she asks those questions to me that 'cause it's happening to me I feel
21 that she would get a lot more."

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23 **Discussion**

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To our knowledge, this is the first study using stimulated recall to ask school-aged children about their experience of health maintenance visits.^{8,20,32,54} Based on our findings, we propose a model in which children come with the expectation that doctors can be helpful and provide useful and supportive information, but that these expectations compete with the anticipation of painful or embarrassing procedures, and a lack of knowledge of the range of topics involved in health maintenance. As others have found, children appreciated providers' efforts to promote a positive working relationship,^{39,55} but these efforts could not completely overcome children's worries about the consequences of participating – feelings of embarrassment, loss of control, and concern that their participation would not be well received – and ambivalence about talking in front of their parents.

Some of the children's worries may be consistent with their developmental stage. Erikson⁵⁶ characterized middle childhood as a struggle between negotiating a place for oneself in the world versus feeling ashamed and marginalized. The children in our study were excited to receive praise and validation, but they were fearful of being found deficient or flawed. They managed these fears by trying to minimize disclosures, a developmentally predictable tactic to protect appearances and avoid negative consequences to themselves and others.^{57,58} Of course, adults have also been shown to sacrifice disclosure to manage their image and the treatments doctors offer.^{35,59}

1 Some of children’s worries appeared to come from not understanding the purpose
2 of health maintenance visits in general and specific areas of questioning and
3 examination in particular. Children’s knowledge of medical care is experience-
4 dependent, and healthy children may have very little experience.⁶⁰ Participation in
5 health care requires a set of cognitive and psychosocial skills that children (and
6 their parents) may need help acquiring.⁶¹ School age children may be particularly
7 unprepared for a shift from visits that focus on early development and
8 immunization to visits discussing their own evolving lifestyle. Even parents,
9 interviewed in a study of pre-visit screening in pediatric primary care, reported
10 being unaware of the full range of topics appropriate for discussion in pediatric
11 primary care.⁶² Schools have been called on to help children prepare to use health
12 care. The National Health Education Standards, developed by the Centers for
13 Disease Control and several partner organizations, call for children, starting in pre-
14 kindergarten, to learn ways to find professionals who can help promote their health,
15 and starting in grade 6, to understand how to decide when professional health
16 services are required. Children may need to practice for health care visits, in the
17 same way that practice has been incorporated into skill-based interventions aimed
18 at reducing youth substance use.⁶⁴ Once visits begin, providers and parents may
19 have to openly empathize with and model risking vulnerability in the service of
20 health. Children may need better explanations of the motivations for providers’
21 questions, more assurance of the value of the information they share, and clearer
22 promises of discussion before action.

23

1 Limitations and strengths

2 Our results are consistent with and extend what others have observed using other
3 methods, though they merit replication with a larger sample and one that is more
4 economically diverse.^{8,65} The sample included children of limited English
5 proficiency parents who are not often included in research,⁶⁶ and some of our
6 findings in fact relate to the difficulty of conducting visits in which children and
7 parents have different language preferences. These parents may have less personal
8 experience with health maintenance and more difficulty orienting their children.⁶⁷
9 The high prevalence of borderline (20%) and abnormal (27%) SDQ scores may have
10 affected the content of the visits and children's reactions, but these rates are similar
11 to those found in a multi-site study of study of unselected children 5-10 years old
12 coming for primary care visits at community sites .⁶⁸ Provider characteristics may
13 have affected the findings – the providers in our study were all female and half had
14 been in practice less than four years, though none less than two. In a national study
15 of health care for young children, female providers included more topics in their
16 visits compared to male providers.⁶⁹ More experienced providers may have better
17 skills interacting with children, though in unpublished data from a prior study of
18 pediatric primary care we found no significant relationship between providers' age
19 and their communication style.⁷⁰ Over 70 percent of current pediatric residents are
20 women, and women are more likely to enter general pediatrics than are men.⁷¹
21 Thus, our study may be increasingly generalizable to pediatric practices.

22

1 Though we interviewed children shortly after visits, there may have been
2 impressions lost despite viewing the recording. Conducting interviews immediately
3 after visits, insisting on interviews out of earshot of parents, or even in a group,
4 might have led to different results,^{37,72} Children may also have given what they
5 thought were socially acceptable responses,⁷³ though the range of expectations,
6 feelings and opinions expressed, some of which were critical of doctors and parents,
7 or revealed that the children had been less than truthful, suggests some degree of
8 candor. Some of the children were new to their doctor, which may have increased
9 their anxiety, but all had experienced prior health maintenance care in the US.

10

11 Some children provided relatively sparse information, but we did not detect a
12 pattern attributable to gender or race/ethnicity. The proportion of children's initial
13 answers to open-ended questions providing no information (6%) was similar to that
14 reported (9%) in a study of somewhat younger children answering doctors'
15 questions during primary care medical visits.⁴⁷

16

17 **Conclusions**

18 School-aged children's limited understanding of health maintenance and worries
19 about their ability to negotiate control over their image and day-to-day aspects of
20 their lives may compete with their desire to access expert advice and form bonds
21 with doctors. The conduct and content of health maintenance visits, as presently
22 designed, may not address these barriers. Our results raise questions about how to
23 help children learn more about what healthcare offers, to use surveillance to their

1 own benefit, and to seek help for potentially stigmatizing conditions? How should
2 providers balance engaging children versus pursuing prescribed surveillance? Most
3 fundamentally, how should children’s health maintenance be structured to achieve
4 its long-term goals – promoting healthy life-styles, encouraging a life-long pattern of
5 surveillance for emerging health risks, and creating bonds with a medical home to
6 which individuals will turn in times of need?

7

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1 Table 1. Visit segments marked for discussion with child in stimulated recall interview
 2

| <u>Segment description</u> | <u>Example of selected segment and possible probes for child’s report of thoughts or feelings</u> |
|---|---|
| <u>a. Segments illustrating provider engagement behaviors</u> | |
| Greeting and opening of visit | <p>What does child think of doctor’s handshake with mom? Did he want doctor to shake his hand too?</p> <p>What did child think when the doctor gave her a “high-5”? What do you (child) think the doctor thinks of you?</p> |
| Discussion of agenda for visit | <p>How did child feel when mom and doctor decided to start with him even though he wanted them to start with his sister (both present for visits)?</p> |
| Provider or parent asking open-ended questions (to child or each other) | <p>What did child think when the doctor asked if she had any concern or questions? And when doctor asked child’s mom?</p> |
| <u>b. Segments related to health maintenance and surveillance</u> | |
| When the provider asked about mood or affect or mental health (asked either parent or patient, both if available) | <p>What was child thinking during this conversation between mom and doctor about his maybe ‘pretend’ illness? Does he feel like he could tell the doctor his side?</p> |
| Review of growth and development | <p>What did child think about conversation about his height? Was this something he was worried about? Did growth chart make sense to him?</p> |
| Immunizations | <p>What does child think when he hears the word “vacuna?” What could the doctor do to make it better? Was child thinking about it before?</p> |
| Physical examination (first point of touching and any other potentially sensitive issue – can be based only on audio) | <p>Response to doctor asking permission. How did child feel when the doctor wanted to check him “down there”? How did child know she could tell her no? How did child feel when doctor said ‘okay’ and didn’t?</p> |

3

Anticipatory guidance

How does child feel when mom and doctor are talking about her eating habits? Does the doctor's advice affect how she thinks?

c. Segments related to conversational challenges

Child appears to have been shut out of conversation or cut off

How did child feel here where he is asking a question but mom and the doctor are talking and not answering it?

Mom breaks in and starts telling the doctor about child's hearing problem. Was child finished talking?

Parent behavior that appears to make child uncomfortable or embarrassed.

How did child feel when her mom was telling her not to lie (in response to doctor's question)?

Doctor asks parent if child has begun her menstrual periods. Mother explains that child has not understood periods.

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2

1 Table 2. Characteristics of 29 participating children and parents. Data are presented as
 2 median (IQR) or n (%).
 3

| Characteristic | Child n = 30 | Parent n = 30 |
|---|-------------------------|--------------------------|
| Age (years; median (IQR)) | 9 (9-11) | 34 (28-40) |
| Female gender | 13 (43%) | 24 (80%) |
| Race/ethnicity | | |
| Non-Hispanic African-American | 8 (27%) | 8 (27%) |
| Non-Hispanic Caucasian-American | 6 (20%) | 6 (20%) |
| Hispanic/Latino | 16 (53%) | 16 (53%) |
| Foreign-born | 4 (13%) | 16 (53%) |
| Years in the US (Median (IQR)): | - | 10 (8-12) |
| Country of origin: | | |
| Mexico | 3 (75%) | 11 (69%) |
| El Salvador, Honduras, Guatemala | 1 (25%) | 4 (25%) |
| Other Latin American countries | 0 (0%) | 1 (6%) |
| English proficiency | | |
| Well | - | 2 (13%) |
| Not well/Not at all | - | 14 (88%) |
| Non-English preferred healthcare language | - | 15 (50%) |
| Years of Education (median (IQR)) | 5 (4-6) | 10 (7-14) |
| Reported health status [†] | | |
| Excellent | 10 (33%) | 3 (10%) |
| Very good | 7 (23%) | 3 (10%) |
| Good/Fair/Poor | 13 (43%) | 24 (80%) |
| SDQ Total Difficulties Score (median (IQR)) | 11.5 (7-18) | |
| Normal | 16 (53%) | |
| Borderline | 6 (20%) | |
| Abnormal | 8 (27%) | |

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 5 † Reported by caregiver
 6

1 Table 3. Selected themes and quotes for conflicting expectations of providers and of visit
2 content

Expectations of the provider as both beneficent and authoritarian

X24: 8 year-old Latino

Child: ...like, she [the doctor] is a good person. She not only helps us a lot, but she helps us a whole lot, and how she wanted to help us, like, it's as if my mom and I were puppies in the street. And she gives us food, where to live, and those things.

X21: 10 year-old Latino

Interviewer: So when the doctor asks you permission to do something, she says, "All right, I'm going to check you somewhere..." Do you think you could say, 'no?'

Child: No, 'cause that's her job.

Mixed expectations of visit content

X11: 11 year-old African-American male

Child: I think that they should do that (physical examination)... because I think it's important 'cause like you probably don't know if you have a mouth disease or something 'cause they might check in your mouth and they might see something wrong, or same with your ears... ear infections.

X37: 9 year-old Latino

Interviewer: So, at the beginning, the doctor is asking you all these questions. How did you feel then?

Child: A little, I felt a little weird.

Interviewer: Can you tell me a little more?

Child: Because no one ever asks me questions like that... she never asked questions like that before.

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1 Table 4. Selected themes and quotes for perspectives on negative reactions during the
2 visit

Fear of losing the doctor's approval

X39: 9 year-old Caucasian-American female

Interviewer: So how did you feel about this part of the visit, where your grandma and your doctor are talking about school work?

Child: Um I guess that like I don't share my business. So I know she's right there, but I don't like telling her bad things in front of her (the doctor's) face and then, I'm like, I said in my head if I don't want to tell my business, why are you telling it?

Wariness about surveillance

X12: 8 year-old Latina

Interviewer: What were you thinking here? (Doctor is talking about diet)

Child: So I was like saying, 'What? I can't even drink, I mean, I can't even eat ice cream? And like, I got into shock, because I really like ice cream.

Interviewer: Would you have ever asked the doctor about that?

Child: I wouldn't feel comfortable... because what if she says, like, 'Oh, you can't because you have something (wrong with you)...'

Intrusion on family space

X34: 10 year-old Latina

Interviewer: OK, were you tell her (the doctor) everything or were you leaving some things out?

Child: I was leaving some things out... like, I don't want to talk to her (the doctor) about it. Since my mom already knows, I prefer me and her to be talking about it instead of telling the doctor.

Parents as a shield and as an obstacle

X25: 10 year-old African-American girl

Interviewer: So, first the doctor asked you about school, and then she checked with your mom. What did you think about that?

Child: I think she should have asked Mommy all the questions because I am very shy and I don't speak loud.

Interviewer: So you think the doctor should have asked your mom all the questions?

Child: Not all the questions, but some of the questions.

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1 Table 5. Selected themes and quotes for perspectives on children’s decisions about
2 participating in the visit

Provider behaviors that influenced participation

X28: 11 year-old Latino

Interviewer: So, uh, what did it feel like when the doctor was like ‘wow’ and gave you a high five?

Child: It felt like, less nervous I guess because like I felt connected.

X41: 7 year-old Caucasian-American girl

Interviewer: How do you feel about how involved you were in the visit?

Child: Um, I think I could be a little more involved, like I said in the beginning, she (the doctor) could have asked me more questions. Like, I think other kids would maybe feel that too, like, if they’re not shy. Like, they might feel this too...like, they might be bored and they wouldn’t be maybe that bored if she, like, asked in the beginning if they, like...if she asked or their doctor asked them about their life.

Children’s concerns regarding negative consequences of participation

X12: 8 year-old Latina

Interviewer: If you noticed that she (the doctor) said something wrong in Spanish what would you think about that?

Child: That’s OK because she’s a doctor. I can’t tell her, like, “You said something wrong.” What if she tells me... she will get mad at me.

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