



# Surveillance or Engagement: Children's Conflicts During Health Maintenance Visits

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## ABSTRACT

**OBJECTIVE:** School-aged health maintenance visits seek to prevent or intervene early with health issues of lifelong importance. Little is known about what children expect to happen in these visits or how they experience them, factors related to their engagement as active collaborators in care.

**METHODS:** Thirty children (53% Latino, 27% African-American, and 20% white) ages 7 to 11 years were video recorded during a health maintenance visit and then interviewed while reviewing the videos. Interview transcripts were analyzed for understanding the purpose of the visit, feelings of comfort and discomfort, and decisions about how much to participate.

**RESULTS:** Children expected doctors to be helpful, caring, and a source of important information. They anticipated visits to include immunizations, a physical examination, and praise for accomplishments, but could be surprised by questions about behavior, family function, and lifestyle. During visits, feelings varied from warmth toward providers to embarrassment, wariness, irritation, and boredom. Even when bored or irritated, children hesitated to interrupt parent-provider conversations or

correct perceived provider misunderstandings, not wanting to be seen as inappropriate or rude. When asked questions they considered off topic, likely to reveal sensitive information, or that could lead to changes in their lifestyle, some were silent or answered evasively. Some said they would have spoken more freely without their parent present but valued parental support and wanted parents to make important decisions.

**CONCLUSIONS:** School-aged children's limited knowledge of what to expect in health maintenance visits, uncertainty about conversational norms with adults, and desire to assert control over their lives compete with their desire to access expert advice and form bonds with providers. Engaging children in health maintenance visits might require more relationship-building and education about the visit's goals.

**KEYWORDS:** disclosure; mental health; primary care; psychosocial information; stimulated recall interview

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## WHAT'S NEW

Health maintenance visits challenge children's evolving autonomy and self-image. Distracted by immunizations and surprised by questions perceived as intrusive, children might remain silent or answer evasively. Worry about surveillance and its consequences compete with children's desire to engage in care.

PEDIATRICIANS WORK TO engage children in health care, “empowering them to participate in making choices and decisions.”<sup>1</sup> School-aged children report desiring a more active role in their care.<sup>2</sup> Children's participation improves their satisfaction and adherence to advice.<sup>3</sup> Self-management interventions for school-age children

with asthma and atopic dermatitis increased participation in visits and improved disease control, knowledge, and quality of life.<sup>4,5</sup>

Many studies of health care have reported that children participate less than doctors and parents.<sup>6</sup> Doctor, parent, and child factors might play a role. Overall, doctors address more conversation to parents than to children<sup>7</sup> and some doctors have assumed that children were not competent to participate.<sup>8</sup> Parents of cancer patients report limiting doctor-child communication to protect children from troubling discussions.<sup>9</sup> Children report limiting participation in deference to the doctor's expertise or when they believe that ‘serious’ decisions require parental input.<sup>10</sup> Children might also lack the language skills needed for effective communication.<sup>11</sup> They might still be learning to use and

understand complex grammar, or to answer questions that require self-reflection. Children might pause before answering questions, creating an opening for parents to answer for them. Children might also modify their participation on the basis of perceptions of their own and their doctor's gender, race, ethnicity, or language,<sup>12</sup> or what they believe is proper when interacting with adults.<sup>13</sup>

Few studies have investigated how to increase child participation in health care. Factors associated with participation include whether the child sat next to the doctor, whether the doctor explicitly invited the child to participate, and whether the parent had been invited to express their own concerns early in the visit.<sup>6</sup> Children shown a video explaining the importance of participation and modeling useful skills perceived more rapport with doctors and wanted a more active role but did not speak more.<sup>14</sup>

In this study, we wanted to understand children's experiences of health maintenance visits and their decisions to participate, with thoughts of developing interventions to increase participation. We used stimulated recall—interviews conducted with children while watching recordings of their own visits.<sup>15</sup> When asked, patients might provide information that cannot be deduced from observing their behavior or even by asking them about it immediately after a visit.<sup>16</sup> Studies among adults show that observers interpreting patients' actions during visits often misjudge the patients' thought processes.<sup>15</sup> A study of children reported that their ratings of interactions during a visit changed depending on how long after the visits they were asked.<sup>17</sup>

Our framework for questioning children about their experiences is on the basis of therapeutic alliance and the "common factors" associated with patients' clinical improvement in psychotherapy.<sup>18</sup> The alliance and common

factors literature posits that patients participate more when they have accurate and positive expectations of clinical interactions, are able to form a trusting relationship with their provider, and can come to agreement with the provider on the goals and means of treatment.<sup>19</sup> We wanted to learn from school-aged children coming for routine health maintenance visits what they had expected of their visit, the extent to which they understood its purpose as it unfolded, feelings of comfort and discomfort as they interacted with providers and, ultimately, decisions about how much to participate.

## METHODS

The study occurred in a hospital-based general pediatric practice. Ninety percent of patients are insured through Medicaid and 75% are children of limited English proficiency (LEP) Latino parents. Health maintenance visits follow national guidelines and include vital signs, growth measurements, medical and social histories, physical examination, anticipatory guidance, and immunizations.

A bilingual assistant approached families scheduled to see participating providers. Stratified recruiting included patients from the practice's 3 major ethnic/racial groups. Eligibility included child age 7 to 12 years, parent-reported child ethnicity/race as African-American, Caucasian-American, or Latino, and parent's preferred language as English or Spanish. Initially, we included only children who screened positive on the Strengths and Difficulties Questionnaire (SDQ) and excluded 5 rated as unlikely to have a psychosocial problem.<sup>20</sup> Subsequently, to speed recruiting, child participants were not required to have a positive SDQ. Parents provided written consent and children assented.

**Table 1.** Visit Segments Marked for Discussion With Child in Stimulated Recall Interview

Segment Description	Example and Probes for Child's Report
Segments illustrating provider engagement behaviors	
Greeting and opening of visit	What does child think of doctor's handshake with mom? Did he want doctor to shake his hand too?
Discussion of agenda for visit	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)?
Provider or parent asking open-ended questions (to child or each other)	What did child think when the doctor asked if she had any concern or questions? And when doctor asked child's mom?
Segments related to health maintenance and surveillance	
When the provider asked about mood or affect or mental health (asked either parent or patient, both if available)	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?
Review of growth and development	What did child think about conversation about his height? Was this something he was worried about? Did growth chart make sense to him?
Immunizations	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?
Physical examination (can be only on the basis of audio)	Response to doctor asking permission. How did child feel when the doctor wanted to check him "down there"? Did child feel he/she had option to agree/disagree?
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?
Segments related to conversational challenges	
Child appears to have been shut out of conversation or cut off	How did child feel here where mom and the doctor are talking?
Parent behavior 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)?

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