

Caregiver and Clinician Perspectives on Missed Well-Child Visits

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ABSTRACT

PURPOSE Despite the benefits of well-child care visits, up to one-half of these visits are missed. Little is known about why children miss them, so we undertook a qualitative study to elucidate these factors.

METHODS We interviewed 17 caregivers whose children had missed well-child visits and 6 clinicians, focusing on 3 areas: the value of well-child visits, barriers to attendance, and facilitators of attendance. Transcripts were analyzed with a grounded theory approach and thematic analysis.

RESULTS Caregivers and clinicians identified similar important aspects of well-child visits: immunizations, detection of disease, and monitoring of growth and development. Both groups identified similar barriers to attendance: transportation, difficulty taking time off from work, child care, and other social stressors.

CONCLUSIONS Further work to explore how addressing social determinants of health might improve attendance of well-child visits is needed.

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INTRODUCTION

The American Academy of Pediatrics recommends 13 well-child visits before the age of 6 years.¹ These visits are an opportunity to deliver immunizations, provide anticipatory guidance, and identify and treat disease.² Attendance of well-child visits has been associated with reduced hospitalizations and emergency department use.^{3,4} Despite these benefits, children miss between 30% to 50% of well-child visits.³⁻⁶ Poor, uninsured, and African American children miss a greater proportion of these visits compared with upper-income, privately insured, and white counterparts.⁵⁻⁷ Many states support safety-net practices to promote access. Despite these efforts, it is not fully understood why more disadvantaged patients miss a disproportionately larger share of well-child visits.

Few studies have explored patient and clinician perspectives on why pediatric visits are missed. Studies conducted more than 15 years ago identified transportation,^{8,9} work,⁹ wait times,⁸ and lack of understanding about the reason behind the visits⁸ as reasons for missed visits. Clinicians in England also identified social reasons and family belief systems as reasons.¹⁰ Because clinicians are not always aware of the nonmedical aspects of patients' lives, they may not fully understand or may have different perspectives on why well-child visits are missed. It is also unclear whether clinician and caregiver perspectives on missed well-child visits align. We aimed to assess current US caregiver and clinician perspectives regarding missed well-child visits in an urban, underserved health care system with a large proportion of African Americans.

METHODS

We selected a purposive sample of 17 caregivers and 6 clinicians (family practice and pediatric physicians) for children aged 0 to 6 years who

missed 2 or more well-child visits at Virginia Commonwealth University Health System (VCUHS) between January 1, 2011, and January 1, 2016. We chose 2 or more missed well-child visits as the cutoff in order to include caregivers of young children as well as those of older children. We hypothesized that using a higher threshold of missed visits would disproportionately select families with older children. We excluded patients without any well-child visits recorded as this group may have used a different health system as their primary care medical home. Well-child visits were identified by relevant International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) or International Classification of Diseases, 10th Revision, Clinical Modification (ICD-10-CM) codes (eg, V20.2, Z00.129) and Current Procedural Terminology (CPT) claims codes (eg, 99381). Because Spanish-speaking children make up about one-third of the pediatric population at VCUHS, we also included Spanish-speaking caregivers in this study.

Caregivers were contacted through direct mailings, while clinicians serving pediatric patients in VCUHS were contacted through e-mail. Individuals who did not respond to the initial mailings were sent another invitation.

Our research team developed a semistructured guide before the study. The included questions focused on 3 domains: the value of well-child visits (eg, "What are important aspects of well-child visits?"), barriers to attendance ("What makes it hard to attend well-child visits?"), and facilitators of attendance (eg, "What would make attendance easier?"). Interviews were conducted by telephone between November 2016 and March 2017 without the use of field notes. Two female interviewers (J.O. and Martha Gonzalez [M.G.]) conducted all the interviews; the former is a medical student, and the latter is a Spanish-speaking qualitative researcher. Both interviewers were trained in interview techniques and the use of the interview guide before the study and completed the interviews in a standardized way (ie, questions were asked in a similar manner to all of the participants). Neither interviewer had relationships with the caregivers before starting the study.

Verbal consent was obtained before the start of the interview. Participants were briefed on the goals of the study before the interviews. We did not record demographics of the participants in order to protect their privacy and encourage forthright dialog between the participant and the interviewer. Interviews lasted between 10 and 20 minutes, and none were repeated. Interviews were conducted until saturation was reached. At the completion of each interview, caregivers were mailed a \$25 gift card. Clinicians were not compensated for participation.

Interviews were digitally recorded and transcribed. Spanish-speaking families were interviewed by a native Spanish speaker (M.G.) and transcripts were translated into English for interpretation. Transcripts were not made available to participants for review after the interviews were complete.

We used a grounded theory approach when analyzing the interviews. After reviewing 5 interviews independently, the research team (E.R.W., J.O., and J.P.) met and created an initial codebook based on the interview guide and topics raised by participants. As a group, the sample of interviews was reviewed with the initial codebook, and the codebook was adjusted based on consensus. With use of an editing style of coding,¹¹ this final codebook was applied to the full data set (J.O., J.P., and E.R.W.) using Word (Microsoft Corp). Coded data were reviewed by coauthors (J.O., J.P., and E.R.W.) and grouped into 3 categories: (1) valuable aspects of well-child visits, (2) barriers to well-child visit attendance, and (3) facilitators of well-child visit attendance. The team then used thematic analysis¹² to highlight the significance of each grouping from the perspective of caregivers and clinicians. Participants did not provide feedback on the results of the analysis. Our study was approved by the institutional review board of Virginia Commonwealth University.

RESULTS

Of 205 English-speaking caregivers and 95 Spanish-speaking caregivers who were mailed invitations, 12 English-speaking and 5 Spanish-speaking caregivers agreed to participate. Of the 23 clinicians practicing at VCUHS who were contacted, 6 agreed to participate.

Both caregivers and clinicians identified immunizations, the detection of illness, and the monitoring of growth and development as important aspects of well-child care (Table 1). The long-term relationship and interaction between the clinician and family was also important to both groups. Clinicians thought that their relationships with the families played a role in determining whether the family would attend future visits, as the following representative quote illustrates:

We have seen time and again that relationship and, like, connection matters for everyone when it comes to the people who take care of them and the system that takes care of them, and so if you can enhance the relationship, I think you increase your chances of helping the patients who are least likely to show up to maybe, like, improve that. (clinician participant)

Caregivers and clinicians cited lack of transportation and difficulty taking time off from work as reasons for missed well-child visits (Table 2). Caregiver-

Table 1. Selected Quotations on the Value of Well-Child Visits

Participant and Theme	Code Definition	Quotation
Caregiver		
Vaccines	Immunizations, vaccinations, or "shots"	"She needs her check-ups to let me know if she's sick or if everything's okay, what shots she needs, make sure she is able to go to school." "Some of those vaccines that she gets, it helps prevent other kids from getting sick."
Growth and development	Monitoring of growth; monitoring of verbal, gross, or fine motor development, or development in general	"It's reassurance for me that he was on track developmentally and socially, and hitting all of the milestones that I know he needs to be hitting at this point."
Health promotion	Counseling in social, behavioral, dietary, or dental domains	"You're looking at, you know, developmental habits. You know, do they have a television in their bedroom or are they drinking a ton of juice and rotting their teeth out."
Literacy promotion	Encouragement of reading or other literacy skills	"I also like the new theme of how they allow the child to take a book home. Um, it promotes that healthy relationship and that ongoing relationship with not only the facility and the child, but also when the physician sees a child with a book, they can mention it."
Detection of illness	Detection of acute or chronic illness through history, physical examination, laboratory tests, or imaging	"Obviously if there is something more severe it's normally caught at well visits; if it's caught early, if not, then it's caught during an emergent visit because it's gone on too long." "He can check for anything that could be wrong or going wrong."
Language	Communication with clinician or staff; use of non-English language or interpretation	"I like to bring my son to the clinic because they speak in Spanish and understand me well."
Clinician		
Vaccines	Immunizations, vaccinations, or "shots"	"I think that part of the big incentive for a lot of families—so I think one of the reasons that they do make it, rather than that they don't make it—so, the reason that they can't get there, there are lots of them; but I think one of the key reasons is that it comes down to shots and the fact that the public school system requires vaccines. So that essentially created an extra incentive, an extra incentive for parents to make and keep well-check appointments because they couldn't get their shots otherwise."
Growth and development	Monitoring of growth; monitoring of verbal, gross, or fine motor development, or development in general	"Pretty much growth and development for most kids is where we're going to focus."

ers said that underlying financial stress made these logistics even more difficult. Caregivers and clinicians also discussed competing priorities, such as caring for young children, older children's school schedules, and the scheduling of the caregivers' own medical appointments. Clinicians also thought that caregivers may prioritize attending well-child visits in which vaccinations are typically given. Clinicians expressed concern that immigration and language differences may be barriers to attendance. Spanish-speaking caregivers thought that availability of language services made them more interested in attending well-child visits.

DISCUSSION

We found that this sample of caregivers and clinicians from an urban underserved health system understood the need for and valued well-child visits. Caregivers and clinicians thought these visits were important to give vaccinations, identify disease, monitor growth and development, and build the relationship between family and clinician. Caregiver and clinician perspectives on reasons behind missed well-child visits were aligned. Both groups thought that transportation,

financial stress, taking time off from work, and difficulty with child care were barriers to attendance. Clinicians identified language differences and immigration status as barriers to attendance, and Spanish-speaking families thought the presence of language services facilitated attendance.

Similar to findings of older studies,⁸⁻¹⁰ both groups primarily described structural and social barriers as contributing to missed well-child visits. The VCUHS is considered a safety-net health system with a large proportion of publicly insured children. Richmond also has a high proportion of single parents and parents working in low-wage jobs who may find it more difficult to take time off from work. The clinics that see pediatric patients are centrally located and on major bus lines; however, some families may feel unsafe waiting at bus stops in areas with high rates of violent crime. It should be noted that since conducting these interviews, parking has become free for patients, although we have not yet studied how this change has affected attendance.

One limitation to our study is the reliance on mailings, which may have resulted in the exclusion of families with low levels of literacy or unstable housing.

Table 2. Selected Quotations on the Barriers to Well-Child Visit Attendance

Participant and Theme	Code Definition	Quotation
Caregiver		
Transportation	Method of getting to clinic, including cars, ride-sharing services, buses, walking, bicycling, and other means	"I had to miss [a well-child visit] because of transportation...me and my fiancé—or husband now—we only had 1 car. And, um, he had to use it for work, so, and I just did not want to take the bus to get there, or it cost too much for the cab to get from where we lived."
Financial stress	Money, finances, resources, cash, income, or poverty	"I just have to pay to park, and sometimes I have to scrape up money to park because of the situation, because I'm not a wealthy individual." "One day I had to borrow money from the parking attendant to get my car out of the lot because I didn't have the money." "Overworked, underpaid, not enough money to pay your bills, worry about food, your kids, and just everything in general." "I'm on a fixed income...and the child support is not enough. Then I'm fighting trying to make sure we have food stamps."
Time off from work	Inability to leave work (either paid time off or unpaid time off), difficulty arranging schedule with employment or employer	"I've actually had to reschedule some of her appointments just because they won't allow me to take off to come take her."
Child care	Care of other children in household, need to pick children up from school	"...when you're juggling multiple kids and you're trying to find a time that's going to work..."
Clinician		
Transportation	Method of getting to clinic, including cars, ride-sharing services, buses, walking, bicycling, and other means	"I think the barrier tends to be more with, um, prioritizing, transportation, and just that there's a lot of other personal stressors that, um, bubble to the top, um, for these people."
Financial stress	Money, finances, resources, cash, income or poverty	"...taking their kid to their well-child [visit] is maybe not as deserving of your attention when you're figuring out, um, how you're going to put food on the table or whatnot..."
Time off from work	Inability to leave work (either paid time off or unpaid time off), difficulty arranging schedule with employment or employer	"...[they've] missed too many days off from work because one of their kids has been sick and this is a preventative visit, that they might miss that preventative visit until they can reschedule for a day that might not have work."
Lack of vaccinations	Included services within well-child visit	"When I tell someone they're coming back for vaccines, that's very clear to me. But, for example, at the 9-month well-child check, we don't have vaccines, and the 2-year or 3-year [visits] often don't require, unless you happen to fall within the winter season. So we're not actually physically giving someone something. And I think there is a sense that some of our patients that if we're not giving a prescription or not giving a vaccine, and we're just talking and weighing and measuring them, that we're not doing 'anything.'"
Immigration	Status of immigration or citizenship, fear of immigration authorities	"I think people who are undocumented are afraid to seek medical care. So a lot of the parents of our patients are undocumented, so I think they may hesitate to come in because often they need to show an ID for their children to be seen." "If you're an illegal immigrant or whatever, there is a lot of anxiety around coming to systems in America where you are worried you might get found out."
Language	Communication with provider or staff, use of non-English language or interpretation	"For many of the patients I work with is that there's a language barrier, um, not understanding when the next appointment is. A lot of them are Spanish speaking so, um, not understanding when the next appointment time is, um, getting that mixed up."

In addition, the relatively low response rate (although typical for studies of this type) may have biased our sample toward those who valued well-child visits to a greater degree than those who did not respond. We plan to elicit additional perspectives from hard-to-reach families in future studies.

Our findings suggest there is a need to further explore the potential relationship between well-child visit attendance and social determinants of health. Although the importance of social determinants of health has been known to the scientific community for some time, attempts to address these determinants have been limited. There may be ways to reduce bar-

riers to attendance through interventions at the level of the family (eg, transportation, child care), the health care system (eg, appointment reminders, care coordination, screening for and addressing of social determinants of health), and the payer (value-based care rather than fee for service). Future research emphasis could be placed on understanding and helping the children missing the greatest number of visits.

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