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Family Engagement in Pediatric Sickle Cell Disease Visits

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Abstract

Adults with sickle cell disease (SCD) report problems in relationship building and information exchange during clinic visits. To explore the origin of these communication challenges, we compare communication in pediatric SCD, diabetes, and asthma visits. We collected visit videos and parent surveys from 78 children ages 9–16 years with SCD, asthma, or diabetes. Coders assessed child, parent, and physician utterances reflecting relationship building, information giving, and information gathering. Associations of engagement with type of chronic disease visit were performed with negative binomial regression. Compared to SCD visits, children in diabetes visits spoke 53% more relationship-building utterances ($p < .05$) and physicians in asthma visits spoke 48% fewer relationship building utterances to the child ($p < .01$). In diabetes visits, physicians gave almost twice as much information to children and gave 48% less information to parents (both $p < .01$) compared to SCD visits. Compared to SCD visits, physicians spoke fewer information-gathering utterances to parents in diabetes and asthma visits (85% and 72% respectively, both $p < .001$). SCD visits reflect less engagement of the children and greater physician effort to gather information from parents. These differences highlight opportunities to enhance engagement as a mechanism for ultimately improving SCD care.

Despite regular interaction with their physicians at routine clinic visits, chronically ill children and their families often struggle to manage their illnesses. In an attempt to improve outcomes, experts recommend these routine disease management visits, suggesting a focus on supporting the family's day-to-day management of a child's disease to optimize health and quality of life (Sawyer, Drew, Yeo, & Britto, 2007; Silverstein et al., 2005). However, despite these visits, many chronically ill children are not receiving recommended therapies, including children with asthma, diabetes mellitus, and sickle cell disease (Halterman et al.,

2002; Kahana, Drotar, & Frazier, 2008; Morris et al., 1997; Thornburg, Calatroni, Telen, & Kemper, 2010).

Although the interactions afforded within these routine visits are thought to be helpful to chronically ill children and their families, data from adults receiving care for sickle cell disease (SCD) suggests that interactions with physicians may not be altogether positive. Among chronically ill children and their families, interactions with physicians are known to influence outcomes such as satisfaction with care and disease self-management (DiMatteo, 2004; Drotar, 2009). However, among adults with SCD, poor interpersonal interactions with physicians are reported (DiMatteo, 2004; Drotar, 2009; Elander, Beach, & Haywood, 2011). For example, adult SCD patients report experiencing a lack of respect and also unclear information from health care staff (Elander et al., 2011; Haywood et al., 2010). These poor interactions are associated with difficulties in building relationships or trust with physicians (Haywood et al., 2010).

Perceived communication issues have the potential to affect the care received and ultimately patient's outcomes, particularly in SCD visits. A growing body of evidence for the efficacy and effectiveness of hydroxyurea (HU) in SCD has resulted in a focus on the barriers to HU adherence for patients with this disease. A National Institutes of Health (NIH) panel identified 11 barriers to HU therapy, many of which arise from failed communication between providers and patients or families (Brawley et al., 2008). Physician–patient communication is theorized to influence adherence indirectly through several pathways (Street, Makoul, Arora, & Epstein, 2009). For example, communication that builds the physician–patient relationship may improve trust and instill hope and confidence, ultimately fostering continuing care (Martin et al., 2008; Nutting, Goodwin, Flocke, Zyzanski, & Stange, 2003) as well as commitment to the selected treatment (DiMatteo et al., 1993). In addition, exchanging information can improve awareness of needed treatment or available treatments (Ayanian et al., 2005; Dohan & Schrag, 2005) and also can enhance the quality of the treatment decisions made by physicians and patients (Epstein, Alper, & Quill, 2004; Gattellari, Voigt, Butow, & Tattersall, 2002). The NIH panel on barriers to HU therapy found problems with both these tasks. Specifically, the panel noted relationship problems such as provider bias and negative attitudes toward treating patients with SCD. Additional challenges occurred with information exchange, such as difficulty in communication between patients and their caregivers regarding the use of HU, as well as failure to engage patients and their families in treatment decision making (Brawley et al., 2008). In addition, many patients with SCD are from racial/ethnic minority groups among whom less participatory visits may occur (Cox et al., 2012; Cox, Smith, Brown, & Fitzpatrick, 2009; Lattimer et al., 2010; Sleath, Rubin, & Wurst, 2003; van Wieringen, Harmsen, & Bruijnzeels, 2002), perhaps due to cultural issues (Harmsen, Meeuwesen, van Wieringen, Bernsen, & Bruijnzeels, 2003), language barriers (Rivadeneyra, Elderkin-Thompson, Silver, & Waitzkin, 2000), or socioeconomic factors (Gordon, Street, Sharf, & Soucek, 2006; Lattimer et al., 2010).

Understanding any potential challenges in communication faced by children with SCD and their families could reveal mechanisms through which SCD outcomes can be improved. To further understand engagement in these visits, this study addresses the question of whether

and how child, parent, and physician engagement in key visit tasks during SCD visits is different from engagement in two commonly studied pediatric chronic diseases, asthma and diabetes. These two conditions were selected because communication and physician engagement are also recognized as key issues in the management of these chronic conditions (Lowes et al., 2015; Pelaez et al., 2015). Findings may assist those caring for children with SCD to provide effective communication that enhances outcomes for these children.

Methods

Sample

We studied 78 children and adolescents of ages 9–16 years from English-speaking families presenting to specialty clinics for routine management of SCD, asthma, or type 1 diabetes at two large Midwestern academic medical centers. This study was reviewed and approved by institutional review boards at both institutions.

Recruitment

We recruited physician specialists in SCD ($n = 4$), asthma ($n = 2$), and diabetes mellitus ($n = 2$) at the participating institutions. Once physicians were recruited, all parents of children ages 9–16 years visiting for routine management of the target diseases were approached by clinic staff prior to their visits until approximately 25 children per target disease were enrolled. No data were kept on children or parents who declined to participate, but recruitment rates for all three disease types were comparable, ranging from 88% to 92%.

Data Collection

Parent previsit surveys included demographic information (child age, race/ethnicity, overall health, length of relationship with physician, parent age, parent relation to child, parent education) selected based on our prior work with engagement in pediatric visits (Cox, Smith, & Brown, 2007; Cox, Smith, Brown, & Fitzpatrick, 2007; Cox et al., 2009). We collected a video recording of the entire clinic visit for each child with a small camera that was turned on when the physician entered the room and turned off when the physician exited. The researcher did not remain in the room during the visit.

Assessment of Visit Participation

To assess participation in relationship building and information exchange, we coded videos with the Roter Interaction Analysis System (RIAS), a widely used and reliable system for assessing talk during a medical interaction, including talk in chronic disease visits and children's medical encounters (Roter, 2009; Roter & Larson, 2002; Wissow et al., 1998). Parent, physician, and child utterances were coded into 1 of 34 mutually exclusive categories (e.g., concern, agreement, medical information giving). A full list of these categories is available at the RIAS website (Roter, 2009). An utterance, ranging in length from a word to a sentence, is defined as the smallest discernable speech segment to which a category classification may be assigned. Talk was coded only for periods in which the physician was present. In instances of more than one parent at the visit (12% of visits), all parent talk was aggregated to represent “parent talk.” Talk between a parent and child averaged less than 5% of visit talk and was not coded. Videos were coded by four trained undergraduate and

graduate students, with a 25% random sample ($n = 20$) double-coded for intercoder reliability.

Variables

The main outcome of interest was parent, child, or physician engagement in three key tasks—relationship building, information giving, and information gathering. Relationship building was comprised of positive talk and social conversation, measured by summing the number of utterances coded as personal remarks, laughter, approval, empathy, concern, reassurance, asking for reassurance, agreement, and partnership. Information giving was measured by summing the number of utterances coded as giving information about medical, therapeutic, lifestyle, or psychosocial concerns. Information gathering was measured by summing the number of questions about medical, therapeutic, lifestyle, or psychosocial concerns. These variables were created by aggregating coded utterances representative of each task, based on meta-analysis of correlations with health outcomes (Hall, Roter, & Katz, 1988) and prior work with RIAS (Cox et al., 2012, 2007, 2009; Cox, Smith, Brown, & Fitzpatrick, 2008; Roter & Larson, 2001; Wissow et al., 1998).

Our main explanatory variable was type of chronic disease visit (SCD, asthma, or type 1 diabetes). Additional covariates included child characteristics (age, race/ethnicity [White, non-Hispanic vs. all other]), single-item parent report of child health status (excellent, very good, good, fair, poor), parent characteristics (age, relationship to the child [mother present vs. another caretaker present but not the mother], education [high school graduate or less, some college, bachelor's degree or more]), and visit length, representing the time spent with the physician and assessed in minutes from the video as the time between the first and last utterances between the physician and the family.

Data Analysis

Intercoder reliability was measured as intraclass correlation coefficients, which are appropriate to the distributions of the coded data. Descriptive analyses were performed, including proportions, means, medians, and interquartile ranges (IQR). Negative binomial regression was used to examine how parent, child, or physician engagement in key visit tasks was related to the type of chronic disease visit, adjusting for parent and child characteristics as well as visit length. Incidence rate ratios (IRRs) with 95% confidence intervals (CI) were computed. For each task, IRR describes the ratio of the number of utterances compared to the reference group or associated with a one-unit change in the explanatory variable. Using physician gender and information giving as an example, an IRR of 2.0 indicates that female physicians made twice as many information-giving utterances as male physicians. Multivariate models did not include race/ethnicity or parent age because these were collinear with other model variables, specifically with disease type and child age, respectively. Because few children gathered information during visits, the association between type of chronic disease visit and the child's information gathering was not examined. All models used robust variance estimators to account for clustering by physician. Significance was assessed at $p < .05$. Analyses were performed in Stata v13 (StataCorp, 2013).

Results

Visit Characteristics

Demographic data and visit characteristics are shown by disease in Table 1. Regardless of disease type, children and parents were of similar ages and most children were accompanied by their mothers. As expected, significant differences in the race/ethnicity of the children were seen by disease type, with 100% of children with SCD identifying as non-White ($p < .001$). Children with SCD reported the lowest overall health, although this was not significantly different from children with the other two chronic diseases. Compared to children with asthma or diabetes, children with SCD had significantly longer relationships with the physician ($p < .05$ for each comparison). Parents of children with SCD had acquired significantly less formal education ($p < .05$ for each comparison). Families attending SCD or diabetes visits had significantly shorter visits with the physician than families at asthma visits ($p < .05$ for each comparison).

Intercooder Reliability and Descriptive Data for Key Engagement Measures

Intercooder reliability, measured as intraclass correlation coefficients, was .80 or greater, indicating near-perfect reliability for assessments of engagement by speaker. Counts of our three key engagement measures by disease type are described in Table 2.

Relationship Building

In adjusted models, the relationship-building talk between the child and the physician was significantly associated with the type of chronic disease visit, but talk by the parent was not (Table 3). Specifically, compared to children in SCD visits, children visiting for diabetes spoke 53% more relationship-building utterances ($p < .05$). However, compared to physicians seeing a child for SCD, physicians spoke 48% fewer relationship-building utterances to the child visiting for asthma ($p < .01$). A similar pattern was seen with relationship-building talk between parents and physicians, in which physicians spoke 45% fewer relationship building utterances to the parent whose child was visiting for asthma, compared to visits for SCD ($p < .01$).

Among the covariates, for each year of child age, relationship building between the child and physician significantly increased while the interaction between the parent and the physician significantly declined. Also, the physician's relationship-building talk with the child was significantly less when the child was in poorer health. Children who had known their physician at least 4 years also did significantly more relationship building than those with less than 1 year relationships. Having the mother present at the visit was associated with significantly greater relationship-building talk to the parent by the physician. Compared to parents who had a high school diploma or less, physicians did significantly more relationship building with parents who had some college education. Overall, each additional minute of time with the physician resulted in about 2–3% more relationship-building utterances among each of the participants.

Information Giving

Similarly, the type of chronic disease visit was significantly associated with the amount of information physicians gave to children and parents (Table 4). Compared to children visiting for SCD, physicians gave nearly twice as much information to children visiting for diabetes ($p < .05$). Compared to the visits for SCD, physicians gave 58% less information to parents in diabetes visits ($p < .01$). Information giving by children and parents did not differ by chronic disease type.

As with relationship building, for each year of child age, information giving between the child and physician significantly increased while this interaction between the parent and the physician significantly declined. Having the mother present at the visit was associated with significantly greater information giving by the parent(s). Overall, each additional minute of time with the physician resulted in about 3–4% more information-giving utterances among the participants.

Information Gathering

In adjusted models, the type of chronic disease visit was also associated with the amount of physician information gathering from parents (Table 5). Compared to physicians in SCD visits, physicians in diabetes visits spoke 85% fewer information-gathering utterances in talking with parents ($p < .001$). Similarly, physicians seeing children with asthma spoke 72% fewer information-gathering utterances to parents than in SCD visits ($p < .001$). Information gathering by parents was not significantly associated with the type of chronic disease visit.

As with the other key tasks, for each year of child age, physicians' information gathering from the child significantly increased while information gathering from the parent significantly declined. Physicians did significantly less information gathering from children who were less healthy. Having a relationship of at least 4 years with the physician was associated with significantly less information gathering by the parent, compared to relationships of less than 1 year. Having the mother present at the visit was associated with significantly greater information gathering by the parent(s). Overall, each additional minute of time with the physician resulted in about 2–5% more information-gathering utterances by the parent and by the physician from the child.

Discussion

This study presents new information on how physicians, children, and parents engage in key visit tasks during pediatric chronic disease visits. Although physician visits in SCD were shorter compared to the other two pediatric chronic diseases, even after adjustment for the time physicians spent with the families, significant differences emerged in the amount of child, parent, and physician talk about these key visit tasks. First, despite similar amounts of relationship building by physicians, children in SCD visits did significantly less relationship building than children in diabetes visits. Second, physicians in SCD visits gave significantly more information to the parent and significantly less to the child, compared to diabetes visits. Lastly, physicians in SCD visits made significantly more attempts to gather information from the parent, compared to diabetes or asthma visits. The findings suggest

opportunities to enhance communication in SCD visits with the goal of improving adherence to therapies and ultimately SCD outcomes.

Compared to children visiting for asthma or diabetes, children in SCD visits appeared less responsive to physicians' efforts to build a relationship. Specifically, although physicians in SCD visits engaged in at least as much or more relationship building as physicians in the other two pediatric chronic disease visits, children in SCD visits demonstrated significantly less relationship building, compared to children in diabetes visits. In the RIAS coding scheme, relationship-building talk is comprised of socioemotional utterances such as laughter, jokes, empathy, or reassurance. With relationship building, a reciprocal pattern is expected where, for example, a physician's joke results in the child's laughter. Or, a child's show of concern might result in a physician's utterance of empathy or reassurance. Our findings about relationship building talk are particularly interesting in light of recent work demonstrating problems with the physician–patient relationship among adult SCD patients and the NIH panel's concerns about negative SCD provider attitudes toward patients (Brawley et al., 2008; Elander et al., 2011; Haywood et al., 2010). Limited child engagement in relationship building suggests that the creation of a physician–parent relationship is challenging even early in life for SCD patients.

With regard to information exchange, results reflected a passive role for children with SCD and their parents. Specifically, in SCD visits the physician posed significantly more information-gathering utterances to the parent, compared to diabetes or asthma visits. Despite the significantly greater number of information-gathering utterances directed toward parents, parents information giving did not give more information in SCD visits compared to diabetes or asthma visits. One possible explanation for this pattern is that physicians' questions in SCD visits were closed-ended, requiring only a one-word answer such as yes or no. Using this strategy, the physician may need to ask multiple questions to gather needed information. Communication challenges with health care providers, including this pattern of passive communication, are widely reported and may be related to race/ethnicity or to parent educational attainment (Cox et al., 2012, 2009; Lattimer et al., 2010; Todd, Green, Bonham, Haywood, & Ivy, 2006). Further, some youths with chronic illness and their parents may actually prefer a more passive role in health care visits (Knopf, Hornung, Slap, DeVellis, & Britto, 2008; Lipstein, Brinkman, & Britto, 2012). Examining the characteristics of parents who present for the routine management of SCD is consistent with this, in that these parents are often less educated than parents of children with diabetes or asthma. In addition, minority patients are often found to participate less in their visits, perhaps due to cultural issues, language barriers, or socioeconomic factors (Cox et al., 2012; Gordon et al., 2006; Harmsen et al., 2003; Rivadeneyra et al., 2000; Sleath et al., 2003). Regardless of the underlying cause, this communication pattern suggests opportunities to further engage the families of children with SCD in routine disease management visits as a potential mechanism for improving SCD care and outcomes.

Our findings also have implications for transitioning the child to adult chronic disease care. Across all three key visit tasks, older children demonstrated significantly greater engagement with their physicians, while the engagement between parents and physicians was less, as might be expected and desirable. This association between child age and

engagement for all three participants is consistent with findings from prior studies (Cox et al., 2009). Yet, when adjusted for child age, physicians in diabetes visits gave significantly more information to the child and significantly less information to the parent, compared to SCD visits. A similar pattern was seen for asthma visits, although this did not reach statistical significance. This pattern could be problematic, especially when one considers that children in the age group recruited for this study are transitioning toward increasing independence and responsibility for management of their disease. However, this finding may also reflect differential communication abilities across children with these three disease types. Specifically, because SCD can affect cognition and development, some children with SCD may be less skilled communicators, so parents may need to participate more in visits. Although our models adjusted for parent report of child health, this item may not have captured communication issues stemming from complications of SCD. With both relationship building and information gathering, we did find greater engagement between the child and physician for children in better health.

The gender of the parent present for the child's chronic disease visit also had implications for engagement. Specifically, having the mother present was associated with greater engagement by the physicians or parents across all three visit tasks. For example, physicians did more relationship building with parents in chronic disease visits when that parent was the mother. Further, with information exchange, having the mother at the visit was associated with more parental information giving and information gathering, compared to visits in which the mother was not present. This is consistent with prior literature in which visits by a female patient have more talk (Hall, Irish, Roter, Ehrlich, & Miller, 1994), more information giving (Hall et al., 1994), and a more participatory style (Cooper-Patrick et al., 1999). Our work did not find any association between gender of the parent present and child participation, although such an association has been reported previously (Cox et al., 2007). In the current study, most children (>80%) were accompanied to their chronic disease visit by their mothers. However, an opportunity may exist to further enhance engagement in visits for families in which the mother cannot be present. For example, simply asking whether the mother had any other concerns, inviting the mother to write down or e-mail her concerns in advance, or sharing a written visit summary with the mother might enhance engagement during visits.

Another salient finding is the consistent association of shorter physician visits with reduced participation for the child, the parent, and the physician. On average, a 1-minute increase in the time spent with the physician was associated with 2–5% more engagement in each of the three key visit tasks (relationship building, information giving, and information gathering), rather than any one task preferentially. The key visit task most impacted by shorter physician visit lengths was information gathering by the parent. This finding is consistent with the Institute of Medicine's concerns about reduced visit length as a barrier to effective health care communication (Institute of Medicine, 2004) and the resultant poorer outcomes for both patients and physicians (Epstein et al., 2005; Gross, Zyzanski, Borawski, Cebul, & Stange, 1998; Hall, Milburn, Roter, & Daltroy, 1998; Linzer et al., 2000). In general, our results are also similar to those of studies of adult health care visits, in which patients report less participation (Kaplan, Gandek, Greenfield, Rogers, & Ware, 1995) and there is less physician and patient talk (Roter, Lipkin, & Korsgaard, 1991) with shorter visits. Shorter

visits are associated with lower ratings of patient-centered care, containing fewer patient questions and more physician-to-patient talk (Laws et al., 2011). In addition, parents who experienced shorter well-child visits also reported receiving less family-centered care (Halfon, Stevens, Larson, & Olson, 2011). While relatively few studies have evaluated the impact of visit length on participation in children's visits, we did find a similar pattern in which shorter visits are associated with reduced participation by children, their parents, and the physician (Cox et al., 2007; van Dulmen, 1998).

As with all observational studies, limitations of the study deserve consideration. While 78 video-recorded encounters is a rather large number in studies of communication, the sample size does limit our ability to consider individual utterance types within each key communication element and to adjust for additional factors in our models. Future, larger scale work could address these limitations. In addition, we did not record the interactions of other members of the care team such as nurses or social workers who may have met with the families. Talk by these team members may have augmented the talk between the child, parent, and physician, especially with information exchange. It is also possible that the children and parents who did not consent to the study may have different participation. Reasons for declining consent typically were concerns about the extra time study processes might take and anxiety about being recorded. Whether these factors are differentially present among families with various chronic diseases is unknown. Also, our sample included patients from only eight physicians, so findings may not be representative of communication with physicians broadly and we are not able to report the characteristics of the physicians nor to examine potential confounding through the influence of individual physician characteristics on communication. We compared engagement in SCD visits to only two other types of chronic disease visits, so our results may not be generalizable to comparisons with other types of chronic disease visits. However, we purposefully selected diabetes and asthma visits for comparison because of similarities between the families (e.g., the children visiting are of similar ages and accompanied by parents), the need for considerable self-management by the child and family, and the health care experience (e.g., routine chronic disease management visits). Further, we are unable to disentangle whether these communication differences in SCD disease visits are due to the disease type or the race/ethnicity of the families in these visits. However, this represents the reality of SCD care in that most patients with SCD are African-American. Lastly, these visits were collected at two academic institutions whose population and care delivery may not be representative of care at other institutions. However, many children with chronic disease do receive their specialty care at academic medical centers.

The findings suggest an opportunity to intervene to promote the active engagement of families of children with SCD during the child's visits. Even simple measures like asking parents and children to write down their questions prior to the visit (Kimberlin, Assa, Rubin, & Zaenger, 2001) may help families ensure their information needs are met. Interventions that actively engage patients with SCD and their families may allow the health care team to address specific concerns or questions and may lead to improved management (Cox et al., 2014; Hoyt Drazen, Abel, Lindsey, & King, 2014; Sarkar et al., 2008; Schillinger et al., 2003; Seligman et al., 2005). Also, given the focus on information gathering in the SCD visits, it might be reasonable to explore other options for getting needed information at each

visit, leaving more time to engage in a dialogue with families rather than rote data gathering. In addition, communication training programs for providers likely to care for children with SCD may benefit from awareness of the potential for these limited communication patterns and ways of further engaging these patients and families in the visit (Haywood et al., 2011; Noordman, Verhaak, & van Dulmen, 2011). Fostering active family engagement represents a potential mechanism to increase adherence and ultimately allow the child to receive therapies such as HU.

In conclusion, we find a pattern of talk in pediatric SCD visits that may reflect limited response to physician attempts to engage families in key communication tasks. Specifically, children with SCD show a pattern of relationship-building talk that suggests they respond less to physicians' efforts to build a relationship during the visit. In addition, findings suggest a passive role in information exchange for children and parents in these visits. This participation pattern may limit opportunities to promote family-centered care in SCD management. Ultimately, this participation pattern may also contribute to less favorable assessments of a family's ability to adhere to and benefit from therapies such as HU. Further, improving communication in these key tasks during SCD visits has the potential to enhance families' awareness of available treatment options, the quality of decisions about treatment, and commitment to treatment, all of which have the potential to improve adherence to SCD treatment and SCD outcomes.

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Table 1Characteristics by chronic disease visit type ($N = 78$).

	Diabetes ($n = 27$)	Sickle cell disease ($n = 26$)	Asthma ($n = 25$)	p Value
Child characteristics				
Age in years, median (IQR ^a)	11.9 (10.5–14.6)	12.1 (10.2–14.5)	10.5 (9.3–13.5)	.27
White, non-Hispanic	100.0%	0.0%	84.0%	<.001
Overall health				.06
Very good/excellent	59.3%	26.9%	52.0%	
Good	33.3%	38.5%	24.0%	
Poor/fair	7.4%	34.6%	24.0%	
Length of relationship with physician				<.001
Less than 1 year	11.1%	11.5%	40.0%	
1–4 years	51.9%	19.2%	36.0%	
More than 4 years	37.0%	69.2%	24.0%	
Parent characteristics				
Parent age in years, median (IQR ^a)	40.5 (38.0–45.0)	35.5 (31.0–38.0)	41.0 (38.0–46.0)	<.05
Mother at visit	85.2%	80.8%	84.0%	.93
Parent education				<.001
High school or less	11.1%	57.7%	4.2%	
Some college	51.9%	42.3%	50.0%	
Bachelor's degree or greater	37.0%	0.0%	45.8%	
Visit length in minutes, median (IQR ^a)	21.1 (17.6–24.2)	19.4 (15.1–25.2)	26.8 (19.8–34.4)	<.01

^aIQR = interquartile range.

Table 2

Median and interquartile range (IQR) for type of engagement by type of visit ($N = 78$).

	Child, median (IQR)	Physician to child, median (IQR)	Parent, median (IQR)	Physician to parent, median (IQR)	
Relationship building					
Type of visit					
Diabetes	46.0 (16, 59)	70.0 (54, 85)	60.0 (39, 88)	44.0 (29, 63)	
Sickle cell	24.0 (11, 33)	49.5 (34, 83)	64.0 (38, 87)	41.5 (28, 62)	
Asthma	13.0 (6, 26)	32.0 (17, 43)	72.0 (44, 103)	43.0 (25, 57)	
Information giving					
Type of visit					
Diabetes	46.0 (31, 101)	48.0 (24, 98)	84.0 (59, 135)	32.0 (13, 70)	
Sickle cell	42.0 (15, 68)	18.5 (7, 43)	114.0 (51, 143)	66.0 (20, 121)	
Asthma	35.0 (23, 65)	31.0 (16, 54)	138.0 (66, 193)	68.0 (36, 110)	
Information gathering					
Type of visit					
Diabetes	3.0 (0, 4)	34.0 (25, 51)	4.0 (3, 11)	3.0 (1, 6)	
Sickle cell	0.0 (0, 1)	47.0 (30, 69)	2.0 (0, 10)	23.5 (10, 36)	
Asthma	0.0 (0, 1)	24.0 (13, 36)	6.0 (4, 16)	7.0 (2, 24)	

Table 3

Adjusted association^a (IRR^b) of participants' relationship building with type of chronic disease visit (*N* = 78).

	Relationship building					
	Child		Physician to child		Parent	
	IRR	95% CI	IRR	95% CI	IRR	95% CI
Type of visit						
Diabetes	1.53 *	(1.05, 2.23)	1.05	(0.78, 1.40)	0.69	(0.50, 0.95)
Sickle cell	—	—	—	—	—	—
Asthma	0.84	(0.46, 1.52)	0.52 **	(0.36, 0.76)	0.72	(0.48, 1.06)
Child characteristics						
Age in years, median (IQR ^c)	1.17 ***	(1.10, 1.25)	1.10 ***	(1.05, 1.15)	0.92 **	(0.87, 0.98)
Overall health						
Poor/fair	0.81	(0.52, 1.26)	0.61 **	(0.44, 0.84)	0.86	(0.57, 1.32)
Good	0.99	(0.67, 1.46)	0.75 *	(0.59, 0.96)	0.91	(0.68, 1.21)
Very good/excellent	—	—	—	—	—	—
Length of relationship with physician						
Less than 1 year	—	—	—	—	—	—
1–4 years	1.39	(0.80, 2.43)	1.21	(0.82, 1.80)	0.96	(0.66, 1.42)
More than 4 years	2.52 **	(1.35, 4.70)	1.44	(0.94, 2.20)	0.83	(0.56, 1.24)
Parent characteristics						
Mother at visit	0.71	(0.47, 1.09)	0.86	(0.64, 1.16)	1.35	(0.87, 2.08)
Parent education						
High school or less	—	—	—	—	—	—
Some college	1.22	(0.78, 1.93)	1.22	(0.88, 1.70)	1.18	(0.80, 1.75)
Bachelors degree or greater	1.43	(0.82, 2.49)	1.17	(0.77, 1.78)	1.13	(0.69, 1.85)
Visit length in minutes, median (IQR ^c)	1.02	(1.00, 1.04)	1.02 *	(1.003, 1.03)	1.03 *	(1.01, 1.05)
					1.02 *	(1.003, 1.04)

^a All models were adjusted for parent characteristics (mother at visit, education), child characteristics (age, overall health, length of relationship with physician), and visit characteristics (visit length).

^b IRR (incidence rate ratio) describes the ratio of number of utterances compared to the reference group or associated with a one-unit change in the explanatory variable.

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cIQR = interquartile range.

$p < .001$.

 $p < .01$.
**
 $p < .05$.
*

Table 4

Adjusted association^a (IRR^b) of participants' information giving with type of chronic disease visit ($N = 78$).

	Information giving					
	Child		Physician to child		Parent	
	IRR	95% CI	IRR	95% CI	IRR	95% CI
Type of visit						
Diabetes	1.30	(0.80, 2.13)	1.95*	(1.08, 3.52)	0.82	(0.57, 1.17)
Sickle cell	—	—	—	—	—	—
Asthma	1.00	(0.60, 1.66)	1.16	(0.62, 2.16)	0.78	(0.53, 1.15)
Child characteristics						
Age in years, median (IQR ^c)	1.25***	(1.18, 1.32)	1.23***	(1.15, 1.33)	0.90***	(0.84, 0.95)
Overall health						
Poor/fair	0.73	(0.45, 1.18)	0.93	(0.59, 1.45)	1.21	(0.79, 1.86)
Good	1.12	(0.79, 1.58)	1.26	(0.84, 1.89)	0.90	(0.71, 1.15)
Very good/excellent	—	—	—	—	—	—
Length of relationship with physician						
Less than 1 year	—	—	—	—	—	—
1–4 years	1.60	(1.01, 2.52)	0.79	(0.49, 1.29)	0.90	(0.64, 1.27)
More than 4 years	1.49	(0.93, 2.37)	1.03	(0.66, 1.60)	0.75	(0.51, 1.10)
Parent characteristics						
Mother at visit	0.83	(0.55, 1.25)	0.84	(0.53, 1.32)	1.61*	(1.11, 2.33)
Parent education						
High school or less	—	—	—	—	—	—
Some college	0.93	(0.55, 1.58)	1.57	(0.87, 2.85)	1.47	(0.98, 2.20)
Bachelor's degree or greater	0.82	(0.40, 1.69)	1.65	(0.80, 3.38)	1.07	(0.67, 1.70)
Visit length in minutes, median (IQR ^c)	1.03***	(1.02, 1.05)	1.03***	(1.01, 1.05)	1.03***	(1.02, 1.05)
					1.04**	(1.01, 1.07)

^a All models were adjusted for parent characteristics (mother at visit, education), child characteristics (age, overall health, length of relationship with physician), and visit characteristics (visit length).

^b IRR (incidence rate ratio) describes the ratio of number of utterances compared to the reference group or associated with a one-unit change in the explanatory variable.

^c IQR = interquartile range.

$p < .001$

 $p < .01$
**
 $p < .05$
*

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Table 5

Adjusted association^a (IRR^b) of information gathering with type of chronic disease visit ($N = 78$).

	Information gathering					
	Physician to child		Parent		Physician to Parent	
	IRR	95% CI	IRR	95% CI	IRR	95% CI
Type of visit						
Diabetes	0.74	(0.50, 1.10)	1.18	(0.68, 2.04)	0.15***	(0.09, 0.25)
Sickle cell	—	—	—	—	—	—
Asthma	0.61	(0.39, 0.93)	0.96	(0.56, 1.67)	0.28***	(0.15, 0.53)
Child characteristics						
Age in years, median (IQR ^c)	1.18***	(1.13, 1.24)	1.04	(0.95, 1.13)	0.76***	(0.70, 0.83)
Overall health						
Poor/fair	0.56**	(0.37, 0.83)	1.61	(0.97, 2.69)	1.43	(0.77, 2.64)
Good	1.02	(0.79, 1.31)	1.59	(1.05, 2.42)	0.88	(0.56, 1.39)
Very good/excellent	—	—	—	—	—	—
Length of relationship with physician						
Less than 1 year	—	—	—	—	—	—
1–4 years	1.13	(0.80, 1.61)	0.92	(0.60, 1.43)	0.71	(0.42, 1.18)
More than 4 years	1.13	(0.78, 1.64)	0.56*	(0.34, 0.92)	0.63	(0.35, 1.13)
Parent characteristics						
Mother at visit	1.03	(0.77, 1.39)	1.80*	(1.13, 2.88)	1.60	(0.84, 3.06)
Parent education						
High school or less	—	—	—	—	—	—
Some college	0.92	(0.59, 1.43)	1.24	(0.68, 2.24)	1.54	(0.86, 2.76)
Bachelors degree or greater	0.67	(0.37, 1.21)	1.30	(0.62, 2.73)	0.78	(0.37, 1.64)
Visit length in minutes, median (IQR ^c)	1.02*	(1.001, 1.03)	1.05***	(1.03, 1.07)	1.01	(0.99, 1.04)

^a All models were adjusted for parent characteristics (mother at visit, education), child characteristics (age, overall health, length of relationship with physician), and visit characteristics (visit length).

^b IRR (incidence rate ratio) describes the ratio of number of utterances compared to the reference group or associated with a one-unit change in the explanatory variable.

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cIQR = interquartile range.

$p < .001$.

 $p < .01$.
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 $p < .05$.
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