Published in final edited form as:

J Pediatr Health Care. 2018 ; 32(1): 21–28. doi:10.1016/j.pedhc.2017.06.005.

Exploration of Parent-Provider Communication during Clinic Visits for Children with Chronic Conditions

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Abstract

Introduction—The purpose of this study was to explore the communication behaviors demonstrated by parents of children with chronic conditions, and provider team members when communicating about the child's care in outpatient clinics using concepts from the Theory of Shared Communication (TSC).

Method—This was a secondary data analysis of 30 previously recorded pediatric clinic visits. Communication among parents and provider team members was analyzed using a researcher developed coding scheme based on the TSC.

Results—Provider team members dominated communication during clinic visits demonstrating more frequent use of 'asking', 'explaining', 'advocating' and 'negotiating' behaviors than parents. Parents, were engaged in communication as demonstrated by frequent 'asking', 'explaining' and 'advocating' behaviors.

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The authors have no conflicts of interest to declare.

Ethical Statement

The authors of this manuscript have no conflicts of interest to declare.

No external funding sources provided support for this study.

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Discussion—Parents of children with chronic conditions and multidisciplinary providers demonstrated the communication behaviors of the TSC in an outpatient clinic setting. Provider dominance of communication in the clinic setting may disempower parents and impair relationships.

Keywords

Parent-Provider relationships; Communication; Pediatric

Background/Significance

Children with chronic conditions and their parents are often seen in outpatient clinic settings by a team of providers including nurse practitioners (NP), physicians (MD), and nurses (RN). Ideally, parents engage in shared decision making about treatments for the child with the provider team (Lipstein, Dodds, & Britto, 2014). Key components of shared decision-making include sharing information, building consensus and eventually reaching agreement about the treatments to be included in the child's plan of care, while respecting the family's preferences (Shay & Lafata, 2014). Members of the provider team may differ from one another in their use of communication behaviors when discussing the child's care with parents. Communication between parents and team members may contain both content and relational elements. Content elements are the pieces of information the speaker is trying to communicate to the receiver. Relational elements are those that influence how each party views the other and their relationship, such as messages of dominance, receptivity and trust. Relational communication affects provider relationships, satisfaction with care, and adherence (Atreja, Bellam, & Levy, 2005; Carnevale et al., 2016).

Providers' use of relational elements such as interpersonal sensitivity, empathy, and positive affect in collaborative dialogue about the child's plan of care have been positively associated with parental satisfaction, adherence, disclosure of psychosocial concerns and the creation of positive relationships (Brand, Klok, & Kaptein, 2013; Hart, Kelleher, Drotar, & Scholle, 2007). However, nurse practitioners, physicians and nurses alike have been found to control conversations with little perceived input from chronically ill patients and parents in the outpatient clinic setting by being directive or dominating the conversation (Berry, 2009; Cabral, Horwood, Hay, & Lucas, 2014). Conflicts may arise from differences in parent and clinician beliefs about the goals of the child's plan of care (Callery & Milnes, 2012) leading to poor relationships.

The importance of relational communication behaviors rather than simple information exchange in the outpatient setting, however, is an understudied area of the communication process (Dean, Oetzel, & Sklar, 2014). To address this deficit and further explore the relational communication behaviors used by the provider team to discuss care with families of children with chronic conditions in the outpatient clinic setting, the Theory of Shared Communication (TSC) was used as a guide (Giambra, Sabourin, Broome, & Buelow, 2014).

The TSC was developed using grounded theory methods to discover parent and nurse perceptions regarding the process of communication that leads to mutual understanding of the child's plan of care in the inpatient setting (Giambra et al., 2014). The TSC posits both

parent and nurse must have respect for each other's expertise as well as a sense of their own expertise to facilitate effective communication. Relational communication behaviors included in the process are asking, listening, explaining, advocating, negotiating roles, and verifying understanding (defined in Table 1). The use of these behaviors was perceived by both parents and nurses to be foundational for the achievement of mutual understanding of the plan of care for the child with a chronic condition while the child was hospitalized (Giambra, Broome, Sabourin, Buelow, & Stiffler, 2017). Whether the TSC communication behaviors used by parents and nurses in the inpatient setting are also used in the outpatient clinic setting to discuss the care of a child with a chronic condition has not been studied.

The purpose of this study was to explore the communication behaviors demonstrated by parents of children with chronic conditions and by the members of the provider team when communicating about the child's care in the outpatient, subspecialty clinic setting. This study was a secondary data analysis of previously recorded clinic encounters including NPs, MDs, RNs and parents of children with inflammatory bowel disease (IBD) or juvenile idiopathic arthritis (JIA). The original study analyzed parent-provider communication during rheumatology or gastroenterology clinic visits to assess shared decision-making around the option to treat the child with biologics. The aims of the current investigation were to 1) describe the communication behaviors demonstrated by parents of children with JIA or IBD and by members of the provider team caring for them in the outpatient clinic setting using concepts from the TSC, and 2) compare the type and frequency of communication behaviors used by parents and by the provider team members in the outpatient clinic setting.

Methods

This study was a secondary data analysis of 30 previously video and/or audio recorded clinic visits and accompanying transcripts. The clinic visits took place at a large, urban, freestanding children's hospital in the Midwest. The original study analyzed parent-provider communication during these clinic visits to identify the extent to which decisions about a very specific treatment option (the use of biologics) were shared between physicians or nurse practitioners and parents (Lipstein et al., 2014). The use of biologics was only discussed during approximately two-thirds ($n = 21$) of the 30 total recorded clinic visits. In this study, we analyzed the process of communication used by each parent and provider team member (MD, NP, RN) during the clinic visit as they discussed the plan of care for the child, treatment options, and the medical decisions included in the plan, beginning when the physician or nurse practitioner entered the exam room. The mean length of time of recorded parent-provider communication analyzed was 46.66 minutes (range 22 – 102 minutes). Parent communication with the RN was only captured in half the clinic visits and only at the end of the visits. Specifically, we analyzed the communication behaviors demonstrated in each utterance, i.e. uninterrupted chain of spoken language, by a parent or member of the provider team.

The previously recorded clinic encounters consisted of interactions between provider team members, parents and patients who were 18 years of age or younger and had either IBD or JIA, who consented and assented to have their clinic visit recorded in order for the

researchers to explore parent-provider interactions involving children and adolescents with chronic diseases. For this study, the utterances of the children were excluded from analysis.

Measure

To analyze the communication among parents and the provider team members, a coding scheme based on the concepts of TSC was developed by the research team. Specifically, codes with explicit definitions were developed corresponding to the components of the TSC; asking, listening, explaining, advocating, negotiating roles and verbalizing understanding and were guided by the work of Cegala (1997). (See Table 1) Once the communication coding scheme was developed, two researchers independently applied the codes to each participant's utterances on a transcript while listening to and viewing the corresponding recording of the clinic visit for context, using established standards (Lombard, Snyder-Duch, & Bracken, 2002). After the first transcript's codes were compared, the researchers met, compared codes and refined category definitions. The researchers then independently coded a sample of 5 additional videotapes and their transcripts, and compared their codes to establish inter-coder agreement and scope of scheme; that is, how much of the recorded clinic visit could be coded with the coding scheme. An inter-coder reliability analysis using the Kappa statistic was performed to determine consistency among coders. Substantial inter-coder agreement was found on the 5 additional videotapes with a mean Kappa of 0.77 (range 0.69 – 0.85) (Viera & Garrett, 2005).

Procedure and Analysis

From the coded transcripts, an analytic data set was created. After the coding scheme and inter-coder agreement were established, two researchers each independently coded 12 of the remaining 24 videotapes and their transcripts and added them to the analytic data set. The researchers met on a regular basis to discuss coding decisions. Differences were resolved by discussion until consensus was reached. For content that could not be coded with the TSC coding scheme, qualitative content analysis, a well described qualitative analysis technique, was employed by the research team to identify themes (Graneheim & Lundman, 2004).

Descriptive statistics were used to examine the observed type and frequency of communication behaviors exhibited by parents and providers when discussing the child's plan of care during the outpatient gastroenterology and rheumatology clinic visits. Chi-square analysis for independent groups was used to determine the differences between parent and provider team member observed communication behaviors. The amount of time parents and provider team members spent together during the clinic visit varied, however length of clinic visit or time in conversation was not controlled for, statistically. All statistical analysis was performed using SAS Enterprise Guide 5.1 software (SAS Institute Inc., Cary, NC, USA, ©2012).

Results

Sample Characteristics

Visits were recorded in either the rheumatology (n = 18) or gastroenterology (n = 12) clinics. Clinic providers' interactions with 44 parents were coded for communication behaviors

across the video/audio recordings of 30 clinic visits using the pre-established coding scheme. Recordings included 29 mothers, 1 grandmother, and 14 fathers. The utterances of 1 NP (n = 2 visits), 13 MDs (n = 28 visits), and 6 RNs (n = 15 visits) were also coded in the same manner. Parents interacted with either the NP or an MD, not both.

Communication Behaviors

Of the 12,482 recorded parent and provider team utterances reviewed, 12,194 (97.7%) were coded for TSC communication behaviors and 288 (2.3%) could not be coded for TSC communication behaviors (uncoded). Of the total coded utterances, the provider team members demonstrated a larger number of communication behaviors (n = 6,605) than parents (n = 5,589) (See Table 2). ‘Explaining’ was the communication behavior used most frequently by both providers (n = 3,480) and parents (n = 2,320). ‘Asking’ and ‘Verbalizing understanding’ were next most frequent with providers demonstrating ‘Asking’ more often than parents (n = 1,549 vs. n = 1,033, respectively) and parents demonstrating ‘Verbalizing understanding’ more frequently than providers (n = 1,412 vs. n = 921, respectively). ‘Listening’ was also demonstrated more frequently by parents (n = 718) than providers (n = 405). ‘Negotiating roles’ and ‘Advocating’ were both demonstrated relatively infrequently. Providers demonstrated ‘Negotiating roles’ communication behaviors (n = 179) more often than parents (n = 51). A smaller difference was found between provider use of ‘Advocating’ communication behaviors (n = 71) as compared with use by parents (n = 55). Analysis of the relationship between the total number of communication behaviors demonstrated by parents and providers revealed a statistically significant difference ($\chi^2 = 517.90$, df = 5, $p < .0001$). The total number of coded utterances for each member of the provider team and each parent varied by length of time spent together and the duration of the clinic visit.

During the clinic visits, the nurse practitioner and the physicians served in the same role on the provider team; eliciting the reason for the visit from the parent and/or patient, examining the patient, and creating a plan of care for the child, ideally with the parent and /or patient. The small number of recorded visits with an NP preclude generalizable comparisons, however the percentages of each TSC communication behavior demonstrated by the NP in total vary somewhat from those of the MD provider group (See Table 3).

Uncoded utterances were noted in nearly half of the visits (n = 14), and were divided among speakers as follows: Parent (n = 155, 53.82%), MD (n = 97, 33.68%), NP (n = 0), RN (n = 36, 12.5%). Qualitative content analysis revealed several reasons for the lack of coding. The most frequent reason (n = 112, 31.5%) for an utterance to be left uncoded was lack of relevance to the discussion of the child or child’s care (e.g. “bless you”, “thank you”). Greeting or parting comments (n = 87, 24.5%), incomplete thoughts (n = 52, 14.6%), and uninterpretable or inaudible utterances (e.g. low volume or heavy accent) (n = 42, 12%) were also noted. Provider or parent instructions to the child regarding the physical exam and not related to the child’s care were not coded (e.g. “open your mouth”) (n = 27, 7.6%). Also, a small number of utterances that were not coded using the TSC scheme were described as banter (n = 7, 1.9%). Thus, no new themes were discovered among the uncoded utterances.

Discussion

The TSC originated in the perceptions of parents and nurses regarding their communication about the care of children with chronic conditions in the inpatient setting. In this study, parents of children with a chronic condition and multidisciplinary providers clearly demonstrated the communication behaviors of the TSC in the outpatient subspecialty clinic setting. Therefore, this study provides additional information regarding the generalizability of the TSC.

The frequency with which parents and provider team members used specific behaviors highlighted the roles each played in the course of the clinic visit. The parental role was generally to describe the reason for the visit and the child's current state of health, then contribute to the creation of a plan of care for the child (Parse, 2017). The role of the physicians and nurse practitioner in this setting, was to elicit the reason for the visit, examine the child, and create a plan of care, ideally with the parent and child. The role of the nurse at the end of the outpatient clinic visit was generally to assess parent/child understanding of the plan of care, clarify the plan as needed, and provide individualized knowledge, service coordination and support for the family to carry out the plan (Nursing, 2014).

The role of each participant in the clinic visit likely influenced the communication used by each. For instance, the physicians and nurse practitioners in this study expected to have a conversation with the parent about a treatment decision for the child (use of biologics). In order to relate content elements such as information about the treatment to the parent, the provider would be expected to predominantly use 'explaining' communication behaviors; a finding borne out in this study. Similarly, Street (1992) found a high percentage of information-giving physician utterances to parents during clinic visits and Lawson and Lawson (2002) found MDs and NPs alike used an informational communication style with patients in the outpatient clinic setting.

Parents given explanations for novel treatment for their child with a chronic condition, such as the use of a biologic would be expected to use communication behaviors such as 'listening' to those explanations, 'asking questions' and 'verbalizing understanding'. However, the results of this study indicated the communication behavior demonstrated most often by the parents was 'explaining', just as it was for the entire provider team. The frequent use of 'explaining' by parents may be indicative of the amount of unique and expert knowledge the parent had or wished to express about their child or child's condition to the members of the provider team (Hoppa & Porter, 2011; Smith, Swallow, & Coyne, 2015). 'Explaining' may also have been prompted by the provider team members' frequent use of 'asking' communication behaviors. Actively eliciting the family goals and concerns is an important aspect of shared decision-making (Alston et al., 2012; Brand et al., 2013); one potential goal of the clinic visit.

Additional aspects of information exchange such as 'asking', 'listening', and 'verbalizing understanding' are foundational in the parent-provider communication process (Dean et al., 2014). All three of these communication behaviors were demonstrated by all participants in

this study, with parents demonstrating ‘listening’ and ‘verbalizing understanding’ behaviors nearly twice as often as provider team members. Along with the difference in parent and provider total number of coded utterances, the inequality demonstrated among the ‘listening’ and ‘verbalizing understanding’ behaviors may demonstrate provider team member dominance in the parent-provider relationship. This finding is not unlike that of Lawson and Lawson (2002) who found providers controlled conversations when engaging in decision making, in their study of nurse practitioner and physician communication with patients in an outpatient clinic setting.

The frequency with which parents used ‘asking’ communication behaviors may have been related to the nature of the clinic visit. As providers embarked on discussions of treatment for the child, their parent likely desired more information and involvement in treatment decisions. Parents who asked more questions of clinic providers have been shown to receive more information from those providers (Street Jr, Gordon, Ward, Krupat, & Kravitz, 2005). In a study of communication among family medicine physicians and their patients, Cegala (2011) noted a desire for information and involvement was significantly and positively associated with patient participation in discourse with providers. Street and colleagues (2009) found active involvement in medical encounters can lead to high quality medical decisions.

Many of the communication behaviors demonstrated in the studied clinic visits may have been enacted to enhance parent-provider relationships, or may have been enacted because of existing relationships. Both informational and relational communication behaviors can positively or negatively influence trust and relationships between parents and providers, in addition to satisfaction with care and adherence (Brand et al., 2013). Dickert and Kass (2009) found patient perception of respect from providers was fostered by information exchange in addition to empathy, caring, support of autonomy, individuality and dignity, and attention to patient needs. Positive physician affect during communication with patients has been found to predict patient trust (Martin-Misener et al., 2012). Likewise, patients and family members perceived information exchange, positive clinician affect, listening, and individualized care were important for creating positive relationships in a study by Mazor and colleagues (2013). Additionally, Thom and colleagues (2011) found physician trust in patients was promoted by patient provision of complete and accurate histories, inquiries, adherence to the plan of care and respect for the physician’s time and personal boundaries.

Other relational communication behaviors, such as ‘advocating’ and ‘role negotiation’ may also impact parent-provider relationships. Parents of children with chronic conditions not only learn to provide the child’s often complex day to day care, they also learn to advocate for optimal care and treatment for their child (Giambra et al., 2014; Lindahl & Lindblad, 2011; Tong, Lowe, Sainsbury, & Craig, 2010). Parents advocate for their child’s needs as well as their own (Kratz, Uding, Trahms, Villareale, & Kieckhefer, 2009) and expect their knowledge, experiences, opinions and values to be respected by providers (Shields, Young, & McCann, 2008; Tong et al., 2010). Provider team members also advocate for patients, parents and their own perception of optimal treatment for the child (Johnson, Church, Metzger, & Baker, 2015; Stivers, 2002; Williams & Gossett, 2001). Our findings revealed parents used ‘advocating’ communication behaviors nearly as often as providers. These

results seem to indicate both parents and providers felt advocacy was needed to persuade the other about a particular treatment or part of the child's plan of care, in accordance with their own unique knowledge and expertise. Similar results were found in a study of parent-provider communication about prescribing antibiotics in the outpatient setting for both well-child and acute clinic visits (Stivers, 2002). Provider acknowledgement of parental expertise and willingness to partner in the care of the chronically ill child enhances parent-provider relationships and satisfaction with care (Porter et al., 2011; Reeves, Timmons, & Dampier, 2006; Thorne & Robinson, 1988).

'Negotiating roles', specifically who will provide or perform certain aspects of the child's plan of care, is also a relational communication behavior. Providers in this study used 'negotiating roles' nearly twice as often as parents, with nurses using this behavior most frequently. The RN use of 'negotiating roles' is congruent with the RN role in the outpatient clinic setting as they attempt to provide coordination of services and support for the family. However, provider team members who limit parental participation or disempower parents to provide aspects of care for their child undermine parent-provider relationships, satisfaction with care, parental involvement in care decisions and may leave parents without critical skills necessary to carry out their child's care (King & Chiarello, 2014; Tong et al., 2010).

Conclusion

This study sheds light on the process of communication used by the provider team and parent of a child with chronic conditions to arrive at a plan of care for the child. The results indicate provider team members may have dominated the conversations. Parents' use of 'asking', 'explaining' and 'advocating' behaviors nearly as much as the provider team, however, suggests active parental engagement in the clinic visit and co-creation of the child's plan of care. The influence of parent and provider team member roles on their use of specific communication behaviors, particularly the differences in behaviors used by the NP and MDs, is an area for further study.

Limitations

This secondary data analysis has several limitations including the very small number of NPs (n = 1) who participated. The data specific to NP communication must be interpreted with caution. Additionally, the amount of time parents spent with any provider team member was not controlled and was not accounted for statistically. Another limitation was the exclusion of children's utterances during the clinic visits from our analysis. In this study, the parents and provider team members provided the vast majority of the utterances during each visit, however the addition of children's communication behaviors should be considered in future studies to enhance our understanding of the child's role in the clinic visit.

Future Research

Understanding parent-provider communication would be enhanced with studies including a larger sample of parents and wider variety and number of providers, including NPs to discover differences among a variety of providers and generate more generalizable findings. Understanding the effect of time on communication between providers and parents is another area for future study. The child's communication with parents and providers in the

clinic setting is another area ripe for future research. Additionally, exploration of parent-patient-provider communication across clinic settings would shed light on how communication behaviors may be used differently by families and providers seeing patients for a variety of reasons. Future studies should also explore the links between parent-provider communication behaviors and child and family outcomes such as decision-making, adherence, and satisfaction with care. Armed with this knowledge, interventions could be designed to enhance parent-provider communication and subsequent child well-being.

Practice Implications

Nurse practitioners should evaluate their role as it relates to their communication behaviors with parents of children with chronic conditions. The NP role may vary depending on the clinic setting and reason for the encounter. Nurse practitioners should tailor their communication in accordance with their own and the family's needs and expectations for each clinic visit. Awareness of their own and parents' communication behaviors will enable recognition of areas for improvement. In particular, NPs should avoid dominating the conversation as this may disempower parents who want to engage in shared decision-making to co-create a plan of care for their child. Actively eliciting the goals and concerns of the parents and child is an important aspect of shared decision-making and includes not only providing information, but also asking questions and listening to the answers and explanations offered. The family's values and knowledge of the child's care can then be incorporated into plans for the child's treatment, and family management of the child's condition. Thoughtful use of relational communication behaviors may enhance family-practitioner relationships, satisfaction, adherence, and ultimately lead to optimal child health outcomes.

Acknowledgments

This work was supported in part by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)/National Institutes of Health (NIH) grant K23 HD073149 to Ellen A. Lipstein.

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Table 1

Coding category definitions

TSC concept	Definition of Communication Behavior	Example
Asking	Intended to gather information: <ul style="list-style-type: none"> Closed, open, or embedded question 	MD to Mom of school age boy: So how did he do over the weekend? Mom of adolescent girl to MD: Are there different levels of Remicaid or are there different doses?
Listening	Indicates one participant heard what the other said: <ul style="list-style-type: none"> Reflective statement or restatement or formulation Utterance demonstrating listening, Non-verbal behavior indicating listening Bracketing (participant signals the others' agenda is recognized, but "put on hold") Interruption/Talking over the other's next statement (demonstrating not listening) 	NP to Mom of school age girl: Ok, that's what I wanted to hear. Mom of adolescent girl to MD: That sounds like...I like that idea a lot.
Explaining	Intended to give information: <ul style="list-style-type: none"> Solicited answers or response to questions Unsolicited informational statement about child's care 	Mom of school age boy to MD: Actually, his appointment was supposed to be next week, but I brought him in early because he's having a lot of pain... MD to Mom of adolescent boy: But the big difference is the shot, and it's once a week.
Advocating	Intended to recommend or support a particular care practice (e.g. treatment, referral, plan): <ul style="list-style-type: none"> Declarative statements or questions 	(Regarding increasing medication dose) Dad of school age boy to MD: I would like to give it another month, myself. MD to Mom of adolescent girl: Let's start it now instead of waiting for something to happen and then we are sort of chasing our tails. Mom of school age girl to NP: Yeah, if she's still going to use prednisone, we want pills.
Verbalizing Understanding	Intended to demonstrate understanding of the other's utterance: <ul style="list-style-type: none"> Direct acknowledgement of understanding Restatement/formulation Response indirectly indicating understanding Non-verbal indicating understanding 	Mom of school age boy to MD: So pretty much, what it's going to do, it's going to do in three months, correct? MD to Mom: Exactly. Mom of school age girl to MD: Right. Okay. So keep her on the Pentasa, do the methotrexate, just to see what happens.
Negotiating Roles	Intended to clarify or advocate who will do particular care activities for child: <ul style="list-style-type: none"> Question of Roles Declarative statement about Roles 	RN to Mom of school age boy: So do you want me to do the TB skin test? Or are you going to go to his physician? MD to Mom of adolescent girl: So we can either do them here in the clinic if you want...or I'll give you a slip for (you) to do it soon. Mom of school age boy to MD: Now, should I send (this school note) back to (child's pediatrician) or can you sign?

Table 2

Comparison of parent and provider team member communication behaviors.

	Parent (%)	Provider (%)	Total (%)
Asking	1,033 (18.48)	1,549 (23.45)	2,582 (21.17)
Listening	718 (12.85)	405 (6.13)	1,123 (9.20)
Explaining	2,320 (41.51)	3,480 (52.69)	5,800 (47.56)
Advocating	55 (0.98)	71 (1.07)	126 (1.03)
Verbalizing understanding	1,412 (25.26)	921 (13.94)	2,333 (19.13)
Negotiating roles	51 (0.91)	179 (2.71)	230 (1.89)
Total	5,589 (45.83)	6,605 (54.16)	12,194 (100)

Table 3

Frequency of coded utterances for each provider team member discipline

	MD (%)	NP (%)	RN (%)
Asking	1,199 (23.82)	173 (27.20)	177(18.93)
Listening	329 (6.54)	24 (3.77)	52 (5.56)
Explaining	2,679 (53.22)	274 (43.08)	527 (56.36)
Advocating	62 (1.23)	7 (1.10)	2 (0.21)
Verbalizing understanding	652 (12.95)	154 (24.21)	115 (12.30)
Negotiating roles	113 (2.24)	4 (0.63)	62 (6.63)
Total	5,034 (100)	636 (100)	935 (100)