RESEARCH ARTICLE

# When Differing Perspectives Between Health Care Providers and Parents Lead to "Communication Crises": A Conceptual Framework to Support Prevention and Navigation in the Pediatric Hospital Setting

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ABSTRACT

**OBJECTIVES:** The communication experience and therapeutic relationships between parents and health care providers (HCPs) impacts the quality of patient care. A guiding "communication crisis" description was created to encourage study participants to describe difficult communication encounters between parents and HCPs where their perspectives regarding the recommended patient care conflicted (ie, parent refusal of a lumbar puncture), which created barriers to the provision of optimal care and the development of therapeutic relationships in the pediatric hospital setting. The purpose of this research was to highlight factors that may contribute to communication crises through the characterization of these circumstances.

**METHODS:** Participants were multidisciplinary HCPs and parents ($n = 37$) with firsthand experience regarding communication crises. Data were collected through focus groups (7), semistructured interviews (2), and a verification focus group where open-ended questions regarding participants' experiences were used. Data were analyzed by using a constructivist grounded theory approach.

**RESULTS:** Three themes and 11 subthemes (communication crisis risk factors) were identified: (1) health care team factors (communication skills, care processes, and interprofessional communication), (2) family and/or parent factors (language or cultural barriers, mental health conditions, socioeconomic factors, and beliefs), (3) patient factors (acute condition, unclear diagnosis, unstable condition, and medical complexity). A core theory emerged: parent trust in their HCP significantly impacts the therapeutic relationship and can mitigate communication crises despite the presence of risk factors.

**CONCLUSIONS:** We highlight factors that may be predisposing to communication crises in pediatric hospital settings. Awareness of these factors can support timely identification and implementation of relationship care and foster the establishment of trusting relationships.

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Drs Barnard, Sandhu, and Cooke conceptualized the study design, created the data collection instruments (focus group and semistructured interview guide), collected and analyzed the study data as well as contributed to all stages of manuscript development and review; and all authors approved the final manuscript as submitted.

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Communication forms the foundation of the physician-patient-family relationship.[1] Optimal communication between parents and health care providers (HCPs) has the potential to improve patient safety and the care experience and to reduce malpractice risk for HCPs.[2] Unfavorable communication experiences can have deleterious effects on patients and families and threaten the therapeutic relationship.[3–5] Communication in pediatrics is unique because of the nature of the physician-parent-child triad.[6] Parents are typically their child's primary advocate, communicator, and decision-maker. Hospitalization of a child may therefore be an understandably stressful experience that evokes strong parental emotions as they support their child through potentially unfamiliar and anxiety provoking experiences. Breuner and Moreno[7] published a literature review regarding difficult encounters and highlighted that pediatricians have unique challenges when providing care in such situations and recommend further research regarding difficult encounters in the pediatric setting. D'Eon[8] highlights the importance of considering difficult discussions as seriously as an invasive procedure and striving to move the art and craft of communication in medicine to a higher level.

The literature commonly refers to "difficult conversations"[9–12] (ie, delivering bad news). However, difficult conversations of a distinct nature that we refer to as "communication crises" have not been specifically characterized. To develop an understanding of communication crises and distinguish these situations from other difficult conversations, an investigator-designed description was created. For the purposes of this research, participants were guided to describe communication crises as difficult communication encounters where conflict regarding recommended patient care existed between a parent and HCP that (1) created barriers to the provision of safe and timely patient care and (2) resulted in a negatively impacted therapeutic relationship between the parent and HCP in the pediatric hospital setting (ie, an emotional parent preventing vital signs monitoring to allow their child to sleep). Not all difficult communication encounters or differing care perspectives between parents and HCPs result in crises. The purpose of this research was to identify factors emerging from the descriptions of difficult communication encounters that were experienced as crises by parents and multidisciplinary HCPs. The identification of these factors can help HCPs understand why communication crises occur and provide a framework to develop preventative and therapeutic relationship care and communication strategies.

## METHODS

This qualitative study was conducted by using a constructivist grounded theory approach.[13–15] The basic premise of constructivism is that lived reality is constructed by social actors: it seeks to understand the complex world of lived experience through the point of view of the individuals who live in it.[14] Line-by-line coding, memoing, and constant comparison were used to analyze the transcripts to understand participants' experiences.[15–17] This study was approved by the local health research ethics board.

### Participants and Setting

The study was conducted at an academic, tertiary care pediatric hospital that provides care in all major disciplines to >90 000 patients each year.

Purposive sampling was used to recruit participants representing key team members who advocate and care for patients in the pediatric hospital setting (Table 1). Potential participants were identified through the institution's family advisory network and HCP e-mail distribution lists. A letter of invitation including the guiding description of communication crises was e-mailed to all potential participants to invite the participation of those who received or provided hospital-based care at the institution of study and felt they had firsthand experience with communication crises. Within this study, the title or role of parent included biological parents and legal guardians or caregivers of patients.

### Data Collection

A focus group (FG) and semistructured interview (SSI) guide (Supplemental Information) was developed by research team members, consisting of open-ended questions aiming to explore participants' experiences. After review of the first FG transcript, 2 questions were reworded to enhance clarity.

Eight FGs (7 core and 1 verification FG) and 2 SSIs were conducted between September 2014 and May 2016. Informed consent was obtained from all participants. Participation was voluntary and participants could withdraw from the study at any point before or during FGs and/or SSIs. The core FGs and SSIs were audiotaped, transcribed, and anonymized by an independent transcriptionist. The verification FG was not audiotaped as requested by 1 participant (field notes were taken instead).

**TABLE 1** FG Participants by Team Member Role

| FG No. and Team Member Role Representation | No. Participants |
|---|---|
| 1. Administrative leaders (including department, section and/or division, and site-level leadership team members) | 5 |
| 2. Nursing leaders (including nurse educators, unit, and patient care managers) | 4 |
| 3. Social workers (providing care in multidisciplinary clinical areas) | 4 |
| 4. Multidisciplinary pediatricians (including subspecialty and general pediatricians) | 5 |
| 5. Parents | 4 |
| 6. General hospital-based pediatricians | 5 |
| 7. Bedside nurses (providing care on inpatient units) | 2 |
| 8. Verification (including social work, nursing, general, and subspecialty pediatrician perspectives) | 6 |
| SSIs (parents) | 2 |
| Total No. participants | 37 |

The core FGs and SSIs were conducted by research assistants. After core FG data analysis, a verification FG was conducted by the research team with a mixture of participant roles. During the verification FG, the emerging themes and core theory were presented to ensure the developing theoretical constructs validated participants' experiences. After the verification FG, 2 SSIs were conducted with parents of medically complex children to ensure their perspectives were represented within the emerging themes and theoretical constructs.

### Data Analysis

All research team members conducted data analysis by employing common coding and grounded theory techniques.[15–17] Data collection and analysis continued iteratively until theoretical saturation occurred. Theoretical saturation occurs when (1) no new or relevant data emerge regarding a theme, (2) the themes are well developed in terms of their properties and dimensions and demonstrated variation, and (3) the relationships among themes are well established and validated.[16–18]

To ensure a comprehensive coding structure, the first 2 transcripts were independently analyzed by research team members using open coding and line-by-line analysis. The coding scheme was discussed as a team, and an initial inventory of codes was agreed on through a consensus approach. QSR International's Nvivo 7 software was used to aid in code cataloguing and data organization.

To identify emerging themes, open-coding concepts were reorganized into broader, mutually exclusive categories. Subsequently, the themes and their context were examined to understand their nature and relationships to support theoretical integration and emergence of the core theory.[16] The core theory represents a central theme in which all other concepts or themes relate to. The core theory must be (1) abstract, (2) appearing frequently in the data, (3) logical and consistent with the data, (4) sufficiently abstract to allow its use for research in other substantive areas, and (5) able to grow in depth and explanatory power as other themes are related to it through statements of relationship.[16] After thematic categorization, analysis shifted from categorical to conceptual to allow the core theory and foundational link between the thematic categories to emerge.[17] Through analysis at the conceptual level, exploration of a potential relationship among the identified themes occurred via an overarching question: Does a central theme exist that embodies a common denominator that is at the heart of what is truly happening during communication crises amid all the themes represented within the data?

The coding scheme, emerging themes, thematic relationships, and the core theory were refined in an iterative manner and established through discussion and consensus by all research team members. After the verification FG, 2 theme descriptors were modified to ensure optimal description.

### Qualitative Rigor

Ensuring the validity and reliability of qualitative research is imperative.[15–17,19,20] Steps to support the validity of this research included (1) purposive sampling and the use of a guiding communication crisis description to ensure participants with relevant experiences participated, (2) ensuring that emerging themes remained rooted in participants' narrative, (3) review of initial transcripts to allow refinement of the FG and/or SSI questions to facilitate relevant data collection, (4) ongoing review of the communication and difficult conversations literature to understand its potential relationship to the data, and (5) deliberate identification, discussion, and unpacking of potential research team member biases. Efforts to increase reliability included the following: (1) all research team members contributed to the creation of the coding system as well as the iterative and consensus driven process of theme, theory, and construct development and (2) a verification FG was held to "member check" and assess whether emerging themes, theory, and constructs resonated with a mixed group of participants.

## RESULTS

Thirty-seven participants attended 1 of 8 FGs ($n = 35$) or an SSI ($n = 2$) (Table 1). The HCP participants who provided demographic information ($n = 23$) reported a range of pediatric clinical practice duration (range 6–30 years, mean 18 years). The majority (85%) of all participants who provided demographic information ($n = 27$) were women and all reported having firsthand communication crises experiences. All parents stated that their child had been hospitalized on >2 occasions with 4 out of 6 (67%) having experienced hospitalization for >2 weeks in duration.

Parent trust in HCPs was identified as the core theory on the basis of its emergence as the theme that truly underpins communication crises and links all themes impacting these situations. This linkage and underpinning became evident by the theme's presence throughout the data as the overriding factor (a parent's level of trust in their HCP) that ultimately impacts whether a communication crisis occurs despite the influence of other factors within each circumstance. In addition to the core theory, 3 main themes and 11 associated subthemes (risk factors) were identified that characterize communication crises and highlight circumstances in which the risk of crisis may be heightened in the pediatric hospital setting (Table 2):

1. Patient factors were represented within 4 subthemes whereby a patient's clinical status or medical condition(s) as the recipient of care rather than a participant in the communication experience were described:
   (a) Acute condition: patients with medical conditions that were severe or sudden in onset, requiring urgent management or a change in management;
   (b) Unclear diagnosis: situations in which the medical diagnosis(es) or issue(s) that resulted in hospitalization remained unknown;

**TABLE 2** Quotes Representing the Core Theory, Themes, and Subthemes (Factors) Emerging From Descriptions of Communication Crises in the Pediatric Hospital Setting

| | Quote |
|---|---|
| Communication crises core theory: Parent Trust in HCP(s) | |
| | "When families have a deep sense of mistrust for the system, it's a piece that's very difficult to figure out how to bridge so that you can move forward… 1 of these underlying things that leads us into crisis more often, if not inevitably…" FG 1 |
| | "If you feel a level of trust, between you and the health care provider and they care about my child who I care about, you've got a mutual goal." FG 5 |
| | "They want to have a positive outcome for their child but try dictating the next steps because they don't trust… so just getting them to comply, believe and trust that what you're doing is in their best interest, sometimes gets very difficult." FG 2 |
| | "Some families tend to be more hesitant with anything that's presented to them, it just depends on their entry into health care and what their experiences have been." FG 2 |
| | "There's certain cultures that do not trust what happens within this system." FG 2 |
| | "So as long as there's that trust level, sometimes you're okay to wait but if there isn't that communication and connection, then you're not okay to wait… You just feel taken advantage of." FG 5 |
| Communication crises themes and subthemes (factors) | |
| 1. Patient factors | |
| a. Acute condition | "…the acuity of the child certainly ups the ante… it's much quicker to get to crisis because you have to act and do what's right for the child, so it limits the time that you can spend to figure out how to come to a common ground." FG 1 |
| b. Unclear diagnosis | "There was really no answer for what had caused the original infection that had brought him to hospital, so it created frustrations for the family…" FG 7 |
| c. Unstable condition | "If there's not great communication and the child's clinical situation changes rapidly, it can be a challenge because you're not only trying to address what hasn't been going well but then it's in the context of a change in the child's medical condition." FG 1 |
| d. Medical complexity | "When you are continually involved with a patient that is long-term and you see the different teams turning over and, you know, people don't listen to you when you say… well, we've tried this in the past." FG 5 |
| 2. Health care team factors | |
| e. Communication skills | "It's not just what you say but it's how you present it… are you halfway out the door when you're having a conversation or are you coming in and taking the time to sit down and say 'I have time for you?'" FG 2 |
| f. Care processes | "We work 8-hour shifts, so parents could get different messages from staff every 8 hours." FG 7 |
| g. Interprofessional communication | "I think there were unintended consequences of different specialists saying something the same way but using different words." FG 1 |
| 3. Family factors | |
| h. Language and cultural barriers | "English was not her first language and she would only communicate via the child's father so we were never sure that what the father was saying was actually what the mother was saying." FG 1 |
| i. Socioeconomic factors | "There's always a back story and sometimes it's a very acute kind of crisis for a family outside of this (hospitalization) such as loss of a job, a marriage breakup, besides the ill child." FG 1 |
| j. Mental health conditions | "If the cause for the family's inability to move forward is from mental illness, I find that especially frustrating because often there's not much that we can do about it as pediatricians." FG 6 |
| k. Beliefs | "They were very religious and had already decided very clearly that no matter what their child was like, they wanted to do everything." FG 4 |

(c) Unstable condition: circumstances in which the patient's medical status was fluctuating or had unexpectedly deteriorated; and
(d) Medical complexity: scenarios in which patients had chronic and/or complex medical conditions that resulted in stresses related to parental advocacy, prolonged and/or multiple hospitalizations, and ongoing contact with and reliance on the health care system.

2. Health care team factors were represented within 3 subthemes. The themes highlight the impact of how HCPs communicate with families as individuals, as teams, and with each other. Furthermore, this theme emphasizes the impact of health care system processes on communication and relationships between HCPs and parents.

Specifically, communication crises were described in association with the following:

(e) Communication skills: the manner and style in which individual HCPs shared information with a parent (ie, verbal and body language as well as clarity, timing, and consistency of messaging);

(f) Care processes: the potentially unfamiliar, stress-provoking, and complex nature of care processes existing within hospital settings such as safety measures and policies (ie, intravenous site assessments) and system structures such as shift or team changes and medical team member hierarchies (ie, attending and trainee physicians); and

(g) Interprofessional communication: the way HCPs communicated information with each other (or failed to do so) and how the delivery of varying or lacking information impacted families.

3. Family or caregiver factors were described within 4 subthemes. These themes collectively illustrate and focus on family circumstances, backgrounds, and previous experiences that influence communication experiences and therapeutic relationships between HCPs and parents. Communication crises were described in association with the following:

(h) Language and cultural barriers: when spoken or understood language differed between parents and HCPs or when family culturally based practices, decisions, or behaviors were not recognized or understood by HCPs. Obstructions or gaps in effective communication and therapeutic relationship development occurred when these factors were not appropriately identified or addressed;

(i) Socioeconomic factors: the impacts of circumstances existing outside of the child's illness and/or hospitalization such as loss of parent employment, low family income, parental relationship instability, and lack of family supports;

(j) Mental health conditions: the impacts of parent mental health status (as perceived or known by HCPs) such as depression, anxiety, posttraumatic stress disorder, personality disorders, etc on communication and therapeutic relationship development as well as HCP perceptions of parent coping, advocacy, and decision-making abilities; and

(k) Beliefs: the convictions held by individuals (ie, regarding religion, health care practices, etc) and how they impacted communication and decision-making, especially when parent and HCP beliefs differed.

The specific situations and conflicts underpinning the perceived communication crises described by participants varied in nature. Examples of these conflicts are provided to create additional context regarding communication crises, the factors, and the core theory (Table 3).

## DISCUSSION

In this research, we characterized communication crises in the pediatric hospital setting through a description of factors that may contribute to these conflictual communication encounters between parents and HCPs. The overarching significance of parent trust in HCPs emerged as the core theory. Trust ties the identified themes together and appears to mitigate communication crises regardless of the existing risk factors.

Breuner and Moreno[7] describe patient, parent, physician, and health care system factors implicated in difficult patient-parent encounters in their literature review. Patient factors were identified with patients being the primary communicators; thus, patient behaviors are described as factors within difficult encounters. Alternatively, in our research, parents represent the primary communicators in the encounters, allowing patient clinical status to emerge as a factor. Breuner and Moreno[7] describe physician factors in the context of their personalities, professional experience, and cultural behaviors or practices, whereas we describe behaviors and personal attributes within the global context of HCP communication skills and how they impact the overall health care system and delivery of care.

An abundance of literature exists regarding the importance of trust across many disciplines including medicine.[21] Trust

**TABLE 3** Examples of Communication Crises Experienced by Parents and HCPs

- Parent refusal of care recommended by HCPs (ie, processes of care, treatments, procedures, taking the child home, or leaving hospital against medical advice)
- Parent medico-legal threat or action against HCPs
- Parent perception or witnessing of repeated trauma, discomfort, pain inflicted on their child as part of care (ie, fasting, multiple intravenous line insertion, or phlebotomy attempts, etc)
- Parent perception or witnessing of unrelenting or inadequately treated discomfort, pain, or symptoms experienced by their child due to medical issues and/or disease
- Differing expectations of processes and/or outcomes of care between parent and HCP
- Parent threats or action to involve the media regarding dissatisfaction with HCPs or patient care
- Parent seeking, valuing, and adhering to alternative opinions regarding patient care (ie, preference of or belief in the opinion or recommendation of a family member, friend, alternative HCP, the Internet, etc)
- Interruption or lack of support regarding physiologic and emotional needs of parents (ie, exhaustion, physical separation from family members, lack of proper nourishment, etc)
- Parental feelings of abandonment, loss of control or hope due to lack of clarity and assurance regarding a plan moving forward as a team
- Perceived parent display of aggressive behaviors such as yelling, swearing and physical threats
- Parent demand of therapies, tests or procedures that were not recommended (ie, perceived to be harmful or unnecessary by HCP)
- Parental perception that their knowledge and expertise of their child was disregarded or disrespected by HCP
- HCP's lack of ability to truly listen to and validate parent's input or concerns with an open mind
- HCP's lack of humility or ability to apologize during times of uncertainty or when an error occurred

is a complicated and multidimensional construct that is central to the patient-physician relationship, yet difficult to study and measure.[22,23] Changes in the health care system and societal views about health care have placed great pressure on the trusting relationship between patients and HCPs.[23–26] The health care system is no longer the primary gatekeeper or source of health information, with information easily accessible via media and the Internet.[27]

Inherent aspects of pediatric hospital–based care could add complexities to the existence of parent trust in HCPs, such as: (1) parents are typically the gatekeepers of trust and the providers of consent and support for their child through the potentially unfamiliar and distressing care processes of hospitalization; (2) with advancements in preventative and ambulatory care, hospitalizations typically occur for the most acutely unwell and complex patients, potentially enhancing parental distress (ie, fear) in this environment; and (3) HCP typically differ between outpatient and inpatient settings. New or transient HCP who are less likely to have established, trusting relationships with families provide care during the stressful experience of hospitalization. These characteristics of pediatric hospital medicine highlight opportunities to develop specific relationship care strategies in this patient care setting.

Now more than ever, parent trust in HCPs is less likely to be unconditional and more likely to be earned. Earning parent trust through the provision of optimal medical and relationship care occurs simultaneously because these aspects of care are intimately intertwined. Relationship-centered care is an important framework for conceptualizing health care, recognizing that the nature and the quality of relationships are central to health care and the broader health care delivery system.[28] The relationship-centered care model views the relationship as the medium of care and focuses on the central role of all relationships in the delivery and outcomes of care,[29] thus providing a pertinent foundation and approach to achieving and supporting trusting relationships within the pediatric hospital setting.

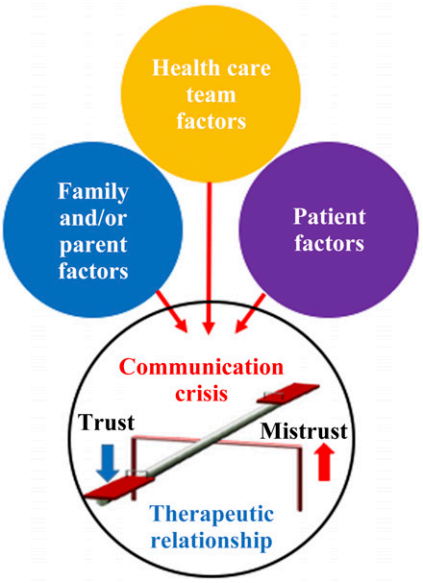


**FIGURE 1** The overarching influence of parental trust in their HCPs on the therapeutic relationship.

Trust in relation to the communication crises factors described in this study can be conceptualized as a teeter-totter (Fig 1), where its position symbolizes the degree of parent trust in HCPs. The teeter-totter's position is likely impacted by the communication crises factors at play in each circumstance, but the teeter-totter's resting position (degree of trust versus mistrust) may occur somewhat independently from the global influence of the factors. The overarching impact of 1 factor (ie, a belief) may cause the teeter-totter to tip into a position of trust or mistrust regardless of the presence (or absence) of other factors. For example, in the circumstance of a non-English speaking family whose child's medical diagnosis is unknown with multiple unfamiliar HCPs providing care, one might predict a communication crisis. However, if the parent trusts their HCP (ie, because of a religious belief) despite the presence of multiple communication crises risk factors, the therapeutic relationship may be protected from crisis purely by the existence of inherent trust.

We acknowledge limitations within this research. The data provide participants' perspectives regarding communication crises that are self-reported, personal experiences. The personal perceptions of crisis described within this research inevitably create some variability in the degree of crisis within these experiences (ie, a crisis to 1 person may not have been a crisis to another). The communication crisis guiding description was provided to create clarity and focus discussions on encounters that participants experienced as crises in contrast to other difficult conversations (ie, disclosing an error).

The aim was to have ~6 participants in each FG, with balanced representation of care team members including parents and multidisciplinary HCPs across FGs. Fewer than 6 participants in the core FGs prompted additional FGs for some participant groups (ie, general or subspecialty pediatricians) and 2 SSIs for parents to ensure thematic saturation and full team member representation. Research specifically exploring parent communication crises experiences could provide deeper insight and elevate this highly relevant team member perspective.

This research was limited to the characterization of communication crises within the investigators' guiding description at a single center. Future research including additional pediatric centers and environments (ie, ambulatory care), patient populations (ie, adults) potentially with additional guiding descriptors of communication crises could enhance this research.

## CONCLUSIONS

Advocacy is crucial, but when 2 important advocates (ie, a parent and HCP) have differing opinions resulting in conflict, a child may suffer when care becomes obstructed. Especially in the hospital setting, where timeliness of care can be critical, prevention and optimal navigation of these conflicts is vital. Through this research, a deeper understanding of communication crises in the pediatric hospital setting was achieved. The identified factors create a framework that can enhance situational awareness regarding

the potential risk of a communication crisis occurring, thus facilitating the timely implementation of factor-specific relationship care. We emphasize that trust is at the heart of therapeutic relationships. This can hopefully encourage HCPs to navigate communication crises with curiosity regarding why trust may have eroded or not exist in these circumstances. The authors suggest future research be aimed at the evaluation of the impact of early factor identification and implementation of factor-focused, relationship-centered care on mitigation and prevention of communication crisis.

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