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Communication Gaps Between Providers and Caregivers of Patients in a Pediatric Emergency Department

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Abstract

Communication gaps between the healthcare team and caregivers of pediatric patients can result in negative consequences. This study aims to identify specific words and phrases used in a pediatric emergency department (ED) that are unclear or confusing to caregivers. Research assistants at the Primary Children's Hospital recorded caregivers' responses to the question, "*What words or phrases have been used during this visit that are unclear or don't make sense to you?*" Across all steps in the care process, 62 of 220 participants (28.2%) reported unclear words and phrases used by the healthcare team. Responses recorded after the discharge step had the highest proportion of communication problems, followed by the initial evaluation and then the update step (χ^2 [2, $N = 220$] = 6.30, $P = .043$). Themes among responses included ED logistics, signs/symptoms, the diagnostic process, treatment/procedures, general confusion, and language barriers. These results provide feedback to pediatric emergency medicine providers about potential communication gaps and point to a need for further efforts to train providers in the practice of high-quality communication.

Keywords

communication, health literacy, language barrier

Introduction

Effective communication is fundamental to high-quality, patient-centered care. The ability of providers to communicate effectively with patients can impact not only patient satisfaction with the visit, but also patient willingness to follow medical advice, share information that may be relevant to a diagnosis, and adhere to treatment plans.(1–5) Furthermore, there is a relationship between patient-provider communication and health outcomes.(5) In the emergency department (ED) setting, higher patient satisfaction scores are more dependent on provider–patient communication than wait times or any other variables.(4, 6)

Studies suggest that patients are often dissatisfied with their provider's communication, while the providers overestimate their own ability to clearly communicate with patients.(7, 8) Factors that may make communication difficult for providers include the rushed environment of the ED, language barriers, and caregiver anxiety.(9) The uniquely rushed environment of the ED might contribute to physicians aiming to maximize efficiency in their interactions with families. Another unique aspect of communication in the pediatric setting is the triad of doctor-parent–child communication rather than a simple dyad of patient–doctor communication.(10) Communication challenges may also be related to low health literacy levels in the population and providers' limited abilities to estimate the health literacy of their patients. Studies have shown that more than one quarter of Americans have low health literacy and physicians overestimate the health literacy of 34% of adult patients.(11, 12) This project aimed to identify words and phrases used by

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healthcare providers in a pediatric ED that were not well understood by caregivers (parents, other family members, or legal guardians) of pediatric patients. It was predicted that language barriers and medical jargon would contribute to miscommunications, especially toward the beginning of the visit.

Materials and Methods

This qualitative, cross-sectional survey investigates the gaps in communication between the healthcare team and caregivers of pediatric patients in a pediatric ED. The study was conducted at the Primary Children's Hospital, which is a teaching hospital and level 1 trauma center in Salt Lake City, UT. The study was conducted in the ED, where the healthcare team includes nursing staff, child life specialists, social workers, research assistants, medical students, residents, fellows, and attendings, with consulting teams from other areas and facilities. University of Utah research assistants at Primary Children's Hospital collected survey responses from 220 participants who were recruited during their visit to the ED between the hours of 6 am to 1 am, Monday to Sunday. Participants were included if they spoke English or Spanish. Trauma 1 and trauma 2 patients were excluded to limit undue burden, as well as any participants that the research assistants did not feel it would be appropriate to approach during their visit. Some examples included cases involving law enforcement, families that refused other research participation during that visit, and families that physicians noted were too distressed to approach for research. Participation was voluntary and without compensation. This study aim is associated with a larger study of health literacy and was given an exemption status from the University of Utah and Primary Children's Hospital Institutional Review Boards (IRBs).

The following survey question was verbally asked to participants by the research assistants in the ED or using a hospital interpreter, *"Healthcare providers often use words or phrases that are unclear or don't make sense to patients and their families. What words or phrases have been used during this visit that are unclear or don't make sense to you?"* The research assistants wrote the participants' responses on hard copy surveys, including the step in the care process after which the survey question was asked (initial evaluation, update, or discharge teaching). The step in the care process was determined through consultation with ED providers. These written survey responses were then transcribed into a secure REDCap database.

A chi-squared test was used to determine if there were differences in the frequency of unclear communication compared to clear communication at each step in the care process (initial evaluation, update, or discharge teaching).

Among the responses that identified a word or phrase that was unclear to the participant, themes were identified independently by three research assistants with qualitative analysis training and then combined into a single thematic analysis. These three research assistants worked independently of one another to identify the themes and categorized the responses. To increase validity, the surveys and survey process were debriefed at least once per month, during which the study team discussed study progress, issues, or inconsistencies in the data collection process. To increase reliability, multiple research assistants cross-checked the data and themes, so all of the responses were coded by more than one research assistant and researchers reviewed each set of coding to identify and discuss discrepancies.

Results

Of the 220 survey responses collected, 63 took place after the initial patient evaluation, 114 took place after an update was given during the visit, and 43 took place after the final discharge teaching was completed (Figure 1). Across all steps in the care process, 62 of 220 participants (28.2%) reported unclear words and phrases used by the healthcare team. Responses recorded after the discharge step had the highest proportion of communication problems, followed by the initial evaluation and then the update step (χ^2 [2, $N = 220$] $= 6.30$, $P = .043$, see Figure 1).

The responses to the survey question, "what words or phrases have been used during this visit that are unclear or don't make sense to you?" include themes related to ED logistics, treatment plans/procedures, diagnostic process/information, research, language barriers, and general confusion. Each participant's response contributes to one of these themes and none were excluded.

Signs/Symptoms and Diagnostic Processes

Participants often reported confusion about the words and phrases used to describe the signs and symptoms during their initial evaluation. For example, words such as "polydipsia," "polyuria," "mottled," "tachycardia," and "post-ictal" were not understood by participants. As diagnoses were discussed, confusion also arose. Responses were sometimes vague, such as "names of diagnoses were confusing" and "kidney problems." Some responses were more specific, such as "diabetes" and "adenovirus."

Throughout the diagnostic process, there was confusion about both the specific names of laboratory tests, such as "liver enzymes" and the general reference to laboratory testing. Multiple participants were confused by the use of the word "labs" or "PCR lab." This category of responses also included multiple references to moments where providers used simpler, lay terms instead of technical terms, but those words were also confusing to the participant. For example, more than one response included the word "pictures," likely describing diagnostic radiology, and one participant stated, "[they] tried to dumb it down, got confusing, kept saying 'pictures' but I think they meant x-ray." Similarly, a participant responded "what does 'stomach full of stuff' mean?"

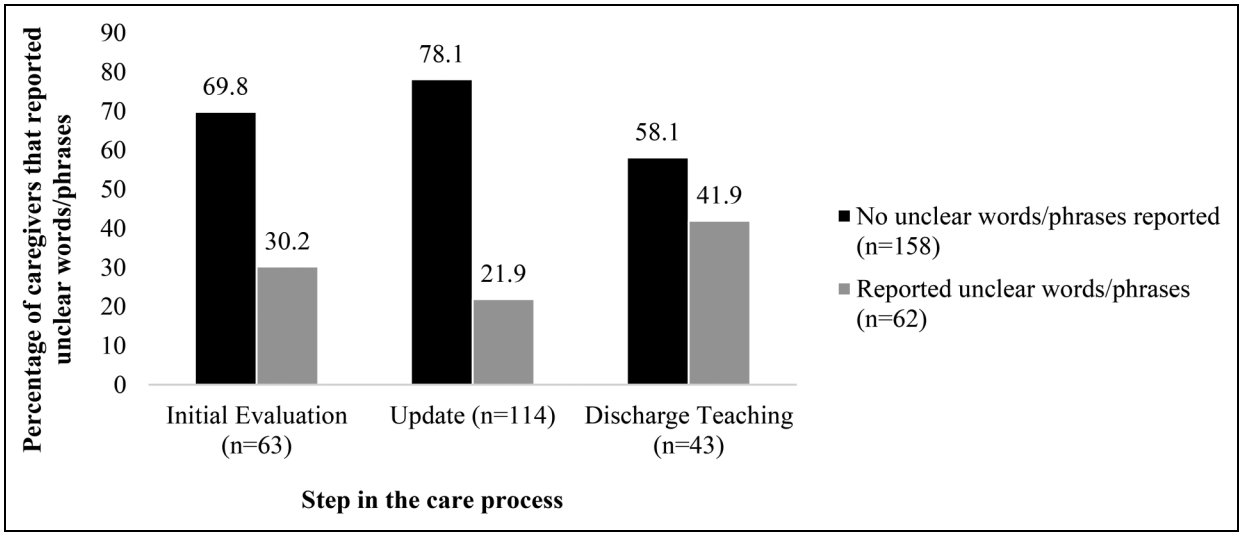

Figure 1. Frequency of miscommunications reported by caregivers.

Treatment/Procedures

Some participants reported that words and phrases related to the patient's treatment plan or procedures were confusing or unclear, such as "NPO," "hemolysis," and "[fracture] reduction." Communication gaps related to medications can also be included in the treatment category. Many participants did not understand either the names of medications, the instructions for use of the medication, or the purpose of a medication. This confusion was most commonly reported after a provider update and after discharge teaching. For example, the phrase "titrate the MiraLAX" was unclear to a participant after they received discharge instructions. Similarly, a participant responded, "they taught her how to use the inhaler, but didn't tell her what was in it. What is a steroid?"

Logistical

Some participants reported unclear communication from the healthcare team regarding the logistics of their visit to the ED. These logistical issues included where they would be taken, who would be involved in the visit, what they needed to do after leaving the ED (follow-up instructions), the reason the provider made a certain decision, and the timing of each step in the process. For example, multiple participants reported confusion about the timeline for cases involving a social worker and reported unclear language and a lack of communication about the steps for a behavioral or mental health emergency. Other responses captured confusion about the roles/titles of each member of the care team. An example of a negative consequence from a logistical communication gap is a 30-minute delay in discharge due to a participant not understanding the phrase "PO challenge," referring to the requirement that the patient must be able to eat or drink without other symptoms such as vomiting or pain before they can be discharged from the ED. Another common communication gap that was most often reported after discharge teaching involved the term "follow-up," which was confusing to multiple participants. Some participants also expressed confusion about patients being "admitted" to the hospital.

Some participants responded with complaints that were not necessarily about a word or phrase that was unclear, but still identifies a potential gap in communication about the process of being seen in the ED. For example, some asked "why it took so long." Another stated, "this was just a visit with social work and I don't understand why vitals and checkup were performed by doctor if they weren't going to explain why they did that or if any part of it was abnormal."

At the Primary Children's Hospital, there are many research projects that patients are involved in, especially in the ED, and one participant reported confusion about the "forearm study," which is likely in reference to a clinical research study taking place in the ED. This response indicates minimal but still present confusion about research as part of a visit to the ED.

General Confusion

Across all steps in the care process, some participants described feeling generally confused or displeased with the communication instead of responding with a particular word or phrase that was unclear or confusing. Some participants, "had problems understanding big words," "did not understand anything that was said," or "had to ask for better explanations." One specifically reported that they "didn't understand what they were asking in the evaluation." Another stated, "some of their questions were confusing and hard to answer, I had to repeat myself a few times and I'm worried my concerns aren't coming through clearly." A participant also responded, "[they] talked to me and my 18-year-old like we were little kids," which potentially

identifies oversimplification as a communication issue as well as using too much medical jargon.

Language Barrier

While participants were not asked to suggest the causes of their confusion or explain why they did not understand a word/phrase, some identified a language barrier as the reason for a communication gap. One participant said they, "would have understand better with an interpreter," and another explained that they used a family member to interpret but would have been less confused if they had used a hospital interpreter.

Discussion

This study identified communication gaps across multiple themes and time points in a pediatric ED visit. One primary finding of this study is that the highest percentage of reported gaps in communication was seen after discharge teaching, rather than after the initial evaluation or update. This result suggests that many caregivers leave the ED without resolving their confusion, which is consistent with a study of parent understanding of ED discharge instructions which showed that about 20% of parents do not fully comprehend diagnostic or treatment directives at discharge.(13) Other studies of adult patients have demonstrated similar findings with higher percentages of misunderstandings about their ED visit and discharge instructions.(14, 15)

Another important finding is the specific words and phrases related to signs/symptoms, diagnosis, and treatment that were confusing to caregivers. The use of technical language by providers that is not understood by patients has been mentioned in the literature, as has parent satisfaction in the pediatric ED related to communication, but a study of specific words and phrases that appear to cause confusion has not been published.(6, 7, 16) Identifying these words/phrases could guide quality improvement efforts, such as standardized education materials aimed at minimizing communication gaps. However, standardized education must be accompanied by verbal explanations/instructions and could result in further confusion if the information is not individualized.(17)

Additionally, the use of oversimplified language that caused confusion for some participants has also not previously been identified in the literature. This language may be unclear due to lack of precision or specificity in the context of the conversation with the caregiver. These particular types of communication gaps are important to identify because they could contribute to a breakdown in the provider's relationship with the patient and caregiver due to perceived discrimination based on health literacy or education level. The use of health literacy testing has not been shown to make patients feel discriminated against, so assessment tools such as the Short Assessment of Health Literacy could be administered to patients while they wait to be seen, potentially helping providers identify those patients/caregivers with a higher risk of confusion.(18, 19) With these results in mind, providers are recommended to aim to use both simplified language and more technical language when possible to allow for multiple, varying levels of communication that can be understood by both pediatric patients and diverse caregivers.

The logistical confusion and complaints identified in these results point to this logistical communication theme that is often not emphasized but impacts caregiver perceptions of the level of care provided to their child, as has been shown in other studies.(6, 20) These specific misunderstandings about ED flow can be used to identify key areas where providers need reminders to communicate more thoroughly with patients and caregivers. For example, the common theme of confusion surrounding the logistics of a behavioral/mental health ED visit might be rectified with a standardized communication of expectations either verbally, in a written handout, or another media form such as a short video. Additionally, a global logistics handout or video might inform all ED patients and caregivers of what to expect during their visit, regardless of the complaint that brought them to the ED. Research of using both verbal and written standardized education has shown success in diagnosis-specific instructions, but has not been studied for global logistics.(21) Logistical confusion has not been identified in other studies with these methods or in this setting, but studies of the general lack of parent satisfaction and misunderstandings related to discharge instructions have identified the connection between poor logistical communication and decreased satisfaction with the visit.(5) "Providers frequently forget that what is routine or obvious for them (triage protocols, the priority given to certain medical conditions, the mechanics of administering a particular kind of treatment) is new or unknown to patients and families," described the authors of a 2002 study of pediatric ED communication.(20)

Another important theme in these results is the need for professional interpretation services. The effects of language barriers on communication, outcomes, and utilization have been widely studied in the pediatric ED setting, showing improvements in all of these metrics, especially communication, when professional interpretation services are utilized by ED providers.(22–25) The results of this study add to this preponderance of evidence that supports shifting resource allocation toward ample professional interpretation services that allow for better communication. At this institution, these findings could provide justification for existing funding and expansion of in-person interpretation to be 24/7 in the ED.

Limitations and Future Directions

The small scope of this survey is a limitation of this study, but the ease of administering a short survey allowed for efficient collection of data within the constraints of the ED

environment and study timeline. A more thorough interview of the caregiver, including a demographic survey, information about what is bringing them to the ED, thorough description of any language barriers, follow-up questions, and recorded responses might reveal more information about the potential causes of miscommunications. Additionally, having many different research assistants collecting data limits the reporting consistency. However, the interviews were structured with a script to increase consistency, research assistants recorded the exact phrasing of the participant, and frequent debriefing aimed to catch any obvious variation in the ways responses were recorded. Another limitation is that participants may overestimate their understanding of the words/phrases used during the visit, as has been observed in other studies.(14) If a participant was instead asked to describe in their own words everything said by the healthcare team, more communication gaps may be revealed. However, these limitations were related to the ease of data collection that allowed for a large sample size and data collection every day of the week that spanned all hours except for 1 am to 6 am, which makes these findings more generalizable across time in the ED. Additionally, the language of the survey question used in this study intentionally places the responsibility of a misunderstanding on the provider instead of the participant to contribute to a trusting relationship between the caregiver and the healthcare system.

These communication gaps might be better understood by additionally measuring the health literacy of the participants, the ability of the providers to estimate the health literacy of the participants, and biases (implicit and explicit) held by the providers. Using tools such as the Implicit Associations Test from Harvard University can aid providers in understanding their own biases, although more evidence is needed to understand the impacts of this bias recognition on clinical communication.(26) Determining the relationship between these measures and the frequency, timing, and type of miscommunications in the ED would allow for further interventions to improve clinical communication. It may also be helpful to provide additional training for providers to learn communication strategies such as the teach-back method, which confirms a patient or caregiver's understanding of a concept or instruction by asking them to accurately "teach it back" to the provider.(27) Further study of interventions might assess how checklists and clinical treatment guidelines might be leveraged to improve communication as well. Interventions used in the more thoroughly studied realm of communication between clinical team members might also be adapted for provider–patient/caregiver communication in future studies.(28)

This study identifies some communication gaps in a pediatric ED setting. These results not only provide feedback to pediatric emergency medicine providers about words and phrases that may be unclear to families, but also point to a need for further efforts to train providers in the practice of high-quality communication. Table 1 contains a summary of recommendations.

Table 1. Summary of Recommendations for Improving Communication.

Category	Recommendation
Communication of ED logistics	Provide caregivers and patients with verbal, written, or video recorded information about global (non-disease-specific) logistics in the pediatric ED
Language barriers	Utilize interpretation services whenever applicable to limit gaps in communication
General communication	When possible, ask open-ended questions to identify communication gaps. For example, "what words or phrases have been used that are confusing?"
	Use tools such as the Implicit Associations Test to identify personal biases that might impact communication
	Use the teach-back method to identify gaps in understanding
	Use standardized education materials in addition to verbal explanations/ instructions tailored to the patient
	When available, use tools such as the Short Assessment of Health Literacy to identify caregivers with a higher risk of confusion
	Aim to use both simplified language and more technical language when possible to allow for multiple, varying levels of communication that can be understood by both pediatric patients and diverse caregivers

ED: emergency department.

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Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Ethical Approval

Ethical approval was obtained from the Institutional Review Boards of Primary Children's Hospital and the University of Utah (IRB_129244).

Statement of Human and Animal Rights

All procedures in this study were conducted in accordance with the Institutional Review Boards of Primary Children's Hospital and the University of Utah (IRB_129244) approved protocols.

Statement of Informed Consent

Verbal informed consent was obtained from participants for their anonymized information to be published in this article.

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