Information Sharing by Caregiver Language in Pediatric Serious Illness Care Conferences

Melissa Rose Martos

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Hendrika W Meischke
K Casey Lion

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Abstract

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Melissa Rose Martos

Chair of the Supervisory Committee:
Hendrika W Meischke
Health Systems and Population Health

Background: Children using a language other than English are known to experience poorer medical care, including at end-of-life. Information sharing is essential to achieve optimal communication outcomes, but little is known about effects of caregiver language.

Objective: We explored differences in quantity and complexity of bidirectional information sharing in English and interpreted care conferences for seriously ill children.

Design/Methods: Care conferences for pediatric patients with serious illness from linguistically diverse families at a single institution were audio-recorded, transcribed, and analyzed using content analysis. Provider and caregiver information-sharing statements were characterized as biomedical, logistical, or psychosocial; caregiver categories also included patient wellness and values/goals. Provider communication practices known to impact information sharing were also tabulated. Mann-Whitney-U tests compared median quantity of information shared by conference language.

Results: We analyzed 29 care conferences from 2018-2021, including 11 (39%) professionally interpreted conferences. On average, providers made 156 statements per conference while parents made 71 ($p<.001$). Providers made significantly fewer biomedical statements in interpreted conferences than English ones (117 vs 176, $p=0.01$). Caregivers made a similar number of statements per conference, regardless of language (78 vs 66, $p=.95$). Meanwhile, use of provider practices supporting information sharing, such as gathering information preferences, were rare.

Conclusions: Providers spoke far more than caregivers, and rarely used practices that support information sharing, regardless of language. They also shared significantly fewer biomedical statements in interpreted conferences than English ones. Strategies to reduce disparities in information sharing may support equitable outcomes for patients and families from all language backgrounds.

INTRODUCTION

Patients and families using a language other than English (LOE) are a growing population nationwide[1] representing over 25 million Americans.[2] In pediatric settings, language discordance has been associated with lower patient and caregiver satisfaction,[3,4] including at end-of-life, with caregivers using a language other than English (LOE) for care more likely to report wishes were not honored.[5] Furthermore, patients and families using a LOE are known to experience numerous downstream clinical disparities, including in inpatient adverse events, pain control, serious safety events, and length of stay.[6–13]

Effective communication is critical in medical care, especially for children with serious illnesses. High-quality communication is known to be essential for a number of outcomes, including patient satisfaction, adherence to treatment plans, psychological wellbeing, and quality of life.[14] Prior studies in the pediatric ICU have demonstrated that "communication and care coordination" as well as "honest and complete information" are key priorities at end of life.[5] "Information sharing" is identified by the National Cancer Institute as a core element of communication,[15] and is essential for family empowerment and shared decision-making.[16] Efforts to strengthen communication around serious illness are essential to meeting the informational and emotional needs of patients and families.

Existing literature examining differences in serious illness communication by language are scarce but growing. Historically, those from marginalized racial and ethnic groups have been underrepresented in communication science,[17] and families speaking languages other than English have often been excluded outright from study.[18] Prior studies of communication in serious illness for families using a LOE have demonstrated concerning patterns, including a dearth of interpreter use and inadequate communication across multiple domains, including fewer supportive statements.[19–21] However, few studies have directly measured information sharing, or they have largely examined speech times,[20,21] which may not fully capture nuances in communication differences. Even fewer studies have examined differences specifically in caregiver information sharing, resulting in a critical gap in how information is exchanged and where breakdowns may occur. In order to develop interventions that promote more equitable outcomes, it is important to understand potential differences in bidirectional information sharing. In this study, we examined bidirectional information-sharing in care conferences for caregivers with different language preferences, seeking to describe differences.

METHODS

Design, Participants, and Setting

In this cross-sectional study, we recorded care conferences (structured meetings between multi-disciplinary clinicians and caregivers discussing medical care) of patients with serious illness at a quaternary care pediatric academic hospital between 2018-2021. This study was approved by the Seattle Children's Institutional Review Board and conducted per Standards for Reporting Qualitative Research (SRQR) guidelines.[22]

Details of recruitment and recording procedures are described elsewhere.[23] Briefly, participants included patients of any age with serious illness who had an upcoming care conference planned, their legal guardian(s), as well as the clinicians who attended their care conference. Serious illness was defined as admission to the pediatric ICU, cardiac ICU, neonatal ICU, or to any

inpatient unit with a palliative care consult. Patients were excluded if they did not have a legal guardian or if their clinical team felt their caregivers were too distressed for study participation. Care conferences were identified by unit-based social workers or palliative care team members. When the COVID-19 pandemic led to conducting some care conferences virtually, study protocols were amended to include these. Caregivers were first approached for informed consent, followed by participating clinical staff. The stated goal of the study was described as "assessing communication in care conferences."

Data Collection

Caregiver demographics, including self-identified racial and ethnic background, educational history, and previous care conference experience (none, 1 or 2, 3 or more) were collected via the electronic medical record and brief survey. Caregivers were also surveyed about information preferences. We adapted 3 questions from the Information Styles Questionnaire and the Information Needs Questionnaire[24,25] to assess parents' preferences regarding detailed information about their child's diagnosis and treatment, likelihood of survival, and likelihood of future limitations. Parents were asked to select response options on a 3-point Likert scale, including: 1: "I do not like to hear a lot of specific details"; 2: "I want to hear details only in certain situations, such as when tests are abnormal or when treatment decisions need to be made"; and 3: "I want to hear as many details as possible in all situations relating to my child's disease and its treatment."

For in-person conferences, research staff set up a recording device at the start of the care conferences, then waited outside the room for conference completion. For virtual conferences, recording occurred via the virtual meeting platform. All caregivers using a LOE for care received professional interpretation with either an interpreter or navigator (bilingual advocate for families that guides communication between providers and caregivers). Audio from English dialogue was transcribed verbatim and deidentified.

Qualitative Analysis

The primary coding team included two pediatric physicians with experience in critical care (AEO) and oncology (MM). Neither coder was present at any of the care conferences. The study team included representatives from patient navigation and interpreter services (BF), the hospital's Center for Diversity and Health Equity (MS, KCL), palliative care (AT) and language equity research (KCL), who were involved in all steps of codebook creation and analysis.

We developed a codebook based on a combined deductive and inductive approach, with iterative revision based on rounds of coding. *Providers* were defined as physicians and advanced practice providers (nurse practitioners and physician's assistants); *Caregivers* included parents/primary caregivers as well as other family members or friends present for the conference. Given the focus of this study was on provider or caregiver behaviors and significant differences in training between disciplines, speech by nursing or social work colleagues was not analyzed. Our codebook included two major categories: (1) Information sharing between providers and caregivers and (2) provider communication practices that impact information exchange. Small talk, or discussion not relevant to the patient's or family's medical or psychosocial condition, was not tabulated. Questions made by caregivers were also not included unless they additionally conveyed information.

Information sharing was defined as any instance conveying information relevant to the patient's care by either providers or caregivers. To characterize types of information shared, we began with the Rotor Interaction Analysis System (RIAS) method,[26–28] then made modifications to address uncaptured categories of information sharing (e.g., inclusion of values/goals). Information sharing codes included *biomedical*, *logistical*, and *psychosocial* for either providers or caregivers and additionally *patient wellbeing* and *values/goals* for caregivers **(Table 2).** Information sharing was quantified by counting individual statements, defined as independent and non-restrictive clause, e.g., the smallest unit of meaning that stands alone.[29]

Provider communication practices that may impact information exchange were gathered based on extensive review of the communication literature,[21,30–32] and included 4 categories: Invitations, Information Tailoring, Information Clarity, and Interruptions (**Table 3)**. *Invitations* included open-ended invitations from providers to caregivers to share information (e.g., "How has your family been coping with everything?"), and were subcategorized as biomedical, logistical, etc. *Information Tailoring* included agenda setting, gathering information preferences, seeking caregiver prior understanding, and checking caregiver understanding. *Information Clarity* included behaviors that support clarity: eliciting family questions, framing statements (those setting the stage for what the provider will share), and summarizing statements (those summarizing provider input), as well as unexplained jargon and acronyms not first used by caregivers, which are known to interfere with clarity.[33–35] Last, *interruptions* included instances of providers interrupting caregivers, which are known to deter effective clinical communication.[36]

Coding was conducted with Dedoose qualitative coding software.[37] The first 4 transcripts were coded independently by both coders, with resolution of disputes, until agreement met. The remaining transcripts were coded by a single coder, which each coder completing approximately half. Based on early experience coding with clear agreement amongst the other categories, we evaluated inter-rater reliability only for information sharing classifications. Classifications were double coded for 9 (approximately a third) of transcripts, and agreement was measured with kappa.[38] One reviewer (MM) counted all statements within each information category.

Quantitative Analysis. Data analysis was conducted using R Statistical Software.[39] Speak times were calculated using an R script to measure the time elapsed between speaker time stamps. Using descriptive statistics, we summarized caregiver demographics, as well as information sharing statements by speaker type (provider or caregiver) and by conference language (interpreted or entirely in English). We also compared speak time duration, instances of provider best practices, and Flesch-Kincaid grade level[40] between interpreted and English-only conferences. We conducted Mann-Whitney tests to compare the significance of differences found between speaker and language groups, and the Kruskal-Wallis test to compare types of information shared within speaker type, with individual pairwise comparisons with Wilcoxon signed-rank tests. P-values less than .05 were considered significant.

RESULTS

Demographic Data

A total of 29 care conferences were recorded and transcribed between January 2018 and January 2021. An additional 40 families were eligible but not enrolled, with 21 declining; the remainder were unable to be reached, or the study team was unable to record the conference. Among participants, 18 caregivers used English for medical care, while 11 (39%) used a LOE (Somali, Spanish, or Vietnamese) and communicated with a professional interpreter (n=8) or professional patient navigator (n=3). A wide range of diagnoses were represented. 81% of caregivers were female. Education level was variable, ranging from less than high school degree to graduate study. For detailed demographic information, see **Table 1.**

Providers versus Caregiver Speech

Across all conferences, regardless of language, care conferences lasted an average of 48 minutes, of which providers spoke an average of 22 minutes and families 9 minutes ($p<.001$). This did not include interpretation time for conferences in a LOE. Providers shared an average of 156 statements per conference while caregivers shared 71 ($p<.001$). Providers made far more biomedical statements than logistical or psychosocial statements (140 vs 22 vs 4 per conference, respectively; $p<.001$; see **Figure 1;** see also **Table 2** for definitions). Families made a wider range of statement types, though they also made significantly more biomedical statements (24 per conference) than logistical (6, $p=.001$), wellbeing (2, $p<.001$), or values and goals (7, $p=.001$). Interrater reliability for classification of information-sharing statements was robust by kappa, 0.83 (almost perfect agreement) overall.

Speech by Caregiver Language

Providers made significantly fewer biomedical statements in interpreted conferences than in English ones (median 117 vs 176, $p=0.01$, **Figure 2**). Providers also made fewer statements overall in interpreted conferences (149 vs 194, $p=.06$), though this did not reach statistical significance. No significant difference was noted in logistical and psychosocial statements across language, although numbers were small. Caregivers made a similar number of statements per conference, regardless of language (78 vs 66, $p=.95$), with no significant differences by information types. In total, interpreted conferences were longer than English ones (56 compared to 44 minutes ($p=.04$); however after removing interpreter talk time, interpreted conferences trended towards being shorter, (30 minutes vs 44 minutes, $p=.16$). Interpreted conferences were also lower in complexity (grade level 4.6 vs 5.7, $p=0.001$) than English ones.

Family Information Preferences by Caregiver Language

On a 3-point Likert scale, all but one caregiver reported wanting to "hear details in certain situations" (2) or "hear as many details as possible" (3) about their child's diagnosis, likelihood of survival, and likelihood of future limitations. The median information preference was 2.5 for each question for those using a LOE and 3 for each question for those using English, which were all significant differences **(Figure 3**).

Provider Communication Practices

Of the provider communication practices that support information exchange, use was scarce overall, particularly around tailoring information. Providers only explicitly asked a question about caregiver information preferences in one care conference (3%); and only explicitly asked about prior understanding before sharing new information in three conferences (10%). While checking caregiver understanding occurred more frequently (in approximately half the

conferences) it was asked in a closed-ended fashion in every instance (e.g., “does that make sense to you? CT Angio and all that stuff?”). Explicit open-ended invitations for caregiver input were also infrequent, with only half of conferences including any kind of invitation (**Table 3**). Meanwhile, use of unexplained jargon and acronyms was rampant and occurred in every conference, though far more common in English conferences (15 unique terms per conference) than interpreted (6) ones (p=.018). Framing was significantly more likely to occur in interpreted conferences (p=0.049); there were no other significant differences between measured best practices by language.

DISCUSSION

In this mixed methods analysis of pediatric serious illness care conferences, we found that providers spoke far more than caregivers, including more than twice the speech duration and number of statements. Additionally, providers shared significantly more biomedical information in English-only care conferences compared to interpreted ones. Importantly, provider communication practices tailoring information to family preferences were rare throughout, suggesting that these differences in information sharing were likely not driven by family preference.

Our findings of a predominance of provider over caregiver speech and differences in provider information sharing add to the existing literature of language disparities in pediatric communication.[20,21] While past efforts have focused on provider speech,[12,21] with analysis based primarily on speech times,[20] our study adds to the literature by exploring information sharing bidirectionally and offering nuance regarding types of information shared. These findings that families of children with serious illness using an LOE receive less biomedical information may help explain a number of known disparities, including lower levels of prognostic understanding,[41] reduced comprehension,[42] and higher degrees of decisional regret.[43] These communication gaps may represent a critical mechanism through which language barriers contribute to broader inequities in care and outcomes.

There is no known standard for quantity of information shared during conferences. The optimal amount likely varies by clinical context and individual family needs. Moreover, the *quality* of information—its directness, clarity, and understandability—is likely as critical as *quantity*. Although we cannot determine what constitutes an “ideal” amount of information, the differences observed between language groups warrant examination. In interpreted encounters, less information sharing may occur for a variety of reasons, including time limitations,[44,45] family preferences, and perceived differences in engagement or health literacy. Notably, while caregivers using a LOE in our study reported less educational experience compared to those using English, educational background is not necessarily reflective of health literacy.[46] While prior research highlights that family informational needs may vary,[47] provider bias has also been implicated in disparities, such as offering less prognostic information to families of color despite universally high desire for it.[24] In our own surveys, we noted a trend of families using English reporting a preference for more information compared to those using a LOE. However, given our small sample and study design not intended to answer this question, we must be cautious in any conclusions drawn from this finding. Despite a small statistically significant difference in average scores, families across all languages still expressed moderate to high desire for information. Furthermore, information needs are dynamic and change across the illness

trajectory.[48,49] To ensure that every family's unique and dynamic needs are met across their treatment journey, it is essential to directly engage them about their preferences at every stage.

Unfortunately, the use of communication practices supporting tailored information exchange was quite limited regardless of language. There were very few instances of providers gathering family preferences, seeking prior understanding, or checking for understanding, all of which can help promote the sharing of information that is appropriate to family desires and needs. The absence of explicitly gathering family input may increase the risk of bias leading to inappropriately disparate information sharing. Rather than making assumptions about what families want to hear and when, we must be more intentional by asking questions to understand their needs, preferences, and priorities around communication. Inquiring about informational needs may reduce reliance on assumptions and ensure providers meet families' unique communication needs.

We also noted a dearth in invitations for families to share information, which may allow for miscommunications and omissions of critical information. Power dynamics can interfere with family involvement in shared decision-making[16] and information sharing, including sharing concerns in the ICU setting.[50] In prior studies, parent-provider miscommunications have been linked to medical errors[53,54] and parental concern has been shown to be a predictor of illness severity,[55] such that not eliciting family contributions may have dire consequences. This is of particular concern for families communicating through an interpreter, where power dynamics can be pronounced[56] and it may be more difficult to insert information and self-advocate. Physicians play an important role in encouraging family engagement,[51,52] but must take active steps to do so. Increasing physician invitations for family perspectives may improve bidirectional communication and support patient safety.

Meanwhile, provider assumptions may also interfere with quality communication for English-speaking families. We noted rampant use of unexplained jargon and acronyms not used first by families, particularly for English-speaking families. Unexplained jargon is particularly suboptimal for interpreted encounters, as terms may be translated inconsistently each time; however, the best practice for all families is to avoid assumptions and use universal precautions.[33–35] Although families may come to learn medical jargon through prolonged medical involvement, high stakes emotion may limit recollection and knowledge may be variable. In our transcripts, there were multiple instances of families requesting a term definition after it had been used numerous times already, suggesting that providers may incorrectly assume patient knowledge. Avoidance of unexplained jargon is important for ensuring clarity of communication with all families.

Our study had several limitations. The population that speaks a language other than English is heterogenous, reflecting significant cultural, racial, ethnic, socioeconomic, and educational diversity. However, the challenges associated with language access are universal across groups. Our population was small and drawn from a single institution, limiting generalizability. Our institution may differ from others in broader access to professional interpretation and patient navigators, although these factors would be expected to narrow disparities that may be more marked elsewhere. Our data may also reflect incomplete conversational information. We captured a single time point and transcribed only English speech, which may imperfectly capture

caregiver intention despite professional interpretation. We also did not conduct conversational analysis or examine nonverbal or subtle verbal cues, which may offer nuance, particularly around invitations for information sharing. Last, all participants were aware that they were being recorded for a study on communication, which may have influenced behavior, although this makes measured differences particularly striking.

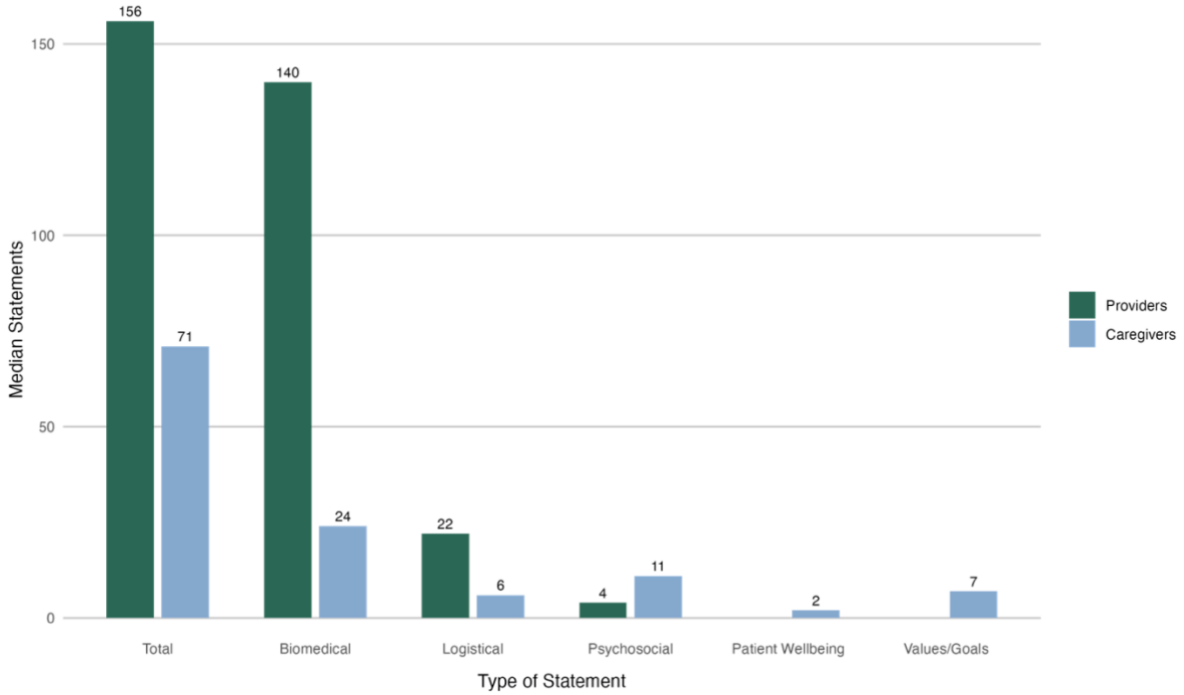
Our study overall found that pediatric serious illness care conferences are largely driven by providers, with a predominance of provider speech and relatively infrequent use of best practices that may increase collaboration and tailoring to each family's unique needs. Future work is needed examining communication needs across diverse cultural and linguistic backgrounds and developing methods to address them. Interventions to identify and adapt to specific communication needs may support clinical practice better tailored to each family's needs, inclusive of all language backgrounds.

CONCLUSION

In this mixed methods analysis of recorded care conferences for pediatric patients with serious illness, providers shared significantly more information statements than caregivers overall, and more biomedical statements for families in English compared to interpreted encounters. Meanwhile, use of provider communication practices supporting information exchange, including gathering information preferences, was scarce. In order to ensure providers meet the needs of families, work must be done to increase positive provider communication behaviors and ensure that tailoring of communication is in alignment with family preferences. Interventions targeted towards supporting families in sharing communication needs with providers may improve equitable communication and care.

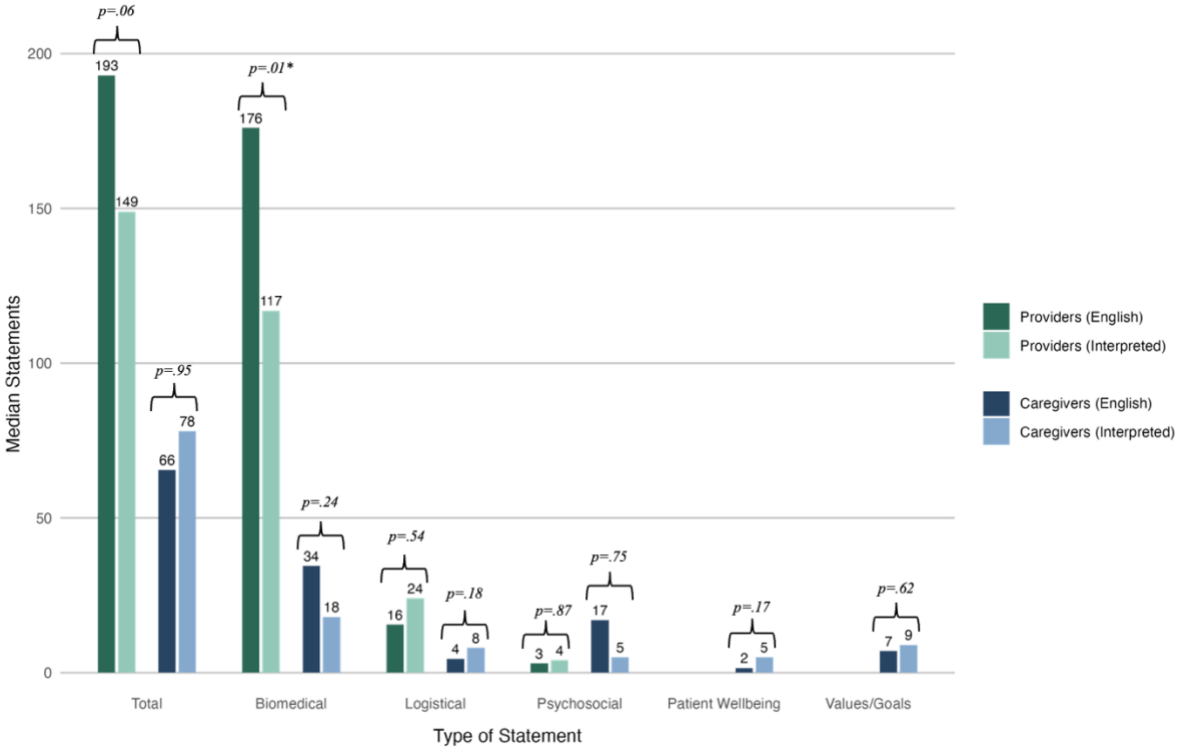
Figures/Tables

Figure 1: Median provider and caregiver statements per conference



Median number of statements per conference by providers and caregivers. Provider statements were categorized as Biomedical, Logistical, or Psychosocial Wellbeing and Family Coping; caregiver statements were additionally categorized as Patient Wellbeing or Values/Goals. Providers shared far more statements than caregivers ($p<0.001$) and significantly more biomedical statements than logistical or psychosocial ($p<.001$). Caregivers shared a wider range of statement types. Abbreviations: Psychosocial (Psychosocial Wellbeing and Family Coping)

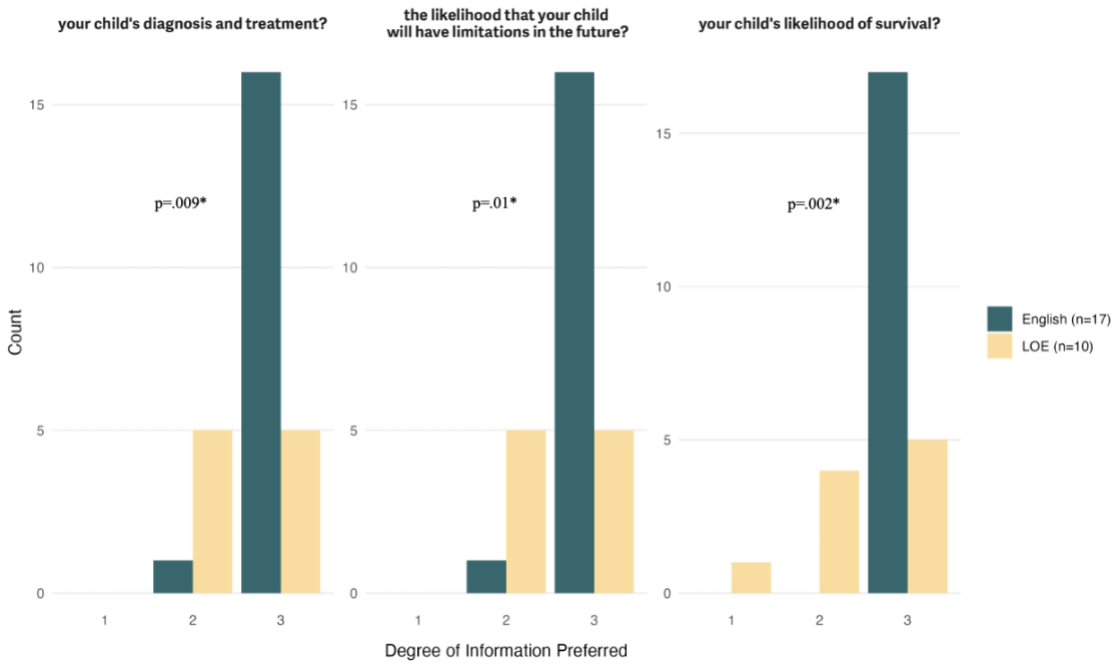
Figure 2: Median statements per conference by language



Median number of statements per conference by providers and caregivers. Provider statements were categorized as Biomedical, Logistical, or Psychosocial Wellbeing and Family Coping; caregiver statements were additionally categorized as Patient Wellbeing or Values/Goals. Significant values designated with asterisk. Abbreviations: Psychosocial (Psychosocial Wellbeing and Family Coping)

Figure 3: Degree of information preferred by caregivers by language

In general, how much information do you like to receive about …



Caregiver-rated degree of information preference on a scale of 1 to 3. Scores ranged from 1: I do not like to hear a lot of specific details; 2: I want to hear details only in certain situations, such as when tests are abnormal or when treatment decisions need to be made; and 3: I want to hear as many details as possible in all situations relating to my child's disease and its treatment. Significant values designated with asterisk. Abbreviations: language other than English (LOE).

Table 1: Caregiver Participant Demographics

	Language Groups	
	English	LOE
Abstracted from electronic medical record (n=29)	(n=18)	(n=11)
Language for care		
English	18 (100%)	-
Spanish	-	8 (73%)
Somali	-	1 (9%)
Vietnamese	-	2 (18%)
Patient hospital location		
Cardiac ICU	2 (11%)	4 (36%)
Neonatal ICU	4 (22%)	0 (0%)
Pediatric ICU	5 (28%)	2 (18%)
Inpatient Unit with Palliative Care Consult	7 (39%)	5 (45%)
Abstracted from surveys (n=27)	(n=17)	(n=10)
Race and ethnicity (n=27)		
American Indian or Alaska Native	1 (6%)	0 (0%)
Asian American	2 (12%)	2 (20%)
Black or African American	1 (6%)	1 (10%)
Hispanic	1 (6%)	7 (70%)
Non-Hispanic white	11 (65%)	0 (0%)
Did not answer/prefer not to say	1 (6%)	0 (0%)
Highest level of education (n=27)		
Less than high school degree	0 (0%)	4 (40%)
High school degree or equivalent	2 (12%)	5 (50%)
Some college but no degree	5 (29%)	1 (10%)
Associate, bachelor's, or graduate degree	10 (59%)	0 (0%)
Care Conference Experience (n=27)		
No previous conferences	3 (18%)	5 (50%)
Attended 1 or 2 previous care conferences	10 (59%)	4 (40%)
Attended 3 or more previous care conferences	4 (24%)	1 (10%)

Demographics were identified from the electronic medical record (language for care and hospital location, n=29; 18 English speaking, 10 speaking a language other than English), and survey (race and ethnicity, highest level of education, care conference experience, n=27; 17 English speaking, 10 speaking a language other than English). Abbreviations: language other than English (LOE).

Table 2: Example excerpts by statement and speaker type

Statement Type	Codebook Definition	Provider Example	Caregiver Example
Biomedical	Summaries and discussion of medical (including psychiatric) information.	"She was on high ventilator settings and a high amount of nitric oxide."	"We tried it the other day and nothing came out."
Logistical	Mechanics of care and discharge, including care coordination, work supports, medical supplies, etc.	"if [child] goes home with oxygen, they will provide the oxygen, which the care coordinator will sort out."	"And if we do decide to get the tracheostomy for her, in the area there aren't a lot of nurses available."
Psychosocial	Experience of psychological side of health, including how it impacts coping and psychological wellbeing.	"Parents have every emotion you can imagine when they're going through their child's illness."	"It's so hard for us family."
Patient Wellbeing	Views on how the patient is doing physically or psychologically; also includes patient perspectives and preferences.	N/A	"She's doing so much better now." "He's very sensitive about that."
Values/Goals	Goals for patient care and outcomes. Values impacting or relating to care of the child.	N/A	"We have a very strong faith." "I don't want that for my daughter."

Provider statements were categorized as Biomedical, Logistical, or Psychosocial Wellbeing and Family Coping; caregiver statements were additionally categorized as Patient Wellbeing or Values/Goals. Abbreviations: Psychosocial (Psychosocial Wellbeing and Family Coping)

Table 3: Provider communication practices by caregiver language

Type of Behavior	English (n=18 conferences) *x* total instances (present in y conferences)	LOE (n=11 conferences) *x* total instances (present in y conferences)
Invitations to Share Information		
Total Invitations	15 (8)	12 (7)
Biomedical Invitation	3 (2)	1 (1)
Logistical Invitation	1 (1)	1 (1)
Psychosocial Invitation	4 (4)	2 (2)
Patient Wellbeing Invitation	2 (1)	4 (3)
Values/Goals Invitation	5 (3)	4 (3)
Information Tailoring		
Agenda Setting *Provider asks family about goals and objectives for meeting. Did not require provider goals to be explicitly mentioned.*	8 (8)	4 (4)
Gathering Information Preferences *Provider inquires how family prefers to receive information.*	1 (1)	0 (0)
Advocating for Patient and Family Concerns *Provider shares a known or previously discussed family concern.*	30 (13)	13 (8)
Asking Permission *Provider asks permission to share information or explore a topic.*	11 (7)	7 (4)
Seeking Prior Understanding *Provider gathers information about family concept of illness.*	1 (1)	3 (2)
Checks Understanding△ *Provider elicits comprehension of what the provider has shared.*	20 (9)	4 (4)
Information Clarity		
Eliciting Questions *Provider asks about questions or concerns.*	45 (16)	36 (10)
Framing *Provider summarizes or describes what they will share*	19 (10)	27 (9)
Summarizing Statements *Provider summarizes discussion overall or provider information*	15 (8)	12 (7)
Unexplained Jargon and Acronyms *Provider uses term uncommonly used in daily speech**	267 (18)	70 (11)
Interruptions		
Provider interrupts family	47 (14)	14 (5)

Provider communication behaviors were tabulated overall and in parentheses, by conference. They were separated into language groups, English vs a language other than English (LOE). △ Checks understanding was closed-ended in every instance; e.g., "does that make sense?" ** Exclude terms used first by families, or if explained by provider. Counted once per term per conference. P values not reported for individual communication practices due to low occurrences overall. Abbreviations: language other than English (LOE).*

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