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Advancing the Field of Communication Research in Pediatric Oncology: A Systematic Review of the Literature Analyzing Medical Dialogue

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Abstract

Historically, communication research in pediatric oncology has relied on surveys and interviews, resulting in cross-sectional and retrospective studies constrained by selection, recognition, and recall biases. This systematic review identifies and synthesizes the published literature analyzing primary data from recorded conversations between pediatric oncologists, patients with cancer, and their families, with the following objectives: 1) to identify the extent and content of the evidence base; 2) to describe methodological strategies utilized in the analysis of recorded medical dialogue; 3) to aggregate salient findings; and 4) to generate recommendations for future prospective research related to analysis of medical dialogue in pediatric oncology.

Keywords

pediatric oncology; communication; recording; qualitative; mixed methods; systematic review

INTRODUCTION

Honest, clear, and empathic communication between pediatric oncologists, children with cancer, and their families is imperative to facilitating therapeutic alliance and ensuring that medical management aligns appropriately with patient and family goals of care.^{1,2} Parents of children with cancer rate the communication skills of their child's oncologist as a critical component of the illness and treatment experience,³ and parents are more likely to believe

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The authors have no conflicts of interest relevant to this article to disclose.

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that oncologists provided high quality information when they also rate the provider's communication style highly.⁴ Better communication also has been associated with parental report of increased hope,⁵ decreased decisional regret,⁶ and improved psychosocial outcomes.⁷

Despite evidence supporting the importance of communication in pediatric oncology, little is known about how pediatric oncologists use different communication styles and strategies to share diagnostic, therapeutic, or prognostic information with patients and families. Practically speaking, investigation around communication in pediatric oncology poses a number of challenges, including concerns related to the feasibility and acceptability of research that touches upon highly stressful and sensitive topics.

Historically, reliance on parent or physician surveys and interviews to study communication in the field of pediatric oncology has led to a limited literature comprised primarily of cross-sectional and retrospective studies that are relatively constrained by selection, recognition, and recall biases. The latter confounder becomes particularly problematic when data are collected months or even years following important conversations and when conversations are highly stressful and overloaded with nuanced and complex information, making it all the more challenging for participants to recall salient information.

To this end, the importance of audio- or video-recording in communication cannot be overstated. The ability of patients and families to retroactively describe the content and quality of information discussed during a medical conversation has been studied and shown to be poor. Following presentation of simple and direct information by the physician, approximately one third of patients were unable to relay the information accurately;⁸ moreover, after presentation of more complicated information, fewer than one-third of patients demonstrated successful recall, and these deficits persisted regardless of health literacy levels.⁹ Similar findings have been reported in the pediatric literature, with only one-third of parents of children with serious illness recalling all of the salient information about their child's treatment following a medical discussion with their child's physician.¹⁰ These data highlight the shortcomings of survey- and interview-centric data and argue for increased focus on direct analysis of recorded medical dialogue to advance the science of communication research.

Sisk et al recently reviewed the small body of literature on communication in pediatric oncology, identifying a total of 90 relevant manuscripts that demonstrate how communication research varies substantially in scope and methodology.² However, a deficit remains in the literature with regards to reviewing primary data from recorded conversations between pediatric oncologists, patients, and families as opposed to retroactive extrapolation from analysis of surveys or interviews. This is the first systematic review to identify and synthesize all published literature reporting on analysis of medical dialogue between pediatric oncologists, patients with cancer, and their families. The objectives of this review are four-fold: 1) to identify the extent and content of the evidence base within this research arena; 2) to ascertain the methodological strategies utilized in published studies on this topic; 3) to synthesize results from prior investigations; and 4) to generate recommendations

for the design and implementation of future prospective research related to communication in pediatric oncology.

METHODS

We conducted a systematic review following standardized rigorous guidelines¹¹ and relied on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for reporting results.¹² The driving question behind our systematic review was: “How does analysis of recorded conversations between clinicians, patients, and families inform the investigation of communication in the context of pediatric oncology?”

Inclusion and exclusion criteria

We included in this review all original research studies that incorporated either audio- or video-recordings of medical conversations between pediatric oncologists, patients, and families with subsequent analysis to assess the content or quality of these conversations. Quantitative, qualitative, or mixed methods studies were eligible for inclusion. The search was limited to articles written in the English language. We elected a priori to not apply a filter that restricted the date range of the search strategy in an effort to ascertain the earliest date of publication of literature on this topic. Studies that recorded only interviews with pediatric oncologists, patients, or family members after medical conversation were excluded from this analysis.

Search strategy

An advanced Boolean logic search strategy was developed through collaboration between EK and an expert medical librarian, as detailed in Supplemental Table S1. The original search strategy was executed across multiple electronic databases including PubMed, Web of Science, Scopus, and PsycInfo. Supplemental manual citation searches were performed using the Web of Science and Scopus databases to identify additional publications, utilizing the additional search strategy of snowballing in which articles are identified manually by reviewing reference lists and review articles.¹³ These manual citation searches yielded several relevant articles that had not been captured in the original search strategy, raising concerns about the comprehensive scope of the original strategy. A team of medical librarians, qualitative researchers, and pediatric oncology clinician-researchers iteratively reviewed and refined the PubMed search strategy to ensure casting as comprehensive a net as possible. Subsequent manual citation searches confirmed adequate comprehensiveness of the second strategy. EndNote was utilized as the reference database to retrieve and screen records.

Study selection

EK, KZ, MG, and JA screened the titles and abstracts of 5353 de-duplicated articles identified by the electronic database search for studies that met the above described inclusion criteria. EK and JB reviewed all articles for which eligibility criteria was not immediately transparent, and discussion was held between authors until consensus was achieved. Sixty-three articles were identified as eligible for full text assessment. Three researchers (AK, MG, IS) conducted comprehensive text assessment on the remaining

articles, and during the preliminary phase of text assessment, an additional 37 articles were excluded due to failure to meet the a priori specified eligibility criteria. EK performed a full audit of the 37 excluded articles, with subsequent confirmation of their ineligibility. Ultimately, a total of 26 articles were identified that met the pre-specified inclusion criteria. Figure 1 depicts the PRISMA flowchart accordingly.

Data collection and auditing

A standardized data abstraction tool was developed by EK to extract information from the 26 identified articles. The domains of this tool are detailed in Table 1. Three researchers (AK, MG, IS) reviewed the articles independently, with each reviewer assessing articles within an assigned category (e.g., all manuscripts related to informed consent were assigned to a single reviewer). Data was extracted from each study in a systematic manner in accordance with the aforementioned abstraction tool. Any questions regarding data extraction were discussed in groups of 2–4 researchers to achieve consensus. A preliminary audit was conducted by AK, during which the accuracy of all quantifiable domains was confirmed. EK subsequently conducted a comprehensive audit of all subjective variables to ensure consistency and accuracy across domains. A total of 11 minor discrepancies were identified out of 364 database cells, yielding a high inter-rater reliability (IRR = 0.97). These discrepancies were resolved by EK and JB through higher level discussion to achieve consensus.

Data synthesis

To present salient findings from articles included in this review, we developed a broad a priori coding schemata informed by iterative close readings of the studies, which was subsequently applied across the results, discussion, and conclusion sections of each manuscript. We first classified articles as “studies of medical dialogue in the context of an informed consent conversation” (ICC) and “studies of medical dialogue not related to an informed consent conversation” (Other). Within the “ICC” category, we applied broad codes for “communication” (i.e., “interactivity,” “topical content of communication,” “alignment of communication content with critical elements of the informed consent process”), which were coded separately for the oncologist and patient/parent, respectively. We also developed broad codes for “understanding” (i.e., “parental understanding of information provided” and “variables that influenced level of parental understanding”). Within the “Other” category, we grouped studies based on their predefined timepoints for recording medical dialogue, and then applied broad codes for “interactivity,” topical content,” and “emotive nature of communication.” Coding was conducted manually, with use of a spreadsheet for organization of data.

RESULTS

Study demographics

All articles were published within the last 15 years from the original search date, with half published within the last 5 years.^{14–27} The majority of studies (20/26, 77%) were conducted in the United States,^{14,15,20–25,27–38} with 3 studies from the United Kingdom,^{16,18,39} 1 study

from Brazil,²⁶ 1 from the Netherlands,¹⁷ and 1 from Norway.¹⁹ A total of 8 separate investigative protocols were conducted, resulting in 26 publications.

Study objectives and design

All 26 studies aimed to describe the content of communication. The majority of studies (n=23, 88%) also aimed to describe the quality of communication.^{14–21,23–30,32–34,36–39} Two studies aimed to describe the impact of an intervention on communication styles and strategies.^{20,36} All but one study involved audio-recording conversations between pediatric oncologists, patients, and families (n=25, 96%); a single study utilized video-recording modalities.¹⁹

The majority of studies (n=18, 69%) involved recordings of informed consent conversations.^{14,15,20–24,28–38} One study recorded conversations at the time of diagnosis,¹⁷ and a minority of studies (n=4, 15%) recorded conversations at random visits across the illness trajectory without aiming to capture a specific time point.^{16,18,26,39} One study recorded conversations at visits following completion of cancer therapy.¹⁹ Two studies (8%) recorded conversations during visits that occurred shortly after patients and families learned about a recent disease relapse or progression.^{25,27} No studies were identified in which conversations were recorded at the time of disease re-evaluation to capture the delivery of bad news in real-time.

Three studies (12%) aimed to record conversations longitudinally, as opposed to capturing single cross-sectional recordings.^{16,18,26} However, in all 3 of these studies, data was aggregated for the purposes of analysis, and no studies conducted analyses to describe or quantify changes in communication styles, strategies, patterns, or quality over time.

Study feasibility

The mean number of recorded conversations per study was 85.6, with a median of 85 and a range of 21 to 140. A mean of 133 parents participated per study, with a median of 102; however, a wide spectrum of sample sizes were represented across manuscripts, ranging from 33 to 140 participating parents per study. Four studies did not report parental enrollment rates. In the remaining studies, mean enrollment was 79%, with a median of 80% and a range of 56 to 94%.

With regards to oncologist participation, three studies (12%) did not report the enrollment rates of eligible clinicians. Amongst the remaining studies, a mean of 43.7 oncology clinicians participated per study, with a median of 34 participants and sample sizes ranging from 3 to 76. Only 4 studies (14%) reported enrollment rates for oncology clinicians, which ranged from 53 to 84%.

Analytic methods

The majority of studies (19/26, 73%) conducted analyses of recorded data using primarily quantitative methods, with application of standardized, validated tools or a priori coding schemata across transcripts to describe frequencies and query associations between values and other demographic features.^{14,15,20,21,24,28–38} Five studies (19%) conducted analyses exclusively through traditional qualitative methodology, using standard constant

comparative⁴⁰ or semantic content analysis⁴¹ to guide the de novo creation of a coding lexicon and subsequently discover themes to inform a conceptual model.^{16,18,22,27,39} Two studies (8%) used mixed methods to integrate quantitative analysis with traditional qualitative methodology.^{19,23}

Measurement of communication quality

Three studies (12%) exclusively aimed to describe the content of communication, without qualifying the perceived value or influence of the communication.^{22,31,35} The remainder of the studies (n=23, 88%) presented data with the goal of drawing conclusions about communication quality.^{14–21,23–30,32–34,36–39} Table 2 describes the tools used to assess communication quality in these studies. Table 3 summarizes the code types utilized to describe content and quality of communication within the 26 studies, and Table 4 comprises the metrics used to quantify communication style.

In the studies that involved recordings of informed consent conversations (n=18), assessment of communication quality focused primarily on quantification of the inclusion and/or frequency of physician statements related to critical consent elements, including: 1) provision of information specific to the clinical trial, 2) review of study objectives, risks, and benefits, 3) explanation of the concept of randomization, and 4) discussion of the patient's rights in the context of an informed consent process.^{14,15,21,28–34,37} Discussion specific to how “quality of life” might factor into the decision-making process was also reviewed in several papers.^{21,33} Physician statements reflecting rapport and partnership building were quantified, along with the frequency of parental communication to physicians, parental question-asking per minute, clinician/parent interactivity measures as defined by word or “turn-taking” ratios, direction of clinician discourse (e.g., directed to the patient vs. to the parent vs. non-directed) and clinician use of open-ended questions to elicit parental understanding.^{20,24,30,32–34,36–38} The frequency of hopeful statements in comparison to statements about disease incurability and/or palliative care involvement as an option was quantified in one study.²³ The impact of race, ethnicity, native language, and use of interpreters on communication content was also investigated in several studies.^{32–34,38} Multiple studies supplemented the recording of medical dialogue with follow-up surveys and interviews to evaluate parental understanding of study objectives and other informed consent elements, as well as their perceptions of decision-making and sense of hope following informed consent conversations; in this way, triangulation of data assisted researchers with identification of gaps in parental understanding of concepts discussed during the recorded conversation.^{15,24,28,29,33,34,36,37}

In the remaining non-informed consent studies, the majority of studies quantified specific physician communication behaviors, including frequencies and types of question-asking and patient vs. physician interactivity as determined by ratios of words spoken and frequencies of speech turns or exchanges.^{16,17,26,39,42} Two studies specifically quantified the occurrence and/or frequencies of “emotional talk,” including discussion of patient or parent fears and hopes and physician responses to emotional cues.^{16,18} An additional two studies quantified physician statements about prognosis, with subsequent analysis of congruence between physician and parental prognostic understanding and description of the impact of physician

communication on parental understanding, hope, and trust in the physician.^{25,27} As discussed previously, several studies also used supplemental interviews after the recorded discussion to identify gaps in parental understanding of discussion content, prognostic awareness, hope and trust in the physician, and overall fears and emotions relative to the recorded conversation.^{16,18,25,27,39}

Synthesis of study findings

A summary of key findings from these studies is presented in Supplemental Table S2. During informed consent conversations, physicians spoke much more frequently than patients or family members,³⁸ and they primarily focused on the potential for therapeutic benefit.²¹ When discussing risks, oncologists discussed rare and more serious side effects in fewer than 1% of informed consent conversations.³¹ Moreover, oncologists often omitted critical elements of the consent process such as discussion about voluntariness, dose finding/escalation, or dose limiting toxicities.^{14,15}

Although randomization was explained by physicians in most informed consent discussions, half of parents did not understand the concept on subsequent assessment. Lower socioeconomic status, racial minority, and non-English language preference all increased the likelihood that a parent would misunderstand the concept of randomization.^{29,33}

Importantly, parents who did not understand the randomization process were more likely to agree to the study as compared to those who did understand.²⁹ Minority groups were more likely to not understand treatment options and specifics related to the clinical trial following an informed consent conversation.^{32,34,37}

In the vast majority of informed consent conversations with children with refractory cancer eligible for enrollment on a Phase I trial, oncologists never discussed that the patient's disease was incurable, and in more than two-thirds of informed consent conversations, oncologists never mentioned that forgoing treatment and/or receiving palliative care were also options.²³ Notably, oncologists rarely mentioned hopes and goals, apart from the hope for cure during these discussions.²³

Finally, but perhaps most importantly, physicians who underwent a communication intervention and corresponding booster sessions demonstrated improvements in their skills during informed consent conversations, including increased used of rapport-building statements and open-ended questions to elicit parental understanding and clarify questions.^{20,36}

Similar to the analysis of recorded informed consent conversations, the analysis of routine cancer visits focused on topical content, interactivity, and emotive nature of the communication. Discussions were often characterized by short-term and procedural discussions with a primary focus on things that were going well and acute clinical management.¹⁶ Socioeconomic status and caregiver level of education were associated with amount of interaction provided by physicians to patients and caregivers.²⁶ Clinicians frequently discussed treatment, but rarely discussed treatment-related decisions or elicited the patient's preferred level of involvement in decision-making.¹⁷

In the two studies that recorded conversations about recent disease progression, the majority of physicians discussed prognosis during the conversation;^{25,27} however, nonspecific statements were often used by physicians to reference prognosis.²⁵ In subsequent interviews, most parents found prognostic information upsetting, yet they still valued frank disclosure. Conversely, excessive optimism or a lack of information was experienced by some parents as a threat to hope and the parent-clinician relationship.²⁷

With regards to emotional content, recorded discussions between oncologists, patients, and parents contained little to no explicit discussion of emotions.^{16,18,19} In one study, the majority of emotional concerns were expressed by patients and families implicitly as hints (“cues”), and these cues were mostly elicited by the oncologist.¹⁹ Notably, parents’ sense of emotional connection with doctors did not appear to rely on the presence of “emotional talk” during discussions. Parents reported that they gained emotional support from doctors’ expertise, calmness, constancy, and exercise of authority.^{18,39}

DISCUSSION

The value added from utilization of recorded conversation methodology is broad and deep, affording researchers unique opportunities to glean real-time information about the authentic language, syntax, organizational structure, verbal dominance, interactivity, topical content, and emotive quality of medical dialogue.⁴³ Importantly, this methodology also offers researchers a gold standard against which to assess concordance between clinician and patient/parent understanding and to identify gaps in comprehension of shared information. Unfortunately, the literature on communication in pediatric oncology, as studied through the recording of medical conversations, is very limited. However, despite a meager body of literature, the field is experiencing a rapid trajectory of growth, with half of the identified papers published within the last 5 years.

Importantly, this systematic review revealed that the majority of studies involving recorded conversations in pediatric oncology center on investigation of the content and quality of informed consent conversations. No studies were found in which conversations were recorded precisely at the time of disease re-evaluation with the goal of studying the communication of difficult prognostic information in real-time. Moreover, no studies were designed to capture or analyze data longitudinally for the purpose of describing or quantifying evolution in communication content or quality over time. Further prospective investigation is needed to better understand the longitudinal progression of prognostic communication between pediatric oncologists, patients, and families, ideally with data collected across serial disease reevaluation time points to better understand how communication around prognosis, decision-making, goals of care, quality of life, and end-of-life preferences evolves as disease progresses.

From a feasibility standpoint, this review also resolves inferred concerns within the field about the use of recording technology to study communication between pediatric oncologists, children with cancer, and their families. In aggregate, the reviewed manuscripts demonstrate excellent levels of participation by physicians, patients, and parents, with relatively limited rates of attrition, suggesting that recording medical conversations is neither

overly logistically cumbersome nor overly emotionally burdensome to clinicians, patients, or families. However, we acknowledge that the dearth of recorded data at the time of diagnosis may indicate ongoing resistance and/or concerns about incorporation of recording technology early in the illness trajectory; in the absence of data, we cannot say with certainty that clinicians, patients, or families will be amenable to recording intimate medical dialogue at the time of diagnosis (e.g., at the time of a “Day One Talk”).

Additionally, this review demonstrated the breadth and diversity of mixed analytic methods employed to facilitate analysis of recorded medical dialogue, with utilization of both quantitative and qualitative strategies to triangulate data from across recorded discussions, surveys, and interviews. Within this review, the bulk of analyses of recorded data were conducted using quantitative application of standardized, validated tools or a priori coding schemata across transcripts to describe frequencies and query associations between values and other demographic features. Although this methodology differs significantly from the more traditional grounded theory or inductive semantic content analyses, there is clear value from the utilization of hypothesis-driven coding frameworks to answer salient research questions with both efficiency and rigor. Mixed methods analysis of recorded dialogue juxtaposed with survey and interview data has been successfully conducted in medical oncology in several contexts, including investigation of the impact of therapeutic alliance on discussion of health-related quality of life between oncologists and patients with advanced cancer.⁴⁴ Importantly, recorded conversations also have been used to develop and test the feasibility, acceptability, and effectiveness of educational interventions on communication quality and therapeutic alliance.^{44–46} Tulskey et al emphasizes the fact that, to improve the quality of communication, researchers must be able to measure it. Essential metrics include the content and style of conversation (e.g., actual words spoken and tone employed) as well as the perception of the conversation (e.g., what patients and clinicians hear, process, and retain); meaningful outcomes for communication research include patient trust, satisfaction, decision quality, and health care use.⁴³ However, challenges in measurement of communication content and quality remain, particularly regarding lack of standardized validated metrics within the field.⁴³ We believe that this review demonstrates the critical importance of developing best practices for mixed methods analysis of recorded medical dialogue.

Ultimately, we advocate for an increase in observational studies that include a component of medical dialogue recording to better understand the content and quality of communication in pediatric oncology. We envision these data will highlight specific areas for improvement in oncologist-patient/family dialogue, particularly with regards to the frequency of prognostic communication and the specific language used to share this information. Findings should be juxtaposed against consensus guidelines for provision of optimal communication^{47–49} to inform the development of pediatric-specific guidelines for prognostic communication in the setting of disease relapse or progression. We then advocate for development of real-time clinical intermediation and experiential training models to promote best practice prognostic communication guidelines, using multi-center randomized control trials to ascertain the efficacy of educational interventions on both quantitative and qualitative outcome measures, including successful application of optimal communication metrics and concordance between oncologist and patient/parent prognostic understanding, perception of therapeutic

alliance, and overall satisfaction with communication quality. Ultimately, we believe that both qualitative and quantitative data have inherent strengths and weaknesses; when used synergistically, each has the potential to inform and strengthen the other. We advocate for the thoughtful combination of recorded data with survey and interview data to improve the overall quality of communication-based research in the field of pediatric oncology.

This systematic review, while comprehensive, has certain limitations. The search strategy was designed to capture eligible published studies, but the search did not extend to include stand-alone abstracts. Additionally, articles published in a language other than English were also excluded, which may have resulted in omission of relevant data.

In conclusion, the literature investigating communication in pediatric oncology through the use of recorded medical conversations is limited, but the field is primed for significant and imminent growth. To date, no studies have investigated prognostic communication through recording medical discussions in real-time at the initial disclosure of disease reevaluation information, and no studies have attempted to analyze recorded data longitudinally to describe the evolution of communication over time. Future research in the field should harness recording technology to enhance our understanding of the content and quality of communication between pediatric oncologists, patients, and families across the illness trajectory.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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*All exclusions based on a priori eligibility criteria.

Figure 1.
PRISMA flowchart

TABLE 1

Data abstraction tool

Item	Data Entry Choices
Title	<i>[enter title]</i>
Authors	<i>[enter authors]</i>
Publication year	<i>[enter year]</i>
Country of study	<i>[enter country]</i>
Study purpose (<i>mark all that apply</i>)	1 To describe content of communication 2 To describe quality of communication 3 To assess the impact of an intervention on communication
Type of recording	1 Audio-recording 2 Video-recording
Type of conversation recorded	1 Medical discussion at the time of diagnosis 2 Medical discussion at a random point in the illness course, excluding times of diagnosis or disease reevaluation 3 Medical discussion at the time of disease re-evaluation (first time family is hearing news) 4 Medical discussion to discuss recent relapse or progression 5 Medical discussion around informed consent 6 Medical discussion during survivorship visit
Total number of physician/clinician participants	<i>[enter number]</i>
Total number of parent participants	<i>[enter number]</i>
Total number of recordings	<i>[enter number]</i>
Longitudinal study design	1 Yes 2 No
Methodology	1 Quantitative 2 Qualitative 3 Mixed
Assessment of communication quality	1 Yes 2 No
Strategy/tool used to assess quality	<i>[free-text]</i>
Findings/main conclusions	<i>[free-text]</i>

TABLE 2

Tools used to assess communication quality

Tool	Description
The RIAS	The RIAS (“Roter Interaction Analysis System”) is a validated a priori coding method for analysis of medical dialogue, completed by raters who assess recordings of consultations (audio or video). The RIAS comprises an exhaustive list of categories that describe and define interactions between clinicians, patients, and families. RIAS coding categories are organized into 4 main pillars of medical dialogue: 1) information/data gathering/seeking, 2) education/counseling/motivating dialogue, 3) relationship-building/rapport development/responsiveness to emotions, 4) partnership-building/activation. Targeted sub-categories within the basic analytic structure facilitate further detailed documentation of specific features unique to each particular dialogue. Codes are assigned to brief units of spoken expression (typically comprising a complete thought), and these “thought units” or “utterances” are operationalized through content, phrasing, speaker, and sequential order in the coding record. Further supplementation is achieved through structured coder notes and content summaries embedded in the coding record. ⁴⁰
The OPTION	The OPTION (“observing patient involvement”) scale is a validated item-based instrument completed by raters who assess recordings of consultations (audio or video). It was developed to evaluate shared decision making, and it was designed to be sufficiently generic for use across all types of clinical practice. This tool measures the extent to which clinicians involve patients in decision-making by coding 12 behavioral competencies on a five-point Likert scale. It also measures participant understanding, role preferences, and if problems are well defined, options formulated, and information provided, with decision making examined from the perspectives of both clinicians and patients/families. ⁴¹
Observer Checklist	The Observer Checklist is a non-validated instrument designed to code communication styles and strategies specific to clinical discussions related to cancer. The Observer Checklist delineates specific information categories as either occurring or not occurring, and as being initiated by the clinician, the patient or the patient’s family. These a priori codes were developed by researchers for the purpose of several studies in this review; the codes are hypothesis-driven and specific to the predefined research questions. ^{25–27}
VR-CoDES	VR-CoDES (“Verona coding definitions of emotional sequences”) is a consensus-based system for coding patient expressions of emotional concerns in medical consultations, as defined as cues or concerns. The VR-CoDES manual comprises 5 categories of cues/concerns, with the capability of describing emotional responses as explicit/implicit and categorizing responses as either providing or reducing space for further disclosure of the cue/concern. ^{42,43}
Coding Software	ENCOUNTER, NVivo, and MAXQDA are coding software systems that each facilitate the application of a prior codes and/or utilization of traditional grounded theory across transcripts (i.e., inductive development of themes and concepts from granular codes).

TABLE 3

A priori coding schemata

Statement Category	Statement Examples
Statements that provide information about the disease or treatment	<ul style="list-style-type: none"> • Statements explaining disease • Statements explaining treatment • Statements providing informational content of the clinical trial: length of treatment, administration of medications, testing, risks, side effects, benefits, decision deadline
Statements about patient rights in the context of informed consent	<ul style="list-style-type: none"> • Statements about the voluntary nature of participation • Statements about the availability of standard treatment as alternative to research • Statements about the right to decline participation • Statements about the right to withdraw from a clinical trial • Statements about confidentiality
Statements to explain a phase I study	<ul style="list-style-type: none"> • Statements explaining the concept of randomization • Statements explaining risks versus benefits • Statements about quality of life • Statements about the informed consent document, including provision of the document, explaining the meaning of the document, and informing parents that they have time to read/consider the document before signing it
Statements about the clinician-patient/parent relationship	<ul style="list-style-type: none"> • Statements about therapeutic alliance • Statements that build rapport/bonding behaviors • Physician statements that reference collaboration and/or partnership-building • Statements of asking and checking • Statements about persuasion • Statements about alleviating pressure • Statements of authority or influence • Statements of disempowerment or passivity
"Emotional talk" statements	<ul style="list-style-type: none"> • Statements of negative emotion • Responses to negative emotion • Statements about worries or fears • Statements about hope • Statements about realism • Statements about coping • Statements about socio-emotional or personal issues • Statements to alleviate fears or emotional concerns • Statements to elicit or respond to patient's doubts
Statements about prognosis	<ul style="list-style-type: none"> • Statements about overall prognosis • Statements about the disease being incurable • Statements about receiving no further treatment as an option • Statements about receiving palliative care as an option/alternative to further treatment

TABLE 4

Metrics used to quantify communication content or style

Metric Categories	Metric Examples
Code frequencies	<ul style="list-style-type: none"> • Presence or absence of a certain type of communication behavior or code • Total number of a code of interest
Code attribution	<ul style="list-style-type: none"> • Attribution of codes to different speakers, e.g., clinician, patient, parent
Directionality	<ul style="list-style-type: none"> • Direction of communication, e.g., physician-to-patient, parent-to-patient, patient-to-parent, patient-to-physician
Interactivity	<ul style="list-style-type: none"> • Frequencies or percentages of words or statements spoken by different participants • Frequencies, percentages, or ratios of specific speech “turns” or “exchanges” between different participants • Question-asking per minute rate
Patient-physician centeredness	<ul style="list-style-type: none"> • Ratio of total number of patient or parent utterances over physician utterances • Percentage of time that patient/parent and physician spent speaking
Responsiveness	<ul style="list-style-type: none"> • Frequencies of oncologist responses to patient cues and concerns
Trust/understanding	<ul style="list-style-type: none"> • Ratio of hope/realism statements • Ratio of persuasion/alleviate pressure statements
“Faithful echo” coding	<ul style="list-style-type: none"> • Clinician remarks directly compared to interpreter remarks to identify divergences
Associative analyses	<ul style="list-style-type: none"> • Associations between code frequencies and patient/parent demographic variables including socioeconomic status, race, ethnicity, native language • Associations between code frequencies and patient/parent level of understanding • Associations between code frequencies and standardized communication models
Comparative analyses against follow-up parent interviews	<ul style="list-style-type: none"> • Comparison of codes from recorded discussions with codes from parent interviews • Comparison of physician statements (from recorded discussions) to parent statements (from subsequent interviews) • Impact of communication on parental understanding about the illness, treatment, informed consent process, prognosis • Impact of communication on parental trust in the physician, therapeutic alliance, report of hope, fears, emotions, anxiety, sense of control