Original Article

Longitudinal Investigation of Prognostic Communication: Feasibility and Acceptability of Studying Serial Disease Reevaluation Conversations in Children With High-Risk Cancer

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BACKGROUND: Prospective investigation of medical dialogue is considered the gold standard in prognostic communication research. To the authors' knowledge, the achievability of collecting mixed methods data across an evolving illness trajectory for children with cancer is unknown. **METHODS:** The objective of the current study was to investigate the feasibility and acceptability of recording sequential medical discussions at disease reevaluation time points for children with high-risk cancer. Mixed methods data (ie, surveys, interviews, checklists, and chart reviews) corresponding to each disease reevaluation conversation also were captured in real-time for 34 patients across 24 months at an academic pediatric cancer center. **RESULTS:** All eligible oncology clinicians (65 of 65 clinicians; 100%) and the majority of eligible patient/parent dyads (34 of 41 dyads; 82.9%) enrolled on the study; of 200 disease reevaluation discussions, 185 discussions (92.5%) were recorded, totaling >3300 minutes of recorded medical dialogue. Longitudinal data were captured for 31 of 34 patient/parent dyads (91.2%). The vast majority of study materials were completed, including 138 of 139 nonverbal communication checklists (99.3%), all 49 oncologist surveys (100%), 40 of 49 parent surveys (81.6%), all 34 oncologist interviews (100%), and 24 of 34 parent interviews (70.6%). Only 1 parent reported participation to be a "very" distressing experience, no parents believed that their level of distress warranted speaking with a psychosocial provider, and the majority of parents (18 of 29 parents; 62.1%) described study participation as "somewhat" or "very" useful to them. **CONCLUSIONS:** The prospective, longitudinal investigation of prognostic communication using a mixed methods approach appears to be feasible and acceptable to clinicians, patients, and families. The study of sensitive content can be accomplished without causing undue participant burden or harm, thereby enabling further advancement of communication research. ***Cancer* 2019;0:1-9**.

KEYWORDS: cancer, child health, feasibility studies, health communication, longitudinal studies, prognosis, prospective studies.

INTRODUCTION

Cancer is a devasting diagnosis that significantly impacts the physical, psychosocial, and spiritual well-being of patients and families.[1,2] For those facing high-risk or progressive disease, transparent and empathic prognostic communication is imperative for building therapeutic alliance[3-5] in the hopes of aligning treatment with goals of care.[6,7] Yet, the communication of highly sensitive information, particularly as it pertains to predictions of life and death, is fraught with challenges.[8] In the fields of medical and pediatric oncology, communication deficits have been described, resulting in discordance in prognostic awareness between clinicians, patients, and families.[3,7,9]

Improving communication around prognosis and goals of care for children, adolescents, and adults with serious illness and their families has been identified as a top research priority by experts in the fields of oncology, pediatrics, and palliative care.[10,11] Historically, research specific to prognostic communication in the context of progressive cancer largely has been cross-sectional, retrospective, and reliant on survey methodology.[12-14] Over the past decade, extensive work by Koropchak et al has revolutionized this paradigm within medical oncology,[15] demonstrating how systematic analysis of audio-recordings of medical conversations can be used to improve prognostic communication.[16,17] Within the field of

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pediatric oncology, several researchers have championed the value of qualitative analysis of third-party observation in synergy with audio-recorded interviews to advance the field of communication research.[18,19] Kamihara et al also have evolved the field through analysis of prognosis dialogue recorded at cross-sectional time points,[20] in conjunction with retrospective surveys and interviews to deepen understanding of the provision and interpretation of prognostic communication.[3,21-23]

In recent years, communication researchers have increasingly recognized the limitations of retrospective and/or cross-sectional analyses.[14] In addition to recall biases, the data derived from post hoc interviews are filtered through the lens of the listener and thereby provide an incomplete view of the communication that transpired. Given these limitations, recorded medical dialogue triangulated with survey/interview data are increasingly considered to be the gold standard in prognostic communication research.[14] Kamihara et al and Salmon et al have demonstrated the value of this mixed methods approach with both adult and pediatric patients.[20,24] However, to the best of our knowledge, little is known regarding the practical achievability of applying this approach prospectively and longitudinally across stressful disease conversations in the context of children with high-risk cancer.

To address this deficit, we designed a prospective longitudinal study of prognostic communication in the context of high-risk pediatric cancer using audio-recording technology to capture medical dialogue across serial disease reevaluation discussions in conjunction with the collection of data from surveys, interviews, checklists, and the electronic medical record. Over a 24-month pilot study, we tracked feasibility and acceptability metrics in parallel with prognosis communication data collection. In this article, we have described the methodology used to investigate prognostic communication prospectively and longitudinally, presented data demonstrating the feasibility and acceptability of these methods in clinical practice, and reviewed challenges intrinsic to this research in conjunction with strategies to overcome these barriers.

MATERIALS AND METHODS

The current study was reviewed and approved by the institutional scientific review committee and the institutional review board at St. Jude Children's Research Hospital (U-CHAT [Pro00006473]; approval date: July 12, 2016).

Study Development

Study conceptualization and methodology design were developed via extensive collaboration between expert clinicians and researchers in the fields of pediatric oncology and hospice and palliative medicine in partnership with an institutional panel of bereaved parents of children who had died of cancer. This cooperative endeavor resulted in a protocol designed to facilitate the real-time capture and analysis of prognostic communication longitudinally across advancing illness and evolving goals of care. Study materials (surveys, interview guides, and nonverbal communication checklists) were developed through a rigorous, iterative process involving an expert panel of clinical researchers representing the fields of hospice and palliative medicine, oncology, psychology, health care communication, and qualitative methodology across multiple institutions. Study materials subsequently were reviewed over sequential meetings by a panel of bereaved parent educators[25] who provided revisions and recommendations based on their unique perspectives. All study materials were pilot tested by separate cohorts of bereaved parents and clinical research experts to enhance content and face validity.

Eligibility and Enrollment Processes

Eligible study participants are described in Supporting Table 1. Eligible oncologists were approached by study personnel and verbally consented in accordance with rigorous institutional procedures. Any clinician who might accompany a participating oncologist during a recorded conversation also was verbally consented. Eligible patient/parent dyads were identified through systematic review of outpatient clinic schedules and institutional trial lists in partnership with administrative personnel who coordinate clinic scheduling and protocols. A simple algorithm was created to identify patients with any of the following diagnoses: 1) high-risk neuroblastoma; 2) any sarcoma; 3) any carcinoma; 4) desmoplastic small round cell tumor; 5) incompletely resected or metastatic retinoblastoma; 6) incompletely resected or metastatic Wilms tumor; or 7) incompletely resected or metastatic melanoma. A researcher with dual training in pediatric oncology and palliative care (E.C.K.) reviewed all identified patients to determine those with an overall survival reasonably estimated at ≤50%. The patient's primary oncologist then was asked to answer the following standardized question: "In your clinical judgement, would you estimate [patient name]'s overall survival at 50% or less?" For patients who met eligibility criteria, permission was requested from the primary

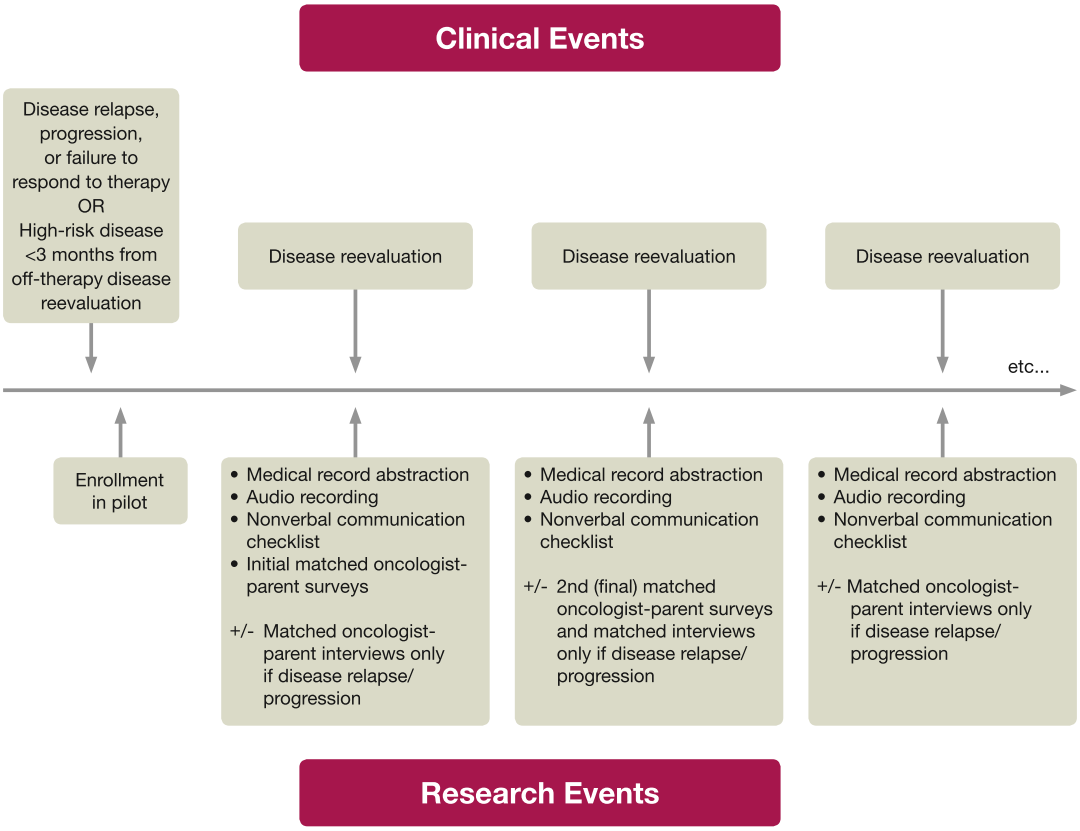

Figure 1. Timeline of clinical and research events across the study. At each disease reevaluation time point, mixed methods data collection was performed.

oncologist to approach the patient and family. With approval granted, patient/parent dyads were approached by study personnel to determine their interest in participation. Enrollment on the study required agreement from both the patient and parent; any disagreement between the patient and parent eliminated the dyad from participation. Patients and parents completed written consent documents. Verbal consent was obtained for any additional family members or friends in attendance during a recorded disease reevaluation conversation.

Data Accrual

Primary data collection centered on serial recordings of conversations between oncologists, patients, and families at the time points of disease reevaluation. A disease reevaluation time point was defined as any intervention conducted for the purpose of assessing disease status, including diagnostic imaging, lumbar puncture with cerebrospinal fluid analysis, bone marrow aspiration and/or biopsy, and surgical biopsy and/or resection. All disease reevaluation discussions were audio-recorded to preclude association of the audio-recorder with the delivery of "bad news."

Additional data were collected for the purposes of triangulation with the primary recorded data,[26] including the following items: 1) abstraction of data from the electronic medical record related to disease status, active treatment regimens, palliative care involvement, and advance directive status; 2) completion of a standardized, validated, 8-item nonverbal communication checklist[27] by any member of the health care team who observed the recorded conversation immediately after the discussion ended; 3) matched validated surveys completed by both oncologists and parents within 7 days after a recording conversation at 2 time points (ie, after the first recording after enrollment and again after the next recording in which disease progression/recurrence occurred); and 4) matched semistructured interviews conducted with oncologists and parents within 7 days after a recorded conversation in the context of disease recurrence or progression for the purpose of ascertaining oncologist–patient/parent

concordance regarding prognostic understanding and impression of communication quality as compared with the gold standard of the recorded conversation. The time frame for collecting survey/interview data was selected in an effort to minimize recall bias, predicated on data from patient-reported outcomes studies demonstrating minimal recall bias occurring within a 7-day window.[28] Protocol review by a panel of bereaved parents resulted in a window of 0 to 7 days as an optimal strategy with which to minimize the stress placed on the parent while also maximizing opportunities for participation. Survey content and interview prompts are described in Supporting Tables 2 and 3, respectively. The overall timeline for data collection is delineated in Figure 1.

Assessments of Feasibility and Acceptability

Based on historical institutional experience with participant accrual within the context of palliative care research, we aimed to enroll at least two-thirds of eligible solid tumor clinicians and eligible patient/parent dyads for a total of at least 30 dyads in the preliminary pilot. With regard to the feasibility of data collection, we aimed to record at least 75% of all possible disease reevaluation discussions. The feasibility of capturing longitudinal data also was investigated, with success defined as recording ≥2 disease reevaluation time points.

The acceptability of the study materials to clinicians and parents was investigated through interrogation of completion rates of the nonverbal communication checklist, baseline and follow-up surveys, and postrecording interviews. During the baseline survey, parents were asked how distressing it was to complete the questionnaire, whether they wished to speak with a psychosocial provider after completing the survey, and whether they believed that participation in the study was at all useful to them. In addition, during follow-up interviews, parents and oncologists were asked whether they felt comfortable participating in the study and whether they had recommendations to change the study to make it more acceptable to participants.

RESULTS

The current protocol opened in the solid tumor division of an academic pediatric cancer center as a pilot study to investigate the feasibility and acceptability of the previously described methodology. Over 24 months, we enrolled 65 of 65 eligible, interdisciplinary solid tumor clinicians (100%), including all 6 eligible primary solid tumor physicians (100%). We also enrolled 34 of the 41 eligible patient/parent dyads (82.9%), whose demographics are presented in Table 1. For the 7 dyads who declined participation, information describing the source, race/ethnicity, and rationale provided for declining are described in Supporting Table 4. Notably, study inclusion criteria allowed the primary oncologist to act as a "gatekeeper," such that an additional 10 patients who technically met disease and prognostic criteria were ineligible for enrollment due to the oncologist's impression that participation on study might place an "undue burden" on the patient and/or parent. Due to institutional review board constraints, we were not permitted to gather demographic information for these dyads.

TABLE 1. Demographics of Enrolled Patient/Parent Dyads (N = 34 Dyads)

Variable	No. (%)
Patient diagnosis	
Ewing sarcoma	9 (26.5)
Rhabdomyosarcoma	6 (17.6)
Other sarcoma	5 (14.7)
Neuroblastoma	9 (26.5)
Melanoma	2 (5.9)
Wilms tumor	1 (2.9)
Germ cell tumor	1 (2.9)
Hepatoblastoma	1 (2.9)
Patient age at enrollment, y	Mean: 10.6 Median: 11.5 Range: 1-22
Primary participating caregiver	
Mother	26 (76.5)
Father	5 (14.7)
Grandmother	1 (2.9)
Grandfather	1 (2.9)
Race	Patient/parent
White	28 (82.4)/30 (88.2)
African American	3 (8.8)/1 (2.9)
White/African American	2 (5.9)/0 (0.0)
Asian	1 (2.9)/1 (2.9)
Ethnicity	Patient/parent
Non-Hispanic	34 (100)/34 (100)
Hispanic	0 (0.0)/0 (0.0)
Disease recurrence/progression status at enrollment	
No history of recurrence/progression prior to study enrollment	17 (50.0)
History of recurrence/progression prior to study enrollment	17 (50.0)
Disease recurrence/progression while on study	
No history of recurrence/progression while on study	18 (52.9)
History of recurrence/progression while on study	16 (47.1)
Death while on study	
Yes	14 (41.2)
No	20 (58.8)

Feasibility and acceptability metrics are presented in Table 2. In this pilot, study feasibility was demonstrated with 185 of 200 disease reevaluation discussions (92.5%) recorded as per protocol. A total of 13 discussions (6.5%) were missed due to logistical and/or staffing issues. Successful recording rates were found to be high irrespective of discussion content, with 145 of 154 recorded

TABLE 2. Feasibility and Acceptability Metrics

Data	No. (%)
Enrollment	
Oncology clinicians	65/65 (100%)
Primary oncologists	6/6 (100%)
Patient/parent dyads	34/41 (82.9%)
Recordings	
Medical conversations captured	185/200 (92.5%)
Missed due to logistics	13/200 (6.5%)
Missed due to patient/parent refusal	2/200 (1.0%)
"Bad news" recordings captured	40/46 (87.0%)
Missed due to logistics	5/46 (10.9%)
Missed due to patient/parent refusal	1/46 (2.2%)
"Good news" recordings captured	145/154 (94.2%)
Missed due to logistics	8/154 (5.2%)
Missed due to patient/parent refusal	1/154 (0.6%)
Minutes of recorded conversations	3363
Minutes of "bad news" conversations	1054/3363 (31.3%)
Missed of "good news" conversations	2309/3363 (68.7%)
Longitudinality	
Patient/parent dyads with ≥2 recorded conversations	31/34
Range of no. recorded conversations	1-11
Patient/parent dyads with ≥1 "bad news" conversation captured within 12 mo from first recording	16/34 (47.1%)
Completion of triangulation materials	
Completion of oncologist surveys	49/49 (100%)
Baseline surveys	32/32 (100%)
Follow-up surveys	17/17 (100%)
Completion of parent surveys	40/49 (81.6%)
Baseline surveys	28/32 (87.5%)
Follow-up surveys	12/17 (70.6%)
Completion of oncologist interviews	34/34 (100%)
Completion of parent interviews	24/34 (70.5%)
Completion of patient interviews (for patients aged ≥12 y)	4/19 (21.1%)
Completion of nonverbal communication checklist (when applicable)	138/139 (99.3%)
Time points when nonverbal communication checklist was not completed due to oncologist having conversation alone	46/185 (24.9%)
Parental distress from study participation	
Not at all distressing	20/29 (69.0%)
A little distressing	6/29 (20.7%)
Somewhat distressing	2/29 (6.9%)
Very distressing	1/29 (3.4%)
Parental perception of usefulness of the experience of study participation	
Very useful	7/29 (24.1%)
Somewhat useful	11/29 (37.9%)
A little useful	9/29 (31.0%)
Not at all useful	2/29 (6.9%)
Parental need to speak with a psychosocial provider due to participation in study	11/29 (37.9%)
Yes	0/29 (0.0%)
No	29/29 (100%)

conversations (94.2%) occurring within the context of good or stable results and 40 of 46 recorded conversations (87.0%) occurring within the context of disease recurrence or progression. Greater than 3300 minutes were recorded, with discussions regarding good/stable disease news averaging 15.9 minutes in length and bad-news discussions averaging 26.4 minutes in length. The feasibility of capturing longitudinal data also was confirmed, with 31 of 34 participating patient/parent dyads (91.2%) yielding ≥2 recorded disease reevaluation discussions (range, 1-11 discussions). Study personnel comprised 1 primary researcher with 1 individual available as back-up; the time required for the researcher to successfully capture a recording ranged from 5 minutes to 3 hours. All nonverbal communication checklists, with the exception of 1, were collected within 10 minutes of completion of the recording; the remaining checklist was collected within 24 hours. All surveys and interviews were conducted within ≤1 week of the recorded conversation.

In addition, the acceptability of recording medical dialogue was established for participating clinicians, with no oncology providers declining the recording of a disease reevaluation conversation over a 24-month period. Similarly, high acceptability was observed for families, with a total of 2 of 200 discussions (1.0%) not recorded at the request of the participating patient or parent. All parents and oncologists reported the recording aspect of the study to be acceptable during follow-up interviews, with only minor recommendations offered regarding ways to streamline study processes. Acceptability of the overall study also was shown, with both oncologists and parents demonstrating a willingness to complete other study materials. Specifically, oncology clinicians yielded 138 of 139 complete nonverbal communication checklists (99.3%), 49 of 49 complete oncologist surveys at baseline and follow-up (100%), and 34 of 34 complete oncologist interviews after discussions about disease recurrence/progression (100%). Parents also appeared to find the triangulation study materials acceptable, with 40 of 49 surveys completed (81.6%) and 24 of 34 parent interviews completed (70.6%). With regard to the surveys, 6 surveys were declined by parents and 3 surveys reportedly were completed but were lost in the mail; in total, 4 baseline surveys and 5 follow-up surveys were declined or lost, suggesting no significant attrition in the context of follow-up. The mean number of days between recording and interview was 2.2 days (range, 0-6 days) and 2.3 days (range, 0-7 days) for oncologists and parents, respectively. Information regarding parents who declined or missed interviews is presented in Supporting Table 5. Oncologists and parents informally reported completion of surveys in approximately 7 to 10 minutes and 12 to 20 minutes, respectively; completion of interviews averaged 5.6 minutes (range, 2.5-15.1 minutes) and 17.8 minutes (range, 1.4-91.0 minutes) for oncologists and parents, respectively. After the baseline survey, parents were asked how distressing it was to

complete the questionnaire; 26 of 29 parents (89.7%) reported "not at all" or only "a little" distressing. Only 1 parent reported it to be a "very" distressing experience; this parent provided feedback that the source of her distress centered on the order of survey items, and that a different order of questions would have mitigated her distress. Notably, this parent still opted to participate in subsequent interviews following disease progression discussions. None of the parents believed that their level of distress warranted speaking with a psychosocial provider. The majority of parents (18 of 29 parents; 62.1%) believed that participation in the overall study was "somewhat" or "very" useful to them.

DISCUSSION

Although communication research in the field of pediatric oncology historically has been cross-sectional, retrospective, and reliant on survey methodology, awareness of the value of the prospective investigation of recorded medical dialogue is growing.[14] Data from this study demonstrate the feasibility and acceptability of recording serial prognostic discussions across a 24-month time frame in the context of serious pediatric illness, with the ultimate goal of better understanding the evolution and impact of communication on prognostic awareness. Importantly, feasibility was established in terms of high levels of enrollment for clinicians, patients, and parents and high levels of longitudinal data capture including serial recordings, nonverbal communication checklists, surveys, and interviews across multiple time points. These findings suggest that researchers can use recording technology in real-time in synergy with the application of written tools, surveys, and interviews without increasing participant burden to the extent that it harms feasibility. This finding is important because triangulation of data sources is imperative to the process of identifying the gaps between what is communicated during a conversation and what is heard and processed by the patient and family. In turn, identification of this gap informs the development of strategies with which to improve communication and enhance prognostic understanding.

In addition, acceptability was established in the context of the participants' willingness to allow recordings and perceptions of a lack of harm and the value added by the study. Surprisingly, only 1% of conversations were not recorded at the request of the participating patient or parent, and no participating oncologists declined a recording. The vast majority of parents described participation in the study as not at all or minimally distressing, and nearly two-thirds of parents believed that participation in the study was "somewhat" or "very" useful to them. These findings challenge the traditional ethos that recording medical dialogue is uncomfortable or stressful for patients and families; rather, the patients and families participating in the current study found the recording processes to be facile, not burdensome, and many considered their participation to be a positive experience.

Importantly, when comparing those patient/parent dyads who enrolled with those who declined participation, we found a similar racial and ethnic composition between the groups. However, the majority of dyads who enrolled and those who declined were white and non-Hispanic, suggesting that greater efforts are needed to ensure representative participation of racial and ethnic minorities. Specifically, the inclusion criteria for the current study mandated that 1 parent speak English, which significantly hindered the enrollment of Hispanic patients and families at the study institution. Future research should include bilingual qualitative and mixed methodology tools to ensure adequate representation across ethnicities.

Although the results of the current study demonstrate the achievability of recording sensitive medical conversations prospectively and longitudinally, we acknowledge several challenges to the application of this methodology. First, the successful execution of methods necessitates extensive logistical coordination by a dedicated research team; however, the current study was conducted by a single investigator without administrative assistance for the first 12 months (and subsequently conducted by 1 investigator and 1 research nurse), and therefore although time-intensive and labor-intensive, these methods are feasible to execute even in the context of limited personnel and/or resources. Second, study implementation requires buy-in from primary clinicians; in our experience, this process took approximately 6 months to achieve and was aided by efforts to demonstrate low study burden for participating clinicians. Third, we wished to preclude any potential participant stress and/or attrition due to the association of the recording device with the receipt of bad news; therefore, we regularly reminded patients and families that all disease reevaluation conversations would be recorded to preclude negative feelings toward the recorder or study processes. Only approximately 1.0% of recordings were declined by the patient and/or parent, suggesting the efficacy of this approach. Additional potential challenges and practical strategies to overcome barriers are detailed in Table 3.

TABLE 3. Challenges and Practical Solutions

Challenges	Problem-Solving Strategies
"Buy-in": developing investment from clinicians	• Formal meeting held with leadership to describe the study; emphasis placed on the importance of the research and the minimal labor/time burden on staff; created T-shirts with study logo for division leadership • Formal presentation of the study objectives and processes conducted for all physicians; targeted the monthly division meeting for a 15-min PowerPoint presentation, followed by a 5-min question-and-answer session; breakfast was provided • Individual follow-up emails sent to all physicians, followed by 1-on-1 meetings to answer remaining questions and to complete the verbal consent for participation on study • Informal meetings held with all clinic staff to explain the study and obtain verbal consent; meetings were coordinated in the clinic at their convenience
Patient/family recruitment	• Upon identification of an eligible patient/family, personal emails were sent by the study principal investigator to the primary oncology team to request permission to see the family; this was another opportunity to remind clinicians about the objectives and low time burden of the study • Met with patients and families in clinic during a regularly scheduled visit so as to maximize efficiency and convenience
Monitoring enrolled patients	• Daily review of the electronic medical record for each enrolled patient to monitor for newly scheduled disease reevaluation time points • Weekly email sent to the study team with the patient's name, clinic team contacts, which family members were consented, and the date and time of upcoming disease reevaluation and clinic visit
Logistics of capturing the recordings	• Reminder emails sent to the primary team the morning prior to a patient's disease reevaluation visit; this email included the patient's name, appointment time, and a contact number of a member of the study team, with the request to call or text if any changes in the appointment time occurred; emphasis was placed on the study team's willingness to meet the team at any time or in any location to obtain the recording • Member of study team waited in the clinic, in direct sight-line of the patient's clinic room, to hand the recorder (already turned "on") to the primary team as they entered the room. This wait could be lengthy; however, it provided an excellent opportunity to develop meaningful relationships with clinic staff and heighten the face value recognition of the study • More than 1 person on the research team had to be trained and fluent in study processes to account for multiple simultaneous recordings occurring in different locations
Building rapport within the clinical environment	• Frequent morning reminder emails and frequent presence within the clinic space created familiarity between study personnel and clinic staff; this facilitated excellent bidirectional communication between the study team and the primary oncology teams to minimize missed recorded visits • Informal visits to the clinic, occasionally bringing treats, heightened rapport and investment in the study

The current study has several limitations. First, it represents the experience of a single, large academic cancer center that treats patients from across the country and internationally, with a large volume of high-risk patients and families. We hypothesized, however, that if it is feasible to record serial prognostic communication discussions within this extremely high-risk population, then theoretically it ought to be feasible across other pediatric cancer centers as well. However, we also acknowledge that the culture of research at this cancer center might positively influence the ability to implement this complex study from the perspectives of participating clinicians, patients, and families. Second, the current study demonstrated feasibility and acceptability specifically within a pediatric oncology population, which is not inherently generalizable across other patient populations. Based on the success of this pilot, the current study will be expanded into additional patient populations to gain a better understanding of how prognostic information is shared, processed, and understood between different cohorts. Third, racial and ethnic minorities were underrepresented in the current study cohort, thereby affecting the generalizability of findings. Fourth, we did not collect demographic information for dyads who were not approached due to oncologist gatekeeping, and we were unable to ascertain whether these missing patients were unique in specific ways that might impact data interpretation. Fifth, several patients who met disease and prognostic criteria were not eligible for enrollment because of the primary oncologist's impression that the study might be an "undue burden" on the patient and/or parent. In this pilot study, the rate of attrition due to oncologists acting as gatekeepers was similar to previously published findings within a different pediatric oncologist population[29]; however, we do not know the impact of these missing patient/parent dyads on the study feasibility or acceptability parameters. Sixth, a small percentage of discussions were not recorded due to logistical and/or staffing issues (6.5%) or at the request of the participating parent or patient (1%); although these low numbers highlight the feasibility of the study,

missed recordings might hinder the future ability to analyze the evolution of prognostic communication across serial discussions. Seventh, the time frame of 0 to 7 days allowing for the collection of survey/interview data, while advancing the science by minimizing recall bias compared with historical studies, still leaves room for potential differences in reported perceptions on day 0 versus day 7. Finally, although the majority of parents completed surveys or interviews, missing data may impact future interpretation of the findings.

Conclusions

The findings of the current study demonstrate the feasibility and acceptability of investigating medical dialogue at highly stressful disease reevaluation time points through the triangulation of recordings with mixed methods study materials to advance the study of prognostic communication in the context of serious and progressive illness. Given the success of this pilot within a pediatric oncology cohort, we advocate for future investigation of the generalizability of this methodology within other populations of children with serious illness. Recording disease reevaluation conversations allows for the real-time capture and analysis of prognostic communication in the setting of diesase progression and evolving goals of care. Achieving a better understanding of how prognostic information is shared, processed, and understood in the context of serious pediatric illness is a critical first step in developing communication-based educational paradigms and real-time clinical interventions geared toward improving prognostic understanding, promoting therapeutic alliance, and enhancing overall communication experiences for vulnerable patients and their families.

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CONFLICT OF INTEREST DISCLOSURES

The authors made no disclosures.

AUTHOR CONTRIBUTIONS

Erica C. Kaye: Conceptualization, data curation, formal analysis, funding acquisition, investigation, methodology, project administration, supervision, writing–original draft, and writing–review and editing. **Melanie Gattas:** Data curation, formal analysis, investigation, project administration, supervision, and writing–review and editing. **Myra Bluebond-Langner:** Conceptualization, formal analysis, and writing–review and editing. **Justin N. Baker:** Conceptualization, formal analysis, funding acquisition, methodology, resources, supervision, and writing–review and editing.

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