Assume It Will Break: Parental Perspectives on Negative Communication Experiences in Pediatric Oncology

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QUESTION ASKED: What are the consequences of negative communication experiences in pediatric cancer, and how can clinicians supportively respond to these breakdowns?

SUMMARY ANSWER: Communication breakdowns in pediatric cancer lead to 12 categories of negative consequences for pediatric patients, parents, and families. Parents indicated five categories of supportive responses from clinicians after negative communication experiences (Fig).

WHAT WE DID: We performed semistructured interviews with 80 parents of children with cancer across three academic medical centers during treatment, survivorship, or bereavement. We analyzed transcripts using semantic content analysis, focusing on the contributors, consequences, and clinician responses to negative communication experiences.

WHAT WE FOUND: Parents reported 12 personal consequences of communication breakdowns: emotional distress (n = 65), insufficient understanding (n = 48), decreased trust or confidence (n = 37), inconvenience (n = 36), medical harm (n = 23), decreased self-confidence (n = 17), decreased emotional support (n = 13), decreased engagement (n = 9), false hope (n = 9), decreased hope (n = 7), financial insult (n = 7), and decreased access to resources (n = 3). We identified five categories of supportive responses from clinicians: exploring (n = 8), acknowledging (n = 17), informing (n = 27), adapting (n = 27), and advocating (n = 18).

BIAS, CONFOUNDING FACTORS: Participating parents were English-speaking and predominantly White, well-educated mothers. Also, participants were recruited from large academic medical centers; it is unclear to what extent these findings can generalize to other settings. Parents might have also been affected by recall bias or conformity bias, especially when discussing negative experiences.

REAL-LIFE IMPLICATIONS: Communication breakdowns in pediatric oncology negatively affect parents and children. Clinicians should plan for communication breakdowns by developing contingency plans in advance. Based on our data, we suggest clinicians respond to communication failures by sequentially exploring (“Could you tell me more about what happened?”), acknowledging (“I’m sorry you went through this”), informing (“Is it okay for me to give you some information about this situation?”), adapting (“Let’s think together about how we can make this better”), and advocating (“We are going to take steps to prevent this from happening again”). In the absence of these supportive responses, parents might engage in confrontational advocacy, which could negatively affect the clinician-family relationship.

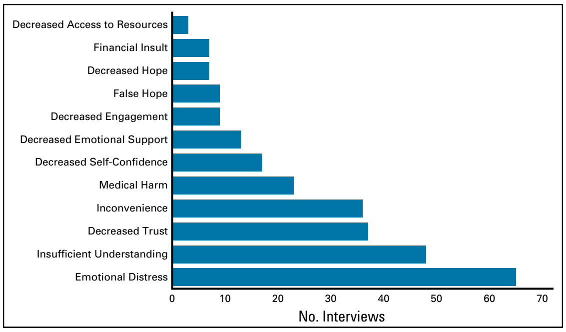

FIG. Consequences of negative communication experiences.

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ASSOCIATED CONTENT

Appendix

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CARE DELIVERY

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abstract

PURPOSE Communication breakdowns in pediatric oncology can have negative consequences for patients and families. A detailed analysis of these negative encounters will support clinicians in anticipating and responding to communication breakdowns.

METHODS Semistructured interviews with 80 parents of children with cancer across three academic medical centers during treatment, survivorship, or bereavement. We analyzed transcripts using semantic content analysis.

RESULTS Nearly all parents identified negative communication experiences (n = 76). We identified four categories of contributors to negative experiences: individual (n = 68), team (n = 26), organization (n = 46), and greater health care system (n = 8). These experiences involved a variety of health care professionals across multiple specialties. Parents reported 12 personal consequences of communication breakdowns: emotional distress (n = 65), insufficient understanding (n = 48), decreased trust or confidence (n = 37), inconvenience (n = 36), medical harm (n = 23), decreased self-confidence (n = 17), decreased emotional support (n = 13), decreased engagement (n = 9), false hope (n = 9), decreased hope (n = 7), financial insult (n = 7), and decreased access to resources (n = 3). We identified five categories of supportive responses from clinicians: exploring (n = 8), acknowledging (n = 17), informing (n = 27), adapting (n = 27), and advocating (n = 18). Parents often increased their own advocacy on behalf of their child (n = 47). Parents also identified the need for parental engagement in finding solutions (n = 12). Finally, one parent suggested that clinicians should assume that communication will fail and develop contingency plans in advance.

CONCLUSION Communication breakdowns in pediatric oncology negatively affect parents and children. Clinicians should plan for communication breakdowns and respond by exploring, acknowledging, informing, adapting, advocating, and engaging parents in finding solutions.

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INTRODUCTION

Communication serves many functions for caregivers of children with cancer, ranging from information exchange and decision making to emotional support and providing validation.[1] However, communication efforts can fail, leading to unmet information needs,[2–6] inaccurate prognostic understanding,[7–9] decisional regret,[10] and distrust of clinicians.[11] In one study, bereaved parents reported how a single insensitive encounter haunted them and complicated their grief even years later.[12]

These negative experiences provide an important lens into communication breakdowns. By understanding how communication can fail, clinicians might be able to mitigate harms to families. Yet, the literature exploring negative communication experiences is sparse. One study found that 41% of complaints at a cancer center related to communication breakdowns and lack of respect.[13] Another analysis of difficult clinical relationships identified underlying problems of connection and understanding, confrontational parental advocacy, mental health issues, and structural challenges.[14] Other studies have identified barriers to specific aspects of communication (eg, shared decision making).[15,16]

Previous work has not characterized the contributing factors, negative consequences, and recovery attempts related to communication breakdowns in pediatric oncology. A detailed analysis of these experiences will support clinicians in understanding how communication fails, key contributors to breakdowns, and how to mitigate harms. In this study, we characterize contributors, negative consequences, and responses to negative communication experiences in pediatric oncology from the parents' perspective.

METHODS

We report this study following Consolidated Criteria for Reporting Qualitative Research.[17]

Participants and Recruitment

We interviewed parents of children with cancer from Washington University School of Medicine (St Louis, MO), Dana-Farber Cancer Institute (Boston, MA), and St Jude Children's Research Hospital (Memphis, TN) between October 2018 and March 2020. We used stratified sampling, aiming for 12-15 parents per stratum[18]: time point (treatment ≥ 1 month, survivorship ≥ 6 months, or bereavement ≥ 6 months), child's age at diagnosis (≤ 12 years or ≥ 13 years), and study site. Parents were eligible if they (1) were the parent most involved in communication with clinicians, (2) had a child with cancer ≤ 18 years at time of enrollment or death, and (3) spoke English. We excluded participants who had clinical relationships with authors. We identified participants from review of patient lists, inpatient census, and outpatient schedules and recruited via telephone, mail, and in person. Institutional review boards at all sites approved this study. We did not track the proportion of approached parents who agreed to participate.

Data Collection

We conducted semistructured telephone interviews using an interview guide informed by previous work[19–21] and two pilot interviews (Appendix Table A1, online only). Fellows with qualitative research training (B.A.S. and L.J.B.) conducted interviews. We audio-recorded and professionally transcribed interviews. We asked parents to describe bad communication and specific negative communication experiences. We asked, "What made this experience particularly bad" and "What could have made this better?"

Data Analysis

We employed content analysis[22,23] by reading transcripts to form ideas, developing initial codes, and refining codes around semantic content. In consultation with all authors, two authors (B.A.S. and J.A.Z.) developed the codebook through iterative consensus coding of 27 transcripts. We defined negative communication experiences as communication encounters that parents described as creating difficulties or undesirable outcomes. We reached thematic saturation for contributors, consequences, and responses to negative experiences. Given the complexity of the codebook, these authors consensus coded all transcripts using Dedoose qualitative software.

RESULTS

Parent Characteristics

Eighty interviews ranged from 24 to 108 minutes. Parents were predominantly White (91%) and female (84%). Diagnoses included leukemia or lymphoma (45%), solid tumors (39%), and brain tumors (16%) (Table 1).

Contributors to Negative Communication Experiences

Parents described negative communication experiences in 76 of 80 (95%) interviews (Appendix Table A2, online only). We categorized the sources of negative experiences as individual, team, organization, or greater health care system. Descriptively, one site appeared to have more negative experiences arising from team issues; otherwise, we did not identify differences based on site or time point.

Individual. Parents described negative interactions (n = 68) with health care professionals across several specialties: oncology, intensive care, emergency, radiology, surgery, anesthesiology, and supportive care teams.

Parents noted deficiencies in information exchange, related to amount, quality, timing, or environment of communication: "The doctor on call wasn't really telling us what was happening. He would just say, 'Okay, well, we're gonna take care of this,' but not really give me definite answer." [Mother, Survivorship] Parents also described concerns about clinicians' competence or reliability, related to honesty, knowledge, technical skills, or failing to fulfill obligations or promises: "If you say that you're going to do something, if you're gonna visit someone, then you have to make the effort." Otherwise, it is like "your child's not as important to them." [Mother, Treatment]

Insufficient care and concern also contributed to negative experiences. Some clinicians used harsh language, failed to show warmth, rushed through visits, or failed to adapt to families' needs: "Comes across in that personality like she was trying to be intimidating, and just really short with any explanations, almost like she was bothered to have to spend any considerable time explaining things." [Mother, Treatment]

Sometimes, clinicians failed to engage parents or their children in medical care or did not appreciate parental concerns: "I would go to this other medical team and tell [my concerns]… They would just brush it off." [Mother, Bereavement] Other parents described having too much or too little involvement in care and decision making. "When he was in the pediatric intensive care unit at [hospital], they made me do a lot of the work. I was like, I'm completely uncomfortable with this." [Mother, Bereavement]

Finally, parents described insufficient emotional support when clinicians failed to anticipate or respond to emotional distress: "They hit you with a lot of info, send you home, and you're lost until you come back and start treatment… We just got punched and then dropped out the door." [Mother, Bereavement]

Team. Parents described inconsistent communication resulting from poor team dynamics (n = 26). Some experiences resulted from poor communication between the primary team and specialist teams: "In our experience, I found that often, the parent is expected to remember specific information and update the non-primary team. And I find that, to me, shows a lack of communication. I think that it's important that a parent… isn't expected to be a messenger between two groups." [Mother, Treatment] Others resulted from poor communication within the oncology team: "Bad or poor communication would be easily summed up in when one set or member of the team is telling you one thing, and the next visit, the next time, or the next set of people that you talk to tells you something that contradicts." [Mother, Treatment] Parents also described challenges with frequent changes in hospital personnel leading to lack of continuity.

Organization. Many parents identified hospital processes and norms that contributed to negative experiences (n = 46). Interacting with multiple trainees was frustrating: "They like to bring a bunch of people in when they tell you awful things. I don't know why… So other people can practice telling people awful things?" [Mother, Bereavement] Parents also described frequent changes in team members during inpatient stays, which decreased familiarity. Furthermore, parents noted difficulties with transitions, especially during survivorship: "All of a sudden, you get to five years cancer free, and you go in the survivorship clinics. It's very different. I feel like they should… soothe you into it a little." [Mother, Survivorship]

Organizations occasionally demonstrated disorder or inconsistency in processes. This disorder manifested in poorly coordinated imaging or laboratory tests and unreliable scheduling practices: "She said, 'Oh, you need to come in at this time,' and we'd come in at that time, and it was the wrong day." [Mother, Bereavement] Some bereaved parents noted the emotional trauma of receiving automated reminders about appointments after their child had died. Other parents described how automated appointment notifications indicated that their child had relapsed or needed additional treatments before the clinical team had discussed with them.

Finally, parents described insufficient personnel or resources to provide support, especially social workers and psychologists: "Right now, in the stage that we're in, I feel like parents need more support. Psychological support… There are things that I need to say to a grown-up who understands what I'm saying, without [patient] there." [Mother, Survivorship]

Greater health care system. Parents also described negative communication experiences caused by systems, norms, and

TABLE 1. Patient and Parent Characteristics (N = 80)

Characteristic	No. (%)
Parent age, years	
21-29	4 (5)
30-39	25 (31)
40-49	31 (39)
50 years or older	20 (25)
Parent sex	
Female	67 (84)
Male	13 (16)
Relation to child	
Parent	79 (99)
Grandparent	1 (1)
Parent race and ethnicity[a]	
White	73 (91)
Black	7 (9)
Asian	2 (3)
Hispanic	3 (4)
Others	1 (1)
Parent education	
High school graduate or less	7 (9)
Some college or technical school	15 (19)
College or technical school graduate	37 (46)
Graduate or professional school	21 (26)
Parent marital status	
Married or living as married	63 (79)
Others	17 (21)
Child age at diagnosis	
12 years or younger	52 (65)
13 years or older	28 (35)
Child sex	
Male	42 (53)
Female	38 (47)
Diagnosis	
Leukemia or lymphoma	36 (45)
Solid tumor (not in brain)	31 (39)
Brain tumor	13 (16)
Time point in cancer trajectory	
Treatment	30 (37)
Survivorship	27 (34)
Bereavement	23 (29)
Site	
St Louis	27 (34)
Boston	29 (36)
Memphis	24 (30)

[a]Not mutually exclusive. Race and ethnicity were self-reported.

processes outside their primary hospitals (n = 8). Parents described communication challenges emanating from insurance companies: “Really, there’s no real simple communication when it comes to insurance. I kept getting calls… and they were saying that they were talking to the hospital, but we couldn’t track down who at the hospital, they were talking with.” [Mother, Treatment] Parents also noted difficulties when transitioning care to different hospitals, describing poor continuity between institutions.

Consequences of Negative Communication Experiences

Parents identified a range of negative consequences that affected them, their child, or their family (Fig 1, Appendix Table A2). Overall, parents most commonly described additional emotional distress, manifesting as anger, frustration, anxiety, or sadness because of the miscommunication (n = 65). Parents also noted insufficient understanding (n = 48), decreased trust or confidence in the clinical team (n = 37), and inconvenience (n = 36). When specifically describing negative effects on their child, parents most often described emotional distress (n = 29), medical harm (n = 23), decreased emotional support (n = 5), and decreased trust or confidence (n = 3). Medical harms included emergent procedures (eg, intubation, surgery, or chest tubes) because parental warnings were ignored, missing key symptoms or side effects, insufficient pain management, and failed attempts to access central lines because clinicians ignored parental advice.

Responses to Negative Communication Experiences

We identified five categories of supportive clinician responses: exploring, acknowledging, informing, adapting, and advocating (Appendix Table A2). Clinicians explored negative experiences (n = 8) by listening to families and exploring the reasons for miscommunications. Some families found group discussions to be helpful: “I finally just got everybody on the same table and like got ’em all in the room at the same time. I said, okay, you’re telling me this and you’re telling me this, and it’s not matching up. Then we got it all figured out.” [Mother, Survivorship]

Clinicians provided acknowledgment (n = 17) by recognizing miscommunications and admitting responsibility. Sometimes, parents referred to this as being “taken seriously” and listened to: “They were on it quickly. I felt like that was a… perfect sign of great communication in that, number one, they listened. They acted on it. They convened. They figured out how to fix or try to fix, and then they communicated back to me.” [Mother, Treatment] Several parents noted the importance of apologies in repairing relationships.

Clinicians informed families (n = 27) by adjusting the pacing of information, directing families toward reliable information sources, clarifying misconceptions, and providing anticipatory guidance or plans: “She just made me feel better because she explained much further.” [Mother, Survivorship]

Clinicians adapted (n = 27) by modifying plans, procedures, or team composition in response to feedback: “I feel like they did the x-ray just to kind of pacify me, and then she started [having] the pain and then they took it seriously.” [Mother, Treatment]

Clinicians advocated (n = 18) by vocalizing concerns and supporting changes on behalf of the family, and taking steps to prevent future miscommunications: “They were really helpful in advocating and spreading the word. No matter what team of physicians was on or other nurses coming on, that our preference was to round outside, and then come in just so we could regroup.” [Mother, Survivorship]

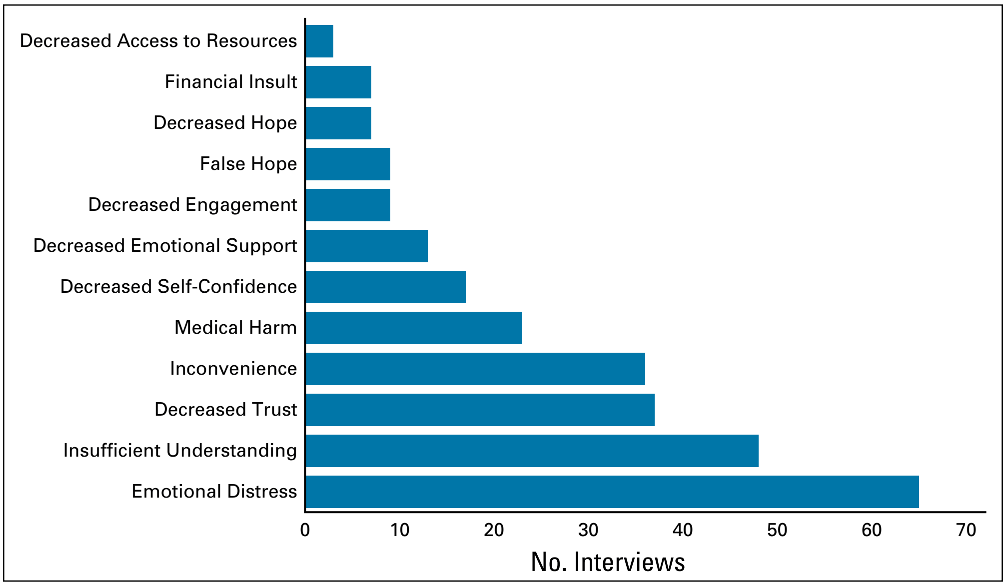


FIG 1. Consequences of negative communication experiences.

Parental advocacy was another common response to negative experiences (n = 47). Sometimes, parental advocacy triggered responses from clinicians. Other times, parental advocacy went unheeded. Regardless, parents valued their role as advocates: “You kind of really have to advocate for your child and say what’s on your mind. At least you feel like, okay, at least I’ve said it.” [Mother, Treatment]

Parents also described how increased engagement in finding solutions could have improved these situations (n = 12): “If she had maybe asked me, ‘Okay. I can see that this is very difficult, and this isn’t really working, so what do you think I could do better? Or what do you need that would help us along in this process?’” [Mother, Treatment]

To prevent communication breakdowns, one parent suggested planning ahead and assuming communication failures will occur: “Whenever we create some system, I’m actually assuming failure. I’m assuming it will break. I’m assuming I’ll need to—there will be an emergency, and I’ll have to fix it. How could I make that—either reduce the risk of that, or how could I rapidly fix it once it does break?” [Father, Bereavement]

DISCUSSION

We identified negative communication experiences resulting from failure to fulfill several communication functions,[1] with contributing factors at individual, team, organizational, and health care system levels. These breakdowns in functions led to negative consequences for parents, such as insufficient understanding (information exchange), emotional distress (responding to emotions), decreased trust (building relationships), decreased self-confidence (enabling self-management), decreased engagement (providing validation), and diminished hope (supporting hope). Addressing this array of negative experiences can be daunting, especially since many contributors are beyond the oncology team’s control.[24] However, a deep understanding of contributors to behaviors is essential to support individual and organizational change.[25,26] By identifying these contributors, clinicians can devise strategies to prevent or mitigate harms.

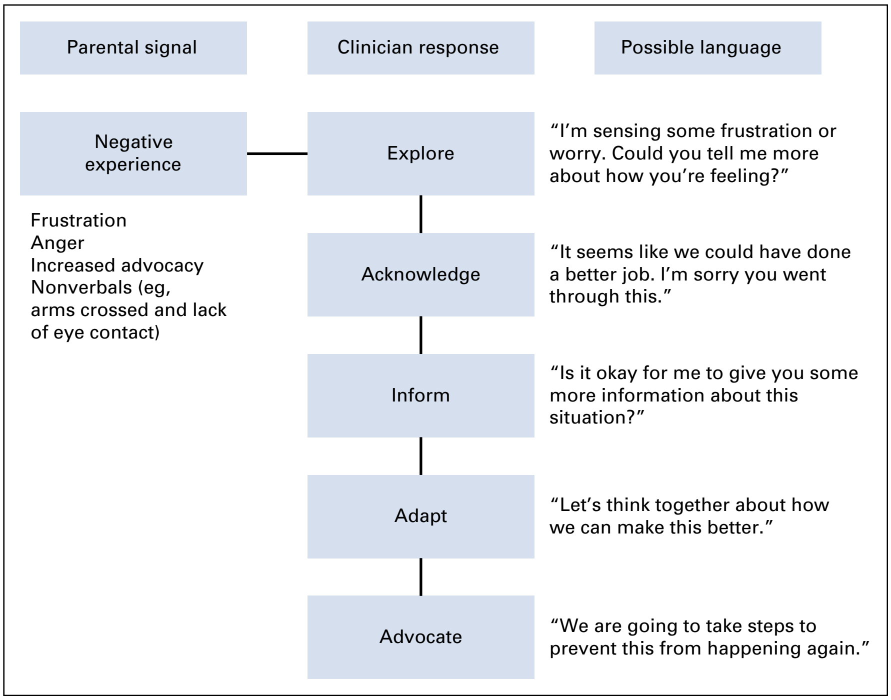
Some communication breakdowns are related directly to the oncology team. For example, parents noted poor team dynamics leading to inconsistent information and decreased trust. Focusing on team building and ensuring shared team mental models might improve this communication. Shared team mental models are knowledge structures held by members of a team that enable them to form accurate explanations and expectations for the task and in turn, to coordinate their actions and adapt their behaviors to the demands of the task and other team members.[27] Building and reinforcing shared mental models requires intentional effort, open communication, and coordination within the oncology team.[28] Teams might improve communication with families by employing communication checklists during team meetings to develop shared mental models, support appropriate distribution and redundancy in communication role assignments, and monitor communication milestones.[29,30] Furthermore, teams can improve written documentation in the electronic medical record and work closely with primary pediatricians to support families’ communication needs.[31]

Other communication breakdowns were beyond the oncology team’s control. For example, oncologists cannot change the insurance company policies or the family’s financial circumstances. Similarly, oncologists might struggle to influence interactions between families and specialists. Even when oncologists cannot prevent negative experiences, they can prepare families with anticipatory guidance and contingency planning. For example, an oncologist might predict struggles with insurance approval, describe how long the process usually takes, collaborate with social workers or care coordinators, and develop contingency plans. Clinicians might also explore financial challenges and make referrals to social workers, financial navigators, and philanthropic organizations. Additionally, organizations should address structural and organizational deficits that negatively affect the family’s care experience, especially related to electronic medical records and patient portals.

Communication breakdowns led to an array of negative consequences for families, ranging from emotional distress and decreased trust to medical harm and financial insults. Previous work suggests that such negative experiences might have longstanding effects.[12] Data-informed communication interventions might prevent some of these harms. Yet, almost no communication interventions exist in pediatric oncology.[20] Past interventions in adult oncology have included communication skills training sessions, question prompt lists, needs assessments, patient navigators, and patient-directed coaching.[20] Developing similar interventions in collaboration with parental advisory groups should be a high priority in pediatric oncology.

Parents noted that clinicians responded to their distress with one of five types of responses. We propose that clinicians consider employing these responses in a sequential process of first exploring the parental perspective, acknowledging the impact of the negative experience on the family, informing the parent about additional context they are not aware of, adapting care in safe and reasonable ways, and advocating on behalf of the family to address the source of the difficulty (Fig 2). Following this structured approach might validate parental concerns, facilitate resolution of the negative experience, and repair damage to the clinical relationship. However, this approach requires validation in future studies.

When clinicians failed to respond, parents increased their own advocacy. Advocating and protecting one’s child are key components of good parenting beliefs,[32–36] and validating parents in this role is a core communication function.[1] However, confrontational parental advocacy could signal diminished trust and unacknowledged communication



"I'm sensing some frustration or worry. Could you tell me more about how you're feeling?"

"It seems like we could have done a better job. I'm sorry you went through this."

"Is it okay for me to give you some more information about this situation?"

"Let's think together about how we can make this better."

"We are going to take steps to prevent this from happening again."

FIG 2. A proposed five-step response to negative parental experiences.

breakdowns. Misguided parental advocacy can also harm the clinical relationship and exacerbate negative experiences for the family and clinicians. If clinicians notice increased parental advocacy, they might suspect parental distress and begin exploring in a nonjudgmental way. If parents demonstrate significant anger, clinicians should employ mediation techniques while exploring the parent's concerns.[37]

Communication breakdowns will happen, no matter how caring or diligent the clinical team. This is especially true as clinicians are asked to fulfill more roles (eg, documentation, increased patient loads, and facilitating care coordination) for increasingly complex patients without additional time or support. Clinicians might follow the advice of one parent by assuming it will break and making plans to prevent or mitigate negative consequences. Preventive efforts are important, but clinical teams should also make plans to address probable communication failures, whether they are in the control of the clinical team or not. Effective responses likely depend on maintaining strong relationships with families, remaining attuned to the family's distress, acknowledging and apologizing, and developing plans to address underlying concerns.[38]

This study should be interpreted in light of limitations. Parents were English-speaking and predominantly White, well-educated mothers. Parents of children with brain tumors and older children were under-represented. Non–English-speaking parents were excluded. Future studies should engage with larger samples of under-represented communities to ensure that all voices are included. Parents might have also been affected by recall bias or conformity bias, especially when discussing negative experiences. All participants received care from large academic medical centers; it is unclear to what extent these findings can generalize to other settings. Finally, we did not address patients' perspectives in this study.

Communication in pediatric oncology is complex, and communication breakdowns will occur. These breakdowns can lead to negative consequences for families. Clinicians should assume that communication will occasionally fail and consider responding by exploring, acknowledging, informing, adapting, advocating, and engaging the family in finding solutions.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Assume It Will Break: Parental Perspectives on Negative Communication Experiences in Pediatric Oncology

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APPENDIX

TABLE A1. Interview Guide

Hello, may I speak with ___________? This is __________, and I'm calling from Washington University in St Louis. Is now still a good time to discuss our research project?
Great, thank you. Have you had a chance to review the consent document from the previous e-mail?
[If no: "Do you have access to your e-mail to review that form now?" If not—"Okay, I can read the consent document to you over the telephone."]
Do you consent to participation in this study?
1. Great. In the following questions, I am going to ask about communication with your child's medical team. By medical team, I mean the nurses, doctors, nurse practitioners, physician assistants, and staff that were involved in your child's cancer care. Keeping this in mind, can you tell me what good communication with your child's medical team means to you? [If unsure how to answer, could be re-stated as "When you think of good communication with your child's medical team, what comes to mind?"]
[2. Now, what comes to mind when you think of poor communication with your child's medical team?] (No need to ask if first question elicits negative experience)
Great. Thank you for sharing those thoughts. During this interview, I am hoping to explore many different aspects of communication between you and your child's medical team. This communication might include the way you were spoken to, the information you received, even non-verbal things like the way the doctor or nurse stood, or whether they made eye contact with you. Even paperwork can be a form of communication. It would be great if you could consider all of these aspects of communication during this interview.
3. Next I'd like to ask you about some of your communication experiences while your child was being treated for cancer.
3.1. Can you tell me about a time when your medical team communicated really well with you?
a. What made this experience good?
b. What did this good communication help you to do?
c. What other experiences stand out as good communication?
d. What else would you like to add?
3.2. Can you think of an example when the medical team communicated really well with your child?
a. What made this experience good?
b. What did this good communication help your child to do?
c. Do any other experiences stand out as good communication with your child?
d. What else you would like to add?
3.3. Okay, now I'd like to ask about a time when communication did not go well? Can you share an experience?
a. What made this experience bad?
b. What did it make harder for you to do?
c. What could have made this communication better?
d. What other experiences stand out?
e. Anything else you would like to add?
3.4. Can you think of an example when the team communicated poorly with your child?
a. What made this experience bad?
b. What did it make harder for your child to do?
c. What could have made this communication better?
d. What other experiences stand out?
e. What else you would like to add?
3.5. Can you tell me about anything you wish your child's medical team would have done, but they didn't?
4. Now, I'd like to ask about your interactions with your child's medical team.
4.1. What types of things were your doctors most likely to talk with you about?
a. What things were hard for you to talk about with your child's doctors?
b. What things do you wish your doctors would have talked with you about, but they didn't?
4.2. What types of things were your nurses most likely to talk with you about?
a. What things were hard for you to talk about with your child's nurses?
b. What things do you wish your nurses would have talked with you about, but they didn't?

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TABLE A1. Interview Guide (continued)

4.3. How was communication with the other specialists that took care of your child?
c. What was frustrating about this communication?
d. What went well with this communication?
4.4. Now I'd like you to think about times when you were home. How frequently did you try to contact your child's medical team in between appointments or hospital stays?
a. What were you contacting them about?
b. Who answered your questions?
c. How did that go?
5. Now, I am interested in learning more about what you might have wanted or needed from your medical team at different stages of treatment.
5.1. What were the best things your medical team did to support you and your family just after your child was diagnosed with cancer?
a. Were there things your child's medical team could have done to help you, but didn't?
5.2. (Only for *survivorship* parents) What were the best things your medical team did to support you and your family around the time your child completed treatment?
a. Were there things your child's medical team could have done to help you, but didn't?
5.3. (Only for *bereavement* parents) What were the best things your doctors did to support you and your family while your child was living with advanced cancer?
b. Were there things your child's medical team could have done to help you, but didn't?
5.4. (Only for *bereavement* parents) What were the best things your doctors did to support you and your family after your child passed away?
c. Were there things your child's medical team could have done to help you, but didn't?
6. Thank you so much for all of your thoughts so far. This has been very helpful. We are almost finished. I only have a couple more questions for you.
6.1. What communication advice do you have for a medical team talking to a family who just learned about their child's cancer diagnosis?
a. (Only for *survivorship* parents) What about advice for the medical team after the child has finished their cancer treatments?
b. (Only for *bereavement* parents) What about advice for the medical team when a child is living with advanced disease?
c. (Only for *bereavement* parents) What about advice for the medical team when a child has died?
6.2. What communication advice do you have for the parents of a child who was just diagnosed with cancer?
a. (Only for *survivorship* parents) What about a parent whose child just completed treatment?
b. (Only for *bereavement* parents) What about a parent whose child is living with advanced cancer?
c. (Only for *bereavement* parents) What about a parent whose child unfortunately did not survive cancer?
6.3. Before we finish, is there anything else you would like to share with us about your communication experiences?

TABLE A2. Contributors, Negative Consequences, and Clinician Responses to Negative Communication Experience (n = 76)[a]

Contributor (No. Transcripts With Code)	**Excerpts**
Individual (n = 68)[b]: Communication interaction between an individual health care professional and the parent or patient	
Information exchange (n = 54): Insufficient amount, quality, timing, or environment of information exchange	"Okay, so the doctor terms instead of layman terms. They talk about absolute neutrophil count and lumbar puncture and blah, blah, blah, but that means nothing to me. I know what an ANC is now, but I had to get—I don't wanna say dumbed down. I'm not dumb, but I'm not doctor smart either." [Mother, Treatment]
Competence and reliability (n = 51): Lack of dedication or ability to perform professional functions	"I got frustrated that first time that—I think it was back in [month 1] when they ran some extra tests, and I didn't hear from anyone. I knew they were send outs, but I didn't hear anything, and I finally had to call. It ticked me off." [Mother, Treatment]
Care and concern (n = 49): Lack of demonstrated empathy, kindness, or caring	"I feel like they're always rushed, that they don't have more than 10 or 15 minutes to sit in a room. We just go over x-rays, and they ask [patient] is there anything I can do for you?" [Mother, Treatment]
Engagement (n = 40): Inappropriate level of involvement for parent or patient in assessment, decision making, and management of patient's care	"I've been in this child's life since the day he was born and I know when something is wrong with him. I know when it's not right. By you not listening to me, it's like a slap in the face like, 'Okay, shut up, dummy. I'm the professional. You're not.' That's not right." [Mother, Bereavement]
Emotional support (n = 16): Failure to anticipate or respond to emotional distress	"It's a teaching hospital so you always have the younger doctors there. There was a time where we had to ask people to leave the room because we were kind of emotional. It might have been nicer if during some of the more difficult conversations not to always have the interns or the younger doctors that are the residents, being there." [Father, Survivorship]
Team (n = 26): Communication within a team or between teams	
Shared mental model (n = 26): Inconsistent or unreliable communication resulting from poor team dynamics	"Sometimes it seems like things aren't fully communicated to either the next person or the next phase, so times when you really feel like you do have to make sure you're paying attention and advocating for your kid otherwise something would slip through the cracks." [Mother, Treatment]
Organization (n = 46): Processes and norms within the primary cancer hospital where the patient receives care	
Standard operating procedures (n = 31): Model of care or standard processes in an organization that predisposed to negative communication experiences	"It was a lot of handoffs that I think—and so imagine there's—each one of those people communicates in a different way and has a different perspective on what the disease actually is and what the prognosis is and—so it was just a crazy time." [Mother, Bereavement]
Organizational disorder (n = 20): Lack of order or consistency in organizational processes, including scheduling and coordination of procedures	"There were a few times where machines were down at the main hospital that ran labs. We probably sat in the clinic for 6 hours, and then finally someone came back and told us, oh, the machine's down… At a certain point, someone should have checked." [Mother, Survivorship]
Support personnel or resources (n = 14): Insufficient personnel or resources to provide tangible support	"They have never sent anybody to talk to me. She's off treatment, so I think they figure that—I'm figuring that the social worker is more for the parents or the kids that are on treatment but—and nobody has ever asked to talk." [Mother, Survivorship]
Greater health care system (n = 8): Systems, norms, and processes beyond control of the primary cancer hospital	
Insurance and accessibility of treatments (n = 5): Difficulty in getting therapies or tests approved, delays in start of therapy or test because of process for insurance approval, or confusion about process	"She was trying to tell me what exactly was going on, what she was hearing from the insurance folks. So, I was a middleman there. It wasn't great communication cuz all I wanted was, 'Okay. Well, here's my insurance. Somebody needs to tell me am I approved for this? Or am I not approved for this? Or what's going on.' I felt like I was more in the middle." [Mother, Treatment]
Transitioning hospitals (n = 3): Poor continuity after transitioning medical care to new hospital	"I think they probably could have explained better about the transition that we would have from going from [hospital 1] to [hospital 2]… I think it would have been better communicating why certain things were done at certain places at certain times would have been better for me." [Mother, Treatment]
Negative Consequences (No. Transcripts With Code)	**Excerpt**
Emotional distress (n = 65)	"Maybe it was or wasn't their fault, but then, his panic level rose, our panic level rose." [Mother, Treatment]
Insufficient understanding (n = 48)	"We didn't really understand the whole process, and I didn't feel like that was explained to us at all even to this day." [Mother, Treatment]

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TABLE A2. Contributors, Negative Consequences, and Clinician Responses to Negative Communication Experience (n = 76)[a] (continued)

Negative Consequences (No. Transcripts With Code)	Excerpt
Decreased trust (n = 37)	"It just made us a little bit worried that they didn't know what was going on—the oncology team maybe didn't know what—hadn't looked at the records, didn't know what was going on or what test they needed to order." [Mother, Survivorship]
Inconvenience (n = 36)	"I'm not gonna wait—you know what I mean? It's hard enough to have to have that conversation. Don't make me sit in his room for 3 hours waiting on paperwork, so we just left." [Mother, Bereavement]
Medical harm (n = 23)	"For us, it was additional stressors. My son had a couple of problems that can directly be correlated back to poor communication… My contention is it was never communicated to me, and we experienced negative things [because of this lack of communication]." [Mother, Bereavement]
Decreased self-confidence (n = 17)	"I remember the medication charts looked like Chinese. I didn't know how to do it and our doctor in [state]—she was a good doctor, but she had a horrible bedside manner. She didn't treat us very nicely and she, actually, only—she was only our doctor for a very short period of time, but I would go home so stressed out and confused, because I wouldn't have a clue what I was doing, because there was nothing was ever explained." [Mother, Treatment]
Decreased emotional support (n = 13)	"Then after she died, for instance, there were resources I know available to us, but we didn't have them because I didn't know how to find them. I didn't have the strength or wherewithal to go looking." [Mother, Bereavement]
Decreased engagement (n = 9)	"I think for [patient] especially, because of his personality, it actually made him shut down a bit. He wasn't very open to communicating with the group as a whole." [Mother, Survivorship]
False hope (n = 9)	"Because of getting her hopes up. That she was cancer-free. Even though they've done—she didn't feel that she was cancer-free there, but she wanted to believe them. That made it a little harder to know that she believed that she was cancer-free for a minute and then had it all ripped away." [Mother, Bereavement]
Decreased hope (n = 7)	"Maybe if [doctor] just spun a little bit of hope on the end, like there's new treatments coming out… I guess she was preparing us in a way, but I wanted some hope on the end of that, like new advances." [Mother, Bereavement]
Financial insult (n = 7)	"I wasn't asked when was best for us, when was a good time for us? I have to be off work those days, 'cause I'm the only one who can sign any of the insurance, consents and stuff like that… It's super hard to get off, and it's basically an unpaid absence, so that hurts our family." [Mother, Treatment]
Decreased access to resources (n = 3)	"Yeah, because we were left on our own to find out about anything outside of treatment, that we had to find out through a network of families that are patients there." [Father, Survivorship]
Clinical Team Response (No. Transcripts With Code)	**Excerpt**
Adapting (n = 27): Modifying plans, processes, procedures, or team composition in response to feedback	"Whoever was the head of that floor did ask everybody to leave because she could see we were all getting distraught. She said I want everybody out of the room. Even the person that blurted it out left." [Mother, Survivorship]
Informing (n = 27): Providing additional information	"They were very understanding, and they took their time with me, and like I said, they always provide materials in anything, in everything that we're going to do and whatever we did." [Mother, Bereaved]
Advocating (n = 18): Vocalizing concerns and supporting change on behalf of the child	"My [child] was uncomfortable. The pump was only set to go so high. Then, [her nurse] got here. She's like, 'Oh, [child's] complaining. [Child's] really in pain. You've gotta up that.'" [Mother, Bereaved]
Acknowledging (n = 17): Recognizing the negative experience and/or admitting responsibility	"Everyone did a good job repairing it the next day and saying, 'You know what? Hey, I shouldn't have pushed you, and I understand, but we were doing it for this reason.' Ultimately, I think it was fine." [Mother, Treatment]
Exploring (n = 8): Reflecting and discussing negative experience to understand contributors	"They had set up a meeting with the oncology team, and [specialist] team and us, and we had talked about it, and we decided, with the oncology team on our side, that we did not want [the intervention]. We wanted to see how it worked out." [Mother, Bereavement]

[a] n = 76 because four parents did not identify any negative communication experiences.

[b] The number listed represents the number of interviews in which the code was identified. Given that some parents identified multiple subcodes in the same interview, the sum of the subcodes does not equal the number of interviews in which the primary code was identified.