

Multilevel Barriers to Communication in Pediatric Oncology: Clinicians' Perspectives

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BACKGROUND: Communication serves several functions in pediatric oncology, but communication deficiencies persist. Little is known about the broad spectrum of barriers contributing to these deficiencies. Identifying these barriers will support new strategies to improve communication. **METHODS:** The authors performed 10 focus groups on perceived communication barriers with nurses, nurse practitioners, physicians, and psychosocial professionals across 2 academic institutions. They analyzed transcripts by adapting a multilevel framework from organizational psychology. **RESULTS:** The authors identified 6 levels of barriers to communication from the clinicians' perspectives: individual, team, organization, collaborating hospital, community, and policy. Individual barriers were subdivided into clinician characteristics, family characteristics, or characteristics of the clinician-family interaction. Within each level and sublevel, several manifestations of barriers were identified. Some barriers, such as a lack of comfort with difficult topics (individual), cultural differences (individual), a lack of a shared team mental model (team), and time pressure (organization), manifested similarly across professions and institutions. Other barriers, such as a need for boundaries (individual), intimidation or embarrassment of family (individual), unclear roles and authority (team), and excessive logistical requirements (policy), manifested differently across professions. With the exception of collaborating hospitals, participants from all professions identified barriers from each level. Physicians did not discuss collaborating hospital barriers. **CONCLUSIONS:** Nurses, nurse practitioners, physicians, and psychosocial professionals experience communication barriers at multiple levels, which range from individual- to policy-level barriers. Yet their unique clinical roles and duties can lead to different manifestations of some barriers. This multilevel framework might help clinicians and researchers to identify targets for interventions to improve communication experiences for families in pediatric oncology. *Cancer* 2021;127:2130-2138. © 2021 American Cancer Society.

LAY SUMMARY:

- Clinicians and families experience many barriers to communication in pediatric oncology.
- The authors performed 10 focus groups with 59 clinicians who cared for children with cancer. In these focus groups, barriers to effective communication were discussed.
- In this article, the authors report on an analysis of the responses. Six levels of barriers to communication were found: individual, team, organization, collaborating hospital, community, and policy.
- With an understanding of these barriers, interventions can be developed to target these barriers in hopes of improving communication for parents and patients in pediatric oncology.

KEYWORDS: barriers, communication, pediatric oncology, physician-patient relationship, psychosocial oncology.

INTRODUCTION

Communication in pediatric oncology serves several functions for families, such as building relationships, exchanging information, providing validation, and supporting hope.¹ Fulfilling these functions can support peace of mind,² hopefulness,³ trust in physicians,⁴ and feeling acknowledged⁵ and comforted.⁶ Parents also report feeling prepared for decision making⁷ and family self-management⁸ when clinicians provide high-quality information.

However, many deficiencies in communication persist. During the first year after a child's diagnosis, for example, approximately 25% of parents report unmet prognostic information needs,⁹ which can contribute to discordant prognostic estimates.^{10,11} When parents report low-quality information, they are more likely to experience decisional regret¹² and express lower levels of trust in physicians.¹³ Low trust can influence whether parents will follow clinicians' recommendations.¹⁴

To address these deficiencies, clinicians and researchers must understand the breadth of barriers that impede communication functions. Communication occurs within a complex organizational system in which clinicians interact with

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families, multiple care teams, insurance companies, and research regulators as well as other personnel and entities. Furthermore, communication takes place in unique local contexts but also within broader contexts of professional and social norms and policies. In organizational psychology, a multilevel framework is foundational to understanding how individuals behave within complex organizations.¹⁵ This multilevel framework maintains that individual, group, organizational, and environmental factors influence behaviors.

Applying a multilevel framework to communication in pediatric oncology could provide important insights into the barriers experienced by families and clinicians. Most past studies, however, have focused on individual barriers. For example, a systematic review of barriers to shared decision making identified power imbalances, insufficient communication skills of the clinician, and emotional distress of the family.¹⁶ Prior studies of clinicians have identified emotional and mental strain, insufficient time, and lack of confidence in communication skills as barriers.^{16,17} Few studies, however, have explored barriers related to the broader context within which communication occurs. To improve communication, we must identify the full spectrum of barriers experienced by clinicians.

In this study, we performed 10 focus groups with oncology clinicians and psychosocial professionals at 2 academic institutions to identify and characterize communication barriers. By adapting a multilevel framework, we aimed to identify multiple levels of barriers from clinicians' perspectives.

MATERIALS AND METHODS

We report this study in accordance with the Consolidated Criteria for Reporting Qualitative Research guidelines¹⁸ (see the supporting information).

Participants and Recruitment

We conducted 10 focus groups with 59 participants across 2 academic centers between December 2019 and February 2020 to examine barriers to communication in pediatric oncology. We performed separate focus groups for physicians, nurse practitioners, nurses, and psychosocial professionals (psychologists, social workers, chaplains, child life specialists, and art therapists; Table 1). We purposively sampled for participants of different ages, sexes, levels of experience, and expertise within various subfields of oncology (eg, leukemia, solid tumor, brain tumor, and hospitalist oncology). We did not record the number of potential participants approached at each site.

TABLE 1. Focus Group Distributions

Nurses	Nurse Practitioners	Physicians	Psychosocial Professionals
1 WUSTL focus group	1 WUSTL focus group	1 WUSTL focus group	1 WUSTL focus group
1 St. Jude focus group	2 St. Jude focus groups	2 St. Jude focus groups	1 St. Jude focus group

Abbreviations: St. Jude, St. Jude Children's Research Hospital; WUSTL, Washington University in St. Louis.

We conducted 2 or 3 focus groups per profession to approach thematic saturation.¹⁹ We included 4 to 7 participants in each focus group to promote rich discussion while ensuring speaking opportunities for each participant.¹⁹ We recruited participants via telephone, via email, and in person.

Attending pediatric oncology physicians were eligible if they dedicated $\geq 20\%$ of their professional effort to clinical work. Oncology nurses and nurse practitioners were eligible if they had ≥ 1 year of clinical experience in pediatric oncology. Psychosocial professionals were eligible if their routine clinical practice involved pediatric oncology patients and they had ≥ 1 year of clinical experience. Institutional review boards at both sites approved this study.

Data Collection

We conducted in-person focus groups using a moderator guide informed by prior work¹ (see the supporting information). To develop the moderator guide, the lead author (B.A.S.) reviewed pertinent literature and preliminary findings from interviews with parents about negative communication experiences. Next, he identified key topics for the focus groups and drafted question prompts. The research team reviewed and revised the guide before conducting the first focus group. At Washington University in St. Louis, a female PhD anthropologist served as moderator, and at St. Jude Children's Research Hospital, a female research nurse served as moderator. Both moderators had extensive experience in social science research and interest in children's health. The lead author trained the moderators for this project by discussing pertinent literature about communication functions, reviewing the moderator guide, identifying high-priority content areas, and planning for difficulties that might arrive during sessions. To ensure standardization across sites, the lead author reviewed the transcripts for focus groups held at his home institution and provided feedback to the moderator and the note taker. Additionally, the lead author served as note taker for the first 4 focus groups

that occurred outside his institution and provided feedback after sessions. Each focus group also included a note taker. Focus groups were audio-recorded and professionally transcribed. Neither the moderators nor the note takers had relationships with the focus group participants. Before the focus groups, participants completed a demographic survey. Participants received \$75 gift certificates.

Data Analysis

Using the multilevel framework from organizational psychology as an a priori framework, we used semantic content analysis.²⁰ This multilevel framework maintains that individual, group, organizational, and environmental factors influence behaviors. Because of the complex web of interactions in pediatric oncology, this framework provided an important lens for analysis of communication barriers. However, we allowed for adaptation of this framework and the emergence of novel codes during analysis.¹⁵ In consultation with all authors, 2 of the authors (B.A.S. and A.B.F.) developed a codebook for communication barriers through iterative consensus coding. We defined communication barriers as factors that make communication functions more difficult to fulfill. We defined communication functions as processes within communication interactions that achieve important goals for families.¹ These same authors consensus-coded all transcripts with Dedoose qualitative software. Our coding reached thematic saturation for levels of barriers after the coding of 6 transcripts.

RESULTS

Participant Characteristics

The average participant age was 40.1 years, and the average pediatric oncology experience was 7.9 years long. On average, focus groups lasted 74 minutes. Participants were predominantly White (86%) and female (85%; Table 2).

Barriers to Communication

We identified 6 levels of communication barriers, which ranged from individual- to policy-level barriers (Table 3 and Supporting Table 1).

Individual barriers: clinician characteristics

Participants discussed individual barriers related to clinician characteristics, family characteristics, or characteristics of the clinician-family interaction. When discussing clinician characteristics, participants across professions noted that a lack of comfort with difficult topics was a barrier: "I've seen others through my training where they

TABLE 2. Participant Characteristics (N = 59)

Participant Characteristic	Value
Sex, No. (%)	
Female	50 (85)
Male	9 (15)
Age, mean (SD), y ^a	40.1 (10.2)
WUSTL, No. (%)	20 (34)
St. Jude, No. (%)	39 (66)
Professional role, No. (%)	
Nurse	10 (17)
Nurse practitioner	18 (30)
Physician	17 (29)
Psychologist	3 (5)
Social worker	4 (7)
Child life specialist	3 (5)
Chaplain	3 (5)
Art therapist	1 (2)
Time in practice, mean (SD), y ^a	7.9 (5.8)
Race, No. (%)	
White	51 (86)
Black/African American	4 (7)
Asian	4 (7)
Ethnicity, No. (%)	
Hispanic	2 (3)
Non-Hispanic	57 (97)

Abbreviations: St. Jude, St. Jude Children's Research Hospital; WUSTL, Washington University in St. Louis.

^aData were missing for 6 respondents.

themselves were not comfortable discussing death and dying and so would skirt that to the patient's detriment." [Physician] Most groups also discussed the difficulty of personal biases when engaging with families: "Your prior experience in certain situations can give you a negative outlook before that situation is even started." [Nurse practitioner]

Establishing boundaries was a common topic in several groups; however, different professionals framed these boundaries distinctly. For example, nurses described the importance of connecting emotionally with families and their tendency to become overly attached: "If you sulk on it too long, then you're being selfish because you're not actually going through this. It's their child. At the same time, we make bonds and connections with these people. It's just as tough on us too." [Nurse] Physicians focused more on their need to maintain work-life balance, which might include limiting their availability to patients and families to protect themselves: "It's establishing a little bit of that work-life balance while still being able to communicate with your patients what they need and sometimes offering alternatives... Trying to negotiate how we can communicate sometimes but being careful to protect yourself." [Physician]

Several groups discussed the feeling of becoming numb or having a blunted response to the family's distress: "We can sometimes blow off low-risk or things that may not be a big deal to us, because we see much

TABLE 3. Identification of Multilevel Barriers to Communication

Level of Barrier to Communication	Manifestation	Nurse	Nurse Practitioner	Physician	Psychosocial Professional
Individual (clinician characteristics): factors related to clinicians	Lack of comfort with difficult topics	+	+	+	+
	Lack of competence or experience		+	+	+
	Numb or blunted response to family's experience		+	+	+
	Personal beliefs or biases		+	+	+
Individual (family characteristics): factors related to patients or families	Need for boundaries	+		+	+
	Ability to understand and interpret information	+	+	+	+
	Expectations, desires, and demands	+	+	+	+
	Misperceptions of beliefs	+	+	+	+
	Disagreement within family	+		+	
	Strong emotional responses	+	+		
	Intimidation or embarrassment		+		+
Individual (clinician-family interactions): factors related to the clinician-family interaction or relationship	Lack of parental self-care		+		
	Cultural differences	+	+	+	+
	Personality mismatch	+			+
	Misunderstanding the other's intentions		+		
Team: interteam or intrateam dynamics	Differing priorities			+	
	Lack of shared team mental model	+	+	+	+
	Inconsistent information given to family	+	+	+	+
	Unclear roles and authority	+	+	+	+
Organization: structures, norms, or processes governed by the hospital	Complexity of teams in academic medicine		+	+	+
	Time pressure	+	+	+	+
	Problematic model of care	+	+	+	+
Collaborating hospital: structures, norms, or processes arising from a collaborating institution	Insufficient structural resources or personnel		+		+
	Different standards of care	+	+		
Community: characteristics of the social communities of families and patients	Limited responsiveness		+		
	Alternative sources of information		+	+	+
	Perceptions of hospital in community		+	+	+
Policy: characteristics of the medicolegal system governing medical care	Limited availability of cultural representatives				+
	Insurance issues	+	+	+	
	Medicolegal issues			+	+
	Excessive logistical requirements			+	

Plus signs indicate providers who identified the specified barrier.

worse.” [Nurse practitioner] Most groups also cited a lack of competence or experience with clinical content as a barrier, especially early in their careers: “I think for me, still being relatively junior as an attending is confidence... It’s very rare that any provider makes a unilateral decision, but also that feeling of, ‘Am I the best provider for this incredibly complex patient right now?’” [Physician]

Individual barriers: family characteristics

Participants described several family characteristics that impeded communication, such as the family’s ability to understand or interpret complex information. Sometimes, families lacked the cognitive capacity to understand complex information. Other times, they lacked fluency in English. Additionally, participants identified the family’s expectations, desires, and

demands regarding the child's care as potential barriers. In discussing this barrier, some participants raised the concept of difficult families. "Family makes communication sometimes difficult. Not only the disease... Nothing will make it better. Good disease, good physician, good hospital. It's going to be a pain regardless." [Physician] Navigating families' misperceptions or inaccurate beliefs was another challenge. "For some individuals, saying the word 'death' or 'die' is giving life to death. Those particular families don't want to talk about that possibility because if they talk about it, they're bringing it to truth." [Psychosocial professional]

Occasionally, different family members could have conflicting needs or priorities. Nurses and physicians described the difficulty of navigating these situations. For example, each parent might have differing priorities for the child's care: "The dad wanted to go full court press on everything possible for the child. The mom wanted the child to be comfortable and to do reasonable things." [Physician] Other times, parents wanted to protect their child from difficult information, although the child was an adolescent or young adult. Nurses and nurse practitioners also described how strong emotional responses from families were challenging: "As a new nurse, it's really scary to have a parent yelling at you. You just blame yourself. What did I do wrong?" [Nurse]

Furthermore, the power differential between physicians and families could hinder communication: "I think sometimes families are intimidated by doctors. Sometimes maybe if their educational level is that they don't understand what the doctor is saying, so then they'll ask someone else." [Psychosocial professional] Lastly, nurse practitioners described how a lack of parental self-care could impair the parent's ability to communicate.

Individual barriers: clinician-family interactions

Some individual barriers manifested within the clinician-family interaction. For example, participants noted cultural differences as a barrier, especially when families came from other countries with different norms and customs. However, cultural differences were not limited to families from foreign countries. Participants described families from smaller towns in the United States who had difficulty adapting to large cities: "A lot of these patients also are not from large urban areas either. Not only are they coming from a couple of hours away where their towns are a bit smaller... It's like they're walking into this alternate universe." [Nurse practitioner] Personality mismatches between the family and the clinical team could also create barriers: "To say that every personality is gonna

get along in the world, you know, that is untrue." [Nurse] Additionally, nurse practitioners described families who misinterpreted the knowledge or intentions of clinicians, or vice versa: "Sometimes [parents] don't [focus exclusively on symptom management at the end of life] because they feel like they don't want to give up or—and the parents feel like, 'Well, the doctor's not saying it's time to stop, maybe we have to keep on doing this.'" [Nurse practitioner] Lastly, physicians described times when their priorities did not align with the parents' priorities: "There's all these other things that are going through [parents'] mind, which are not the things that are necessarily my—I want your kidneys to survive it. I'm thinking about these immediate concerns. They're thinking about other immediate concerns." [Physician]

Team barriers

All groups identified barriers related to communication between the oncology team and other subspecialist teams and within the oncology team itself. For example, groups described the lack of shared mental models within and between teams: "The breakdown in communication among just our division. Inpatient versus outpatient or nursing... I think communication comes from all levels." [Nurse practitioner] As a result, families could receive inconsistent information: "One of the things we hear often from our families is that one team will tell them one thing, and another team will tell them something else, which is very confusing. It can be very upsetting to a family." [Psychosocial professional]

Across professions, participants also described unclear roles and authority, although these challenges differed by profession. Nurses and nurse practitioners described uncertainty about their role in discussing bad news with families: "What information do I divulge? I don't feel like a parent wants to hear that their child has cancer from their nurse practitioner. I feel like they want that information from their physician." [Nurse practitioner] Physicians described unclear decision-making authority when patients were transferred to intensive care units: "Usually, if a change was to happen, it would go through us first. When a patient goes to the intensive care unit, potentially they will be making the decisions on our patients... It's like, who has the ownership." [Physician]

Participants also described how complex academic teams impeded communication: "Maybe you see the medical student and then the resident and then the fellow and then the attending when that service stops by, so you can see as many as four different people from one service in one day." [Nurse practitioner]

Organizational barriers

Participants described organizational barriers related to the structures, norms, and process governed by the hospital. Time pressure, for example, was a common concern: “We all need more time, but we’ll never have more time.” [Nurse practitioner] This time pressure often resulted from high patient loads and complex needs of sick patients. The model of care at each institution also created challenges at times. Most commonly, participants referred to difficulties with family-centered rounds: “I think it’s a lot of information we’re giving to the patient. I see it in the ICU with these family-centered rounds. We disagree with each other in front of the family. I think that’s not good communication, but it’s the new fashion.” [Physician] The model of care also created challenges related to coverage models in which clinicians frequently changed, and this led to less familiarity with patients. Lastly, insufficient resources or personnel created barriers, especially for families who were not fluent in English: “We don’t have [interpreters] here overnight. We have way too many Spanish only speaking families to not have 24-hour Spanish interpreters.” [Nurse practitioner]

Collaborating hospital barriers

Structures, norms, and processes arising from collaborating hospitals also created barriers. Collaborating hospitals, for example, often had different standards of care, which could be difficult for families who transferred their care or received care across multiple institutions: “I think another outside barrier is that we have more relapse patients, and so they’re already coming in with this way that their hospital did things or what their first protocol was... I think that is a big barrier, just be like, ‘No, we do it—’ Everyone hates that, but ‘this is the way we do it here.’” [Nurse]

At times, collaborating hospitals failed to respond to requests for information or failed to follow hospital-specific guidance for patient care: “When our patients go to a completely outside institution, and you’re calling to give them our recommendations. I feel like sometimes those ER doctors are just listening to me like, what is this nonsense you’re telling me?” [Nurse practitioner]

Community barriers

Certain characteristics of families’ communities created communication barriers. Social media communities, for example, served as alternative information sources. Several groups described these communities as facilitating

the spread of inaccurate information: “Social media and oncology online forums. It’s great. It’s a support network that they find. But they’re also not educated enough to recognize why their child is different from this other child.” [Physician]

Perceptions of the hospital in communities also created barriers. A psychosocial professional noted, “I get conversation in the community... ‘I don’t see how you can work there, that’s got to be such a sad place and horrible things happen there.’ These patients may come thinking that... [and] come doom and gloom from the beginning.” [Psychosocial professional] However, overly positive perceptions were also problematic. “The idea that [hospital] is Disney World, and we can solve all problems, fix all issues.” [Nurse practitioner] Lastly, psychosocial professionals described limited access to diverse religious representatives in their local community.

Policy barriers

All professionals identified policy issues related to the medicolegal system governing medical care as barriers to communication. Physicians noted the onerous logistical requirements that occupied much of their time, such as charting, informed consent conferences, and contacting insurance companies: “I think that consents and the forms and the documenting, it’s out of control. It really is not good for the initial relationship building, etc., when you have to come in with a huge pile of forms for them to sign and go through.” [Physician]

Participants also noted how insurance coverage created uncertainty in communication with families: “I think insurance communication’s an issue. Because there are studies that our patients could get enrolled on. Things can’t happen because insurance companies won’t approve it. Treatments are delayed because they’re waiting for insurance to approve it.” [Nurse] Lastly, physicians described difficulties navigating the medicolegal system, which could lead to behaviors that did not support patient care. One physician noted, for example, how malpractice concerns seemed to lead radiologists and pathologists to use vague language and document unlikely diagnoses in their interpretations of images and specimens: “Everybody tries to go on safety to cover their responsibility.” [Physician]

DISCUSSION

In this study, we identified barriers to effective communication from the perspectives of physicians, nurse practitioners, nurses, and psychosocial professionals. These barriers manifested at 6 different levels: individual, team,

organization, collaborating hospital, community, and policy. With the exception of the collaborating hospital level, these levels were noted across all professions. Our findings suggest that this multilevel framework can support the evaluation of communication barriers across professions and across institutions. By assessing barriers at each level, researchers and clinicians can identify similarities and differences for different health care professionals and different hospitals.

We found that some barriers manifested similarly for all professionals at both institutions in this study, such as a lack of comfort with difficult topics (individual), cultural differences (individual), a lack of shared team mental models (team), and time pressure (organization). Limited professional experience and feelings of incompetence were also noted across most professions. Often, this lack of experience was related to technical skills or knowledge about treatments and medical care. These participants expressed their worry about whether they were the right person to communicate with the family about complex and emotionally laden topics. Addressing this lack of confidence or experience might require education, mentoring opportunities, and team-building strategies that leverage the varying strengths present within each group. Taking steps to address these crosscutting barriers might benefit all professionals and families in their care.

Other barriers, however, manifested differently across professions. For example, nurses and physicians both described the need for boundaries, but their attitudes toward creating boundaries differed. Although nurses described the importance of boundaries to protect themselves from emotional trauma, physicians described the need for work-life balance. For nurses, these boundaries were necessary for well-being but seemed to interfere with their central duty of building relationships. For physicians, these boundaries were needed to allow them to fulfill their professional duties. In light of such differences, it is important to understand not only which barriers exist but also how they manifest for different professionals at different institutions.

Although past studies have sought to identify barriers to aspects of communication, none have simultaneously explored these multiple levels. Instead, most prior work has focused on individual barriers, such as non-English speaking parents,²¹ limited parental knowledge,²² intimidation,²² a lack of trust in clinicians,¹⁴ and a lack of comfort with difficult topics.²³ Additionally, some studies have identified team-level barriers, such as inconsistent information.²⁴ Few studies, however, have explored

the effects of organization-, community-, or policy-level barriers. Addressing these latter barriers will be essential for changing communication behaviors across professions and organizations.

Overcoming these barriers will require data-driven, multimodal communication interventions. However, few interventions have been studied in pediatric oncology.²⁵ Recent review articles identified only 6 communication interventions in pediatric oncology^{25,26} but 88 interventions in adult oncology.²⁵ Furthermore, these pediatric interventions were communication skills workshops, which target primarily individual-level barriers. In adult oncology, the majority of studies also evaluated communication skills workshops.²⁵ To improve communication, researchers should develop interventions that address these multiple levels of barriers to communication. Figure 1 proposes ways that clinicians might intervene upon barriers at each level.

Implementation science literature shows that personal motivation is only 1 contributor to how individuals behave within an organization.²⁷ To implement widespread change throughout an organization, one must understand not only the characteristics of individuals but also the culture of the institution and the broader environment in which the organization functions.²⁷ As we have shown, barriers across these levels can affect communication. By understanding what impedes communication at each level, researchers and clinicians can develop interventions to ameliorate the negative effects of these barriers.

This study has limitations worth noting. First, focus groups are useful for identifying shared values and beliefs among groups of individuals. However, social desirability and hierarchy could prevent some individuals from sharing personal thoughts. Additionally, our study did not include trainees, and the participants were predominantly White women. Self-selection bias also might have led to participants with greater interest in communication topics than nonparticipants. We also conducted this study at 2 academic centers, and the specific barriers that we identified might vary at other institutions. This study also lacked the perspectives of parents and patients. Future research should include these perspectives as well as direct observation of clinical practice. Such an approach could corroborate the barriers identified in this study while also providing unique insights. Furthermore, our focus groups lacked palliative care providers, who often work closely with oncology teams to support communication. Lastly, this study was not designed to understand how barriers

Level of Barrier	Manifestation	Potential Intervention	Potential Outcome
Individual	Differing priorities between clinicians and parents	Decision Aid	Increase parental engagement and shared understanding of priorities
Team	Lack of shared team mental model	Checklist for communication milestones	Increase parental understanding; Increase trust in clinicians
Organization	Problematic model of care – Family-centered rounds	Offer parents options for rounding	Decrease parental distress; Increase relationship building
Collaborating Hospital	Limited responsiveness	Outreach and education with community hospitals	Improve adherence to standard emergency care for patients
Community	Alternative sources of information	Offer medical advisory board to vet information	Normalize parental information seeking; Decrease misinformation
Policy	Excessive logistical requirements	Staged consent process with consent summary document	Increase parental understanding; Decrease emotional distress

Figure 1. Potential communication interventions targeting multiple levels of barriers. This figure provides concrete examples of communication interventions that target barriers at multiple levels.

affect particular types of conversations, such as diagnostic conversations versus end-of-life conversations. Future studies should explore how these barriers vary on the basis of the content and context of discussions.

Nurses, nurse practitioners, physicians, and psychosocial professionals experience communication barriers at multiple levels, which range from individual- to policy-level barriers. Yet their unique clinical roles and duties can lead to different manifestations of these barriers. Assessing barriers through a multilevel framework might help clinicians and researchers to identify targets for interventions to improve the communication experiences of families in pediatric oncology.

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The authors made no disclosures.

AUTHOR CONTRIBUTIONS

Bryan A. Sisk: Conceptualization, design, implementation, formal analysis, drafting of the initial manuscript, and review and revision of the manuscript. **Annie B. Friedrich:** Formal analysis and review and revision of the manuscript. **Erica C. Kaye:** Conceptualization, design, and review and revision

of the manuscript. **Justin N. Baker:** Conceptualization, design, and review and revision of the manuscript. **Jennifer W. Mack:** Conceptualization, design, and review and revision of the manuscript. **James M. DuBois:** Conceptualization, design, and review and revision of the manuscript. All authors approved the final manuscript as submitted.

REFERENCES

- Sisk BA, Friedrich A, Blazin LJ, Baker JN, Mack JW, DuBois J. Communication in pediatric oncology: a qualitative study. *Pediatrics*. 2020;146:e20201193. doi:10.1542/peds.2020-1193
- Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Peace of mind and sense of purpose as core existential issues among parents of children with cancer. *Arch Pediatr Adolesc Med*. 2009;163:519-524.
- Nyborn JA, Olcese M, Nickerson T, Mack JW. "Don't try to cover the sky with your hands": parents' experiences with prognosis communication about their children with advanced cancer. *J Palliat Med*. 2016;19:626-631. doi:10.1089/jpm.2015.0472
- El Malla H, Kreicbergs U, Steineck G, Wilderang U, Elborai Yel S, Ylitalo N. Parental trust in health care—a prospective study from the Children's Cancer Hospital in Egypt. *Psychooncology*. 2013;22:548-554. doi:10.1002/pon.3028
- Arabiat DH, Alqaissi NM, Hamdan-Mansour AM. Children's knowledge of cancer diagnosis and treatment: Jordanian mothers' perceptions and satisfaction with the process. *Int Nurs Rev*. 2011;58:443-449.
- Young B, Hill J, Gravenhorst K, Ward J, Eden T, Salmon P. Is communication guidance mistaken? Qualitative study of parent-oncologist communication in childhood cancer. *Br J Cancer*. 2013;109:836-843.
- Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Parents' roles in decision making for children with cancer in the first year of cancer treatment. *J Clin Oncol*. 2011;29:2085-2090. doi:10.1200/JCO.2010.32.0507
- Stinson JN, Sung L, Gupta A, et al. Disease self-management needs of adolescents with cancer: perspectives of adolescents with cancer and their parents and healthcare providers. *J Cancer Surviv*. 2012;6:278-286.
- Sisk BA, Kang TI, Mack JW. Prognostic disclosures over time: parental preferences and physician practices. *Cancer*. 2017;123:4031-4038. doi:10.1002/cncr.30716

10. Mack JW, Cronin AM, Uno H, et al. Unrealistic parental expectations for cure in poor-prognosis childhood cancer. *Cancer*. 2019;126:416-424. doi:10.1002/cncr.32553
11. Rosenberg AR, Orellana L, Kang TI, et al. Differences in parent-provider concordance regarding prognosis and goals of care among children with advanced cancer. *J Clin Oncol*. 2014;32:3005-3011.
12. Sisk BA, Kang TI, Mack JW. The evolution of regret: decision-making for parents of children with cancer. *Support Care Cancer*. 2020;28:1215-1222. doi:10.1007/s00520-019-04933-8
13. Mack JW, Kang TI. Care experiences that foster trust between parents and physicians of children with cancer. *Pediatr Blood Cancer*. 2020;67:e28399. doi:10.1002/pbc.28399
14. Baenziger J, Hetherington K, Wakefield CE, et al. Understanding parents' communication experiences in childhood cancer: a qualitative exploration and model for future research. *Support Care Cancer*. 2020;28:4467-4476. doi:10.1007/s00520-019-05270-6
15. Pugh DS. Organizational behaviour: an approach from psychology. *Hum Relat*. 1969;22:345-354. doi:10.1177/001872676902200405
16. Boland L, Graham ID, Légaré F, et al. Barriers and facilitators of pediatric shared decision-making: a systematic review. *Implement Sci*. 2019;14:7. doi:10.1186/s13012-018-0851-5
17. Udo C, Kreicbergs U, Axelsson B, Bjork O, Lovgren M. Physicians working in oncology identified challenges and factors that facilitated communication with families when children could not be cured. *Acta Paediatr*. 2019;108:2285-2291. doi:10.1111/apa.14903
18. Tong A, Sainsbury P, Craig J. Consolidated Criteria for Reporting Qualitative Research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19:349-357. doi:10.1093/intqhc/mzm042
19. Tolley EE, Ulin PR, Mack N, Robinson ET, Succop SM. *Qualitative Methods in Public Health: A Field Guide for Applied Research*. 2nd ed. Wiley; 2016.
20. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15:1277-1288. doi:10.1177/1049732305276687
21. Simon C, Zyzanski SJ, Eder M, Raiz P, Kodish ED, Siminoff LA. Groups potentially at risk for making poorly informed decisions about entry into clinical trials for childhood cancer. *J Clin Oncol*. 2003;21:2173-2178. doi:10.1200/JCO.2003.03.003
22. Holm KE, Patterson JM, Gurney JG. Parental involvement and family-centered care in the diagnostic and treatment phases of childhood cancer: results from a qualitative study. *J Pediatr Oncol Nurs*. 2003;20:301-313.
23. Frederick NN, Campbell K, Kenney LB, Moss K, Speckhart A, Bober SL. Barriers and facilitators to sexual and reproductive health communication between pediatric oncology clinicians and adolescent and young adult patients: the clinician perspective. *Pediatr Blood Cancer*. 2018;65:e27087. doi:10.1002/pbc.27087
24. Clarke JN, Fletcher P. Communication issues faced by parents who have a child diagnosed with cancer. *J Pediatr Oncol Nurs*. 2003;20:175-191. doi:10.1177/1043454203254040
25. Sisk BA, Schulz GL, Mack JW, Yaeger L, DuBois J. Communication interventions in adult and pediatric oncology: a scoping review and analysis of behavioral targets. *PLoS One*. 2019;14:e0221536. doi:10.1371/journal.pone.0221536
26. Kaye EC, Cannone D, Snaman JM, Baker JN, Spraker-Perlman H. The state of the science for communication training in pediatric oncology: a systematic review. *Pediatr Blood Cancer*. 2020;67:e28607. doi:10.1002/pbc.28607
27. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci*. 2009;4:1-15.