



Published in final edited form as:

Patient Educ Couns. 2022 January ; 105(1): 56–61. doi:10.1016/j.pec.2021.05.003.

Conflicting Goals and Obligations: Tensions Affecting Communication in Pediatric Oncology

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Abstract

Objectives: To describe the tensions experienced by clinicians and psychosocial professionals that affect communication in pediatric oncology.

Methods: Ten focus groups with nurses, nurse practitioners, physicians, and psychosocial professionals at 2 US institutions. We analyzed transcripts using thematic analysis, assessing tensions experienced when communicating with parents.

Results: We identified 5 themes of tensions, defined as challenges experienced when clinicians and psychosocial professionals are trying to achieve multiple conflicting goals or obligations while communicating: 1) Supporting parental hopes while providing honest opinions and information; 2) Disclosing all possible outcomes while avoiding the creation of new worries or uncertainties; 3) Building relationships while maintaining personal boundaries; 4) Disclosing sensitive information while adhering to professional role and perceived authority; 5) Validating parental beliefs or decisions while fulfilling obligation for honesty. Some tensions represented conflicts between different communication goals. Others represented conflicts between a communication goal and another obligation.

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Contributors Statements

Dr. Sisk participated in conceptualization, design, and implementation of the study, participated in formal analysis, drafted the initial manuscript, and reviewed and revised the manuscript.

Dr. Schulz participated in formal analysis, and reviewed and revised the manuscript.

Dr. Kaye, Dr. Baker, Dr. Mack, and Dr. DuBois participated in conceptualization and design of the study, formal analysis, and reviewed and revised the manuscript.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Conclusion: Clinicians and psychosocial professionals experience tensions that affect communication with parents in pediatric oncology. Some tensions might be addressed with interventions or education. Others will require further analysis to provide sufficient guidance to clinicians.

Practice Implications: Unaddressed tensions might lead to poor communication and clinician burnout. Future work should explore solutions to these tensions.

Keywords

Communication; Barriers; Physician-Patient Relationship; Supportive Care; Psychosocial Oncology; Pediatric Cancer; Bioethics

1. Introduction

Communication in pediatric oncology fulfills several purposes for families. In previous work, we identified 8 core functions of communication in pediatric oncology that support family-centered care: building relationships, exchanging information, making decisions, enabling family self-management, managing uncertainty, responding to emotions, providing validation, and supporting hope.[1] By fulfilling these functions, clinicians can support trust,[2] peace of mind,[3] hopefulness,[4] and feelings of being acknowledged[5] and comforted.[6] However, communication is a complex interpersonal process that can fail for myriad reasons, ranging from individual and team-level barriers to community and policy issues.[7] When communication fails, families can experience unmet information needs,[8–13] decisional regret,[14] lower trust,[15] and decreased adherence to clinicians' recommendations.[16]

Although prior studies have explored barriers to communication and consequences of negative communication,[7, 13, 17, 18] few of these studies explored how clinicians approach conflicting goals in communication. The multiple functions and goals of communication might not always align. For example, clinicians might feel a tension between sharing bad news (exchanging information) and protecting the family from emotional harm (responding to emotions). Other clinicians might feel a tension between validating the parent's role (providing validation) and making a decision in the child's best interest (making decisions). In these situations, clinicians might have difficulties in balancing these competing goals despite their motivations to fulfill the family's communication needs. To support clinicians in their communication, we must first understand the range and characteristics of the tensions that they encounter when communicating. With this knowledge, researchers can then explore potential solutions and provide communication guidance to clinicians. In this paper, our aim was to describe the tensions experienced by oncology professionals when communication goals conflict by performing a secondary analysis of focus groups.

2. Methods

We report this study following Consolidated Criteria for Reporting Qualitative Research.[19] (Appendix 1)

2.1 Participants and Recruitment

We conducted 10 focus groups with 59 participants at 2 academic centers between December 2019 and February 2020. We performed 2 or 3 separate focus groups for each of the following disciplines: nurses, nurse practitioners, physicians, and psychosocial professionals (psychologists, social workers, chaplains, child life specialists, and art therapists.) We purposively sampled for age, level of experience, and expertise within subfields of oncology. Detailed inclusion/exclusion criteria are included in supplemental table S1. Members of the research team were excluded from the study. We included 4 to 7 participants in each focus group to promote rich discussion while ensuring speaking opportunities for all participants.[20] We conducted 2 or 3 focus groups per profession, because this number of focus groups is generally considered to approach thematic saturation if participants have relatively homogenous experiences.[20] Participants were recruited via telephone, email, and in person, and they provided informed consent prior to participation. All participants signed a confidentiality agreement at the beginning of the focus group. We did not track the number of participants who declined participation. We chose to perform focus groups rather than semi-structured interviews because we wanted to understand the shared views about communication within these professions. Focus groups are well suited to discerning group norms and expectations, and this method allows for dissenting opinions and debate within groups.[20, 21]

Attending pediatric oncology physicians who dedicated 20% of professional effort to clinical work were eligible. Oncology nurses and nurse practitioners with 1 year of clinical experience in pediatric oncology were eligible. Psychosocial professionals with 1 year of clinical experience caring for pediatric oncology patients were eligible. Institutional review boards at both sites approved this study.

2.2 Data Collection

Moderator guide development was described previously.[7] (Appendix 2) We first asked participants open-ended questions about “good communication” and what communication helped parents to do. Then we provided participants with a handout containing definitions of 8 communication functions.[1] We asked for their reactions to these functions, including whether any functions surprised them and if they disagreed with any functions. We did not explicitly ask about tensions, instead asking which functions were easiest or hardest to fulfill. Lastly, we explored multilevel barriers to fulfilling functions, which was previously published.[7]

At Washington University in St. Louis (WUSTL), a female, PhD anthropologist served as moderator. At St. Jude Children’s Research Hospital (St. Jude), a female research nurse served as moderator. Both moderators had extensive experience in qualitative research and interest in children’s health. The lead author (BAS) trained moderators by discussing pertinent literature, reviewing the moderator guide, and identifying high-priority content areas. To ensure standardization across sites, BAS reviewed transcripts at WUSTL and provided feedback to the moderator. Additionally, BAS served as note taker at St. Jude and provided feedback. Each focus group also included a note taker. Focus groups occurred in person, were audio-recorded, and professionally transcribed. Neither the moderators nor

note takers had relationships with participants. Participants completed a demographic survey and received \$75 gift certificates.

2.3 Data Analysis

We employed thematic analysis[22] to inductively identify communication tensions experienced by clinicians and psychosocial professionals. BAS and GS read transcripts to form ideas, developed initial codes, and refined codes through iterative consensus meetings. In consultation with all authors, the two coders initially coded all obstacles, defined as personal or contextual aspects of communication that impeded the oncology professional's ability to fulfill goals when communicating. The purpose of this initial coding was to identify every obstacle that participants noted as interfering with communication. After developing this codebook of obstacles, the coders discerned that several obstacles indicated tensions between competing goals. The coders defined "tensions" as challenges experienced by clinicians and psychosocial professionals when they are trying to achieve multiple conflicting goals while communicating. All transcripts were coded using Dedoose qualitative software.

3. Results

3.1 Participant Characteristics

Mean participant age was 40.1 years. Participants averaged 7.9 years of clinical experience. Focus groups lasted an average of 74 minutes. Participants were predominantly white (86%) and female (85%). (Table 2)

3.2. Communication Tensions

Below, we describe 5 themes identified from the transcripts. Table 3 shows which professionals identified these tensions.

3.2.1. Supporting parental hopes while providing honest opinions and information.—Many participants recognized the importance of honest disclosure, but they also described difficulties in supporting parental hopes in improbable outcomes. This tension was apparent when participants provided difficult news, often requiring a "delicate balance": "Supporting that hope, and still being real with the parents and giving them, you know, the prognosis and so on is a delicate balance, but I think it's essential." [Physician] Another participant described the need to align hopes with realistic goals: "At different points during the journey, supporting hope and what that hope is, and sometimes you have to redirect them in what their hopes and goals are, trying to align." [Nurse Practitioner]

This desire to support hope also led to tensions in decision making. A nurse described how clinicians can feel pressured to offer treatments with low probability of success near the end of life: "We have so many resources and so many different research projects and all this stuff that sometimes it's hard even as a provider to step back and say, 'Yeah, we have all this, but as far as quality of life goes, go spend it with your child.'" [Nurse] Participants described how adjusting the parents' expectations might require an emphasis on the low probability of success: "The parents may hear ['clinical trial'] as, 'new, up and coming therapy' and not

fully understand that it's really a last ditch effort... You have to kind of be Debbie Downer a little bit, I feel like, for them to be able to make a conscious choice of continuing with that treatment or not. You're providing a lot of hope by offering further therapies that may not actually be hope." [Nurse practitioner]

When confronted with these challenging decisions, some participants had difficulty determining their appropriate role in decision making: "Some parents will specifically ask you, 'If this was your child, what would you do?' How do you word that without being too biased and also knowing that usually one direction's not 100 percent guarantee of anything? You never want them to have regrets in their decisions, and it's very complex sometimes." [Physician]

3.2.2. Disclosing all possibilities while avoiding the creation of new worries or uncertainties.

—Participants highlighted the importance of transparent and honest communication, but they worried that sharing some low-probability risks could exacerbate uncertainty for families and cause undue worry: "I personally struggle the most with managing uncertainty because I think there's multiple aspects of that and I think there's this tension between providing information about possibilities and then basically setting up for worrying about possibilities that are highly uncertain." [Physician] This tension was prominent during informed consent conferences: "Inevitably, as part of that consent, there's a huge list of side effects and no patient gets all the side effects and basically no patient gets none of the side effects and so you've just given them this world of uncertainty." [Physician] A nurse described how disclosing hypothetical outcomes could affect the family's trust: "I would hate to tell a parent that X, Y, and Z will happen, and then parents are like 'Whoa, but A, B, and C happened instead.'" [Nurse] Physicians described how family-centered rounds created worries for families:

“Physician 1: I think it's a lot of information we're giving to the patient. I see it in the ICU. This 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, and everybody—family-centered care with every specialty talking in front of the family, and then sometimes it's different. I think there's something called too much information.

Physician 2: Then you create uncertainty a lot of times with that.

Physician 3: Instead of managing uncertainty, it creates uncertainty." [Physicians]

3.2.3. Building relationships while maintaining personal and professional boundaries.

—Participants indicated that developing relationships is central to communication. Yet, participants noted how this desire to build relationships was in tension with the need for boundaries. Physicians mostly focused on their difficulty in setting workload boundaries related to extra effort or work they felt comfortable undertaking: "We have other things, and if we all had our patients have our personal numbers and things like that, then everybody'd burn out, and it wouldn't be good for anyone." [Physician] This need for boundaries conflicted with their motivation to support families:

“We all go into this field because we really care, and so then you can carry away those behaviors, because you’re like, ‘Man, their child has cancer. They’re not doing well. If they really need to see me, then forget it. I’m just gonna leave my family right now and go talk to them.’ It’s not necessarily the best move, but we all have a lot of empathy for our patients, which is why we do this.” [Physician]

Another physician commented: “For me personally it’s the most challenging because I acknowledge in myself that part of good communication with families is both sides should have boundaries... I frequently find myself pushing those boundaries a little bit in a way that allows our families to be overly reliant on our help.” [Physician]

Other participants described the need for emotional boundaries: “[Being] a mom has opened up a whole other sense of emotion. I think it’s very—I still struggle emotionally with it.” [Nurse] A nurse practitioner described the difficulty of finding the right balance of emotional involvement: “We have so many patients that we see and are dealing with similar things. I won’t say we turn it off, but if we internalized everyone’s emotions, we would not be very effective. Knowing when and how to respond to some of those emotions can be difficult and still be a person and not a robot.” [Nurse Practitioner] Psychosocial professionals also felt this emotional burden, but they worried that other colleagues struggled with boundaries: “We certainly grieve the loss of our patients, but it’s very different. I feel like I can still continue on with the work that I’m doing. Whereas, I do worry sometimes about our other staff members, given their poor boundaries at times.” [Psychosocial professional]

Participants also discussed the need to prevent personal struggles from affecting patients and families: “Life outside doesn’t stop for either party. Unfortunately, sometimes life happens for both the clinicians that are helping support these families, and then life happens for the families that we’re supporting. Sometimes, that communication on our part can be very challenging.” [Psychosocial professional] Another psychosocial professional noted: “You have to separate your junk from their junk so that your personal history, your life shouldn’t be in play in the situation at all.” [Psychosocial professional]

Lastly, participants described difficulties in maintaining professional boundaries, often manifesting as requests from families to connect via social media and support fundraising ventures. Some disciplines struggled more than others, especially nurses: “With us [psychosocial professionals], we would never ‘friend’ a family on Facebook. That is a no. You don’t do that, but nursing staff are friends with families on Facebook, and they—I don’t know—view their boundaries differently than we do.” [Psychosocial professional] One psychosocial professional suggested that other clinicians (especially nurses) struggle with this boundary because they lack explicit professional standards related to social media: “I think because [professional expectations] look so different for us compared to maybe our medical counterparts where it seems like we have very clear ethical standards outlined by our disciplines and our code of ethics. I feel like maybe those aren’t equally represented in other disciplines.” [Psychosocial professional]

3.2.4. Disclosing sensitive information while adhering to professional role and authority.—Nurse practitioners described situations where families did not have all the information they needed: “I have been in situations where... the communication wasn’t as transparent as it should have been to allow the parents to manage uncertainty.” [Nurse practitioner] However, some participants felt that they lacked authority to share certain information: “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 from their physician.” [Nurse Practitioner] Another nurse practitioner stated: “Are we the one to communicate a relapse or something like that? I think that’s where the role of a nurse practitioner is kind of [unclear].” [Nurse Practitioner] One nurse practitioner described how her role was at the physician’s discretion: “It’s knowing your limits and knowing what you can communicate or what you should or you shouldn’t. I think it varies physician to physician on who thinks that we should or shouldn’t.” [Nurse practitioner]

Nurses described similar tensions when they were aware of a test result before the clinicians had disclosed the information to the family:

“A lot of times, we can see when pathology comes back on bone marrow or a tumor, or we get to see the scan before. A lot of times the physicians will say, ‘Tell that family that we’ll be by at about 3:00 p.m.’ Well, it’s 10:00 a.m., and here all of this is just sitting on my mind and my heart because we’re human. Mom and Dad are just sitting there so anxiously. ‘I know that these results are gonna come back today,’ so every time you walk in the room, ‘Have you heard anything? Are they back yet?’ I know that the results aren’t good, but here I have to put on a face, right, that says that I don’t know things.” [Nurse]

Physicians encountered similar tensions when caring for their colleagues’ patients: “Not wanting to overstep my boundary.” [Physician]

3.2.5. Validating parental beliefs or decisions while fulfilling obligations for honesty.—Participants described their motivation to validate parents’ “good parenting” beliefs that conflicted with their obligation to be honest with the family. Often, this tension related to helping parents feel like they made the right decision for their child:

Nurse 1: I had a patient last week that relapsed during treatment, and Mom decided to start [intensive chemotherapy]. Mom looked at me at 3:00 a.m. and she—the patient was asleep. Mom was like, ‘Was this what I was supposed to do?’ As a parent, well this is what we have available. Of course you’re gonna want that. As a nurse, that’s terrifying. How do you respond in that situation? Not saying it’s right or wrong. I just said this is a decision that you guys both made together and we’re gonna get you through it day by day. Right now, this is what you decided, and that’s what we’re gonna stick with and go with. Nurse 2: I think when you come to that situation, you always have to point out the positive because there’s not turning back. They’ve committed to this. You focus on the positives.

A physician commented: “We recently had a [cancer] patient who died within 36 hours of being at this institution. I don’t know if the family had brought him to medical care sooner if there would’ve been a different outcome, but it doesn’t matter because what the

parent needs to hear is that there's nothing they could've...If I say to them, 'maybe if you brought him [earlier],' that's not gonna make anything better." [Physician] A nurse succinctly summarized: "I think even putting on that brave face as a nurse and supporting them, even if you don't agree with it, is good communication." [Nurse]

4. Discussion and Conclusion

4.1 Discussion.

We identified 5 themes of tensions that clinicians and psychosocial professionals experienced when goals and obligations conflicted during communication. Some of these tensions represented direct conflicts between communication functions. For example, participants described the conflict between supporting parental hopes while honestly exchanging difficult information. They viewed supporting hope as a central duty, but they simultaneously recognized the harms of withholding information. Participants also described conflicts between information exchange, managing uncertainty, and emotional support. They expressed the importance of providing full and transparent information about side effects of cancer treatments, but they did not want to create additional uncertainties and worries for families, especially for low-probability risks.

Other tensions resulted from conflicts between a communication function and other goals or obligations. Building a strong clinical relationship, for example, conflicted with the need to create workload, emotional, and professional boundaries. Participants also described the desire to share information with families, but feeling limited in their authority to communicate by hierarchy within the medical team. For example, a nurse described her discomfort at knowing that a child's disease had progressed, but feeling unable to respond truthfully when the parents asked if the results were available. Lastly, participants described their desire to validate parents in their beliefs, but struggling with their obligation to be honest if they thought the parents had made a bad decision.

The extent to which certain tensions affected communication seemed to differ by profession. For example, physicians struggled most with creating workload boundaries and setting limits on how much time and effort they would expend to fulfill a given family's needs. Nurses had more difficulty with setting emotional and professional boundaries (e.g. social media interactions and fundraiser participation). Furthermore, nurses and nurse practitioners described situations where they felt restricted in their communication by the physician's hierarchical authority. Physicians described the tension between honest disclosure and avoiding unnecessary uncertainties, probably because the hierarchy created a responsibility for them to communicate this information.

Each of these tensions represents a challenge that clinicians and psychosocial professionals must navigate in their daily practice while attempting to fulfill general ethical principles of beneficence, nonmaleficence, autonomy, and justice. Childress et al. published a framework for addressing moral conflicts in implementing public health policies. [23] Although public health and interpersonal communication have many differences, this framework might provide a starting point to help oncology professionals to navigate these conflicting communication goals.

This framework includes 5 justificatory conditions to help determine whether promoting one goal or obligation warrants overriding another goal or obligation: effectiveness, proportionality, necessity, least infringement, and public justification.[23] “Effectiveness” requires that infringing upon one goal will likely lead to fulfillment of a second goal. “Proportionality” requires that the benefits of this second goal are important enough to justify the infringement upon the first goal. “Necessity” requires that the infringement is necessary to achieve this second goal. “Least infringement” requires that clinicians and psychosocial professionals infringe upon the first goal to the least extent required to achieve the second goal. “Public justification” involves justifying intrusive public health policies to the affected population. To adapt this framework to tensions in communication, we propose replacing “public justification” with “transparency and engagement,” which requires engagement with parents and patients when resolving the tensions between goals.

Applying this framework to tensions from our study might provide guidance on how to address conflicting goals. (Figure 1) For example, participants described a tension between the obligation to provide honest information and the goal of supporting parents in their hope. In this scenario, the literature on hope demonstrates that many hopes can coexist,[24–26] hope for cure is only one of these hopes,[25, 27–29] and that disclosing a poor prognosis can *support* parental hope.[30] Additionally, a growing body of literature recommends that clinicians and psychosocial professionals assist parents in regoaling over time by identifying important and achievable goals as clinical realities change.[31] As such, withholding difficult information is unlikely to support parental hope, and the conditions of “effectiveness” and “necessity” are not met. Furthermore, this justificatory model calls for transparency with involved stakeholders. Oncology professionals who worry about disclosing difficult information can transparently engage parents to determine their preferences, rather than engaging in paternalistic protection of the parents’ emotional state. With education, clinicians might also learn to explore uncertainties and worries with parents and patients[32], and to set new goals as certain hopes become unattainable.[31]

When these tensions go unaddressed, clinicians and psychosocial professionals might experience moral distress. Moral distress occurs “when an individual has made a moral decision but is unable to act on it.”[33] For example, a nurse might feel morally obligated to disclose test results to parents, but the medical hierarchy prevents this disclosure. Physicians might experience moral distress if, in order to validate and support parental authority, they offer a treatment that will worsen symptoms with limited prospect of benefit. Nurses might feel moral distress in administering these “unwise” treatments to the patient. Some tensions might be addressed with education, communication training, or strengthened team dynamics. Others will require further ethical analysis to provide guidance. Failing to acknowledge and address these tensions, however, could lead to emotional distress and burnout for clinicians and psychosocial professionals who care for children with cancer.

This study should be interpreted in light of limitations. Social desirability and hierarchy could have prevented some individuals in focus groups from sharing personal thoughts, although we attempted to mitigate this mum effect by conducting focus groups by discipline. Also, our study did not include trainees or palliative care professionals, and participants were predominantly white women. We conducted this study at 2 academic centers, and

tensions and conflicts might differ at other institutions. Lastly, this study lacked perspectives from parents and patients, which would have provided richer context to these tensions and conflicts.

4.2 Conclusion.

Clinicians and psychosocial professionals experience several tensions between competing goals when communicating in pediatric oncology. Some of these tensions might be addressed with communication training, education, or improved team dynamics. Other tensions will require further study and normative analysis. As a starting point, oncology professionals might apply the framework of justificatory conditions to help determine whether promoting one goal warrants overriding another goal.

4.3 Practice Implications.

Clinicians and psychosocial professionals identified 5 tensions that they experienced when communication goals and obligations conflicted. Each of these tensions represents a challenge that clinicians and psychosocial professionals must navigate in their daily practice while attempting to fulfill general ethical principles of beneficence, nonmaleficence, autonomy, and justice. Applying the justificatory framework might support oncology professionals as they navigate these tensions with the goal of providing optimal care for patients and families. Unaddressed tensions might lead to poor communication, moral distress, and clinician burnout. Future work should explore the effect of these tensions on clinicians and develop approaches to resolving these conflicts.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

This work was supported by the American Society of Clinical Oncology – Conquer Cancer Foundation [Young Investigator Award], and by the National Center for Advancing Translational Sciences of the National Institutes of Health under Award Number [UL1 TR002345].

References

- [1]. Sisk BA, Friedrich A, Blazin LJ, Baker JN, Mack JW, DuBois J, Communication in Pediatric Oncology: A Qualitative Study, *Pediatrics* 2020;146:e20201193. [PubMed: 32820068]
- [2]. 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;548–54. [PubMed: 22228677]
- [3]. 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. [PubMed: 19487607]
- [4]. 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;626–31. [PubMed: 27115314]
- [5]. 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;443–9. [PubMed: 22092322]

- [6]. 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, *Brit Journ Cancer* 2013;109;836–43.
- [7]. Sisk BA, Friedrich A, Kaye E, Baker JN, Mack JW, DuBois JM, Multilevel Barriers to
Communication in Pediatric Oncology: Clinicians' Perspectives, *Cancer* 2021;Online ahead of
print. DOI: 10.1002/cncr.33467
- [8]. Sisk BA, Kang TI, Mack JW, Prognostic disclosures over time: Parental preferences and physician
practices, *Cancer* 2017;123;4031–8. [PubMed: 28369836]
- [9]. Mack JW, Cronin AM, Uno H, Shusterman S, Twist CJ, Bagatell R, Rosenberg A, Marachelian
A, Granger MM, Glade Bender J, Baker JN, Park J, Cohn SL, Levine A, Taddei S, Diller
LR, Unrealistic parental expectations for cure in poor-prognosis childhood cancer, *Cancer*
2019;126;416–24. [PubMed: 31584705]
- [10]. Rosenberg AR, Orellana L, Kang TI, Geyer JR, Feudtner C, Dussel V, Wolfe J, Differences
in parent-provider concordance regarding prognosis and goals of care among children with
advanced cancer, *J Clin Onc* 2014;32;3005–11.
- [11]. Greenzang KA, Fasciano KM, Block SD, Mack JW, Early information needs of adolescents
and young adults about late effects of cancer treatment, *Cancer* 2020;126;3281–8. [PubMed:
32365227]
- [12]. Greenzang KA, Cronin AM, Kang T, Mack JW, Parent understanding of the risk of future
limitations secondary to pediatric cancer treatment, *Pediatr Blood Cancer* 2018;65:e27020.
[PubMed: 29603610]
- [13]. Sisk BA, Zavadij JA, Blazin LJ, Baker JN, Mack JW, DuBois JM, “Assume It Will Break”:
Negative Communication Experiences in Pediatric Oncology, *J Clin Onc - Oncology Practice*
2021;[Accepted - In Press].
- [14]. Sisk BA, Kang TI, Mack JW, The evolution of regret: decision-making for parents of children
with cancer, *Supp Care Cancer* 2020;28;1215–22.
- [15]. Mack JW, Kang TI, Care experiences that foster trust between parents and physicians of children
with cancer, *Pediatr Blood Cancer* 2020;67:e28399. [PubMed: 32827346]
- [16]. Baenziger J, Hetherington K, Wakefield CE, Carlson L, McGill BC, Cohn RJ, Michel G,
Sansom-Daly UM, Understanding parents' communication experiences in childhood cancer: a
qualitative exploration and model for future research, *Supp Care in Cancer* 2020;28;4467–76.
- [17]. Mack JW, Currie ER, Martello V, Gittzus J, Isack A, Fisher L, Lindley LC, Gilbertson-White S,
Roeland E, Bakitas M, Barriers to Optimal End-of-Life Care for Adolescents and Young Adults
With Cancer: Bereaved Caregiver Perspectives, *JNCCN* 2021;1–6.
- [18]. Mack JW, Ilowite M, Taddei S, Difficult relationships between parents and physicians of children
with cancer: A qualitative study of parent and physician perspectives, *Cancer* 2017;123;675–81.
[PubMed: 27727442]
- [19]. 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;349–57.
[PubMed: 17872937]
- [20]. Tolley EE, Ulin PR, Mack N, Robinson ET, Succop SM, *Qualitative methods in public health : a
field guide for applied research*, Second edition. ed., Wiley, San Francisco, CA, 2016.
- [21]. Barbour R, *Doing Focus Groups*, 1 ed., SAGE Publications Ltd.2008.
- [22]. Braun V, Clarke V, Using thematic analysis in psychology, *Qual Res Psychology* 2006;3;77–101.
- [23]. Childress JF, Faden RR, Gaare RD, Gostin LO, Kahn J, Bonnie RJ, Kass NE, Mastroianni
AC, Moreno JD, Nieburg P, Public health ethics: mapping the terrain, *J Law Med Ethics*
2002;30;170–8. [PubMed: 12066595]
- [24]. Hill DL, Nathanson PG, Carroll KW, Schall TE, Miller VA, Feudtner C, Changes in Parental
Hopes for Seriously Ill Children, *Pediatrics* 2018;141:e20173549. [PubMed: 29567813]
- [25]. Feudtner C, Carroll KW, Hexem KR, Silberman J, Kang TI, Kazak AE, Parental hopeful patterns
of thinking, emotions, and pediatric palliative care decision making: a prospective cohort study,
Arch Pediatr Adolesc Med 2010;164;831–9. [PubMed: 20819965]
- [26]. Feudtner C, The breadth of hopes, *N. Engl. J. Med* 2009;361;2306–7. [PubMed: 20007559]

- [27]. Sisk BA, Kang TI, Mack JW, Sources of parental hope in pediatric oncology, *Pediatr Blood Cancer* 2018;65:e26981. [PubMed: 29369485]
- [28]. Hill DL, Nathanson PG, Fenderson RM, Carroll KW, Feudtner C, Parental Concordance Regarding Problems and Hopes for Seriously Ill Children: A Two-Year Cohort Study, *J Pain Symptom Manage* 2017;53:911–8. [PubMed: 28062346]
- [29]. Hill DL, Miller VA, Hexem KR, Carroll KW, Faerber JA, Kang T, Feudtner C, Problems and hopes perceived by mothers, fathers and physicians of children receiving palliative care, *Health Expect* 2015;18:1052–65. [PubMed: 23683168]
- [30]. Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC, Hope and prognostic disclosure, *J Clin Onc* 2007;25:5636–42.
- [31]. Hill DL, Miller V, Walter JK, Carroll KW, Morrison WE, Munson DA, Kang TI, Hinds PS, Feudtner C, Regoaling: a conceptual model of how parents of children with serious illness change medical care goals, *BMC Palliat Care* 2014;13:9.
- [32]. Snaman JM, Feraco AM, Wolfe J, Baker JN, “What if?”: Addressing uncertainty with families, *Pediatr Blood Cancer* 2019;66:e27699. [PubMed: 30848085]
- [33]. Deschenes S, Gagnon M, Park T, Kunyk D, Moral distress: A concept clarification, *Nurs Ethics* 2020;27:1127–46. [PubMed: 32249662]

Highlights:

- The authors performed 10 focus groups with 59 pediatric oncology professionals.
- Clinicians indicated 5 themes of tensions that interfered with communication goals.
- A framework of justificatory conditions might help if communication goals conflict.

Justificatory Condition	Question to Ask
Effectiveness	Will infringing upon one goal likely lead to fulfillment of a second goal?
Proportionality	Are the benefits of this second goal important enough to justify infringement upon the first goal?
Necessity	Is infringement upon the first goal necessary to achieve the second goal?
Least Infringement	How can I least infringe upon the first goal while achieving the second goal?
Engagement and Transparency	Have I engaged with the family to resolve the tension between goals?

Figure 1.
Applying the Justificatory Conditions to Tensions in Communication

Table 1.

Participant Characteristics

Participant Characteristics (N=59)	n (%)
Gender	50 Female (85%) 9 Male (15%)
Age (Mean, Standard Deviation) ^a	M=40.1 years, SD=10.2
WUSTL	20 (34%)
St. Jude	39 (66%)
Professional Role	
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%)
Years in Practice (Mean, Standard Deviation) ^a	M=7.9 years, SD=5.8
Race	
White	51 (86%)
Black/African American	4 (7%)
Asian	4 (7%)
Ethnicity	
Hispanic	2 (3%)
Non-Hispanic	57 (97%)

^aData missing for 6 respondents

Table 2.

Definitions of Communication Tensions

Communication Tension	Definition
Supporting parental hopes while providing honest opinions and information	Clinicians can struggle to provide difficult information in a direct, honest manner while also attempting to support the emotional wellbeing and hopes of the family.
Disclosing all possibilities while avoiding the creation of new worries or uncertainties	Clinicians strive to provide clear and transparent information about toxicities, late effects, and prognosis, but they also worry they might create new uncertainties and worries for families by sharing too many low probability risks or hypothetical scenarios.
Building relationships while maintaining personal and professional boundaries	Clinicians can struggle to develop an empathic relationship and demonstrate fidelity to the patient while also maintaining boundaries that protect their emotional wellbeing, work-life balance, and professional obligations.
Disclosing sensitive information while adhering to professional role and perceived authority	Clinicians recognize an obligation to share sensitive medical information with families, but might feel restricted in their ability to provide this information due to their professional roles and hierarchy within the medical team.
Validating parental beliefs or decisions while fulfilling obligation for honesty	Clinicians strive to validate parents and help them avoid regret, but this intention can conflict with their perceived duty to provide their honest opinions and to support the best interests of the child.

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Table 3.

Communication Tensions Reported by Profession

Communication Tension	Nurse	Nurse Practitioner	Physician	Psychosocial
Supporting parental hopes while providing honest opinions and information				
Disclosing all possibilities while avoiding the creation of new worries or uncertainties				
Building relationships while maintaining personal and professional boundaries				
Disclosing sensitive information while adhering to professional role and perceived authority				
Validating parental beliefs or decisions while fulfilling obligation for honesty				

The blue shaded areas indicate tensions that at least one clinician identified within each profession. The white areas indicate that clinicians did not describe this tension during focus groups.