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## Seven Types of Uncertainty When Clinicians Care for Pediatric Patients With Advanced Cancer.

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## Seven Types of Uncertainty when Clinicians Care for Pediatric Patients with Advanced Cancer

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### Abstract

**Context**—Clinicians deciding whether to refer a patient or family to specialty palliative care report facing high levels of uncertainty. Most research on medical uncertainty has focused on prognostic uncertainty. As part of a pediatric palliative referral intervention for oncology teams we explored how uncertainty might influence palliative care referrals.

**Objectives**—To describe distinct meanings of the term “uncertainty” that emerged during the qualitative evaluation of the development and implementation of an intervention to help oncologists overcome barriers to palliative care referrals.

**Methods**—We conducted a phenomenological qualitative analysis of “uncertainty” as experienced and described by interdisciplinary pediatric oncology team members in discussions, group activities and semistructured interviews regarding the introduction of palliative care.

**Results**—We found that clinicians caring for patients with advanced cancer confront seven broad categories of uncertainty: prognostic, informational, individual, communication, relational, collegial, and inter-institutional. Each of these kinds of uncertainty can contribute to delays in referring patients to palliative care.

**Conclusion**—Various types of uncertainty arise in the care of pediatric patients with advanced cancer. To manage these forms of uncertainty, providers need to develop strategies and techniques to handle professionally challenging situations, communicate bad news, manage difficult interactions with families and colleagues, and collaborate with other organizations.

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## Keywords

uncertainty; palliative care; advanced cancer; life threatening illness; pediatrics; prognostic uncertainty; informational uncertainty; individual uncertainty; communication uncertainty; relational uncertainty; collegial uncertainty; inter-institutional uncertainty

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Clinicians caring for patients with serious illness often confront uncertainty.(1–5) Low tolerance for uncertainty (2, 6, 7) can result in excessive diagnostic testing, avoidance of discussing prognosis, delays in addressing goals of care, suboptimal symptom management, and failure to initiate palliative care in a timely manner.(3, 8–11) This dynamic is especially problematic in pediatrics because children with life threatening illness have extremely variable life expectancy.(12, 13)

We recently conducted a project with interdisciplinary pediatric oncology teams (physicians, social workers and nurse practitioners) to codesign an intervention to help oncologists overcome barriers to palliative care referrals.(14, 15) We expected, based on the published literature, that a major barrier to palliative care referrals would be prognostic uncertainty: specifically, not being certain what morbidities the child would experience or how long the child would live. Accordingly, we focused discussions, intervention activities, and interviews on their experience of “uncertainty”. Oncology team members reported, however, that prognostic uncertainty was rarely the main source of uncertainty when considering a palliative care referral.

We therefore sought in this qualitative analysis to clarify the different types of uncertainty that these clinicians experience when caring for patients with advanced cancer.

## METHODS

We conducted a qualitative study concurrent with the codesign and evaluation of our intervention to understand factors that shaped implementation.(14, 15) Methods included ethnographic observations of team meetings and semistructured in depth interviews with interdisciplinary oncology team members before and after the intervention. Our goal in the interviews was to understand how clinicians experience caring for children with advancing cancer, their perceptions of specialized palliative care and their opinions about the intervention. This study was approved by the IRB at The Children’s Hospital of Philadelphia (CHOP). All participants provided verbal informed or written consent.

### Participants

Twenty-nine interprofessional oncology staff (attending physicians, nurse practitioners, social workers, and fellows) from three pediatric oncology teams (Bone Marrow Transplant, Neuro-Oncology, and Solid Tumor) at CHOP were recruited from April 2016 to May 2017 for either the codesign or the intervention phase of the project (Table 1).(14)

### Sources of Data

We took detailed field notes during all codesign and intervention sessions, noting verbatim commentary, participant body language and interactions. In order to triangulate our

observations, we interviewed 16 clinicians (8 attending physicians, 5 nurse practitioners, 3 social workers) in person using a semistructured guide. Questions were open-ended and designed to elicit clinician experiences caring for children with advancing cancer and their perceptions of specialty palliative care and the intervention. Interviews were conducted by a research assistant who was trained and supervised by a medical sociologist. The interviewer elicited rich and detailed descriptions from clinicians that characterized their experiences caring for children with advancing cancer. The interviewer probed for additional detail when appropriate. The interviewer and medical sociologist met every other week during data collection to review the interview transcripts, identify emerging themes, monitor for saturation of key concepts and prepare data collection memos documenting decisions and emerging interpretations.

## Analysis

Interviews were audio-recorded and transcribed. Transcripts and fieldnotes were imported into NVivo 11 for analysis. Two coders analyzed the interview transcripts and fieldnotes. We created our code book using a hybrid inductive-deductive process, creating codes ahead of time based on our interview guide while also allowing salient themes to emerge. The code book was discussed among the research team members. Intercoder reliability was periodically evaluated during analysis using the coding comparison function in NVivo 11. Discrepant interpretations were examined and resolved by consensus among the research team.

We adopted a phenomenological approach during analysis to conceptualize “uncertainty” in our data.(16, 17) By closely examining the terms in which our respondents described and interpreted the lived experience of caring for children with advancing cancer, we sought an understanding of uncertainty that better reflected the complexity of the lifeworld of pediatric oncology than is currently presented in the literature. (18) Throughout the codesign and intervention sessions, a variety of questions and specific tasks addressed the phenomenon of “uncertainty” in the context of advanced cancer, wherein participants either cited uncertainty as a factor in individual or group behavior, or expanded upon aspects of this uncertainty. The results presented here are based on our analysis of how participants described experiencing uncertainty in caring for children with advancing cancer. Through examining these descriptions, we sought to identify how uncertainty manifests within and influences pediatric advanced cancer care and the potential introduction of palliative care.

## RESULTS

We identified seven types of uncertainty that clinicians confront when considering whether to propose a palliative care consultation for patients with advanced cancer: prognostic, informational, individual, communication, relational, collegial, and inter-institutional (Figure). Although these types of uncertainty overlap and interact, they each present distinct challenges.

## PROGNOSTIC UNCERTAINTY

Prognostic uncertainty has long been identified as a major challenge in clinical medicine.(1, 19) The clinicians in our study acknowledged that prognostic uncertainty can make care planning more difficult. As one physician stated: “One of the challenges of modern medicine is that patients live longer who in the past would have died by a certain time. So, you no longer know how long patients might live.” (14) While prognostic uncertainty was invoked as a challenge, our respondents suggested that it alone was not the major way in which uncertainty influenced the delay in receipt of specialty palliative care. Their experience of uncertainty had multiple dimensions beyond whether a child would live or die. A physician described a clinical scenario he encountered during training that highlights the complex way in which uncertainty is experienced:

One that I'll remember my whole life was when I was very young. There was a patient in the ICU who had terrible complications. It was a very refractory disease and it wasn't going to get better. All of us younger specialists of all stripes came in and said, 'I'm 99 percent sure that she's going to die. I've never seen someone recover. ' The parents were very astute people and said, 'Are you sure?' All of us were so afraid of being wrong that we left the door open a tiny bit because we want to be wrong. A senior person came in and said, 'I'm sure. It's done.' The parents were so relieved that somebody with gray hair finally said, 'Enough. Ninety-nine percent is garbage. I've been doing this a long time. It's time.' They were so relieved. It just changed the whole thing. I thought, 'I want to be like that. I want to be that person. ' I think he felt like, 'I could be wrong but I'm not. ' We all thought that they kept asking about uncertainty because they had hope and they didn't want to let it go. They were pushing us in one direction. This senior person saw it totally differently and perceived it as, 'I'm helping them to somewhere else.' It was so incredible. It was what we all wanted to say but we were afraid. I felt at that time me being afraid of being wrong doesn't matter. They actually needed someone to reassure them that she didn't have a snowball's chance in hell. Close the door. We mistook our anxiety for their anxiety. It was the opposite of what we thought they wanted.

In this case, prognostic uncertainty was invoked, but was not the primary experience of uncertainty for this clinician. Uncertainty emerged as a property of interpersonal relationships and professional identity. We found similarly nuanced and complex narratives emerge across respondents. While prognostic uncertainty was implicated in many sessions and interviews, our respondents described experiencing six other types of uncertainty.

## INFORMATIONAL UNCERTAINTY

Participants described how involving palliative care can be difficult in pediatric oncology because of informational uncertainty about a child's diagnosis or the availability and efficacy of treatment. As one physician explained:

So, there are the children who have refractory disease that gets bigger on therapy, and that's an easy decision because clearly your therapy is not helping them. The

decision requires a lot of thoughtful consideration if the tumor just isn't getting smaller. Because the question is, is the risk and benefit balanced if you're doing that? And what therapy do you have that is better? And that's really the linchpin to the decision is... if you think there is better therapy you can switch to it. But many times, there isn't anything that's proven to be better.

The clinician may wonder: Are there new treatments available? Is the patient eligible for any clinical trials? New, sometimes experimental, treatment options may be very helpful for some patients but toxic for others.(20, 21) One of the dangers of trying to reduce this informational uncertainty is that clinicians may end up ordering unnecessary testing and putting off difficult decisions.(3, 22)

## INDIVIDUAL UNCERTAINTY

Clinicians also expressed uncertainty about their own personal or professional values framework, and how to handle situations where two core values are in conflict. In some cases, advocating too much for palliative care went against other professional values. One social worker said, "I wouldn't tell the parent what to do [stopping treatment]. I need to let the parent feel they did everything they could do."

Even clinicians who regularly consulted the specialty palliative care team acknowledged sometimes waiting too long because they were emotionally involved with the family. As one physician who was a self-described "champion" of early involvement of palliative care described in an interview:

You have to have some sort of emotional and philosophical barrier to enable you to have distance to make that kind of recommendation [to consult specialty palliative care], because we are people...There are definitely two patients that I can think of off the top of my head that I'm too close to [consult palliative care]. I would go batshit crazy trying anything on the planet to try and save the lives of those two children... I would need someone else to step in and have that conversation, because I couldn't do it.

Our respondents also described how clinicians may associate their own professional identity and competence with successful treatment, which exacerbates individual uncertainty about the ramifications of consulting palliative care. Physician respondents, in particular, equated a poor patient outcome with "failure" on their part. Physicians may also be reluctant to admit uncertainty to patients and family members because they worry they will appear incompetent.(23)

Even if a patient had a definitive diagnosis of a fatal condition and no good treatment options existed, clinicians expressed uncertainty regarding what a good doctor, nurse, or social worker should do in this situation. Should they be bluntly honest? Should they break the news gradually to give the family time to adjust? Or should they be deliberately vague, so the family can maintain hope for a little longer?(24)

## COMMUNICATION UNCERTAINTY

Our respondents suggested that they might be uncertain of how to communicate information about palliative care in an honest, caring and accurate way. Respondents described experiencing uncertainty about how families receive the intended message:

[I'm] not sure how much the family hears at diagnosis, if you are giving numbers or percentages to describe survival, they many not hear even if the numbers are not good.

Other respondents reported that sometimes there is uncertainty about whether trainees have mentioned possible treatments in a way that unintentionally misleads a family. In several sessions, participants requested suggested wording for introducing the palliative care team to parents. In our interviews, respondents described that training about how to communicate with families was not formal, but was based on observing skilled senior clinicians.

## RELATIONAL UNCERTAINTY

A fifth type of uncertainty that our respondents described as particularly stressful is uncertainty about the future of their relationship with patients and families as a result of bringing up palliative care. Our respondents described one of their biggest concerns as mentioning palliative care before the family was ready, negatively impacting their relationship with the family, and undermining future attempts to provide support. Respondents perceived the introduction of palliative care as emotionally risky<sup>(15)</sup> and requiring a high level of emotional intelligence to do successfully, as the following excerpt illustrates:

One reason you might delay a PACT referral is there is too much emotion on part of family, and things are already too complicated. You don't want to introduce something else right away.

Respondents described introducing the specialized palliative care team as a potential “bombshell,” largely because they had difficulty predicting how a given family might react. One physician described a case of a family with which he had a long-standing relationship. He was sure this family would hate the idea of palliative care, “but they ended up loving it. But other families react badly, saying ‘Why are you calling in the death team?’”. Clinicians worried that a family might perceive a palliative care referral as the medical team giving up on their child. Negative emotional reactions from families caused high levels of negative emotions for clinicians. Some providers had particularly vivid memories and stories about families that had reacted negatively to the mention of palliative care – a so-called “trigger” for families who associated palliative care with death<sup>(15)</sup> – leading these providers to be hesitant about introducing palliative care too soon with other families. Clinicians were anxious about the possibility of upsetting the family.

## COLLEGIAL UNCERTAINTY

Uncertainty about how colleagues might react to the suggestion of a palliative care referral was another type of uncertainty that our respondents identified. Certain physicians were



known to be more or less receptive to palliative care. Clinicians reported being less comfortable with suggesting palliative care on teams they didn't work with regularly because they were unsure how the team members might react. As one physician stated:

If it is [a colleague that] you have a prior truth telling relationship with then you can say 'what the hell are you thinking? Stop this madness. This is ridiculous.' So it is all based on your prior relationship. If it is someone with whom you don't have a good line of communication with you have to be careful.

Even physicians on the same hierarchical level felt they had to be very tactful about suggesting palliative care to their colleagues. A social norm prevailed, such that a physician could ask another physician if palliative care had already been involved, but directly suggesting that the other physician should consider a palliative care referral would be rude and condescending. Team members exhibited deference to the primary oncologist around the timing of palliative care consultation, even when a number of other clinicians thought the primary oncologist's opinion was wrong.

## INTER-INSTITUTIONAL UNCERTAINTY

Children receiving oncologic treatment frequently receive second opinions from multiple institutions and even travel between institutions to receive treatment. Consequently, the beliefs and actions of medical professionals outside of the institution were another source of uncertainty reported by our participants. Sometimes the pediatric oncology team was caught off guard when an oncologist outside the institution reacted badly to the mention of palliative care. The outside provider might assure the family that the situation was not that bad yet, and that they personally would find some new treatment options. Such mixed messages were of course confusing and upsetting for the patient and family.

One nurse practitioner described a case in which she questioned whether a treatment proposed by a physician at another institution was really in the patient's best interest given the potential negative effects on the patient's quality of life. This physician dismissed her concerns abruptly; a physician at her own institution, however, validated her concerns and did not allow the outside physician to dismiss them. In other cases, providers offered treatments that they stated were unlikely to be effective instead of referring the family to palliative care because they worried that the family would otherwise go to another institution that might offer experimental treatments with poor symptom management and little chance of benefit.

Note that in some cases, different types of uncertainty may overlap and compound each other. In the example above, the nurse practitioner might not have challenged the physician at the other institution if she had been uncertain regarding the appropriateness of her doing so given her role or if she was uncertain about whether she would be supported by colleagues at her own institution. Uncertainty about the care provided at other institutions can also increase the importance of protecting the clinician relationship with the family. One social worker said: "Trust issues are important. If we get to a point where we have no more curative therapies to offer, families often look elsewhere. [You have to] let the dust settle... [and] then offer [palliative care.]"

## DISCUSSION

Through this qualitative analysis of discussions, activities, and interviews with pediatric oncology clinicians, we found that they experience many kinds of “uncertainty” well beyond the traditionally recognized uncertainty about prognosis. Clinicians may be unsure how patients, family members, colleagues, other institutions, and even they themselves will react when confronting life threatening advanced cancer and contemplating the introduction of palliative care.

While a single-center study cannot ensure that this catalogue of types of uncertainty is complete, or generalizable to other sites, other reports have hinted at or explicitly identified forms of uncertainty beyond narrowly conceived prognostic uncertainty. One conceptualization of uncertainty among family caregivers in healthcare situations draws a distinction between uncertainty about facts (such as the chances that a given treatment will work) and a broader existential uncertainty (such as what one’s role as a caretaker should be).(25) Another theoretical model suggests that clinicians deal mostly with uncertainty about medical knowledge or probability and patients deal more with uncertainty about practical and personal issues.(26) In our conceptualization, clinicians also confront existential, practical, and personal uncertainty, especially in difficult situations such as end-of-life care. Our argument is supported by studies finding that the biggest barrier to referrals to palliative care is the perception that the patient and family are not ready for the discussion.(10, 27) Other studies have found that personal or professional values framework uncertainty may be experienced as an aversive state.(28) Clinicians may question their professional abilities and feel like a failure when they are unable to find a cure for a patient, and this aversion may prevent them from living up to other values they may affirm in other contexts.(11, 29, 30) Communication uncertainty has been identified as a major source of ethical difficulties and stress for clinicians.(31, 32) Clinicians may see talking about upsetting topics with families as an innate specialized talent that one either has or does not have, and may be unsure of their ability to emotionally support families while discussing these topics.(15) Some researchers have suggested that a major reason for the delay discussing end of life care with families is that clinicians do not feel ready or comfortable initiating discussions about these difficult topics.(33–37)

Pending further research to expand, refine, or establish the generalizability of various types of uncertainty that hinder the introduction of palliative care, there are nevertheless strategies and techniques for addressing these forms of uncertainty that warrant discussion (Table 2).

### Positive ways to frame uncertainty and palliative care

One nurse practitioner said the capacity to admit uncertainty was part of her professional identity: “It’s up to us to give them the information and then support them in the decision. It’s ok to say I’m stumped but I’m going to tell you XYZ. Some families you can talk out loud with. The best conversations you have are the ones where you can be honest about what you know and what you don’t know.” Other participants reported using prognostic and informational uncertainty as an opening to involve palliative care. One physician said, “uncertainty can be a way to open the door to [specialty pediatric palliative care]. I can say I need to consult with other colleagues who can help us with the uncertainty in this situation.”

Some studies have found that patients and family members appreciate providers being honest with them when the medical situation is uncertain.(4, 38)

### **Clarifying professional values and managing negative affect**

Clinicians may be able to manage individual uncertainty by engaging in exercises to clarify their professional values.(39, 40) Techniques based on acceptance and commitment therapy may help manage anxiety and other negative feelings associated with discussing palliative care with patients without needing to avoid or suppress these feelings.(41–43) Mindfulness training may be beneficial in reducing stress and increasing skills for handling difficult situations.(44–46)

### **Articulation of team values**

Team retreats may enable individuals and teams to clarify their guiding ideals and what they hope to achieve when they care for patients with a poor prognosis. Such retreats may reduce collegial uncertainty if participants become more familiar with other team members' ideals and hopes. In our study, some participants reported being more comfortable talking to other clinicians who had participated in the study because they could say “This is like we talked about in that palliative care study ...”

### **Communication training**

Training clinicians to give serious news in a sensitive and caring way can help them to introduce palliative care.(47–50) Many participants in our study identified the most valuable activity as the simulation in which a clinician introduced palliative care to an actor portraying an upset parent.

### **Being prepared for and accepting negative family reactions**

A recurring theme among our participants was the desire to find ways to introduce palliative care without upsetting families. For example, social workers often emphasized sibling support services or home visits as a reason to involve palliative care. While these techniques may work for some families, they do not address the core challenge of communicating about an inherently upsetting topic: inevitably, some people will get upset. Clinicians should practice how to respond to and support upset or angry family members. Effective techniques, which can be learned via role playing exercises, include using empathetic listening techniques such as labeling the emotion or allowing for silence as families come to terms with bad news.(47, 49)

At the same time, clinicians should remember that many patients and families want their own uncertainty to be reduced with accurate information, even if the information is bad news.(51) Even parents initially upset or angry may be grateful for and appreciative of the clinician's honesty once they are past the initial shock, if the clinician delivers the news or introduces palliative care in a thoughtful and empathetic manner.

### **Collegial standards**

Medical teams may have complex unspoken rules for discontinuing active curative care for patients.(52) Team members who perceive themselves lower in the medical hierarchy are

often less comfortable making end-of-life-care suggestions to a senior physician and in some cases will only raise concerns when no senior physicians are present.(32, 53–56)

Clinical teams can work to reduce these barriers to discussing palliative care referrals with colleagues. Specifically, team leaders can establish a default custom of regularly evaluating patients who meet certain criteria for palliative care referral and encouraging all team members to participate in the discussion.

### **Inter-institutional standards**

Clinical teams and organizations also need to have plans for informing primary care clinicians and other individuals outside of the institution of the patient’s referral to palliative care and why this referral was made. Team members should be ready to explain why palliative care is appropriate for the patient and support junior team members if they encounter push back from other clinicians. Clinical teams may also need to establish relationships with teams at other organizations with the goal of facilitating communication and transfers.

Participants in our study reported encouraging families to be open about seeking second opinions from other organizations. By so doing, the clinicians could discuss the advantages and disadvantages of the family seeking treatment elsewhere and help parents make decisions in the best interests of their child. Teams might also develop a list of standard questions they could provide parents to ask other institutions regarding available services and how certain common situations might be handled.

## **CONCLUSION**

The concept of “uncertainty” as a barrier to the introduction of palliative care needs to be expanded beyond prognostic uncertainty to include other forms of uncertainty regarding how patients or family members, colleagues, other institutions, and even the clinician introducing palliative care will react.

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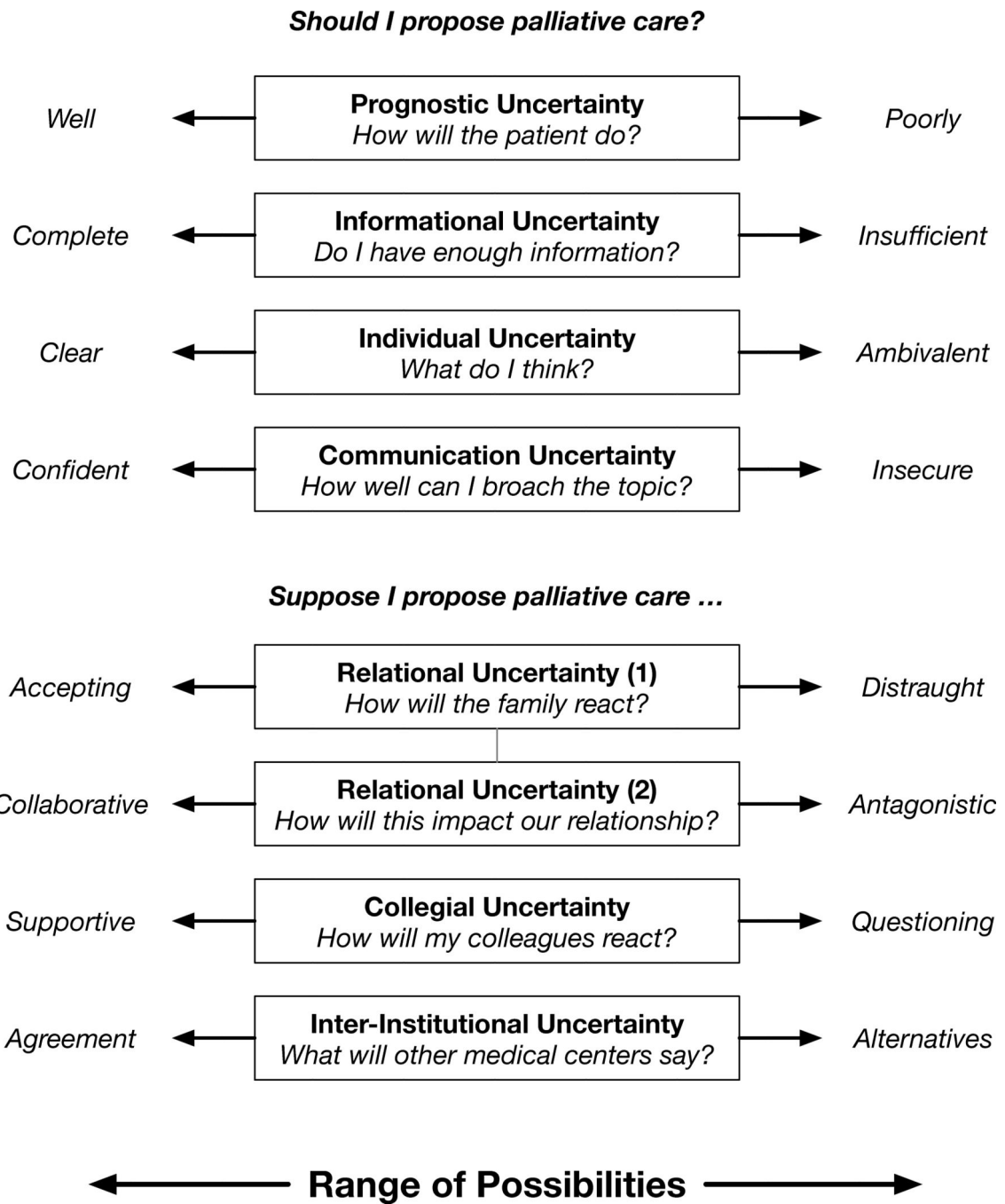
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**Figure:**  
 Seven types of uncertainty that can influence whether a clinician proposes palliative care



Characteristics of study participants

**Table 1:**

Sub-Specialty	Attending Physician (% of participants)	Nurse Practitioner (% of participants)	Social Worker (% of participants)	Fellow (% of participants)	Total (% of participants)
Bone Marrow Transplant	6 (21%)	4 (14%)	1 (3%)	0 (0%)	11 (38%)
Neuro-Oncology	6 (21%)	2 (7%)	2 (7%)	0 (0%)	10 (34%)
Solid Tumor	2 (7%)	2 (7%)	2 (7%)	2 (7%)	8 (28%)
Total	14 (48%)	8 (28%)	5 (17%)	2 (7%)	29 (100%)

## Seven types of uncertainty when clinicians care for pediatric patients with advanced cancer and potential strategies

Table 2:

Type	Definition	Potential Strategies
1. Prognostic	Inability to predict patient outcomes including how long the patient will live or what the patient's future quality of life might be.	<ul style="list-style-type: none"> <li>• Openness about prognostic uncertainty with families</li> </ul>
2. Informational	Unknown medical information such as diagnosis or appropriate treatment options.	<ul style="list-style-type: none"> <li>• Uncertainty as reason to consult palliative care</li> </ul>
3. Individual	Personal or professional values or how to apply them appropriately are unclear in a given situation.	<ul style="list-style-type: none"> <li>• Clarifying professional values</li> <li>• Managing negative affect</li> </ul>
4. Communication	Uncertainty about the best way to tell a patient or family bad news in an honest and caring way.	<ul style="list-style-type: none"> <li>• Communication training</li> </ul>
5. Relational	Uncertainty about how relationship with patient or family might be affected by telling them bad news.	<ul style="list-style-type: none"> <li>• Acceptance of possible negative family reactions</li> <li>• Role play difficult conversations</li> </ul>
6. Collegial	Uncertainty of how professional colleagues might react to suggestion of palliative care or end of life care.	<ul style="list-style-type: none"> <li>• Articulation of team values/retreat</li> <li>• Regular reevaluation of patient care goals</li> </ul>
7. Inter-institutional	Uncertainty of how to discuss initiating and managing palliative care with professionals at other institutions.	<ul style="list-style-type: none"> <li>• Communication plans for and relationships with other institutions.</li> </ul>