

**TITLE: Communicating uncertainty: A step in the right direction?**

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HRBT	High-risk brain tumor
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As pediatric oncologists, many of us take as a given that patients with cancer and their families should be fully informed about their diagnosis and prognosis. Notably, disclosure of information about a cancer diagnosis is a relatively new phenomenon; in the 1960s, 90% of clinicians preferred not to tell patients that they even had cancer, much less about their prognosis and treatment options.<sup>1</sup> Today, most medical oncologists report typically telling patients with cancer about their diagnosis/prognosis,<sup>2</sup> and nearly all parents of children with cancer report being told the same.<sup>3</sup> Clearly, outcomes for children and adults with cancer have improved significantly in recent decades. That is not to say, however, that the challenges related to prognostic communication are behind us.

Rather, clinicians continue to cite concerns about causing added distress and/or stifling hope as barriers to prognostic communication.<sup>4</sup> They worry that—particularly for children with poor prognoses—detailed discussions about prognosis may have unintended, harmful consequences.<sup>4,5</sup> In recent years, researchers have found quite the opposite to be true. In pediatric oncology, not only does compassionate, thoughtful delivery of high-quality information about prognosis not cause distress or eliminate hope, but it can actually support parents' peace of mind, trust, and hope for the future, even among parents of children with less favorable prognoses.<sup>5</sup> Unfortunately, though, increased prognostic disclosure is not associated with increased accurate parental understanding of prognosis, a finding also seen in medical oncology.<sup>6</sup>

With this context in mind, Professor Bluebond-Langner and colleagues report in this issue of *Pediatric Blood & Cancer* the results of their ethnographic study of prognostic communication between clinicians and parents of children with high-risk

brain tumors (HRBTs).<sup>7</sup> In their qualitative study, the authors examined conversations between the parents and clinicians for 13 children with HRBTs over 40 unique clinical interactions. They utilized a process of conversation and discourse analysis to explore in detail both how clinicians presented information about prognosis and how it was received by parents soon after their child's diagnosis. With this methodology, they were able to provide a nuanced description of how prognosis is discussed in this population, filling what had been a conspicuous gap in the pediatric oncology literature.

Bluebond-Langner et al. report that clinicians expressed prognosis to parents in a variety of ways (including both statistical and descriptive terms), often using multiple strategies for discussing prognosis in a single patient encounter, or even in successive utterances. The clinicians described in this study often utilized population-level descriptions (e.g., general survival statistics), and many also described prognosis utilizing dichotomous descriptions (e.g., what is possible versus what is most likely to happen). In response, parents sometimes paraphrased the clinicians' statements into their own words and often attempted to apply clinicians' population-level statements to the individual level – their child. Clinicians in turn frequently referenced the uncertainty of this application, uncertainty that appeared not always to be satisfying to parents.

The authors should be lauded for examining communication about prognosis in a population previously largely absent from the literature. Children with HRBTs (defined by the authors as high-grade gliomas, diffuse intrinsic pontine gliomas, atypical teratoid rhabdoid tumors, and high-risk embryonal tumors) continue to have quite poor survival outcomes despite continued incremental progress,<sup>8</sup> but to date, little is known about the communication process in this unique patient population. It is easy to imagine that

communication about prognosis would be more challenging and/or less comprehensive for patients expected to have poor outcomes, an assumption supported by parental report of prognostic communication in prior work.<sup>5</sup> The data presented here cannot reliably assess how accurately prognostic estimates were framed or how comprehensive the information was that clinicians provided, but this study provides a glimpse into the prognostic communication process for this population. Similarly, while this work does not tell us whether the described communication processes resulted in accurate parental understanding of their child's prognosis, it provides valuable insights regarding another complex but important area of pediatric oncology: uncertainty.

The authors thoughtfully acknowledge the significant role of uncertainty in prognostic communication, a welcome and much needed step forward in the field. In recent years, clinicians and researchers have increasingly identified how central the role of uncertainty is in pediatric oncology,<sup>9</sup> though it remains elusive how optimally to discuss the inherent uncertainty of prognostication, decision-making, and the many other inevitable unknowns in clinical care and research. The era of precision cancer medicine, the growing use of targeted therapeutics, the identification of (and continued hope for) exceptional responders even among those with poor prognoses, and the blurring of lines between research and clinical care highlight the fact that uncertainty is unquestionably here to stay in the care of children with cancer.<sup>10,11</sup>

As a result, we as pediatric oncologists must learn how to discuss uncertainty with our patients and their families and how to navigate the discomfort that might ensue. As Professor Bluebond-Langer and colleagues aptly point out, survival statistics, while an important part of our communication with families, have their limitations. A child with

a 75% chance of survival ultimately will either survive or die; the statistic for them ultimately will be 0% or 100%, population survival statistics notwithstanding. Great uncertainty remains in how to apply survival probabilities to the individual, and similarly how optimally to communicate these uncertainties. To support patients and parents in tolerating this uncertainty, we must improve how we communicate about this uncertainty.

Work is ongoing to assess the efficacy of communication skills training at improving physicians' ability to communicate about uncertainty with patients with cancer.<sup>12</sup> Similar training programs focusing on delivery of bad news, communicating about prognosis, and other related concepts have proven successful, providing optimism that such skills can be taught. In the meantime, it is vital that we continue to improve (and study) communication in pediatric oncology. We are better today than ever before at communicating about prognosis, even for those expected to have poor outcomes. The next frontier in communication is improving our communication with patients and families about uncertainty. The communication reported here represents a needed step in the right direction.

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