Reflections on Communication and Care in Cancer

Bryan A. Sisk, MD, MSCI, Ashlee Erwin Neu, MA

Jake was 20 months old when he was diagnosed with leukemia and began 4 years of chemotherapy. In this article, his mother (Mrs Erwin Neu) reflects on her family’s experiences caring for a child with cancer, from diagnosis through treatment. A pediatric oncologist and communication researcher not involved in Jake’s care (Dr Sisk) provides additional reflections on the basis of his experiences. Mrs Erwin Neu met Dr Sisk when she participated in his communication study. Together, they developed this article to highlight the dynamic care and communication needs of families afflicted by pediatric cancer.

DIAGNOSIS

Mother

In just 8 hours, my husband and I went from relief to a real-life nightmare. Our 20-month-old son had been experiencing fevers and fatigue for months. After another visit to the doctor’s office, we thought we finally had a relatively benign diagnosis for Jake’s illness. Our pediatrician suspected mononucleosis, a common infection in children. But a blood test proved otherwise, and suddenly, we were the parents of a child with leukemia. It was the beginning of the most mentally, physically, and emotionally challenging time of our lives.

I had always believed in science and medicine, but I found myself in disbelief after his diagnosis, questioning his new oncologists. What made them sure it was leukemia? Having dealt with his fevers for months, I had questioned everything to figure out what was wrong. Had he swallowed the fridge magnet that was missing? Was there something wrong with our water at home? I needed to know that it wasn’t something else, and I needed to know that he wasn’t going to die. The doctors did the best they could, providing a simplified version of terminology that would soon become familiar and reassuring me that his cancer was treatable. But as my husband and I walked onto the hospital floor, we saw children much sicker than Jake. And we worried about what was to come.

Researcher

Parents experience overwhelming emotional distress after their child is diagnosed with cancer.1 This distress can impair their ability to process information, make informed decisions, and manage their child’s care at home.1–3 Parental distress is also linked to worse quality of life and poorer psychosocial adjustment for children with cancer.4 Emotions and communication are inextricably linked.1,5 Parents cannot communicate effectively when they are emotionally overwhelmed, and clinicians cannot support parental emotions without high-quality communication.5 Parents will likely need information to be repeated and provided in different formats. Clinicians might consider offering another meeting with parents the day after diagnosis, with the goal of
reiterating information, describing the short-term and long-term plans, and empowering parents as part of the care team. Furthermore, effective written and visual communication from clinicians could bolster parental understanding.

Mother

Dr Sisk’s use of the term impaired describes exactly how I felt on the day of our son’s diagnosis. Two oncologists came to our emergency department room after we had spent hours worrying and struggling to entertain our bored and irritable 20-month-old son. They confirmed it was leukemia and told us we had 3.5 years of treatment ahead of us. Three and a half years! My husband and I were in tears, and my son was screaming that he wanted to go home. I had to step out of the room just to hear the doctors. Looking back, we needed a diagnosis deep dive after coming to terms with the reality of it; we had so many questions. We needed somebody who could help us process the complexity of it all and someone who could show us (visually) what was wrong with our son and answer questions once we were able to process the answers. What did the cells look like? How did they harm his body? Were they sure this wasn’t just a big mistake? Although this information would not have changed his care, it would have given us some sense of control and confidence in an uncontrollable situation.

INPATIENT CARE

Mother

Those first weeks in the hospital were a crash course in medical terminology, pharmacology, and hospital organizational structures, all while taking care of a sick and angry toddler. Looking back, we were hungry for information, but we did not know who could answer our questions. We did not yet understand who was coming into the room and why. We did not know the differences between attending and fellow, nurse and nurse practitioner. Much of our time and energy initially was spent trying to understand the organizational structure of the hospital.

Mostly, we had patient and helpful medical professionals. An issue with Jake’s central line, or the long intravenous catheter that delivered his chemotherapy, revealed how quickly team communication can falter. Nurses began having trouble drawing blood from his central line, which for Jake, was a port placed under the skin in his chest. Our oncology team ordered a radiograph but reassured us it was a problem with positioning. The needle was not sitting correctly, but they reassured us that we could still use the line. A radiologist disagreed, saying in a side conversation that the line could not be trusted to deliver our son’s life-saving medicine. This disagreement might seem minor, but it became one of our central worries for weeks. We struggled to get consistent answers from different medical professionals.

Researcher

No matter how strong the relationship between the family and individual clinicians, poor team dynamics can diminish faith and trust in the team. These communication breakdowns can occur within the cancer team. For example, a nurse and a physician might provide different plans for timing of chemotherapy, or a fellow and attending physician might describe different treatment plans. These breakdowns can also occur between different specialist teams, as Mrs Erwin Neu described. To address communication breakdowns within the oncology team, clinicians can advocate for team-based approaches that generate shared mental models about the patient’s care and each team member’s responsibilities. Shared team mental models are “knowledge structures held by members of a team that enable them to form accurate explanations and expectations for the task, and in turn, to coordinate their actions and adapt their behaviors to the demands of the task and other team members.” For example, 1 group implemented a communication milestone checklist that teams reviewed during team meetings to ensure the families received critical communication. For communication difficulties between teams, individual clinicians might strive to serve as the point person when a multidisciplinary problem arises. Fulfilling this role could give parents confidence that their concern has been heard and acted on. Each team will need to determine who should fulfill this role on the basis of unique team dynamics, personal strengths, and areas of expertise. Additionally, some studies in adult cancer have revealed that question prompt lists, communication checklists, and written needs assessments can empower patients in communication. However, these approaches have not been studied in pediatrics.

Mother

The concept of shared mental models and milestone tracking resonates with me. Although we were frustrated with the central line problems, we were more frustrated that we kept hearing different answers from different doctors, and it was not clear that they were talking to each other. It is okay for different doctors to have differing opinions. It is not okay for them to hold these differing opinions without discussing with each other. I felt like we had to serve as the middleman and troubleshooter. In
hindsight, this was not a huge problem in the grand scheme of things, but it was a major worry for us at the time. The lack of communication between teams made it worse than it had to be. We needed someone to establish themselves as “in charge” of the central line issue across specialties so we could have confidence the problem would be solved.

**OUTPATIENT CARE**

**Mother**

Although we were overjoyed that Jake was in remission after induction therapy, my husband and I struggled with the transition to outpatient treatments. We went from around-the-clock care and certainty that he was getting the right drugs to the day-to-day personal responsibility for managing all medicines, side effects, and at-home health care visits. Additionally, our team changed. The inpatient professionals we had come to love and trust were replaced by a new outpatient team, bringing with it new organizational dynamics we had to learn.

**Researcher**

Enabling parents to care for their child at home is a core function of communication that becomes even more important during transitions, like the inpatient to outpatient transition described by Mrs Erwin Neu. My research team has identified 4 clinician actions that support parents in managing their child’s care: (1) providing anticipatory guidance and planning in advance, (2) training parents in technical skills, (3) identifying the family’s needs and directing toward resources, and (4) providing guidance during acute illnesses. Each member of the clinical team can play a role in providing this support. Physicians might offer long-term plans, expected outcomes, and contingency plans. Nurses might educate parents about side effects and typical experiences during hospitalizations. Social workers and psychologists might explore psychosocial burdens and direct parents to supportive resources. Additionally, clinical teams might consider using written, image, and video-based materials to support family learning. Coordinated attention to these 4 aspects of family self-management can support families in every outpatient visit and hopefully improve their physical and psychosocial well-being.

**Mother**

We certainly needed someone to fulfill these 4 actions described by Dr Sisk. For us, our nurse coordinator was a major source of stability and support during this transition. She was the lifeblood that sustained us. She picked up the phone whenever I called, offering reassurance and guidance that I desperately needed. She anticipated my questions, coordinated answers quickly from the oncology team, and had printouts ready of the data she knew I liked to review. She knew my son and how he handled different procedures, and she passed that information to the nursing team.

We soon felt capable of handling the technical aspects of our son’s care. We felt confident in our ability to monitor our son and manage side effects, and we had already navigated stressful and scary moments like a violent allergic reaction, a central line infection, pneumonia, and months of nausea. Emotionally, however, those experiences took a toll on our family.

Interestingly, the cancer experience affected my husband and me differently. I craved a return to normalcy, and I wanted others to see us living that normal life despite the challenges. As such, I focused on pragmatic questions about daily life. Should Jake go back to day care? What activities could he do? Could we travel? I wanted to live a normal life, so I downplayed the bumps in our path. My husband, however, needed friends, family, and our medical team to realize that what we were going through was not normal. Although Jake only had monthly chemotherapy infusions, we still struggled with cancer every single day. My husband would get frustrated when friends and family expressed surprise that Jake was still undergoing chemotherapy after the initial hospital stays. We called it “chemo fatigue.” Everyone heard so much about the initial year full of hospital stays and treatments and much less about the outpatient treatment and chronic side effects, so some people thought we were done. But we were far from done.

**Researcher**

Distress in pediatric cancer is not restricted to diagnosis and end of life. Even when things seem to be going according to plan, parents can experience psychological, social, and financial distress. In fact, 5 years out from their child’s cancer diagnosis, 66% of parents still report low peace of mind related to worries about late effects and relapse. Yet clinicians might assume that parents are no longer distressed, for example, when their child is receiving maintenance chemotherapy and only coming to the clinic monthly. One approach to addressing these persistent uncertainties and worries is to engage in “what if” questions with families. These conversations focus on normalizing worries and offering families the opportunity to raise difficult questions, discuss their worries, and have their concerns validated. In my past research, we found that clinicians can develop blunted reactions to a
family’s distress. For example, 1 clinician noted, “We can sometimes blow off low-risk things that may not be a big deal to us, because we see much worse.” Asking these what if questions might help clinicians to appreciate the impact of cancer on psychosocial well-being, even when families are navigating routine care for low-risk cancers.

**Mother**

Jake successfully finished treatment in June 2020. We still see his oncology team monthly, and there is comfort in that routine. But even now, every cough, every virus, and every expression of pain trigger worries that these could be symptoms of something more. We have accepted that worry will be part of our lives for a long time, perhaps forever.

**CONCLUSIONS**

**Mother**

In addition to being a “leukemia mom,” I am a corporate communications professional. In my profession, we focus on knowing our audiences and making sure we have the right people delivering the right messages at the right times. Communication is not just the job of the top executive. Each team member must know the main story line, be trained in how and when to tell their part of the story, and have the right authority, structure, tools, and tactics to fulfill their communication responsibilities. This is especially true for managers; research has revealed that employees rate them as the top and most trusted communications channel for understanding news, getting work guidance, and filtering important information. To me, attending physicians, nurse practitioners, nurse coordinators, and floor nurses are the equivalent of managers in handling my son’s care. They are talented people, and they deserve structural supports that enable communication with families.

**Researcher**

Relying on clinicians’ good intentions will be insufficient to support effective communication if the system does not create structure and space for them to act on these intentions. Future studies are needed to explore how to build communication skills, how to create communicative environments, and how to implement systems that facilitate communication. This approach could make clinicians’ jobs easier, while also improving patient and family experiences and outcomes.

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