

# Elevating the Art of Medicine: A Caregiver's Reflection

Kristin Hoyt Siyahian, BA 

The following narrative chronicles the unlikely events of the author, an editorial director of an oncology publication, whose experience with cancer was purely academic in nature until 2 family members were diagnosed simultaneously with breast cancer and melanoma, respectively. The perspective-altering encounters from inside the healthcare system revealed critical lessons regarding the importance of patient-centered care as key to empowering patients and creating a sense of peace for survivors. **Cancer 2020;126:4084-4086.** © 2020 The Authors. *Cancer* published by Wiley Periodicals LLC on behalf of American Cancer Society This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

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Mom looked beautiful on the day of her niece's wedding. She was beaming with health, strength, and joy. She had every reason to be elated as just weeks before she had received the wonderful news that her most recent scan was clear. Remission and her attendance at the wedding marked 2 personal victories in her fight against breast cancer and gave all of us reason to celebrate.

Two years earlier, just before her diagnosis, I was the editorial director of an oncology journal. At that time, my exposure to cancer was purely academic in nature. I did not yet understand the patient and caregiver experience, and I had no appreciation at all for the tremendous importance of receiving patient-centered care.

Then, I received the phone call from Mom: "They say I have cancer. I'm scheduled for surgery 3 weeks from Tuesday."

Being thrust into this personal experience with cancer radically changed my perception of it from an area of scientific advancement to that of imminent threat. Cancer became the enemy, and I began to understand the resolve of patients to engage in a fight to reclaim their bodies and lives. Part of that resolve—perhaps the most important part—is establishing a partnership with an oncologist.

I was aware of the report from the Institute of Medicine that called for patient-centered care to include the free flow of information between patient and clinician, patient-centered communication, and shared decision making.<sup>1</sup> When outlining desirable outcomes, the report includes "attention to interpersonal aspects of care" and gives examples of addressing patients' concerns and expectations, maintaining patients' sense of dignity, and encouraging patients' participation in decision making.

I admit, I believed that patient-centered care and attention to interpersonal aspects of care were standard practice. Furthermore, as an engaged caregiver, I believed that my participation would be welcomed, if not expected, by oncologists. My understanding of the terms *patient-centered care* and *interpersonal aspects of care* translated quite simply to a good relationship between patient and physician. As in any relationship, respect, trust, and dignity are central to its success. However, I was about to learn that patient-centered care and interpersonal aspects of care were not necessarily routine practice. I would also learn that these concepts are vastly important for fostering a sense of empowerment and peace for patients and their caregivers. Unfortunately, I learned that the inverse is also true: The absence of patient-centered care and interpersonal aspects of care can create negative feelings of helplessness and fear.

Three weeks later, after her surgery, we learned that Mom had stage IV hormone receptor–positive breast cancer. The medical oncologist recommended chemotherapy as the best treatment approach. In the spirit of open communication, I asked if a hormone therapy could be considered.

However, my question was immediately dismissed. Without a promise of additional research or an explanation of the exclusion of hormone therapy, the physician reiterated that chemotherapy was our best option. There was no discussion around my question. The responsibility that I had assumed in participating in the process faded into intimidation, helplessness, and fear. The concepts of patient-centered communication and interpersonal aspects

**Corresponding Author:** Kristin Hoyt Siyahian, BA, Green Hill Healthcare, The Lynx Group, 13260 Arroya Vista Rd, Poway, CA 92064 (ksiyahian@the-lynx-group.com).

Green Hill Healthcare, The Lynx Group, Cranbury, New Jersey, USA

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of care suddenly felt ceremonious and pointless. The physician's authoritative style hindered communication and excluded us from decisions as we were simply informed of a previously conceived plan. We left the office with a promise to consider chemotherapy, but we never returned.

A week later, Mom and I walked into a different oncology office, seeking a second opinion regarding her treatment. The difference in our experience in this office was palpable. This physician welcomed us into his office, where we spent a few moments getting to know one another outside the context of cancer. Then, he spoke to us about Mom's case, and together we explored several therapeutic options. He explained, he listened, he answered our questions about mechanisms of action and side effects, and he set realistic expectations. He welcomed our input. He guided the conversation and accepted my presence as part of the care team. He provided the information that Mom and I needed to make a confident decision.

Here, I was not a ceremonious addition to the care team. This physician's ability to establish a relationship and engage in meaningful conversation instilled us with confidence and hope. Collectively, we agreed that the oncologist would prescribe hormone therapy.

For the next several months, our family rallied around Mom in a strong show of love and support while she underwent therapy. Our relationship with her oncologist continued to develop and strengthen. Each interaction affirmed our choice to partner with him. Our questions were answered in a timely way, he treated us with dignity and respect, and he consistently encouraged our involvement in decisions. As a result, the relationship itself provided an emotionally supportive environment, which empowered us to participate in decisions.

Everything related to Mom's care was moving along as expected when we were blindsided by another cancer diagnosis in our family. After seeking medical advice for a mild pain in his side, Dad underwent surgery for a mass in his chest and was diagnosed with stage IV metastatic melanoma.

Our family reeled from the unjust reality of 2 stage IV diagnoses, and I grappled with the mortality of 2 otherwise healthy, vibrant people. I knew that metastatic melanoma was not curable, but I was also aware of new treatments based on the assessment of the *BRAF* gene that might help to extend his life. After our last experience in finding a physician, I recognized the importance of partnering with an oncologist who would provide support through a patient-centered model of care.

Hoping to talk through treatment options and set realistic goals, Dad and I met with his oncologist. At our first meeting, the physician made a treatment recommendation without knowledge of Dad's *BRAF* status. Respectfully, I asked if we could test the tumor sample for genetic mutations in the hope of making a better informed treatment decision, but the physician wanted to "save" testing in the event that the initial therapy failed for Dad.

I implored the physician to initiate testing as part of our decision-making process, not to save it as a last resort. Reluctantly, he agreed. However, in challenging the prescribed course of action, my relationship with the oncologist changed. It suddenly felt as though the physician and I were on opposite sides of the table, facing each other instead of sitting together as a unified front and facing the cancer. I desperately wanted him to understand our need to make a confident choice. We needed his support and guidance; instead, I sensed his indignation. My future interactions with the physician felt strained. Instead of welcoming questions as opportunities to provide care, my questions seemed a burden to him; he no longer made eye contact, and he rushed through appointments. The strain of that relationship amounted to an additional difficulty for Dad in an already difficult situation. The oncologist's demeanor added insult to the devastating injury of a cancer diagnosis. His lack of patient-centered and interpersonal aspects of care exacerbated our feelings of helplessness and fear because we could not turn to our own physician for compassionate guidance and support.

Looking back, I believe that testing for a *BRAF* mutation was a blessing, even at the expense of our relationship with the physician. Without those results, I would have been forever tortured by the possibility of Dad receiving the wrong treatment. Although we were able to make a confident, correct treatment choice, Dad was unable to complete treatment when complications resulted in hospitalization. The disease claimed his life just 4 months after his diagnosis.

Despite her grief, Mom's health continued to improve over the next 9 months. Her fight against breast cancer culminated in the victory of the clear scan just in time for her niece's wedding. Her attendance at that event was a bright spot for our family and a memory that I will cherish. Our decision to proceed with hormone therapy afforded her 2 relatively good years and gave her the precious opportunity to be present for family milestones. In no small way, our partnership with her oncologist made this possible.

It pains me to say that, although I am forever grateful for it, Mom's remission was short-lived. The cancer returned several months later. She passed at home on Christmas Eve.

Comparing my experiences with the 3 oncologists I encountered, only 1 practiced in a patient-centered model of care. He engaged in a relationship with us and honored the tenets of respect, trust, and dignity. I felt empowered to help Mom to make confident decisions with him. This style of practice elevated the art of medicine into something so special, so beautiful and, in my experience, something quite rare. In the trusting bonds of that relationship, we were heard, understood, and supported. To Mom's oncologist, I will always be grateful for that gift.

In sharing my story, I hope to remind oncologists that they are uniquely capable of improving the patient and caregiver experience. Recognizing that patients with cancer require more than just good technical execution of care, oncologists have an obligation to attend to the delicate, personal aspects of care in order to support, engage, and empower patients and their caregivers. In the world of academia, the literature touts the value of patient-centered care, but my message to oncologists based on

my real-world experience is simple: Only good can come from inserting a little humanity into your practice. Please, welcome patients and their caregivers into your office, listen to them, and respond to their questions, needs, and fears. Please, lean into the relationship. Participate in the free flow of information, genuine communication, and the shared decision-making process. In doing so, you will keep patients at the center of care and remove any doubt in their minds related to their treatment course. In this way, you will help to empower patients to make confident decisions and create a sense of peace for survivors even when facing death. In providing peace to survivors, you will elevate the practice of medicine to something truly artful.

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#### REFERENCE

1. Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. National Academies Press; 2001.