

Engagement & Empowerment in Action

BY JENNIE R. CREWS, MD, MMM, FACP



A few weeks ago in St. Louis, leaders in the cancer care field gathered for three days of invigorating discussion and sessions at the ACCC 33rd National

Oncology Conference. We had the privilege of hearing not just one, but two inspiring presentations on the topic of adolescent and young adult (AYA) cancer patients. On the provider side, clinical social worker Lauren Lux of UNC Lineberger Comprehensive Cancer Center spoke about engaging with AYA cancer patients. Lux came into her role via the *Be Loud! Sophie Foundation*. After being diagnosed with germ-cell cancer, 14-year-old Sophie Steiner expressed a strong desire to help other adolescents and young adults with cancer “stay true to their authentic selves in the face of overwhelming illness.” The *Be Loud! Sophie Foundation* granted Sophie’s wish by partnering with UNC Lineberger to hire Lux as their Adolescent and Young Adult Program Director. According to Sophie’s parents, who also spoke at the meeting and introduced Lux, Sophie wanted any money raised from her cause to be invested in a person, not a building.

Lux spoke about the unique needs and common issues she sees in her AYA patients. Because the age range of AYA patients is typically classified as 15-39 years old, these patients often feel too mature for pediatric oncology, while also feeling out of place in the adult unit. Clinical trial enrollment for AYA patients is low, and they are less likely to access adult oncology support services. This subset of patients may also experience poor outcomes due to delays in diagnoses, non-compliance issues, and lack of insurance.

Patient-centered care is critical to AYAs. As Lux stressed to attendees, “You need to be authentic, flexible, compassionate, honest, and willing to get to know the *person*—not just the patient.” With her AYA patients, Lux tries to talk about topics other than cancer and treatment, so she can better understand what may frame that patient’s decision-making.

Often, Lux said, this group is making plans for the future while also making plans for their death. She empowers her AYA patients to make better treatment decisions by getting to know them and helping them articulate their aspirations and beliefs. Adapting communication styles by getting to know the personal side of a patient (not just the diagnosis) can make all the difference, Lux told meeting attendees.

On the patient side, Suleika Jaouad, Emmy Award-winning *New York Times Well* columnist, cancer survivor, and health advocate spoke to attendees about her cancer journey. At the age of 22, Jaouad was diagnosed with myelodysplastic syndrome and acute myeloid leukemia. After three years of chemotherapy, a life-saving clinical trial, and a bone marrow transplant, she is now in remission.

“We talk a lot about patient-centered care, but you can’t have that unless the patient is an active part of the care conversation,” Jaouad told attendees. She described feeling lost when speaking with her care team, and that their use of medical jargon felt like another language. When early in her treatment she did her own research on fertility preservation, Jaouad said she felt a breach of trust that her medical team had not mentioned this option to her. Once her care team became more attuned to Jaouad’s personal needs, they could then empower her by connecting her to resources for fertility preservation. “This lack of communication showed me that open communication with my medical team is not always a given. I had to play an active role,” said Jaouad.

ACCC is working with our members and oncology thought-leaders to identify patient-centered practices in oncology. The just-released white paper, *Empowering Patients, Engaging Providers: The Future of Patient-Centered Care in Oncology*, is a reflection of the conversation from the ACCC Institute for the Future of Oncology forum held in June 2016.

Truly patient-centered care requires engaged care providers like Lauren Lux, empowered patients like Suleika Jaouad, and the research talents and practice innovations of our cancer programs. So let’s start those conversations with our patients.

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