



A Call to Care

I recently gave a talk at the Keck School of Medicine of the University of Southern California at the David Shroud Adolescent and Young Adult Oncology Symposium. I was honored to speak alongside many other experts, and it was a really good symposium with accomplished speakers and great learning opportunities. I have just published my second book about young adults with cancer, *Meeting the Need for Psychosocial Care in Young Adults With Cancer* (Katz, 2015). Although I have been immersed in the literature in the process of writing the book, hearing the words of young adult survivors always hits home in a way that research and articles just do not.

The morning session ended with a panel of four young adult survivors telling their stories and explaining to the oncology care providers in the audience what they would have liked to have seen done better. This was a very articulate and educated panel, and their insights and recommendations serve as a reminder for all of us who work in oncology and not just those of us who work with patients aged younger than 35 years.

Each of the survivors told their cancer stories quietly—the lump found here, the pain felt there, and the terror and confusion that resulted. Most were far from their family of origin when cancer changed their world, and they had to rely on friends or friends of friends for their basic needs. Imagine waiting alone in an emergency department with no one to hold your hand or tell you that you will get through whatever “this” is.

There were many “do nots”—do not underestimate the intelligence and resourcefulness of your patients; they will find the answers they need even if you stall them or stand in their way. Do not stereotype your patients based on age, race, or culture; they are all unique individuals, and making assumptions will only lead to errors and offense. Do not stand above your patients when you are talking to them; sit down, get on the same level physically, and make eye contact.

There were many “dos” too—do touch your patients to give reassurance or to show support; a hand on their shoulder or arm expresses more than words in some instances. Do be human; if you find that the seriousness of their diagnosis does not cause an emotional response in you, then maybe it is time to take a vacation. Do show humility; oncology care providers do not know everything, and demonstrating that you are not all-knowing or powerful indicates to the young adult that you are on the learning journey with them and that you are willing to learn from them. A young man suggested that we give our young patients our cell phone number. “I’m not going to call you,” he said with a smile, “but knowing that I could if I needed to comforted me when I was scared and alone.”

They talked about the challenges of transitioning from active treatment that we provide so well into survivorship care that leaves them frightened and uncertain that they will get the care they need. One young woman asked that we find a way to help the young survivor move from the fight-or-flight response of diagnosis and treatment to acceptance and hope that comes after treatment has ended. Another young man talked movingly about how he was trying to find the meaning in what he had been through and, if he could not do that, he was not sure what the experience was for.

This same young man said something that will stay with me all the days of my life as a nurse. He asked that when we talk to someone who has cancer, that we speak with compassionate candor. I have been thinking about those two words since then, separately and as a concept. Compassion. Candor. Compassionate candor.

I like to think that we all understand and treat our patients with compassion. But do we? Are we really consistently compassionate? I see so many nurses who are tired and frustrated and on the verge or in the throes of burnout. And there are those who are way past being burned out

and are just going through the motions of providing care. I see nurses talking on the phone to patients and rolling their eyes as they mouth the words that somehow bypass their heart. I know that none of us intends to be the nurse who has checked out of compassionate care, but if we lose our compassion, what do we have to give to our patients to help them through the crisis of cancer?

Do we use candor when talking about what cancer is going to do to a life half-lived? Do we tell them what we think they want to hear, or do we have the difficult conversations? It is often easier to repeat the time-worn platitudes rather than have emotionally draining discussions. Our patients can tell the difference between authenticity and going through the motions; a life-threatening illness will make subterfuge clear.

I have been thinking about that phrase since the young man spoke those words. Our patients want the truth, but they want room for hope. They want hope, but it needs to be based on factual evidence, not on what we think will make the patient feel better in the moment. Our patients need for us to be caring, present, informed, and engaged in the work we do. I try to be that every day—how about you?

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Reference

Katz, A. (2015). *Meeting the need for psychosocial care in young adults with cancer*. Pittsburgh, PA: Oncology Nursing Society.

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