Distress Screening Is a Good Beginning

Joan Heller Miller, EdM

It was May of 1999. Having just turned 41 years old, I was on top of life. Adoring my role as a hands-on mom for our three young children, the oldest one deaf since birth, I enjoyed using my background in special education and psychology and my creativity and love for music, drama, and art. My work brought me fulfillment and gave tremendous meaning to my life. I was celebrating the publication of my first book for parents and professionals on helping children with special needs develop language skills, and giving book presentations was great. Between teaching college students majoring in special education and serving on the board of several committees to advocate for special education services for students, I was traveling, entertaining, playing guitar, and singing in a local choral group. I was on the move every minute of every day.

I was practically as busy as Ken, my husband of 20 years, who is a medical oncologist and hematologist in a private practice. His schedule was so grueling that, at times, I'd confess to friends and family, "In order to get some real attention, I'd probably need to get cancer."

Diagnosis

The spring flowers in my garden had just bloomed, and I noticed feeling particularly tired for a few weeks in a row. I tried to sleep more and cut back on my workouts, reassuring myself that I was simply overdoing it. Then I began noticing a dull, pounding headache and mysterious black and blue marks on my legs, arms, and hands. Soon, my body went from feeling tired and weak to feeling relentless pain. Once breathing became difficult, it was undeniable. Something was terribly wrong. Next came the anxiety of appointments with various medical specialists and repeated laboratory work leading to the shocking physician report.

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> Mrs. Miller, a pleasant 41-year-old woman, has been diagnosed with high-grade myelodysplastic syndrome. She has an advanced case, with a white blood count of 40,000 with a 24% blast count in the peripheral blood and 18% blasts in the bone marrow. The only therapy with a curative intent is a bone marrow transplant. An unrelated donor transplant carries a higher morbidity and mortality rate; however, there is data suggesting that an allotransplant may be curative. We need to activate a search as soon as possible given the aggressive nature of her disease.

Treatment

Acute myelogenous leukemia, with a remote chance of survival, just when life was going so well? I wanted to say: "It's not fair! I'm not ready to die! I'm just a young mom with three little kids. Who will be there to take care of them, as well as Ken, who will be all alone?" Any chance of survival meant being admitted immediately to a leading cancer hospital specializing in blood disorders, getting inpatient treatments for the first five weeks, and then returning for three additional inpatient stays. Between cycles, outpatient treatments would require platelet transfusions, filgrastim (Neupogen®) shots to boost my white blood cell count, and occasional overnight stays at the hospital in case of infection or other serious complications.

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The doctor's description of my treatment complications read like this:

- Day 1: Four computed tomography (CT) scans, four magnetic resonance

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