

Listening to the voice of patients

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Commentary on *My mom, the cancer warrior* by Kimberly Lastinger.

The stories of patients and families, like this one presented by Kimberly Lastinger, offer powerful lessons for health professionals about the human experience of illness and its impact on the person and family. Furthermore, patient narratives present ‘experiential truth and passion’ that compel us to re-examine medical practices and ethical perceptions of care.¹ However much we think we know from our years of medical practice and our observation of many patients and families, we are not ‘in the patient’s shoes’. The content of patient narratives supports ethical decisions by helping us listen and hear what patients say, how they say it, and by clarifying why it matters. The patient story can help us focus healthcare on the patient and to recognize that the patient is the ultimate authority when it comes to the interpretation of his or her illness experience. Until one has been there, it is impossible to imagine the impact of a life-threatening illness. I am reminded of my own surprise at seeing, feeling, and experiencing the loss of a loved one to cancer. I have been a medical oncologist and palliative care physician for more than 25 years, and I thought I understood the experience I could expect when my husband died. Instead, I was stunned to find that I didn’t have a clue! It has taught me to listen more carefully and ask more questions. When listening occurs, understanding increases, and narratives can be jointly constructed by the patient and healthcare provider. This leads to power that is shared and the sharing of power constitutes an important ethical safeguard within the relationship.²

The narrative presented here suggests a remarkably positive experience of a devastating illness and its potential impact on the patient and family. The patient was someone with tremendous resiliency and optimism. She was committed to living on her terms and for caring for her daughter. Her story is an inspiring one. Ms Lastinger recalls her mother’s amazing support system, but also her mother’s fear of dying. The latter learned only years after her mother’s death from reading her journal. I wonder if, as too often happens, we failed to offer adequate psychosocial support. This service is too often not

offered.^{3,4} This occurs for many reasons including, I suspect, when there is the perception of a supportive social network embracing the patient. It behooves us as healthcare professionals to remember that patients may not want or be able to share some of their deepest fears, the threat of dying or of being dependent, with the people they love. The patients who seem to be doing well emotionally, those with ‘great support’ may also benefit from professional counseling.

No matter how hard one fights for that ‘normal’ life and whether or not the patient outlives statistical predictions, the truth is cancer impacts every aspect of life. Work and life are arranged around the requirements of treatment. Tremendous energy is devoted to doing what most of us take for granted—doing the things we love—whether it’s gardening or drawing or dancing at a child’s wedding. Plans, dreams, relationships are turned inside out by cancer. College plans are altered, a child becomes her mother’s caregiver. This poignant narrative reminds us of the complexities of a person’s life and the need to consider treatment recommendations in the context of the individual’s values and goals.

The recent IOM report, “Delivering High Quality Cancer Care” underscores this reminder.³ The IOM committee developed a conceptual framework of quality cancer care focused on patient-centered care. Meeting the needs of patients with cancer and their families through patient-centered communication and shared decision making is recognized as the most important goal of cancer care. To accomplish this, healthcare providers must understand the needs, values and preferences of patients and families. Only by continuing to listen and hear the patient’s interpretation of illness in the context of their beliefs, culture and life can we deliver high quality cancer care.

References

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