Family Ties

There are a number of articles in this issue of the Oncology Nursing Forum (ONF) that describe phenomena related to the family of the person with cancer. Nursing has long recognized that the patient’s family is very important in everything that we do. We have come a long way from the days of physician-centered care, to person- or patient-centered care, and now to family-centered care. This is a good thing for everyone—the patient is supported by a well-informed family and we also can support the family, which is always impacted by the illness experience of one of its members. The family is an ally and a source of information about how the patient is coping and can help us do what we need to do more effectively. But what about the family that hinders rather than helps?

While reviewing the articles for this issue of ONF, a quote from a participant in the study described by Lim, Baik, and Ashing-Giwa (2012) moved me.

The doctor said to do reconstruction surgery. . . . My son asked a doctor in Korea. But the doctor said that if it were his mother, he would not recommend it. . . . So my son didn’t want me to do it. So I didn’t do it. . . . Now, I have regrets that I didn’t make that decision (p. 395).

This reminded me of an interaction I recently had with a patient who came to see me after he had a radical prostatectomy to treat his prostate cancer. He was struggling with the side effects of the surgery and was experiencing a great deal of regret. He is of Chinese descent and immigrated to Canada when he was a child. His older adult mother lives in another city and she forbade him to have radiation therapy, which was his preferred treatment choice. I don’t know how she decided that radiation was not a good treatment; unlike the participant in the study quoted earlier, she may not have consulted a physician but may have made the decision based on her beliefs about radiation or surgery or cancer. My focus with this man was not on why his mother had advised him in that way, or even why he obeyed her against his own desires, but rather on helping him deal with the side effects that now impacted on his quality of life. As an adult, and a nurse to boot, I would never have asked my mother to advise me on a treatment choice. But every family is different.

I am acutely aware of the importance of attitudes and beliefs when it comes to treatment decision making for my patients. They out trump knowledge any day, and I am always careful to be respectful of this and not use my professional knowledge and power to invalidate the opinion of the patient, no matter how poorly informed. But it is not easy. If a patient believes that a treatment will not help and may even harm, then how can they agree to that treatment when there is doubt about it in their minds?

A study by Underwood, Poch, and Orom (2012) reported that 17% of surveyed men believed that air can spread cancer, so surgery was rejected as treatment for prostate cancer; 33% said they didn’t know if this was true; and only 51% stated this was false. How do you educate and inform when a significant proportion of patients have erroneous beliefs or are unsure about something that we know is implausible?

I think the challenge is even greater when it is not the patient whose beliefs negatively impact his or her treatment decision, but rather a family member who is not present and is out of range of our explanations and education. This is something that has challenged me over the years: How do you balance respect for patient and family autonomy and beliefs when they fly in the face of knowledge and evidence? This is not easy, and I know that many of us struggle with this challenge on a daily basis. As always, I’m interested in your thoughts and experiences—how do you deal with the family ties that bind your patients, and not always in a productive way?

References


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