



The Power of Story in Delivering Cancer Care

Ann Reiner, RN, MN, OCN®

I have been an RN for 40 years and all but three years have been in oncology. Many parts of the cancer experience have changed during those decades. Treatment plans have changed and, thankfully, there are now more effective ways to manage symptoms of the disease and treatment. I am also thankful for how these changes have contributed to cancer survivorship. People with a cancer diagnosis live longer now than 40 years ago, longer even than 15 years ago. Also, within this time period, a paradigm

had to spend so much time thinking about his or her daily living and how his or her cancer and treatment has disrupted cherished routines and important relationships. Bergholz (1988) described the moment she heard her diagnosis of breast cancer: “The only thing that seemed the same was the blue sweatsuit I was wearing” (p. 1).

Story has always been important in the lives of humans. Cultural norms are transmitted through the spoken word. Personal meaning is shared through story. As an educator, I recognize and use the strength of story when I teach students. Patients tell us stories about their lives before their diagnosis, from which we gain insights and understanding of their strengths, their concerns, their values, and potential strategies to help them manage their cancer experience. Heiney (1995) aptly described the benefits of story as having the ability to “help bind us together, communicate more effectively, build trust, and work toward a common purpose” (p. 899).

Another change during my career to reflect on is healthcare reform. Although the healthcare system has always had barriers, we still found time to be present for the patient by listening, encouraging, and working to honor the individuality of those for whom we cared. However, another idea for system reform gaining momentum over the past few years is the “triple aim.” This suggests decreasing

the cost of providing care by moving the focus from episodic or acute care to improving the health of populations and, in addition, improving the experience of the patient when in the healthcare system (Berwick, Nolan, & Whittington, 2008). From my perspective, this is what nurses do best: managing the impact of illness and treatment on a patient’s and family’s daily living. We assist our patients with managing the treatment-related symptoms using evidence, advocacy, and patient-specific knowledge. We know what treatments work based on the literature. We negotiate for orders that give us leeway to titrate medications to manage pain and preserve the patient’s ability to interact with others. Effectively managing symptoms may reduce costs by decreasing emergency department visits or hospitalizations. How do we improve the patient experience? We ask questions. We listen. We ask more questions. We are present with the person by giving our attention to his or her words. Because we’ve long elicited the patient’s story, we become skilled at engaging the patient and family in self-care strategies. And when people feel as if they are being heard, they feel more satisfied (Dimmitt, 2011). Only then can we shift from, “What’s the matter with you?” to, “What matters to you?” (Berwick, 2013).

Remember the time when your patient displayed a reluctance to do what

For all the progress that has been made over these past 40 years, this is something that hasn’t changed: We must know our patients.

shift has occurred within cancer treatment. Cancer is now even considered a chronic illness (World Health Organization, 2014). This is a huge transformation. Many of us have witnessed and contributed to these changes.

What has not changed, however, and remains as significant as the evolution of treatment, is that there is always a person facing this disease. And that person has a story—a story that describes his or her diagnostic process; a story that uncovers his or her meanings, fears, and hopes; and a story that also reveals his or her life prior to cancer. Although the diagnosis can become the primary focus of the person’s life, I try to never forget the person had a cancer-free life before the start of his or her cancer experience. I try not to forget that, although familiar to me, the person has likely not heard the words we use to describe illness and treatments and has not experienced the medical system, nor has

Ann Reiner, RN, MN, OCN®, is a clinical assistant professor in the School of Nursing at the Oregon Health and Science University in Portland. The author takes full responsibility for the content of the article. No financial relationships relevant to the content of this article have been disclosed by the author or editorial staff. Reiner can be reached at reinera@ohsu.edu.

Key words: patient story; oncology nursing practice; oncology care

Digital Object Identifier: 10.1188/15.CJON.10-11

you asked him or her to do? Perhaps you stopped and wondered to yourself, “Was it how I explained the task? Is there some other physical symptom distracting him or her from the task?” Perhaps the answer to your question is more related to psychosocial issues than physical or instructional ones. Perhaps it was embarrassment. After all, nurses do for others in public what they do for themselves in private (Diers & Fagin, 1983). Perhaps he or she was not feeling comfortable in new situations or did not understand because of literacy issues. Nurses take time to sort through all of these possibilities. Our curiosity, our willingness to tailor evidence-based care to our patient’s abilities and goals along with our understanding that illness affects daily living, and our ability to be present when interacting with the patient and family, all help us tailor our approach to the patient’s particular ways of being.

Kramer (2014), a physician, reflected on his work with patients with long-term psychiatric diagnoses. He concluded with the following insight: “We need storytelling, to set us in the clinical moment, remind us of the variety of human experience and enrich our judgment” (p. 1). For all the progress that has been made over these past 40 years, this is something that hasn’t changed: We must know our patients. While all care, no matter who provides it, should be based

on the best evidence possible, we must keep the patient at the center of what we do. This is the unique contribution of nursing—to assist with managing the impact of disease and treatment on the patient’s requirements and resources of daily living (Carnevali & Reiner, 1990). How can we do this without knowing the patient’s story?

References

Bergholz, E. (1988). Under the shadow of cancer. *New York Times*. Retrieved from <http://www.nytimes.com/1988/12/11/magazine/under-the-shadow-of-cancer.html>

Berwick, D. (2013). “H4”-IHI 25th National Forum keynote address. Retrieved from <https://www.youtube.com/watch?v=r5Tbikk44jY>

Berwick, D., Nolan, T.W., & Whittington, J.

(2008). The triple aim: Care, health and cost. *Health Affairs*, 27, 759-769.

Carnevali, D.L., & Reiner, A. (1990). *The cancer experience: Nursing diagnosis and management*. Philadelphia, PA: J.B. Lippincott.

Diers, D., & Fagin, C. (1983). Nursing as metaphor. *New England Journal of Medicine*, 364, 193-196.

Dimmitt, J. (2011). The benefits of being listened to. Retrieved from <http://ezinearticles.com/?The-Benefits-of-Being-Listened-To&id=5923410>

Heiney, S.P. (1995). The healing power of story. *Oncology Nursing Forum*, 22, 899-904.

Kramer, P.D. (2014). *Why doctors need stories*. Retrieved from: http://opinionator.blogs.nytimes.com/2014/10/18/why-doctors-need-stories/?emc=eta1&_r=0

World Health Organization. (2014). New global cancer country profiles. Retrieved from <http://www.who.int/cancer/en>

New Websites for Journals and E-Books Now Available

Readers of the *Clinical Journal of Oncology Nursing (CJON)* and *Oncology Nursing Forum (ONF)*, as well as those interested in e-books, can find all of the great content online at the following websites:

- CJON: cjon.ons.org
- ONF: onf.ons.org
- E-Books: ebooks.ons.org

These sites replace MetaPress and provide our members with a single sign-on. This means you can use your existing Oncology Nursing Society profile name and password to access the sites. Check them out today and see the ad on page 6 in this issue for more information.