What Matters to the Patient Is What Really Matters: Quality in Oncology Nursing

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On the occasion of the Oncology Nursing Society’s 40th anniversary, it is fitting to look back and appreciate how far we have come in the area of quality cancer care. So much has changed, fueled in part by advances in healthcare quality improvement across the United States.

At a Glance
- The past 40 years have brought many improvements in the quality and safety of oncology nursing practice.
- Beyond the technical aspects of care, advances in patient-centered care have improved patient experiences and outcomes.
- Consistent, personalized, human caring may be the focus of change in the next 40 years.

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Reflecting on the 40th anniversary of the Oncology Nursing Society led me to recall my own 30-plus years in nursing and how, as a new graduate nurse, almost all oncology care was delivered in the inpatient setting. In my first few years of practice, I mixed my patients’ chemotherapy in a medicine room without a ventilated hood and administered those medications without personal protective equipment or the independent RN double checks that have become standard to safe practice today. Through advances in science, tools are now in place to test and make changes, measure impact, and sustain improvements over time. Through advancements in nursing science and oncology research, the ability to treat and cure many cancers and to manage the symptoms and side effects of treatment has improved. Those improvements extend survival; enhance quality of life; and keep patients, staff, and practice environments safer than ever before. In addition, the human side of care has advanced with respect to the quality of interactions with patients and families. Some call this the art of nursing. I call it the essence of our practice. Increasingly, nurses are able to name specific interventions, measure impact, and document outcomes of this so-called art. It is to this human side of our practice that I dedicate this column.

A few years ago, I attended a special lecture given by a man who had been greatly affected by spousal breast cancer. The man’s narrative illuminated for me how far we have come in 40 years. His first wife was diagnosed with breast cancer in the early 1970s. Despite the fact that they had sought care at a premier cancer center in the United States and received the best medical treatment available at the time, she died within six years. He remarried during the subsequent 10 years but, unfortunately, his second wife was diagnosed with breast cancer in early 2002. However, her cancer was detected much earlier and was successfully treated and cured at the same cancer center. The man compared and contrasted the experiences of being the husband of a patient with breast cancer in the early 1970s and then again in 2002. The journey with his first wife was one that he characterized as “in the dark.” Neither he nor his wife were brought into the conversation about the gravity of her disease, and they were not included in decision making about what the best approach to treatment would be. They received what they thought was excellent care, but they were passive recipients instead of active partners, and they felt vulnerable and afraid. No end-of-life planning or discussion took place, and the husband felt unprepared for the loss that he eventually sustained. His second experience was quite different. He characterized it as much more enlightened. He felt as vulnerable and scared as he had the first time, but he and his wife were taught about her diagnosis; more than one treatment option was available to choose; and each option was presented, compared, and contrasted with the others. They felt involved and part of the team and were guided in decision making about all aspects of care. She had surgery and chemotherapy and was still disease-free five years later.

Patient-Centered Care

In addition to the advances in cancer research, the advent of new technologies, and more effective drugs and clinical...
trial options, the understanding of what it means to provide patient-centered care is advancing, and nurses are beginning to measure the impact of engaging patients as full partners with their healthcare team. Organizations, such as the Institute for Healthcare Improvement and the Institute for Patient- and Family-Centered Care, raise awareness, provide education, and study what it means to deliver health care that fully integrates patients and families. Some areas of the country have even passed legislation mandating the institution of patient and family advisory boards inside hospitals to ensure that the voices of patients and families are heard and incorporated into all areas of the clinical operation (Institute for Healthcare Improvement, 2015; National Patient Safety Foundation, 2003–2008). The Joint Commission has instituted initiatives like the Speak Up program, which encourages patients to ask questions of their clinicians to ensure safety in their care (Joint Commission, 2015). In addition, several reports from the Institute of Medicine (2001, 2003, 2013) have called for greater patient involvement as full partners in the clinical team. Healthcare providers are learning that we are a better team when we work together with patients, and the impact of this closer integration is beginning to be measured.

One-on-One Interactions

Although this work has made a huge impact on the quality of the patient and family experience, I have become convinced that the real “make or break” impacts in oncology nursing occur inside the one-on-one interactions patients have with their nurses as they navigate the many appointments, treatments, and procedures that are the norm of the cancer care experience. I am convinced of this because of experiences that I have encountered who have eloquently shared their stories with me and from my own recent, intimate experience of a 15-year cancer journey with a dear friend and fellow oncology nurse. These patient narratives consistently revealed two themes that were part of the everyday experience in the lives of many patients with cancer: intense vulnerability and fear of the unknown. In the case of my friend, sometimes her feelings of vulnerability were so intense they threatened to impair her usual ability to speak her mind, assert questions, and be in charge of her situation. In the earlier years, I was stunned by this phenomenon that I witnessed. After all, she was an oncology nurse being treated in the cancer center where she worked by clinicians she knew. Despite this, her sense of vulnerability and fear surfaced regularly, and together we learned to name it for what it was and find ways to push forward without allowing it to limit her full participation in her care. Her care team was exceptional in the ways that they anticipated these feelings and consistently and purposefully created a safe space for her to explore and express them. This consistency, like the steps a nurse takes to ensure safe administration of chemotherapy, seemed hardwired into the team’s daily routine. It allowed my friend to bring to them what mattered to her, so that it could be woven into the equation of care they were planning to provide on that day. Sometimes what mattered was as simple as needing a break from treatment for a week. Other times it was a need to validate where she was on the journey and what her fears were in that moment. In contrast, other patients have described experiences and interactions where they felt too frightened and vulnerable to ask questions, to tell their team what was on their minds, or to disagree with them in any way. Often these stories have been accompanied by descriptions of hurried interactions with a nurse who was visibly stressed, preoccupied with the technical tasks of administering chemotherapy, or distracted by the needs of other patients.

Consistent Care

How consistently do we take time to think about what it is like to be the patient sitting in front of us? How consistently do we make time to explore and address the myriad fears, uncertainties, and loss of control that characterize so many of our patients’ experiences? Where and how do we create space for the opening of a safe path for patients to tell us what matters to them in the moment, every time we see them? With medical colleagues, nurses have developed standards of practice around the safe administration of chemotherapy. These standards have become hardwired steps, ensuring that patients get the right medication, dose, and route in an environment that keeps everyone safe and protected (Neuss et al., 2013). Today, an oncology nurse would not consider administering chemotherapy without the independent double checks that are part of the process. Making these checks a standard of the workflow results in reliable, safe administration of chemotherapy in countless oncology settings every day.

What would happen if we applied that same rigor and reliability to the human aspect of our care? What if we created a space for every patient every day where, in a consistent manner, we assess and address the issues that are most important to them? What would we discover by making this as important and as consistent a practice as the safety steps in chemotherapy administration? Some might say that what matters most to patients is what should matter most to the clinicians caring for them. If so, maybe we should spend the next 40 years uncovering what that is in the patients we treat by creating that space and hardwiring the right questions into our daily interactions.

References