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Marilyn K. Bedell, RN, MS, OCN®

## Between the River Denial and the Oncology Highway: Trying to Find a Balance

I remember how irritated I was. Once again, my sister, Nancy, could not make up her mind if she and her new husband would join us for a few days of house boating on the Trent Severn Canal System in Ontario. Little did I know that her vague physical complaints (hip pain and constipation) and statements about fatigue were ominous precursors to ovarian cancer. I just assumed that her fatigue was due to her working too hard as an events planner at a college; the hip pain was from lifting something she should not have lifted, and the constipation was "just Nancy." But primarily I was not dealing with her inability to do any advance planning in her personal life.

Now, looking back, I realize that this is when I began my personal journey of balancing travel between the River Denial and the Oncology Highway. Every nugget of oncology nursing knowledge I had ever obtained and stored in my gray cells (my brain) would become valuable tools to help me support my sister on her cancer journey.

At the point that Nancy was diagnosed, I had been practicing as an oncology nurse for 30 years. I believed myself to be a very competent nurse, but dealing with my sister's diagnosis was transformational. I will never consider a cancer diagnosis the same way again. I have reflected back to my knowledge of cancer in 1971, when I started my career, and to my knowledge today. The strides we have made in supporting patients on their cancer journeys are astounding. I am grateful to the pioneers in oncology nursing, who are described in the book *It Took Courage, Compassion, and Curiosity: Recollections and Writings of Leaders in Cancer Nursing* (Johnson, Baird, & Hilderley, 2000). They paved the way for my generation to become much more fully engaged and aware of what a significant role oncology nurses play in the lives of their patients. In addition, during the 1970s, the Oncology Nursing Society (ONS) was formed. This organization has been instrumental in formalizing the practice of oncology nursing and has provided me with resources to refine the art and science of my own oncology nursing practice. I would not be the oncology nurse I am today without the help and support I have received from this organization over the years. Fortunately for me, throughout Nancy's journey, I was surrounded by caring and competent oncology nurses at home in New Hampshire, where I work, and in Maryland, where Nancy lived. These nurses emulated what is unique and so

very special about oncology nursing. I was able to witness firsthand all of the values that are near and dear to my heart as an oncology nurse. I used this experience to validate my own practice.

This experience has helped me define and describe the work of oncology nurses. As Nancy traveled the twisting, bumpy, and uneven oncology highway, I kept a journal. As I have re-read my journal notes, I realize that as an oncology nurse, my knowledge of what was ahead for my sister prevented me from having many moments of denial about the seriousness of her disease and her poor prognosis. Hopefully by telling my story, you will learn more about the essence of oncology nursing.

When I had returned from vacation, I called Nancy to wish her a happy birthday. Very quickly, my words of celebration were tempered with news of her health. She told me that although she had been to her primary care physician many times over the summer for her complaints of right hip pain, she decided she needed to go one more time because she was still very uncomfortable. She said at this visit, the physician had become very concerned and ordered a CT scan. The scan showed she had two baseball-size tumors, one in her right ovary and one in her pancreas. Nancy also told me that her belly had become very swollen and tense. From that moment, I knew that either an ovarian cancer or pancreatic cancer diagnosis was a possibility and that her prognosis would be grim.

I wished I could float on the River Denial, but this was not a luxury open to me. I needed to remind myself that Nancy, our mother, our sister, her husband, my husband, and her many friends did not need to be confronted with the full gravity of the situation at this point in time. As an oncology nurse, even though I had clinical knowledge beyond what my sister knew, I needed to be careful about sharing information. I needed to focus on being her sister, who just happened to be an oncology nurse. I understood that my messages needed to be tempered and managed in a way that fit her situation. Rather than leaping to doom and gloom, my job at this point was to help Nancy develop the skills to be a good consumer of oncology care. Nancy's education at Hood College had prepared her to be a consumer advocate. I knew she would need to ask questions and read everything she could find to make decisions. Nancy asked me for help in generating the list of questions for her physicians and nurses to help her start her journey on the Oncology Highway. As I thought back to the *Statement on the Scope and Standards of Oncology Nursing Practice* (Brant, 1996) and the 11 high-incidence problem areas that are defined (see Figure 1), I was working to help Nancy understand the issues related to detection of the disease and the information she would need to cope with her cancer diagnosis.

**Figure 1. Eleven High-Incidence Problem Areas**

- Prevention and early detection
- Information
- Coping
- Comfort
- Nutrition
- Protective mechanisms
- Mobility
- Elimination
- Sexuality
- Ventilation
- Circulation

*Note.* Based on information from Brant, 1996.

We talked of her wishes and desires, discussed what was important

to her, and spoke of practical things, such as durable power of attorney for health care, living wills, a personal will, and other legal matters. I reminded her that talking about death would not make it happen. Dealing with issues was an important step in allowing her to face the future with fewer worries, and, hopefully, we could avoid having tough discussions about these issues if problems arose later.

Nancy quickly progressed to having difficulties in all of the other high-incidence problem areas. From her first appointment with the surgical oncologist, it became clear to me that the quality of the nursing care would make a difference in Nancy's life. Of course, the clinical expertise and skill of the nurse is what I valued most, but genuine caring and compassion were other key attributes.

My journal entries and reflections on them highlight what I believe to be the essence of excellence in oncology nursing, and the knowledge I gleaned from this experience highlights what it is like to be cared for by Oncology Certified Nurses (OCNs®). This has refined my approach to creating environments where patients and families can heal. Creating such an environment always has been my chief mission as an oncology nurse administrator.

Many of the entries I wrote talked about the nurses we met along her journey. My entries began on the day of Nancy's surgery. I will try to convey how the framework of the high-incidence problem areas affected Nancy's journey.

From the beginning, oncology nurses worried about Nancy's comfort—her level of pain and her metabolic stability. I wrote, "She assured you that she would keep your pain under control. She discussed that an epidural catheter would be placed to help manage your pain. At this time she also alerted us that your potassium was only 2.8, and you would need replacements, so the surgery would be delayed. She attempted to use your peripheral line to infuse the potassium replacements, but it caused too much discomfort. So she talked to the anesthesiologist and got a central line placed so the replacement potassium could be infused more rapidly." How reassured I felt by this approach to Nancy's comfort. Working to ensure that pain issues are dealt with in an appropriate, timely manner always has been part of my mantra. Hearing these words from an oncology nurse from day one helped me relax and feel confident in the care my sister would receive.

The day of surgery, Nancy's husband (Ed) and I were eager to receive information. Once again, it was her oncology nurse practitioner who kept us informed. "She came to see us about 1:30 pm. She was headed to the OR to get an update. She came back with news that they were not able to resect the pancreatic tumor. At this point, your right ovary, omentum, and gall bladder had been removed. The good news was that your intestine did not look involved, therefore no resection was done, and they anticipated that your 'gut' would wake up easily."

Having information and access to Nancy was important to me. I was relieved to hear that Nancy had made it through surgery. I was not surprised with the news but relieved to hear we were now at a new crossroad. At that point, her nurse came to get Ed and me to come and see her in the post-anesthesia care unit. "You were in a stupor, foggy and in and out of sleep. You

would wake up and ask a bunch of questions, then drift off to sleep again. It was so good to see you. Your vital signs looked fairly stable, but you weren't making much urine. We visited with you several times before they moved you to ICU."

I was amazed at how many of Nancy's friends surrounded us during her illness. One of her friends was a fashion historian. When he called during the immediate post-operative period, he promised me that he would be Nancy's fashion consultant. He would help her manage the body image changes that were bound to happen. He reminded me that Nancy was very lucky to have so many friends and colleagues who cared about her. I wrote in my journal that "each of Nancy's friends will bring a different skill or talent to help her on her journey." Finding ways to help Nancy to cope would come in a wide variety of shapes and forms.

Initially, Nancy's post-op course went as predicted, but the second post-operative day presented us with new challenges. I wrote, "When I arrived at the hospital at 6:30 to say good-bye and to tell you I was headed back to New Hampshire but would be back as soon as you were cleared for discharge, I found you to be restless, scared, and somewhat agitated. The longer I sat with you, the calmer you became, but I sensed something was changing. I still made a decision to head to New Hampshire, after you were able to reassure me that you would be OK."

Even though I left, I still felt concerned. I vividly remember talking to her oncology nurse, who understood that I needed to leave, but she could see why I was concerned and vowed she would stay on top of things. I also remember that she told me she would be caring for Nancy that day and for the next two days. This was so reassuring. She said I could call her anytime.

I remember wanting to believe that everything would be okay. This is one point where I let myself float on the River Denial. I was not ready or able to admit that her post-operative course would be a rocky, pothole-filled dirt road.

Within 48 hours, it became clear that Nancy's ascites was again accumulating rapidly, and she was becoming metabolically and hemodynamically unstable. Two new high-incident problems blocked our journey: ventilation and circulation. Nancy was quickly slipping into acute respiratory distress syndrome (ARDS).

I packed my bags and headed back to Baltimore. My journal entry stated, "Nancy, my journal writing stopped once your condition became critical. I was too worried to write. We were so worried about you. Your doctors and nurses patiently explained your situation, and, depending on the day, optimism was tempered by pessimism. You remained in critical condition for two weeks. Although we all had moments of terror, we tried hard not to lose optimism. Ed told me he would figure out how to accept your death, but he refused to waste his energy thinking about that as long as there was reason to hope."

During this period of time, spiritual support was important to all who cared about Nancy. It was an essential part of our coping. I wrote about ministers who supported us during this time, "The 'God squad' each brought their own style of pastoral care. Each was effective and supportive but in very different ways. FT prayed in a volume that could wake the dead; GM was softer, more

intimate and sensitive to you; CM brought songs and hugs; and RW was direct, questioning, and could be like a bulldog working to get information to help us. No one pushed religion on me but gently offered spiritual support and guidance."

While Nancy was in the ICU, I became more fully aware of the need for oncology nurses to stay involved in the care of my sister. The surgical oncology nurse practitioner was a key member of Nancy's care team. I know that she brought expert knowledge of Nancy's cancer to the nurses in ICU. I also know that she did tons of work helping some ICU nurses understand why someone with such advanced disease should be offered the skills and services of an ICU. Although I knew that Nancy probably did not have long to live, based on my conversations with her pre-operatively, I knew she wanted more time. There was work left for her to do.

Thanksgiving week, Nancy made a decision to re-enter the world. Against all odds, she was beginning to recover from ARDS. I wrote, "It's been amazing watching you re-enter the world. From tears, to smiles, to confusion, to puzzlement, to curiosity, to learning how to communicate, to regaining small bits of physical strength, you are making improvements daily. We smile when you are frustrated, because it is a sign you are improving. Your first coherent thoughts were of your physical therapist that helped you after your shoulder injury. Even though you couldn't talk, the few words you could write made it clear you needed him. This is when I knew you were going to be with us for now." Helping her to become mobile would be another major challenge for the care team.

Nancy was finally able to be moved to a respiratory step-down unit. But again, even here her oncology nurses would play a huge role in her life. Within days, the oncologist talked to us about getting chemotherapy started. But this would not be easy. She was still dependent on her ventilator. During the ICU stay, her implanted port had become infected and had to be removed. It left a large open wound in her chest, and I was worried about protective mechanisms. At one level, I knew she needed chemotherapy, but at another, I was worried it would make matters even worse. In the long run, I knew Nancy's cancer was not taking a holiday. After discussion with Ed and me, Nancy made the decision to accept the risks and get chemotherapy started. A piece of me wished I could travel on the River Denial, but I knew too much. I wrote, "It's been a couple of days; I'm continuing to learn about myself. I can't write when I am unsettled and distressed. You've been worried about the chemotherapy. This part of the journey will have many unknowns. What side effects will you experience, how will you tolerate them? A nurse from the oncology unit came to teach you about chemotherapy. She will be back tomorrow to administer it to you. She assures me she will stay as long as she is needed. I am relieved. Chemotherapy will only be administered by nurses educated to give chemo." ONS's practice standards have positively impacted the care of patients. Oncology nurses would stay involved in my sister's care.

Many times through her journey, I learned that keeping her comfortable would be a challenge. One day I wrote, "I was worried about you. You looked so sad; your eyes looked vacant, and at times, nothing was right with the world. Your nose hurt from the NG tube. Your butt rot (our words for a sore bottom)

was driving you crazy. No change in position helped, and you had right upper quadrant pain. Your nurse did such a nice job working with you to try and make you comfortable. He obtained orders to adjust your pain medications, and we played your relaxation tape for you. You asked us to play it two more times; it really seems to help." He convinced the medical team that it was time to discontinue the tube feeding and let her eat on her own. He understood that getting Nancy to eat independently was another major goal to prepare her for discharge. This reminded me that nutrition was another problem area that would be continually monitored and assessed by the nurses.

Throughout this experience, I was reminded that many patients with cancer would need the support and consultation of a variety of nurses with a wide array of skills. I must admit that I was awed by the expertise of the staff on the step-down unit. They taught me that weaning a patient from a vent was both a science and an art. The step-down unit staff worked with respiratory therapists and found a portable ventilator so Nancy could walk. They even took her up and down stairs with her ventilator. Being focused on both ventilation and mobility made a huge difference in the rate of Nancy's recovery.

Another nurse entered our lives at this point. She was Nancy's case manager who was charged with coming up with a plan to get her home. She was able to secure several additional days of hospitalization so her formal rehabilitation could be completed at the hospital. She worked with the step-down unit and physical therapy to come up with an aggressive rehabilitation plan that could be accommodated on the unit. This nurse knew a transfer to a rehabilitation center for several days might slow down Nancy's progress. She was able to argue that because Nancy still had chemotherapy on board, she needed acute care. She really helped us maximize Nancy's benefits and was a true advocate.

But with discharge to home, I was required to consider the following high-incident problem areas in new ways. Below are some insights into what we faced.

1. Information: I learned firsthand about all of the home healthcare services that were available to us. Although Nancy was not emotionally ready for hospice services, I was able to work with her case manager and the visiting nurses to arrange for palliative care for symptom management.
2. Coping: I set up a plan to ensure that Nancy's spiritual needs were addressed. The "God squad" made visits, and her friends assured us that Nancy was placed on prayer lists. I also encouraged Nancy to get some formal counseling and join a support group. Nancy's home library was always filled with self-help books, so I knew these activities would be important to her. Nancy also asked friends to provide healing touch.
3. Comfort: Pain became an everyday part of Nancy's life. Her oncologists and the visiting nurses were committed to keeping her pain under control. This was accomplished with long-acting narcotics, with the availability of narcotics for breakthrough pain. I was so relieved that this never became an issue or a battleground. Pain management has changed in 30 years of practice.
4. Nutrition: This became a major challenge. Nancy lost her appetite. Her friends and family would obsess that she was not eating enough. Her husband knew if she did not eat, she would die from malnutrition. I found this one of the greatest challenges of home care. Nancy and I grew up with

an "Eat, I love you" mentality. Discussion about food could bring Nancy to tears. Helping her friends and family understand the anatomy of a cancer diagnosis and its impact on nutrition was essential. Both her oncologists and my oncology nursing colleagues in New Hampshire helped me navigate this emotionally charged topic with friends and family.

5. Protective mechanisms: Fortunately, her oncology team was supportive of the use of filgrastim and epoetin. By keeping her granulocyte count within normal limits and her hemoglobin and hematocrit in a reasonable range, I truly believe this enhanced the quality of her life. Nancy not only had the open wound from her implanted port site to contend with, but a permanent peritoneal catheter was inserted to permit her to self-drain her ascites. She only had one infection in the year she had her peritoneal catheter. This was quite amazing because about every two to three days, she was draining 1–2 liters of fluid. In addition to the filgrastim, her oncology nurses consulted with renal nurses who instructed Nancy on the proper care of the peritoneal catheter, and her oncology nurses instructed her husband how to meticulously care for the former port site.
6. Mobility: The physical therapist she wrote to me about when she was recovering from ARDS was the therapist who was able to come to her home. He was amazing. He could motivate Nancy in ways that I could not. He also taught her skills to keep her safe at home. He taught me how to assist her in ways that would help her recover strength.
7. Elimination: Narcotics brought with them issues of constipation. I will be ever grateful for the work that the staff on my own oncology unit did to develop a set of narcotic bowel orders with our oncologists. I had Nancy follow the care plan they developed, and constipation never became a huge issue for her. Many nursing instructors have stated that every nurse should be able to manage constipation. This experience reminded me that they were correct.
8. Sexuality: Even though Nancy was extremely limited by her disease, she was a newlywed. She had only been married about a year when she was diagnosed. She wanted to be intimate with her husband but did not have the physical strength to have intercourse. She and I had quiet conversations about this and talked about alternative ways to be intimate. I sensed that these conversations were helpful. Her husband was amazing throughout this entire journey. He made it possible for Nancy to stay in the community she loved. He also demonstrated in many ways how much he loved and cared for her. He was patient, kind, and gentle.
9. Ventilation: Fortunately, by the time Nancy was discharged, she no longer needed her tracheostomy, and she did not require oxygen. She only needed to keep her ascites drained so she could keep her lungs expanded. She also needed to stay mobile.
10. Circulation: Fortunately, Nancy's heart withstood all of the insults that happened as a result of the cancer and ARDS. I continued to worry about sudden fluid shifts as she drained her ascites. Her nurses taught her to drain the fluid slowly and to take time moving from a sitting to standing position. She was able to maintain a delicate equilibrium for a long time.

11. Prevention and early detection: Although this is listed first in the standards, I have chosen to write about it last. Unfortunately for Nancy, early detection did not happen. She died from her disease in September just after the 9/11 crises. Her diagnosis has heightened my awareness about the disease for my older sister, Marsha, and myself. Our mother is a breast cancer survivor, so we know our risk of developing either disease is potentially higher. At the moment, I have chosen not to seek genetic counseling but have made the commitment to annual physical examinations and yearly mammography and Pap examinations, and had a transvaginal ultrasound screening performed. I do not know what lies ahead for me, but through this experience, I have learned that as a nurse, I must think beyond the immediate problems that are caused by a diagnosis and consider the long-term impact on family members. I am trying to balance my strong desire to deny that this could happen to me with my need to stay on the prevention and early detection highway.

In closing, I want to share a few final thoughts on how some of Nancy's nurses made a difference in our journey on the Oncology Highway. Here are some things I came to value immensely:

- Nurses who really wanted to hear Nancy's story and wanted to know more about her as a person.
- Nurses who made a real effort to connect in a meaningful way with her family.
- Nurses who explained everything they were doing, even when Nancy was heavily sedated.
- Nurses who encouraged me to be a sister first and a nurse second.
- Nurses who respected my nursing knowledge and provided me with clinical information.
- Nurses who educated me about clinical issues that I was not familiar with (e.g., vent settings).
- Nurses who worked as a team and pitched in even if they were not assigned to Nancy.
- Nurses who checked in on me even when they were not directly assigned to Nancy.
- Nurses who made Nancy believe that she was the center of the universe even when they were extraordinarily busy.
- Nurses who introduced themselves several times. To me, this indicated that they really wanted to us to know them.
- Nurses who do not assume they know everything. I valued nurses who would raise questions to their peers and other members of the care team.
- Nurses who gave me hugs.
- Nurses who made sure that Nancy was participating in decision making. Those who made physicians slow down and wait for Nancy to write questions when she could not speak because of her tracheostomy. They made sure her questions were answered.
- Nurses who encouraged Nancy to write down her thoughts, feelings, and fears when she was unable to speak even though this took tons of patience and time.

- Nurses who touched Nancy's balding head and held her hand.
- Nurses who frequently assessed Nancy's comfort level and anticipated when things might hurt.
- Nurses who understood that even though we all knew Nancy would die soon, she wanted every opportunity to live life to the fullest. Nurses skilled in symptom management were her biggest allies.

This life-altering experience validated that nurses make a tremendous difference in patients' lives. I thank every oncology nurse for being the glue that holds patient care together. As oncology nurses, we need to celebrate our profession! A special thanks to the amazing oncology nurses I met in Maryland and my oncology nursing colleagues at the Dartmouth-Hitchcock Medical Center and ONS who supported me on my journey. Every day, these nurses validate why oncology nursing is unique and special. They are a very special group of nurses. Thanks for helping Nancy, her family, and me navigate the Oncology Highway.

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## Why Should You Become a Nurse?

When I was five years old, I was hospitalized for more than a month. This was a time when moms were not allowed to stay with hospitalized children. Because my mom could not be there all the time, I really needed my nurses. Even at that early age, I knew what I liked in my nurses. I vividly remember the nurses who let my mom stretch the rules and stay a few minutes longer; they knew how homesick I was. I remember the nurse who made sure that *Captain Kangaroo* was on the TV in the morning and not the *Today Show*. I remember the nurses who gave me Lorna Doone® cookies. I remember the nurses who really listened to me and comforted me when I was afraid and feeling so sick. I know that I am alive because they knew how to care of me, technically, emotionally, and spiritually.

The "good" nurses, who cared for me in 1956, started the revolution in the care that children receive in hospitals. They could not change all the rules at once, but they started to question why hospitals had to be so rule-driven about visiting. Through nursing research, the rules changed.

I hope you will decide you want to become a "good nurse," a nurse who knows when it is appropriate to ask "why?" and a nurse who will work hard to make a difference in the lives of his or her patients.

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