Ian was a patient with multiple myeloma. His wife, Judi, chronicled their journey and experiences with myeloma and the healthcare system. Through her own eyes, Judi provides a view of the positive and negative consequences of actions or omissions by the healthcare team. The other authors, oncology nurses affiliated with a myeloma treatment center, collaborated with Judi to tell her story and remind oncology nurses that they can and do make a difference when focus is placed on the basics: assessment, communication, caring, and follow-up.

At a Glance
- The most basic aspects of health care often are the ones that suffer from neglect.
- Seemingly trivial actions or omissions of the healthcare team can have life-altering consequences for patients and their families.
- Viewing healthcare interactions from the perspective of the caregiver can help oncology nurses understand the difference they make.

patients with myeloma being able to complete their hematopoietic stem cell transplantations in the outpatient setting without hospital admission for symptom management or complications. In addition to the communication directed at patients and their caregivers, the context in which the care takes place may be communicating in ways that may not have been considered. In response to her experiences as a caregiver for her husband,
Ian, Judi McBride-Wilson became committed to helping other families navigate the difficult journey.

Case Study

In her journal, Our Journey With Multiple Myeloma, Judi chronicled her experience with the healthcare system after her husband, Ian, was diagnosed with myeloma. Judi’s story helps healthcare professionals look at the positive and negative consequences of their actions and omissions through the eyes of a patient’s spouse.

We decided early on that Ian would fight the disease and I would take care of everything else. Neither knew what we were taking on. . . . We soon learned that this battle is too hard to fight alone, one needs support to fight. . . . Diagnosis in September 2000 was both a massive shock and a huge relief. Ian had suffered often crippling back pain for about five years. An x-ray in 1995 recommended urgent referral for a lesion found at L4. This was ignored by Ian’s general practitioner and we only knew of this when Ian collapsed in agony when the vertebra broke, compressing the spinal cord, and somebody had to take the pain seriously.

Whether the report was intentionally disregarded or misplaced, or whether some clerical error caused this situation, the result was enormous suffering that might have been avoided. After reconstructive surgeries,

Ian had left the ward barely able to eat, wounds still unhealed, with postoperative pain a real issue, almost mobile and weak as a kitten. We had next to no community support to ease our way. We discovered when he got home that we didn’t know if and how long he could sit without damaging the metal work, how to mobilize him, what he could and couldn’t do, and we had nowhere to turn for help. It was very difficult, appalling really. . . . The notes (two pages) were to tell me how and when to use the drugs. I couldn’t understand what to do. I was unable to figure out how to sort all these drugs out. I remember sitting, weeping in fear and desperation.

Caregiver Support

Ian and Judi needed more complete discharge instructions in a format that was easy to understand and follow as well as a support person to contact if they had questions. Judi’s savior was Sandy, a local pharmacy employee making a delivery. “[Sandy] found me in all my misery. Through the sobs she understood; she scooped up all the drugs and left. When she returned, it was with everything packaged for the entire week, hour by hour.”

Sandy also understood that shopping would be impossible for Judi and offered to bring bread, milk, and other supplies. Sandy’s small acts of kindness and understanding relieved a great burden of worry and fear and made a critical difference in Judi’s ability to cope with her role of caregiver. Healthcare professionals seldom know the full impact that certain acts, which often are routine and easy to accomplish, have on the quality of life of the recipients. Unfortunately, not understanding how those small acts make a difference, coupled with pressure to care for many patients in a limited amount of time, can numb professional caregivers’ awareness of patients’ and families’ perspectives and distress (Felton, 1998).

Healthcare providers can become desensitized to the overall impression of clinic waiting rooms. They are accustomed to seeing patients with cachexia, alopecia, and various forms of disfigurement resulting from cancer or cancer treatment. How ill patients look is relative to how ill they could look. How often do healthcare professionals stop to consider how newly diagnosed patients and their families might react to the sight of a waiting room full of patients with cancer? Do they take time to prepare patients for the experience? Patients who refuse treatment typically consider quality of life, personal values, and previous experiences when making decisions (van Kleefens & van Leeuwen, 2005). How many patients decide to forgo treatment based on what they encountered in the waiting room?

In all our subsequent visits to [the cancer center] we have never seen a waiting room so full of sad, disfigured, sick people, and while Ian ended up looking pretty horrendous himself at times, this was shocking. We were so fearful anyway that this first visit was almost more than we could manage. We waited hours to see a consultant who was uncommunicative, unhelpful, and left us devastated. We decided this was our first and last visit to that dreadful place, we would not return, the cancer had won, there would be no treatment. The doctor called us a few days later. He knew it had been a bad consultation and asked Ian to return.

They did return and began their “new life as part of the cancer center.”

Basic care often is affected by the limitations of physical space. Crowded environments and lack of privacy are not conducive to patient teaching and support, even though patients often spend hours waiting and are available for such interactions. When the interactions are facilitated, they can be enormously therapeutic.

We were terrified again when a nurse came to us, a beautiful, shining young woman. She sat with us, she talked about ward life, venous access devices, Hickman lines, side effects, potential problems, and help available. She refilled our hope and restored our shattered confidence.

Ongoing support and encouragement are essential for caregivers who are forced to learn and perform complex tasks (Coleman et al., 2002; Kalnins, 2006).

Caring for the Hickman line scared us silly. It was so complicated when we had to do it in front of staff. At home, it was simple, I broke the bags of supplies into neat little packs that had everything we needed. . . . It was a gentle, good time, we were in control and doing something positive well. . . . We loved the freedom. The Hickman lasted six months; we never had another infection from it.

Once mastered, self-care can improve self-esteem, sense of control, and quality of life (Forbes, 2001; Gammon, 1991), as well as reduce nosocomial infections (Tokars et al., 1999). Making patients and their caregivers comfortable with their new responsibilities requires tuning into their cognitive and emotional states to apply appropriate pacing and reinforcement.
Helping Patients Maintain a Sense of Normalcy

Healthcare providers must help patients and families keep their lives as normal as possible (Coon & Coleman, 2004; Wengstrom, Haggmark, & Forsberg, 2001).

When Ian was in the hospital, he rose at his normal time, hours before hospital breakfast was served, got dressed and drove the staff nuts by heading out for a walk every day, trailing his drip trolley around the hospital car parks. The walks in the parking lot may not be an option, but patients can wear comfortable clothes instead of hospital gowns, be out of bed for meals, and walk in the halls when their conditions permit. New hospital designs and renovations can include plans for more home-like surroundings as well as natural areas for sitting and walking. Pleasant surroundings and distractions can aid symptom management (Cimprich & Ronis, 2003; Frumkin, 2001; Magora, Cohen, Shochina, & Dayan, 2006; Wismeijer & Vingerhoets, 2005).

Ian’s Pain Experience

Ian’s pain transformed him and his relationships, revealing that uncontrolled pain affects more than the patient.

The pain had crept up and overtaken Ian; he became the grumpy granddad to the young ones who had adored him. His pain made any social or family occasion difficult because he couldn’t sit through a meal or enjoy being with people, he had to move constantly, we just didn’t understand. It overshadowed everything about our lives, quietly and completely taking him from us, invading and destroying his business and our relationship, all relationships, because he was so difficult to be around . . . . Neuropathy was becoming an issue. Eventually, Ian could not walk; he needed a wheelchair . . . . Nobody would tell Ian what was happening, we were lost and alone in our misery; the frustration was as hard to manage as the pain . . . . Because morphine produced a raft of very difficult side effects . . . and . . . no positive reaction . . . a pain specialist . . . banished the morphine and insisted we use tramadol, an expensive nonsubsidized drug that we could not afford to buy. Once again cruel pain became a constant, we just lived with it and I watched it eat him up again.

Healthcare providers must assess each individual patient’s reaction to specific analgesics and determine whether the patient can obtain the prescribed medication. “Methadone relieved Ian’s pain, but his treatment program was terminated due to a ‘nonfunctioning bone marrow.’ He turned to Chinese herbal tablets along with methadone and antiemetics.” Judi reported similar issues with Ian’s persistent nausea when the medication that finally was effective had limited availability. Ian suffered from the time his allotted supply ran out until he could get his next supply.

Reactive Symptom Management

Judi chronicled a chain of events in June 2005 that illustrate the cost of reactive versus proactive symptom management. Because Ian’s antiemetic allotment was inadequate to last through his radiation treatments, he suffered from constant nausea, vomiting, and anorexia when it ran out. As a result, he was seriously dehydrated and had two newly cracked ribs from the violent retching and vomiting. Unable to get an appointment in the outpatient clinic where the staff was familiar with his case, Ian went to a crowded emergency room where, after a long wait, he received a dose of the antiemetic. Unfortunately, during his wait, he was exposed to people with upper respiratory and flu symptoms. Three days later, Ian presented with a serious infection and epiglottitis. While Ian waited in the crowded outpatient clinic, Judi and her son watched helplessly as Ian’s symptoms progressed to the point where he was struggling to breathe. The registrar (equivalent to a medical resident in the United States) in attendance failed to recognize the seriousness of Ian’s symptoms or to respond to Judi’s pleas to have a senior staff member assess Ian. Nine hours after he presented to the clinic, Ian suffered respiratory arrest. “No living soul should have been allowed to suffer like this, either actively as Ian did or passively as our son and I did.”

The sequence of unfortunate and unnecessary events was expensive, requiring an 11-day hospitalization that included four days in an intensive care unit. The system and personal factors that culminated in Ian’s life-threatening event involved seemingly small, discrete barriers or errors related to access to services, triage, assessment, or judgment. The events demonstrate the point made by Woolf et al. (2004) that many medical mishaps are the end result of a string of seemingly small mistakes.

Discussion

Ian and Judi’s experience happened in New Zealand, but it could have happened anywhere. New Zealand has a population of 4.2 million (Statistics New Zealand, 2007). Wellington Blood and Cancer Center, where Ian received treatment, serves a region of about 500,000 people, of which about half live in the capital of Wellington. Almost all cancer treatment is provided by state-funded public hospitals and cancer centers, which means that all oncology and hematology services are provided free of charge (New Zealand Ministry of Health, 2006). Patients with cancer can have some surgery in private hospitals, but chemotherapy and radiotherapy are available only within the public system. The government subsidizes most medications. In some cases, patients have to pay for approved but nonfunded drugs. Some drugs required by patients with cancer are not approved for use and, therefore, are not available. In New Zealand, about 230 cases of multiple myeloma are diagnosed each year (New Zealand Ministry of Health).

More treatment options are available for patients in the United States, yet many access-to-care and medication issues are related to dependence on public assistance, complicated insurance coverage rules, or lack of coverage. Patients and families living on opposite sides of the world have similar experiences and needs. Assessment, communication, caring, and follow-up are important for all patients. Seemingly small oversights, mistakes, miscommunications, or thoughtless remarks can have life-changing consequences, as can acts of kindness, words of encouragement,
or creative solutions (see Figure 1). Healthcare providers often forget the enormous power, both positive and negative, that they have over people’s lives. Healthcare professionals themselves can struggle with issues of poor communication when they or their loved ones are suddenly at the mercy of the system (Weston & Weston, 2006; Woolf et al., 2004).

Lack of capacity, long waits in clinics and emergency rooms, and failure to appropriately separate those who appear to have communicable diseases from other waiting patients are system issues. Healthcare workers must be persistent advocates for sensible, substantive changes and hold politicians, institutions, and corporations accountable. They also must hold themselves accountable, know the limits of their knowledge, and put patients’ welfare above their egos, fears, moods, or convenience. Healthcare professionals can and do make a difference every day when they focus on the basics: assessment, communication, caring, and follow-up.

As the primary caregiver for her husband during their six-year journey with myeloma, Judi decided that someone independent of all the various medical and social disciplines needed to raise awareness of the needs of patients with myeloma and those who care for them. Judi coped by taking action. She became a vocal advocate for patients with multiple myeloma and their families. She promoted awareness and understanding of the disease by participating in cancer support groups and organizing a myeloma support group. She invited experts from the Myeloma Institute for Research and Therapy in the United States to give presentations to the myeloma support group and cancer professionals at the Wellington Cancer Center in New Zealand. She is editor of Myeloma Matters, a newsletter for families coping with myeloma. Because Judi understood that, at some point, Ian would lose his battle with myeloma, she was aware of the need to integrate palliative care services into the overall support for those living with myeloma and their families.

Judi attended the annual myeloma workshop in May 2005 in Sydney, Australia. At that time she wrote, “He could walk for four hours in the morning, hide during the heat of the day, and enjoy the afternoon and evening out and about.” Judi ended with, “We know the myeloma is not going to remain quiet forever. We hope for access to the new drugs before it is too late. In the meantime, we are going to make the most of every precious moment we have and be grateful for them and to those whose care and dedication has given this time to us.

Ian died in the fall of 2006.

Storytelling and journaling have been used as therapeutic modalities to help individuals and couples cope with the illness experience (Gale, Mitchell, Garand, & Wesner, 2003; Sakalys, 2005), and treatment or symptom diaries have been used to facilitate clinical care (Freynhagen et al., 2005). Although Judi’s journaling helped her cope and facilitated Ian’s care, she shared her journal for another purpose. She wanted to speak directly to healthcare professionals. She wanted them to tell her story to those who could make a difference. She hoped that her story would inspire professional caregivers to take that extra moment to listen, assess, inform, and reassure. She wanted to communicate how poorly controlled symptoms create suffering and loss not only for the patient but for the whole family. She wanted healthcare professionals to understand that seemingly trivial acts of kindness can have tremendous positive impact while seemingly trivial omissions or miscommunications can have devastating consequences on the well-being and quality of life of patients and their families.

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