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Instrumental Care and Human-Centered Caring

Rhetoric and Lived Reality

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This article explores the nursing discourse on relational caring as a context for examining the authors' recent lived realities with the health care system. Two narratives detail experiences of instrumental care and human-centered caring as the authors journeyed with a loved one who was dying. Commonalities across the stories are identified and caring analyzed using Halldorsdottir's ways of being with another. From weaving an analysis of the realities with the literature emerges a recognition of a critical turning point in nursing and health care.
Key words: *caring*, *fragmentation of care*, *relational caring*, *self-determination*, *workplace environment*

> *Turning points occur in the history of a profession when radical questioning and clarification of major tenets become essential for further growth. We recognize such a turning point now in nursing. The direction which nursing develops will determine whether the profession draws closer to the medical model, with its commitment to science, technology and cure; reverts to historical nursing models, with their essentially intuitive approaches; or creates a new philosophy that sets contemporary nursing distinctively apart from both traditional nursing and modern medicine.*[1]
>
> *—Gadow S*

GADOW[1] wrote these words more than 30 years ago, as she proposed existential advocacy as a philosophy for nursing as a distinctive discipline and practice profession. Her ideas have influenced contemporary nursing science, for example, Watson's caring science (CS)[2,3] and the *Best Practice Guideline: Client Centred Care*.[4] And yet, in recent parallel experiences in 2 large teaching hospitals in 2 different cities in 2 different Canadian provinces, each of the authors found herself advocating almost feverishly but often futilely for human-centered caring of a dying family member, rather than the instrumental care we often witnessed. Our experiences called us to reexamine what is known and what we believe about caring.

We are differentiating instrumental care from caring, that is, relational, human-centered caring as it is widely described in the nursing literature[2,5] and nonnursing literature.[6,7] Instrumental care, as we experienced it, may include a range of care-giving actions, which Halldorsdottir[8] described as biocidic, biostatic, or biopassive ways of being with another. We reserve the term caring for ways of being in which the nurse-patient relationship is a central feature and that Halldorsdottir refers to as bioactive and biogenic.

This article begins with a brief review of relevant literature to contextualize the stories of each of our experiences with a dying family member, which follow. The purpose of this article is to examine those journeys within

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the context of nursing discourse and consider Sumner's[9] question, "Is caring in nursing an impossible ideal for today's practicing nurse?"

THE CENTRALITY OF RELATIONSHIP IN NURSING DISCOURSE

Nursing, by its very nature, is an interpersonal enterprise. Building trustworthy relationships is considered essential to the provision of safe and competent care in the Canadian Code of Ethics for Registered Nurses and described as foundational in establishing "meaningful communication. . . . and understanding people's needs and concerns."[10] Moreover, as early as the 1950s, the therapeutic potential of the nurse-patient relationship has been explicitly postulated in nursing theory (eg, Peplau's Theory of Interpersonal Relationships). Most recently, Benner et al,[11] in exploring clinical wisdom, emphasize the need for engaged reasoning that requires skilful involvement with the patient and family.

Caring theories began to emerge in nursing literature in the late 1970s.[5] Smith,[5(p19)] in her analysis of caring in nursing discourse over the following years, essentially described caring as a therapeutic relationship, "Caring is the art of nursing, the way of being, the comportment of the nurse in the sacred dance of healing with the client." Her concept clarification of caring distilled the essence of caring in 5 constituent meanings from the perspective of the Science of Unitary Human Beings (SUHB), identifying semantic expressions of those meanings in nursing caring theories. That work was critical in establishing a bridge between what had become 2 major silos in nursing science, CS, and SUHB. That bridge was strengthened a few years later through a synthesis of CS and SUHB into what was posited as a transtheoretical direction for nursing with transdisciplinary potential.[12] Using Watson's transpersonal CS as an exemplar of CS, Watson and Smith[12] identified commonalities between the major tenets of each. Among those commonalities were connectedness of all, relating Watson's concept of mutuality within the caring relationship with the SUHB concept of integrality and characterizing the transpersonal caring relationship as one that "connotes a spirit to spirit unitary connection within a caring moment, honouring embodied spirit of both nurse and patient within the unitary field of consciousness."[12(p458)]

Watson[3] acknowledged the early influence of Gadow in her conceptualization of the transpersonal caring relationship. Its emphasis on the whole nurse engaging with the whole person in a healing relationship is a critical cornerstone of existential advocacy.[1]

Gadow[1,13] proposed existential advocacy as an ethical framework for nurses' decision making. Her work, published originally in 1980, coincided with and/or augmented the caring theories emerging at the time in nursing science. Rejecting beneficence, either in the form of paternalism or consumerism, as an ethical principle consistent with nursing values and practice, Gadow[1] based her model on the principle of autonomy. She identified 2 prevailing perspectives in health care, still relevant 30 years later, which prevent authentic patient self-determination. First, professional standards of behavior that prohibit nurses from becoming personally involved with the patient. Gadow argued, professional standards made it impossible for nurses to regard patients as whole human beings because the standards prevented nurses from engaging in therapeutic relationships as whole human beings themselves. Second, Gadow identified the prevalent view of patient as object self, rather than lived body or situated subjective self as a barrier to self-determination. Disease and incapacity, she noted, can create in patients a discrepancy between lived and object body that is reinforced by the prevailing scientific paradigm in which objective knowledge is valued over subjective and the body is viewed as a machine and described in terms of clinical findings, such as diagnostic and laboratory findings.[14] Gadow believed nurses were in ideal positions to ameliorate, rather than perpetuate, the effects of this objectifying approach by assisting patients in reconciling the lived/object body:

> *[Nursing] affirms the value of the lived body through the intimacy of physical care and comforting. At the same time, it affirms the reality of the object body by interpreting to patients their experience in terms of an objective framework—usually science, in Western cultures—which enables them to relate an otherwise hopelessly unique and solitary experience to a wider, general understanding.... neither aspect [lived or object body] is meaningful without the other.*[1 (p49)]

Although Gadow[13] translated existential advocacy into language that would be familiar to nurses at the time as 5 "steps" of the ethical decision-making process, the context clearly positions them as 5 interrelated facets in which the nurse-patient relationship is central. As Gadow's work evolved away from rational, principle-based ethics and moved into relational narrative, that centrality and its existential roots became even more evident.[15-17] Relational narrative, she asserted, "expresses engagement between nurse and patient... it is a form of shelter, a provisional account of the good constructed by patient and nurse as a way of making their situation habitable."[16]

The coming together of nurse and patient and through their engagement, creating new possibilities for healing and meaning, is a commonality shared with other caring theories. In transpersonal CS, it is the "caring moment" in which "the nurse connects at a spirit-to-spirit level with another."[18(p82)] In SUHB, inviting creative emergence conveys a similar meaning that Smith[5] found prevalent in other caring theories as well. In Halldorsdottir's model,[19(p643)] it is the biogenic way of being, exemplified with this patient's experience: "the sense is somehow that your and my spirit have met in the experience and the whole idea that there is somebody in that hospital who is *with* me, rather than working *on* me."

Halldorsdottir's[19] recent theory explicates the caring nurse-patient relationship from the patient's perspective. In identifying the prerequisites to forming a caring relationship, Halldorsdottir[19] observed that the unanimous perception of research participants (former patients) was that "they had not formed any relationship with the nurses perceived as uncaring. The perceived indifference and lack of concern by those nurses made them distrustful and there was detachment with total distance between the nurse and the patient."[19(p649)] Although Halldorsdottir acknowledged research demonstrating that patients and nurses perceive caring differently, the 6 stages of forming a caring biogenic relationship delineated in her theory are congruent with the nursing discourse reviewed earlier. Fundamental to such a relationship is an acknowledgment of the personhood of both nurse and patient.

This focused review of the centrality of relationship in nursing discourse is intended to be neither a comprehensive nor an exhaustive review. It is meant to contextualize our stories, which too often strike a sharp contrast with the ideals set forth earlier.

PAUL'S JOURNEY

"Hi Paul," the oncologist said as she walked into the room. "The good news is that this is curable." My son, in his prime at 40 years of age, had been diagnosed with stage III gastric adenoma 2 weeks earlier, 1 week before Christmas—no other organs involved but a "suspicious" lymph node nearby. It was now December 31 and the oncologist's astounding pronouncement was indeed welcome news on this eve of a new year. There was hope! And when Paul raised questions about a much more dismal prognosis, which seemed the consensus of web information, she dismissed it as being "out-of-date." She proceeded to outline the course of treatment, which, she said, was widely accepted as the "magic bullet" in this type of cancer: 9 weeks of chemo, surgery, and then 6 more weeks of chemo. "2010 won't be your year," she concluded, "but 2011 will be." The next time Paul saw this oncologist—designated as his primary oncologist—was 4 months later when she walked into his hospital room and said, "Paul, this disease is going to kill you sooner, rather than later." Unfortunately, her second prediction was more accurate than her first and Paul passed from this world about 3 weeks later, on May 7. What happened in the intervening weeks merits reflection on medical and nursing care within what is all-too-probably a typical medically dominated large teaching hospital in a major metropolitan center in Canada.

My son lived on his own approximately 6 hours' drive from where I live. He had asked me to be with him when he had his endoscopy in December and again when he heard the biopsy results on December 18. It was clear that I was to be his major support so I was with him whenever he wanted or needed me there, which included all medical appointments.

Chemo began on January 8. The day before, Paul had an appointment in the cancer clinic and was seen by a resident on the oncology team. I asked the resident how quickly the chemo was likely to work—when could Paul expect to notice any relief of symptoms. He replied, "It works about 40% of the time." I tried clarifying the question but the resident simply repeated his answer. At that visit, Paul reported that he had vomited and observed a bit of bright red bleeding. The resident brought in a radiation oncologist to assess whether some radiation was indicated, in effect, to cauterize the bleeder. But, the latter indicated that he first needed a consultation with the surgical team because if the tumor was deemed inoperable and radiation the preferred course of treatment, its effectiveness would be compromised by a small dose of radiation now. What did this all mean? Forty percent chance? Possibly not operable? This was only 1 week after the oncologist's confident pronouncement and adamant refutation of information to the contrary. As I was driving Paul home after the appointment he uttered the words I had been dreading to hear, "So, there's more than a 50% chance this won't work." Confidently, I reassured him, "Paul, there is no way they're going to start you on a regime that works less than half the time." After all, the oncologist had said this was curable!

Because the tumor sat at the esophageal opening of the stomach, Paul had been unable to swallow any solids for the 2 weeks before the chemo began. His fluid diet, now consisting of high-protein nutritional supplements and any nutritious liquids I was able to make, was quickly becoming tiresome for him. But January 9 brought some exciting changes. Paul awoke feeling hungry, walked into the kitchen, and began munching on some crackers! I made scrambled eggs and he ate a sizeable portion with some toast. The adverse effects of the chemo seemed easy to tolerate when it had so quickly begun to alleviate the swallowing difficulty. And, even more importantly, it was evidence that the treatment was working! Hope and optimism bordered on euphoria!

During the next couple of weeks, Paul continued to experience improvement in the relief of his symptoms—no more bleeding and increasingly less difficulty swallowing. He went out for Chinese food and baked and ate chocolate cookies. It was remarkable! Yes, he experienced the typical chemo side effect of nausea but it was manageable, even with the bothersome hiccups, which seemed a side effect of the antinausea medication, and a small price to pay. The chemo was working and he was going to get better!

By approximately the midpoint of the chemo, the bleeding had not recurred but I had a residual uneasiness from the radiation oncologist's suggestion that this tumor may not be operable. We also had not heard from the surgical team regarding their appraisal of the operability of the tumor, and I began to encourage Paul to press for answers. After a few weeks of repeated inquiries, the word from the surgical team was "good to go" for surgery as scheduled. Hallelujah!

The resultant euphoria did not last long, however. Paul began vomiting after eating and very soon tinges of blood returned; by the end of the 9 weeks of chemo he was vomiting blood. He went to the emergency department (ER) and was admitted to an oncology unit. When I arrived, he was in a 4-bed ward with the curtains drawn around him. His color was ghastly—I hoped it was merely the shadow of the curtains. Slowly, reality would not be denied—his color, the odors of the unit—I knew them only too well. *My* son really had cancer! The bleeding subsided and he was discharged within 48 hours, but not before a nurse tried to give him a blood thinner injection. “Why?,” he asked. “It’s routine for all patients on this floor,” was the reply. “But I’m in here for bleeding,” he said, as he refused it.

He was at home for about 10 days when, around midnight a week later, I was awakened by a phone call no mother ever wants to get. “I’ve sent you a picture. I vomited and it’s a strange colour.” I rushed to the computer. “You need to go to the ER, Paul,” I said. “Can you drive or do you need to call an ambulance?” He remained in the ER and we texted as the signal allowed it. Between 5 and 6 PM on Sunday, March 28, I received the chilling text—“Just saw the resident—he says my days are numbered.” My heart seemed to stop. He was alone in a busy ER with no support and had just been told the tumor was not operable and he was going to die. How could this happen?

By the time I reached the hospital early the next morning, Paul had been admitted, this time to a different oncology unit. The admission was a few days before Paul was scheduled to have preoperative computed tomography and positron emission tomography scans to confirm that the cancer had responded to the chemo. He also had an outpatient appointment to meet with the surgeon to discuss the results on April 1, the Thursday before the 4-day Easter weekend began. Still hoping that the surgery would proceed on schedule, we were anxious to ensure that those appointments were kept, despite his being admitted.

I was happy to be with Paul that Monday morning to meet the various members of the team who each had some responsibility in providing his medical care: a palliative care team (physician and nurse), a general practitioner who seemed to function as a unit “case manager,” a social worker, and the only face familiar to Paul, the radiation oncologist whom he had met in the cancer clinic at the beginning of his treatment. His primary oncologist, we were informed, was away but in touch by e-mail. A different oncologist was “on-call” to provide expertise to the unit when needed. I expressed my outrage at the cold, insensitive, uncaring way in which a surgical resident had communicated such devastating news in emergency department. We were in a state of shock and disbelief—after all, Paul had not heard from the surgeon since the “good-to-go” message. We demanded some answers, which the team, even though sympathetic, could not give us. They had also not been able to reach the surgeon. What had changed? On what authority did the resident pronounce the finality of his awful sentence? Finally, toward the end of the day, the case manager physician was able to reach the surgeon. She informed us the surgeon still expected to be proceeding with the surgery. Whew! Now to get the bleeding stopped.

The radiation oncologist was anxious to start radiation to stop the bleeding but he needed to personally confirm with the surgeon that the surgery was still on schedule first, as the dose of radiation was dependent on the answer. He admitted to some difficulties in being able to reach him. Thursday came, and we were advised Paul’s outpatient appointment with the surgeon had been cancelled but despite our requests that he visit Paul in the hospital, he had yet to make an appearance. Our anxiety escalated. In the afternoon, the radiation oncologist told us he would go directly to the surgeon’s office for the answers he needed and, at our request, agreed to ask him to stop in and see Paul. Finally, at approximately 5 PM on Thursday evening, the evening before Good Friday when all “nonemergency” care effectively stopped for 4 days, he came. The news was not good.

The positron emission tomography scan had shown a suspicious area in Paul’s right hip and the surgeon believed a magnetic resonance imaging (MRI), which had to wait until after Easter, was needed to confirm that the tumor had metastasized. If that were the case, he said, surgery would no longer be the best option, because its goal was complete recovery with the removal of all the cancer. The surgery was not without its risks, with the tumor lying so close to major blood vessels, and if there were no chance of removing all of the cancer, less risky treatment options, such as radiation and more chemo would be the best choice. He assured Paul that if the MRI did not confirm metastasis, he would operate. "How long do I have if you can't operate?," Paul asked. Six to eighteen months without surgery was the answer to the best of my memory. I must admit that both Paul and I were numbed by the news and I cannot be absolutely sure. But certainly it was a length of time that would have allowed Paul to put his life in order and perhaps live out 1 or 2 of the dreams on his "bucket list." Paul and I spent the next few hours talking about what this news meant for him. He talked about his loss of a future and dreams. I listened and encouraged him to consider how he could use the time to fulfill as many of those dreams as possible.

Because it was now "after hours," the long Easter weekend had essentially begun. Radiation, we were told, could not start until the following Tuesday, despite the radiation oncologist's earlier goal of beginning it before and having it continue through the long weekend. On Friday, Paul's hemoglobin dropped as the bleeding increased so intravenous infusions were started and the first of what were to be many units of blood hung. His veins quickly became very difficult to find, causing not only the discomfort of interstitial fluids, bruising, and repeated venipunctures but significant sleep deprivation. My repeated requests for a peripherally inserted central catheter (PICC) line were futile. One nurse, diligently tried to advocate for Paul's having one inserted, but failed. "On a long weekend," she reported, "they only insert PICC lines in emergency cases." "What is this?" I asked, but received no answer.

The nursing care on the unit was less obviously organized than the medical care from a patient/family perspective. A different nurse seemed to be assigned every day and care generally involved tasks, ranging from changing linens, administering medications, and monitoring vital signs to establishing and maintaining intravenous lines when they became necessary. An office at the entrance to the unit was identified as belonging to a nursing practice manager but the role of the occupant was unclear to me. Paul did not seem to know of him and during the 4 to 5 days a week I was there over the next 6 weeks, not once did I observe this manager making rounds by himself, with a nursing team, or with members of the medical team. The nurses who cared for Paul only rarely identified themselves by first name, even more rarely by credential, and, as the names on their name tags were often difficult to read, neither Paul nor I generally knew the credential of his care giver. There were a few brief exceptions—Paul was moved to a semiprivate room about his third week in hospital and a white board on the wall at the foot of the bed was used by a few of the nurses to write their name and the date on the board. One nurse suggested to me that I bring in pictures to put on the corkboard. I will be forever grateful for that suggestion as I brought boxes of pictures and Paul and I went through, reminiscing about better days. He chose the pictures that were most meaningful to him—some I never would have guessed!! Those pictures brought much joy to him over the next few weeks.

Despite such random acts of caring kindness, what concerned me most about his nursing care generally was its seeming lack of relating to the human being who should have been at the center of care. It was not until Paul was in intensive care unit (ICU) that I witnessed nurses acting on the understanding that a therapeutic trusting relationship is not only the basis for caring actions but is in itself healing. Only there did I witness nurses willing to be authentically present to him. During his 6-week hospital stay, the only person who made an effort to understand how Paul, in the prime of his life, constructed the meaning of this illness, this prognosis, this hospitalization was a very exceptional palliative care physician. While I am deeply grateful to him, I asked myself over and over where is human-centered nursing?

I must admit my bedside nursing experience is ancient. We gave backrubs in those days—yes, to stimulate circulation but for so many better reasons. It was a time we could get to know patients and begin to understand the person's situated reality—their life, hopes, values, fears, and anxieties, doing our best to comfort and support. It was a time for being present, for building a trusting relationship, for understanding that the person in the bed was a human being just like us, only much more vulnerable. Our language and understanding were not as fully developed as today but the ideas were there. Now we have language to express the importance of presence and healing relationships in our science and best practice guidelines to identify the essential qualities of "client-centered care." But neither CS nor client-centered care was evident and my heart broke not only for my son, but also for nursing.

And so as mother and nurse, I rubbed Paul's back, and massaged his feet because it brought him comfort. I regularly emptied utensils with body fluids, including bloody emesis, to remove reminders of his vulnerability and create a more comfortable environment. Naively, I had tried to show a basin with bloody emesis to his nurse in the early days of his hospitalization, assuming she would want to note the amount and color. "You don't need to show it to us," she said. "We'll know that he's bleeding from his haemoglobin." Cells, laboratory values, technology—aspects of a mechanical, object body. Terror, despair, grief, and loss are not measurable by laboratory results.

Paul was not eating or drinking sufficiently but that did not seem to be a nursing concern. Meal trays were brought in and collected by food services staff. Nurses never inquired about whether he was eating or drinking adequately. Often I witnessed the untouched tray being removed without anyone ever observing what had not been eaten. I asked to meet with the unit's nursing practice manager. I expressed my concern that no one seemed to be attending to the man—the human being—in the bed and no one seemed to even know that he was not eating. The manager seemed genuinely surprised and responded something about "it being in" the patient care plan. He told me that they did not like to use total parenteral nutrition because cancer cells thrive on it. Although Paul and I had been told that at his initial visit to the oncologist, I argued that starving did not seem a reasonable alternative.

A dietician came to visit Paul fairly regularly after that, presumably as a result of my meeting with the practice manager. She made every effort to provide him with food that appealed and that he could tolerate. But, what he could tolerate one day, he could not the next so his nutritional intake was largely dependent on my bringing food to him. The nurses never did become any more involved in his nutrition—apparently it was someone else's piece of the anatomy.

On the Tuesday after Easter, Paul's PICC line had been inserted, the radiation therapy had started, and the MRI done, which, we were informed by medical staff on the floor, was still not conclusive of metastasis. Our hopes once again rose and we waited impatiently for news of when the surgery was scheduled. The days passed but no such communication came.

A couple of weeks into the hospitalization, I arrived one morning to find a different patient in Paul's bed. When I inquired, I was informed he had been moved to a semiprivate room. Why? His insurance coverage had not changed. I asked the unit social worker; she was 1 of the few consistent health professionals Paul and I encountered, had been very helpful in assisting Paul with some of the legal/insurance issues, and seemed to be included in team meetings. She responded that it was because of the length of time he had been hospitalized. I regret I did not press for a better answer but at that time, Paul and I had no reason to doubt the surgeon's promise—if the MRI was not conclusive of metastasis, he would perform the surgery.

The radiation was not stopping the bleeding; in fact, a day or two after moving to the semiprivate room, vomiting and blood loss increased significantly and Paul's condition destabilized. As I arrived in the morning, blood was being warmed and pumped in. Paul was clearly in mental and physical anguish; he was vomiting copious amounts of blood, plagued by intractable hiccups, clearly exhausted, and understandably highly anxious. Various medical consultants were in and out of the room and an endoscopy under anesthetic in ICU was decided upon in hopes that a bleeder could be identified and cauterized. Paul agreed but wondered why he just could not have the surgery. The only person who could answer that question, the surgeon, was apparently unavailable. In his stead, a resident was dispatched. Unfortunately, and unknown to me in the moment, it was the same resident who told him in the ER that his time was limited. This time, in the midst of Paul's struggle for his life, with a multitude of people adjusting equipment, trying to stabilize Paul's vital signs, and preparing him for transfer to ICU, he told Paul he only had a couple of weeks to live. When Paul told me it was the same resident, I insisted that he had the right to hear the truth, if not from his own surgeon, then another one of the thoracic surgeons. Thankfully, a surgeon whom we had heard of by reputation but never met, responded quickly and with a gentle and compassionate manner told Paul that his tumor was no longer operable because it had grown dangerously close to major blood vessels. Why had this not been discussed with us earlier? "But," he said in answer to my question regarding the resident's prediction, "no one knows how quickly the disease will progress."

Paul was transferred to the ICU, had the endoscopy, and remained intubated and sedated for approximately 16 hours. It was probably the best sleep he had in many weeks. Once while he was awake, he told me he had seen the resident, who had now twice pronounced his death sentence, outside his ICU room. He did not need to tell me he did not want to see him again. I asked the nurse to ensure the resident never again had any involvement in Paul's treatment and to put such a notation on his chart.

The nursing care in ICU was outstanding. Even in a technologically intense environment, and with Paul asleep for most of the time, it was apparent that his subjective self, not objective other, was at the center of the nursing care. The same nurse cared for Paul each of the 2 days and it was clear that Paul trusted her. Empathy, compassion, respect, and competence were evident. It seemed the nurse understood and tried to ameliorate his vulnerability and feelings of powerlessness to the small extent that was possible. She invited him into making decisions about the small parts of his life he could—decisions about hygiene and diet, as well as readiness for discharge back to the oncology floor and for resumption of radiation therapy. It was also clear that her nursing judgment was valued by other members of the health care team, as I observed her actively participating in and sometimes leading discussions about his condition. Why was nursing care so different here?

Although no specific bleeder had been found during the endoscopy, the bleeding did stop—perhaps because he was hiccup-free while under sedation. Paul was discharged back to the floor and the radiation therapy resumed. The hope returned—radiation would be effective and he would have a little precious time to live out some of his dreams.

Our optimism did not last long. Within a few days, the relentless hiccups returned and with them, the bleeding. There were some aspects of his medical and nursing care that had begun to trouble me. It felt like the team knew something we did not and had given up on him. Besides the blood and blood products he was receiving, a number of intravenous medications were running—chemo had resumed, antinauseants, a medication to try to stop the bleeding, and various ones to try to stop the hiccups regularly hung. But, at night, they had started total parenteral nutrition. What was going on? I called the social worker and asked for a family meeting. "It seems that the team is operating with different knowledge than we have," I said. I asked for his primary oncologist, the thoracic surgeon, and the radiation oncologist all to be at the meeting (I have to admit, by this time I had despaired of any meaningful support or input from nursing). The meeting was scheduled but only the primary oncologist and social worker came. The oncologist spoke about research that showed how little progress had been made in treating this disease and that chances for recovery were no better in 2010 than in Napoleon's time. She confirmed, as though she had told us this from the beginning, the 40% success rate for the treatment regime she had instituted but this time made the very different pronouncement alluded to earlier—"This disease is going to kill you sooner, rather than later."

I have asked myself many times why I did not press for answers to the questions that niggled at me. Probably, as clear as they are in hindsight, I could not think the unthinkable and can only say I was incapable of asking at the time. Certainly Paul and I clung desperately to the hope that he would "turn the corner" and be able to live out those few months the thoracic surgeon had estimated only a few short weeks ago. We had no reason to interpret "Sooner, rather than later" as anything different than the short end of his prediction of 6 to 18 months' life expectancy without surgery. At the moment, approximately 4 weeks into his hospitalization, he once again seemed better able to eat and I often brought him food from the cafeteria. He had strange cravings: soft ice cream, grape juice, jelly beans, chocolate bars, salt-water taffy—all with specific brand names or flavors. I was happy to indulge him as they brought him joy. We talked about his love of photography and he came very close to buying the camera he wanted online so he could get to know it and be ready to pursue his photography hobby when he was discharged.

But, a few days later, Paul twisted on his leg as he got out of bed and collapsed back in pain. He was sent for radiography and before I left for the day the case manager physician told me happily she had received a verbal report that there was no fracture. Fabulous! Now we could start physiotherapy so that when the bleeding finally was under control, he would still have some muscle strength. Maybe he could come home for a couple of hours—the weather was warming and he was anxious to see his blooming apple tree and lilac bushes.

The next morning—Friday—shattered those hopes. Radiography had made "a mistake." There was a fracture. A different oncologist had begun his rotation consulting on the unit. He was much more involved than the previous one had been, at least from a patient/family perspective. Suspicious of the fracture, he reviewed the record. The fracture was in the spot identified as possible metastasis, he told me. My heart sank, but even though I knew now that the pathological fracture confirmed metastasis, nothing could have prepared me or Paul for the rapid decline in his health.

At midnight 2 days later, I received a midnight call to tell me Paul's vital signs were not stable and he had been transferred to ICU. Paul seemed to sleep most of the night but Monday morning, I noticed changes in his cognition—he seemed to be hallucinating at times. Frequently when he woke, he spoke like he was still in a dream and had not realized he was now awake. Then at other times, he was perfectly lucid. He asked me, "How worried are you that I won't be here at the end of the week, Mom?" "Very worried," I replied.

Over the next few days, Paul's condition continued to deteriorate and I began to feel pressure from ICU physicians that he should no longer be in ICU. Paul had indicated he wished heroic measures to be taken in the event of a cardiac arrest. He hoped and believed until the end that he would be able to live those precious last "few months." On Thursday, I asked, finally successfully, to speak to the thoracic surgeon, the radiation oncologist, and the unit medical oncologist. One by one, they confirmed that there were no more treatment options—no more radiation, no more chemo, no surgery. Ironically, it was the first time I was hearing the straight truth directly from each of the players. And Paul's cognitive state now compromised his ability to comprehend it.

My daughter joined me Thursday and we spent most of the night at his bedside. Around 2 AM, 2 residents came by and asked Paul what he wished done in the event his heart should stop (essentially challenging his heroic actions directive). His breathing had become somewhat labored by this time, and I feared pulmonary edema. He replied angrily, "You're treating me like a chicken breast." The residents interpreted his response as a sign that he was no longer cognitively able to direct his care. I was not so sure—it characterized the objectification he had experienced for most of the previous 6 weeks. I tried to calm him and told him of my meeting with the medical team and, as gently as I could, that there were no more treatment options. "It's okay to let go, Paul," I whispered. The residents turned to me and told me I would now have to make the decision about resuscitation, suggesting that intubation immediately would be much easier than in a crisis, but I refused. That would mean he would be sedated and not able to interact with his family. "What if he goes into cardiac arrest?," they asked. "Ask me then," I replied. Of this I was sure: Paul wanted heroic measures to prolong his living, not his dying.

On Friday morning, Paul's vital signs remained relatively stable. Throughout his hospitalization, his pain management had been excellent. His major source of distress was still the intractable hiccups. I asked his nurse if nothing could be done—all treatment efforts thus far had failed. She found an online summary of recently published evidence on treatment of hiccups and returned with a printout, which she gave to us. The research, she said, suggested a large dose of chlorpromazine was effective in stopping hiccups. I expressed concern that it would adversely affect his blood pressure and she gave my daughter and I time to read and consider the materials she had given us. We each took a section but in the same moment read about folk remedies, such as a spoonful of sugar. We looked at each other—his cravings for sweets and their seeming effectiveness in temporarily stopping his hiccups! We told the nurse. She said, "If that's what you would like to try, I'll go to the kitchen and get some." Paul was, we thought, no longer cognitively able to process the information and participate in the decision making. He acknowledged we were there, from time to time, but seemed to sleep most of the time. I spoke to him and told him I had some sugar for his hiccups. As I put the first little bit in his mouth, he opened his eyes and made a face. "What are you doing?," he asked. "Giving you some sugar for your hiccoughs." His grimacing made it clear that he did not appreciate the effort but he did accept the sugar. His protests, however, discouraged me and I said to my daughter, "So much for that idea!" "Mom," she said, "Look—his hiccoughs have stopped!" That was about noon and they never returned.

Eighteen hours after I had suggested to Paul that it was okay to "let go" he passed gently into another dimension. My daughter, his best friend, and I had been with him all afternoon and evening, looking at pictures and telling stories. At around 8:30 PM, both my daughter and Paul's friend had to leave for a few minutes and I remained alone with Paul. Within a few seconds, his vital signs changed dramatically. I knew he was dying and held him, kissed his cheek, and said good-bye. The nurse had come into the room and was gently rubbing my back as I sobbed. But, I could hear music! How was that possible? Who had the radio on in ICU? And at this time when my son was dying! "Where's the music coming from," I asked, trying to hide my irritation. "I don't hear any music," she said. "The choir, it's choral music, has someone got a radio on?," I asked rather impatiently. "Adeline, I don't hear any music."

In my ensuing grief, she suggested to me that Paul, being the private person that he was, chose the brief time when we were alone to leave this earth. I accepted it as a sacred privilege. “The music,” she continued, “was his Mother’s Day gift to you.” Her words comfort me still.

ROGER’S JOURNEY

My father-in-law Roger died at 93 years of age. Three months before his death he was living independently with his wife Lilian and driving his own car. In November it was obvious when we spoke to him on the phone that he was not well. However, Roger was a man who never complained. On December 8 we traveled 7 hours by car to attend a pulmonary consultation with a physician and Roger and his wife because he had on radiography a suspicious tumor in his lung. The physician did not have the radiography report or laboratory test results and was not sure why Roger had an appointment with him. Roger said he was feeling great. I informed the physician about the tumor and obtained the radiography report from the hospital for him to view. He acknowledged that it “looked serious” and arranged for a “GI consult” for Roger. We returned again on December 18 to bring Roger to his appointment. We were shocked to see his extreme pallor, fatigue, shortness of breath, and loss of weight. At this appointment the physician decided additional tests were needed and “booked” them for January. We were very concerned after we brought him home from the appointment and saw him crawl up the stairs because he could not walk. That day, in response to what we saw, we brought Roger to the ER. It seemed like he was dying in front of our eyes as he waited for the diagnosis and treatment plan in January.

Roger was admitted to a gurney in the ER. He received the expected care: diagnostic tests, an intravenous infusion, cardiac monitor, and 4 units of blood. Because the room was so crowded, there was no curtain to go around his bed. Instead of a curtain he was surrounded by others’ pain, fear, suffering, crying, diarrhea, sputum, and blood. The nurses commented how “crazy busy” it was in the ER.

According to the posted sign and security guard, patients were allowed only 1 visitor in the ER. After much discussion I convinced the nurses to allow me to stay with the 85-year-old Lilian because she was hard of hearing and would not understand what was happening. They agreed. I believed I needed to be vigilant because of the surrounding chaos and Roger and Lilian’s fear as they watched the events that surrounded them. I asked a nurse for a chair for Lilian to sit in by Roger’s side as we waited for any news. She was afraid to miss important information on Roger’s condition, and so was I. A medical student and resident visited Roger and asked me in a meaningful way if I had noticed my father-in-law’s cardiac rhythm. I had seen the atrial fibrillation. I asked about the plan. The resident said, “Someone will let you know when we know.”

I told any nurse or doctor who would listen that Roger never complains and that he lived in a duplex with 2 flights of stairs. I wanted them to see and hear him, especially when I was not there to speak for him. I spoke to a nurse and stood by her while she put into the electronic record my concerns for discharge and the need for the family to be included in the plan of care. Most attempts at obtaining information from the nurses resulted in responses about what a nice man he was and that he never complained. Roger not saying how he felt was part of the problem and our concern.

On day 2 in the ER, nurses continued to come and go, and they provided technologically skilful care. A nurse who graduated from a school of nursing I had previously taught said she liked working in the ER because “you don’t have to get to know anyone here, there is a fast pace here.” When we left the hospital after 10 hours waiting for information and receiving none, I left Roger with a heavy heart in the hands of that “fast paced” nurse.

On the evening of day 3 in the ER, Roger signed papers to be admitted to a unit on one of the floors. We left the hospital interpreting that this meant he would be leaving the ER and would be receiving the diagnosis and treatment he needed. At 8 AM the next day, Lilian received a call from the ER—he was being discharged immediately and we needed to come and get him right away. When we arrived in the ER I said to one of the nurses that we would not leave until we saw a physician who could provide us with some information. An impromptu meeting was called with the ER physician, geriatric nurse, Roger, and the family. We were told there would be palliative care services "put in place." When and what they would be they did "not exactly know." In that family meeting, with all of us standing in the ER and Roger and all the patients in the ER lying on their gurneys, the physician said in a loud voice, "Roger, this is your last Christmas." This information was provided in one sentence. Then the physician and nurse left.

When Roger arrived home after being discharged from the ER he partially crawled up the stairs and we carried him up the rest of the way. We were assured that palliative care services were in place with a nurse visiting every day and an unlicensed worker would come once a day to provide hygiene care. The next day we hesitantly drove to our own home 7 hours away. As I feared, things did not go well.

Because of our concern for what we were hearing about the care Roger was receiving, his decreasing health, and Lilian's inability to manage his care, we returned to their home a week later. We arrived in time to meet the palliative social worker and nurse. Roger was now in a hospital bed in the dining room. I asked what would happen if Roger became dyspneic. I was told Lilian would give him medication. Lilian did not know about the 3 types of injectable medications that were sent from the pharmacy and now in the bedroom in a bag. The nurse said she would teach Lilian to draw up and administer the injectable drugs. I knew this was not going to work. I started asking questions. I learned that Roger in the last week was not washed because he said he did not need to be washed. I learned he had not been turned because he said he was comfortable. I learned that he had not had a bowel movement in 5 days. The nurse said she would give him a suppository. I asked how his skin was on his back. The nurse went and checked, "there was skin breakdown." I asked how Lilian would do all things that needed to be done for Roger. We were told it was better for Roger to die at home and they were respecting his wishes. Roger said he was fine. Roger always said he was fine.

The next day another nurse visited and told us it was up to the family to manage Roger's care. We explained how we did not live in the city and that this was too much for Lilian. We were concerned what would happen if he was incontinent, needed turning, needed pain medication, and so on. Lilian could not move or lift him. The nurse waved her finger at us and repeated that it was up to the family to do these things. Palliative care was provided by the family.

The next day another nurse came to visit. When he came into the dining room and *saw* Roger he said this is too much for Lilian and not the best for Roger. Someone finally saw without us speaking and then heard when we spoke. I gratefully thanked him. He called the supervisor nurse and when she arrived she agreed that this situation was not appropriate. These nurses left a message for the palliative care physician to have Roger admitted to palliative care services.

The next day the original nurse and social worker spoke to us and tried to convince us that Roger needed to stay at home. We were told it was the best for Roger. We insisted that staying at home was not possible, safe, or in the best interests of Roger. We stood firm and the palliative care physician agreed to admit Roger to a palliative care hospital. The next day Roger died. The ER doctor was right; it was Roger's last Christmas.

COMMONALITIES ACROSS STORIES

Common themes emerge in the stories. Some are more specific to one discipline than another; some cross disciplinary boundaries. Our discussion conveys our perspectives as family members and nurses bearing witness to what we observed and experienced and our comparison of those experiences with nursing research and literature.

Fractured health care delivery models

Although the more common term is fragmentation of care, the word fractured connotes deliberate actions that result in fragmentation of care. Health (sickness) care was systemically organized in a way that could not avoid fragmenting care. In the cancer clinic, different physicians—some medical residents, some general practitioners—saw Paul each time he attended. In the hospital, different oncologists assumed inpatient responsibilities on a rotational basis. In ICU, it seemed that a different resident was responsible every shift. Specialization, a potential benefit to patients, contributed to the fragmentation through poor communication and inaccessibility among medical team members for both Paul and Roger. In nursing, the fractured delivery model took the form of patient assignment practices on the oncology floor and in the ER. In the former, nurses were seldom assigned to Paul for 2 consecutive days; in the latter, no nurse was clearly assigned to Roger as he lay for days on the gurney. In both instances we searched for information about our loved ones and were left without answers.

The effects, we observed and experienced, were significant. Continuity of medical and nursing care suffered when delivery systems were structured to fracture care. First, they made establishing trusting, caring, healing relationships difficult for patients, family members, and health professionals. Second, the fragmented system both made it easy for patients to fall between the cracks and difficult for patients and families to know who to approach for answers to their questions. As a result, fractured health care delivery heightened feelings of powerlessness and vulnerability in both patients and family members. Silences between patients/families and the health care providers are the deafening result of a fractured model. Those silences, or lack communication, are a symptom of a system that has shattered and broken.

Nursing literature supports the suggestion that fractured delivery models adversely affect nurses providing care.[1,18,20] Askinazi,[21] writing from her experiences as a nursing student, argued for a more universal need to practice and promote skills of caring to counter the increasing trends toward technological advancement and profit. "Nurses are key players in the battle of humanism versus the science-propelled system of medicine . . . . Those relationships with patients are the essence of what we as humans are capable of expressing—loving, caring, touching, responding, needing, moving, connecting with life . . . "[21(p34)] Not to be able to do that, she asserted, "leaves a hole in us."

Relationship-based caring has emerged as a nursing delivery model designed to support nurses being caring professionals.[22,23] Modified from primary nursing to fit with the current reality of 12-hour shifts and reduced length of stay, it recognizes, as the name implies, the centrality of the therapeutic relationship. As was the case with the original primary care model, relationship-based care creates a system wherein nurses have autonomy for decisions and nursing actions within the full scope of nursing practice[22] and offers a possible amelioration to fractured nursing care delivery models with potential for informing health care delivery systems more widely.

Institutional/unit culture

Manthey and Lewis-Hunstiger[22] cautioned that a healthy work culture is foundational to support a relationship-based care delivery model. A healthy work environment is one that values and respects nurses, maximizes continuity of care, and supports nurses to work to their full scope of practice.[24] On the oncology unit and in the ER, from a patient/family perspective, neither nurses nor continuity of care seemed valued. Nurses did not seem to be working at their full scope of practice—they did not assume patient coordination responsibilities, for example—they seemed unable to advocate effectively for their patients, and did not seem to be respected as fully participating members of the interdisciplinary team. It is unclear whether the nursing delivery model we saw resulted in or reflected the devaluing of nurses but regardless, it must have contributed to how nursing was practiced. What seemed to be valued was the technologically excellent instrumental care that nurses generally provided. These are likely not unique situations. Pearcey[25(p53)] speculated that institutional values lay behind one of her study participant's definition of caring as the "little things we are not supposed to do anymore" and Sumner[9] reported similar results in her research.

The contrast between ICU and the oncology unit was remarkable. ICU nurses also provided technologically expert care but within the context of a trusting healing relationship that grew out of a mutual recognition of personhood, described by Halldorsdottir[19] as a necessary task for the development of a healing relationship. Certainly it appeared that nurses were valued by other members of the ICU team. What made the difference? Was it a different unit culture? Was it the staffing ratio? Was it the patient assignment practices? Swanson's[20] meta-analysis of caring research identified numerous organizational conditions that enhanced or created barriers to caring, such as poor staffing, too little time, poor physical environment, and too intense workloads. Sumner[9] identified hierarchical power-over dynamics as barriers to nurses in her study being able to realize their potential as caring professionals.

We can only speak to those units of the hospitals with which we had experience and cannot be certain that the prevailing values we saw were a reflection of broader institutional values. Clearly, there were major differences between units. But our observations suggested to us that both institutions valued a scientific, medicalized approach to cure above a humanistic, caring, healing approach to health.

Barriers to authentic self-determination

One of the barriers to self-determination Gadow[1] identified was a professional standard of not becoming personally involved with patients. Paul's and Roger's stories provide ample examples of both physicians and nurses remaining detached and impersonal. Whether their detachment was related to professional socialization or not is unknown but the effect on patients and families was the same. Gadow's[13] first step in facilitating patient decision making is the provision of information the patient deems relevant.[13] Examples of mixed messages, frequent inaccessibility of members of the medical team, and information being withheld or misrepresented abounded in the stories. What choices would Paul have made, had he been honestly provided with the chances of treatment success at the outset?

Deliberately making treatment decisions without involving the patient may be a professionally acceptable expression of beneficence. But in disenfranchising patients by denying their perspective of what is in their best interests, it also adds to the second barrier Gadow[1] identified, viewing the patient as object self. This was subtly communicated by nurses with a detached and cold manner and who attended to technology rather than the patient as a storied human being and, specifically, in the decision to discharge Roger from the ER without consideration of what his living arrangements were at home and without involving him or his family in any collaborative planning. Equally blatant examples included privileging laboratory values over subjective and objective patient evidence of bleeding and Paul's own graphic characterization of being treated as a chicken breast in the last hours of his life.

The earlier commonalities represent largely systemic issues, which significantly impacted the experiences of patients and families in the stories. A closer examination of the nature of the care we witnessed adds another dimension to the discussion.

INSTRUMENTAL CARE AND HUMAN-CENTERED CARING

Halldorsdottir[19] identified 6 stages in the development of a biogenic caring relationship, each stage requiring successful completion or the relationship cannot evolve to the next. Although she does not equate stagnation at any of the first 5 stages with a specific way of being on her uncaring-caring continuum, it is reasonable to assume some relationship exists.

A biocidic or life destroying way of being is described by Halldorsdottir[8] as the most inhumane form of being with another. In addition to the more obvious actions causing bodily harm she identifies those that wound the human spirit and psyche, ranging from coercion and manipulation to humiliation, fostering dependency, and cold heartedness. Unfortunately, evidence of this mode was present in the stories, both in medical and nursing care. Disenfranchising patients from active involvement in decision making about their care is a way of fostering dependence; cold and callous communication announcing one's imminent death in the absence of support is spiritual violence, which both Paul and Roger experienced.

The life-straining, or biostatic mode of being is defined by Halldorsdottir[8(p39)] as one that negatively affects the other through being "insensitive or indifferent to the other and detached from the true center of the other." She noted it may take the form of fault-finding and blaming to simply being unfriendly and cold. In finding examples in the stories, we found it difficult to distinguish clearly between the biocidic and biostatic mode—it seemed to us that harm was done in both modes but was perhaps more devastating in the biocidic mode. The cold, indifference of Paul's primary oncologist in her second and final meeting with Paul provides a medical example. Similarly, nursing examples are evident in both stories. The nurse's apparent lack of concern with Paul's physical symptoms—unless reflected in abnormal laboratory values—and what those symptoms symbolized for him in terms of his psychological and spiritual well-being provides an example of a biostatic mode of being. Another was the home care nurse's assignment of sole responsibility for keeping Roger alive, should he become dyspneic, to his 85-year-old wife who, despite never having held a syringe in her hand, would in that situation need to administer an injectable medication left in the refrigerator.

Halldorsdottir[19] postulates that perceived uncaring, through modes of being, such as those described earlier, is a barrier to developing a nurse-patient relationship in that it creates distrust and discourages meaningful communication, essential to completing the first stage of the relationship, initiating a connection. The patient-as-object orientation of care providers in a biocidic and biostatic mode denies, ignores, or diminishes the subjective reality of the patient and poses yet another barrier to establishing a healing nurse-patient relationship.

The biopassive mode of being is described as being detached from another without adversely or positively affecting the other.[8] The situated reality of the patient is still ignored, which, according to Halldorsdottir's theory of the nurse-patient relationship, means that the second stage, mutual acknowledgment of the personhood of nurse and patient cannot be successfully completed. Because patients are in hospitals, clinics, and home care because of the need for nursing care and/or medical treatment, we found it difficult to find examples where the interactions with nurses and physicians were neutral. Halldorsdottir gave examples in which patients perceived nurses to care about the tasks and routines, but not about the patient as a person. While we observed this very phenomenon in what we refer to as instrumental care, we experienced the failure to acknowledge the patient as a person negatively, even when the care was technically excellent.

The third stage of the nurse-patient relationship seems to be mostly from the patient's perspective and that is the realization that a connection has been made.[19]

Patients in Halldorsdottir's study said they knew this through warmth and caring being communicated through verbal and nonverbal communication. The fourth stage, reaching a level of truthfulness, speaks to authenticity of the nurse and a sense of safety for the patient. These stages would need to be successfully completed in Halldorsdottir's theory for a bioactive mode of being with another—what she called professional nurse caring and an example of what we reserve the term caring for—by attending to both the person and specific needs. The nurse who demonstrated such caring in Paul's story was the one who tried to advocate for the PICC line. It was the compassion she showed in tending to his needs that provided the basis for his trusting her sufficiently to advocate for him. Another example of bioactive caring was seen in the heroic home care nurse who saw the impossibility of a frail 85-year-old woman taking care of her bed-ridden husband at home and advocated for Roger to be admitted into palliative care.

Halldorsdottir[19(p647)] described the fifth stage of the relationship as "reaching a level of solidarity." Patients in this stage reported feeling like the nurse was on their side, that they were not alone, and felt some equality in the relationship. This is a prerequisite to the final stage, the biogenic or life-giving stage, in which true negotiation of care takes place, in Gadow's terms, the nurse facilitating authentic self-determination. Paul did experience this biogenic mode as he engaged actively with the palliative care physician in pain management strategies. The biogenic caring was also demonstrated by several nurses in the ICU on both admissions. In the first admission it was the nurse who, as soon as Paul was conscious, invited his participation and direction in all aspects of his care. In the second, the biogenic caring extended to the family as we were invited to participate and make decisions about managing the hiccups. Sadly, Roger did not experience such solidarity. His family repeatedly pleaded for a collaborative approach to his care that recognized the uniqueness of Roger and his life but all their attempts were either directly or indirectly thwarted.

CONCLUSION

Buber's[26(p54)] fundamental premise was that "the basic word I-You can only be spoken with one's whole being" whereas "the basic word I-It can never be spoken with one's whole being." The influence of his work on nursing theories that have been influenced by existentialism is evident; only whole nurses can care for patients as whole human beings.[1,18] We have witnessed the detrimental effects not caring for patients as whole human beings had on our loved ones and experienced the effects it had on ourselves, as families. And yet, when Paul and Roger were not treated as whole human beings, it meant the wholeness of the nurses and other care providers had also been shattered.

In examining the commonalities across stories, we identified systemic and environmental factors that we believe contributed to the preponderance of instrumental care: fractured delivery models, organizational and/or unit cultures that devalued caring, and professional/personal barriers to engaging patients and families in authentic self-determination. Our assumption is that nurses we encountered entered nursing for the purpose of caring for whole human beings but somehow were sidetracked from their initial intentions. A nursing best practice guideline[4(p8)] highlights the imperative of supportive organizational delivery models in fostering client-centered care both to develop the necessary knowledge and skills but also to create care delivery models that "allow nurses and clients to develop continuous, uninterrupted, and meaningful relationships."

Is caring in nursing an impossible ideal in today's realities? Sumner[9(p100)] did not directly answer the question she posed but, on the basis of her research, concluded that nurses wish to be caring but are too often prevented from doing so by external constraints. She cautioned that nurses "are a fragile resource that need protection." On a similar note, Watson,[27] in revisiting an editorial asking "Can an ethic of caring be maintained," observed both ominous trends that increasingly obstruct an ethic of caring and others that support its resurgence. She warned that the consequences of failing to maintain an ethic of caring were dire for nursing and for humanity, later proposing instead that nursing lead the way in sharing its caring knowledge with other disciplines.[12] The urgency for action in that regard, for nurses to lead the way in transforming health care, is evident in Roger's and Paul's stories.

Thirty years ago Gadow[1] wrote that we were at a turning point in nursing. She saw choices between coopting the biomedical, scientific model, regressing to intuitive approaches, or charting a new course. Very clearly, the discipline of nursing has charted that new course. But our experiences force us to question the degree to which the practice of nursing has been able to adopt that new course within the corporate bureaucracies that employ most nurses. Unfortunately, they suggest to us that nursing is still or again at a critical turning point. In a recent blog, Thomas Cox[28] likened the recent nuclear disaster in Japan to the state of health care in the United States and many other countries:

> *the butterfly's wings for our health care (finance) systems, the decision to transfer insurance risks to health care providers, have been developing for the same last 4 decades [as nuclear power plants have existed in Japan] and we are seeing and will see more in the future of the full force and effect of those decisions and their cumulative effects.*

He cautions that risks do not disappear simply because they are ignored and urges nurses to "not ' . . . just go gentle into that good night' of our demise, of the loss of all we trained for, struggle to protect, and say we want." Our hope is that telling Roger's and Paul's stories may be a helpful reminder of what is at risk if we do not head the call.

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