

EDITORIAL

Patient- and Family-Centred Care: A Long Road Ahead

More than 20 years ago, in the middle of my nursing education, a Hollywood movie starring William Hurt was released. Titled simply *The Doctor*, it is the tale of a powerful but arrogant and insensitive cardiothoracic surgeon whose approach to patient care is transformed after he encounters the health-care system at its coldest when treated for throat cancer. Critics generally loved the film, as did the public. The movie's messages were simple: first, that neither social status nor money are of much benefit when life-threatening illness strikes and one's fate lies in the hands of others and of forces unknown; and second, that no health-care worker should take an officious or distant approach to their work before walking a mile in their patients' shoes. Indeed, in the closing scenes of the movie the now-redeemed lead character makes a point of exposing his trainees to the vulnerabilities of being on the other side of the bedrails, with firsthand "learning experiences" as part of their initiation to practice.

From the time I walked into my first class and stepped into the community and the hospital as a nursing student, I was socialized to be sensitive to the personal and human side of health care — even to the point of letting health-care organizations with their hierarchies and operations fade into the background. I was taught to take the responsibility of being a professional seriously but to treat the "cloak" and trappings of professionalism warily. I was required to learn about and of course attend to the diseases, treatments, medications, and procedures connected to my patients' conditions, but not to let technical details rule the way I related to patients and families. My classmates and I were reminded again and again that patients are individuals finding their way through life in spite of the challenges of illnesses and life transitions, accompanied by whomever they called their families and often in spite of the barriers and limitations imposed by the health-care system. Repeatedly, we were reminded to view negative feedback and "difficult" behaviour on the part of patients and families as an opportunity to better understand and address needs, rather than as an affront or as something to be "managed" by pushing back against expectations. I was educated to see nurses as facilitators of "safe passage" through the health-care system and, when at

the bedside, to always think about the kind of care I would want my own family to receive.

This past summer, my family lived through a dramatic and heart-wrenching encounter with the health-care system alongside my mother-in-law, who ultimately died of metastatic lung cancer. We came equipped with a great deal of knowledge and experience concerning the medical decisions that she would face. We knew about how health services operate and the situations that would need to be managed. We followed her through institutions where building layouts and sometimes even faces were familiar, and where knowledgeable and dedicated friends were never further away than a phone call or a walk down the hallway. As individuals, the professionals, technicians, and other workers were, almost to a person, exceptionally kind and competent. And as someone attuned to patient-safety issues, I was pleased to see the outward attention to safety concerns and inspired to see how hard so many people in the institutions were working to do right by patients. We were very lucky in so many ways.

However, we also saw poor communication between groups of professionals and between the health-care team and us (causing much distress), a narrow focus among many members of the teams, and seemingly endless delays. Even more disturbing, we saw resignation on the part of staff (which we might have mistaken for nonchalance had we not known better) to situations that, simply, patients and families should not be expected to endure. Were there bright spots — points of connection and victories — in a very difficult set of circumstances? Were we grateful for the attention and care my mother-in-law received? Absolutely. But I did have my *The Doctor* moments — different in some ways but strikingly similar in terms of feeling that somewhere along the way we have managed to get things very wrong.

I like to think that I am a successful, albeit imperfect, product of my socialization in patient- and family-centred care. From my clinical training I went on to become a nurse researcher and educator and to study health-care systems and how they succeed and fail. I have spent most of my teaching career delivering courses on the contexts of health care that affect what nurses are able to do in partnership with patients and other workers. I had the problems in health-care across systems carefully catalogued in my head. But it took my experience this past summer to show me, in my gut, just how far we are from where we need to be as a profession and as a health-care system.

For years I had listened to the countless personal stories of my colleagues, family, and friends about huge gaps in patient- and family-centred care. I had heard for decades that only a fool would leave a loved one with a serious illness unaccompanied in the hands of the health-care

system (and, indeed, at least one of us was at my mother-in-law's side from the beginning of the journey to the end). But when we lived through a crisis firsthand I realized that I have been an apologist for the system's failings — despite being involved for more than a decade in research showing how systematic and widespread those failings are. It hit me that, apart from the “points of light” (inspiring individuals and settings that keep us all from losing hope), our system of care is nowhere close to being patient-centred and that I have been overly optimistic about the prospects for improvement. In the coming years, with health-care financing expected to grow less and less secure, services are bound to shift to accommodate political and economic forces. Barring a major change in how we organize care, our health-care system will become increasingly unsafe and toxic for those who work within it and those who have no choice but to rely on its services. It is clear that we have other fundamental work to do as a health-care system and as a profession besides worrying about individuals being people-focused and humane.

It seems that we in nursing and our colleagues in the other health professions and occupations are too lost to find our first steps. Quite possibly we are just too comfortable with the status quo to seriously question what is happening in health care. Perhaps we think we have too much to lose by changing the structures and operating principles in our institutions and agencies, when keeping our heads above water consumes so much of our time and energy. However, we need to start asking ourselves why vested interests have created and continue to sustain the system we now have. Moreover, we need to determine what our next steps will be if patient-centredness is to be more than just a buzzword, and what we are willing to sacrifice as a profession and as individuals in terms of security and certainty in order to deliver better care and forge a better future for our patients and, ultimately, ourselves. The public is counting on us all to find a better path on so many fronts. And sometimes it takes a deeply personal experience to see things that our various socializations and interests prevent us from seeing.

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