A VOLUME IN THE SERIES

The Culture and Politics of Health Care Work

*Edited by* Suzanne Gordon *and* Sioban Nelson

A list of titles in this series is available at www.cornellpress.cornell.edu

# COLLABORATIVE CARING

## Stories and Reflections on Teamwork in Health Care

EDITED BY

**SUZANNE GORDON,**

**DAVID L. FELDMAN, MD,**

**AND MICHAEL LEONARD, MD**

**ILR Press**

*an imprint of*

Cornell University Press

ITHACA AND LONDON

JILLIAN CHANDLER, RN is a Patient Educator on an inpatient Psychiatry unit in Toronto. She is passionate about nursing and nursing issues and is also involved in the Registered Nurses Association of Ontario (RNAO). She was a fellow in the Collaborative Academic Practice Innovation and Research Fellowship Program at University Health Network.

# A Second Chance

*Illana Perlman*

Monday is always the busiest day of the week for me. Nine years ago, I experienced a Monday that was no exception. As the social worker in the trauma unit of a large urban teaching hospital, I had been urgently paged to meet with the parents of two newly admitted trauma patients. The sisters, Sarah, twenty-two, and Lisa, twenty-four, had been in a motor vehicle collision when the car in which they were traveling was struck by another vehicle that had crossed the center line and collided with them head on. They had been airlifted to our trauma center, and their parents and younger brother arrived within a few hours in a state of disbelief and shock.

Sarah was intubated in the critical intensive care unit, having suffered a severe brain injury, a chest injury, and a lacerated liver. Her initial score on the Glasgow Coma Scale was 4. (The Glasgow Coma Scale is a neurological scale that aims to give an objective way of recording the conscious state of someone for initial and subsequent assessments. The total score is 15, so the lower the score, the more severe the brain injury.) Sarah was exhibiting decorticate posture, a sign of severe damage to the brain in which a person is stiff with bent arms, clenched fists, and legs held out straight. Lisa was in the step-down intensive care unit where patients are not on a ventilator or life support and there is a patient-to-nurse ratio of two to one rather than one to one. She had chest injuries and a spine fracture for which they applied a halo vest, an orthopedic device to immobilize the neck and head that is attached to the skull by pins. Sarah was certainly the more critical of the sisters, and for two weeks her brain continued to swell and her condition deteriorated. At one point, she had to undergo emergency neurosurgery, and the "guarded" prognosis was changed to a "poor" prognosis. Her pupils were fixed and dilated, and she had no gag reflex. I remember the meeting clearly; I sat with her parents and the intensive care physician as he told them that

Sarah had a less than 10 percent chance of survival. He suggested that they consider the withdrawal of life support and presented the issue as if the decision needed to be made quickly. I expected that they would reach that decision with some haste.

I met with the family two to three times per day, providing support to them throughout this critical time. We quickly developed a strong bond as is often the case at a time of crisis and vulnerability for our patients and families. In my social work role, I represent the one consistent staff person at a time of enormous anxiety and uncertainty in an overwhelming hospital complex that comprises multiple units and a myriad of constantly changing physicians and nurses. I was frequently the interface between these parents and the various team members, ensuring an awareness of key information and care plans.

The admission of a critically ill relative to an intensive care unit creates considerable anxiety and stress for family members. Medical and nursing care focuses primarily on maintaining the physiological stability of the patients, while social work focuses on meeting the emotional needs of the patient and family. The team also looks to the social worker for clarification of the wishes of the patient and family, as well as their informational needs. Understandably, it was very challenging for this family to attend to Lisa's recovery at a time of uncertainty about whether or not Sarah would survive. I informed the parents about the hospital's staff, procedures, and communication processes and assisted them with practical matters, such as accessing insurance benefits and legal aspects, discharge planning for Lisa, and linking them with resources that they needed to sustain them.

The hospital became their home, and for days they slept in the waiting room, keeping a vigil at Sarah's bedside. Their level of crisis was immeasurable as they experienced a rollercoaster of emotions with the fluctuations in her condition. Despite Sarah's decline, their faith was unwavering, and to know them was to know that they would not easily withdraw life support. Although her voice trembled, Sarah's mother's words were strong and resolute in responding to the physician during that pivotal meeting, and I can still hear them now: "I waited nine months for my daughter to be born; I shall not



decide to end her life in an afternoon." That meeting triggered significant turmoil for this family, and it was in this context that I engaged one of the most significant interventions of my social work career.

I had walked into that meeting with the same approach that I had for most meetings in the critical intensive care unit: to be a support to the family, an extra pair of ears, so to speak, particularly to ensure their understanding of the information presented. I was not aware that the focus was going to be on the possibility of withdrawal of life support. I believed it was for the purpose of updating the family on Sarah's condition. As the meeting progressed, it became clear that the physician was requesting that the family make a decision regarding withdrawal of Sarah from life support. He explored the severity of the injury and the likely long-term impacts on her quality of life, presenting statistics in this area. He also shared a personal story from one of his own family members in a similar situation, which I believe was a reflection of his empathy.

A physician's role in leading end-of-life decision-making conferences for families in the intensive care unit is an extremely delicate one. The physician is working in a climate of pressure for access to limited beds (often referred to as "rationing") and balancing the delivery of information to families about the very sensitive issue of their child's condition. Studies have emphasized that strong communication skills are critical, particularly the ability to listen, to give families time to absorb the information, and to provide them with emotional support in the process. At times during the meeting I felt as if I were walking a tightrope between supporting the family in their state of immense shock at the choice with which they were being presented and ensuring that their perspective was being heard, while still working collaboratively with the physician who was pressing them to make this life-and-death decision.

In facilitating the close of the meeting, I summarized the parents' perspective and their evident need for more time. After the meeting, the physician took me aside and expressed his dissatisfaction at my "undermining" his meeting with the family. As we debriefed, I clarified that my role was one of support to families, irrespective of their decisions and that he was misinterpreting my joining with this

family as working counterproductively to his perspective. I affirmed the family's position on withdrawal, which I had learned over the two weeks of getting to know them through numerous conversations, to help him understand that their approach prevented them from making any "quick" decisions, regardless of the information he had presented. This situation reinforces the importance of role clarification and mutual understanding and respect among health care team members as critical components of effective collaboration and teamwork in a hospital context.

Leaving that meeting, I experienced an uneasy realization that this family did not have sufficient medical information with which to make this grave decision, irrespective of the path that they would choose. While they had met with the intensive care physician and heard from him about their daughter's condition and limited potential for a quality of life, they had not spoken to the neurosurgeon and had not received details more specific to the brain injury and the prognosis. I knew that for the family to live with whatever decision they made, it would be essential for them to be able to look back and know that they had obtained all the necessary and relevant medical information and that they had weighed it all in order to reach the best possible decision.

I shared my concern with the family and set about advocating with the intensive care team to engage the neurosurgeon on the case to review the patient's condition. That afternoon, I contacted the neurosurgeon and set up a meeting with him and Sarah's parents. Within a couple of days, the neurosurgeon had reviewed Sarah's chart and test results and had given the parents his perspective on her prognosis. He also engaged a colleague neurosurgeon at the hospital to provide an independent consultation on this matter. I was present with the parents when they met with the neurosurgeon and received his information, which was in fact in direct opposition to that of the intensive care physician. In short, he stated his belief in the patient's potential for recovery and a quality life, however uncertain, and said that he did not support withdrawal of Sarah from life support at this time.

This was a whirlwind time for this family, within the raging storm through which they were already living. They clearly communicated



to the intensive care team their intent to continue all care for their daughter and stayed with her day and night, moving into our hospital's hostel in order to be close at hand. Sarah underwent a tracheostomy and a feeding tube insertion and remained in intensive care for several more weeks. This was a particularly dark period for the family, following on the heels of that meeting with the intensive care physician. During this time, Sarah's mother shared with me her fear about what she knew she would need to do, out of respect for her daughter, if they had made the "wrong" decision and Sarah did not emerge from the coma. Sarah had been so intensely vibrant and vital with such a zest for life. They knew that she would not want to live in a persistent unresponsive state.

We waited and wondered, and Sarah remained unconscious for six weeks. It was a struggle for this family to cope, given that both parents were staying at the hospital, sleeping in our hostel, and taking turns at Sarah's bedside day and night. In between they tried to visit Sarah, but they felt torn because their major anxiety was related to Sarah's survival but, although Lisa was not critical, she certainly also needed family support.

Slowly, Sarah emerged from the coma and started to respond to voices. She began to move purposefully and to track her visitors. She started to engage with her family and with our therapists, first in gestures and then verbally. Our team was incredulous at her recovery, and the neurologist who had first assessed her to have a poor prognosis in the critical intensive care unit returned to reassess her on the trauma ward. He documented her recovery as "remarkable . . . she is alert with mild aphasia . . . good comprehension, fluency . . . good limb movement . . . walking . . . eating."

Miraculously, Sarah had beaten the odds. Two months after admission to the trauma unit, she was discharged from the hospital into the care of her family, where she continued to receive extensive and intensive community rehabilitation for several years. Her long-term injuries include being legally blind, suffering from constant vertigo, and not being able to taste or smell. As a testament to her strength and resiliency, she returned to school and is now a registered holistic nutritionist. She is also a motivational speaker, regularly presenting at our hospital's injury prevention program that targets high school

students and is aimed at reducing risk-related trauma in youth. Both Sarah and her family acknowledge the "second chance" that she has been given in life.

Decision making about treatment continuation or withdrawal for patients with severe brain injury involves tough discussions about the benefits and the burdens, and about outcomes that are difficult to predict. While Sarah experienced a substantial recovery of cognitive and physical function, her outcome could also have been an early death or survival with extreme physical and cognitive disabilities. In these situations, although the outcome may always be in doubt, what should always be clear is the need for interprofessional discussion, such as that which I facilitated for Sarah's family. The concept of interprofessional education is developing as an integral component in the training of health care professionals throughout Canada; it emphasizes the importance of effective collaboration and teamwork for the efficiency and quality of health care delivery. In the hospital context, social workers are particularly well positioned to champion and facilitate teamwork and collaborative practice among members of the health care team, given their training, their close alliance with the patients and families, and their role and function in the Intensive Care unit and other units.

I have worked in the trauma unit for more than twenty years, and while many situations arise that speak to the importance of interprofessional communication and collaboration, the experience of Sarah and her parents is an exemplar for several reasons. First, it highlights the critical importance of ensuring that all families receive adequate medical information related to an injury and sufficient time in which to absorb this, particularly when difficult decision making is involved. Second, it emphasizes the importance of advocacy in working to support families during hospitalizations. Indeed, it is incumbent on every member of the health care team, irrespective of their role, to act on behalf of the patient and family, especially if one believes that there is a concern, such as supporting a family's need for more time or, if there is a gap in information, to facilitate their obtaining that information. Third, it emphasizes the importance of ongoing interprofessional communication among the members of the health care team to ensure mutual awareness, ongoing respect,



and the understanding of the patient and family perspective. Respecting one another's professional perspective is a cornerstone of effective teamwork. It also minimizes the potential for tension through misunderstanding or misinterpretation of actions, as was the case when the physician considered me to be undermining his position. Hospitals and health sciences schools throughout North America are recognizing the need for and benefits of interprofessional practice, both in terms of enhancing patient care and more satisfaction among health care workers.

As a result of the experience with Sarah and her parents, the practices and processes for our communication and teamwork in the intensive care units have changed for the better.

• • •

Illana Perlman, MSW is a clinical social worker in the Trauma Program at Sunnybrook Health Sciences Centre, Toronto. She has held this position for twenty-two years, specializing in crisis intervention and adjustment counseling with patients and families who are experiencing life-threatening injury. She is also an Adjunct Lecturer at the Factor-Inwentash Faculty of Social Work, University of Toronto, and is responsible for coordinating all facets of the social work student education program at Sunnybrook Health Sciences Centre.