CHAPTER 19

Canaries in the Mine:
Filming Women Working in Health Care

Laura Sky

Introduction

For a decade during the 1990s, I worked alongside nurses, doctors, social workers, and first responders, researching and producing a series of documentaries and reports about the state of our health care system. I wanted to explore, dialectically, the strengths and gaps in health care systems from the perspective of patients, families, and health care providers.

For more than 30 years, our organization, the SkyWorks Charitable Foundation, has been committed to a participatory model of research and documentary production based on that research. We developed a method of film dissemination built on the principles of contributing to community engagement for purposes of social change. The foundation of our work rests with the long-term relationships we develop with individuals and organizations that are committed to equity and social justice in their workplaces and communities.

From Factories to Hospitals

My earlier and overlapping research and documentary production focused on working conditions in the manufacturing industry and the public service. I was particularly interested in the "working lean" model in the private and public sectors. I explored the effects of new technologies, peer and management expectations of the rate and speed of work, and the clash between human need and workplace productivity. I witnessed the formal and informal role of gender, power, and authority in the workplace. I saw the effects of these changes in physical and psychological workplace injuries, including the haunting consequences of overwork, peer pressure, and conflict.

When my closest friend Cathy became critically ill, I spent eight weeks at her side in a downtown teaching hospital. I was often joined by a mutual friend, Philip, who had recently completed his PhD in ethics, and was currently studying medicine. The three of us were also political buddies, active in social justice organizations. I rarely left Cathy's hospital room and often processed my observations with Philip and, as she improved, with Cathy, too.

I decided to turn my attention to hospitals as workplaces. I wanted to understand how power, gender, class, technology, and the human spirit determined the care that patients could expect and experience. I became particularly interested in what I saw as the collision between the organization of health care work, the ever-changing technology, and the tensions and dilemmas that these elements imposed for front-line staff.

The feature-length documentaries that were seeded by this research process included *The Right to Care*, *To Hurt and to Heal*, *Crying for Happiness*, *Jake's Life*, and *Crisis Call*. In fact, this research has informed most of my documentary work in the years since. These explorations taught me to unpeel the layers and levels of personal and collective values that inform daily workplace activities. In hospitals I learned to question the visible and invisible assumptions that lead to clinical decisions that promote or undermine healing. I learned that moral suffering in the workplace can create trauma and its consequences for patients, families, and providers.

Although unions and workplace leaders have long been committed to advocating for workers who are injured on the job, what I came to see as moral distress or ethical injury

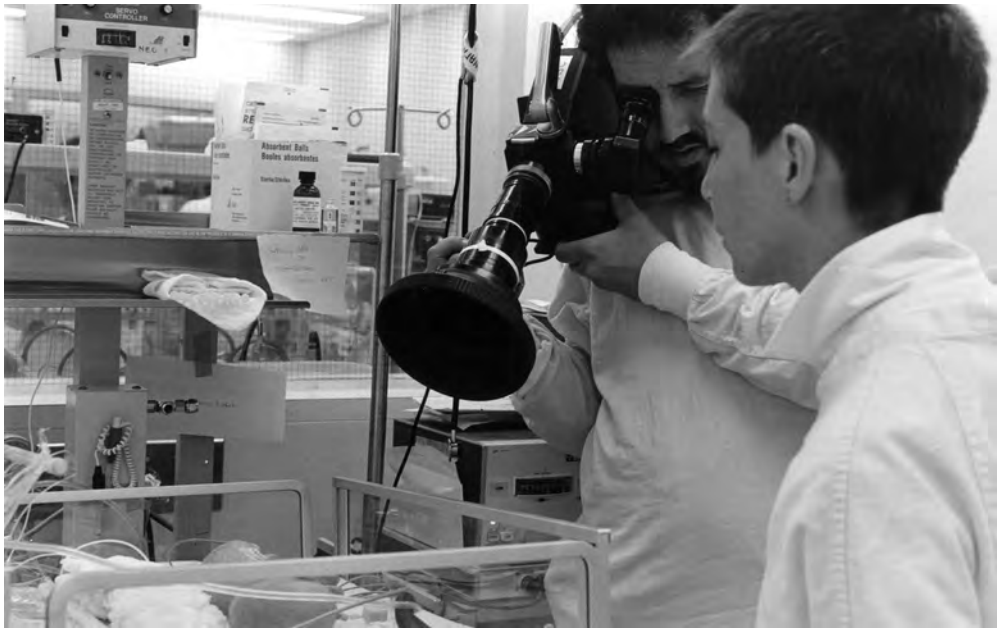

FIGURE 19.1

has been generally under-recognized by health care workers and their union or professional association representatives. At that time, there was little conversation among colleagues about these troubling dilemmas. Staff often suffered in isolation. My chosen mandate was to identify and document these very real issues and their consequences as staff, patients, and families experienced them in hospital and later in their homes.

To prepare my research and to inform the future filming, I rotated through various clinical disciplines in five teaching hospitals. I was usually granted access by clinician-leaders who had their own professional interest in the issues I wanted to explore. I agreed to various conditions in order to research in this way. I committed to maintain patient confidentiality, and to respect the privacy of patients, families, and staff. I agreed to leave the room should my presence impose discomfort for others. I promised to contain my questions or comments, waiting for the opportunity to express these at appropriate times and in appropriate settings. I observed for extended periods of time at various adult and pediatric intensive-care units (ICUs) and neonatal intensive-care units (NICUs). I also teamed up with members of a family practice clinic and followed their work in their emergency department. I worked closely with a neurosurgeon, attending surgeries and daily rounds. I shadowed a director of nursing at a downtown teaching hospital, which took me into executive and management meetings. I studied the consequences of ever-evolving federal and provincial health policies. I spent many nights and days in hospital rooms, by incubators, in surgery, in emergency rooms, following clinical rounds, at presentations and lectures. I observed report during shift changes, family conferences, and countless informal conversations between clinicians of every rank and denomination.

I began this work in a series of pediatric units. These are a series of memories from that time.

Researching and Filming in Pediatric Settings

While researching at various pediatric settings, I can call to memory events during long hours at the bedsides of very fragile children while standing with very capable nurses. I say "standing with" because my relationship with many of the nursing staff involved far more than observation. They permitted me to enter their personal-professional spaces as they processed all manner of experiences, considerations, and dilemmas. I witnessed their struggles, their pride, and their despair.

They cared for critically ill children and their families who were facing intense clinical and emotional needs. The kids were often post-surgical patients as a result of injury or congenital anomalies. Children who were struggling with life-threatening illness required a combination of clinical skills, attentive waiting and watching, interdisciplinary consultation, and definitive action.

FIGURE 19.2

Establishing Our Rules for Filming, Privacy, and Consent

While filming, our three-person crew created our own protocol in agreement with the hospitals, staff, and families. We carried the most minimal equipment and used no extra lighting. We spent time waiting quietly, away from the bedsides, before we filmed. I would always talk with the patient's parents before we planned to film, discussing with them what we were doing and why we were filming. I would explain that we were producing a documentary that would be a teaching tool for clinicians, medical and nursing students, and one that would be useful for families dealing with similar situations. It was unlikely that the film would be on television, but should that eventuality present itself, we would revisit them for their additional decision about consent. If they agreed to allow us to film, I promised that we would stop at any point if they became uncomfortable with our presence. I also agreed that they could change their minds about participating at any point, no matter how much we had already filmed about their situation.

I promised the front-line health care staff the same opportunities for their participation and their rights of refusal or consent.

I approached these situations as a parent as well as a filmmaker. I cannot imagine a situation more precarious, more intimate, and more demanding than the events that parents were experiencing. The last thing that families stressed to this degree needed, I felt, was the intrusion of a film crew. Similarly, front-line staff were doing the best that they could, devoting their knowledge, skills, and commitment to care to the utmost of their abilities.

If being filmed interrupted their concentration or distracted them from the tasks at hand, we would pull back with no questions or negotiation.

Each of the film's adult participants would have the opportunity to see the footage that we hoped to include in the completed film. This would give them the opportunity to grant or withdraw their final consent.

Given that understanding and agreement, I entered the patient's room first to observe. If events allowed, I would quietly and briefly check in with parents and staff as events unfolded. If they all agreed, I would call in the camera and sound recordist. They would quietly stand back and observe. I would whisper quietly about what was happening and what I hoped we could film. Once filming, they would follow the events from a respectful distance and, if required, stop on a moment's notice.

FIGURE 19.3

A Small Boy with a Fragile Heart

One little boy, about three or four, had just had major heart surgery. I will call him Paul. His slender body was long and pale in the pediatric ICU hospital bed. He was intubated, his chest swathed in padding and bandages, and fluorescent with the antibacterial liquid that had protected the surgical site. Paul was silent, but very expressive. His body moved with the rhythm of pain that he was experiencing. His eyes remained closed. The nurse, whom we will call Linda, could read him—she read his pain, his fear, and his need for help. She adjusted his IV pain medication to the prescribed limit and knew when to call for additional help. She was his advocate and his protector.

Linda was also there for his parents. They came to Paul's bedside in a world that was so alien for them. They approached their son's bed as outsiders to this high-tech world that held his fragile life, tethered with tubes, wires, and announced by all manner of alarms. The centre of their focus was their little boy. They could not hold him close; they stroked his cheek with cautious fingers. They were subservient to the technology, alarms, and wires that dominated his small body. Their love was in his room, in his bed, embracing him through this living, breathing struggle. The sounds came from their own murmurs, their silence, the nurse's quiet explanations. They observed, they touched their boy, and they were vigilant, looking for signs of his life in this complex space.

FIGURE 19.4

The pediatric resident came into the room a number of times. David was a young father himself. In fact, he had earlier told me that he and his wife had lost a baby themselves. He knew the pediatric ICU setting as a clinician and as a parent.

The resident paused by the bedside, and spoke softly to the small boy. He stroked the child's face and added another light blanket, avoiding the drainage tubes, IVs, the monitors, and breathing apparatus.

As the child's condition worsened, various doctors attended at his bedside. The conversations became increasingly sombre in tone. Our crew withdrew, leaving the room for discussions between the doctors and the parents. It was decided that the little one would go back into surgery. His situation had become increasingly critical.

Hours passed. Although there were other areas for filming, we were distracted by the medical crisis that we had observed. In fact, each of our crew had young children at home. We observed with the eyes and hearts of vulnerable parents. We felt part of the vigil, awaiting his return from the operation room. Day became night, and finally the child returned. His chest remained open for quick access to his fragile heart should it need to be restarted in another crisis. Staff and parents were now gowned, gloved, and masked. Our crew stayed out of the room, discreetly observing when possible through the large glass window.

The little one survived and slowly recovered. The nursing and medical team went on to the next patient and family. I continued to work beside Linda, the nurse who was the lead with the child and family. The more we worked together, the stronger the bond grew between us. She was my teacher, my guide, and I chose to offer her my support in the hours of care she provided for very ill children.

FIGURE 19.5

Working in a Parallel World

As I looked out the windows of this ICU to the streets below, I came to feel that there was a profound distance between the parallel world in the unit and the ordinary day and night activities in the city. I became aware of how difficult it was to talk about the nature of my observations with my own friends and family. I could not have informal conversations about ill and dying children, especially with friends who were parents. I imagined these

realities for nurses who left the universe of intensive care, vulnerable children, and frightened parents, returning to their homes, families, and friends.

I also observed the institutional and collegial support systems that existed and that were scarce, given the intensity of this work. There was evidence of informal supports between nurses while working, on breaks, and, to a lesser degree, in team meetings. These exchanges varied depending on the expressed needs of particular nurses and the capacities of their co-workers. At each bedside, each nurse was dealing with complexities, urgency, predictable and unexpected needs of their young patients and their families. "Normal" was illusive at best.

I felt that it was appropriate to be able to offer my support for their workplace experiences in exchange for their remarkable support for my work in this setting. We built trust.

An 18-month-old child was admitted through the emergency unit, severely injured. It was suspected that he had been beaten by one of the people living in his family home. The child was not conscious, and was severely brain damaged. He never woke up. Linda provided his primary nursing care.

The child's mother, grandmother, and the person who came to be known as "the boyfriend" spent long hours waiting in the family room, going out for frequent smokes. They were interviewed a number of times by staff and the police. I observed a palpable yet undeclared class difference between the clinical staff and these family members. Staff empathy was clouded by their suspicions. The boyfriend was described in team rounds as a "Mediterranean" type—clearly a pejorative designation. The mother and grandmother were tense, sorrowful, defensive—all understandable under these terrible circumstances. The staff believed that the boyfriend was responsible for this beating, but the women were seen as culpable as well. There was a wall of tension between the staff and family.

I encountered this disturbing situation while researching the documentary and had no intention of filming. Even had the cameras and crew been available, I would have decided not to film. Dealing with crew and equipment was the last thing that the family and staff needed in the midst of this terrible time. Although child abuse is a matter of grave public concern, at that time, in this critical-care setting, in the dreadful intimacy of these events, each and all participants had their rights to be protected from the filming process.

The child lingered for a day and night. The clinical staff explained to the family that repeated neurological testing had shown that the baby no longer had brain function. Linda and the other members of the team prepared the family for the moment when they would take the child off life support. Linda sat with the mother and grandmother as this time grew near. She offered them comfort, putting aside judgment and condemnation. Once the breathing tubes were removed and the respirator turned off, the child and the room grew still. Linda handed the blanket-covered child to the women and encouraged them to say goodbye. The family left together, trembling and crying, leaving the baby in Linda's arms.

I stood with her, quietly bearing witness and offering her my presence. Otherwise, Linda

would have been alone. For all the sophisticated clinical systems that were in place, there was no support for a nurse enduring this tragedy, this immense sorrow.

Linda washed the child and prepared his small body. And then, together, we began the long walk to the hospital morgue. I could not leave her side at that time. She never asked me explicitly to accompany her, but I felt that the bond between us in sharing this experience allowed me to take this journey with her. We talked infrequently as we walked. We entered the morgue, a still and cold place, and left the child there, so alone. Together, Linda and I returned to the ICU silently.

These events speak to a role of nursing that few people outside the profession see. There is trauma and tragedy woven into this job description, this experience of work. Linda and her colleagues bring strength and integrity to the many layers of their work. This is the space where a nurse's skills are informed and nurtured by her compassion and, at times, her sorrow.

Over my 30 years as a documentary filmmaker, a witness, and an advocate, relationships like the one I developed with Linda provide the heart and soul and the veracity of this work.

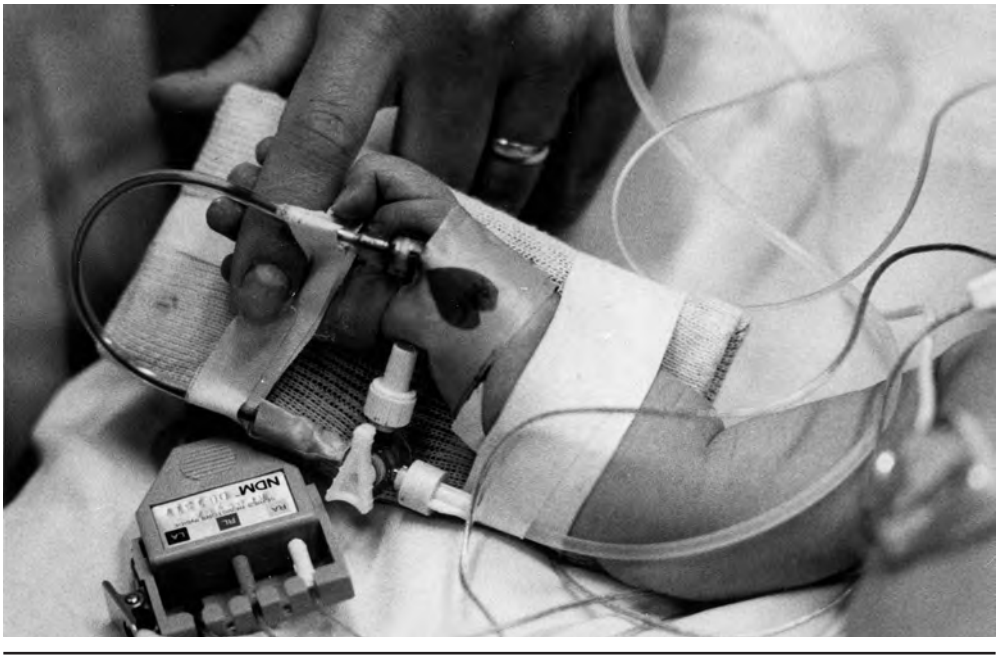

FIGURE 19.6

The Nurse as Truth Teller

These ICU experiences reflected the highest quality of care and skill in clinical nursing and medical care. This is the workspace where compassion and commitment combine to provide patients and families with the best of care while giving nurses the opportunity to be the best that they can be.

I also witnessed the dark side of nursing, which I came to see was the consequence of the industrialization of health care. This included fundamental reorganization of standards, responsibilities, job descriptions, and job security in the pursuit of downsizing and contracting out.

I saw that nurses are the canaries in the mine of the health care system. Delivering nursing services at the hospital or home bedside, they live with the scarcities, the gaps, and the inadequacies of health care policy and practice on a daily basis. They live with the corporate-speak that promises professional satisfaction and excellence, but enshrines cutbacks and scarcity. They work with what is possible and impossible in the delivery of their services. Yet they continue to deliver that care with their heads and their hearts.

I embarked on the research and production on *The Right to Care*, a documentary about how nurses struggle to deliver health care with integrity and commitment to the needs of their patients. As the title implies, the documentary also explores the right of individuals who need health services to receive the care they need.

Donna was a 25-year veteran in the delivery of home care nursing services. I met her through a letter to the editor she sent to the *Toronto Star*, decrying the decline of home health care services in the face of provincial cutbacks. When we met in person, she was fierce and smart. She worked on the front lines of a large national nursing service that she felt was disintegrating in front of her eyes. She believed that her employer was adopting corporate and industrial values that were contrary to the principles of good nursing care, advocacy, and compassion. She felt that this negatively affected the quality of care that patients could expect and the quality of work that front-line nurses could provide. Donna showed me and our audiences the parallel between industrial work systems and the new rules reshaping home and institutional nursing.

We could all count on Donna to tell the truth about health care policies, straight out. Within five minutes of meeting her, I decided to invite her to be filmed for *The Right to Care*.

Donna's clinical and personal skills with her home patients were inspirational—rushing from patient to patient to provide dressing changes, nursing assessments, palliative care, and seamless compassion.

She introduced me to a group of her colleagues at the local coffee shop and to a number of her patients in their homes. I watched, fascinated, as her community nursing colleagues used their lunch breaks to compare the latest information from management, form strategies, complain, buoy each other's spirits, and exchange coveted nursing supplies from the trunks of their cars.

In the *Right to Care*, we watched Donna relate to Edna, an older woman at home recovering from advanced breast cancer surgery. Donna takes a much-needed break, sharing a pot of tea with Edna. "I've been waiting for this cup of tea with you all day. I thought if I could just get to Edna's and have tea with her, I'll be OK. I don't want to bring tears to your eyes, Edna." The warmth and humour of this moment is so authentic and speaks to the spirit of their relationship.

Donna describes preparing Edith, another older patient, to go into a palliative care setting, after having cared for her for a year. "She asked me to get her the cream out of the cupboard so she could get rid of the hair on her chin . . . she was getting ready to die. I wanted to be there when the ambulance came for her, but I couldn't. I had to get to my next person. . . . I was rushing out the door when she called out to me, 'Donna, I just wanted you to know that I loved you.'" Donna savours the memory. "That to me is the meaning of this job."

In contrast, in the film Donna laments the transformation of home care nursing. She analyzes the new language of health care, how "addressing a self-care deficit" is corporate-speak for giving a patient a bath. Referring to her employer, she tells us, "They're making this [organization] into a business. At an administrative level, when I see the work I do treated like a corporation, I get frightened. . . . They laid off 27 of us [full-time nurses], and then advertised in the local paper for 'flexible' staff. What they mean is part-time, casual workers. . . . As a woman I feel angry—for all of us women."

Donna expresses the grief and anger she experienced in being unable to provide the care that has motivated her as a community nurse. She finds herself in the midst of the turmoil created by the reorganization of nursing work, where she is the canary in that mine.

The Toyota System of Health Care

I witnessed with great alarm the work systems based on the Toyota model of workplace organization adopted in our hospitals and community agencies. A few years earlier my documentary *Working Lean* showed the reorganization of factory work in the automotive industry, and the language and work conditions I witnessed in car plants were now appearing in hospitals. I was deeply disturbed that *patient-focused care* appeared to be anything but, and that Toyota's KAIZEN—continuous quality improvement, just-in-time production—was increasingly applied to work policies and practices in health care. The quality of nursing care, which was so important to nurses and patients alike, was being eroded in the name of increased "efficiency" and the "elimination of waste." Cutbacks had become pervasive. The casualization of labour, the reorganization of licensed responsibilities, and increased patient loads reformed training and clinical practices. As health care workforces were depleted, employees were trained and pressured to embrace systems that were to their own detriment and that of their patients.

In the early 1990s, in response to my work with front-line health care staff, I was hired by CUPE to prepare a major report on the erosion of the Canadian medicare system, and the struggles of front-line health care providers to "keep medicare healthy." My research focused on the consequences of policies and practices that enshrine privatization, and the reorganization of work. That research has informed my documentary work in the decades since.

The work took me across Canada and to Newfoundland, Prince Edward Island, and Nova Scotia, where I interviewed nurses, cleaners, and dietary workers—all health care

soldiers in the trenches. They had so much to say; they wept, they laughed, and they told their truths.

I witnessed the incursion of private corporations into Canada's public health care system. I followed the progress of large corporations into hospitals large and small: Baxter, Marriot, Johnson, all flourishing, as hospital workers and their patients struggled.

Overcrowding and understaffing, inadequate services, early discharge and readmissions, increased acuity managed by depleted staff and contracting out—all these were key concerns for health care staff and patients alike. I could be documenting this research today—the issues have become the new normal.

I sat with groups of front-line employees, many crying as they talked and listened. They were so deeply troubled about what they witnessed during each shift.

"When there are no beds left on our unit, and we have to admit someone from emergency, we have to send one of our patients to another unit. Often times, the doctor doesn't follow the patient to the new unit and he or she loses the continuity of care. With the pressure to discharge early, they may find themselves home alone, still very sick."

Emergency patients may be invisible in terms of admission statistics. For example, "a patient can come in through emergency for chest pain. Because there are no beds available upstairs, it's in emergency that you stay—for days perhaps. In fact, you can be in emerg for any number of days, and be discharged home directly from there and never been admitted at all. The stats look like business as usual."

Another concerned CUPE member described a still familiar situation, when a parent brings an ill child to hospital and is sent home with medication and instructions for the child's care. "You can just imagine, their child is getting sicker and sicker and the mum is just thinking, 'the doctor said that she should just be at home, all I need to do is give her this medication. . . .' This one mum came in with her little one six times before she could get her admitted."

Listening to their stories, I felt then, and do now, that the economic crunch behind the reorganization of health care leads to the ethical tension that health care providers experience in their workplaces. Many described ethical and moral injuries—traumatized by feelings of professional and personal helplessness in the face of impossible working conditions.

At the conclusion of my research period in Newfoundland, as I was leaving for the airport at five in the morning, I agreed to share a taxi with the Baxter director of operations for Atlantic Canada. At that time, Baxter, an American multinational company, was the largest health care supplier in North America. The morning was dark, foggy, and damp. I was barely awake, but the tears and despair of the health care workers I had interviewed were very much with me. I recognized an unexpected opportunity that this taxi ride offered. I asked the Baxter representative how business was for his company in Newfoundland. "It's never been better," he answered, and I knew there was something terribly wrong in the contrast between the losses felt by health care workers and their patients and the substantial profits enjoyed by these private health care businesses.

When Professional and Personal Experiences Collide

I am a long-time filmmaker and researcher, but also a concerned family member. Five years ago, my husband underwent cancer surgery in one of Canada's most respected teaching hospitals. He endured many complications; some were critical.

Days after his initial discharge, he became increasingly ill at home. An ambulance brought us to that hospital's emergency unit, where he waited in agony for hours. I watched him deteriorate in front of my eyes. He was moved to a hallway waiting space with one frazzled nurse attending to very ill patients. At 2:30 a.m. he began projectile vomiting. He was hot to the touch and in and out of consciousness. The nurse was nowhere to be seen. I roamed the halls frantically, looking for help. Then I saw the sign on the wall from the one of the nursing departments: "Kaizen Workshop Monday at 10am." By that time I was in tears.

I stopped two nurses chatting as they walked. "Please, you have to help my husband. He is so sick." One took my hand and said, "We hear you. Someone will be there soon." They moved on. This was this hospital's version of patient-focused care. Six hours later, just after shift change, my husband was barely hanging on and was finally recognized by a nurse who saved his life. This nurse assessed him and acted immediately. He assembled a team and everything possible was done for my husband on an urgent basis. His kidneys were failing. He had septicemia, his blood pressure spiked, and his diabetes gave way to ketoacidosis. This began a three-month stay in hospital. He underwent a number of surgeries and subsequent stays in the ICU, going from crisis to crisis.

Paradoxically, I was always relieved when Verne was readmitted to the ICU, where he would get the best nursing care the hospital had to offer. When he was finally discharged to go home, he had daily nursing care for dressing changes on a deep post-surgical wound. On a regular basis, the management of the community home care agency tried to cut back on the nursing visits. I strategized with his primary physicians to countermand those attempts. As his advocate and family case manager, I was constantly struggling to stay one step ahead of the agency's version of patient-focused care. I had learned so much from the hospital and community nurses with whom I had researched and filmed.

Verne recovered, but the memory remains. At that time, I was not a filmmaker but a witness to a profound failure of care with dire consequences.

Yes, I have filmed women who work in health care. I have filmed their patients, their working conditions, their strengths, and their suffering. I have served as a witness, a documentarian, and an advocate in my professional life, in my activist activities, and in my family responsibilities. I, too, have become a canary in the mine.

Further Reading

Armstrong, P., H. Armstrong, & K. Scott-Dixon. (2008). *Critical to Care: The Invisible Women in Health Services.* Toronto: University of Toronto Press.

Armstrong, P., A. Banerjee, M. Szebehely, H. Armstrong, T. Daly, & S. Lafrance. (2009). *They Deserve Better: The Long-Term Care Experience in Canada and Scandinavia*. Ottawa: Canadian Centre for Policy Alternatives.

Koren, M. J. (2010). Person-Centered Care for Nursing Home Residents: The Culture Change Movement. *Health Affairs* 29(2): 312–317.

Relevant Websites

Canadian Health Coalition: www.healthcoalition.ca
Laura Sky: https://laurasky.ca