Privileged Presence

Personal Stories of Connections in Health Care

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It Was as Hard as It Gets: The Impact of a Global Crisis on Family-Centered Care

SARS. Severe Acute Respiratory Syndrome. Even today, the term provokes a profound response from those who were closest to the outbreak.

SARS is a severe type of pneumonia that is rapidly progressive and sometimes fatal. SARS is highly communicable and is spread by direct and droplet contact.

In the early months of 2003, SARS appeared as a new infectious disease. It originated in China and became a disease of global proportion in a relatively short period of time. International travel made it easy for the disease to move from country to country. Cases were reported in 29 countries, and there were 774 deaths worldwide.

On March 7, 2003, Toronto, Canada, had its first identified hospital case of SARS. By March 26, a provincial emergency was declared. On April 23, the World Health Organization issued a travel advisory (in effect for only six days). The provincial state of emergency continued until May 18. And then a second outbreak of SARS occurred on May 22, and the crisis didn't wane until August 2003.

During the acute phase of the outbreak, the Ontario Ministry of Health imposed strict guidelines with a single focus of wanting to protect patients, families, and staff. Many decisions, designed to provide safety for the greatest number of people, resulted in a terrible push-pull between the losses of some individual rights and the larger context of protecting the public good.

The severity of the guidelines varied from hospital to hospital, depending on the number of staff who had become sick with

SARS. Hospitals were rated according to a numerical scale. In hospitals where no staff had become sick with SARS, the rating was low and the guidelines were less restrictive than in hospitals where staff had become sick.

For example, in a hospital where no staff were sick with SARS, non-SARS patients could have one visitor. By comparison, non-SARS patients in hospitals where staff were sick with SARS were not allowed any visitors at all. Patients with SARS were not allowed any visitors, no matter what the hospital's rating. The different ratings and corresponding rules created confusion for the public.

Many hospital and health care professionals in Ontario hospitals were passionately committed to collaborating with and involving patients and families in care. They had worked long and hard to bring about positive changes in institutional and staff attitudes and practices and then suddenly found these gains compromised, overwhelmed, and paralyzed by forces beyond their control. Although controlling the outbreak and protecting people from harm were the objectives, there were significant consequences.

Overnight, hospitals and care practices went from being family-centered to system-centered. Overnight, hospitals went into what felt like a lockdown mentality: entry points were limited, all patients and staff were screened for symptoms, and security personnel made sure no one got past the front door. Overnight, many families were told they could not be with their loved ones. Overnight, the support, information, and additional care families typically provided were no longer easily available to staff, overruled by infection-control priorities. Overnight, all volunteers and several categories of staff, including psychologists and

chaplains, were declared nonessential and were prevented from going to work. Overnight, health care professionals became bigger, taller, wider, and more removed from their patients because of protective clothing. Overnight, people became afraid.

In the world of pediatric medicine, it is common for parents to stay with a hospitalized child. During the SARS outbreak, however, if a child had been exposed to SARS, the child would typically be whisked away in an ambulance and that child's parents were not allowed to enter the hospital. If a child was hospitalized for a non-SARS reason but a parent had been exposed to SARS, the parents were denied access to the hospital. Nurses reported that they couldn't bear hearing children, from small babies to teenagers, crying because they wanted their mothers and fathers.

Staff would do their best to make up for parents' absence and facilitate some sort of communication between child and family. Staff would take pictures and send them home; they would ask for pictures of family members to be sent in. Cards would be mailed and emails would be sent. Phones became critically important to families trying to stay in touch and provide support for one another. Some calls would last for hours, with parents at home providing comfort for children undergoing procedures, and children being reassured that their family members at home or in other hospitals were still healthy and alive.

Hospital-wide precautions required children to be confined to their rooms. All playrooms were closed. In such conditions of isolation and boredom, children often became depressed and anxious. Child life specialists did their best to find ways for children to play and overcome this new profound sense of being cooped up.

Special toss- and target-style games were created; the closed-circuit television system was used for group games such as Bingo;

and one child life specialist even arranged for children to sit at the entrances to their rooms where they could at least see and interact with others and play verbal trivia games. Additionally, some of the volunteers no longer allowed access to the hospital made craft kits off-site to be delivered to isolated children to work on in their rooms.

Various stories from adult hospitals convey some of the tragic side effects of this outbreak. For example, a female patient in intensive care was unable to talk and was going blind. Her husband had been with her nonstop. Overnight, he was told he would no longer be allowed to visit his wife. Desperate to communicate, he emailed his wife daily love letters, which the staff would read to her and then laugh and cry together.

In one excruciating situation, all members of a single family had been exposed to and become sick with SARS. Tragically, they were all in different hospitals, sick themselves and worried about the others. Staff from these different hospitals did their best to be in touch with one another and to convey information and messages of hugs and comfort.

The mother of an eighteen-year-old boy who had been in a car accident begged to be able to stay with her son. He had been a bright, intelligent young man and had suffered a terrible head injury. He was just starting to communicate again. The mother was completely prepared to waive her rights to safety to be with her son and help him recover, but she was told she had no rights to waive. The system was larger than her love.

A calm, reasonable, rational, dignified immigrant woman, already struggling to adjust to a different culture and language, lost all composure when she was told and finally understood that she could not visit her sister. She was forcibly restrained by security staff until she could bottle up and contain her personal agony.

Hospital staff had to wear special clothing, including face shields and masks. Smiles designed to try to brighten a dark day were hidden from view. Patients could not even recognize a nurse they knew until that person spoke. Staff talked about how difficult it was to not be able to provide the comfort of touch to patients because there was always a protective layer of clothing in the way. Many reported feelings of guilt; because the striker suits were so hot, staff desperately wanted to just get out of their patients' rooms to be able to breathe again. Others described they felt "fog, fatigue, and exhaustion" from wearing masks for twelve hours.

Compassionate staff were caught in this web of complexity. They tried their best to keep patient and family lines of communication open and to show kindness in the midst of delivering care. And yet all the while, they were terribly aware that when patients are not surrounded by the support of family, their recovery is diminished.

Staff also talked about how hard it was to do their jobs while they were coping with their own stress. One woman said she felt like a leper whenever she left the hospital. Another was teaching a part-time course at the University of Toronto at the time, but when she arrived to give her class, she was asked to leave. Others spoke of being denied dental care for themselves or daycare services for their children.

And for those health care heroes who worked directly with patients who had SARS, they experienced "work quarantine." This meant they were confined to their wards in the hospital, no longer allowed to leave the floor to meet other colleagues for meals in the cafeteria or to go to meetings. And when these brave men and women went home at the end of an exhausting shift, they were quarantined within their houses and from their families. They could

not leave their homes to do errands, and, inside their own walls, had to wear masks and eat and sleep alone. As they headed off to their next shifts, they often took with them their neighbors' curses, their partners' anger, and their children's fears that they would get sick and die. As one nurse put it, "It was as hard as it gets!"

Even though the SARS outbreak has been over for several years, the damage lingers. Although no one really knows the depth of trauma that still haunts patients and families from that period, many staff will privately admit to suffering from post-traumatic stress. One hospital had a psychiatrist who would meet with the staff most affected every day during the crisis and debrief with them, but staff from another hospital had no support at all—not during the outbreak or since. "We're professionals. We're supposed to be tough. We love what we do and we went into health care to help people. We learned that we have to help one another at times like this. But the emotional burden of dealing with this is huge." Some quietly express fears about possible future outbreaks of infectious diseases: "I think some staff will just refuse to come to work, and then where will we be?"

For those committed to family-centered care, it has been additionally difficult to hear some of their colleagues say how much they enjoyed not having what they called the "noise and chaos" of having family members around during SARS, that they found it more peaceful to work. As families return to the hallways of these hospitals and staff adjust to the increased traffic, hopefully too will come the reminders that patient recovery, competence, and satisfaction are all increased with the information, support, and presence of families respected for their contributions.

One team of nurses and social workers put it this way: "Certainly SARS showed that in a time of crisis, elements of care

we value can be easily lost or destroyed. We are passionate about family-centered care. Even under the best of circumstances, it can be difficult to implement. We have worked long and hard to change the culture of our hospital. The fruits of our labors disappeared overnight, and the road back is proving to be tenuous. The challenge now is for leaders in health care to ensure that policies and systems are in place to allow us to respond to a public health crisis without sacrificing the relationships among patients, families, and health care providers."

The word *pandemic* is commonplace in the news of the day, and the world feels somewhat endangered. Consequently, the lessons learned and questions raised by SARS are timely and present a great opportunity for reflection and evaluation. The SARS experience provides an informed basis for planning for the future and, as such, it would be almost unethical to make plans that do not address the emotional side effects of family separation and patient isolation.

In the words of one hospital team, "We need to fully understand the cost/benefit of isolation procedures and find answers to questions such as:

- How restrictive do limits on contact between professionals and patients and families need to be?
- Might the steady presence of a family member naturally reduce the number of contacts while helping the patient and providing support for overworked staff?
- How restrictive does access to the hospital need to be?
- How widespread is the need to use protective equipment?
- How do we use families as advisors to help us answer these questions?
- What support network needs to be in place for staff and their families?"

A lesson learned from the SARS experience is that there must be proactive planning to provide appropriate support for all those who are directly affected in such public health emergencies—from public health officials and health care professionals to patients and their families. There's no question that the first priority in these situations is to protect the safety of people and control the spread of an outbreak. At the same time, however, it is also important to find ways not to abandon the standards of family-centered care and to ensure that post-traumatic stress be averted or treated.

Now is the time to plan for "the next infectious disease emergency." It is essential to bring many different points of view to the table to find the best ways to respond—including public health and infection control specialists charged with protecting public safety, patients and family members, hospital leaders, and those front-line staff who tried their best to deliver compassionate care. It is only through such an inclusive collaboration that the full ramifications of the SARS crisis will be addressed, innovative solutions will be suggested, and responsive systems will be put in place to sustain and support patients, families, and staff.

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Government officials, infection control specialists, public health personnel, hospital leaders, and front-line staff caught in the vortex of the SARS experience were faced with phenomenal and frightening uncertainty. They were called upon to demonstrate tremendous courage, day in and day out. They are to be praised for caring, coping, and finding creative ways to adapt clinical practice in a climate of such restrictions. Their wish is that others "get ready."

This SARS story is the result of many conversations with and contributions from staff from different Toronto hospitals and infection control specialists in the United States.